How do people with multiple long-term health conditions experience the self-management approach to health care?

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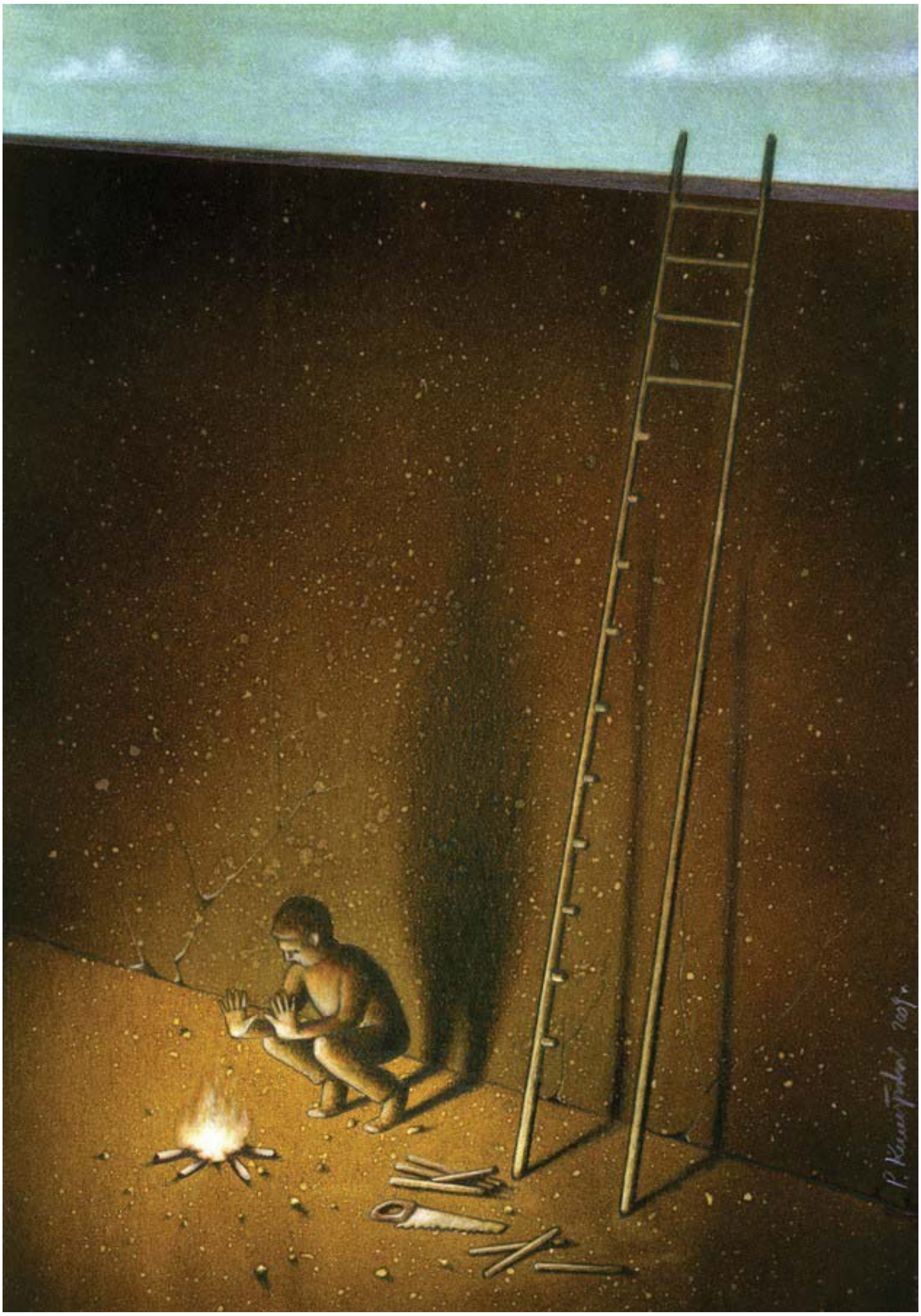

Figure 1. **PawelsKuczynski37**

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Abstract

The health system in New Zealand has devised approaches intended to meet the needs of people with long-term conditions (LTCs) based on the international theories of the Chronic Care Model (CCM) and a self-management framework (Bodenheimer, Wagner, & Grumbach, 2002b; Lorig, 1993; Wagner, 1998). LTCs and multimorbidity are socially patterned so often people with several LTCs are also contending with chaotic lives as well as the implications of their Illnesses. The self-management framework is based on the assumption that everyone has the agency or freewill to make the daily decisions that would benefit their health and ignores the powerful effect of social context. Because the behaviours recommended to optimise health are so entwined with a person's social context, LTCs are particularly sensitive to the social determinants of health.

This multiple case study follows the complex lives of sixteen people with several significant long-term health conditions using the theories of both Cockerham (2005, 2010, 2013b) and Link and Phelan (1995, 2010) to explore their experiences. Ongoing contact with the patient-participants comprised two interviews, four-weekly contacts and interviews with their primary health care clinicians. The patient-participants' stories reveal complex, entangled lives marked by loss, poverty and daily challenges. They are significantly constrained by the overwhelming social contexts of their lives and reduced to survival mode by their cumulative losses across the four domains of the Whare Tapa Wha model. Personal agency is neither a choice nor readily achieved. They are left too exhausted to work their way through a health system that does not recognise their needs, empower them or compensate for their lack of energy.

The weary patient-participants in this study bear little resemblance to the idealised expert patient of the self-management framework. Clinicians are left manoeuvring to compassionately and pragmatically support the patient-participants as best they can within an unhelpful system.

The findings however do surface examples of care that are valued by both patient- and clinician-participants that sit outside the self-management approach. These valued aspects are explored alongside the harm reduction, recovery and palliative models of care. These all offer contributions towards an approach that would optimise the quality of life for people with significant, multiple LTCs.

An exploration of this re-awakened approach to care is described. Care that is constricted self-management approach could wrap around the patient and support them to use their residual agency in a direction of their choosing. Clinicians would be released from their current programmed response be able to more fully utilise their clinical expertise. Clinicians and patients would have the freedom to be more pragmatic around quality of life and the issues that matter to the individual with LTCs.

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Your unswerving belief and pride in me are priceless. Love you both to the moon and back.

This is dedicated to my Mummy, Margaret West (1943-1963). I hope that somewhere, she is proud.

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List of Abbreviations

ACC	The Accident Compensation Corporation is the New Zealand Crown entity which administers the universal, no-fault accidental injury scheme
CCM	The Chronic care model is the most widely utilised framework for offering health care to people with LTCs (Wagner, 1998).
CPAP	Continuous positive airway pressure is a treatment typically used for breathing conditions such as sleep apnoea that uses mild air pressure to keep the airways open. A mask, attached by tubing to a motor, is worn over the nose and mouth
DHB	District health boards are responsible for providing or funding the provision of health services in their district (Ministry of Health, 2016a)
GP	A general practitioner is an appropriately qualified medical graduate who has particular knowledge and skills to provide personal, family, whānau and community-orientated, comprehensive primary care (The Royal New Zealand College of General Practitioners, 2016)
HbA1c	Glycated haemoglobin measurement of the average blood glucose over the previous three months obtained via a blood test. Judged to be the most reliable way to measure glycaemic control in people with a of diabetes or as a diagnostic test
LTC	Long-term conditions are health conditions that are progressive, life-long and limiting in terms of quality of life. They can rarely be cured, only controlled (Welsh Assembly Government, 2006)
MRSA	Methicillin-resistant *Staphylococcus aureus* is a bacterium that is resistant to many antibiotics. In hospitals it can cause life-threatening infections, pneumonia and surgical site infections, therefore patients with an MRSA infection are cared for in isolation
PHO	Primary health organisations are funded by DHBs to ensure the provision of essential primary health care services, mostly through general practices, to those people who are enrolled with the PHO (Ministry of Health, 2016a)
PN	Practice Nursing is a sub speciality within nursing concerned with primary health care provision for individuals, the family and the community, … usually based within a general practice setting (New Zealand Nurses Organisation, 2007)

WHO	The World Health Organization

Glossary of Māori terms

Hauora	Health, wellbeing or health care. Hauora is also used extensively as a description of health care systems and health organisations including the Manatū Hauora [Ministry of Health]
Hoha	Something tiresome or tedious
Hui	Conference or meeting
Kanohi ki te kanohi	Face-to-face
Kaumātua	Respected Māori elders
Kōrero	A talk or speech. For this research, it means patient narratives
Māori	The indigenous people of New Zealand
Mana	The prestige, reputation or esteem a person holds
Manaakitanga	Hospitality, kindness and support
Marae	The traditional meeting house for Māori communities
Mauri	The term that can be used in several ways. For this study, mauri is used to mean the dynamic life force, life energy or essence that everything and everyone has.
Pae Ora	A list of principles described by Sir Mason Durie (1985, 2001) that contribute to a healthy future for Māori. The principles are: Mauri Ora - healthy lives, Whānau Ora, healthy families, Wai Ora, healthy environment
Pākehā	A term for non-Māori, which tends to mean people of European descent.
Taha hinengaro	The psychosocial context of a person’s thoughts and feelings
Taha tinana	Physical aspects of health
Taha wairua	Often summarised as spirituality but also relates to an individual’s faith, sense of purpose and vitality
Taha whānau	Concerns the social influences on health as well as extended family (Glover, 2005; Rochford, 2004)

Wananga	A tertiary education institution, which provides education in a Māori cultural context
Whakamā	A psychosocial construct that is often understood as shyness, modesty or embarrassment
Whakapapa	Often translated as genealogy, “whakapapa can be likened to a map of existence.” (O'Hagan, Reynolds, & Smith, 2012, p. 59). In the context of research recruitment, whakapapa sampling means establishing and maintaining relationships
Whānau	An extended family group
Whanaungatanga	Interconnectedness or belonging. The term has traditionally concerned kinship relationships but can also mean something that can be shared between people with a common purpose (O'Carroll, 2013)
Whare	A building
Whare Tapa Wha	A model of health also developed by Durie (1985, 2001) that features in many health policies in New Zealand. The model uses the image of the four walls of a house (whare) to describe four interdependent aspects of health. These are taha hinengaro, taha tinana, taha wairua and taha whānau, described above.

Te Reo Māori is an official language of New Zealand Aotearoa. Both Māori and non-Māori, when speaking English, also regularly use many Māori words.

Chapter One: Introductory chapter

Introduction

In New Zealand, as in many other countries, there are increasing numbers of people living for many years with complex, multiple, long-term health conditions (LTCs). LTCs and multi-morbidity are socially patterned so many of the people who have several LTCs are also contending with complicated lives alongside the implications of their Illnesses.

Health systems internationally have devised approaches intended to meet the needs of people with LTCs, based largely on the theories of the Chronic Care Model and the self-management framework (Bodenheimer, Wagner, et al., 2002b; Lorig, 1993; Wagner, 1998). In New Zealand there has been strong attention paid to self-management approaches and these have been implemented in various guises. Such approaches assume patients[1] have an innate capacity for personal agency and their own health needs have primacy in their lives.

The experience of living with multiple LTCs has a significant impact upon a person's quality of life. This study sets out to discover how people with multiple LTCs live their lives and manage their health over time and how they engage with and experience self-management approaches in the health care system and specifically General Practice.

Research question

How do people with multiple LTCs experience the self-management approach to health care within primary care settings?

Aims

An underlying aim is to give primacy to the voices of people with LTCs in the course of exploring their engagement with self-management.

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[1] The appropriate term to use for consumers of heath care can be problematic. The term 'people' will be used where possible, but where there is potential for confusion with health professionals, the term 'patients' will be used, albeit with reluctance. As a term, 'patient' may position people with LTCs as sick or as 'belonging' to a particular health professional. The term patient is preferred slightly to consumer or customer by this group (Deber, Kraetschmer, Urowitz, & Sharpe, 2005).

Context for the research

The study explores in depth the lives of 16 people living with complex, multiple LTCs and tells their stories. Their experiences and needs, as articulated by the participants, are compared and contrasted with the care offered to them, especially under the auspices of the self-management approach. The role primary care clinicians play is also included.

The purpose of this first chapter is to describe the research context. The need for, and potential significance of, the study is explained. The background context is provided, addressing the increase in multiple LTCs and the implications of this continued trend for both patients and the healthcare system. Assumptions within the biomedical paradigm are shown to have significantly affected health policy and clinical practice. These assumptions have shaped the development of care for people with LTCs.

Long-term conditions

Long-term conditions are defined as health conditions that are ongoing or recurring and are usually non-communicable. They are life-long and in most cases they cannot be cured, only controlled or managed and have a significant impact on a person's quality of life (Charmaz, 1999; National Health Committee on Health and Disability, 2006). The terms 'long-term' and 'chronic', 'condition', 'disease' or 'illness' are used interchangeably in the literature (Department of Health, 2004). The term 'long-term conditions' has been used more in both the UK and New Zealand in an attempt to ostensibly focus more directly on the patient's experience rather than any disease process or resulting disability (Weisz, 2014). Additionally, the less familiar term 'non-communicable disease' is used by the World Health Organization (WHO) (2008a, 2014), despite some LTCs such as HIV being communicable. For this study, the term long-term conditions will be used. The most frequently occurring LTC is arthritis (Berzins, Reilly, Abell, Hughes, & Challis, 2009; Healey et al., 2015). Other common LTCs, both internationally and in New Zealand, are asthma, chronic obstructive pulmonary disease (COPD), diabetes, cancer, cardiovascular disease and depression (Ministry of Health, 2009b).

Identified as the major health challenge of the 21st century, LTCs are increasing worldwide, accounting for up to 80 percent of the global disease burden and over 60 percent of deaths globally (ABCC NZ Study, 2011; Committee on Quality of Health Care in America, 2001; Ham, 2005; Horton, 2012; Ministry of Health, 2016b; WHO, 2002; 2008a, 2013, 2014). In late 2011, the United Nations convened its second-ever

General Assembly meeting on health, where 192 countries heard LTCs referred to in vivid terms including ‘plague’ and ‘slow-motion disaster’ (Beaglehole et al., 2011; Bristol, 2011; Rosenbaum & Lamas, 2011).

People who are socioeconomically disadvantaged are significantly over-represented in the LTC statistics and their situation is especially bleak. In New Zealand, the groups more likely to experience LTCs include disproportionate numbers of Māori and Pasifika. Māori are the indigenous people of New Zealand. Pasifika are people from the Pacific region (including Tongan, Samoan, Fijian and Cook Island peoples) who live in New Zealand and either migrated or identify as Pasifika because of ancestry or heritage (National Health Committee on Health and Disability, 2006). Māori, Pasifika and people living in the geographic areas with the highest 20% of relative socioeconomic deprivation are defined in health legislation as the high needs population (Cumming & Gribben, 2007).

Transition to long-term conditions

Over the last century there has been a gradual epidemiological transition from predominantly acute or infectious and episodic conditions, which usually occurred one at a time, to the current predominance of LTCs (Bodenheimer, Wagner, & Grumbach, 2002a; Budrys, 2010; Glasgow, Orleans, Wagner, Curry, & Solberg, 2001; Porter, 1997). The transition is due to several factors. Firstly, LTCs are more common as people age and people now live longer (Kane, Priester, & Totten, 2005; Marengoni, 2008; Martin & Peterson, 2008). Acute and infectious illnesses are also more readily cured or prevented and advances in health care mean that previously fatal diseases such as cancer, cystic fibrosis or HIV/AIDS have themselves become LTCs (Fee & Krieger, 1993; Fortin, Lapointe, Hudon, & Vanasse, 2005; National Health Committee on Health and Disability, 2006; Oni et al., 2014). Finally, the factors that contribute to many LTCs, such as hypertension, hyperlipidaemia, inactivity and morbid obesity are increasing (Budrys, 2010; Ministry of Health, 2009b; National Center for Health Statistics, 2011; NCD Risk Factor Collaboration, 2016). The exception is cigarette smoking, which is decreasing, albeit at glacial speed (Gould, 2014; Ministry of Health, 2007, 2009a; Zulman, Kerr, Hofer, Heisler, & Zikmund-Fisher, 2010).

Multiple long-term conditions

Unfortunately, LTCs tend not to occur in isolation and the norm is for people to have several (Fortin, Soubhi, Hudon, Bayliss, & Akker, 2007; Mercer, Smith, Wyke, O'Dowd, & Watt, 2009; Ministry of Health, 2016b; Salisbury, 2012; Wolff, Starfield, & Anderson, 2002). More than one LTC is termed multimorbidity, multiple morbidity or comorbidity.

These terms, though often used interchangeably, technically have slightly different meanings, dependant upon whether the diseases occur simultaneously but independently or are related, with one of the LTCs an index disease (Almirrall & Fortin, 2013; Feinstein, 1970; Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009). Generally, they refer to a person with several coexistent medical conditions that may or may not be linked (Fortin et al., 2005; van den Akker, Buntinx, Metsemakers, Roos, & Knottnerus, 1998).

For physiological reasons, LTCs can occur in clusters, such as diabetes, renal disease and cardiovascular disease (Anderson et al., 2007; Collie-Akers et al., 2007; Kerr et al., 2007; Schäfer et al., 2013). These tend to have treatment regimens that are complementary (Mercer, Gunn, Bower, Wyke, & Guthrie, 2012). However, there is also frequent co-existence of seemingly unconnected LTCs. An example is heart failure and COPD - two conditions with potentially conflicting medication regimens (Hawkins, 2009; Mascarenhas, Azevedo, & Bettencourt, 2010).

When a person has several LTCs, the disadvantages, unpredictability and complexity of living with one are compounded, with an interplay of symptoms and treatments (Brettschneider et al., 2013; Kadam & Croft, 2007; Kleinman & Hall-Clifford, 2010). Multimorbidity is associated with poorer overall health and quality of life and a higher level of disability compared to a single LTC (Chen, Baumgardner, & Rice, 2011; Congdon, 2016; Navickas, Petric, Feigl, & Seychell, 2016; Radner, Smolen, & Aletaha, 2009; Sprangers et al., 2000). Multimorbidity is also associated with poorer experiences of primary care (Paddison et al., 2015).

The wide-ranging effects of living with multiple LTCs create a succession of physical, psychological and social losses, a theme covered comprehensively in the literature (Ahlström, 2007; Bury, 1982; Charmaz, 1983; Strauss, 1997). The losses include impact upon a person’s sense of self, identity and retention of autonomy (Kleinman & Hall-Clifford, 2010; Kralik & van Loon, 2010; Tang & Anderson, 1999; Williams, 1984). Alongside any decline in bodily function, people “witness their former self-image crumbling away” (Charmaz, 1983, p. 168).

The impact on the individual is most significant if one of the conditions causes either chronic pain or is a mental disorder (Healey et al., 2015; Loza, Jover, Rodriguez, & Carmona, 2009; Pinto-Meza et al., 2009). Mental illnesses, particularly depression, have a special place as comorbidities. There is a symbiotic relationship between physical and mental health LTCs. Mental illnesses can both coexist with a physical LTC independently or be a direct consequence of having an LTC (Brooks, Rogers, Sanders, & Pilgrim, 2015; Naylor et al., 2012). People with a physical LTC, particularly COPD and diabetes, experience high rates of depression (Gask, Macdonald, & Bower, 2011; Lustman, Griffith, & Clouse, 1997; Maurer, 2008). Any co-existence tends to worsen the course of both and is associated with both increased clinical complexity and poorer health outcomes (Detweiler-Beddel, Friedman, Leventhal, Miller, & Leventhal, 2008; Fagiolini & Goracci, 2009; Mercer, Gunn, et al., 2012; Sanna et al., 2013).

Where depression is one of the LTCs, there can be a significant impact on the individual’s motivation to care for their own health needs. Martin, Williams, Haskard and DiMatteo (2005) find that people who experience depression are 27% less likely to take their medication as prescribed than people without depression, which affects their subsequent health. Other authors have found that the symptoms of depression decrease the likelihood that people with LTCs will follow health advice (Anderson et al., 2007; Ciechanowski, Katon, & Russo, 2000; Harrison et al., 2012). Thoits (2006) also found people with poorer mental health have less capacity for personal agency because of their compromised coping resources and higher levels of distress.

In turn, the physiological impact of sub-optimal management of an LTC can reduce cognitive ability by various mechanisms, which leaves people less able to care for their health and so leads to further deterioration in cognitive function (Dickens et al., 2012; Tran, Baxter, Hamman, & Grigsby, 2013). The deterioration results in poorer physical health outcomes and higher death rates (Cameron et al., 2013; Ciechanowski et al., 2000; Hoyt & Stanton, 2012; Scherrer et al., 2011).

The implications of the increasing prevalence of LTCs on the future funding of health care delivery are significant (Kendall, 2010; U.S. Department of Health & Human Services, 2010). In England, already over half of primary care appointments and nearly two-thirds of hospital outpatient appointments are for people with LTCs, which accounts for almost 70 percent of the total health care budget (Berzins et al., 2009). As numbers increase, the Australian National Health and Hospitals Reform Commission (2008) describe the threatened fiscal blowout as a “tsunami” of LTCs (p.153).

Long-term conditions do not respond to the reactive health care approaches that worked well for acute or infectious diseases, so health systems struggle to cope and the care offered often falls short of the ideal (Committee on Quality of Health Care in America, 2001; Healey et al., 2015; Starfield, 2009; Wagner, 1998; WHO, 2002). The solution has been a combination of programmes and approaches that collectively relate to the Chronic Care Model and the self-management approach[2] (Bodenheimer, Wagner, et al., 2002b; Lorig, 1993; Wagner, 1998). These will be explored in more depth in the following chapter.

Biomedicine

The self-management agenda has emerged from the assumptions of scientific rationality that underpin the quest for curative medicine and so the development of the health system has led to biomedical dominance (Aronowitz, 1988). Biomedical dominance is based on the Cartesian idea of the body being reducible to its mechanical parts. Illness is explained in terms of underlying pathology, which, if corrected, leads to the restoration of health (Seedhouse, 2001, 2005; Starfield, 2011).

Care for people with multiple LTCs continues to be offered within an organisational structure that evolved to care for a largely bygone disease profile. Bodenheimer, Wagner, et al. (2002a) describe mainstream primary care as continuing to be ruled by the “tyranny of the urgent” (p.1775) and Moore (2006) characterises it as “reactive and chaotic, rather than proactive and organized” (p.37). The acute disease hangover also means health systems are largely configured for single diseases rather than multimorbidity (Barnett et al., 2012b). Care is targeted at an individual patient despite the many people who consider their own health needs in relation to their family, whānau [extended family group] or community. The subsequent care received by people with complex health needs is typically discontinuous, fragmented, full of duplication and unsatisfactory (Boult, Karm, & Groves, 2008).

The extensive literature about biomedical dominance, including Willis (1983, 2006) and Wilson, Kendall and Brooks (2007), has concentrated on the role of medicine and doctors. The part played by other health professionals, including nurses, is less clear. Nursing has historically been simultaneously controlled by medicine, while its own practices also dominate patients (Holmes & Gastaldo, 2002). Teasing these issues out is beyond the scope of this study. For the purpose of discussion here, the power and dominance expressed by health care (and medicine specifically) have been conflated to include nurses and nursing. Therefore when using the term medical dominance in this thesis, I am assuming, like Fredericks et al. (2012) that medical dominance is not

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[2] The combined ideas and philosophies encapsulated within the Chronic Care Model and the self-management literature are forthwith referred to as the self-management approach or framework.

limited to doctors but looks at the hegemonic authority and power that is held by all health professionals as well as the health system as a whole.

Biomedical dominance shapes what is accepted as credible knowledge but also, more surreptitiously, shapes thinking and approaches as it continues to influence the way health care is thought about, organised and delivered. The ‘scientific rationality' claims of biomedicine shape which research is valued. There are many excellent qualitative studies that have explored the complex lives of people with multiple LTCs, such as those by Bury (1982), Charmaz (1991) and Williams (2000). Despite these, the enduring assumptions of biological reductionism within the biomedical model have given primacy to research that presupposes an individual patient, devoid of social context, with a single LTC (Berwick, 2009; Schoenberg, Bardach, Manchikanti, & Goodenow, 2011).

The focus on a single LTC is well demonstrated in the prestigious Cochrane review of LTC self-management (Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007). The review initially considered 1478 papers, but the application of the inclusion criteria meant that only 18 ultimately made their way into the finalised guidelines. The inclusion criteria of Fortin, Stewart, Poitras, Almirall and Maddocks’ 2012 study, which considered all articles from a 30-year time period in both English and French, resulted in the consideration of findings from just 21 articles. More recently, in Boger et al.’s (2015) systematic review of the abstracts of over 20,500 articles about LTC self-management, only 41 met the inclusion criteria. It is this tiny proportion of studies that are deemed of a suitable quality upon which to build clinical guidelines (Nieuwlaat et al., 2014). Serrano-Gill and Jacob (2010) noted that only 18% of the randomized control trials that studied diabetes, measured outcomes that patients said mattered to them. This highlights the patients’ invisibility in research supposedly about them.

People with multiple morbidities are also systematically excluded as subjects in research, despite multimorbidities being the norm that clinicians encounter (Clayman et al., 2010; Cooper, Collier, James, & Hawkey, 2010; New Zealand Guidelines Group, 2011). One meta-analysis of interventions for chronic care looked at 56 studies, only seven of which dealt with more than one LTC (Coleman, Mattke, Perrault, & Wagner, 2009). Guidelines and performance measures both in New Zealand and internationally are based on these studies. Smith and O’Dowd (2007) call these guidelines “clinically naïve” (p.269) and others found the costs of their development and dissemination outweigh any benefits to patients (Grimshaw et al., 2004). The mismatch between the prevalence of multimorbidity and the proportion of LTC-related literature which addresses the multiple morbidities continues, despite the many authors who highlight this omission (Fortin et al., 2006; Fortin et al., 2005; Nardi et al., 2005; Starfield, 2011; Valderas et al., 2009; Van Weel & Schellevis, 2006). The utility of single disease guidelines is weak when the reality of multiple LTCs is the norm.

For clinicians who work within a system framed by the biomedical model, a patient’s successful management of LTCs is often measured in terms of mastery of specific tasks or biomarkers such as HbA1c (Dorr et al., 2006; Hoyt & Stanton, 2012; Thorne, Paterson, & Russell, 2003). For the person living with LTCs, there is a big difference between these objective signs and symptoms and their experiences, their reported pain or their functional ability (Boyd et al., 2005; Hale, Treharne, & Kitas, 2007).

Self-management

A major difference between acute illnesses and LTCs is the activities or tasks that a person with LTCs must do (or perhaps should or could do) to maintain their health. These activities are called self-management and are the focus of this study. These “tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions” (Institute of Medicine, 2003, p. 57). As well as self-management, the term self-care is also used in the literature. Self-care tends to refer to a wider set of behaviours that are part of peoples’ daily living to maintain their well-being (Department of Health, 2005a). However, these terms are used inconsistently and interchangeably in the literature (Jones, MacGillivray, Kroll, Zohoor, & Cannaghan, 2011; Kendall, Ehrlich, Sunderland, & Rushton, 2011; Pearce et al., 2016). The term self-management will be used throughout the thesis to encompass both terms.

Many of these activities are integral to people’s everyday lives and social world. LTCs are therefore managed, to a lesser or greater degree of success, by individuals within their everyday lives. For many people, facets of their lives other than their health drive their behaviour and decisions about health. These often complex, social contexts are not taken into consideration by a biomedical framing of health care. Bodenheimer, Lorig, Holman and Grumbach (2002) describe the challenge of self-management well when they state, “the question is not whether patients [with LTCs] manage their illness, but how they manage” (p.2470). The patients are managing their own health, not necessarily as clinicians would advise, but they are self-managing. For patients therefore, self-management means whatever it is they do to manage living with LTCs, although they may not think of it in those terms. Self-management support refers to the help clinicians offer patients to acquire the skills and confidence to self-manage their

LTCs (Adams, Greiner, & Corrigan, 2004; Zwar et al., 2006). Self-management support is described in more detail further on.

The term self-management in health policy and clinical practice does not reflect this broad understanding. Instead, self-management is conceptualised within the narrow focus of the biomedical model, accepted as the optimal way to improve the health of people with LTCs. It is built upon assumptions and a health system that has been developed to meet the needs of a different disease profile (Bodenheimer, Wagner, et al., 2002a; Glasgow et al., 2001).

Self-efficacy

The active patient role required for self-management sits in contrast to the previous largely passive role necessary for acute illnesses. The active, empowered patient role, or expert patient, is described in the following chapter. A concept central to the idea of the expert patient is self-efficacy. Self-efficacy is the individual's confidence and belief in their own capacity to “take control over their life despite the disease” (Department of Health, 2001, p. 25). Self-efficacy in the health context means that people who believe they will be successful, are more likely to carry out a behaviour or task and persist if they experience difficulties (Williams, 2010b; Williams & Bond, 2002). Self-efficacy is built on the expectation that LTCs can be controlled and there is nothing in the way of a person with LTCs achieving that mastery through personal agency (Greener, 2008).

Agency and structure

The key assumption of the self-management approach, that patients have the innate personal agency to carry out those activities or behaviours deemed necessary, ignores the place of structural determinants of health. These terms form a part of the theoretical terrain used in this thesis and are discussed further in the third chapter.

Agency can be described as free will or choice, where people are imbued with the ability to select their personal behaviour, or control their personal fate (Cockerham, 2013b; Link & Phelan, 1995; McGettigan, 2008). Agency is an idea that resonates within the liberal conception of an individualistic society, where it is assumed free will and choice are possible and individuals are innately self-sufficient and self-determining (McGettigan, 2008; Williams, 1989). In Western society, and particularly in health care, choice and autonomy are “celebrated ideal[s]” that are assumed to be readily achievable and desirable (Mol, 2008, p. 1).

However, alongside agency, there is ‘something’ that exists beyond the individual that can affect capacity for agency (Cockerham, 2013b). The something is structure, which Williams (2003) describes as “what is beneath the surface ebb and flow of social life” (p.132). Structure encompasses all the factors that may limit or enhance a person’s ability to act as an autonomous agent. Structure includes both material and non-material resources such as finances, housing, socioeconomic status, sex, race and education. These are distributed unevenly and either constrain or enable a person’s capacity to demonstrate agency (Abel & Frohlich, 2012; Einspahr, 2010).

These structural determinants of health are powerful forces in the lives of people with multiple LTCs. However, the assumption of innate agency is a fundamental premise of the way health care is delivered. With health care organised and delivered around a biomedical framework, these determinants are not given due consideration. The barriers that prevent an individual from carrying out activities that have been deemed important are overlooked, which further increases health inequities.

Social determinants of health: inequities and multiple long-term conditions

The potential conflict between various perspectives of self-management described thus far is apparent. The importance of the social determinants of health upon the lives of people living with several LTCs is not catered for by a health system still anchored in the biomedical model. This conflict is now explored further.

The social determinants of health are the circumstances in which people are born, grow up, live, work and age. They include social structures and resources such as education, income distribution, employment and housing (Marmot & Bell, 2012; Weitz, 2014). These have profound effects upon health, sometimes more than formal health services. For example, it has been suggested that improving a population’s educational level would achieve more than improving formal health care (Mirowsky & Ross, 2003; Woolf, Johnson, Phillips, & Philipsen, 2007).

LTCs occur unequally in the population due to these social determinants. Social disadvantages both lead to and compound the effects of LTCs (Ministry of Health, 2002). Disadvantaged members of society feel their impact disproportionately in the causation, development and outcome of LTCs (Blaxter, 1990; Budrys, 2010; Ministry of Health, 2002, 2009b, 2013; Sheridan et al., 2011; Sykes, Sadler, & Priest, 2008; Wilkinson & Marmot, 2003). The most affected groups are those living in poverty and those from indigenous or racially disadvantaged groups. Internationally, poverty and racial disadvantage co-exist so frequently that they are difficult to untangle (Rumball-Smith, 2009; Scambler, 2011). Marmot and Bell (2012) describe these various areas of social injustice as “killing on a large scale” (p.S4). These profound and persistent inequities are important concepts in this thesis**.**

Poverty

Any measurement of deprivation is inevitably clumsy, but overall it is the interdependence of a number of unequally distributed economic, cultural and social resources (Christensen & Carpiano, 2014). However poverty is measured, it is consistently highlighted as the most accurate predictor of ill health throughout the world (WHO, 2002; Lima-Costa, De Oliveira, Macinko, & Marmot, 2012; Mirolla, 2004; Semyonov, Lewin-Epstein, & Maskileyson, 2013; Violan et al., 2014). Phelan and Link (2013) summarise economic inequalities as “very large, very robust and very well documented” (p.105). Conversely, higher socioeconomic status leads to better health across the lifespan (Fell & Hewstone, 2015; Hudson, Puterman, Bibbins-Domingo, Matthews, & Adler, 2013).

Poverty has also been found to influence the way people “think, feel and act” (Fell & Hewstone, 2015). A large British study establishes that children living in poverty fall behind developmentally by the age of three and never catch up (Social Mobility and Child Poverty Commission, 2013). Multiple morbidities are also more common in the most deprived population (Mercer, Guthrie, Furler, Watt, & Tudor Hart, 2012). A study of almost two million Scots clearly establishes that multimorbidity is linked to socioeconomic deprivation (Barnett et al., 2012a).

The financial disparities experienced by people with one or more LTC are self-perpetuating. As well as being experienced disproportionately by people living in poverty, LTCs can also both “cause and entrench poverty” (Beaglehole et al., 2011, p. 449). It is perhaps self-evident that people with multiple, complex health conditions are likely to be high users of health services and so incur much higher expenses. Iatrogenic poverty, where the cost of being ill increases the poverty of those who experience the illnesses, occurs due to both a decrease in a family’s earning capacity and the expense of ill health (Detweiler-Beddel et al., 2008; McRae, Yen, Jeon, Herath, & Essue, 2012; Meessen et al., 2003). Both direct and indirect costs to families living with LTCs are high, even in countries such as New Zealand with universal health care (Jan, Essue, & Leeder, 2012; Williams, 2010a). In New Zealand the overall cost of living with an LTC can be up to 28% of a family’s income, which leads to inevitable poverty for many (Jeon, Essue, Jan, Wells, & Whitworth, 2009; Walker, 2007). The costs of LTCs increase with both multiple LTC and with the severity of each condition (Ackerman, Ademi, Osborne, & Liew, 2013; Barnett et al., 2012a).

Ethnicity

The effect on health of ethnicity and poverty is intertwined, but health status remains unequal across racial groups even when accounting for socioeconomic status (Bartolome, Chen, Handler, Platt, & Gould, 2016; Mathur, Hull, Badrick, & Robson, 2011). Worldwide, the health of indigenous people is always poorer than that of the total population (WHO, 2011). Māori clearly experience poorer health across the spectrum of conditions (Cram, 2014a; Ministry of Health, 2010; Robson & Harris, 2007). The other group who also feature negatively in New Zealand health data are Pasifika.

For Māori and Pasifika, the experience of living with LTCs is comprehensively worse than for non-Māori/Pasifika (Blakely, Ajwani, Robson, Tobias, & Bonné, 2003; Harris et al., 2006; McCreanor & Nairn, 2002; Ministry of Health, 2002, 2010; Tobias, Blakely, Matheson, Rasanathan, & Atkinson, 2009). Māori experience LTCs 10-15 years earlier than non-Māori and get more complications, earlier (Simmons, Shaw, Scott, Kenealy, & Scragg, 1994; Thompson, McWilliams, Scott, & Simmons, 1993). They typically present to health services later in the disease and die younger (Human Rights Commission, 2012; Rochford, 2004). For example, Māori men are three and a half times more likely to develop diabetes than non-Māori men, and an astonishing six and a half times more likely to die as a result (Ministry of Health, 2007). Māori experience the renal complications of diabetes at a rate eight and a half times that of non-Māori (Human Rights Commission, 2012; Ministry of Health, 2007). The precursors to LTCs are also disproportionately high in Māori and Pasifika people. Both male and female Māori smoke more, consume more calories, have a higher proportion of dietary energy from fat and a higher average Body Mass Index (Ministry of Health, 2012).

As well as differences in health outcomes, there is a wealth of evidence that Māori and Pasifika receive fewer health services. Māori and Pasifika were found by Cooper-Patrick et al. (1999) to receive less health information and other studies found them in receipt of less diagnostic, treatment and rehabilitation services (Jansen, Bacal, & Crengle, 2008; Maly, Stein, Umezawa, Leake, & Anglin, 2008; Ministry of Health, 2006; Saffar, Williams, Lafata, & Divine, 2012; Westbrooke, Baxter, & Hogan, 2001; Yanez, Stanton, & Maly, 2012).

Although ethnic minorities and poorer people experience a higher incidence of LTCs, their experiences are researched less frequently. Examples from the USA show that African American people experience a higher incidence, at an earlier age, of both heart failure and diabetes. Yet they have been less involved in research than the white population (Anderson & Granger, 2014; Sherman, Hawkins, & Bonner, 2016). Despite this, study findings are often extrapolated to the entire population.

Many of the risk factors or barriers to health previously associated with poverty have been eradicated or significantly reduced, such as poor sanitation, overcrowding and infectious diseases. An exception is the recent recurrence in New Zealand of many of the infectious diseases associated with poverty (Baker et al., 2012). The impact of socioeconomic status on health outcomes however persists (Phelan & Link, 2013).

The whare tapa wha health model

Mason Durie's whare tapa wha holistic model of health features in many New Zealand health policies (1985, 2001). The model uses the analogy of a whare or house with the four walls representing the "holistic interdependent relationship between all aspects of health" (Glover, 2005, p. 14). These are taha hinengaro (emotional or mental), taha tinana (physical), taha wairua (spiritual) and taha whānau (social) aspects of health (Rochford, 2004). As the analysis in this study proceeded, I became increasingly aware of the model's relevance and utilised it during the process. This brief explanation of the model is offered here for readers unfamiliar with its use, in preparation for data analysis further on.

My journey to the changing question - or my changing understanding of the question. A personal reflection

As well as the way biomedicine has shaped the development of care for people with LTCs, my own journey in this study was also significantly affected by what Gordon (1988) calls the "tacit understandings" of biomedicine (p.19). I had not previously questioned my own biomedical socialisation, nor had I reflected upon my initial approach to the research question, which just seemed 'common sense.' The realisation of this was an important moment in the development of the thesis when what had appeared self-evident to me turned out not to be so.

The development of ideas began with an interest in understanding why the care offered to people with multiple LTCs, from my perspective as a clinician, felt piecemeal and 'bitty.' It appeared that people's health outcomes frequently were far from optimal.

What was it the patients were not doing or did not understand? Why did patients do what they do? Alternatively, how was it that clinicians did not explain the self-management approach well enough so patients 'got it'?

My personal realisation thankfully occurred early on in the research process when I became aware of how the biomedical model has captured how I, and therefore others, think about self-management. This realisation occurred in two ways at about the same time. Firstly, for the patient interviews, I initially unquestioningly looked to the accepted self-management frameworks. I selected the domains of self-management from the Flinders™ Programme Partners in Health and Cue and Response tools as a loose template for patient and clinician semi-structured interviews (Battersby, Ask, Reece, Markwick, & Collins, 2003; Petkov, Harvey, & Battersby, 2010).

On reviewing the first few transcripts and listening to the recorded interviews, it became apparent how the biomedical framework had channelled my questions, and therefore patient-participants' responses, down pre-ordained pathways. The interviews had been severely restricted by the framework and the Flinders™ tools were in themselves a product of the self-management process I was beginning to critique.

The insight I gained was that the interviews were falling into the biomedical trap of framing the patients' experiences in a discourse created by the health care system and stifling dialogue by steering the conversation into a template. The results were lightweight data that did not reflect what mattered to the participants. Fortunately**,** this revelation came early enough, and the research design offered opportunities, to ensure I subsequently heard the full stories from those with whom I had already completed the first interview.

Secondly, my reading led me to be increasingly interested in the role of structure and agency, and the work of Cockerham (2013b) and Link and Phelan (1995). In particular, I was intrigued by their arguments that biomedicine's failure to acknowledge the social determinants of health causes health inequities to persist. I found this social justice lens very appealing.

Diffusion of the self-management innovation

These insights shaped my overall approach to the remainder of the data collection and research design, the direction of the literature review and the theoretical terrain that underpins the study. I began to think about the biomedically shaped self-management agenda in a different way. Self-management is a term with layers of meaning, which range from its idealised conceptualisation in the literature, to its adoption into policy, through to the interpretations of clinicians, to the experiences of patients with multiple LTCs. To explore these layers, I have used Rogers' (2003) diffusion of innovation theory as a vehicle to explore the notion of self-management/support as an innovation that was diffused in a certain way and translated and taken up in each of these tiers.

The diffusion of innovation theory was first described by Everett Rogers (2003) in the late 1950s as a "useful way of looking at change" (p.xviii). He described diffusion as "the process in which an innovation is communicated through certain channels over time among the members of a social system" (Rogers, 2003, p. 5). Rogers (2001, 2002, 2003) developed his diffusion of innovation theory in rural Iowa, during a sociological exploration of the uptake of various agricultural innovations. He identified a process through which an innovation is adopted by a group, organisation or community. His framework offers a way to consider change and the many variables that affect the adoption of an innovation (Wejnert, 2002).

The first stage of Rogers' (2003) theory is the innovation-development process, which relates to the development of the innovation in response to an identified problem. This phase includes all the decisions and activities that occur from the time a problem is identified, through the development of the innovation as a solution, to its diffusion and adoption (Rogers, 2003). The theory is germane because it provides a conceptual scaffold to explore how people with multiple LTCs experience the self-management approach to health care as self-management diffused from policy and strategy, to clinical practice, to the patient with multiple LTCs.

Summary

The purpose of this research is to explore how people with multiple LTCs experience the self-management approach to health care within primary care settings. The chapter has outlined the context for the research. Multiple LTCs are the norm and affect all parts of individuals' lives. Long-term conditions are especially sensitive to the structural determinants of health and for people from poorer socioeconomic groups and, in New Zealand, Māori and Pasifika are much more affected.

Both health care for people with LTCs and its research have been dominated by the biomedical paradigm. Biomedicine continues to shape how care is delivered and received as well as the original planning of this research. The realisation of this altered the direction of the research.

I am not aware that the overarching self-management framework has been previously explored in this way through the simultaneous lens of both patients' and clinicians' experiences. This thesis will thus examine the tension between the interpretation of self-management by the health system and by people living with LTCs and the subsequent effect upon the patients' experience of care and quality of life.

The following literature review chapter explores in more detail the genesis of the self-management framework.

The study overview

To explore the topic, the thesis is structured in the following way, organised into eight main chapters.

Chapter One: This first introductory chapter has set the scene for the study and includes reasons for the increasing prevalence of LTCs and the subsequent implications for both patients and the health care system. Concepts central to the study were described, particularly the biomedical paradigm's continued dominance of health care. The background to self-management and the ideas of self-efficacy, agency and structure were then introduced. A personal revelation was then shared which altered the direction of the study. Rogers' diffusion of innovation was then briefly outlined as it will be used as a vehicle for examining how self-management has become the unquestioned best practice for caring for people with multiple LTCs in New Zealand.

Chapter Two: In the second chapter, the literature review establishes the way the Chronic Care model and the self-management approach, with roots anchored firmly in the biomedical paradigm, emerged and became accepted as the best way to offer care to people with LTCs.

Chapter Three: Chapter three describes the theoretical terrain that underpins the thesis. Two complementary theories guide the exploration of the lives of people with multiple LTCs, expanded from the narrow perspective that has both dominated the literature and so shaped how patients' self-management has been adopted at policy level. The theories facilitate the subsequent broad exploration of the self-management approach, particularly redressing the position of structural determinants of health and the consideration for the contextual aspects of patients' lives.

Chapter Four: The methodology and research methods chapter outlines the way the research area influences the choice of paradigmatic position. A constructivist point of view supports the selection of a multiple case study research method. The research methods are then outlined. A multiple case study will explore the experiences of 16 people living with multiple LTCs.

Chapter Five: The patient-participants all offer rich kōrero [narratives] about their complex lives.

Chapter Six: The chapter uses thematic analysis to explore the data from both patient- and clinician-participants. The concept of mauri or life force is used to explore the lives of the patient-participants. The overall theme of loss across the four walls or domains of the Whare Tapa Wha model of health is described.

Chapter Seven: The final findings chapter, analyses how the weary patient-participants engage with a health system misaligned with their needs. The frustrations that clinician-participants experience when they try to help the patients are explored. The chapter concludes by highlighting various aspects of care that are valued by both patient- and clinician-participants that sit outside the self-management approach.

Chapter Eight: The final chapter includes the discussion and the concluding statement. The valued aspects of care surfaced in the previous chapter are explored alongside three models of care. This exploration offers some ideas about a new philosophy or approach to care that could improve the quality of life for people living with LTCs. These are explored, again using the framework of the Whare Tapa Wha model.

Chapter Two: Literature review

Introduction

The previous chapter outlined the background and purpose of this study and established the significance of multiple LTCs. The chapter also described the powerful effect of health care’s biomedical foundations upon the way health care for people with LTCs has developed. The influence of biomedicine continues to be seen through this literature review chapter as it affects the way the Chronic Care Model and self-management frameworks have diffused from literature and policy to clinical practice and patients.

The first chapter introduced self-management as a concept that has different meanings in the literature, in health policy, in clinical practice and for people living with LTCs. The literature review now explores these layers. The initial exploration is of the literature that takes a broad interpretation of self-management as how people with LTCs look after themselves amidst their social context. The chapter then moves to look at literature that narrows the interpretation to activities and behaviours that people are encouraged to comply with for optimal health. Finally, exploration moves to the version of self-management as it is mostly understood within the biomedically dominated health care system and the implications of this for the patient. The main models and frameworks of self-management support are outlined, which include both the ideal and the reality of the changing roles and relationships for people with LTCs, and for clinicians.

Self-management

Beginning with a broad interpretation, Blakeman, Bower, Reeves and Chew-Graham (2010) describe self-management as concerned with the subjective feelings and experiences of an individual with LTCs. They describe self-management as relating to ways of:

> managing or minimising the way conditions limit individuals’ lives … [and] what they can do to feel happy and fulfilled to make the most of their lives despite the condition (p.13).

Kendall, Ehrlich, Sunderland and Rushton (2011) summarise that for patients,

> self-management involves navigating and responding to a myriad of information sources and experiences, many of which originate in their own lived bodily experiences and personal knowledge (p.87).

Corbin and Strauss (1985) describe three areas of self-management that people have to accomplish when living with LTCs. They talk of these as areas of ‘work,’ which relate to their illness, their everyday life and the biographical work that is necessary for an individual to reconstruct their own biography and sense of self in the light of their illness.

Despite this rich literature, biomedicine’s dominance has meant the illness-related, task-focussed end of the research spectrum has been taken up disproportionately at policy level in the self-management discourse (Dickson, Lee, & Riegel, 2011; Gandar, Dale, Young, & Field, 2008; Mirolla, 2004). Many definitions of self-management concentrate solely upon specific physical tasks and clinically-related aspects (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). The important emotional aspects of having an LTC are overlooked (Beaglehole, Bonita, Horton, Adams, & McKee, 2004). Even when emotional or social aspects of living with LTCs are considered, it is still assumed that the LTCs have primacy in an individual’s life.

The task-focussed, biomedically driven interpretation of self-management aims to improve a person’s health status by “persuading individuals to change their health behaviour” (Baum & Fisher, 2014, p. 213). These behaviours are based upon the rationale that the way a person integrates these tasks into their life influences the disease(s)’ severity, prognosis and the patient’s quality of life (Audulv & Norbergh, 2010; Gatchel & Oordt, 2003). The physical task orientated portion of the literature describes self-management as all the behaviours a person can carry out to alleviate symptoms or prevent complications or deterioration of LTCs (Lorig & Holman, 2003). These activities are carried out on a daily (or more frequent) basis and the list of self-management tasks for just one condition an individual is expected to do can be onerous (Russell, Suh, & Safford, 2005; Yen et al., 2013). Anderson (1985) observes that, for some, the treatment regime is more of a problem than the disease. This is called disease or treatment burden, which is defined as the “practices that patients with chronic illness *must* [emphasis added] perform to respond to the requirements of their healthcare providers” (Gallacher et al., 2013, p. 2). The language of this definition gives a flavour of the medical dominance that permeates the literature where the goal is to follow medical instructions.

The task focussed part of the literature, alongside management of medication, monitoring regimens (Ham, 2005; Hinder & Greenhalgh, 2012) and smoking cessation, is dominated by advice around physical activity and dietary intake (Munir et al., 2009). Both diet and exercise often require changing life-long habits (Gomersall, Madill, & Summers, 2011). The WHO (2013) has determined that these “behavioural risk factors” are, along with smoking cessation, the greatest culprits for both developing and managing LTCs (p.5). They are positioned as central to effective self-management despite no evidence on their efficacy for people with significant multiple LTCs (Brown et al., 2007).

For people with several LTCs, being an active patient becomes exponentially more complicated as they try to “integrate … tasks for coexisting and often interacting diseases” (Bayliss, Ellis, & Steiner, 2007, p. 395). Morris, Sanders, Kennedy and Rogers (2011) identify often contradictory care regimens amid constantly shifting self-management priorities. Examples include the conflict between increased activity for diabetes or heart disease and the breathlessness of COPD or the mobility restrictions of arthritis (Townsend, 2005; Wolff et al., 2002). Recommendations from clinicians using single disease guidelines can be contradictory for someone with multiple LTCs (Wolff et al., 2002). An example is the weight bearing exercises advised for osteoporosis and its contraindication in people with diabetic peripheral neuropathy (Boyd et al., 2005).

The implications of self-managing long-term conditions

Unlike acute illness, most of the activities and behaviours that are recommended for optimal care of LTCs are increasingly deemed to be under the ongoing control of the individual. Many of these were previously considered part of the domestic sphere and integral to private and whānau life, but are now part of ‘treatment.’ With responsibility for self-management increasingly placed upon patients’ shoulders, it is now the individual’s responsibility to keep as well as possible. Any failure to do so is seen as a personal failure (Barnett et al., 2012a; Bhattacharya, 2012; Cockerham, 2005; Cockerham, Rutten, & Abel, 1997; Mercer et al., 2009; Paddison, 2013).

Kotarba and Bentley (1988) describe health as being increasingly viewed as an achievement and terminology echoes these judgements. Activities are referred to as a lifestyle ‘choice,’ which suggests there is a genuine option. However, the “freedom to make healthy choices is out of line with what … people experience … in their everyday lives” (Williams, 2003, p. 147). For instance, a study of poorer health among indigenous compared to non-indigenous Australians describes the health difference as being due to lifestyle “choices,” hinting at blame and ignoring the many structural determinants of health with which Aboriginal Australians contend (Whelan & Wright, 2013). The belief that managing one’s health is a personal choice ignores the social and cultural constraints that prevent people with LTCs adopting “healthy practices and lifestyles” (Paterson & Hopwood, 2010, p. 124). With lifestyle being a choice, the social system shifts responsibility for ill health to the patient (Filc, 2004).

People with long-term conditions are especially prone to society’s strong moral judgements about their lifestyles, which are increasingly viewed as deviant (Royal Australian College of General Practitioners, 2003), disobedient or deficient (Kendall et al., 2011). LTCs “occur within a moral narrative of lifestyle excess” (Manderson & Smith-Morris, 2010, p. 6). The dominant assumption is that LTCs are a result, not for instance of longevity, but of lifestyles marked by inactivity and excess - deficits that would be resolved by parsimony and manual labour. Increasingly, lack of health is viewed as a moral failure and people who experience LTCs are blamed for their sickness (Brady, Gingras, & Aphramor, 2013; Clarke & Bennett, 2013; Cockerham, 2005; Crawford, 1980, 2006; Galvin, 2002).

The transfer of responsibility (and often cost) to the patient can be seen as part of the economic strategy that underpins self-management (Boult, 2014). With cure rarely an option, the tasks and behaviours they are encouraged to adopt are permanent. With the long-term physical damage of suboptimal care usually pernicious and invisible, prioritising health advice among complex lives is problematic. Therefore, to repeat Bodenheimer, Lorig, Holman and Grumbach’s (2002) statement, people with LTCs inevitably self-manage their health; the question is how they manage.

Compliance

In 1979, Haynes described compliance as “the extent to which a person's behaviour (in terms of taking medications, following diets, or exercising lifestyle changes) *coincides with medical … advice* [emphasis added]” (p.3). The idea of patients who should follow the rules, largely remains unchanged despite being several decades old and replaced with new terminology. Any non-compliance continues to be interpreted as a wilful disregard for these instructions (Glasgow & Anderson, 1999). Victim blaming occurs rather than any attempt to explore the source bias of whether the care offered may be deficient (Comaroff, 1982). Rogers’ (2003) work on innovation theory echoes the victim blaming - “if the shoe doesn’t fit, blame the foot” (p.115).

Within the biomedically-dominated literature, any vetoing of recommendations by patients is variously called non-compliance, non-adherence or more recently discordance (Armstrong, 2013; Bodenheimer, 2007; Boult, Giddens, Frey, Reider, & Novak, 2008). Patients face the implicit judgements of health care professionals and are labelled ‘difficult’ (Department of Health, 2006; Jansa et al., 2010; Randall & Ford, 2011; Roy, 2001; Wilkinson & Whitehead, 2009). The picture often painted of compliance seems over-simplistic, as patients usually know what they should do, but symptom control may not be their first priority (Corbin & Strauss, 1985; Kane et al., 2005; Townsend, Wyke, & Hunt, 2006). One study, which looks at how people with diabetes follow *instructions* found all patients were doing their best to control their diabetes (Hunt, Haynes, Hanna, & Smith, 2008). However, they had all adapted the recommendations in some way, with none following them exactly.

The impact of social context

Because the behaviours recommended to optimise health are so entwined with a person’s social context, LTCs are particularly sensitive to the social determinants of health. With the resources needed to deal with LTCs unevenly distributed, social disadvantages take away many of the choices people have to mitigate the effects of their illnesses. Individuals’ experience, knowledge, attitude and socioeconomic status have far-reaching effects upon their health. Paterson and Hopwood (2010) highlight that not everyone is in a socioeconomic position to prioritise health.

In contrast, because the self-management movement developed from within the biomedical paradigm, both the problem and any potential solution are positioned within that narrow framework which overlooks social context and assumes an innate agency. While attempting to persuade individuals to change their health-related behaviour, self-management policy often ignores the social determinants that both lead to the development of LTCs and affect self-management practices (Baum & Fisher, 2014; Choby & Clark, 2014; Filc, 2004; Klainin & Ounnapiruk, 2010).

Exploration of the diffusion of the self-management paradigm

The idea of self-management of health is not new. Its thread has run unbroken since the Ancient Greek maxim of ‘*epimelesthai sautou*’ or ‘take care of yourself’ (Martin, Gutman, & Hutton, 1988). In the 1700s, John Wesley, the founder of the Methodist church, wrote a best-selling book about self-care, and the self-help movements of the 1960s were based on similar ideas.

An early mention of the term self-management in health literature was by a team working with asthmatic children (Creer, 1976; Creer, Renne, & Christian, 1976). Since then, self-management has become increasingly "positioned as essential to the optimal management of many chronic diseases" (Broom, 2003, p. 61). Therefore, despite people with LTCs having always self-managed their health, from the late 1970s onwards, self-management was 'discovered' by health care professionals (Kickbush, 1989).

Since the turn of the century, self-management has become the dominant discourse in health care, introduced predominantly as a strategy for demand management of health care services (Kendall et al., 2011; Rogers et al., 2008; Royal Australian College of General Practitioners, 2003). As the numbers of people with LTCs continues to increase, health systems are threatened with financial crisis (Ham, 2005; Holman & Lorig, 2000; Jecker & Self, 1991; Wiener & Strauss, 1997; WHO, 2002; 2008b). The health system is described by Thorne (2008) as "[being] left scrambling to respond" (p.7).

The lure of potential cost savings from self-management was strong in a system working within severe fiscal constraints. The unchallenged assumption was that people with increased knowledge about their own health and how to care for that health would inevitably decrease the demand upon health services (Dongbo et al., 2003).

The way in which ideas about self-management grew in popularity can be explained using Rogers' (2003) diffusion of innovation conceptual framework, which was defined in the introductory chapter. The process will be considered in terms of how the self-management paradigm was developed, its subsequent eager adoption at the strategic tiers of government ministries and its insertion in the policy framework. Unlike Rogers' Iowan farmers, the innovators and initial adopters were not the people who were intended to self-manage - the people with LTCs - but members of health academia and policy makers.

Self-management programmes and models

The self-management approach diffused in the way it did from policy to practice level, because the goal of policy level innovators was to be able to offer health care to people with LTCs and simultaneously reduce health care expenditure. The implicit biomedical underpinning of the innovation led to the term self-management becoming synonymous with models, frameworks and formalised programmes (Berzins et al., 2009; Foster et al., 2007; Franek, 2013; Glasgow, Davis, Funnell, & Beck, 2003; Lorig & Holman, 2003). It allowed the development of a fairly simplistic solution to a very complicated problem. The distillation can be seen in the following definition from a Cochrane review that defines self-management as a “term applied to any formalised educational programme aimed at teaching skills needed to carry out medical regimens specific to the disease…” (Effing et al., 2009, p. 2).

The Chronic Care Model

There are several well-known models and programmes that have developed to frame the health care of people with LTCs. One of the earliest and probably most widely known and accepted frameworks is Wagner’s Chronic Care Model (1998). It is an operational framework devised from the findings of a Cochrane systematic review of chronic care interventions. Other less known health care organisation models share similar features (Coulter, Roberts, & Dixon, 2013).

The Chronic Care Model aims to improve health outcomes through system-wide changes to the planning of clinical care delivery for people with LTCs (Barr et al., 2003). The primary care setting has been identified as the best setting for delivery of health care for people with LTCs (Cunningham, 2006; Mirolla, 2004; WHO, 2008b). These changes aim to enhance the interactions between the health care team and the patient, and locate care for people with LTCs firmly within primary care. These idealised interactions require an active, informed, and often expert patient and a prepared, proactive team of clinicians who will work together to produce better health outcomes (Barr et al., 2003; Bodenheimer, Wagner, et al., 2002a; Forbes, Sutton, Richardson, & Rogers, 2016; Wagner, 2011; Wagner, Austin, et al., 2001; Wagner, Glasgow, et al., 2001).

The clinician-patient relationship is characterised in the model as continuous and healing (Committee on Quality of Health Care in America, 2001; Scott, Plotnikoff, Karunamuni, Bize, & Rodgers, 2008; Wagner, Austin, et al., 2001). Through collaborative encounters, both parties work together towards a sharing of expertise and participatory decision making (Bodenheimer, MacGregor, & Sharifi, 2005; Mead & Bower, 2000; Parchman, Zeber, & Palmer, 2010; Zeber et al., 2008). Self-management support is one of the six pillars in Wagner’s model (1998, 2011) and is often identified as the most critical to the model’s success (Bodenheimer, Lorig, et al., 2002; Connolly et al., 2008; Lorig, 2001).

Evidence for the model’s effectiveness is equivocal. Because the Cochrane findings upon which the model is based used strict positivist exclusion criteria, many of the people with complex multimorbidities for whom this model applies are the same people who would have been excluded in the original research. Other authors such as Boult (2014) criticise the Chronic Care Model as being “too woolly,” an opinion that Oprea, Braunack-Mayer, Rogers and Stocks (2009) echo. They argue “the pathways through which [the model] aims to improve patients’ health outcomes are not made explicit” (p.55). Murray Cram and Nieboer (2015) describe the model as “limited by its focus on clinical and functional outcomes and the improvement of health behaviour…while largely neglecting consideration of patients’ overall quality of life and well-being” (p.247).

Throughout the remainder of this study the combination of the Chronic Care Model, particularly the self-management support pillar, and the ideas of the expert patient working in a collaborative relationship with clinicians, will be referred to as the self-management framework or approach as shorthand for the combined ideas.

The expert patient

As the assumptions of the Chronic Care Model and its self-management support pillar were adopted at policy level, “the discourse of the patient as an active agent in managing illness and health care has become very important” (Salmon & Hall, 2003, p. 1969). The idealised active, empowered patient is called the expert patient. Expert patients are described as those living with LTCs, who ‘choose’ to manage their own health by gaining expertise and self-efficacy and so control over their life and quality of life (Department of Health, 2001; Fox, Ward, & O’Rourke, 2005). As the patient is an expert in their own life, they are able to negotiate what will work for them with their clinician (Anderson, 1985). The autonomy promised to the expert patient promises to free patients from medical oppression (Mol, 2008).

The notion of the expert patient has been challenged (Greenhalgh, 2009). Authors question whether the idea holds any merit while it remains so embedded within the biomedical model (Fox et al., 2005). The clash between the self-efficacy of self-management and the biomedical assumption that patients should be doing as they are told, highlight an obvious dissonance in the self-management discourse (Koch, Jenkin, & Kralik, 2004; Weitz, 2014). The expert patient is such a fundamental part of the self-management paradigm that the UK group in charge of developing self-management initiatives was called the Expert Patient Taskforce (Department of Health, 2001). The model expects a motivated, self-actualised, undistracted person with the capacity for agency. Charmaz’ (1983, 1991, 1999) extensive research however, found no evidence of the emergence of any new, improved sense of self.

Patients’ increased responsibility for health-related decisions is described by Armstrong (2013) as the attribute which “separates the passive patient of 1958 from the active one today” (p.172). Armstrong appears comfortable that previous passivity has been replaced by a brave new dawn of collaboration. However, other authors challenge whether biomedicine constrains personal agency to such an extent that any possibility of an emancipatory agency, where patients are able to challenge the rules that underpin self-management, is negated (Greener, 2008; Hoggett, 2001). New roles for clinicians in this framework are also not straightforward. Many clinicians feel challenged if patients do develop expertise, as confidence and self-efficacy challenge the previous power balance in the relationship (Snow, Humphrey, & Sandall, 2013).

Hurdles to any wide scale transformation of these relationships appear overlooked in the literature. These hurdles include the uneasy fit between the ideals of supported self-management and the traditionally directive nature of clinical practice and patients’ traditional subservient role of cooperation and compliance (Barber, Parsons, Clifford, Darracott, & Horne, 2004; Funnell & Anderson, 2000; Harris, Williams, Dennis, Zwar, & Powell, 2008).

There is limited exploration of all aspects of the patient-clinician relationship, and studies have tended to concentrate on the clinician’s view of the dyad (Blakeman, 2010; Townsend, 2005). One study, which explored challenging relationships between patients and their primary physician, did interview both patients and physicians (Ratanawongsa, Wright, Vargoc, & Carrese, 2011). However, it was the physician who selected which relationships were challenging, a move unlikely to offer a balanced representation. Two more studies, which look at aspects of patient-clinician communication, again sought only clinicians’ opinions (Carlfjord, Andersson, Bendtsen, Nilsen, & Lindberg, 2012; De Stampa et al., 2013). Another study looks at particularly good doctor-patient relationships and once again the doctors selected the patients (Scott, Cohen, et al., 2008). None of these experts were patients.

Despite the rhetoric of partnership and collaboration, much of the literature does not reflect an egalitarian relationship. Deakin, McShane, Cade and Williams (2005) use the term “training” when they define self-management as “the learned ability to perform an act competently” (p.3). Boger et al.’s (2015) large systematic review recognises the paucity of research that attempts to determine the aspects of self-management patients value. Closer to home, a major New Zealand report into LTC care aimed to “gain experts’ views on the current state of [CCM] practice” (Connolly et al., 2008, p. 5)

Self-management support

Self-management support is the part clinicians play to support a patient and their whānau to optimally self-manage their LTCs (Bodenheimer, Wagner, et al., 2002b; Wilson, 2007). Adams, Greiner and Corrigan (2004) define it as "the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems" (p.57). Some definitions of self-management support capture a broader concept in which health care professionals work collaboratively with people with LTCs in various ways. It involves the support of patients to develop the knowledge, skills and confidence they need to care for their condition(s) effectively (Coulter et al., 2013). It is worth drawing attention to the emphasis here on both the educational and supportive aspects of self-management support. The broad concept has been significantly narrowed by the powerful influence of biomedicine. The quantifiable, educational aspects of self-management support have gained supremacy, largely at the expense of the supportive aspects (Battersby et al., 2007; Dickson et al., 2011). This is despite the findings of significant studies such as the PRISMS meta-analysis of self-management support interventions concluding that to be effective, self-management support needs to be an integral part of good quality care rather than a stand-alone activity (Pearce et al., 2016).

The process of focussing on particular parts of the self-management support discourse is reflected in the terminology as well as in practice. Language slippage occurs and the 'support' of self-management support is increasingly omitted in the literature (Kendall et al., 2011). Self-management support is increasingly described as something clinicians do *for* or *to* the patients, or as another commodity to be dispensed by the health system (Dugdill, Graham, & McNair, 2005; Koch et al., 2004). The changing, or blurring, of terminology reflects the motives and reinforces the worldview of biomedical dominance and reduces the patient's visibility in the discourse.

Indeed, the term self-management/support has been narrowed even further and is viewed by many health care practitioners and literature almost exclusively in terms of formal educational programmes (Alderson, Starr, Gow, & Moreland, 1999; Johnston, Liddy, & Ives, 2011; Kendall et al., 2011; Trappenburg et al., 2013). Successful self-management is judged in terms of an individual's programme attendance (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008; McGowan, 2005; Nieuwlaat et al., 2014). Examples include Loh, Packer, Chinna and Quek (2013), for whom breast cancer self-management meant women had attended a four-week group programme and Phillips et al. (2013), who looked at how clinicians decided which programme to "use with a patient" (p.263). Thus self-managing changes from a verb to a "pre-packaged noun" (Kendall et al., 2011, p. 95), something far removed from how self-management support was originally envisaged.

Programmes

There are three main formal self-management support programmes in use in New Zealand. The first is the Chronic Disease Self-management (Stanford) programme, developed by Kate Lorig (1993; 2001) in the United States. Internationally, it is the most widely used and evaluated self-management group programme. By 1991, 120,000 people had attended the programme in the USA, Australia and Canada (Lorig & Holman, 1993). By 2015, this number had reached 500,000 (Lorig, Ritter, Moreland, & Laurent). Based upon Lorig's work, in 2001 the Expert Patient programme was formally adopted in England as a national programme (Department of Health, 2001; Kennedy, Rogers, & Gately, 2005; Taylor & Bury, 2007).

Built on an existing arthritis self-management programme which began in 1984, the Stanford programme is a lay-led, six-week long course with a two-hour session per week, delivered under licence (Gately, 2008; Lorig & Holman, 1993). The highly structured curriculum, which includes goal setting, is delivered by course leaders who also have LTCs (Taylor & Bury, 2007). Recent developments include an online and a mailed toolkit version of the course (Lorig, Laurent, Plant, Krishnan, & Ritter, 2013; Lorig et al., 2015).

In its early days, evaluations of the programme found no link between health behaviour and health status. To explain this finding, the authors claimed that self-efficacy is the most important attribute for a patient to self-manage well and so self-efficacy became the central tenet of the programme (Lorig & Holman, 1993; Lorig et al., 1989). Self-efficacy theory suggests that an individual's belief in their capability to achieve something is a strong predictor of their success (O'Leary, 1985). Both Klainin and Ounnapiruk (2010) and Nodhturft et al. (2000) identify strong associations between self-efficacy and how people carry out the more practical aspects of self-management behaviour. The premise of the programme is that, with a little training and armed with the confidence gained on the course, people with LTCs can (and must) take responsibility for their own health (Greener, 2008).

Lorig's interest in self-efficacy came from working early in her career with Albert Bandura (Wilson & Mayor, 2006). Bandura (1996) promoted the idea of self-efficacy from within the framework of social learning theory, which itself sits within, and reinforces, the biomedical model (Johnston et al., 2011). With self-efficacy as the measurable marker of change, biomedical ideas of agency and individualism are given prominence (Kendall, Foster, Ehrlich, & Chaboyer, 2012; Kendall & Rogers, 2007).

The second programme is the Flinders™ Program. In response to critique of both disease specific and lay-led programmes, Flinders™ takes a generic, non disease-specific approach to the individual with LTCs, which aims to be more appropriate for multiple LTCs (Battersby, 2011). The research that led to its development, identifies patients' capacity for self-management as more influential upon their health outcomes than the severity of their illness(es). The programme identifies a list of essential facets needed to effectively self-manage (Battersby, 2009; Battersby et al., 2007). These are used as the skeleton for the programme delivery with the Partners In Health Scale and the other tools used in the process (Battersby et al., 2003; Petkov et al., 2010). Widespread use of the Flinders Program™ in New Zealand has been hampered by problems of capacity within general practice to carry out the compulsory full assessments (Horsburgh et al., 2010).

The third and final programme is Care Plus, a New Zealand initiative that forms the cornerstone of policy-level self-management support implementation for people with LTCs (Ministry of Health, 2004). The aim of Care Plus is to improve access to primary care for people whose LTCs mean they require intensive clinical management. The programme, introduced in 2004 as part of the Primary Health Care Strategy (Ministry of Health, 2001b), has seen impressive uptake, unlike other models. It differs from the first two programmes outlined because it involves an additional funding stream for free or subsidised visits to a nurse practitioner, practice nurse (PN) or general practitioner (GP).

Compulsory goal setting and care planning are parts of the programme which requires people to strive for improvement (Lhussier et al., 2015; Martin & Peterson, 2008). Studies from the UK, where care planning for people with LTCs is a policy priority, report a large cohort of people with multiple LTC who are unaware whether or not they had a care plan, or even of the term care planning (Burt et al., 2012; Newbould et al., 2012).

Evaluation of programme effectiveness

Evaluations of the structured formal self-management programmes are mixed. The Cochrane review suggested improvements were modest and short-term efficacy "sparse" (Foster et al., 2007, p. 14). One meta-analysis, which reviews 550 self-management support projects in the UK, shows some positive results, especially when the programmes focus on self-efficacy and behavioural change (Health Foundation, 2011). Another large group of evaluations conclude them to be moderately effective (Clark, Whelan, Barbour, & MacIntyre, 2005; Clark, MacIntyre, & Cruickshank, 2007; Kennedy et al., 2007 ; Rogers et al., 2008; Wilson & Mayor, 2006).

Other authors challenge these conclusions and state that their efficacy is unproven or presents a mixed picture (Breedland, van Scheppingen, Leijsma, Verheij-Jansen, & van Weert, 2011; Chodosh et al., 2005; Jonsdottir, 2013; Warsi, Wang, LaValley, Avorn, & Solomon, 2004). Despite some positive findings, the Health Foundation (2011) in England found a significant gulf between the political rhetoric of the programmes and the reality of clinical practice. Comprehensive analysis of programme outcomes are described as modest in Canada (Franek, 2013), disappointing in the UK (Griffiths, Foster, Ramsay, Eldridge, & Taylor, 2007) and to have yielded no evidence of improvement in self-efficacy, self-management behaviour or health status in the Netherlands (Elzen, Slaets, Snijders, & Steverink, 2007).

A further critique is the length of time any improvement 'sticks,' called decay of impact. For instance, both Franek (2013) in Canada and Krebs et al. (2013) in New Zealand conclude effects only last up to six months after the end of any programme. Many studies follow patients only for a short period after programme attendance, so any decay is often not evident. Studies that do consider a longer timeframe, disagree on the level of improvements retained by programme participants between six months and two years after a programme has finished. Although Barlow, Wright, Turner and Bancroft (2005) find improvements persisted for 12 months, others conclude that initial benefits are soon lost (Berzins et al., 2009; Bischoff et al., 2012; Sprague, Shultz, & Branen, 2006). One longer term study concludes that very few changes persist after three years (Khunti et al., 2012). Park et al. (2013) found that efforts to prevent decay of impact fail. For conditions that by definition go on for years, the seemingly inevitable and relatively speedy decay of impact diminishes even the modest improvement found in these programmes.

Referring back to the Institute of Medicine's (2003) inclusion of both the educational and supportive aspects of self-management support in their definition, the Stanford programme has been criticised for its "overt strategy" of knowledge enhancement (Wilson, 2007, p. 228). Again, language slippage reveals the emphasis of the educational aspect when Park, Green, Ishikawa and Kiuch (2012) refer to “self-management education.”

Both the Stanford and Expert Patient programmes have been beset with issues of poor uptake, recruitment and attendance and difficulty in reaching priority populations - the very groups whose needs are greatest (Greenhalgh, 2009; Rogers et al., 2008; Strine et al., 2005; Wilson & Mayor, 2006). Men are also significantly under-represented among group attendees (Galdas et al., 2014; Galdas, Fell, & Bower, 2015; Warsi, LaValley, & Wang, 2003).

In a systematic literature review, Grover and Joshi (2015) note the lack of research into the use of the chronic disease models and self-management support programmes with socially or ethnically varied populations. This leads to evaluations occurring with what Trappenburg et al. (2013) describe as “very heterogeneous patient populations” (p.136). Like research into LTCs generally, there is unequal uptake by, and so research into, people from different socioeconomic, ethnic and gender groups. Yet the results of programme evaluations are still generalised to the entire population (Elzen et al., 2007). For example, Murray Cram and Nieboer’s (2015) large study explores the health outcomes of over 5,000 people who had attended a self-management programme. The study’s moderately positive conclusions came from a 50% response rate from the self-selected attendees. There is questionable value in the generalisation of the conclusions to a population with perhaps a very different collection of resources, who have not previously engaged well with structured programmes.

Potential cost reduction in health care expenditure by decreased utilisation of health services remains a powerful rationale for the implementation of self-management support (Gately, Rogers, & Sanders, 2007; National Health and Hospitals Reform Commission, 2008; Wilson, 2005). Despite the goal of cost reduction as a key driver for the adoption of self-management support, a succession of studies have found no evidence of cost-reduction (Department of Health, 2003; Franek, 2013; Hibbard, Greene, & Tusler, 2009; Kennedy et al., 2007; Koch et al., 2004; Lee et al., 2013; Panagioti et al., 2014). Cost saving was one of the initial aims of Care Plus. However, early evaluations identify that patients enrolled in Care Plus have on average upwards of three more visits per year to their primary health care provider than those not enrolled (Rodenburg, Dryden, & Rodrigo, 2007). Regardless, the rationale of cost saving continues to be used to promote self-management (CBG Health Research Limited, 2006; Redman, 2007). Financial drivers were part of the rationale for the UK’s wholesale adoption of Lorig’s adapted programme as their Expert Patient Programme (Greenhalgh, 2009; Greenhalgh, Collard, & Begum, 2005).

The impact of the biomedical framing of self-management support

The development of the programmes from within a framework of biomedical assumptions has suppressed their effectiveness (Johnston et al., 2011). Within the self-management paradigm, the three programmes described (and others similar) have become de facto self-management support. Kendall et al. (2012) describe the Stanford programme as a good example of the overall dominant approach to self-management, which “tends to reinforce the current medical model of chronic disease and fails to adequately address the social factors that impact on the lives of people who have chronic conditions” (p.1).

The enduring pull of biomedicine has ensured a continued power imbalance in the relationship between the patient and clinician. The imbalance sees professional knowledge remain privileged over lay definitions and clinical values given primacy. Clinicians determine whether or not a patient is an expert using criteria that reflect biomedical values. For instance, Wilson et al. (2007) describe the common characteristics of expert patients as to be able to communicate clearly, to be organised and able to compartmentalise emotion.

The biomedical model provides what Rogers (2003) might term “a set of intellectual blinkers” for innovators to ensure the innovation fits their existing schema (p.107). That ownership of health knowledge rests with clinicians is unchallenged (Wellard, 1998). Overall, biomedicine’s continuing intellectual dominance has led to self-management support becoming part of medical knowledge, something to be dispensed, rather than something owned and carried out by people with LTCs (Seedhouse, 2005; Wheeler, Harrison, & Homes, 2009).

The importance of self-efficacy in self-management support, with its biomedical origins, has been criticised for its focus upon the individual (Taylor & Bury, 2007). Within the framework, the individual is envisaged as an autonomous actor, who lacks a social context, has an innate capacity for agency and who assumes responsibility for their self-management (Armstrong, 2013). More realistically, the individual’s family and entire social and psychological context both affect, and are affected by, the illness(es) (Korp, 2010; Williams, Manias, & Walker, 2009).

The inappropriateness of the focus on the individual is especially true for many cultures for whom decision making often occurs as a collective. For Māori in particular, the collective way of considering actions described by Metge (1986) does not sit well with ideas of personal agency and the individualistic assumptions of the self-management paradigm. The programmes that result have been critiqued as “homogeneous and fixed interventions … applied to a passive and decontextualised individual” (Clark et al., 2007, p. 515). These formalised programmes appear to be a “one-size-fits-all” solution offered to a cohort whose needs differ enormously.

The idea of self-efficacy is closely aligned to the belief that the most successful approaches to self-management support are those that aim to empower patients. Empowered patients are presumed to have the confidence to manage their LTC well and are therefore more likely to achieve behaviour changes (Health Foundation, 2011). These ideas are also intimately connected with the ideas of an innate personal agency which, in simple terms when related to self-management, makes the assumption that if a patient is ‘told what to do,’ self-management will result.

Ongoing diffusion

The UK Department of Health’s (2005a, 2005b, 2005c) implementation of the Chronic Care Model added evaluations from the United States, as well as work done by groups such as Kaiser Permanente, which stratified patients according to their health needs (Ham, 2009; Ross, Curry, & Goodwin, 2011). The pyramid stratifies the population into three broad groups according to the level of support required. Case management is prescribed for those in the top tier who are very high users of unplanned secondary care (Challis et al., 2010). The evidence for the benefits of case management is fairly weak and often conflicting (Brown et al., 2007; Ross et al., 2011; Singh, 2003).

The implementation of the model in the UK has been sporadic and the criteria not applied consistently (Challis et al., 2010). Alongside the care aimed at each tier, the policy format specifies that self-care skills training should be offered to people in each tier, self-care underpinned by “advice and support [on] healthy choices” (Challis et al., 2010, p. 11). The implementation process has led to formal self-management programmes being offered to people with significant LTCs (NHS Modernisation Agency, 2005).

Adoption as policy occurred alongside the presumption of a trouble free filtering down to people living with LTCs, via clinicians. The ongoing diffusion process occurred via professional publications and presentations from well-respected clinicians and academics. These included medical doctors such as Ed Wagner, Malcolm Battersby and Thomas Bodenheimer and nurses such as Kate Lorig. Two New Zealand medical doctors, Janine Bycroft and Jocelyn Tracey (2006) were influential in its adoption in New Zealand. Opinion leaders like these have been identified as crucial to any innovation's success (Vedel et al., 2013). Where the opinion leader shares the characteristics of the adopter, then the innovation has more chance of being successfully adopted (Rogers, 2003). The important role opinion leaders play in the diffusion of any innovation resonates with the role played by the health care luminaries whose clinical backgrounds were similar to the people they wanted to adopt self-management support.

Overall, there is relatively weak evidence of the programmes' efficacy to either improve people's self-management long-term or contain health care expenditure. Despite the weak evidence, the various components of the self-management paradigm have been eagerly embraced in New Zealand (as in most Western countries) at the government and policy levels for system-wide adoption. Wilson, Kendall and Brooks (2007) describe the programmes as "evangelised globally" (p.247). The rate of the adoption and initial diffusion was relatively speedy and widespread with no apparent dissent. The paradigm's salience with the values of these adopters accelerated the process and resulted in diffusion "in a form that is … palatable to health-policy planners" (Thorne, 2008, p. 9).

Self-management has been framed and absorbed to form a part of medical knowledge to be dispensed to patients, rather than something owned and carried out by people with LTCs. Unlike many successful innovations, the developers and initial adopters of the paradigm were not those who ultimately need to self-manage - patients - but policy makers (Adams, Price, Tucker, Nguyen, & Wilson, 2012; Rogers & Shoemaker, 1971). The innovation met the needs of the policy makers but ultimately it "lacked compatibility with the needs and behaviours of those expected to benefit from it" (Rogers, 2003, p. 106). With self-management, an innovation that purports to empower, paradoxically the 'self' to whom the innovation refers, has had an innovation imposed.

Summary

The literature review has explored the extant literature about self-management, moving from broad concepts down to the biomedically driven way self-management/support has diffused throughout the health sector. The assumptions of the self-management approach to care of people with LTCs, which largely fall out of its biomedical origins, have a powerful effect upon the way the paradigm has diffused and how it has been operationalised at policy, clinical and patient level.

The wealth of research into LTCs has tended to focus on aspects which have synergy with the biomedical model, especially research with a positivistic stance. Models and frameworks have been adopted at policy level and are the narrow part of the LTC/self-management research spectrum that has been eagerly embraced.

Because of the way self-management was built on to the pre-existing structure and strategies of health care delivery, it takes as implicit the assumptions of the biomedical model. The framework built upon the biomedical model has “failed spectacularly” to halt the increasing prevalence of LTCs (Jones, Hofman, & Quinn, 2009, p. iv).
The effectiveness of self-management support, as it has been implemented, as the best path to optimal health for people with multiple LTCs has been contested. Self-management support’s economic and commercial drivers are also challenged. The assumptions of biomedicine are woven throughout the models and frameworks. They have constricted the conceptualisation of both the problem and the solution. Of particular relevance is their assumption of agency and focus on the individual. The narrow focus has meant that the models assume that everyone has the choice to self-manage if they have the knowledge and that the best way to focus interventions is on the individual, an approach that ignores much of their social and whānau context.

I now move on to look at the theoretical terrain for the study that explores the experiences of people with multiple LTCs, which is directly shaped by the substance of the literature review.

Chapter Three: Theoretical terrain

Introduction: background and rationale for choice of frameworks

I now link the literature review and research approach with theories intended to broaden and frame the exploration of how people with multiple LTCs experience self-management of their health. Initially, I struggled with how to think about the data usefully in terms of a theoretical framework. My early thinking drew me to Actor Network Theory, which held potential for trying to explain the “entanglement of the social and the technical” (Ponti, 2012, p. 3). However, rather than something that would support and illuminate the analytic process, the ‘fit’ felt forced. At that stage of the study, the diffusion of innovation theory began to occupy a central theoretical position as described in the introductory chapter (Rogers, 2003). The importance of this theory gradually lessened as my interest in the association between inequality and the poverty of people with LTCs directed my reading towards the two complementary theories that eventually formed the theoretical terrain of the study.

The theories selected are Cockerham’s health lifestyle theory (2005, 2010, 2013a, 2013b) and Link and Phelan’s fundamental cause theory (1995, 2002, 2010; 2013). Both theories focus on how structural determinants affect health. These are used as a vehicle to consider aspects of the lives of people with multiple LTCs that are largely silenced within the current self-management discourse. They offer a framework for paying particular attention to the effect of social inequalities upon the self-management of LTCs. This chapter outlines these theories along with the rationale for their choice and considers how these scholars arrived at their conclusions. The standpoints of other authors who support or contest the theories are then described. The chapter concludes with a description of how this theoretical approach supports exploration of the collected data.

The current self-management approach is based on the premise that individuals have the capacity to shape the circumstances in which they live through personal agency (Emirbayer & Mische, 1998). The focus on innate agency ignores the importance of structural determinants and the two selected theories will support an attempt to redress that balance.

Cockerham’s Health lifestyle theory

Together, the influential Canadian Lalonde Report (1974), “Health for All” declaration (WHO, 1978) and the Ottawa charter (WHO, 1986) clearly articulate the effect of the structural determinants of health upon an individual’s life. The eminent medical sociologist William Cockerham’s health lifestyle theory focuses on these structural aspects (2005, 2010, 2013a, 2013b). Cockerham developed his theoretical approach to health inequalities in order to explore how and why all individuals are not offered equal opportunities to be healthy. In order to consider Cockerham’s theory, it is first necessary to summarise the work of the two authors whose work influenced his ideas, Max Weber and Pierre Bourdieu.

Max Weber

Weber (1922) was the first influential researcher to look at lifestyle in the late nineteenth and early twentieth centuries. The sociological exploration of lifestyle involves the articulation of the concepts of agency (or choice) and structure (or chance), which are discussed in more detail shortly. Despite Weber’s work not relating specifically to health, his work moved sociological thinking beyond the individual explanation for health outcomes.

Prior to Weber, lifestyle had been considered as something associated with taste and refinement and as something carried out by the most affluent socioeconomic classes, first outlined in Veblen’s 1899 book, the Theory of the Leisure Class (2008). The ongoing association of lifestyle with what Giddens (1991) calls “trivial superficial consumerism” (p.81) may be partially because some of Weber’s nuances were lost as his work was translated (Abel & Cockerham, 1993).

Sociological wisdom generally accepts that Weber viewed lifestyle as a choice (Abel & Frohlich, 2012; Cockerham, Abel, & Lüschen, 1993; Cockerham et al., 1997). Indeed, on balance Weber did believe in an individual’s capacity to choose their behaviour (Mommsen, 1989). However, scholars believe Weber’s main contribution to medical sociology to be the way he highlighted the dialectical interplay between the opposing ideas of agency and structure (Abel & Frohlich, 2012; Cockerham, 2006). This dualism identifies the inevitable interaction, or often an opposition, between the two and allows those that followed Weber to apply his work to social inequality.

Weber’s term lebensführung, or life conduct, was a major contribution to an understanding of lifestyle through his acknowledgement that people’s choices are constrained by their material resources (Weber, 1991; Weber & Kalberg, 2005). Weber also identifies that non-material aspects of structure also act as constraints, which include the normative rules of the community or status group to which people belong (Weber, 1991; Weber & Kalberg, 2005). Weber states that people have no choice but to adapt their lebensführung to the prevailing social and economic circumstances, an argument that leads to the conclusion that chance is very much socially determined.

Pierre Bourdieu

Bourdieu (1984) studied leisure activities in France in the 1960s. He noted that activities are shaped by both income and social status, with, for instance, tennis clubs or gym memberships beyond the economic and social reach of many. Bourdieu (1984) also explored the interplay of agency and structure, which led to the disposition to act he calls habitus. His work focused very much on class-orientated behaviours. He observed that the practices linked with lifestyle were so enmeshed in an individual's routine behaviour that they are acted out unthinkingly.

Like Weber, Bourdieu was very interested in the structural aspects of lifestyles. He believed that a person's experience of their social world creates the disposition to act in a certain way. Korp (2010) describes how, "in this way, habitus guides the individual's thoughts and actions in all social situations" (p.805). Bourdieu (1993, 1996) uses several evocative words to describe structure, including the German word trägen, which captures the idea of an individual being subjected to the dejecting burden of a heavy weight. Similarly, Bourdieu also uses the French term *la m*isè*re*, translated as the "weight of the world."

Bourdieu has been criticised for being deterministic, seeing individuals as trapped within their habitus, with little space left for agency (Abel & Frohlich, 2012; Williams, 2003). However, Bourdieu (1984) does state that normative behaviour patterns are not fixed and it is possible for individuals to deviate from their class trajectories.

Cockerham's work

Neither Weber nor Bourdieu focus specifically on health or inequalities. Cockerham (2005) aims to rectify the gap in sociological theory by building upon their work, to explain the effect of lifestyle on health. Cockerham (2004) describes health lifestyles as "collective patterns of health-related behaviour based on choices from options available to people according to their life chances" (p.95). In Cockerham's theory, the concepts of agency (choice) and structure (chance), and the effect of the interplay between them, are powerful influences upon health inequalities. The social context provided by structure acts as a counterbalance to agency (Cockerham, 2005).

The interactions between chances and choices configure health lifestyle and are demonstrated both by individuals and groups (Angel, 2011). Shared lifestyle practices are a characteristic of groups and these shared activities offer a sense of social cohesion and belonging for group members (Cockerham et al., 1997). Cornwell (1984) describes how shared living and working conditions shape group members' beliefs and expectations about health. These lead to shared social codes which guide group members according to the appropriateness of lifestyle choices (Cockerham, 2014). Intangibles such as group culture or expectations form part of the structural context which affects each individual (Abel & Frohlich, 2012). Cockerham's (2010) ideas about collective patterns of behaviour challenge the individualistic focus of many of society's current ideas about the causes and treatment of LTCs.

Cockerham (2005) describes his own work as the beginning of a theoretical formulation for day-to-day behaviour. Before his work, there existed a wealth of research which linked lower socioeconomic status to poor health. There were however, few attempts to theorise this relationship between class, health and lifestyles or the effect of the relationships between structure and agency (Abel & Frohlich, 2012; Williams, 2003).

Cockerham's (2010) theory "accords structure a role that is consistent with its influences on the empirical world" (p.178). His theory states that social factors do not merely influence health, but have a *direct causal* effect on health (2013b). *Every* phase of *any* disease can be shaped by its social context. They range from the rate of exposure and host susceptibility through to the course and outcome of any disease. The causal effect is "regardless of whether the disease is infectious, genetic, metabolic, malignant or degenerative" (Cockerham, 2013b, p. 1). The structural determinants or chances ensure that choices are not available equally to all and "chance mitigates choice" (Cockerham et al., 1997, p. 334). Cockerham's work is significant because his argument goes further than many previous authors, who merely point out the association between lower socioeconomic status and poorer health.

Weaver, Lemonde, Payman and Goodman's (2014) study provides an exploration of the tensions between agency and structure by examining the ability of individuals with diabetes to cope with the recommended dietary restrictions. They found the lack of "economic, social, and cultural resources conspired to undermine dietary management" (p.58). People with the most resources were more successful and this translated as appearing more motivated to clinicians. A study of the health of people in a Welsh coal mining community offers another example (Williams, 2003, commenting on Jones, 1991). For the residents, "the weight of structural conditions was so heavy that individual capabilities and capacities were ineffective" (p.54). Emirbayer and Mische

(1998) believe there is no hypothetical moment in which agency actually becomes ‘free’ of structure.

Health lifestyle theory and long-term conditions

Health behaviour that is linked to lifestyle increasingly has a central role in the health outcomes of people with LTC (Cockerham, 2006). Most lifestyle decisions that influence health sit firmly outside the health care system and range from alcohol intake to whether to wear a seat belt in the car. Much health care, including self-management support, is based on the assumption that patients have the freedom to make healthy choices (Williams, 2003). Stockols’ discussion of community health promotion, describes how these initiatives almost universally emphasise strategies for individual behaviour change and neglect the “social underpinnings of behaviour” (1996, p. 282).

There are a number of health models which underpin the self-management suite of interventions. These include the popular Health Belief and Stages of Change models (Brewer & Rimer, 2008; Champion & Skinner, 2008; Prochaska, Redding, & Evers, 2008). These models, and many others have an individualistic focus with a common goal to eliminate individual risk factors (Cockerham, 2005; Link & Phelan, 1995). Risk factor epidemiology focuses on the individual behavioural patterns which affect health and allow society to ignore the effect of structure on health (Frohlich, Corin, & Potvin, 2001; Paterson, 1981). Yet individually based health behaviour interventions have “limited reach and staying power” (Orleans, 2008, p. xiv). Dumas (2014) states bluntly that individually based health interventions that ignore context do not work.

Models of health care that do consider multiple physical, social and cultural dimensions and focus on the interplay between the situational and personal factors to influence health outcomes are called socio-ecological models of health (Golden & Earp, 2012; Stokols, 1996). One well articulated example is Delormier, Frohlich and Potvin (2009) who conclude that interventions to resolve obesity that aim at individual level eating behaviours, fail because food and eating are social practices and eating patterns form from within groups, relationships and the wider social context.

Abel and Frohlich (2012) report on a successful programme aimed at increasing physical activity among socially disadvantaged German women, which did consider their structural context. The programmes promoted and used interventions that worked on both individual agency and structural opportunity and the interactions between the two. However, despite many similar documented successes, these types of programme have not diffused widely.

Fundamental cause theory

Cockerham’s health lifestyle theory (2005) looks to restore the balance between structure and agency when considering lifestyle and health. He highlights the significant and persistent disadvantages poorer populations experience. Lifestyle activities that are considered unhealthy are consistently carried out more by disadvantaged populations where any improvements are much slower to occur (Cockerham, 2013b; Ministry of Health, 2009a, 2015). Cockerham did not explore why these inequalities persist. However, two authors whose work meshes well with Cockerham’s thinking did explore the link with inequalities.

Bruce Link and Jo Phelan’s writing appears as a chapter in a sociological textbook edited by Cockerham (Phelan & Link, 2013) and Cockerham (2014) discusses their theory in his own articles. Link and Phelan’s (1995, 2001, 2002, 2010; 2013) fundamental cause theory appears to offer an opportunity to explore this additional facet of the issue and so adds to the depth of analysis possible in this thesis.

Link and Phelan’s ideas of fundamental causality offer a way to understand the relationship between socioeconomic status and health outcomes (Lutfey & Freese, 2005). Their work explores why the association between socioeconomic status and mortality persists, and is reproduced over time, despite changes that have improved so many disease risk factors such as poor sanitation or housing. For example, inequalities in health persist in countries such as New Zealand and the UK where a welfare state removed many of the financial barriers to health care (Link & Phelan, 2010). They propose that inequalities endure because people with a similar social status have “a set of flexible resources” (Phelan, Lucas, Ridgeway, & Taylor, 2014, p. 22). These resources include knowledge, money, power, education or social connections and can be used to benefit health regardless of health condition and “protect health no matter what mechanisms are relevant at any given time” (Phelan, Link, Roux, Kawachi, & Levin, 2004, p. 267).

Link and Phelan (2010) developed their theory in the 1990s in response to the risk factor hypothesis. That hypothesis argues very plausibly that ill health occurs as a direct result of factors such as poor sanitation and links social conditions to a disease in a chain of causality. Despite the explanation that this chain of events has led to the decline of many diseases and conditions through the removal of the intervening risk factor, health inequalities persist. Link and Phelan argue that every health advancement improves the lot of the affluent more than that of the poor.

Link and Phelan, along with several co-authors, propose that “regardless of the disease, people use their available resources to overcome risk factors for any disease” (Carpiano, Link, & Phelan, 2010, p. 242). They argue that living in a lower socioeconomic group will always mean having fewer resources (whether psychological, financial or social) to mobilise when faced with any health issue. Therefore, social class embodies something that is fundamental. Whatever the disease, the resources enjoyed by those of a more affluent social class will be used in a variety of ways and result in them experiencing the disease less often and less severely. Link and Phelan (1995) describe these resources as extensive and wide-ranging enough to make socioeconomic conditions a fundamental cause of (ill) health.

Many authors have used the fundamental cause theory to examine how groups with more resources are more able to embrace an innovation earlier and more thoroughly as a disease becomes more preventable due to medication, technology or healthier lifestyle practice innovations. For example, Chang and Lauderdale (2009) identify the marked difference in uptake of statins and Lutfey and Freese (2005) the different usage of insulin pumps between socioeconomic groups. The earlier uptake means these groups disproportionately benefit.

An example of this process is colorectal cancer, which was once more prevalent in people in higher socioeconomic groups. Saldana-Ruiz, Clouston, Rubin, Colen and Link’s American study (2013) found that once ways to prevent, detect and treat the cancer became known, the social and economic resources held by an individual began to affect prevalence. People in lower socioeconomic groups now have a markedly higher prevalence of colorectal cancer than the more affluent. The trend has been reproduced in England, where the uptake of the national free bowel cancer screening programme introduced in 2006 is markedly less by those in lower socioeconomic groups (Von Wagner et al., 2011).

Rubin, Clouston and Link (2014) also demonstrate the fundamental cause theory. Their study tracked and compared changes over time in the mortality rates of people from different socioeconomic groups who had either pancreatic or lung cancer. Forty years ago, both types of cancer had higher death rates amongst the more affluent. However, medical advances in both prevention and cure of lung cancer have been rapid, contrasted with pancreatic cancer where there are still few preventative or treatment options. Since the advances in lung cancer care, incidence has plummeted amongst the more affluent and decreased much more slowly among poorer populations. Pancreatic cancer rates remain unaltered. A large study in Scotland also identified a clear socioeconomic gradient for avoidable causes of death, but none for causes of death that are currently unavoidable (Scott et al., 2013).

Lutfey and Freese (2005) capture the causal relationships between socioeconomic status and diabetes outcomes when they compare ethnographic data between two American diabetes clinics. Overall, people with a higher socioeconomic status have fewer predisposing factors and are better resourced to deal with the condition. They therefore have better health outcomes when, and if, they do develop diabetes.

Therefore, although the mechanisms that cause ill health have changed over time, new mechanisms replace the old. Those with more resources can better deploy them and are able to “move in a more fluid fashion to embrace new health behaviours” (Cockerham, 2005, p. 58). The recent work of McAuley (2014) found new digital health technologies were utilised more by the better off and so likely to increase health inequalities. A study by Polonijo and Carpiano (2013) tested Link and Phelan’s theory when they investigated the uptake of the human papilloma virus vaccine. The theory predicts that the free vaccine, which will prevent cervical cancer, would be taken up more by girls of higher socioeconomic status, and the vaccine become another thing to maintain health inequalities. The results show exactly that.

Link and Phelan’s ideas have received criticism around three main issues.
First is the lack of clarity around both their use of socioeconomic status as the criteria to differentiate between social groups and any explanation of the intervening mechanism in their fundamental theory (Lutfey & Freese; Mirowsky & Ross, 2003). Secondly, researchers from diverse disciplines have attempted to disentangle the selection and causal mechanisms between social factors and health (Goldman, 2001). There are still advocates of the social selection hypothesis. That is, people with ill health tend to move downwards towards a lower socioeconomic group, or are less able to move out of it through social mobility. This “drift” has been associated particularly with long-term mental illness since the work of Goldberg and Morrison in 1963. For example, Thoits (2006) found employers systematically screened people with mental illness out of skilled jobs, so they drift down the social hierarchy. The UK’s influential Black and Health Divide reports support the idea of some social selection (Townsend, Davidson, Black, & Whitehead, 1992). However, although there are some people for whom social selection appears to be true, overwhelmingly the evidence supports the social causation hypothesis – lower social class itself leads to ill health (Marmot, 2005). The third criticism comes from advocates of the risk-factor hypothesis. The introductory chapter introduced authors who described ways poverty can both lead to, and result

from, ill health without necessarily seeking an explanation (Marengoni, 2008; Mirolla, 2004; Wolff et al., 2002). Support for a specific risk factor hypothesis is still strong and many authors claim that a specific intervening variable causes the enduring link between poor health and poverty (Mackenbach, 2012). For instance, Batty, Der, Macintyre and Deary (2006) believe IQ or personality account for at least some of the differences.

Proponents of the influence of other risk factors include Stronks, van de Mheen, van den Bos and Mackenbach (1997), who explore the relative strengths of the association between income, education or occupation and health. Mirowsky and Ross (2003), Cutler and Lleras-Muney (2010) and Goldthorpe and Jackson (2010) all argue that educational achievement alone is the most significant influence on a person’s subsequent social status. Benzeval et al. (2014) argue that financial status is central to health status, through a number of specific causal mechanisms. These various pathways include the mechanisms where money buys both the goods and the ability to access a health-enabling social life as well as avoiding the stress of insufficient funds. The theory seems to share many similarities with the work of Link and Phelan, without the specific advocacy of social class as a fundamental cause of health inequalities.

The enduring strength of the risk factor hypothesis means that studies continue to offer interventions that remove or insert a specific variable in order to reduce inequalities. For instance, in a recent Australian study, Sharma, Hauck, Hollingsworth and Siciliani (2014) conclude that an increased tax on sugared drinks would lead to more weight loss amongst the people from poorer homes than the more affluent. Link and Phelan’s theoretical reasoning would instead argue that any reduction in consumption of sugary drinks would occur more amongst the more affluent so increasing inequalities, and high sugar sodas would be replaced as a cause of obesity by another intermediary factor.

Current preventative health care and self-management programmes tend to focus on risk factors and so ignore the fundamental causes that lie beneath these (Link & Phelan, 2010; Rose, 1992). Therefore, the current system disadvantages “the less empowered groups while serving at the same time to advantage the dominant group” through informal processes which are accepted as normal and yet perpetuate discrimination (Human Rights Commission, 2012, p. 3).

A framework for exploring self-management

Cockerham’s (2005) health lifestyle theory aims to “restore structure to its appropriate position” (p.54). Between these freedoms and constraints, agency and structure are effectively co-dependent and the relative contributions of both need to be considered. Structure both limits options and shapes decisions and for many individuals structure can be so overwhelming that “agency is rendered inert” (Cockerham, 2013b, p. 54). It must also be remembered that structure works in two directions. As well as constraining the agency of those who are disadvantaged, structure reinforces the agency of the affluent through the extra resources they can bring to bear on any situation to influence the outcome. Especially relevant to the long-term nature of LTCs, these advantages or disadvantages accumulate over time into bundles of privilege (Cockerham, 2013b). If the self-management of LTCs is considered in the light of Cockerham’s (2010) ideas, the failure of the narrow individualist paradigm to consider that choices are structurally constrained becomes very apparent.

The effect of family and community groups is also significant for those living with LTCs. Cockerham (2010) describes Weber’s work, which explores the values or rules of the groups to which an individual belongs and develops his ideas. He identifies how different aspects of lifestyle merge to form patterns of conduct and behaviour that represent habitual ways of acting. Rees Jones, Papacosta, Whincup, Wannamethee and Morris’s (2011) work reinforces the idea of each individual’s behaviour being profoundly affected by the social groups in which they live. The weight of community norms further dilute agency and make behaviour changes less likely. The importance of collective identity on people’s decision making is overlooked where self-management support interventions are aimed at an individual.

People who live in the same circumstances internalise the same life chances and so share a class perspective, which leads them to “configure their lifestyles in particular ways” (Cockerham, 2006, p. 5). Townsend (2012) describes specific behaviours that seem perfectly normal to the individual member of a group that might not appear so from the outside. These individual routine practices are influenced by structure and combine to form a “cognitive map for the individual’s social world” (Cockerham, 2006, p. 8). Examples range from smoking and tattoos to spray tanning with “bodies a site on which cultural practices of social classes are inscribed” (Turner, 1992, p. 90). These collective aspects have relevance because people make decisions, such as about activity or meals, in their whānau or social context, yet the self-management framework addresses these in terms of the individual.

The idea of a cognitive map for people in the same circumstances is also relevant when considering clinicians who care for people with LTCs. They are likely to share similar life experiences and levels of affluence with each other that may differ from people with LTCs and so make patients' decisions less easy to understand.

The fundamental cause theory would suggest that self-management can be considered as another factor that people in higher socioeconomic groups can adopt more readily since they possess a wider range of resources. So self-management becomes another fundamental cause of inequality (Frohlich & Potvin, 2008). The unequal uptake of self-management support in different social groups suggests this to be so. There is, therefore, potential for the changing disease profile of more prevalent LTCs to increase the inequalities within society, as those attributes essential to managing LTCs well are less available to the already disadvantaged (Redman, 2007).

Summary

This chapter positions the work of both Cockerham (2005, 2010, 2013a, 2013b), and Link and Phelan (1995; 2010) as a framework to explore how individuals with multiple LTCs self-manage and experience self-management support. Both theories consider the wider context of patients living with multiple LTCs that are likely to have a significant effect on their health but are not currently considered within the self-management discourse.

Cockerham urges the restoration of structure to equal prominence with agency when explaining the effect of lifestyle on health. Link, Phelan and their collaborators add the additional lens of the fundamental causes of inequality, where the combined lack of material and non-material resources ensures inequalities persist.

The fundamental, contextual aspects of ill health are well known. However, the power of the biomedical model has meant that these issues and concerns are in practical terms largely overlooked. Link and Phelan's exploration of how social class influences multiple diseases in multiple ways highlights how any study of ill health needs to be considered in a framework that is wider than the narrow biomedical model and considers the economic and cultural forces that influence people's lives (Williams, 2003).

The next chapter builds on the terrain set up by these theoretical perspectives and describes the most appropriate methodological stance and research methods to support the exploration of these ideas.

Chapter Four: Methodology and research method

Introduction

The previous chapter laid out Cockerham's health lifestyle theory (2005, 2010, 2013a, 2013b) and Link and Phelan's fundamental cause theory (1995, 2002, 2010; 2013). These form a theoretical terrain for an in-depth exploration of the experience of people with multiple LTCs. I now move to outlining the paradigmatic position that supports the ontological and epistemological stance for this research topic and the subsequent research design. The methodological decisions made in this study aim to ensure a logical flow between the area of research, the data and the theories outlined in the previous chapter (Clough & Nutbrown, 2012; Foss & Ellefsen, 2002). Following this the rationale for, and assumptions behind, the analytic strategy and my positioning as a researcher within the research are explored (Braun & Clarke, 2006; Yin, 2013).

The research process is then described. Firstly, the overall study design will be outlined, including the interdependent Māori consultation and ethical review. The study participants are then introduced and the recruitment and data collection processes described. Data analysis and the quality criteria for the study are then outlined.

Paradigmatic position

Ontology and epistemology

My paradigmatic position is influenced by both the research question of how people with multiple LTCs experience the self-management approach to health care and the gaps revealed in the literature review. The first two chapters addressed the ongoing dominance of the biomedical model, with both LTC care and associated research found to be rooted firmly in its assumptions. The self-management discourse has developed in a certain way influenced by the taken for granted, but largely silent, assumptions of biomedicine. In order to challenge that hegemony, a particular research approach is required.

A relativist ontological stance was adopted as it posits that, what is seen as truth varies: there is no single truth 'out there' (Denzin & Lincoln, 2000). Alongside this stance, sits a socially constructed and subjectivist epistemology. The nature of knowledge is constructed and each aspect of reality can be viewed from several vantage points (Cheek, 2000). These multiple viewpoints are an integral aspect of this thesis in order to explore patients' experience the self-management approach, whilst problematising the nature of the biomedical model.

The intent of the study was to explore the experience of individual patients living with complex multiple LTCs and the significance to the participants of self-management, however it is conceptualised. Individuals actively negotiate their own meaning (Broom & Willis, 2007). It is these patients' beliefs, attitudes and version of truth that affect their daily decisions about their health. Whether these beliefs and understandings correspond with some objective truth is irrelevant. Similarly, clinician-participants' understanding of reality is also valuable because their beliefs affect their actions.

Constructivist/Interpretivist paradigm

A relativist ontology and subjectivist epistemology led toward a constructivist or interpretivist methodology. The approach acknowledges the fact that people make what Guba and Lincoln (1994) called "multiple, intangible mental constructions" (p.110) and interpret the world around them in active and ongoing ways (Gately, 2008). For LTCs, an interpretivist approach acknowledges that illness is to a degree socially constructed – shaped by its social and cultural context (Barker, 2010). The constructivist perspective is relevant for exploring self-management support. From a constructivist educational context (which has implications for the educational focus of much self-management support), Twomey Fosnot (2005) acknowledges that education can not be directed "to get everyone to the same 'aha' at the end of the lesson" (p.80).

Constructivism values context

Social constructivism insists we take a critical stance against our taken for granted ways of understanding the world. It challenges the view that conventional knowledge is based upon an "objective, unbiased observation of the world" (Burr, 1995, p. 2). Constructivism places value upon both context and subjectivity, reflected in Udlis' (2011) statement that "self-management does not occur in a vacuum" (p.131). The approach led to a research design that aims to understand and value the participants' subjective and experiential perspective of living with multiple LTCs (Creswell, Plano Clark, Gutmann, & Hanson, 2003; Guba & Lincoln, 1994).

My personal positioning in the study

Constructivism's transactional epistemology affects my position as the researcher. The interpretive nature of the research focuses on the intersubjectivity between the research participants and myself. Researchers are part of the research, whether acknowledged or not (Clough & Nutbrown, 2012; Oakley, 1993). For interviews, the interviewer inevitably affects the outcome as the interview discourse is jointly constructed with the participant (Cornwell, 1984; Hertz, 1997; Mishler, 1986; Wells, 2011). Inevitably the relationships built with research participants influences the research findings (Brodsky, 2008; Griffin & May, 2012).

Historically, the primacy of objectivity in positivism has meant the researcher attempted to distance herself from the participants within scholarly discourse (Jones, 1997). Charmaz and Mitchell (1996) call this distancing the “myth of silent authorship” and Lincoln and Guba (2000) state that it is impossible for there to be no trace of the author in a scholarly text. As data collection progressed, I became increasingly aware of my own role within the data collection. Finlay (2002) describes reflexivity as an explicitly self-aware analysis of one’s own role. An increasing number of authors talk about the personal reflective voice of the author (Grbich, 2004; Lincoln, Lynham, & Guba, 2011; Riessman, 2008).

A constructivist approach acknowledges that as the researcher, I interpret the data during the research process and select which parts of the data convey the essence of its meaning (Sandelowski, 1993). It is therefore important to be explicitly aware of these interpretations, explore the biases I bring to the research and demonstrate evidence of taking responsibility for the choices (Cohen & Crabtree, 2006; Rivas, 2012).

Part of the research process involved an examination of my own interpretations and how they emerged, as my values inevitably affected the inquiry (Brink, van der Walt, & van Rensburg, 2012; DeForge & Shaw, 2012; Hertz, 1997). My own position in society influenced the research at each stage of the process, despite efforts to both minimise and acknowledge any effect. My presence as a white, female, educated nurse influenced both the data produced and the analytic process. As well as wanting to reflect some of these reactions, I was also aware that any prejudices held, or judgements made, were likely to be replicated in many clinicians, and in the values of the system as a whole, through shared cognitive maps (Cockerham, 2006). These were potentially representative of what the patient-participants experience when they receive health care. The final chapter contains further personal reflection on this process.

An analytical strategy was selected to best explain the research findings, make the data meaningful and link the case study data to the concepts of interest (Gibbs, 2007; Liamputtong, 2013). After the data collection period, along with a wealth of data, I was left with a very strong sense of having been told rich and complex stories, which often seemed utterly detached from the self-management programmes with which I was so familiar. I also had a strong sense of obligation to the participants, whose powerlessness amidst their LTCs was tangible. I wanted as far as possible to both try to respect their experiences and to retain the uniqueness of their stories in their entirety.

The complexity of the data is also a key part of the findings. LTCs are often only a small part of patient-participants' lives, yet they are expected to engage with a health care system that overlooks these complexities. Each of the patient-participants' unique contexts sits in stark contrast to the homogenous health system.

As a consequence, several decisions were made about ways to analyse and report the findings. The first issue was how to avoid fragmentation of the individual's story and to give the reader a real sense of each participant, avoiding a biomedical focus on disease and consequent neglect of the patient experience (Bury, 2001; Mishler, 1986; Riessman, 2012). The intent was, as Sandelowski (1993) described, to reduce the story in order to grab its essence, whilst trying not to fragment people's experiences (Elliott, 2005).

My intent to foreground the individual patient-participants' stories and to convey a sense of each participant to the reader is reflected in the decisions about research methods. The theoretical terrain then serves as a lens through which the issues are surfaced through thematic analysis. The health lifestyle and fundamental cause theories are operationalised to focus on the aspects of living with LTCs that relate to the impact of inequalities in and structural determinants of health (Cockerham, 2013b; Link & Phelan, 1995). The theoretical position sits well with a multiple case study research design. The emphasis upon context and maintaining the patient at the centre of the research allows a rich description in the participants' individual natural context, bounded by space and time (Hancock & Algozzine, 2006).

Overall study design

The study set out to explore the patient-participants' experience of multiple LTCs, including consideration of the range of factors that affect their health and the health services delivery of self-management support. The person-centred research attempted to explore these individuals' experiences over time and meet the research aim to give primacy to the voices of the participants with LTCs.

Multiple case study

A multiple or collective, exploratory case study research design was selected, which is congruent with an interpretivist paradigm that assumes that reality is a social construct (VanWynsberghe & Khan, 2007). Case study appears to be an appropriate design to keep the experiences of the complex individual with multiple LTCs intact through an observational and reflective process (Finlay, 1998). Keeping experiences intact is important when it is suspected that contextual conditions are relevant to the phenomenon being studied (Baxter & Jack, 2008; Lauckner, Paterson, & Krupa, 2012). The holistic focus of case studies has the potential to redress some of the imbalance caused by the wealth of reductionist research into LTCs. Case study retains the fibres that hold a story together rather than reductionist methods, which discard them (Thomas, 2011).

The two main authorities on case study are Robert Stake (1995, 2005a, 2005b) and Robert Yin (1994, 1999, 2009, 2011, 2013, 2004). The authority whose work resonated most with the needs of this project was Stake. Boblin, Ireland, Kirkpatrick and Robertson (2013) describe Stake’s epistemological approach as based upon a constructivist paradigm. Stake’s philosophical position differs to Yin’s, although the two authors' approaches did move closer in their later work. Stake viewed subjectivity as an essential aspect of understanding, with emphasis upon holistic treatment of a phenomenon (Boblin et al., 2013).

Stake’s stance can be contrasted with Yin’s more structured approach to case study research with a ‘neutral’ researcher (Boblin et al., 2013; Brown, 2008). Yin and Stake emphasise different features of case study. Yin favours data collection with a more methodical, quantitative flavour to data collection and analysis techniques (VanWynsberghe & Khan, 2007). Stake’s more interpretive intent that “builds a clearer view of the phenomenon” offers a better fit with the epistemological stance of this study (Brown, 2008, p. 6).

Stake’s idea of commencing with a flexible conceptual framework also resonates (Boblin et al., 2013). Stake’s intent with case study is to better understand the specific case in its “particularity and ordinariness” (Baxter & Jack, 2008, p. 548). For Stake (2005a), the object of study is the most important thing, rather than specific methods or a desire to understand an abstract concept or build a theory (Boblin et al., 2013).

The previous two chapters identified the gap in research that involves patients with several LTCs and complex health needs. Conducting case studies within their natural contexts, using what Geertz (1973) calls a thick description, offers rich descriptions of complex phenomenon and gives an in-depth understanding of a small number of cases set in their real world (Baxter & Jack, 2008; Gerring, 2007; Hancock & Algozzine, 2006; Johansson, 2003).

The status of case study has been debated and has been described as a methodology (Creswell, 2007), a method (Crotty, 1998) or neither. VanWynsberghe and Khan (2007) put forward the latter argument and claim that because case study offers no clear guidelines about exactly how data collection and analysis ought to proceed it is not a method itself. Yin (2009) echoes Creswell's sentiment that case study is more than a mere "data collection tactic" and holds a significant position as a methodology (p.14). Stake's (2005a) belief is that "case study is not a methodological choice but a choice of what is to be studied" (p.443).

Another rationale for the choice of multiple case study is a hope that it will mesh well with the Māori participants, who are over-represented amongst people with multiple LTCs and under-represented in research (Smith, 2005). Although this is not a study initiated for Māori by Māori, case study echoes some of the principles of Māori-centred research approaches, which aim to "uncover the many experiences and 'voice' of the participants emphasising complexities rather than commonalities" (Bishop, 1995, p. 78). It stresses the importance of the whole person situated firmly in their social and whānau context and considered in their entirety (Cram, 2013).

Study design

The data collection methods allowed the exploration of how the wider context of people's complex lives impacted upon their experience of self-management and ultimate health, and explored the intermediate factors that lay between their illnesses and self-management (Gerring, 2007). A broad phenomenon to be studied, the chosen research method allowed space to be left within the research enterprise for unexpected issues to become apparent - a "target not a bull's eye" (Stake, 2005a, p. 6).

Māori consultation

The placing of the Māori consultation is important. The ongoing process began before recruitment and design planning started and continued throughout data collection, analysis and writing. The recruitment of Māori participants required careful consultation with local Māori support people.

As a Pākehā [non-Māori or New Zealander of European descent] researcher, the role ethnicity plays is important to consider and was addressed from the outset. Bad experiences by Māori research participants have previously led to reluctance to be part of mainstream research (Bishop, 1997; Wilson, 2008). Historically, Māori have failed to benefit from mainstream research, which was often underpinned by deficit-base assumptions (Cram, 2013; Smith, 2005). Tollich (2002), noted that sensitivity in the area has led to what he called Pākehā paralysis, where researchers exclude Māori participants from their research for fear of offending.

During the research process, the group I refer to as my Māori research whānau offered encouragement, advice and support. The initial consultation process began with approaching two Kaumātua [respected Māori elders] who were known to me and experienced in the health field. These two remained a constant support throughout the study and suggested (and when necessary, introduced me to) other potential support during the study to help at specific times. The intent was to achieve, as much as possible, culturally responsive research to help me understand all the patient-participants' lived realities of LTCs. The aim was to ensure the participants reflected the people who have multiple LTCs, and to ensure ongoing engagement over the extended data collection period.

A consistent message from the group was the importance of the initial engagement process, of long-term relationships and kanohi ki te kanohi [face-to-face] encounters. They recommended several texts, which also stressed these features (Bell, Tumilty, Smith, Hale, & Kira, 2016; Cram & Pipi, 2000; Keefe, 1999). The research design of longitudinal case study data collection, where enduring relationships are inevitably developed, sat well with their advice. Cram (2014b) summarised that “establishing relationships is the foundation of working with Māori in a culturally responsive way” (p.5). The support continued throughout the research process to maintain the focus on the implications of cross-cultural research and to ensure that any cultural issues were not overlooked or misinterpreted but considered and addressed promptly.

An example was my struggle to understand why one participant attended, or perhaps over-attended, his general practice but apparently ignored any advice he was given. Discussion with a member of the group explained whakamā more deeply than I had previously understood. Whakamā is a psychosocial construct in Māori, with no exact

Western equivalent (Sachdev, 1990). Whakamā is often understood as shyness, modesty or embarrassment, but it has a wider meaning, including feelings of self-abasement, being misunderstood or feeling incapable and afraid. Whakamā is explored more in the findings chapters. The research whānau also stressed the importance of not presuming a response was due to culture. The consultation provided some reassurance that issues that related to culture were not being overlooked.

During the research process, it became clear that several of the themes were better explained using Māori terms. Translations can vary and often seem to offer a shallow or superficial comparison. However, I was advised to collaboratively settle on definitions and clearly explain how a term is to be used then to stick with that meaning. As a non-Māori, I am using the definitions that the research whānau have offered. I appreciate my understanding may be simplistic, but hopefully respectful and consistent.

The support from the research whānau comprised regular face-to-face meetings, text and email questions and answers, telephone and Skype sessions. These helped to mitigate the inevitable view of the data through a Pākehā lens and helped me do the participants' stories justice. Feedback received after I shared the first two anonymised interview transcripts, was that the approach was right because the participants were "opening up to you." The amount of contact varied. During recruitment and data collection, it was sometimes more than once a week, at other times, every two months. There is more information about the Māori consultation process in Appendix one.

Sample and recruitment

Sixteen people who had several significant long-term health conditions and were enrolled in mainstream primary care were recruited for a multiple or collective case study (Stake, 2005a). The main data sources were two face-to-face, individual, semi-structured interviews with each patient-participant. In addition, these patient-participants' GPs and the PNs of eight patients were each interviewed once.

An ideal recruitment process would have been to first recruit the patient cohort, around whom the research is firmly centred. However, historically, researchers have found it difficult to engage in research with GPs for many reasons (Carryer, Budge, Hansen, & Gibbs, 2011; Chang, Horsburgh, Norris, & Braund, 2011). It was necessary to consider this issue. The sample needed to have a willing GP, to ensure patients were not recruited and their GPs subsequently found to be unwilling to participate. To address the issue, the recruitment process occurred in several phases.

Firstly, a number of group general practices were approached to identify a pool of ‘research-friendly’ practices that were generally supportive of being involved in the research process. Six group practices situated in provincial New Zealand, all with a high percentage of patients from high needs populations were approached. They all agreed to participate in principle. Once the agreement had occurred, the second phase occurred in two threads.

Initial engagement with potential Māori patient-participants occurred with support from the Māori research whānau and network, whakapapa[3] or snowball sampling, which acknowledges the importance of the chain of relationships during recruitment. They talked to their community networks and came back with contact details of people willing to participate. Their GPs were then telephoned to ensure they were still willing to participate (they all were), following which the potential patient-participants were telephoned to explain more about the process. If patient-participants were still keen to participate, information sheets and consent forms were posted or hand delivered (depending on the individual’s preference) and arrangements for further contact that suited the participants were made. A similar process was undertaken for the Pasifika participants. They form a small percentage (3.4%) of the local population, but their experience of LTCs and utilisation of services often differs from the rest of the population (Sopoaga, Buckingham, & Paul, 2010; Young, 1997).

For the non-Māori, non-Pasifika population, flyers and posters were distributed in the research-friendly practices (see Appendix three). In addition, GPs and PNs pointed out the flyers to patients whom they thought might be interested. The follow-up from initial contact progressed in the same way as the previous section. One Māori and seven Pākehā participants were recruited this way.

The recruitment plan successfully ensured that of the 16 patient-participants, six were Māori, another two Pasifika and another four of the European participants live in the poorest quintile. The result was 12 of the participants were from the high needs, most disadvantaged population who experience much higher rates of LTCs.

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[3] In this context, whakapapa sampling means recruitment via established relationships

Data collection

The number of participants is not fixed in qualitative methodology (Beitin, 2012; Kumar, 2011). Recruitment was initially planned to continue practice by practice until data saturation occurred. However, another issue to be considered was practicality. Because of the prolonged engagement planned with the patient-participants, after 16 participants had been recruited and interviewed, it seemed the maximum manageable number had been reached. Mason (2010) identified that often in doctoral studies there are factors other than data saturation that ultimately influence the number of participants.

NAME	AGE	SEX	ETHNICITY
Yvonne	67	F	Samoan
Losefo	67	M	Samoan
Tane	47	M	Māori
Rawiri	68	M	Māori
Huia	57	F	Māori
Aroha	56	F	Māori
Tamati	74	M	Māori
Wiremu	76	M	Māori
Diane	65	F	European/Pākehā
Beth	88	F	European/Pākehā
Eva	56	F	European/Pākehā
George	69	M	European/Pākehā
Lou	67	F	European/Pākehā
Margaret	56	F	European/Pākehā
Hayley	26	F	European/Pākehā
Paul	51	M	European/Pākehā

Table 1. Patient-participant demographics

Sixteen patient-participants offered a good range of patient experiences and allowed for diversity of LTCs, ethnicity and socioeconomic group. The number also allowed leeway for some participants potentially dropping out. Data collection lasted from March 2012 until December 2013 and the timetable can be seen in Appendix six.

Participant interviews

Patient-participant interviews

The aim of the semi-structured interviews was to attain rich, personalised information (Hancock & Algozzine, 2006). Yin (2013) describes interviews as central to case study analysis. They are a useful tool for seeking to understand the perspective of the interviewee as well as the events they experience (Kumar, 2011; Mol, 2002). The process enabled the exploration of participant lives in “its daily details” (Borer & Fontana, 2012, p. 45). This was appealing, as it seemed possible that it was those small details that had big effects on participants’ lives and LTC self-management.

The interviewees each chose the venues for their interviews. All interviews were digitally recorded with permission and most were professionally transcribed, apart from a few shorter interviews that I transcribed. All patient-participants’ first interviews and most of the second occurred at their homes, which offered a fuller picture of the participants’ lives. The duration of patient-participant interviews ranged from forty minutes to two hours.

Following transcription, the recordings and transcriptions were carefully cross-checked for accuracy and further notes made in a research log. Each participant was offered the opportunity to read the transcript, which several patient-participants chose to do. All but one chose to receive their transcripts via email and provided feedback the same way.

The shape of the second patient-participant interview evolved after preliminary analysis of the data from the other interviews and contacts. Using these data to help inform the second interview allowed the uniqueness of each individual’s experiences to be preserved whilst facilitating an understanding of the phenomenon under investigation (Streuber Spezialet & Carpenter, 2011). The two interviews were approximately 18 months apart.

Four-weekly contacts

Four-weekly contact was made with each patient-participant between the two interviews, at which time notes were taken. Several participants preferred face-to-face contact to telephone calls and these occurred frequently. Initially, the intent of these contacts was to capture any critical health incidents and usage of both primary and secondary health services. Once again, I became aware that the approach also narrowed the view of the participants' lives to focus solely on the use of health services. Therefore, although I did collect these data, as the study progressed the conversations presented an opportunity to develop an ongoing dialogue with each patient about what it meant to them to live with several long-term health conditions and the realities of how self-management support is viewed by the health system and by them.

These contacts evolved differently for each patient-participant with some very keen to participate in discussions about the issues that were most important to them and what impacted on their well being. The depth of the dialogue varied, guided by the patient-participants. The development of these relationships facilitated mutual trust as the disclosures often moved from the public to private accounts of illness experience, something Cornwell (1984) also identified. Hancock and Algozzine (2006) support an evolutionary and flexible approach to asking questions in case study.

The flexible format had several advantages. Firstly, it allowed discussion of ‘this is what I have noticed,’ and gave the participants a chance to review the data for accuracy and check that, as far as possible, an accurate picture of their meanings was being captured, something recommended by Liamputtong (2013). Member validation helped establish credibility (Lincoln & Guba, 1985; Stake, 1995; Yin, 2013). Where intriguing issues did arise during an interview with a patient-participant, the issue could be explored in general terms, where appropriate, with another participant. As data analysis was ongoing, issues identified as having been missed or dealt with superficially could also be raised at the next monthly contact.

Clinician-participant interviews

The rationale for the initial use, and subsequent abandonment, of the Flinders™ tools as an interview template was described in the introductory chapter, when it became apparent that a biomedical framework had unwittingly influenced many aspects of planning and conducting this research. The revelation also changed other aspects of the research. For instance, initially, along with patient interviews, the purpose for the patient-participants’ GP interviews was to provide some degree of triangulation in order to double-check what the patient-participants were telling me. My moment of clarity led me to change the character of the GP interviews and to add the PN cohort. The change allowed me to gain more of an understanding of clinicians' experiences of working with people with complex, multiple LTCs.

Fifteen GPs were interviewed (two patient-participants are related and share a GP and PN) shortly after the first patient-participant interview, once transcription and initial familiarisation with the interview content had occurred. The interview followed a loose format to explore the GP's insights and reflections on the patient-participant experience of living with their LTCs. Just before the patient-participants' second interview, the PNs for eight of the patient-participants were interviewed. In addition to the interview format of the GP interviews, the nurses' understanding of, and thoughts about, the self-management framework they practise within was also discussed in general terms.

The initial intent was to use the clinician data to supplement and triangulate the patient-participant data. The intent changed, but the majority of the data still came from the patient-participants, an imbalance reflected in the findings chapters.

Additional data

A broad range of data collection strategies are recommended in case studies (Hancock & Algozzine, 2006; Stake, 1995; Yin, 2011). Patient-participants' demographic data and information about their LTCs were gathered from them before their first interview. Data about the patient-participants use of primary and secondary health services were collected over a six-month period, but was not used as it did not usefully contribute to the findings.

Field notes were taken to capture observations about the person's social setting. Notes were taken in a research log, in a recursive process that is common in case studies, where the researcher continues to interact with the data throughout the research process (Hancock & Algozzine, 2006; Stake, 1995). These enhance robust data collection in case study methodology (Blakeman, 2010; Simons, 2009; Stake, 1995).

Terminating the research relationship with patient-participants

My relationships with the patient-participants became close over the duration of the study, with many intimate details of the participants' lives willingly shared. Careful consideration was given to the process of how to respectfully terminate the relationships. A conversation was had with each participant during the final interview, to make it clear that this was the end of the formal part of the study, which did not mean there must be no more communication. Participants were asked how they wanted things to be in the future. I ensured they all still had a contact number or email in case they wanted any further contact, and many of the patient-participants have subsequently made contact, mostly enquiring how the study was progressing.

Ethical considerations

The ethical implications of the proposed study were considered before the study commenced. Formal ethical review took place via Health and Disability Ethics Committees' processes. Expedited approval was received in March 2012 (CEN/12/EXP/007, see Appendix two). In March 2013, approval was received for an amendment that covered the addition of PNs to the participant cohort and clarification of the topics in the second patient-participant interviews, which were developed from first interview data (also see Appendix two).

The following section outlines the measures taken to ensure the ethical integrity of the study. These centre on patient-participants not feeling coerced to join or continue participating, any concerns they may have over their regular care if they did decline, ongoing consent and the confidentiality of information gathered.

To ensure the participants were fully informed and understood the nature of the study, the study was explained and participants' informed consent obtained (Appendices four and five). Particular care was taken to ensure that patients did not feel coerced to participate, especially if told about the study by their GP or PN or if they had seen the poster at their general practice.

Efforts were made to ensure potential patient-participants were confident their normal care and treatment would not be affected, whatever their decision about participation. Special care was taken during recruitment of participants from my own workplace which had too high a proportion of the population to exclude from the study. No patient known to me was recruited to avoid clouding professional and research roles. It was also explained that if they were referred to my service in the future, they would have the option of being cared for by a colleague, if they so wished. Discussions were held with the organisation's Chief Executive, Directors and the PHO all of whom felt the issue to be a very manageable one and remained keen to be part of the study. Some of the mitigation strategies suggested to the Ethics committee were deemed unnecessary.

The longitudinal nature of the study meant that verbal consent for continued participation was requested at each contact and participants were reassured that their signed consent did not preclude them from withdrawing from the study at any stage. At each contact, participants were asked if they remained happy to continue with the research and at the conclusion, asked again if they were comfortable to be contacted again in a month. One participant chose not to continue after the first interview and another telephoned me because he thought I was a few days late with my phone call.

The processes in place to maximise confidentiality were also explained in the information sheet (Appendix four). Nothing the patient or clinician-participants said was to be disclosed to any other party, other than supervisors and advisors. The stated exception was that if the patient-participant disclosed, or I noticed, any situation that was potentially or actually dangerous, the patient would be encouraged to discuss it with their GP or nurse. If necessary, due to my duty of care, I would inform the clinician. This circumstance only occurred once when I observed a participant was taking a contraindicated combination of medicines due to not stopping one medication when starting a new one. This was speedily resolved.

Confidentiality was also a priority when decisions were made about the transcription process and organisation of secure data storage. The experienced transcribers were not local and signed confidentiality agreements. To address confidentiality and data management, interview recordings were stored as MP3 files on a password protected laptop and phone. Once transcribed, interview data were also stored on a password-protected laptop, with data backed up in Dropbox and a secure auxiliary hard drive. Any hard copies of transcripts or notes from monthly contacts were identified only with a code, date and time.

In a small community, being identified was a risk discussed with each patient-participant. They were offered the option of using a pseudonym for their contributions. Only three chose to use a pseudonym, although during the writing phase of the study I eventually gave each patient-participant a pseudonym and informed them, as there were sensitive issues covered and statements made that I felt could potentially identify them or their family members.

Particular care was taken when discussing the interview content with the Māori research whānau to mitigate the chance of identifying participants and breaching confidentiality. The Māori participants were told about the research whānau membership. Two participants knew research whānau members so care was taken how information was shared between those people, although in both cases the participant had already discussed their interview with my advisors.

Data analysis

The firm intent of the analysis phase of the study, to meet the study aim of giving primacy to the voices of people with LTCs, was to honour the stories the patient-participants shared and to ensure these stories and the spirit behind them was conveyed as accurately as possible. The intent to respect their unique experiences affected several decisions about analysis. The first analytical stage aimed to capture the rich, compelling participants' kōrero or stories (Hollingsworth & Dybdahl, 2007). The intent mirrors Stake's (1995, 2005a) ideas about getting an initial thorough understanding of each case and its uniqueness before looking at commonalities. The longitudinal nature of data collection also enhanced thinking "along cases rather than across them" (Abbott, 1990, p. 148).

Data from each patient-participants' two interviews and from their four-weekly contacts were collated to complete their stories. The aim was to bring together aspects of the data that either seemed important to the participants or illustrated an aspect of their personality or lives and captured something important about them. The purpose of the stories was to foreground the individual patient-participants, to make them known to the reader and allow the reader to see the place of LTCs in the patients' lives. To "experience the … participants in depth rather than through reductive analysis" (Ellingson, 2006, p. 14). The stories helped avoid data being "pre-emptively reduced" through cross-case analysis (Morse & Richards, 2002, p. 2). The central role story-telling plays in much Māori research also resonated (Smith, 1999). The clinician data was not used at this stage.

The data analysis began immediately after the first interview. Following transcription and checking for accuracy, the transcripts were repeatedly read while listening again to the recordings to maximise familiarisation and to retain as many nuances of the interviews as possible. On the printed transcripts, phrases were highlighted and comments written, to note preliminary observations and thoughts (Smith & Firth, 2011).

Transcriptions of the first few interviews were shared with my supervisors and supervisory sessions provided me with a fresh perspective on the data, which helped with data interpretation. I also shared these early transcripts with members of my research whānau, who further contributed to the direction of the analysis.

Case study analysis involved what Stake (2005b) calls observational and reflective “brainwork” (p.449). Initially, I found using manual analysis gave more of a sense of the desired familiarisation, immersion in, and intimate engagement with, the data (Braun & Clarke, 2012; Marshall & Rossman, 2011; Vaismoradi, Turunen, & Bondas, 2013). Data stored in various locations facilitated frequent re-listening, with long car, train or plane journeys especially convenient. The data immersion lasted throughout the data collection period.

Some of the principles of narrative inquiry were used to surface these stories. Narrative inquiry has often been used within case studies (Wells, 2011) and is a useful way to allow the case to “tell its own story” (Stake, 2005b, p. 239). Narratives portray participants’ lives in what Charmaz (2002) termed “all their complexity” (p.307) and allows the reader to visualise experiences through the eyes of the participants (Gibbs, 2007). As a form of analysis, it has been successfully used for exploration of the lives of people living with LTCs, especially individuals’ illness career and sense of identity (Bury, 2001; Charmaz, 1991; Williams, 1984). These seminal works are extensive and although the intent is to take the ideas behind narrative inquiry into consideration, it is beyond the scope of this study to emulate them.

Thematic analysis

Thematic analysis was chosen for the second stage of analysis as a flexible method most appropriate for identifying, analysing and reporting patterns from the data corpus (Braun & Clarke, 2006). It can provide “rich insights into complex phenomena" (Smith & Firth, 2011, p. 54). Thematic analysis is consistent with this constructivist epistemological stance, with meaning seen as socially produced (Vaismoradi et al., 2013). Thematic analysis conducted within a constructivist framework seeks to explore “the sociocultural contexts, and structural conditions, that enable the individual accounts that are provided” (Braun & Clarke, 2006, p. 85). Fereday and Muir-Cochrane describe thematic analysis as a process of pattern recognition (2006), which Braun and Clarke state “reflects and unravels the surface of reality” (2006, p. 81).

Cross-case comparisons across the complete data set began with the manual identification of patterns of meaning across the data, coded into themes and categories, which appeared to capture participants’ experience, views and practices about their illnesses (Boyatzis, 1998; Denzin, 2001; Seale, 2000; Taylor & Stanton, 2007).

Due to the volume of data, the decision was then made to re-examine and code all data using a software programme (Dedoose Version 5.1.26, 2014). The software facilitated the breakdown and exploration of the text and the devising of a coding framework, identifying and refining themes. The software helped in the process of construction and identification of “repeated patterns or themes within the data of meaning” (Braun & Clarke, 2006, p. 86). Braun and Clarke’s (2006) checklist for thematic analysis was invaluable at this stage.

The process involved labelling chunks of data which captured participants’ experience, views and practices (Boyatzis, 1998; Denzin, 2001; Liamputtong & Serry, 2013; Seale, 2000; Taylor & Stanton, 2007). Throughout this stage of the process, there was continued engagement and re-engagement with the raw data and the patients’ stories, “to ensure that the developing themes were grounded in the original data” (Fereday & Muir-Cochrane, 2006, p. 83).

Quality criteria

The process to demonstrate the robustness of qualitative research is not straightforward and there seem to be many possibilities for ways to do this (de la Cuesta Benjumea, 2015). The term rigour is comfortably utilised in positivistic settings but becomes contentious when utilised in the post positivist environment. Loosely, rigour can be deployed to describe the means by which the integrity and competence of the research are demonstrated (Tobin & Begley, 2004). In the post positivist domain, however, more nuanced notions are preferred.

Santiago-Delefosse, Gavin, Bruchez, Roux and Stephen (2016) have recently summarised the many possible criteria for use in post positivism. The important issues revolve around trustworthiness, credibility and Lincoln and Guba’s (1985) deceptively simple “truth.” The quality criteria that were applied in this research context to maximise robustness were that of truthfulness, credibility, reflexivity and triangulation.

Truthfulness was solicited in two main ways. The longitudinal research design allowed relationships to develop with the participants, which facilitated a fuller understanding of their perspectives and their truth (Grinyer & Thomas, 2012). The multiple contacts with the patient-participants also promoted repeated conversations around similar issues to ensure their meanings were captured as well as possible. Using several sources of data and methods of collection, as well as paying attention to a transparent research process, also enhanced truthfulness. Truthfulness overlaps with the idea of credibility, which is a way to consider whether the explanation of the study fits the description (Shenton, 2004; Tobin & Begley, 2004). Case study research design enhanced the credibility or believability of the research through rich data, prolonged engagement and what Flick (2007) calls “intimate familiarity” with the participants (p.20).

Reflexivity and triangulation are two of the criteria advocated by Lincoln and Guba (1985) and Lincoln et al. (2011), who described them as central to high quality qualitative research. Reflexivity, described by Cornish, Gillespie and Zitton (2014) as another step towards transparency is important because it involves several of the concepts already described earlier in the chapter and encourages the researcher’s introspection (Ellingson, 2008). I constantly tried to challenge my own assumptions throughout the research process and to maintain an explicitly self-aware analysis of my own role and effect upon the research outcomes (Finlay, 2002; May & Perry, 2014).

Triangulation refers to the use of more than one approach to answer the research question in order to enhance the confidence in the outcome. It is a term that originates in trigonometry, a hangover from positivist methods which implies that a “fixed goal is the object of (the) study” (Settlage, Southerland, Johnston, & Sowell, 2005, p. 11). In case study, Thomas (2011) believes that “viewing (the case) from several points is better than viewing from one” (p.68). In this study, observation and interviewing methods added to the depth of the findings. Other authors suggest this process can offer a more in-depth understanding of the phenomenon (Denzin & Lincoln, 2000). Unlike Yin (2013) who suggests that the purpose of using multiple sources is to assist the researcher in identifying convergence of findings, both Stake (2005a) and Angen (2000) suggest triangulation can be used to identify divergence.

Careful attention to these processes seemed to be successful in ensuring robustness and integrity in the course of the research. The exception was triangulation. Although this study does have several sources of data, so could claim to be triangulated, as the study progressed I became less comfortable with the idea of triangulation of some fixed point of reality (Richardson, 2000). Recall of issues or incidents between patient- and clinician-participants ranged from a neat synergy to a juxtaposition of the differing perspectives of the patient-participant and clinician, right through to there sometimes being no common ground in recollection of an incident. Where the perspectives were not reconciled, this gave interesting data for reflection on why this should be and insight into varying perspectives (Yin, 2013).

An image I found more useful was that of crystallisation (Ellingson, 2008;

Richardson, 2000; Richardson & Adams St.Pierre, 2005). Richardson calls crystallisation a “post-modern deconstruction of triangulation” (2000, p. 934) and an approach where a wide range of angles are used to view a topic – something that resonates with the ideas of case study. Building on the idea of crystals’ quality of reflecting externalities and refracting within themselves, Ellingson (2008) suggested that crystallisation offers several different ‘takes’ on the same topic. Richardson and Adams St.Pierre (2005) say it “honours each voice as separate and distinct” (p.966), while Tobin and Begley (2004) describe crystallisation as a means of establishing completeness by seeking a more inclusive view of the participants’ world.

Crystallisation is epistemologically in tune with the rest of the study as it “celebrates knowledge as inevitably situated, partial, constructed, multiple and embodied” (Ellingson, 2008, p. 13). Each partial perspective or account potentially complements or illuminates the other. Although I am drawn to the idea of crystallisation, Ellingson’s work suggested the various angles should include approaches as varied as poetry and surveys, so I can only state that I am influenced by the ideas of crystallisation, rather than adhering to them. When a disagreement between members of different cohort groups did occur, care was taken to avoid privileging either version, acknowledging that “what we see, depends upon our angle of repose” (Richardson, 2000, p. 522). Within a case study, the facets of crystallisation fit well with the subjectivist epistemology, described by Liamputtong (2009) as a way to expose the different perspectives of reality.

An aim of the research was to look at the gaps in the research into people living with multiple LTCs that has been dominated by the positivistic research favoured by the biomedical model. Crystallisation fits the idea of exploring that gap by seeking a deep interpretation (Ellingson, 2008; Richardson, 2000).

Summary

The purpose of this research is to discover how people with multiple LTCs experience the self-management approach to health care. An additional aim is to give primacy to the voices of people with LTCs throughout the study. To answer the question, this chapter draws together the theoretical framework of health lifestyle and fundamental cause theories with the area of research and the theoretical terrain that points towards a particular methodological stance. A relativist ontological stance and constructivist/interpretivist methodology facilitate the collection of data from more than one perspective to offer a broader view of the topic. Decisions about how the research methods operationalised the methodological choices were discussed.

The gaps in the literature identified suggest that the research design will highlight the aspects of living with LTCs and engaging with health services that have been given scant attention. The next three chapters comprise the findings section of the thesis. The chapters introduce the patient-participants and explore some of the commonalities they experience due to the cumulative losses incurred by living with multiple LTCs.

Chapter Five: Findings one: Sixteen patient Kōrero

Introduction

The chapter offers introductions to the 16 patient-participants' data seeking the "ordinary happenings" for each case (Stake, 2005a, p. 29). The intent of this structure is to ensure that the complexity of each person's life is captured as fully as possible before cross-case analysis begins.

The sixteen kōrero [narratives] of the patient-participants are the distillation of each of their two interviews and between 18 and 20 four-weekly contacts. The initial intent was to keep these stories intact in order to do justice to the stories and, as much as possible, to express stories in their terms rather than mine. It soon became very evident that the complex, convoluted messiness of most of their lives actually *is* part of the findings. These complex kōrero are full of examples of social determinants directing people's lives, multiple LTCs and cascading complications. These are overlooked in the biomedically driven Chronic Care Model and self-management approach.

The patient-participants all felt it important to describe the sequence of their journey to multiple LTCs to how they had made sense of that process, and for me, it was important "to see the stories unfold and hear the voice" (Pipi et al., 2004, p. 148). Overly condensing or prematurely amalgamating the kōrero would have meant doing to the findings what biomedicine does to their health care.

Tane

Tane was a 47-year-old, articulate, intelligent and endearing Māori man. He moved back home to live with his mother 10 years ago after having worked for many years in Wellington in a range of occupations. He described his "descent into ill health" as being like inadvertently stepping onto a descending, spiralling conveyor belt. By the time he realised he was on it, he was unable to step off or change direction. Tane described his journey. He said:

> I really think I should start with the diabetes - that was pretty much the first thing that I got, around about 28 or 29 [years old]. It was something that just sneaked up on me. Around that time of my life I was living the good life, I was young, parties all the time. Wasn't really looking after myself as much as I should…. Back then I drank a lot, I was addicted to Coca Cola. My password on

> everything was Coca Cola, that’s how bad it was. I was drinking around seven litres a day.

The combination of Coca Cola, cigarette smoking, a diet of take-aways and a work injury that led to forced inactivity, meant Tane “started to put on a bit of weight.” He also spent some time working in a paint factory where there was no protective gear available and he developed industrial poisoning. He felt the incident caused permanent damage to his heart and lungs. Following the diabetes diagnosis, he also developed angina and COPD, despite having given up smoking as the result of a lost wager when the All Blacks won the Rugby World Cup in 1987.

Tane then began work in the restaurant industry, which he loved but found incredibly stressful. Eventually, he believed the stress, compounded by his physical ill health, led to clinical depression.

> I got depression big time and I just went in a big downward spiral. One minute I was there on top of the world and you know it just started getting harder and harder for me… the stress of it just got on top of me.

After he returned home, Tane’s health continued to decline. His weight increased until he became morbidly obese, with a BMI of 66. By this time, he had also experienced a myocardial infarction and developed gout. His mother, who had cared for his father until his death, moved right on into caring for Tane. She insisted on doing all the cooking and Tane felt pressured into eating what she gave him. He said:

> Mum is going “you haven’t eaten your thing,” and I’m like “I don’t feel like eating, I’m not hungry.” And she’s “you didn’t eat your breakfast” and I’m “yes I did.” And she’s “you only had half a pottle of yoghurt” and I’m “I’m not hungry Mum.”

Tane said she equated caring with food and overfed him, his brother and the cat:

> when you see her cat, how fat that is. Sometimes I look at the cat and I go, “Oh my God, you poor thing. You're me.” Every time that cat will cry, Mum will feed it.

Tane knew what a healthy diet was and enjoyed searching for healthy recipes on the Internet. However, he felt his mother ultimately sabotaged his efforts and he felt powerless to stop her.

Tane needed oxygen 16 hours per day but tried to do without so he did not become ‘addicted.’ The only time he felt he could breathe freely was when he was out fishing on a boat with his brother. If he won Lotto, he said he would buy a boat and a seafront property in a nearby town. He needed a CPAP machine at night for sleep apnoea and had recurring cellulitis. The cellulitis led to chronic leg ulcers, which often took years to heal so he was rarely without them. His cardiovascular conditions had led to heart failure and he had experienced both a small stroke and a pulmonary embolus.

Tane’s health was incredibly fragile and he was frequently hospitalised for cellulitis or a chest infection. These developed rapidly and he had several bouts of septicaemia. Until recently, Tane had always “bounced back” to his previous state of health but he said this was no longer the case and each exacerbation left him with less energy and more pain. During one of his recent hospitalisations, a nurse asked him whether he knew he was ‘not for resuscitation.’ The discovery was a real shock to Tane who said:

> I mean, here’s your mortality mate, right there. You’re not bullet proof and I’d gone through you know 30-40 something years of thinking I was bullet proof. I’d go into hospital, yeah I’ll be all right, I’d get out again.

Tane’s activities were significantly restricted by his size and breathing. He had a paid carer who helped him shower and a hairdryer was needed to get him properly dry. The carer had steadily taken over tasks such as blood sugar monitoring that Tane said he could manage himself.

Tane’s mood was tied up with his physical health. He said sometimes he felt “almost dead” and with heartfelt wistfulness said he was “practically a prisoner” in his bedroom. In contrast, he fluctuated to wild optimism with lofty goals and plans. His goals included visiting international friends made online or building a gym and workshop in the garden. And he saw no irony in having just described how he can barely get down the ramp from the kitchen door to his car and that last week he had fallen doing just that and could not get up again.

Tane’s favourite exercise was swimming and he loved the freedom of weightlessness but the almost constant compression bandages on his leg ulcers made swimming a rare event. He spent many hours computer gaming where his physical limitations did not restrict him. The friends Tane had made locally were through a local Māori health provider gym. Most of these friends also had multiple LTCs, so being sick was a main part of Tane’s identity. Their time spent at the gym meant the health and fitness of many of these friends was improving. Whilst Tane was thrilled for them, he had an abiding sense of being left behind. For example, Tane had spent six months planning a pig hunting expedition with “the boys” and ultimately he was the only one unable to go, due to his health.

One reoccurring topic for Tane had been the option of bariatric surgery. He said the option of surgery was offered to him ten years ago but he turned it down. He said, “I thought I could get there on my own.” Tane still mentioned surgery as an option, but he also said he had been told “no anaesthetist would go near me.”

Tane’s relationship with hope was complicated. Although he often seemed to have lost hope, for example saying, “when is it all going to end?” he also said he needed to believe he would get better and was still seeking “a magic pill so I can do the things I used to do.”

Rawiri

Rawiri was a 68-year-old Māori man who spoke in a considered and precise way and took early retirement from a career in finance. At the beginning of data collection, Rawiri lived alone as his wife had died two years earlier after a long illness. He had recently begun another relationship and the woman moved in with him during the course of the study. A son and a daughter lived locally and another son lived in Australia. Most of his grandchildren were in Australia and he visited there usually twice a year.

Rawiri had several mild LTCs, which included well-controlled gout and arthritis and mild sleep apnoea. He believed “the emotional stress of the loss of my wife probably triggered everything.” He was diagnosed with prediabetes a couple of years ago and the condition had remained stable. Despite this, Rawiri told people he had diabetes and insisted on having regular diabetes checks and using a blood glucose monitor. His GP and nurse went along with this to maintain a relationship with Rawiri. It was a similar story with his hypertension for which he had purchased a home sphygmomanometer. On one occasion his “BP was higher than I like it to be when I went to see the nurse, although she said it was fine. So I have been monitoring it at home myself.” He had recently started wearing a heart rate monitor all the time now “to keep an eye on things.” He had very firm opinions on most matters, particularly his health, and rarely deviated from these once his opinion was formed.

Rawiri had atrial fibrillation for which he was on warfarin, an anticoagulant where regular blood tests were needed. The frequent blood tests meant he was at the practice most weeks and often telephoned the nurses between these visits. His GP changed his anticoagulant therapy to dabigatran, which required considerably less monitoring, but Rawiri felt dabigatran did not suit him or offer sufficient monitoring, so he insisted on changing back to warfarin.

Rawiri mentioned on several occasions his unilateral decision to change his medication including one potentially life threatening incident that occurred during the data collection period. Rawiri had mentioned over several months how he was “unhappy about the state of my health. Some of my medication is a little bit suspect.” He chose to stop all his medicines and felt better, so continued to not take them. After a week, Rawiri returned to the practice and saw a locum GP, who urged him to restart some of the medicines but Rawiri felt they were unnecessary. Rawiri became quite angry that the GP was not in agreement with him and felt his concerns were not being taken seriously, leading to a couple of unpleasant incidents at the surgery. The end of that week Rawiri was rushed to hospital:

> I was actually having heart failure… And I woke up in Intensive Care unit, didn't know where I was, and I didn't know how seriously ill I was. I finished up being in hospital for about three weeks. Eventually, they put me on a diuretic that made me lose all this fluid.

Following the hospitalisation, it seemed Rawiri had not understood the causes of his heart failure and said:

> it was just one of those things I guess. But I felt I wasn’t taken seriously. And the locum GP didn't [take me seriously] either. The hospital did say [the cause] was me not taking certain medication, but that wasn’t true. That didn't do any harm.

Diane

Diane was a 65-year-old Pākehā woman who lived with her husband. She had worked in not-for-profit development and community care at both local level in Auckland and national level. She had a son and a daughter, who both had complex family lives and lived several hours drive away. Diane moved to the area to retire as she had found her health had always improved during frequent holidays here.

Diane was a reflective person who added to the data with several emails during data collection as ideas occurred to her, or when she had come across something in her reading she thought would be of interest to me. One of these emails I found so compelling I have included in its entirety (except for minor de-identifying editing) as Appendix seven.

Diane had had severe asthma all of her life and her first memory was the doctor coming out on a Sunday when she was three, due to an attack. She felt asthma had shaped her entire life. She also had “bloody awful” eczema ever since she could remember. She said her health was currently the best it had ever been, she felt due to purer water in the area.

She had also always experienced many allergy-related issues. An example occurred during data collection when she developed a persistent rash and lethargy with apparently no trigger. During one sleepless night, she realised the only thing that had changed was a move to a generic cholesterol-lowering medication, which the pharmacist had assured her contained exactly the same ingredients as Lipitor. At 3 a.m. with the help of Google, she identified that one of the “inactive ingredients” was different. She later rang her GP, went back onto Lipitor, and noticed an immediate improvement, with the rash gone within five days.

Diane had finished an extended period of treatment for breast cancer some years ago, which included a radical mastectomy, radio- and chemotherapy. She now had diabetes, which she said was mild and well controlled, and also arthritis. She had also had keratoconus [a degenerative disorder of the eye with no known cause], which had left her blind in one eye and reduced vision in the other.

She felt that during the years of treatment for breast cancer, her other health conditions were ignored and she was only now “uncovering the layers of this whole chronic stuff.” She had noticed the focus on one LTC only was a recurring pattern with each new specialist and the entirety of her life never considered. For instance, when she saw a surgeon about sinus problems, he said, “go away for three months, take doxycycline.” For keen gardener Diane, not going out into sunlight as summer began due to its contraindication with sunlight, meant “being out in the garden at seven o'clock in the morning, like a little troll.”

She said her gradual loss of capacity crept up on her unnoticed, which she explained as, “the life I have is a good life but thoroughly conditioned by a lifetime of letting go. So I'm now at the point where letting go is how I live.”

Diane experienced several periods of depression in her life. However, she was also aware that for her, low mood could also be an early sign of a chest infection or sometimes it was “actually grief for the things I have missed out on that I have to work through.”

She reflected on feeling her life was defined by the restrictions of her LTCs. She said,

> I mean, when you can’t laugh wholeheartedly without coughing it really puts a damper on things. I lasted 5 minutes doing meditation… she said “breathe into your whole body!” and that was me stuffed… When [the Bible] says “love the Lord your God with all your strength,” and you haven’t got any strength I sometimes wonder what the point is …

The data collection coincided with Diane working towards more of a sense of control in her life and a better life/health balance. The change came when she realised she was so intent on doing what she thought she should do, that she was:

> using up my scarce energy on going to the gym there was none left for living. It felt like a millstone around my neck - yet another thing I have to do because I am sick.

She therefore stopped going to the gym and said she now “use my excess energy for living. In addition, I feel like I am taking charge. I can now walk around Mitre 10 [a warehouse sized hardware store] – whoa, dream big!”

One event she felt was significant was getting a walking frame with a seat, something she resisted for a long time:

> but then I started to think about it as a piece of exercise equipment like a treadmill, rather than as a symbol of decrepitude. And it is wonderful because my mobility was hindered by my arthritis, my vision and my breathing, and this

> helps with all three, especially my eyes because I don't have to look so carefully down.

She felt the frame allowed “me to get spontaneity back in my life – we can just go to the museum without wondering if there was going to be a seat there for me.”

Diane described her “ongoing struggle to be my own person despite my health conditions.” She riled against identifying, or being identified, as an old, sick person “but I can feel myself being sucked into [the role of] passive, cranky old people who just go round doing bus trips. That is not me!”

Beth

Beth was an intelligent, articulate 88-year-old Pākehā woman who lived in a villa in a retirement village with her 89-year-old husband, who was both deaf and visually impaired. Beth had worked as a primary school teacher and had seven children, one of whom had died recently. She still drove and kept busy with her friends, joined in social activities in the village and was a famous chutney maker.

She had experienced frequent urinary tract infections for most of her adult life, which she said start suddenly with no apparent trigger. She said, “the story of my life is a never ending list of infections.” The infections have led to kidney failure and she had been self-catheterising intermittently several times a day for four years.

If she did not self-catheterise, she was incontinent so she avoided staying away from home overnight in case she should have an accident. The fear of incontinence also limited her visits to see her family. She also experienced frequent, severe constipation, had diabetes and hypertension. She tended to understate her conditions and described her hospitalisations for constipation as “a spot of bother with my bowels.”

Beth had absolute faith in her GP and was not concerned about what conditions she did and did not have, but just followed her GP’s advice and took the prescribed medication. When asked if she was on medication for her diabetes, she replied “probably.”

Beth was aware of getting increasingly tired and not bouncing back as she used to. During eleven months of follow-up conversations, Beth had several hospital admissions for constipation. She gradually lost her confidence, experienced increased confusion and could no longer remember how to self-catheterise. As her short-term memory declined, she was diagnosed with dementia with superimposed delirium and was therefore no longer able to participate in this study. Beth was eventually admitted to the rest home in the retirement village that contained her villa.

Eva

Eva was a 56 year-old Pākehā woman who lived with her husband Dan, three teenage daughters, a foster child with significant developmental problems they hoped to adopt, plus a lodger. Both Eva and Dan had several significant LTCs and their daughters, aged between 13 and 17, all had physical or mental health issues. These include anaemia and vitamin D deficiency, both likely caused by poor nutrition, and had each had fractures from relatively minor trauma. They had five dogs and two cats. During the course of the study, Eva's eldest daughter became pregnant. She, her partner and baby now live in a caravan in the garden.

As both Eva and Dan were on invalid benefits, they struggled financially. Eva admitted their financial priorities were not their health or nutritious food. She said they needed to have Sky TV and a laptop each as they did not go out much, "and although it seems there are a lot of animals, there's only one each." Eva's big heart was admirable, but it was hard for me to understand or empathise with her ceaseless "taking on more strays" as she called it, when she was unable to care for herself and immediate family as far as, for example, a nutritious diet or paying her bills.

Eva was the carer and 'go-to' person for everyone in the house, but she seemed to receive scant respect. She said, "the atmosphere in the house is a constant build up, then an explosion, then it settles for a while. None of them support me. Dan tries but fails." She said the girls "seem to compete as to who will be the biggest drama queen." For our first interview, Eva had told the family she did not want to be disturbed, but there were nine interruptions. Eva herself suggested our later conversations should be away from the house. Eva talked about the constant arguments and crises in the home: "it's like living on Coronation Street here, there are so many bloody dramas, but without the comedy."

One typical month she listed these "dramas." Her husband had a kidney problem, the youngest daughter had a persistent vomiting bug, middle daughter was off from school with abdominal pain, her eldest daughter was:

> up and down with baby and we've had no hot water for 3½ weeks. I'm the last man standing as usual. And we are having to have lots of meetings to sort out adopting (foster child) – she's got an IQ they say of 52. And they think she was abused by her stepfather.

Eva's LTCs included COPD, diabetes, she was morbidly obese and had sleep apnoea for which she had a CPAP machine. She also had hypertension, hyperlipidaemia and arthritis of her back and hips. Possible irritable bowel syndrome meant she had occasional faecal incontinence. She experienced frequent bouts of depression and said she just wanted “to sit in the corner and cry half the time.” She used phrases such as "I'm living in the middle of World War II” to describe the turmoil of her life. She talked extensively about the “continuing saga” of her life. There were many occasions when she talked for 20 minutes or more before she mentioned herself or her own health.

Overall, Eva and her family seemed entrenched in the sick role, explaining most of the problems in their lives in terms of illnesses or chemical imbalances. There was a strong theme of passive acceptance and powerlessness coupled with low expectations for how things would work out. Eva explained her own obesity as a very delayed outcome from a head injury as a child coupled with a sugar addiction. She added, “but I am full of excuses.” When her daughter was pregnant, Eva said several times that the daughter would “end up with post-natal depression.” Once the baby was born, Eva appeared to use post-natal depression as an explanation for her daughter spending all day on the computer and not liking to hear the baby crying. Inevitably, her daughter's problems meant Eva cared for the child most of the time.

Eva found solace in her faith and attending church. She described how:

> at a new women's group at church they asked me what I wanted to pray for. I said “the strength to meet everyone else's needs”… I cannot give up. I've got no one to take over. Each day I wake up in the morning and think “what's it going to be today?” and then I think “come on Eva, you can cope.”

George

George was a 69-year-old Pākehā man who lived with his wife and worked from home as a craftsman. He was gregarious and a great raconteur, which led to fascinating and wide-ranging interviews which digressed dreadfully. His two grown children lived in Wellington and grandchildren often came and stayed in the school holidays. He and his wife had recently finished an extensive renovation project at his house, which he thought might be the last.

He had been “a little bugger” most of his life he said as far as healthy living went, being a heavy drinker, smoker and fairly inactive until a couple of years ago. He had now stopped smoking, walked most days with his wife and drank in what he calls moderation. He said:

> one can say that I don't drink as much, but that is really on the basis of how much did you drink before? Well I mean let's face it, there were many occasions there where I couldn't get any more in.

He and his wife were a sociable couple and their walks usually involved frequent stops to talk to people. He saw exercise as a way of keeping in shape, rather than watching his weight, as he was still “a vain old cove.” He was generally fairly active and on more than one occasion had to come down from a ladder to answer the phone when I called.

His LTCs include atrial fibrillation, which he said he was told “in no uncertain terms was caused by my drinking,” hypertension and hyperlipidaemia. He was diagnosed about five years ago with diabetes. He said, “sometimes I’m not even really sure I've got [diabetes].” He said he initially did not take the diagnosis very seriously. It was only “when they sent me for the eye test [retinal screening] then I thought ‘well, this is getting bloody serious.’” He did not think of himself as a sick person and was very taken aback when his PN suggested he participated in this study. He said he “was reading your blurb and realised – Good God – that’s me!”

For George, his main health concern was his prostate cancer coupled with chronic prostatitis, from which he had frequent vague symptoms, so he could never forget his “prostate area.” George had been told the cancer was not aggressive and the surgeon had taken a “watch and wait” approach, something that caused him constant concern. His understanding of treatment efficacy for prostate cancer was influenced by his experience of a close friend dying of the disease with the watch and wait approach. He was never happy with the decision and mentioned it in both interviews and at each monthly contact.

George understood the evidence base of this approach, but simultaneously “knew” that watch and wait did not work. He said, “it’s OK for them saying it’s the best course – but I am doing the waiting and I hope to God they are doing the watching.” George said he knew his feelings were illogical, but he “just can’t shake it.” He felt the cancer specialist, “is always almost in the corner of my eye. Just out of sight but I know he is there.” He hoped “they will do something. I've got this damn sword of Damocles – I hope will be dealt with soon, so I can get on.”

George felt that being old crept up on him and he found his 70th birthday “very significant – I am coming belatedly to realise I am not bullet proof.” He felt the ever-increasing list of ailments were a usual part of ageing as he was “gradually crumbling – arthritis, eyesight, memory, varicose veins. I aim to continue getting old and grumpy gracefully. But I’m living an idyllic life, really.”

Yvonne

Yvonne was a 67-year-old Samoan woman who moved to New Zealand when she was in her teens. She raised three daughters as a solo parent and now lived alone. All three daughters had ongoing problems, including significant physical and mental health issues, marital and financial problems. One daughter rarely spoke to her mother after a health related disagreement. The youngest daughter lived locally and Yvonne spent a lot of time helping to care for this daughter’s four young children.

Yvonne was an active member of the small local Samoan community and was a Justice of the Peace. She was very active in her local Samoan Mormon church and a lot of her socialising was at the church, much of which involved the preparation and sharing of food. She particularly enjoyed church trips and went on mini-missions to Hamilton as often as she was able.

Her LTCs include COPD and heart failure. She experienced frequent shortness of breath, although being significantly overweight was thought to be responsible for much of her breathlessness. She was diagnosed with diabetes about eight years previously when in the hospital for her heart condition. About four years ago, her GP suggested she started insulin and she understood “controlling my blood sugars is important to protect my other organs.” However, her strong antipathy to insulin meant she resisted commencing insulin for eighteen months and would still not increase to the optimal dose. The reluctance was despite her mentioning her real fear of kidney failure, as she had seen many family members die from this complication, and having received results from her latest health check that showed early kidney disease.

She said she ate as she felt like and said, “with me, I just eat whatever … I have, or what I feel like eating. I know I'm naughty. I don't discipline myself.” Cooking was a huge part of her community life. During several monthly telephone calls, she said she was “baking up a storm” for a function and on one occasion she said, “I’ll forget about my diabetes today.” She volunteered that if she was going to continue to eat as she did, she really should be on a higher insulin dosage but said she did not want to either change her diet or increase her insulin.

She had gained 6Kg per year for the last three years and tiredness was a constant companion. Her increasing obesity meant she had developed significant sleep apnoea and stopped breathing during one of her surgeries. Other LTCs included gout and arthritis and Yvonne also suffered from a sore back. During this study she had several falls as well as surgery on a cataract and a blocked tear duct.

Yvonne’s own relationship with her stepmother, who was only a few years older than her, had been increasingly prickly over the last couple of decades. She said her stepmother was hypercritical and interfering. Yvonne resented her stepmother, but she laughingly acknowledged she was exactly the same with her own daughters and her friends and interfered in their lives. Her efforts were rarely appreciated. She was very strong in her opinions and said she had alienated many of her friends and family over time because of her behaviour.

As well as caring for her grandchildren and ferrying them around, Yvonne also visited her daughter’s home to do housework and laundry, despite her daughter asking her not to, which sometimes caused friction. For instance, Yvonne hung out their laundry on the Sabbath, which was against her daughter and husband’s religious beliefs.

Yvonne had always been hardworking, house-proud and a good budgeter, and she hated that her children did not share those qualities. Yvonne appeared to be stuck in a cycle where she offered, indeed insisted, on helping family and friends. She then felt exploited and exhausted and complained that people expect her help.

She was very aware that her lifestyle was harmful to her health. She felt that if she needed to be cared for, there was no-one who would do it in the same way she had done for so many people. She said, “I’m always busy. I realise how silly it was, how busy I am because I just end up so tired and no one was looking after me.” She said she had “no time to look after myself” and that this was now catching up on her. She was currently responsible for a friend in a local rest home and took over the arrangements for the care, and eventual burial of, her terminally ill brother in Auckland, despite there being other family members much closer.

She volunteered that doing some gentle exercise would help her: “I need to do exercise. But ... running around my grandchildren, I thought well, I don't think I can cope with any more exercise.” Yvonne knew she needed to nurture herself and had occasionally started activities which she had enjoyed. She said, “I went to the Tai Chi. And I love it. This is what I need to do: look after myself.” However, it seemed she was easily diverted back into caring for others and then neglected herself again.

She said it had “been a tough year.” She and her family recently watched a DVD filmed at a family reunion earlier in the year. Yvonne said:

> oh, I felt so sorry for me. ((laughs)) You know, I had tears coming down. I look at it, and I look so tired. And I could feel the tired I was feeling then – and I'm still feeling like that now.

By the end of the data collection, Yvonne was not in a good place. She had thought her children were all settled but recent domestic upheavals for all of them had left her low in mood:

> I've let go my house. I can't be bothered doing anything. Usually I love being on my own, and then when they first left, they were going steady and good. As soon as they collapse, I feel I collapse too.

Huia

Huia was a tiny, resolutely cheerful 57-year-old Māori woman who wears thick glasses for her very poor vision. She lived in a small, cold, rented, stucco unit where one or more of her whānau were usually staying at what she calls the “family halfway house.” During one fairly typical month one “nephew moved out and another with his dad moved in - as well as a couple of nieces staying over.” Huia described her house as “ground zero,” with all the comings and goings, which she said she liked.

Her estranged husband had died a few years ago and she had one adopted son who she saw infrequently. The whānau she was close to were her many siblings, nieces and nephews, who lived locally and with whom she was in daily contact and shared social activities.

She had had lifelong asthma with frequent chest infections, diabetes, ischaemic heart disease and arthritis in her back. Her asthma had prevented her working for much of her life. She managed seasonal work in a pack house until a few years ago but the combination of worsening arthritic pain and breathing issues made even this work impossible now. She managed on a sickness benefit supplemented by sporadic rent from whānau tenants.

During our many conversations, her positive attitude to life persisted. She frequently cracked jokes and told anecdotes about whānau goings-on. Only occasionally did she reveal a resigned acceptance of her lot and she saw illness as “just part of life. If you're going to get sick, you're going to get sick. Too bad.” Her attitude to life was shared by her siblings and neighbours, who also experience poor health, “so they have to plod along like I do.”

Others’ needs seemed to take precedence over hers – she was often without her mobile phone (and had no landline) because she had lent her phone to a relative. Her brother Eru had significant health problems, which included paranoid schizophrenia, diabetes and heart disease. Huia acted as his advocate with health and welfare agencies, and he stayed with Huia twice for extended periods of time during data collection. Eventually, she managed to get him into a flat next door to her and transfer his care to her own GP, which made things easier for her. When he was in her home, he chain-smoked and she could not get him to smoke outside which made her asthma significantly worse. She said, “I’m glad he’s moving out – mostly cos he smokes and takes no notice when I tell him to stop doing it inside. My breathing is much worse now."

She was studying at the local Wananga [a tertiary education institution] for a qualification, which included weaving, Māori language and computer skills. She was a gifted weaver and hoped to earn a living running a weaving business once she qualifies.

Huia viewed her multiple health conditions as just one small part of her life and part of her identity, as she had suffered from asthma and poor vision all her life. She rarely thought about her health and accepted the significant limitations without question. She seemed to have low expectations of any potential for health improvement in the future. When she did get low, she talked in terms of, "just pulling myself together and then I just turn round and, 'Oh, shut up and do something' ((laughs))."

Poor health had always been a part of her life. She said:

> asthma's been with me all along. And I guess not seeing so well doesn't help eh? And it's just carried on. [My health is] just there. I don't think about my health - no, I just don't think about it. Sometimes it's better than others but just there.

She described her own life as "just one thing after another." Her unquestioning attitude meant she just "get on with things" when faced with a health issue and her already restricted life contracted further. She said, "oh well, I'll just carry on. ((chuckles)) It's just that I'm so used to it … I just slow down even more."

Occasionally frustration with illness flare-ups did show through, such as the whooping cough she had for three months during data collection. The whooping cough exacerbated her asthma and also led to urinary incontinence every time she coughed. Her pragmatic attitude was demonstrated when I asked her how she managed with the continuing stress incontinence, to which she replied, "I do a lot of washing" ((laughs)).

The LTC that bothered her most was her arthritis, which was "always painful. It drives me mad" and was the condition that stopped her doing what she wanted to do. She described her pain as both a nuisance and a barrier:

> like I just love my weaving, and the best way, the traditional way to do that is to sit on the floor with the weaving in your lap. But I just hurt too much. I do the heavy stuff on the table and other stuff on my lap.

Although pain hindered her, she was determined not to take the analgesics as prescribed and took as few as possible. She said her GP, nurse and pharmacist had all explained the benefits of regular analgesia and to not wait for the pain to get too bad, but she was determined not to take “too many.” She said she did not want to become addicted and was looking forward to when she could take less. The result was her pain was often overwhelming “like yesterday I just wanted to take the whole packet. But I never would.”

Her social activities were all done with whānau. She was reliant on them for transport and said she only enjoyed doing activities with others. Therefore, although she mentioned frequently how she enjoyed various physical activities, if whānau stopped going, so did she. During this study, she took up Zumba, Waka Ama and a walking group, all on the instigation of a sibling. None of these lasted once her siblings stopped. She also appeared to miss out on other things that were precious to her. She had a deep faith and belonged to the Ratana church but her siblings no longer wanted to attend, so much to her regret, she no longer went. Instead, she adapted her activities, as this dialogue demonstrates:

> Huia: I just do it myself. I get up every morning and I sing hymns. And I don’t care who is asleep or awake in my house.
>
> Helen: So your faith is important?
>
> Huia: Well I’ve never not had it so I don’t know, but I can’t imagine not having it. And how would you make sense of all this without it?
>
> Helen: All this?
>
> Huia: All of this. The arthritis. Eru. The pain.

Neither her health needs, nor those of her whānau were a priority. She seemed resigned to what many would rile against, with shortage of finances, multiple family issues and a lifetime of ill health. She lived in a world where ill health and multiple LTCs were both expected and accepted as normal and she seemed neither bitter nor angry.

Aroha

Aroha was a 56-year-old Māori woman who raised 5 children as a solo parent. She had worked for many years as a carer in a dementia unit but, in the last few months before the first interview, had gone onto the sickness benefit for a year due to her ill health. One of her daughters had also recently attempted suicide, so Aroha had taken custody of five grandchildren who ranged in age from sixteen down to four. She said,

> she had mental health problems - and having all them kids is never gonna help that is it? About three times I think she tried to commit suicide. Eventually, I just said “well, that's enough. The kids are not being dragged from here to all over the place till you're good and ready ... that’s just selfish.” And I wasn't too great myself at that time. But I took them all … and her two dogs!

Aroha described the children as a handful and found them exhausting. She said she yearned for some peace and quiet and yet “I'll tell you what, I send them away on holiday sometimes, and I miss them. The house is so quiet, I hate it.”

She was getting great support from the daughter who lived nearby until sadly during the study, one of this daughter’s sons developed leukaemia. During his lengthy treatment, Aroha often had that daughter’s other son to care for while they were at Starship Hospital [New Zealand’s leading children’s hospital that is a five hour car journey away]. Aroha became “brassed off” with no word from the daughter whose children live with her. She said: “I just dream of the day some of these will wake up and say ‘O yeah - I’ve got some children - how about I look after them?’” Aroha’s eldest granddaughter finished her final year at school during the study. Aroha had hoped that she would join the army and learn a trade, but the girl had decided to study early childhood teaching at the local college, so was not moving out. Aroha “thought I only had to get them to eighteen” so was appalled there was no sign of having one less person in her care.

Aroha’s illnesses began with COPD, which was severe. She said she was told if she stopped smoking it would improve, but instead it had worsened. Her COPD was quickly followed by three myocardial infarctions and subsequent heart bypass graft surgery. She said she had always tended to ignore any symptoms and “when I had my heart attack I just thought it was indigestion and I walked the 3Km home in my lunch break to get some Quickeze [an antacid]. Until I collapsed.”

She had chronic sinus problems and experienced recurrent infections and headaches. The sinus problems had affected her hearing increasingly over time and she spoke with a pronounced nasal twang. At the time of the first interview Aroha had been waiting for sinus surgery for well over a year. She said “this operation's supposed to be the miracle one, and I'm thinking well, this is the last time you're going to play around with me. So it'd better be bloody good.” She eventually had the operation but sadly, the benefits were very short lived. She also had sleep apnoea and severe arthritis of her back and shoulders. When she worked full shifts she had needed to take considerable doses of analgesics:

> just to get through the [patients’] showers in the morning. I was filling up with the painkillers, and trying to get myself through the day. You know, and then another lot at lunchtime to get me through to three o'clock. But it was like that all the time. It was continuous.

She had recently been into hospital with gastro-intestinal symptoms, which she was told were due to over-use of non-steroidal anti-inflammatory drugs. She said the hospital doctor told her to stop taking them, but did not offer alternative analgesics, so her pain had worsened. She was obese which she knew “doesn’t help the breathing or my back.” She managed to lose 10Kg over the duration of this study and said she felt better as a result.

She said one of the problems with having so many health issues was that “you’ve got to try to distinguish - now, is that the heart pain, or is that the arthritis in the shoulder?” She found being sick a “bloody nuisance” and thought her body was just worn out and she was constantly tired. “I ran my body into the ground - smoking, drinking and hard physical work.” She struggled mentally with being sick as she was “so used to being the tough one.”

After a lot of persuasion from her GP, Aroha negotiated a year off work from the dementia unit and was promised a move to the less physical laundry when she returned. She had always gone out to work and found she hated being at home. Work, she said, “gives structure to the day and motivation to get up.” She missed the routine and got very low in mood.

In total, she managed about four months away from work entirely before she started to pick up some casual half-day shifts. By the end of the study, she was trying to work two short shifts and two full days per week. The work was still as a caregiver because the promised move to the laundry did not materialise. Aroha felt conflicting pressures from her GP, who recommended she did not work at all and Social Welfare who insist she should work a minimum of 15 hours per week in order to get a benefit. Her own needs were lost amongst that. Aroha thought physically she could not manage much more than she was doing. Finances were a struggle, as the children seemed to always “need something for school and get through shoes at an astonishing rate.”

Aroha had had a lifetime of putting others first, something reflected in how she cared for her own health - once everyone else’s was sorted. Last year she went on her first ever holiday, which her sister paid for, because usually “I have to use my annual leave and sick leave for being sick.” Aroha said she did get down and felt her life was in a holding pattern because of the children:

> I can’t think about the future. I just take each day as it comes. It is just a case of pushing myself to keep going and ignoring the pain. I do sometimes think “why me?” I haven't had a good day for ages. For a long, long time. You know, where I could just wake up and, “Oh gosh, it's a good day today, I feel good.” But I don't.

She laughed about a friend of hers, who lived alone in a one-bedroom unit and complained of being lonely. “I say to her, ‘you come stay with me, you’ll be begging to go home within the hour!’” Aroha said she keeps trying to pick up more shifts:

> it’s a bit much isn't it when I go to work in a dementia unit mostly to get away from the madness here?

Tamati

Tamati was a softly spoken, 74-year-old Māori man who lived with his wife, Tui. Born and raised in a small rural town in the north of the area, where his wife also grew up, he was one of 11 siblings. When they married, Tamati joined Tui's Mormon church. Their religion had meant he had neither smoked nor drunk alcohol since they married over 50 years ago. They moved to the area and had two sons, one of whom died. Tamati worked on the railways most of his working life, and Tui was a nurse until they had children.

Both were heavily involved in their community, Marae [the traditional meeting house for Māori communities] and church, where Tamati was in the choir. For Tamati, culture "means giving back to the community." They both worked three mornings a week at a breakfast programme at a local primary school and he was Kaumātua for two local schools. Tui said Tamati was a man:

> that needs to feel useful. Women - we draw our sense of purpose from many aspects of our lives but I've seen men, especially Māori men, who lose that when they retire. That's why they all die young.

Tamati had heart failure, gout and had had several transient ischaemic attacks. He felt these were all due to ageing as his "health caught up with me and there isn't much I can do about it." Overall, he felt well, although Tui said, "whether we do or don't do something revolved very much around his health."

Eight months before the first interview, their twelve-year-old granddaughter moved in with them. She brought a huge amount of joy to their lives, but they found the experience exhausting, especially as things were so different than when they raised their boys.

Tui was very involved in Tamati's care, gave him his medication and monitored his symptoms. Tamati referred to her several times as "my nurse" and tended to refer any discussion about his health to his wife:

> Helen: So how have you been, Tamati?
> Tamati: Ask her.
> Tui: No, she's asking you.

Tui said Tamati had always had a calm, passive demeanour, but this had become much more pronounced recently. The passivity was a huge frustration for Tui, as Tamati now seems vague and slightly disengaged from life. Tui said he was "in a dream most of the time." She wondered whether:

> when he had those TIAs it sort of knocked out one level of his energy - that's the level where he looks after himself and thinks about everyday things. If I didn't do things he would just sit there - he's just sort of unplugged from all those things.

Being "unplugged" meant that Tui felt she had to frequently:

> keep taking over. I wish I didn't have to. I try not going to appointments with him, but when I don't he doesn't tell the doctor the truth about how he has been and I never get to hear what the doctor says. I don't know how much of this is his memory affected by his TIAs or how much it's just that stubborn old Māori man over there ((laughs)).

During data collection, there were four episodes when Tamati stopped taking one or two of his medications for several weeks and had not told anyone. On one occasion, as a result of stopping all of his medicines except allopurinol, he was hospitalised with heart failure. On another occasion, it was frusemide, another dabigatran. Tui really wanted to understand why he made that decision - "I just don't understand it although I really try and listen to what he was saying" - and in fact took over the interviewing of Tamati on this subject.

Tamati said the doctor told him during the first incident that "if you want to die, just carry on the way you are." Clinically his clear risk was a serious cerebrovascular accident. Although Tamati volunteered that information, further conversation suggested he did not really believe it. He talked of worrying about the medicines harming his kidneys and having a fear of dialysis, of which he had whānau experience. However, he also said he knew his medicines were not toxic to his kidneys. He mentioned he felt "hoha" [something tiresome or tedious] of taking and being reliant on tablets, yet said he would never stop taking allopurinol. I failed to gain an understanding of Tamati's reasoning.

Tui said she often "just feel[s] like leaving him to his own devices - but I know he wouldn't live long without me." She used the language of dealing with a naughty child and comments on this fact herself. Overall, she felt the "combination of medication, the fabulous doctor he's got - who understands Tamati - our belief, and me growling him now and then that's contributing to his wellbeing.” To keep going she:

> keep(s) thinking about when we were young. And when you're young, you don't think about being old. And now we're old, you know, that older age, and ... he's been a good husband, a good father, good grandfather. So I just think about that, not about how he is now.

Wiremu

Wiremu was a 76-year-old Māori man with a twinkle in his bright blue eyes. He was widowed many years ago as his wife had very unstable diabetes and died in her late thirties. He and his wife had two stillborn children due to her diabetes, and another that survived and now lived in Australia. He now lived with, and cared for, his partner who had severe aphasia as a result of a stroke in her fifties. He said the situation can be trying, as his partner becomes frustrated at not being able to express herself, and he said one-way conversations drag after a while. She attended a centre four days a week. Her son also lived with them, lodged in the garage and seemed a bit of a recluse. Wiremu said, “he doesn't do nothing - he's hopeless.” They lived in a state house and Wiremu said they managed well financially because neither of them smoked or drank and he was a good budgeter.

Wiremu was an avid country and western music aficionado and kept very busy listening to, and sharing, music and making karaoke machines from old hard drives, which he then sold. He became interested in karaoke when a friend took him to a club when he was widowed and very low in mood. He loved going to clubs “for a bit of a yodel” and karaoke competitions. He was happiest when a singing festival was coming up and he travelled to them around New Zealand when he was able.

He had ischaemic heart disease and had bypass surgery after a heart attack. He had a large aortic aneurysm, which was getting larger. He talked about the surgeon finding a “lump near my heart which didn't look too good,” but Wiremu understood it as something left behind after the surgery. He knew there was nothing to be done about it but he was aware that keeping his blood pressure well controlled would help. He also had an unusual psoriasis, which flared up once or twice a year. The only effective treatment was the ultraviolet light treatment offered at the hospital. However, as receiving treatment involved several 45Km round trips, Wiremu usually was unable to afford the petrol so missed out on the treatment.

He had both cataracts operated on during the study and had also lost most of the use in his right hand due to a misadventure when having blood gases taken at the hospital. He was told the nerve damage would resolve after two years, but this had not happened, so he could no longer play the ukulele. Although Wiremu had diabetes he said he was “on the lower rung of it.”

Wiremu’s major health concern was his worsening mobility, which he felt threatened his ability to attend his music clubs. He had had two new hips and thought they “won’t operate” on his knees due to his age. His knees increasingly “give way on me” and so he usually mobilised using crutches. Wiremu sometimes became low in mood and lonely and found his limited mobility stopped him being as sociable as he would like. He still drove but increasingly found “it’s the getting in and out of the car that’s getting to be a problem.”

Losefo

Losefo was a 59-year-old Samoan man who worked as a diesel mechanic and lived with his wife. They were regular churchgoers and enjoyed frequent visits to their daughters and new granddaughter in Auckland. He had two myocardial infarctions and bypass surgery five years ago. When he had his heart attack, he carried on working for a day or two until his wife insisted he went to the GP. He considered his hypertension and heart attacks were his body telling him to slow down. He also had both diabetes and gout, which he managed well. For Losefo, the idea of control was important for the management of both of these conditions. He felt “it boils down to my personal attitude towards the sickness. What I want to do.”

He knew he could “do as [he] likes within reason as far as diet goes” as the physical activity of his job helped him maintain good health. He also said he liked being monitored by the doctors and nurses as then “I know where I am.” He felt his faith helped him: “I'm fortunate that I allow God to help me through.” He said he was a violent young man but that when he found God, he was given control for that as well.

After our first interview and the interview with his GP, Losefo chose not to continue participating in the study, but consented to the information I had gathered being used.

Lou

Lou was a 67-year-old Pākehā woman who lived alone. She was devastated by the death of her much-loved husband 10 years ago from cancer - “you make all your plans and then here I am at his funeral.” After her bereavement, she developed a severe and rare chronic autoimmune skin disease called bullous pemphigoid, mostly on her legs, which she had been told was stress related. The symptoms she described:

> you can't see them but you feel them coming because your skin starts to feel like hundreds of bee stings underneath. You daren't scratch because you don't know what you're taking off. So you've just got to wait till it comes up. Then once it's come up it just itches and itches and itches. It just about drives you crazy. I've even - at one stage I started to use sandpaper because it was just so itchy and I couldn’t get it to settle.

Flare-ups can be triggered by many things, from stress to a blood transfusion. She said, “if you can have a reaction – I’ll get it.” Sadly, this illness started an apparently endless cascade of side effects and complications. Firstly, Lou developed lymphoma, probably as a result of the treatment for her skin condition. During treatment, she was in isolation due to hospital acquired MRSA. She said, “it was hard. I knew nobody. And the cleaners wouldn't even come in and clean the room. They had expandable mops. And it was shocking.”

Chemotherapy for the lymphoma tissued, “leaking poison into my arm,” which led to several reconstructive surgeries. She said:

> my hand was enormous and within a fortnight, it had swollen up and gone black. And one night, it burst and I can't describe the stuff that came out, and the smell, and it was just so sore, and my hand went black, completely black…. I even asked the orthopaedic surgeon to cut it off, because it was just so sore, I couldn't stand it.

Lou had worked in the mental health unit but had to give up work due to loss of the use of her arm:

> And I had to fight for compensation because nobody would take responsibility. They said I should have known chemo wasn’t going in a vein – how was I supposed to know? It didn't hurt and I was sedated.

Already feeling isolated after her bereavement, Lou really missed work, which had given her “a purpose.” Unable to pay her mortgage she was eventually forced to move to a small rental unit. She then started experiencing abdominal pain, which she put down to becoming a “hypochondriac with nothing else to think about.” Her symptoms were eventually diagnosed as endometrial cancer, which meant further surgery and another harrowing bout of treatment. Both of her cancers were in remission but she said, “of course I still worry. The fear is always there.”

She felt she had a good relationship with her children and the grandson she raised, as well as her other grandchildren, but was fiercely independent. One grandson had a congenital condition that needed frequent hospitalisation and Lou spent a lot of time at Starship hospital with the boy and his mother. A granddaughter Lou was especially close to went through a very traumatic episode during the data collection, which caused Lou a lot of anxiety and worry. The knowledge that her grandchildren needed her became her sense of purpose.

Other health conditions included diabetes, hypertension, arthritis, chronic anaemia “from one of my treatments - take your pick which one,” and she was waiting for her second knee replacement. She had had to battle for the first one, as some surgeons would not operate while her skin was broken – and that was most of the time. During this study, a non-healing “pimple” on her nose was excised and turned out to be a melanoma.

She described her mind as, “willing, but my body won't do it. And I get so frustrated. I hate being dependent.” She experienced constant tiredness due to her medication and anaemia for which she had regular blood transfusions. She struggled to sleep and experienced a lot of pain. For many years she was prescribed 200mg a day of oxycontin [an addictive, opiod analgesic] but as a result of a conversation with a pharmacist she decided to carefully and slowly taper off this medication with her GP’s full support and admiration. At the end of data collection, she was taking 5mg twice a day and was thrilled with herself at this achievement. She subsequently stopped all oxycontin.

Unsurprisingly, she often felt depressed or angry but had an amazing ability to keep going and think positively. She did worry about the future and talked often about not wanting to be a burden. She said:

> I was very angry for a long time, I thought I'd had enough and there's nothing more I can do about it, learn to live with it … once you sort of reach that right at the bottom. You start [to] rise up again and things don't seem that bad.

More than any other participant, she often mentioned suicide. She had made her future plans with characteristic style, with a tattoo above her left breast reading DNR - do not resuscitate.

Figure 2. DNR With permission

Margaret

Margaret was a 56-year-old Pākehā woman who lived with her second husband and daughter from her first marriage. Margaret had been in one caring role or another all of her life, looking after her grandmother, father, mother and daughter. Her father had been a naval officer during the Christmas Island nuclear testing. He died of cancer, Margaret had cancer and she had two daughters with spina bifida, so she suspected many of these problems were a result of the testing. Her first daughter died aged three weeks and the second, Hayley, lived with her. Margaret said, “it seems like I've always looked after somebody.”

During the first interview, Margaret mentioned her daughter Hayley also had significant LTCs, had read the study information sheet and would like to also participate. Hayley and Margaret’s lives and stories were intertwined, with each supporting and encouraging the other and attending all health related appointments together. Initially, the intent was to keep their data separate but it soon became apparent the division was both artificial and impossible as they were “one hell of a tag-team” as their GP commented. Their connection became even closer with the need for Hayley to have a kidney transplant and Margaret going through the tortuous process of becoming accepted as a potential donor.

The story of Margaret’s health issues started with moderate obesity, which she felt led to her hypertension and diabetes. She also had asthma where the sound of her own wheezing used to keep her awake. During a routine cervical smear, she mentioned an itchy white spot to her GP and vulval cancer was subsequently diagnosed, for which she had successful surgery.

She experienced severe back pain for a prolonged time. The referred pain meant diagnosis was slow but eventually several cracked vertebrae were diagnosed. Because of the injury, Margaret had to give up her physically demanding job with a home care agency. There was a likelihood that she would need back surgery in the future but Margaret’s priority was Hayley’s transplant.

When she had to quit work, she “went into a state of depression. I felt quite useless.” She was frightened to move because the surgeons had mentioned they were not sure how stable her back was. The timing coincided with Margaret’s mother dying from dementia after being ill for many years. Her GP suggested antidepressants, which she likened “to somebody turning the lights on.”

A ruptured Achilles' tendon complicated her health even further. Once she eventually saw an orthopaedic specialist, "he said losing weight would help your foot and your back and everything, and I thought well, I'd better do what they say." The physiotherapist who treated her back suggested swimming, which she started doing for 45 minutes a day. "I started trying to fit in being more active because I found the diabetes made you tired anyway and I was sort of dopey all the time." She said her GP team tell her she was their poster girl for lifestyle change and self-improvement. She had lost 17Kg, her back pain had been largely relieved, and she no longer needed antihypertensives or her asthma inhaler. Her blood glucose levels were now, she said, close to normal. Her major incentive to improve her own health was to be well enough to potentially donate her kidney. She said this goal had made getting healthy much easier. However, she did believe that "once this is all over I've got into good habits as far as exercise and diet go" so believed she would maintain those.

Hayley

Margaret's daughter, Hayley was 26-years-old. She was born with spina bifida and therefore many physical issues, which she described as:

> it wasn't right when I was all coming together in the womb. I didn't come out quite right. So there's a lot of things I've needed doing to correct that. It's kind of like trying to add sugar to a cake at the end of the baking - you can do it but it's not quite the same. It works, but…

Mobility had always been one of her biggest issues and she had had countless surgeries. She could "walk around, and get around and stuff, but just not as great as normal people" and movement caused considerable discomfort. Surgery had included having both feet "reconstructed - pins, buttons, everything. Bone taken from my hip and put in my foot. You name it."

She was born with malformed ureters, which meant she was a sickly child due to constant urinary tract infections. Her ureters were reconstructed and bladder augmented when she was 12 but this happened too late to avoid the gradual onset of kidney failure from years of reflux. It took until three years ago for her kidneys to fail completely.

From a tiny baby, Margaret's clear vision of as normal a life as possible for Hayley could be seen – she did Hayley's intermittent self-catheterisation (which Hayley learned to do herself as soon as she was able) rather than have the offered indwelling catheter. Hayley said:

> Mum's been the one who's managed it for me until I was able to do it myself. And even then, she's ... I mean she's here right now, so everything ... she knows everything and anything.

Hayley had been on home haemodialysis for three years, which she did three times a week. The home had a lovely bright spacious area all set up for her treatment – a big factor when they chose the house. Each session lasted seven hours including set up and clearing up. Afterwards, she was so tired and washed out she just ate and then slept. She said it was really a “half life - I was told it's only just keeping me alive.”

During data collection, she had a new arteriovenous fistula[4] constructed and also parathyroidectomy surgery as these were “leaching all the calcium out of my bones.” Post parathyroid surgery was an awful experience. She had to take a large number of calcium supplements and said “I was choking them down, literally choking them down - they were huge. And when you’re not allowed much fluid it is even harder.” These high calcium levels led to distressing faecal urgency, which, due to her anatomy, meant “shower time.” It was during this time that this young woman was starting a new relationship. “Can you imagine?” she said. Her boyfriend also had dialysis so was “incredibly understanding, but there are limits.”

Her other interests included music and computer gaming, and during data collection, she went to a couple of big rock concerts with her father. She was able to stay with him in Hamilton occasionally, as she could reserve a place at a mobile dialysis unit. However, as the dialysis van needed to be booked six months ahead, “spontaneity is out of the question.”

Hayley spent a lot of her childhood in and out of hospital and had countless surgeries: “actually, if you want to get technical, my left arm's the only one that doesn't have any sort of surgery or scar on it.” She spent at least three birthdays as a child in hospital and often ended up comforting other children who were homesick. She said, “I speak hospital” and knew her anatomy, physiology and details of dialysis “more than half the doctors and nurses do.” The renal unit called on Hayley when they wanted someone to

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[4] A direct connection, created surgically, between an artery and a vein to allow haemodialysis

speak to a pre-dialysis patient. Hayley’s positive disposition was remarkable: “everybody has said I've always been happy and smiley.” Her attitude to dialysis was “yes, I hate it, yes it's a big pain in the arse, but I do it, and I do it the best I can.” Her sense of humour and teamwork with Margaret helped them both. They joked, “the only thing we do as a family is go to the doctor’s.”

Eventually, depression did hit Hayley but did not last long:

> it was a long time coming, but eventually it just got on top of me. But I'm alive, I'm doing well, I've got my mum, I've got the dog and it's all good. Going to get a kidney and get on with it.

She hoped to have a family one day and knew conception may be difficult due to a septate uterus[5]. She had already had genetic tests, which have excluded her “passing on any of what I went through.”

For Hayley and Margaret, their long list of hurdles to accomplish activities that others would do without a second thought was normality. They said that neither of them had known any different and the perspective they adopted was that Hayley had a much longer list of things to do to function normally than most. Hayley said:

> I do all these things to get my body to function normally. I've got to do dialysis to get my kidneys to work, and I've got to wear glasses because my eyes don't work properly, I've got to take Recormin because my body's not producing it. It does get hard, but I try not to think about it, and I just get on with life.

This study coincided with the wait for the possible transplant. Margaret said, “we jump through all the hoops - all the tests are good - the tissue typing couldn’t be closer - and still we wait.” They were told if all compatibility tests went well the transplant would be in early 2013, but a year and a half later there was still no word. Both were driven to distraction by the hospital system – almost every month saw them attending one or more appointments with little action from the tertiary centre. One month Margaret’s 24-hour urine test was lost and the hospital rang to ask Margaret if she was sure she had done it. Another time the hospital insisted they had done the tissue typing when Margaret and Hayley knew they had not.

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[5] A type of congenital uterine anomaly, which can make conception and viable pregnancy less likely

Along with tissue compatibility and physical checks for both Margaret and Hayley, both were set weight targets by the tertiary hospital to reach prior to surgery. Hayley was malnourished for so many years with constant infections and vomiting that once she had the bladder augmentation, she “ballooned” and became overweight. Both Margaret and Hayley initially progressed well with their weight loss, but with Hayley’s extra problems with movement, she found it “hard to keep motivated amid the deafening silence about a date for surgery.” They were both confident once they have a date she could lose the last 4-5Kg quickly, with the goal of freedom “from that machine.”

Hayley said she was “waiting to start living**.”**

Paul

Paul was a 51 year-old Pākehā man who lived with his wife and two teenage sons and who spent most of his working life in the food industry with his own business. Twenty-six years ago, he suffered a ruptured anterior cruciate ligament playing soccer, which was misdiagnosed at the time. Since then, he has had nineteen surgeries, mostly on the knee, which include replacements, revisions and second replacements. He also developed fairly widespread arthritis of the other knee, shoulders and spine, and was currently deciding whether to have shoulder replacements. He was keen, due to the severe pain, but he said the surgeons were reluctant to operate on someone so young. He was, until last year, a heavy smoker and drinker with hypertension and gastric reflux but recent lifestyle changes had improved those.

He had experienced recurrent, significant infections within the knee prostheses. The last one led to widespread septicaemia and a prolonged ICU admission during which time he was very near death. He said, “I remember when I was in ICU, and I was all going downhill, I thought, ‘this is ridiculous! Dying from a bad knee.’” He was deeply affected by the ICU experience including flashbacks, and a few months into the data collection, he organised a trip to ICU, which he felt would help him. He was pleased that he did, as “lots of things that I thought I imagined, did happen.”

He was still worried about getting another infection, although was pleased to state one day that it was now sixteen months since his last surgery – a record for him. He struggled to keep active as his knee became swollen after physical activity and he had fallen several times – which he had been told were because of his altered gait after so many surgeries.

His chronic pain and physical limitations had led to him experiencing several bouts of depression. He said “getting stuck [at home] all the time certainly gets you down alright. It's like being trapped in your own body.” He did find that usually he could “talk myself out of being down.”

He had also recently become increasingly concerned about his memory and feared he had Alzheimers disease. He said his memory fluctuated and “certain days, I’m just hopeless.” One day he said he had driven through a red light but usually he was pleased to report, “I've not done anything stupid this month.” After a long process of various tests and appointments over five months, he eventually got an ‘all clear’ from the neurologist. The all-clear was a great relief: “now I know I'm just a bad driver and not going bonkers.” He now believed his memory issues were due to multiple anaesthetics and the delirium he experienced in ICU, and he was optimistic for improvement.

Paul had been told he must no longer do any physical work, so he was working part-time for a community organisation providing support for young men with mental health issues who live in the community. He really enjoyed this work, although the poor remuneration made life difficult. He hated not being able to work fulltime and fulfil his previous roles.

He struggled living with the severe pain and his enforced change of role: “I’m just like a broken down car and I've just got to accept I’m not getting better.” Most days his shoulders “give me hell.” One month he had been to see his GP and said she was pleased. Generally, he said, “I try to keep away from her - God only knows what she’ll tell me next.”

Kōrero summary

This chapter introduced the 16 patient-participants. These extensive data provide the heart of the findings and describe people contending with a huge breadth and complexity of circumstances in frustrating, escalating tales of woe. The participant narratives described the chaotic and complex realities of living with LTCs and offered insight into 16 very different physical, psychological and social contexts. Their lives differed greatly and the implications for these individuals of interacting with the health system will be explored in later chapters.

The next chapter begins to draw together some commonalities. The patient-participants share experiences of multiple losses across every aspect of their lives and these are now explored.

Chapter Six: Findings two: Mauri

"Life just gets on top of people. We are worrying about their health and they are worrying about their lives." (GP)

"People impoverished in spirit do not care about smoking, being beaten, taking P and having asthma, when their pockets and hearts are empty."
(Tracee TeHuia, personal communication, 18th March, 2014)

Introduction

The previous chapter presented the 16 patient-participants' kōrero and offered an insight into their complex, entangled lives. An overall sense of loss in relation to how a person is able to live their life comes through strongly in the data. To explore this further, the Māori concept of mauri is employed.

Mauri is a term that can be used in several ways. For this study, mauri is used to mean the dynamic life force, life energy or essence that everything and everyone has. It means the forces that affect health, from Mason Durie's Pae Ora [healthy futures] principles of Mauri Ora [healthy lives], Whānau Ora [healthy families] and Wai Ora [healthy environment] (Durie, 2011; Ministry of Health, 2014). Mauri provides a way to structure this second findings chapter to explore the participants' lives in their entirety. The idea of mauri is relevant because the idea of a person's life force resonates with the innate sense of motivation or purpose that is a fundamental requirement of the self-management approach.

The findings fall almost neatly into the four quadrants of Durie's Whare Tapa Wha model of health (1985, 2001). Durie developed the model, following a health hui [conference or meeting] in the 1980s, in response to the narrowed biomedical framework of health that was failing to meet the health needs of Māori. His unified model of health uses the image of four walls or cornerstones of a whare [building] that represent the interdependent physical, emotional/psychological, whānau/social and spiritual aspects of a person's life. When there is damage to any of the walls, it undermines the person's wellbeing. There is a need for balance for optimum health and deficits in one area can be compensated by strength in the others (Durie, 1985; Rochford, 2004). The model is well known in New Zealand and is referred to in many policy documents.

Taha tinana

Durie’s first cornerstone, taha tinana, describes the physical aspects of the participants’ lives. In the tinana quadrant, the findings describe people living with steadily deteriorating physical capabilities. With steadily increasing weariness, participants have to force themselves to accomplish previously effortless physical tasks that become harder and harder as time passes.

The patient-participants used words such as unremitting, inescapable and cascading to describe their decline in health. Tane’s experience was typical of the others, when he recounted his life journey, where:

> it wasn’t so bad at the beginning but then it got worse and worse … and then I got COPD, then I had a PE [pulmonary embolus]. I started off with one medication, then I was on two, then three, then the heart.

The physical slow down is insidious. Tane described his decline as “circling round, lower and lower round the toilet bowl.” Diane said:

> with chronic stuff, you don't know you're losing it. [It’s] like the frog thing – put a frog in boiling water, and it'll jump out quick. Put it in cold and just gradually increase [the heat] and it will die. Well, it's that dynamic. Sometimes I don’t realise how much I have adapted – how I slowly creep around and eventually get everything done.

Amongst the various physical symptoms, those consistently mentioned as the most distressing by the participants were pain and fatigue, which led to loss of energy and mobility. Several people talk of getting used to, or learning to live with, their pain but experienced the extreme fatigue as far worse. The loss of energy revealed as severe fatigue was universal. Aroha said, “ah, tiredness. That's *very* hard to cope with sometimes.” Lou tried to explain her physical fatigue:

> I can actually live with my pain. You learn to live with it, which is what I've done. But I just wish I wasn't so tired. I hung the washing out and almost didn’t know how to get back indoors. The mind is willing – but goodness the body is not. I never knew the true meaning of that until now.

Physical symptoms and decreased functional ability are the aspects of living with long-term conditions explored most extensively in the literature. It is on these physical aspects of a person’s life that the biomedically, risk factor driven self-management approach concentrates. In contrast with the self-management approach's focus on patients' physical domain, the study data relating to the tinana theme is relatively sparse. Once people had described the chronology of their illnesses, they moved on from discussing their physical problems. Aspects of their lives that relate to Durie's other domains were more important to them.

Taha hinengaro

Taha hinengaro refers to the psychosocial context of a person's thoughts and feelings. The participants were very aware of the effect their feelings had on their wellbeing. As Tane explained, "of course when you're struggling emotionally, that can really stop things."

Endless unresolved grief

The participants all described ongoing grief, which Diane called "a lifetime of letting go." Lou talked about how "the grief all just flows into each other. I try not to dwell or look back. I've lost everything really." An incessant stream of losses left participants with grief that is still unresolved by the time another loss occurs. Eva describes, "sometimes I think nothing else can go wrong, and I've got nothing left to lose, or no tears left. But then it does happen. And I don't have time to get my head round it." Several participants liken the experience to being on a treadmill. Aroha describes:

> it never ends and you never get a chance to catch up. I mean you just get used to one thing and then there's something else. You never come to terms with it. You just never get a chance to.

Roos' (2002) term for this residual grief is chronic sorrow. It is often unrecognised. Diane experienced grief that was overlooked by others when she lost the sight in one eye and again with the loss of her breast when "no one once asked me how I was feeling about it."

The loss of participants' freedom and autonomy was also keenly felt. Tane hated the resulting sense of powerlessness he felt, as he increasingly had to fit his plans around other people and was progressively less able to leave his house. Along with other participants, Tane described himself as a prisoner. The loss of autonomy left participants feeling frustrated and resentful. Lou said she "get(s) so frustrated, you know, [but] I just haven't got the energy to fight it." Despite her battle to retain it, Lou was aware of her waning energy, which curtailed her autonomy.

Getting me down

The participants' circumstances often led to low mood and what they called self-pity. Yvonne described her feelings and her fears for the future and said:

> it's a feeling of not being able to cope, and it was getting me down ... it was terrible … what am I going to do? what's going to happen to me? … oh I felt so sorry for me ((laughs)) ... sometimes it gets a bit too much.

Lou said, "on lots of days, I just have to will myself to get out of bed." Tane expressed his despair more strongly. He said, "half the time, I don't live really - I just exist." He talked about how his mood went "down and down, and it's grey, and it's crappy, and then it just turns to custard."

Most participants described their experience of clinical depression that they felt they had 'got over,' usually with medication. Talk of suicide, although never asked about specifically, was raised by several of the participants, many on multiple occasions, sometimes as an aside or sometimes 'joking.' For Eva, every interview and monthly conversation contained references to "not being here anymore" or wanting to "drive into a tree." Lou had often considered suicide and said only the impact it would have on her family stopped her. She often raised the subject and commented, "we don't keep animals alive, do we? You don't. And we should have that right as well." Another time she spoke seriously:

> sometimes I do think I could quite easy top myself….I get so down, and then something will happen and I'll pick myself up. [And say] "you stupid bitch." You know, sometimes you're feeling down, your health isn't the best, and [think] why do I hang on? Why?

Taha whānau

More than the whānau or extended family alone, taha whānau concerns the social influences on health (Glover, 2005; Rochford, 2004). The theme includes the social aspects of culture and religion (rather than beliefs) and the socioeconomic aspects of the participants' lives. These influences are closely interwoven and affect how participants prioritise aspects of their lives and the primacy they do or do not give to their own health status and the associated tasks, which a self-management approach requires.

Whānau were experienced as both a source of support and of conflict, sometimes simultaneously. The collective wellbeing of whānau impacted on the participants' own sense of wellbeing, with both collective strengths and weaknesses seen in the data. A strong sense of whanaungatanga [interconnectedness or belonging] between individuals was noted relating to these family and social roles. Although especially marked in the Māori participants, almost all participants expressed a sense of interdependence and collective identity. Engagement with family brought associated responsibilities for caring for others. In the context of the often present diminished financial resources those responsibilities were often chaotic and stressful and utilised precious or scarce energy.

Caring for others

An integral aspect of being part of a family is the responsibility and desire to care for others. For the seven patient-participants who also fulfilled a specific carer role, addressing their own health needs fell well behind their commitment to others, despite their own significant health issues. Eva captured this idea when she said, “health just gets lost amongst everything else.” Huia recalled taking her brother to his GP and coming out with medication for herself despite having not acknowledged that she was especially unwell:

> it was a rip-roaring infection [the GP] told me. Almost pneumonia. I didn't think about going [to GP] for myself. That wasn't the biggest prob[lem] for the family - that was Eru. He was worse than me.

Overall, caring responsibilities were experienced as a double-edged sword, particularly for those participants who cared full time for their grandchildren. Any emotional energy they gained was often counterbalanced by sheer physical and psychological exhaustion. Tamati explained both the benefits and extra challenges of caring. He described his granddaughter as “the apple of my eye … a lovely girl but exhausting. Not something I would recommend to the elderly.”

Aroha, caring for her five grandchildren despite very significant multiple morbidities, found the children exhausting and said “even I don't know how I do it sometimes. I'm just on automatic pilot.” She riled against having them, whilst simultaneously felt they kept her well and she missed them when they were away. She acknowledged her own ambivalence of both wanting the children's parents to “step up,” whilst at the same time not trusting her daughter to be a “good enough mother” to the children if she did ever want them back.

Staying connected

The Māori and Pasifika participants experienced their culture in the communal and social aspects of their lives, which were reflected in their everyday behaviour and way of thinking. These were particularly influential on their health. The Pākehā participants from the dominant culture did not discuss aspects of their lives in terms of culture. Black (2010) suggests this is because they perceive their worldview as ‘normal’ rather than related to their culture.

The commonalities did vary between the Māori, Pākehā and Pasifika participants. However, the differences were by no means based exclusively on ethnicity and overlapped considerably. Within the overlap, Eva [Pākehā] belonged to a predominantly Māori church and expressed many cultural similarities with Māori, including her strongly held collective ideas about health, contrasted with Aroha [Māori] who said she “can’t be doing with any of that cultural stuff.”

The influence of culture, along with the social aspects of organised religion can increase a participant’s sense of belonging and often provided support in difficult times. A sense of belonging and connectedness are vitally important against the persistent sense of diminished identity described. Sometimes those connections produced conflict with the requirements to manage their health in the way that clinicians might expect.

Yvonne’s Samoan socialisation and experiences had created her cognitive map, which affected her reluctance to have insulin. She said,

> I never really wanted to go on insulin. Once you mention you're on insulin, you're the worst, you know. When I hear my people [at church] saying they're on insulin, it's like a bad thing. Because people have different thinking.

She had a thorough understanding of the physiology of insulin, yet her belief about its badness persisted even as she admitted that she felt better when she took even her current tiny dose.

Feeling diminished

Despite their commitments to caring, participants spoke sadly of a loss of identity and sense of purpose that resulted from diminished family and social roles. Both Diane and Eva described how their ability to parent as they had once imagined they would was altered by their illnesses. Eva often spoke about the activities she had not been able to do with her children. She explained, “[my health has] stopped me doing things with the girls, like as far as being able to play with them and that sort of thing when they were younger.”

Diane suspected her fractious relationship with her daughter stemmed from her daughter’s lifelong resentment of her mother’s ill health. She said of her daughter, “I'm not the mother she wants me to be.”

Although the participants who lost their jobs due to ill health mentioned financial difficulties, of more importance to them was the loss of their previous sense of purpose and identity, which had been tied up with their work. Lou said:

> I did enjoy going to work, especially after [husband] dying. It gave me a purpose. It was a reason to get up every day. And now I feel I don't have that purpose any more. Sometimes I get really down.

Paul reported that, “not working's horrible. People don't believe me. ‘Oh yeah, that must be great’ - they just don't understand - you lose all direction. I hate it.”

Lou spoke of how LTCs “cut out so much that you’ve taken for granted.” As participants watched their own social and whānau roles diminish, they compared themselves to their former selves and to others who they perceived as “being normal.” Two participants described their glimpses of this normality whenever prescribed a course of prednisone for a COPD exacerbation. Tane said, “I love those little pink pills. I feel like superman. Or perhaps [I] just feel like a man?” Diane’s goal of being normal would appear a humble ideal to many. She said,

> I've been thinking about what is normal. And I think it is just being ordinary – not standing out from the crowd …I was on prednisone a while back for a few weeks and I was amazing. And that’s the dilemma. You know that’s what you could be if you were really well. It’s like this tantalising glimpse at normality… The energy comes back … [and] for a couple of weeks you keep up with everyone else and you’re all good. And then you stop taking it, and you slowly go back to snail speed.

Diminished resources

Unequally distributed resources among the patient-participants are a strong economic theme in the data, with most participants living in poverty. Their socioeconomic positioning meant they accumulated fewer supports and resources to cope with their challenges. These resources include finances, knowledge and beneficial social connections, something that resonates strongly with Link and Phelan's work (1995, 2002; 2013). Wiremu discussed the struggles he and his whānau had with a number of social agencies, the poor outcomes of which he felt were because neither he nor his whānau understood "who to go to or who to ask." One winter day, in Huia's bitterly cold home, she said her chest was "playing up." I asked her about house insulation and she replied:

> we tried to get him [landlord] to insulate it. The nurse told me there were a few schemes that could help through the health department. But [landlord] wouldn't pay his little bit, like it was about $100, so no go. The form said we could appeal for extra help, but we don't. We didn't. This is just how it is here.

For Huia, the cost of insulation was less influential upon the outcome than her lack of agency to challenge her landlord's decision or seek additional help, because that "is just how it is here."

The existence of a significant inequity of resources for people to utilise remains largely unchallenged in the self-management approach. Participants are served by social agencies, including the health care system, which overlook the pernicious hopelessness created by poverty. They assume everyone has the capacity to get the services they are entitled to as well as readily embrace a healthy lifestyle. Clinicians, whilst often critically aware of the real life struggles of these participants, had few available strategies to respond to what they know about their patients. The experiences of clinicians will be further addressed in the next chapter, which moves to consider the mutual entrapment experienced by the patient- and clinician-participants as they are similarly captured by the strictures of current approaches to long-term condition management.

Taha wairua

Taha wairua is often summarised as spirituality but also relates to an individual's faith, sense of purpose and vitality, motivation and identity. It has been described as the most basic (Durie, 1985) or essential (Cram, Smith, & Johnstone, 2003) requirement for health. It is related to a person's connectedness, feeds a person's life force or mauri and is closely linked to an individual's emotional wellbeing. Despite the importance of taha wairua, attention to an individual's spiritual wellbeing or sense of purpose is noticeably absent in the biomedical model.

Each concept within wairua provides subthemes to explore aspects of the individual's wellbeing that relate to wairua, although some consideration of identity and sense of purpose have already been described in the preceding taha whānau theme. Wairua is discussed here in terms of 'the something' that is life enhancing, the lack of which Diane described as causing the "daily pain of no longer being able to do or contribute to life, in what were life enhancing ways."

Wilson (2004) explains wairua as essential for being at peace with oneself and Valentine (2009) described wairua as having an anchoring quality, which enhances growth and provides balance. Wairua has traditionally been a strong component of Māori health and wellbeing, which Valentine (2009) described as "one of the most important aspects of Māori wellbeing it is also the most complex, multifaceted and elusive construct to describe and understand" (p.149).

Vitality

The wider understanding of taha wairua, that goes beyond religious faith, encompasses an individual's vitality. Participants spoke of vitality as the energy, spirit or the "secret sauce" they needed, but often lacked, to cope with multiple LTCs. As well as the term wairua, they also described losing their "oomph," "hutzpah," "surplus" or "mojo." The meanings of each of these terms to the participants seemed similar.

Participants often conflated the ideas of wairua and energy. Tamati's wife said, "when he gets ill, it just knocks him. His wairua was low and he doesn't have that surplus." They gave vivid stories of how the LTCs steadily sapped this energy or motivation. Tane explained:

> when your spirit's flat … you know, if that's not running properly, then that can affect how everything else is going. I mean it's like that Mason Durie said, Whare Tapa Wha. You know, the four walls of the building. Yeah. You know, your body, mind, spirit and your family.

The stoical Aroha explained how, "it's nothing physical. It's just me. I can't be bothered. It's like I've lost that thing - my mojo is it? - to do anything."

Motivation and sense of purpose

The loss of participants' vitality drained their motivation and sense of purpose, leaving most with an overall sense of inevitability and pessimism and little hope for their future. The endless uncertainty of living with LTCs overwhelmed any anticipation of some positive future possibility that the idea of hope contains. For these participants, hope appears both scarce and sporadic. Their loss of realistic hope led to apathy and was experienced as despair.

Participants shared their social networks with others who are exposed to the same socioeconomic drivers of ill health and who were also often living with LTCs. The shared loss of hope resulted in an apparent resigned acceptance of poor health as normal or even inevitable in their whānau or community, something especially marked in the Māori participants. Huia's resolute cheerfulness and what she termed a positive attitude could be interpreted as a passive acceptance of her poor health and her social circumstance and what Cockerham (2013b) calls "pervasive fatalism" (p.15). The driving forces behind these low expectations are complex, multi-factorial and are linked to generational disadvantage.

Hope

Hope is a psychosocial resource (Duggleby et al., 2012) directed at a future good (Barilan, 2012). It is influential in both the taha wairua and taha hinengaro domains. The idea of hope involves choice and free will, is closely linked with ideas of personal agency and an individual's sense of being able to shape their own future (Barilan, 2012; Bryant & Ellard, 2015; Duggleby et al., 2012; Snyder, 2000; Tong, Fredrickson, Weining, & Lim, 2010).

The part choice plays in the experience of hope, identified in Duggleby et al.'s (2012) metasynthesis, suggests that hope is likely to be another structural resource less available to the socioeconomically disadvantaged. Hope plays an essential role in the goal setting aspects of care planning. Therefore, its absence significantly disadvantages participants when they come to engage with the self-management approach.

Some participants mitigated their lack of hope by consciously choosing to ignore the severity of their LTCs. Tane's health was possibly the most fragile of the patient-participants and he had a very complex relationship with hope. He seemed to be able to feel genuinely both hopeless and hopeful simultaneously, with neither state apparently connected to any objective health status.

He discussed the likelihood of death from one, or a combination, of his LTCs and was acutely aware of his own mortality. During a recent hospitalisation he discovered that he was both ineligible for bariatric surgery due to his anaesthetic risk and also that he was not for resuscitation. He said, “ah man, that was gutting… that means I’m a hopeless case.” However, he concurrently talked of his almost grandiose goals and could express both these ideas during the same conversation. Tane used hope as a coping mechanism to sustain him as he deals with his poor health. He said:

> I have to be positive. I have to believe I can get better… I still think there's a chance. As long as I can walk, I can get there. It's still achievable. But when I actually get up to go do it, my body's saying - hang on! … In my mind … I'm not an invalid, [but] I kind of am feeling that way. But I'm trying to deny it, because I [have to] feel I can get back.

Taha wairua is perhaps the most slippery and subtle of the four cornerstones of the Whare Tapa Wha model and deficits in that area are significant. Although biomedicine has paid it scant attention, aspects of wairua have a significant impact upon an individual’s capacity to demonstrate the essential prerequisites of motivation and hope necessary to engage with the self-management approach.

The complexity of food

Mealtimes and food sit at the intersection of the Whare Tapa Wha cornerstones. They are the focus of much of the health advice patient-participants with LTCs receive as well as being an area of tension between clinicians and patients that gave rise to a shared sense of mutual failure. As such, the activities around food are a source of the most obvious and direct conflict. From the taha tinana cornerstone, food offered literal nourishment through its calorific value. Equally precious and relating to taha hinengaro, food represented an aspect of patient-participants’ lives over which they retain some control. Eva’s strong sense of powerlessness over her LTCs coloured her approach to both the LTCs and self-management. She said:

> if I'm feeling hoha, then I usually crave something sweet and I need something to pick me up because I need to keep going. And I know I shouldn't do it, and I sort of feel guilty with doing it.

Tane talked of food in relation to taha wairua and how food temporarily replaced his loss of vitality. He said,

> sometimes … I'd be exhausted and sore, and the only thing I could think of that would make me feel good ... would be a burger or a pie or something. You know. That was my reward. It's something that made me feel good. Inside and

> out. It would lift my spirit - give me some oomph back. And then … I'd sit there under those trees … and have something to eat. And then feel crap about it. You know, because it's like I know it's not good for me, it's not good for my weight loss, but it made me feel good for that small amount of time.

The participants all volunteered information about advice they have received about their dietary intake. The overall messages were perceived as being about enforced restraint and missing-out on something desirable. The adoption of this advice was sporadic at best. Yvonne, for example, was aware of the harm high sugar drinks create, due to her diabetes, but felt they gave her the temporary lift she needed. For Eva, food was something she clearly identified as an immediate way to deal with stress and when resources were limited, her focus tended to be on resolving the problem closest to hand.

From the taha whānau cornerstone, family eating practices are integral to whānau life and are associated with a sense of belonging rather than being an individual behaviour. There was also the emotional energy gained from eating or preparing food in a group. Participants also spoke of their family “leading each other astray” by not making healthy food choices. Eva explained how the family “talk each other out of” both good food choices in the supermarket and being active.

For the Māori participants, manaakitanga [hospitality, kindness and support] was one of many areas where culture and health overlap. The sharing of food has traditionally linked hospitality, nurturing and identity. For example, each Marae has a speciality dish or two. Several of my research whānau discussed how manaakitanga could be carried out to excess and so affected the daily habits of Māori and Pasifika and their subsequent health.

The same traditions are also present both with Pasifika cultures and New Zealand Church of the Latter Day Saints where many Māori and Pasifika attend, including two patient-participants in this study. Manaakitanga is a significant part of giving and belonging in participants’ lives and usurped any attempts to eat a healthy diet. Yvonne experienced these ideals of manaakitanga with her Samoan Mormon church involvement from which she gains much comfort. She said that the majority of the church community and worship involves gatherings where large quantities of food are prepared and eaten. Her culture trumped any knowledge she had about the impact on her health of her weight and diabetes. She said,

> my goals are to get my sugar levels down. That doesn't happen. I've been busy cooking for a church friend's birthday celebration this afternoon. I've been cooking cakes and savouries - and of course I have to try them dear! ((laughs)).

Tane's genuine yearning for better health was powerless in the face of his mother's control over his diet, something that was important to her and he felt reflected their culture. He said,

> she's naughty like that ... that's the way she is. She thinks giving love is feeding. She feeds up everyone that steps foot in here. She's been raised in manaakitanga. A lot of mums are like that, especially Māori mums. You know, like you see on television, all those … Italian mamma … they smother you with food and love, and that gives them satisfaction.

Findings revealed participants caught in a complex web wherein their connections to family, whānau, culture and commitment are important aspects of maintaining a sense of purpose and identity when much else had been lost. Yet more often than not, these very connections directly conflict with or reduce their ability to focus on or engage with the essentially selfish requirements of the self-management approach.

Summary

The idea of mauri or life force as an essential requisite for wellbeing suggests that a person needs to have strength in the four interdependent cornerstones of Whare Tapa Wha model. However, the chapter concludes with participants weary and depleted of the positive life force of mauri and deficient in each of the model's domains. Their overall sense of weariness and movement towards apathy, passivity and inertia was summarised by Eva who said, "it is really much easier to just sit and do nothing ... much easier."

Participants are weakened, frail and lack the very resources needed to meet the demands of living with LTCs. A person depleted of energy by a succession of losses across the four cornerstones of the Whare Tapa Wha model is positioned unfavourably to engage with the self-management approach and unlikely to be receptive to the messages of health promotion and self-improvement. One GP captured the impact of the overall losses. She said:

> life just gets on top of people. We are worrying about their health and they are worrying about their lives. Health often doesn't get a look in.

The GP’s comment highlighted the disconnect between a health care system that assumes the primacy of health in people’s lives and the weary participants whose complex lives and social contexts rarely allow them to prioritise their health.

The patient-participants experienced a journey towards inertia that worked directly against the possibility of agency. Such a contradiction is important because the way self-management of LTCs within health care delivery is conceptualised is dependant upon the presence of an informed and activated patient with the motivated self arising from a patient’s personal agency (Bodenheimer, Lorig, et al., 2002; Bodenheimer, Wagner, et al., 2002a). The energy depleted patient-participants’ engagement with health services, alongside their clinicians, is explored next.

Chapter Seven: Findings three: Hauora

“Did anyone ask us or the patients what actually might be helpful?” (PN)

Introduction

The previous two chapters describe patient-participants who were reduced to survival mode by their cumulative losses. They were left exhausted with an overall feeling of physical, psychological and spiritual weariness and loss of mauri. To support them, what was needed was a hauora [health care] system that recognised these deficits and compensated for their lack of energy. In this chapter, hauora is used to explore the data that related to the patient and clinicians’ experiences with the health system.

The Chronic Care Model and self-management framework provide a structure for the chapter. Findings often sit in contrast to both the aspirations of the idealised model and the formalised programmes that are the vehicle for the diffusion of the approach into practice. Core components of the Chronic Care Model are the informed, activated, empowered, expert patient and the prepared, proactive practice team working together in a collaborative partnership (Bodenheimer, Wagner, et al., 2002a, 2002b; Kennedy et al., 2005; Wagner, Davis, Schaefer, von Korff, & Austin, 1999; Wilson, 2007).

The findings surface several inherent contradictions between the idealised expert patient and its position within a health care system that remains entrenched in biomedicine. These contradictions between patient expertise and the biomedical paradigm, described by Wilson et al. (2007) as the “paradoxical nature of the expert patient” (p.430), are explored throughout this findings chapter.

The chapter concludes with an exploration of the examples in the data where care is working well - what the patients and clinicians say do work, what they value and what could be different. These data provide a platform for the discussion chapter to explore the pockets of excellent care for people living with multiple LTCs and how these either intersect or diverge from the current care approach.

The expert patient

The idealised notion of the expert patient is a central tenet of the Chronic Care Model and self-management framework. The patient-participants in this study belong to the group to whom funding for self-management is directed and where patient expertise and active engagement is anticipated. The weary and distracted participants described in the previous chapter encountered many barriers that prevented their engagement with the expectations of the self-management approach.

The term self-management was unfamiliar to all the patient-participants. Paul asked what it meant and I replied with a definition that reflected the literature. He disagreed with the explanation. He said:

> so for me, self-management isn't something I have to do physically. It's all mental. It's deciding every day whether I can face it. If I can struggle through another day in pain ... that's the self-management. And Care Plus just doesn't cut the mustard with that.

For the patient-participants, self-management was articulated as how they got through the day and on with their lives, with scant reference to any aspects of the self-management framework. With the term self-management unknown, the patient-participants' capability to be able to adopt the role of an expert patient and engage with the approach seems problematic.

Expert knowing

A corollary of self-management support, permeated by biomedical dogma, is that behaviour change is achieved by an increase in patients' knowledge. In contrast, the findings showed participants with sophisticated knowledge of LTCs not reflected in their subsequent behaviours. Some participants demonstrated exemplary knowledge of complex concepts. For example, Eva explained the pathophysiological rationale for commencing insulin when she:

> still had some function left in the pancreas, [so] we decided that it was probably better to try and save that, so that it did its bit if it possibly could, and to go on the insulin … I know that as long as I take my insulin, optimally exercise, watch what I eat, and take care of myself, that I should be okay and be able to carry on.

Patient-participants, in an act of agency, occasionally used the knowledge they had to help them live with their LTCs, rather than to comply with instructions they may have received. For instance, Eva utilised her knowledge of physiology to continue to eat confectionery and maintain a steady blood sugar by adjusting her correcting factor dosage of insulin. She said,

> I can pander to my sweet tooth. I mean I do try. It's just ... my downfall is the sweets. And I just can't seem to stop myself from buying them, and then they're there. So the correction factor helps that – keeps my HbA1c good.

She used the knowledge in a way that helped her cope, rather than the way the clinicians intended. This was her own patient expertise, but neither Eva nor her clinicians recognised it as such and it is not reflected in the self-management approach.

The literature suggests patient expertise is a discrete state that people either do or do not achieve. However, the findings did not show this neat, dichotomous picture. Although most patients understood the advice, other factors intervened. Some participants had good intentions to follow the advice, yet lacked the energy or structural resources to follow through. Participants' engagement with their health also waxed and waned over time and was dependant on other aspects of their lives. Some followed some parts of the health advice they received and not others; some understood but did not believe the advice; some did all of it sporadically; whilst others over time did less and less as they became increasingly passive. Very few of these important nuances are catered for within a self-management support framework largely organised in one-size-fits-all programmes.

Selective action

The aspects of caring for their LTCs carried out most dutifully overall by the patient-participants were those that reflected the values of the biomedical model. Taking medicines and attending appointments were most frequently mentioned, the same behaviours prioritised in the self-management literature (Audulv, Asplund, & Norbergh, 2011). One GP described taking medicines and attending appointments as "sort of do[ing] the basics … but not perhaps tackling the big issue, yeah. Literally." Participants consistently showed this pattern of "doing the basics," whilst not managing to incorporate the prescribed lifestyle changes of activity and diet. Patients and clinicians seemed equally as colonised by biomedicine and they both privileged its knowledge, which they believed to be the remedy for any LTC complications. Eva knew the potential complications of diabetes, "like dialysis. Like vision. But I take my insulin so I will be OK."

Another result of the primacy of biomedical knowledge is that although a few participants did understand what kept them well, they often did not award this knowledge equal value with clinical advice. Diane recounted how "last week I was singing and dancing in church and felt wonderful. I took my peak flow when I came home and it was way up.” Diane knew that singing and dancing helped her breathing and that the recommended pulmonary rehabilitation course did not suit her combination of LTCs. However, despite knowing this, she privileged biomedical knowledge and did not consider singing and dancing as part of her self-management. The privileging flies in the face of the rhetoric behind self-management and so stifles any true collaboration.

Tailoring expertise

Despite the respect often accorded to biomedical knowledge it does not mean that participants will necessarily believe what clinicians tell them. The expert patient concept presupposes that patients believe the health messages they are given. However, patients’ wider beliefs could be more influential upon their behaviour than knowledge received from clinicians or the health system. When these beliefs do not coincide with information received, there are implications for health behaviour. For example, Wiremu’s wife had “brittle diabetes,” which led to her early death, and this shaped his beliefs about the disease. He felt “I know what they tell me, but I don't even think I've got it, to be quite honest. I know what diabetes is.” Yvonne’s beliefs filtered a fairly gloomy recent health assessment. She said:

> the nurse says everything is going fine. Just those fizzy drinks and my eating. My weight [is] up 6Kg in a year and kidneys getting tired – like me. Sleepy all the time. They [GP] say it’s my high blood sugars and I need more insulin, but I think it’s just me doing too much. I need to exercise more but my foot hurts and I’m so busy with the [grand]children.

On another occasion, Yvonne was admitted to hospital for increasing shortness of breath. She said her GP had told her the cause was “to do with putting on weight and … my heart doesn’t like the extra strain.” The hospital specialist concurred with the GP and said she could find no other cause apart from Yvonne’s steadily increasing weight. On both occasions, Yvonne steadfastly held onto her belief that the reasons for her ill health related to “doing too much” and a change of medication. These beliefs directed her decision-making and interpretation of her symptoms. She possibly missed the implications for her health and saw no possibility of incorporating any changes into her life.

For the patient-participants, any facts or ‘truth’ contained in information they were given was irrelevant, because it was their beliefs and the conclusions they drew from these that shaped their subsequent behaviour. The ways they made sense of their illnesses directly affected their health, in contrast to the assumptions of rational behaviour and decision-making that the self-management approach assumes.

Seeking control

Although often unsuccessful, the energy-depleted patient-participants usually continued to strive for some semblance of control in their lives. When they did lose control of the big things such as health, they tended to concentrate on smaller, manageable aspects of their lives over which they retained some control. Small acts of resistance occurred when patients felt these were the only control they had left. Behaviour that was labelled non-compliance may instead have been an example of trying to exercise their little remaining control and stretching their agency muscle. These may have been unwise decisions or have made no sense from the clinician perspective, such as continuing to overeat or not taking medicines. Paul’s GP understood. She said:

> he was a pretty awful patient before because he would never comply with anything. And he wouldn’t stop smoking and his blood pressure was high… Then he’d stop his medication because he’d think, “I've cut down on my smoking I don’t need to be on it.” So then you’d go through all that education, and of course then [his wife who is a nurse] would go through the same thing. I just think he felt he was being nagged and I often think you just have to remember the only thing patients *can* do is to decide to stop taking their pills.

Eva’s ever increasing number of people and pets in her home was another example of expressing some control in her life. Short-term planning horizons, often associated with poverty, are the norm when short-term needs are great and the future uncertain. These directly and explicitly contradict the requirements of the self-management framework. The increasing number of animals was a source of frustration to her GP and PN. Her PN said:

> whenever we talked about diet she would always say, “we can’t afford meat – only sausages.” We had a cattle beast in the fridge [at nurse’s home], so I took it round and she was just – wow – so grateful. And then the next time she saw me she was telling me about their new dog. I give up!

The reaction of Eva’s PN was intriguing. The comment “I give up,” suggested that despite obviously being a kind and well-meaning person, she felt unable to work with

Eva unless Eva changed her ways. Although the nurse's subsequent conversation showed she did not give up, it also revealed her struggle to consider ways to support Eva on Eva's terms. She wanted Eva to fit in by stepping up to the biomedically-framed ideas of what was necessary. The cognitive map that emerged from the nurse's own socio-economic status, meant she often struggled to understand or empathise with Eva. These differences compound any disconnect between clinician and patient (Protheroe, Brooks, Chew-Graham, Gardner, & Rogers, 2013). In these circumstances, clinicians are less able to embark upon collaborative relationships with patients.

Other examples of these intentional strategies, which Demain et al. (2015) call rationalised non-adherence, were both Rawiri and Tamati unilaterally stopping medication, which resulted in both of them being hospitalised. Tamati's wife explained these occasional decisions as "a rebellion." She said:

> the stubbornness comes in. I don't know whether it's a man thing or what, I don't know. But maybe it's just him, just flexing his ... because what's happened, with the illnesses that he has, he's losing some control of his life. Like he's limited in some things that he ... and that took him a while to come to terms ... so I think sometimes he does what he can to get some [control].

Compliance

The findings also highlighted the dissonance between the rhetoric of patient autonomy and biomedicine. The tension between an empowered patient making informed decisions and the classification of any decision that does not correspond with medical advice as non-compliant is another inherently problematic piece of the expert patient discourse. Non-compliance is a term frequently utilised by health professionals, although there is also a general awareness that to use such a term is inappropriate and counterproductive to current notions of patient expertise and partnership. Both Wiremu and Huia had very good reasons for non-attendance at hospital outpatient clinics, which related to the cost of travel and their responsibilities as carers, yet were both labelled non-compliant. The hospital doctor's response to Huia's explanation of her conflicting priorities was, "well, if you don't think your health is important …" The lack of insight into Huia's collective ideas around health, echo what Thirsk and Clark (2014) called a "problematically oxymoronic" aspect of self-management (p.691).

Diane could not manage the exercise machines at a pulmonary rehabilitation group due to her arthritis, so she stopped attending. The feedback letter to her GP suggested she was reluctant to attend and her decision labelled non-compliant without Diane's reasoning ever being sought. Her comorbidities were overlooked, yet she had far more than her asthma to consider when contemplating a self-management programme. She said:

> tell me to exercise and I have to take into consideration asthma, allergies, eyesight and arthritis. Go for a walk – is the footpath even? – no tripping and jolting – no things I will not see. Is the wind blowing? Is there space to take a breather? These are not excuses - they are the challenges I face.

Diane summarised that "saying 'yes, but' is not always a denial - it is an invitation I give to help me find a solution." Wilson (2004) agrees with Diane's description, saying:

> not seeking help does not equal ignorance or defiance but occurs within a complex social context that is influenced by a number of factors such as whānau priorities, a lack of financial resources, fear and past experiences (p.180).

Another layer to the inherent contradictions concerns health care's traditional principles of beneficence versus respect for the patient's autonomy (Merrick, 2016). Biomedicine's interpretation of beneficence has typically been a paternalistic 'doctor knows best' and this challenges the notion of patient autonomy within the expert patient model. For the clinicians, there is an understandable struggle between encouraging patient autonomy and fear of 'allowing' them the freedom to potentially harm their own health. Before Rawiri's hospitalisation, both his clinicians described frequently "going along" with Rawiri to maintain a good relationship. Even if, as the GP said, "I had to compromise my diagnostic standards to reach a mutual agreement about the diagnosis with him, because he was *so* adamant [that it was gout.]" On one particular occasion the nurse recalled the team's struggle with his decision to stop his medication and their failed attempts to explain their necessity to him. The PN said:

> He is forever chopping and changing [his medications] because "I didn't like that so I'm not having that this month" … and last time he ended up in ICU. I've had several conversations with him since and said "you are a very lucky man" … but I don't think he knows the danger he put himself in … I think he was trying to advocate for his health in thinking he knew best. But not actually realising we are here for a reason, we have training for a reason, and we pass exams for a reason … He was lucky.

Rawiri’s hospitalisation showed the delicate path the clinicians tried to tread between respect for Rawiri’s autonomy and their sense of clinical responsibility for his safety.

Being undermined

Rather than clinical encounters that encourage expertise, patient-participants shared vivid stories of being undermined and disempowered in multiple ways as they were forced into a passive role. Time and waiting were mentioned many times. Diane felt the health system assumed patients had infinite time available to devote to their health but found the dominance health activities have over her life overwhelming. She said:

> I get so many instructions from all these people that I often tend to just give up and settle into doing nothing. I look at my calendar - which is a reflection of my life - and every week - every day it seems sometimes - there is something. Blood. Prescription … This week eyes, next week boobs … I cancelled the dentist today as I am sick of being prodded.

The extended data collection period highlighted participants often waiting for many months for something health-related and receiving no communication or feedback. The uncertainty and enforced passivity could be seen to slowly leach any sense of agency. Aroha was without her CPAP machine for over a year, waiting for a mask to be fitted. Both Lou and Margaret waited over 11 months for orthotics to help their mobility. The wearers deemed both orthotics to be unwearable when they arrived and Lou’s verdict was that she would have “been better off with the bloody shoe box.” Neither ever wore them and Margaret said, “if that had been a shop, I would have taken them back and got a refund.” Both Lou and Margaret’s responses are not those that would be expected from an empowered customer. One interview with Hayley coincided with “yet again” a delivery of dialysis fluid being damaged in transit:

> oh, I’m sick of them. This is my life literally in their hands. I mean, things I need every day that I can’t do myself. It’s got bloody FRAGILE written on it. It’s not a mystery, is it?

The wait for an outpatient appointment was also frequently mentioned and Aroha described her interactions with the hospital as “a waiting game ... you're waiting for every different department to hurry up and sort themselves out.” Margaret said, “yep - that’s what we do, wait … and you don’t know if something is going to be two weeks or two years.”

Several participants also mentioned the frustration of constant rule changing for services they were seeking. Margaret talked about these changes, “yes, I can donate a kidney if I am on [anti]hypertensives. No, I can’t. Hayley needs to get below 90Kg. No, it’s 105Kg. No, it’s 100Kg.” Similarly frustrating for Lou was her experience of surgeons’ frequently changing opinion about whether her skin condition precluded orthopaedic surgery, something that led to many months of unnecessary suffering. She said, “I just kept thinking ‘for goodness sake, make up your bloody minds!’”

Diane described trying to understand the rules of an almost impenetrable health system. She gave an example:

> this week I have spent a lot of time to try and work out the system for getting a new breast prosthesis. You’re entitled to one every four years. And it is so complicated - and that’s for one condition only … It’s all so energy sapping that you often give up.
> I think I actually have the energy now to battle to get the right one. Last time I gave up in the end - this time I am going to get one that fits - I've had four years of looking at myself with one boob up and one boob down.

She used the language of battle - giving up and feeling defeated - rather than the language of dealing with a supportive and enabling system. Four years ago, her lack of energy had left her too weary to battle, which left an enduring dent in her sense of self-worth. Rather than supporting people to gain the status of expert patient, the system seemed to do the opposite and steadily enforced passivity until eventually, all gave up trying. Diane demonstrated that even apparently confident and articulate patients are disempowered within a harsh health care system.

Whakamā

The participants described their sense of failure and talked of feeling shame or guilt, with many using language that related to being naughty. The terms Eva used about herself include being weak-willed, silly, naughty or needing a slap on the hand. Māori participants described the psychosocial concept of whakamā. Although whakamā is often translated as shyness, shame or embarrassment, the wider meaning of an overall sense of disadvantage affected the health interactions and experiences of many of the patient-participants. Participants described feeling whakamā when they felt they had failed to meet a clinician’s expectations or achieve a health related goal not of their own choosing. Whakamā compounded any sense of failure and increased reticence to engage with health services. The response can be misinterpreted as indifference.

There was little evidence that clinicians overtly expressed disapproval but it could be sensed and participants seemed to have internalised a set of expectations and self-imposed a sense of guilt as they police their own behaviour. Being whakamā amplified this internalised self-oppression and heightened any feelings of inadequacy or inferiority and so has profound implications for Māori engaged (or not) with mainstream health services.

Whakamā can be a response so powerful, such an intense emotion, that people will actively avoid situations to escape feeling it (M. Bennett, personal communication, 17th November, 2014). Metge (1986) also describes whakamā as a “withdrawal from communication with others” (p.25). As some participants felt more ostracised, their feelings created a vicious circle, which decreased engagement with health services in response to being afraid of what they would be told. Yvonne demonstrated the process saying , “I often just don’t go [to the practice] – I know how bad I am going to feel when I see disappointment in darling [nurse’s] eyes.”

The disengagement could be literal as in non-attendance, but for several participants more commonly involved ‘playing the game’ by saying what was expected of them whilst mentally disengaging from their surroundings. For example, Tane talked about, in the early days of his illness being told to complete a food diary:

> which I didn’t really do. I said I had a lot of vegetables. A bit of lettuce in the burger that’s all I was having! I mean, sometimes when … you're talking to the doctors and things, you feel ... you feel whakamā - you know that some of the things that you're doing are bad, and you don't want to admit it, so you go into denial. And then you just say whatever [you think they want to hear].

Without consideration taken of the impact of any feelings of shame, the participants’ ability to engage with the self-management approach is overestimated.

Clinical expertise

The patient-participants neither sought expert status nor believed many clinicians wanted them to have it. Many patient-participants volunteered that they would rather someone else make decisions for them. Huia said, “my doctor seems to be really well up with the play, so ... I mean there isn’t no point in me finding myself a good doctor and then not doing as he said, is there?”

No assumptions can be made about the reasons for the patient-participants' apparent lack of ambition to gain expertise. However, alongside a lack of energy, possibilities include their seemingly unquestioned acceptance of the status quo, as biomedical hegemony by its very nature supports consensual submission by the dominated. Nevertheless, it cannot be discounted that people utilised their agency to make an informed decision about retaining their non-expert status. Although they might not have gone along with their clinicians' recommendations, they perhaps appreciated their expertise and did not seek expertise themselves. Tane noted:

> I've collected them. I collect good people who do their job well. But you do don't you? Like [GP and PN]. I collect doctors, nurses, pulmonary rehab, same as I've got a good plumber ... and I stick with those and do as they say. On the whole ((laughs)).

Patients also did not believe clinicians truly wanted expert patients. Diane said (in this case talking about a community pharmacist):

> people don't want expert patients – they just say they do. I've had to make sure I go to the pharmacy when one particular one isn't there because she won't have it that I know more about all my allergies than her.

Hayley, whose knowledge of physiology was exemplary, agreed, and said:

> yes - they have me on speed dial to talk to their groups. And I love doing it. I love helping. They want their expert patients. But Helen - you try being an expert, sticking up for yourself with these [hospital speciality] guys. They don't like it. They get really shitty. Start treating me like a kid. And they've got the power. I can't tell them to go get fucked like I want to do - it might be slightly counter productive ((laughs)).

There is scant alignment between the expert patient literature and any expert status revealed by the participants. Hayley explicitly captured her position of being asked to fill an expert patient role to talk to people pre-dialysis, but when she tried to express her expertise or demonstrate any personal agency, the hospital clinicians reverted to traditional authoritarian roles. These clashes did not escape the attention of the patients.

Alongside participant's lack of aspiration for expertise, the complexity of their experiences, beliefs and daily lives precluded realistic attainment. The further disempowerment they experienced when engaging with some health services forced the patient-participants back into the passive sick role that the Chronic Care Model purports to reject. The expert patient may instead simply be rhetoric to change the language of health care whilst failing to take into account the complex power relations within a patient-clinician encounter or long-term relationship. Robertson, Moir, Skelton, Dowell and Cowan (2011) argue that the gravitational pull of biomedicine's entrenched and established roles may be too strong for true collaboration to occur.

Collaborative relationships with an expert patient

Collaborative relationships or partnerships between clinicians and patients are another essential aspect of the self-management discourse and another area of tension in the model. Collaboration requires reciprocal communication, which supports rather than undermines the patient's autonomy. The patient-participants instead gave multiple examples where poor communication with secondary care clinicians left them feeling further disempowered. Aroha recalled a conversation she had with a doctor during one admission to hospital. She said:

> Then they stopped my bendro[fluazide]. Then he said, "you've got too much fluid." I said, "isn't bendro a water tablet? What did youze stop that for then?" He went on about something. Some long word. I said, "I wish you'd talk to me in English - I have no idea what you are talking about." I ended up coming out of hospital way worse than when I went [in]. And a bloody sight angrier. I had to go and … [see GP] and say to her, "I don't know what they're talking about." She deciphered what she thought they meant.

The language of the biomedical discourse used by the doctor perpetuated the imbalance of power in the relationship. Participants also described feeling disrespected or having their opinions overlooked and these incidents remained in their minds for many years. Tane recounted going with his carer to meet a surgeon about potentially life-changing surgery and said he was treated with disrespect. He described the surgeon talking to the carer as if Tane were not in the room, or "not worth his time talking to." A year later, he was still angry:

> we went in and [the surgeon] practically ignored me. And he was looking at [the carer] and he was talking to her, and he goes, "look… we've run out of funding, so we won't be able to do this operation for Tane." And I said ... "oh, so you can't do the thingeys." He goes, "no, no, we can't." And he said, you know, "but

> I am prepared to do the operation" ... he's looking at *her* again ... "in my private clinic."

In direct contrast to the way the surgeon treated Tane, the collaborative relationship between expert patients and clinicians described in the Chronic Care Model suggests a partnership of equals. The concept resonated with Diane, who said:

> I want to be treated like an intelligent person who, in spite of being an overweight, asthmatic, diabetic, arthritic, short sighted human, can and have been self aware and self caring for a long time.

Despite the clinicians' awareness of what patients needed and their desire to be supportive, they spoke from a position of biomedically derived authority and in direct contrast to Diane's expressed needs as she described. The qualities clinicians appeared to value in patients include coping, listening, "knowing the limitations" of any knowledge, not complaining or being difficult, doing their best or making the effort, taking medicines, making appointments and turning up (whilst not over-attending).

Diane's GP described her as "an expert patient in my eyes because she knows [the] limitations of her knowledge, which can be a problem [with other patients]." Diane's expertise was acceptable because she did not overstep the boundaries from her GP's perspective. Lou's GP valued the medical aspects of Lou's knowledge more than any organic type of expertise she had developed and said:

> I do think by virtue of her rather uncommon diagnosis of her bullous pemphigoid condition, she knows, certainly her dermatology, and probably most of her medical history and medical management as well as I do. Or better.

Expertise remained a quality that only clinicians can bestow, rather than something that emerged from within a collaborative partnership. Expertise was considered through a biomedical lens and patients were subtly rewarded for doing as advised and remaining pleasant: as such, this was more reminiscent of a passive, compliant patient than an active participant in self-management.

Clinicians also sometimes struggled to understand the decisions patients made. Although Eva's clinicians knew of her social complexities, they still assumed more of a capacity for constructive agency than Eva felt she had. Both strove but failed to understand what they saw as her priorities. Her GP said:

> if you're struggling to adequately feed your family, not just volume but nutrient-wise, then you shouldn't really have any pets. Or, at least if you do, you should have one, not four or five. Because it just doesn't make sense to me to spend all that money on animals, when you can't look after your own family properly.

The idea was echoed by Eva’s PN, who said “it's always frustrating when people aren't prioritising their health more highly than their pets, or their entertainment.” After six years of frequent visits, Eva’s PN admitted to:

> saying probably the meanest thing I’ve ever said, which was “you’re just not trying.” And I was at the point where I was thinking, “gosh, what on earth do we do with these people?” In addition, they’re just treading water really and still sliding down the hill. To mix my metaphors … rather horribly ((laughs)).

Although both GP and PN spoke of Eva’s powerlessness, this did not entirely translate into an understanding of her need to feel some control in her chaotic life. A genuine partnership is precluded in these conditions.

Structured mutual entrapment

The literature review highlighted how structured programmes have become shorthand for self-management support in health care, far removed from the original intent of the Chronic Care Model. The word ‘support’ is also frequently absent in the literature and self-management appears to have become something the health system dispenses *to* people. These programmes, in various guises, provide the context in which much long term condition care is funded, discussed, focused and provided. As such, both patients and clinicians are caught in a web of desired behaviours.

Before and during data collection a range of programmes were available at no cost to the patient-participants, who are precisely the target demographic. Surprisingly, with the exception of Care Plus, uptake by the participants was almost nil which showed a significant gap between the programmes on offer and patient-participants accessing them. Although Care Plus was well utilised, the main attraction for both participant cohorts was the free or subsidised visits to the doctor or nurse.

The Chronic Disease Self-Management (Stanford) course, run by the PHO, was also available and several of the practices had the course poster in their waiting rooms. One PN knew about the poster, “but no. I haven’t thought to actually … send them on that.” Another PN laughed, “yes, we certainly put it up on the wall.” None of the other nurses knew about the course. When I mentioned the course to one nurse, she asked, “is there? Oh! And who has access to that? (answered - everyone) Oh really? Is it a secret?”

The PHO had also invested heavily in the Flinders™ programme a few years previously and all but one of the nurses interviewed had completed the considerable training. However, none had used it once the training was finished and their thoughts were unanimous. They appreciated the concepts behind Flinders™ especially the patient-led goal setting. However, they found the tool impractical and described it as too time consuming, inflexible and cumbersome. One PN spoke of Flinders™ as “just another PHO thing, they brought it in, threw some money at it. Then nothing.” She continued, “amazing isn’t it? All those nurses got sent off to do it, and nobody ever uses it. Did anyone ask us or the patients what actually might be helpful?”

The nurses were particularly vocal in their disappointment at the money wasted on the training, which they felt could have been better utilised. Overall, rather than perceiving the programmes as a useful addition to the care they were able to offer, the clinicians instead spoke of them as part of the straightjacket they had to work within.

Imposed expectations

The clinicians did not feel connected to the self-management programmes available. They spoke of programmes as being imposed upon them, referring to both the Ministry of Health and the PHO as external agencies, rather than as part of the health system they practised within. Typical comments included one GP who described Care Plus as an “initiative the PHO do,” and another who said:

> the Care Plus programme is a funny thing the government's put in. I don't really know what exactly *they* want to get out of it. I wonder what the thought behind it was? - as goal-setting rarely changes people's behaviour.

The disconnect between clinicians and the formal programmes was a barrier to them becoming the prepared, proactive practice teams of the Chronic Care Model and echoed the patient-participants’ disengagement from the expert patient discourse. In a similar manner to the patient-participants, clinicians also felt constrained by seemingly constant rule changing within the health system and felt they had minimal control. A consistent lament from all nurse participants, and many of the GPs was having to work within the restrictions of a succession of piecemeal programmes and pilot schemes in which the rules and processes change with no demonstrable impact on their ability to provide care for patients.

Patient- and clinician-participants alike believed that access to a free exercise programme would have been useful. Although the Green Prescription, a physical activity programme, was available, clinicians described several impediments that prevented them referring patients into it. Firstly, there was considerable disagreement and confusion about the programme's "seemingly ever-changing" and complex eligibility criteria. Clinicians also expressed frustration that if a patient was unable to attend one or two of the compulsory sessions they were "kicked off" the scheme. Clinicians believed that the complexity of patients' lives made missing some of the sessions highly likely. One nurse explained, "we need to just make [exercise participation] easy for them. And the schemes seem to do the exact opposite."

Clinician participants also questioned the relevance of the programme to people with significant LTCs. Several questioned the relevance of compulsory educational sessions for people for whom a more realistic or achievable goal was a ten-minute walk. The homogenous programme fitted none of the patient-participants' needs. Aroha alone enjoyed the gym, but had "used up my allowance" of sessions, so had to purchase a full-price gym membership herself, despite money being very scarce. Diane had completed the programme and continued for a few months but then stopped because initially, "I thought I was supposed to go, but with my illnesses … [after the session] that was me stuffed for the day. And sometimes the next [day] too."

The clinicians also described how the generic programmes failed to accommodate the idiosyncrasies of patients' social contexts or unique health needs. Their data revealed a palpable sense of trying to deliver care within a system where one size was supposed to fit all yet appeared to fit very few. A PN complained that the patient's needs rarely corresponded with what was available. She continues:

> I think I have a pretty good handle on a lot of my families. But frankly what I think might help, or what I think they need, bears no relation to what the system allows me to offer them. It's so frustrating and drives me to drink.

Aroha's GP also described her frustration at not being able to offer Aroha the care she thought Aroha needed, which was the long-term support of a counsellor. Her frustration was tangible:

> without the diagnosis of depression, would I even get the funding for that? I don't know. We get a few [mental health] packages a month … And she needs to score between what is it, 15 and 24 or something? Not too high. Not too low. [Even if she did qualify] her chronic conditions aren't going to go away in six weeks are they?

The result was a sense of impotence for the GP:

> I don't know how to even ... what even to tell her, how to be better. So all I do really - I repeat her medication, I treat her when she's got infections. Aroha's a really good person, who in essence gives to others, but seems to have too much of a load to carry. And I don't know how to improve her lot.

Another PN also expressed this sense of powerlessness when she said, "so much of this is one-size-fits-all, and it really doesn't fit. But how do you make it different, what can you use to make it different?"

Clinicians described having to fit patients into available schemes and not the other way round, which a GP summed up well:

> We'll get sent through some information about a new course or something. And then we scratch around trying to find a patient that fits the criteria. And that is just arse-about-face isn't it?

Clinician-participants' knowledge of the patients' circumstances and what their clinical expertise tells them, was outweighed by the rigid structure of the programmes. The process left them feeling trapped, with clinical expertise stifled and capacity for critical thinking squashed. One GP expressed his frustration at the situation. He said:

> so you [have to] say, look, your HbA1c is getting better - great. And your weight is going down - that's great, and your blood pressure's great. So you've passed the numbers test. Now, how are you feeling?

Within the rigidity of the way self-management processes had diffused, clinicians were manoeuvring to subversively manage what they felt was a dysfunctional system. They described "making the best of it," an approach which bears little resemblance to self-management support taking centre stage in all routine health care as envisaged in the Chronic Care Model. A GP reflected on this manoeuvring:

> I can’t think there is anything [available] that would suit Losefo. There’s that problem isn’t there? The courses really suit those that don’t need them. With all of these things, they come and go and it’s a case of just hoping to goodness that you can somehow fudge things enough to fit them in.

The GP’s comment that the courses suit those who do not need them highlighted the clinicians’ dilemma of trying to offer care to people with several debilitating LTCs from within a selection of programmes designed for a completely different set of circumstances. Clinicians expressed clear awareness of the lived realities of their patients. They also described a feeling of entrapment as they struggled to deliver the care they could see their patients needed, within the seemingly rigid confines of the trappings of the self-management framework. Clinicians’ and patients’ shared frustration is a poor platform for collaborative and productive relationships.

There is some evidence of limited movement or loosening of eligibility criteria, course structure or funding streams in the time since data collection. An example is the relaxation of attendance requirements at the previously compulsory education sessions that form part of the Green Prescription programme. Whilst the direction of these changes is encouraging, and suggestive of sector feedback being listened to, these changes are as yet, too minimal to make a significant difference.

Rather than the anticipated outcome of productive interactions from the model’s collaborative partnership, the findings described circumstances of mutual entrapment and mutual disempowerment. The mutual entrapment both cohorts experienced, delineated and constrained what they were able to achieve together. This is never more obvious than in the central self-management platform of goal setting.

Goal setting and care planning

The Care Plus programme contains a core ingredient of the self-management approach - compulsory goal setting and care planning. For the patient-participants, with complex health and social needs and limited energy for agency, the data showed genuine goal setting to be patchy at best and an irrelevance to most patient-participants. Diane believed, “goals are OK for multimorbidity if all your ducks are in a row. Mine just never are.” For most, the chaotic nature of their lives meant, as Aroha said, “you can't set goals, I sort of tell them … I never know ... each day is different. So I don't set goals for myself. No.”

The reality of goal setting for people with progressive, multiple morbidities is a pledge to commit to something unachievable, which resulted in a subsequent almost inevitable sense of failure for both patient- and clinician-participants. For Eva, goal setting was “just something else I’m no good at.” She said:

> well, we did [goal setting] at the beginning – but I’m not much good at that sort of thing. Yes, there are goals I’d really like, like losing weight but it doesn’t work. So the goals are what I’d like to be able to do, but know I really can’t. And I feel a bit of a flop when I haven’t met them, so we gave up. They are a pain for the nurse anyway – they are supposed to do them but they know I won’t do my part so they are a waste of everyone’s time.

Tane talked of never meeting his goals, so that now he just “plays along” with the process. He said his:

> long-term goals … keep getting pushed back - I've probably had the same ones for years. Lose weight and get fit. And I have done the opposite. I tend to leave my goals in the car park [at the health centre] when I leave … I get so frustrated by my lack of progress.

For people already with a depleted sense of self worth, failure to meet goals was another blow to their self-esteem.

Implicit within the goal setting process is the idea of hope and a constant striving for improvement. The relationship with hope for the patient-participants was problematic. Many of the participants felt hope-less and struggled with the contrast between the future orientated nature of goal setting and their own ongoing cascade of losses. Enforced unrealistic expectations did not facilitate the patient-participants reaching a level of acceptance, or even resignation, to the permanence of LTCs. Diane described this as “a life time of letting go.” The unrealistic expectations left participants waiting for the day they could stop their medications or oxygen, rationing their use of helpful devices such as a CPAP machine, or planning for “when I’m better.” A common phrase was “I’m gonna.” Tane said, “once I’m back in the pool I’m gonna be able to start my carving.” Aroha also talked throughout the two years of data collection of “I just need to sort myself out, then I’m gonna…” It proved impossible to find out what ‘being sorted’ would look like.

The patient-participants felt no connection with goal setting, which Rawiri summed up:

> Care Plus is almost invisible as far as I am concerned. Originally we set a few goals - but they were more what *they* wanted to see. I achieved a couple so that was that. One I didn't want to achieve so didn't bother.

For some people, their personal goals were clearly linked to their health. For instance, Wiremu’s primary goal was to be able to continue to go to his club and sing. He said, “while I’m still singing - I couldn’t ask for more than that. Without music, I'd be lost.” The goal was distinctly health related as it needed him to continue to be both mobile and to have “plenty of puff.” However, the goal did not appear in the care plan he kept by his armchair. Instead, ideal blood pressure and a target weight were listed**.**

For clinicians, Care Plus goal setting had become, as a PN described, a process where “we tie ourselves in knots counting and measuring, but none of that matters to the patient.” Another nurse captured the process well:

> when you start off doing Care Plus, goals are “to exercise more,” “to eat more healthy food.” Well, it doesn’t mean diddly-squat. And they tend to be *our* goals. It’s *nothing* to do with the patient.

The findings showed clinician-participants captured by biomedicine’s paternalistic stance. Clinicians agreed that setting the popular goals of going for a walk or eating less were rarely effective, yet they persisted in pursuing these. They had been indoctrinated to believe these were the only acceptable types of goals for a programme such as Care Plus. With imposed goals, neither cohort felt ownership of the process and both spoke of playing the game. There was an overall sense of the futility of goal setting, in contrast to its message of compulsory hope. The clinician-participants felt self-management support programmes met neither their needs nor those of their patients. As such this was a clear example of innovation dissonance, where the opinions of those for whom an innovation was intended differ from those who imposed the innovation (Rogers & Shoemaker, 1971).

Valued care

Among the struggles of manoeuvring within the self-management approach, the findings also described many examples of excellent care being delivered or received and valued by both patient- and clinician-participants. It was, however, notable and deeply ironic that the aspects of primary health care that patients needed, wanted and appreciated, and what clinicians’ clinical judgement suggested was most efficacious, generally sat outside the confines of the self-management framework and the health sector.

Being known and listened to

Patient-participants valued both the long-term relationships with their primary care clinicians and that clinicians were familiar with their families and some of their social context. For many, their top priority often concerned a whānau member and they appreciated being able to discuss their concerns with someone they knew and trusted. George's GP gave an example of the importance of a thorough background knowledge:

> what are his personal experiences with other people with prostate cancer? Because that actually does affect them, and … the person that comes in … and said, "can you look at this spot?" And if you didn't know that their mother died of melanoma you might say, "oh, what are you worried about that for?" So they have their preconceived thoughts on their own illness. And prostate cancer is one of those. So you've got to kind of really tune in to those expectations and those worries.

The clinician-participants described their insights into patient-participant lives and had a good grasp of how it was for the patients living with multiple-morbidities. Diane's GP accurately thought:

> daily tasks I imagine are quite a struggle for her. I suspect she probably has to work out exactly what she's going to do each day, and have a time-scale around it, whereas we would just get on and do it, so I imagine that things take a lot longer and she has to pace herself.

Paul thought it must be easy for his GP to tell him what to do because "she's not waking up in my body every morning is she?" But the GP's understanding echoed Paul's own words:

> I'm sure it is not easy for him… but he is the one waking up every morning in pain and not quite knowing how he is going to be.

Being cared about as well as cared for

Patient-participants repeatedly mentioned the sense of being cared for that occurred in the clinical encounter. Lou said, "sometimes when you're ill, what you need is a hug, and she knows that." Although the clinician-participants felt enormous time pressure, several of the patient-participants volunteered how they appreciated not feeling rushed. Diane said of her GP, “you always appear to be the only patient he's going to have that day.”

Several of the clinician-participants described a patient-participant as an over-attender, which they defined as attending for issues that seemed trivial when there was perhaps a free visit pending and finances were tight. It was thought provoking to contemplate what it was about their care that failed to meet patients’ needs, leading to such frequent visits. The answer for this cohort was interesting. The long-term nature of the relationship provided many of the things patients said they wanted, which was to be able to talk to someone who knew them, who cared and who would listen, and not necessarily a clinical problem. Diane said “somewhere you need a space in the system to tell your story. That’s critical.” Eva said her PN:

> is always an ear, especially when I have no one else to talk to… and [GP] sort of pats me on the back and she says, “take care” and so yeah, she understands.

Aroha talked of her GP:

> oh, I like her. She's massive. She's a lovely doctor. You can talk to her. She's easy to approach and very caring.

The patients felt they *were* receiving what they needed from the consultations and did not feel they were over-attending. Being listened to and cared about seemed to be the purpose of many visits and sadly, for several patient-participants, their GP or PN was the only person they had to fill this role.

Navigating

For the clinician-participants, integral to the long-term relationship was continuing to support the patient, whatever they did or did not achieve, and “never abandoning them.” The patient-participants, often using metaphors of travel, contrasted these relationships with those they experienced with hospital clinicians where they were, as Huia described, “left high and dry.” A PN acknowledged that:

> we may never get anywhere with them – we just stick with them. If they were with the [hospital] they would just discharge them as non-compliant … We carry on walking with them.

The clinicians frequently fulfilled the role of navigator, translator or intermediary and the patient-participants valued this. These roles all echo Youngson's (2016) definition of compassion as the recognition and feeling for another's suffering alongside the motivation to address that suffering. Aroha talked of her GP "going in to battle" for her. Another example of 'fighting alongside' was described by Lou's GP when Lou received her most recent cancer diagnosis. The GP said:

> she was quite devastated with that. I … sort of said, "You know what Lou, you should be worried, and you should be unhappy and mad at the world for putting you through this, but you know what? We're going to go get the treatment, and we're going to go get this cleared out and that'll all be good and clear and you can go on with it." And she did.

Intriguingly, these clinicians fulfilled a role as translator or facilitator between the hospital and the patient. The primary care clinicians positioned themselves at the interface between the self-management and Chronic Care Model innovation imposed from above, delivered within a biomedically dominated health care system, and the lives of the patients with multiple LTCs. Although schooled in the biomedical model, clinicians had long-standing relationships with their patients, so adopted the role as an intermediary. These roles were valued and prioritised by both cohorts.

Summary

The health care system and the self-management approach assume a rational, managing, expert patient with innate capacity for personal agency. The empowered activated patient, full to the brim with self-efficacy, who works in partnership with their clinician, stands in stark contrast to the literally disempowered, weary, energy-depleted patient-participants. The introduction of the self-management approach was not accompanied by a corresponding paradigmatic shift in biomedical thinking. This left a number of inherent contradictions between the self-management approach and the biomedically dominated hauora system. The exhausted patient-participants are caught within these tensions.

The patient-participants needed a hauora or health system that replenished their energy. Instead, they experienced a system that further depleted their energy and nudged them further towards inertia. In contrast with the rhetoric of self-management, the data provided repeated examples of the patient-participants being forced into passivity with their energy depleted by a process and system that purportedly empowered. Passivity was enforced through endless waiting, poor communication and frequently changing, complex rules.

Engagement with the hauora system further disempowered and undermined the patient-participants. The tension between the articulation of hope captured within the framework’s goal setting and the reality of the patient-participants’ lives added an unnecessary sense of failure and shame. The privileging of biomedical knowledge by both cohorts has a number of consequences. Foremost is the clear contradiction that any decision by the patient that does not correspond with the clinician’s viewpoint is labelled non-compliant.

The findings showed agency as neither a choice nor readily achieved. Patient-participants struggled to express any residual agency and were significantly constrained by the complex and overwhelming social contexts of their lives. The idealised expert patient discourse largely overlooks these contexts. The influence of these showed that the provision of knowledge to patients is far from a simple path to changed behaviour. Instead of supplementing the participants’ energy, the ideas of the Chronic Care Model and the self-management approach have become part of the structural aspects of an individual’s life that counteract any agency.

The innovation-decision process shows that the diffusion process for self-management has resulted in the approach being enthusiastically embraced at policy and strategy level, but remaining largely unknown or irrelevant at patient level. The patients are poorly placed for the idealised partnership.

Although the literature review suggested that the approach was built around the needs of clinicians rather than the patients, this was not seen in the data. Clinician-participants also felt powerless within the approach and they too were disengaged and disempowered, and the confines of imposed homogenous programmes stifled their clinical expertise. Their sense of frustration painted a picture of mutual entrapment for both patient- and clinician-participants, with neither groups’ needs met. There was a sense of clinicians’ good will, compassion and professionalism being wasted.

Members of both cohorts manoeuvred amidst existing programmes and subverted aspects of the self-management approach to achieve the best outcomes. There was a significant disconnect between how the self-management approach was envisaged and how it was experienced by patients and clinicians. The “making the best of it” described, had little in common with self-management support taking a central role in all routine health care as envisaged in the Chronic Care Model.

The findings suggest that many aspects of the expert patient and self-management approach are either unknown or unwanted. The aspects of care delivery that both cohorts appreciated sat outside the expert patient and self-management framework. The patient-participants described these aspects of care as giving them a sense of being valued and bolstering their sense of self-esteem. The relationships showed that care was offered to patients in a respectful, mana [esteem or reputation] enhancing way based upon knowledge of the patients and compassion for their circumstances, with the clinician acting as an advocate and buffer between the patient and parts of the hauora system.

The inherent contradictions in the findings lead into the final discussion chapter, where the aspects of primary care that are valued are built upon, to explore possibilities to enhance the health care for people with multiple LTCs. George’s PN summarised:

> but I think self-management is not maybe being like as healthy as somebody who doesn’t have all these things wrong but self-management is how they can manage best themselves within *their* health context.

Chapter Eight: Discussion and concluding statement

Introduction

The purpose of this research was to discover how people with multiple LTCs experience the self-management approach to health care. The findings showed diverse, weary patient-participants living in trying social circumstances. These findings sat in contrast to the self-management approach's expectations of people with a sense of agency and direction. The multiple losses participants experienced across all aspects of their lives left them without the assumed energy for personal agency required to deal with the self-management approach.

Far from supporting the patient-participants, the biomedically framed self-management approach further disempowered in numerous ways. Patient-participants contended with the progressive nature of LTCs and felt hope-less and exhausted. Yet, they were expected to engage with health care that exhorted them to improve, and included engagement with compulsory goal setting. The framework also trapped primary care clinicians and their clinical initiative was stifled.

In this chapter, I will explore the aspects of care in the findings that sat outside the self-management approach and were valued by both cohorts. These were being known and heard, being cared about and cared for, and the roles the clinicians adopted as a navigator, ally and buffer between the patient and hospital system. These offer a foundation on which to explore three additional approaches to care with potential to augment the way care is currently conceptualised and delivered to people with significant multiple LTCs.

The first approach, the harm reduction model offers a realistic way to focus on the physical needs of people with multiple LTCs within an approach based on compassion. The second approach is the recovery model, which offers an alternative to biomedicine's interpretation of hope based on personal agency. The philosophy behind the final model, palliative care, resonates strongly with the aspects of care valued by both groups of participants and so offers a useful way to think about the unmet needs of these patients.

Building on the sparks of promise from the findings, there are aspects within each of these models that offer a way to re-imagine care delivery for people with multiple, complex LTCs. The findings showed compassion and a clear sense of connection in the care given and received between the patient- and clinician-participants. To build on these connections could mean to overtly focus on each individuals' quality of life within their unique circumstances and limitations. Care can be offered that supports them to find their own path that sits somewhere between striving for a cure and 'giving up.'

The findings suggest that care for people with LTCs, that works with their authentic agency, would result in care that wraps around the patient and supports them to use their residual agency in a direction of their choosing. To align personal agency and hope in a reframed approach would change from the way they are currently framed within the self-management approach. Clinicians and patients would have the freedom to be more pragmatic around quality of life and the issues that matter to the individuals with LTCs.

By moving towards an expanded understanding of care, the sparks of promise could enrich and fill the identified gaps from all quadrants of the Whare Tapa Wha model. Clinicians would be released from their current programmed response and enabled to offer care that is tailored for each individual and be able to more fully utilise their clinical expertise.

Findings summary

Participants in this study revealed diverse lives as the context for their shared status of living with multiple long-term conditions. Despite their diversity, they also had much in common. They struggled to live lives marked by loss, poverty and daily challenges, which eroded their personal agency. The experience of living with multiple LTCs and the resulting depleted energy, suggests there is a need for a health system that wraps around people and addresses their needs by supplementing their energy and acknowledging and sustaining them within their unique social contexts.

This position should have been the starting point for the development of the self-management framework. Instead, the self-management approach was diffused from policy to practice level, weighed down by biomedical hegemony and "touted as a panacea for the health system" (Kendall et al., 2011, p. 87). The findings clearly demonstrate that the innovation process of self-management was largely unknown by, and meaningless to, the patient-participants and its assumptions were a mismatch with their expressed needs. The findings captured health care encounters that depleted rather than supplemented energy in a variety of ways. The already weary patient-participants were ill equipped to deal with the self-management approach with their mauri too overwhelmed to express agency, choice or free will.

The chronic care and self-management models, rooted in biomedicine, were introduced and predicated on the basis of an informed, activated, expert patient (Bodenheimer, Wagner, et al., 2002b; Wagner, Austin, & Von Korff, 1996; Wagner, McCulloch, Price, & Hindmarsh, 1998). Patients were presumed to have significant capacity for personal agency, which would outweigh any structural determinants in their social contexts. From a place of innate agency, an expert patient was to be armed with knowledge about their health and the self-efficacy to carry out health-related behaviours in a collaborative relationship with their clinical team. The weary patient-participants in this study bear little resemblance to an idealised expert patient. They were both unwilling and largely unable to demonstrate the kind of expertise the model promotes.

Self-management in its widest context is something patients naturally do. However, as self-management was taken up and absorbed by the health care system, it was squashed into a formulaic shape and disabled with the language, biases and behaviour of biomedicine. A one-size-fits-all template is ill matched to deal with the diversity of the participants within their unique social and health contexts.

The diffusion process saw international research transferred from the USA to England, to New Zealand and many aspects were ‘‘lost in translation.” The Kaiser Permanente framework recommended self-management support to be offered at all levels of their pyramid (Singh & Ham, 2006). Evaluations from England show that as self-management support came to mean structured programmes, inappropriate programmes were offered to patients (Challis et al., 2010; Ross et al., 2011; Singh, 2003). In New Zealand, the implementation conflated different ideas from the models with the application of self-management support to a higher level of disability than that for which it was intended (Carryer, Doolan-Noble, Gauld, & Budge, 2014).

Implementation of the self-management approach was unusual as an innovation as it did not involve the very people who were the intended recipients. Instead, eminent health academics, working within elite institutions like the Stanford University Patient Education Research Center, the MacColl Institute for Healthcare Innovation and the Robert Wood Johnson Foundation, introduced the innovation into the policy and strategy levels of health care. These institutions helped its gradual spread and wholesale adoption and its subsequent endorsement by bodies such as the American

Institute for Healthcare Improvement and the WHO (Martin, 2007). The adoption at strategic and policy level has been fairly rapid and largely unchallenged. Ironically, the approach reinforces the medical dominance that it sought to revoke and the approach continues to be promoted at policy level, with the policy authors seemingly oblivious to the impact of biomedicine (Minister of Health, 2016; World Health Organization, 2014).

Biomedically framed goal-setting

Goal setting is a fundamental component of the New Zealand implementation of self-management, delivered under the auspices of Care Plus. The programmes locked patient- and clinician-participants alike into a pre-ordained script of the goal-setting/lifestyle agenda. The findings of this study clearly surface the gap between goals that would be meaningful to the patient-participants and the ones that are set (if any are) between patient- and clinician-participants.

Despite well-intentioned, high-level beginnings, Care Plus was unwittingly imbued with biomedical assumptions. The subsequent documentation and wording in policy and clinicians' computerised patient management systems reflect this infiltration. For example, the Ministry of Health's Care Plus documentation (2004) puts "intensive clinical management" as a compulsory eligibility criteria, which assumes the patients' priorities to be things directly amenable to clinical care. In contrast, the findings from this study showed patients' priorities predominantly associated with aspects of life unrelated to clinical care. Additionally, although goals are described as "patient-led" the examples in the documentation are weight loss and exercise and patients choose the "key symptoms" to address. These all sit as compulsory fields within the electronic forms that have to be completed in order to secure funding. The formulaic care plans imposed on reluctant patients with an "eat less, move more" template are usually irrelevant to, or impossible for, the person with established, complex LTCs.

The clinician-participants appeared aware that what the patients needed and wanted in a clinical encounter was to know that the clinician understood what they were grappling with and to feel listened to and valued. Even when these aims were achieved, the clinician-participants still felt powerless to judge the clinical encounter a success if the boxes for the pre-set targets had not also been ticked. It is useful to question how much of the clinicians' reluctance was unavoidable due to the system and how much the clinicians' own biomedically-framed expectations or worldview shaped their behaviour. It is possible that clinicians have more freedom than they believe they have and there is more opportunity to craft goals that suit people rather than the current template.

The unmet need of people with multiple LTCs

The intent of the self-management approach has been colonised at policy and practice level by biomedical expectations. The inherent contradictions between the self-management and expert patient approaches and the biomedical paradigm are not an appropriate basis for the health care of people with multiple, significant LTCs. Salmon and Hall (2003) argue that user empowerment in health and illness management is more a product of a discourse within health academia, rather than the patients' own aspirations. An example of this thinking can be found in the Cochrane review, which states that self-management programmes are "designed to *allow* [emphasis added] people with chronic conditions to take an active part in the management of their own condition" (Foster et al., 2007, p. 3). Therefore, people are given permission to take an active part in their own care, rather than claiming some inalienable right. The articulation of self-management in policy and in the literature from international (WHO, 2002, 2013, 2014) to national level (Connolly et al., 2008; Sheridan et al., 2011) sits in stark relief against the realities of the patient-participants' worlds as revealed in this study.

I have described the many ways in which the self-management impetus has been imbued with the paradigmatic characteristics of biomedicine. Complex contradictions were captured between the aspirations of the self-management approach, the biomedical paradigm it was delivered from within and the daily realities of people living with multiple comorbidities. The result was people not experiencing as good as possible quality of life.

Self-management as a structural impediment

There is a consensus within the self-management literature that evidence for its efficacy is weak but, at worst, the interventions are "not effective" (Redman, 2010, p. 152). However, the side-effects of any intervention are often unacknowledged or unrecognised, and all have potential for creating unexpected outcomes, something Mol (2008) describes as the "bad effects of good intentions" (p.103).

The findings showed unacknowledged and unintended harm caused to patient-participants by their increased sense of failure as they were forced to struggle towards unrealistic goals in which they were not invested. Data from the clinician-participants showed they were aware of this harm and were equally distressed by their perceived powerlessness. Furthermore, the unchallenged acceptance of the self-management framework's status as best practice has inevitably been a barrier to the development of alternative approaches to care for people with LTCs.

Additionally, rather than supplementing the loss of energy and tendency towards inertia that result from living with multiple LTCs, Link and Phelan (1995, 2002, 2010; 2013) would argue that the self-management framework inevitably increases health inequalities, as those with more resources take up the framework disproportionately. Thus, the self-management approach itself would become a structural impediment to health. The position of self-management as a structural impediment is not entirely straightforward. It is evident that the self-management approach is taken up less by the socioeconomically disadvantaged, who also continue to experience more LTCs. The associated health inequalities also continue to widen in New Zealand as well as overseas (Carroll, Casswell, & Huakau, 2011; Hajizadeh, Mitnitski, & Rockwood, 2016; Teng et al., 2016). However, the weakness of the evidence for the long-term efficacy of the self-management approach for *any* group makes the position of self-management as another cause of health inequality likely, but difficult to confirm.

A way forward - a fresh approach

I now move to look at potential alternative ways of thinking about the health care for people with multiple LTCs that might more ably meet the patient-participants currently unmet needs. Data from both clinician and patient-participants showed glimmers of excellent care that were valued by both cohorts, which bore no resemblance to the idealised form of self-management support. Patient-participants valued being known, cared about and cared for, something explored further on. Their needs revolved around how to minimise and deal with their losses and for support to harness any residual agency and supplement energy in ways that made sense to them. The data showed that the clinicians adopted various roles to meet patients' needs. These were as an advocate, a passionate ally, a translator or an intermediary and these roles were united in that they sat outside the self-management approach. The chapter will draw on these valued aspects and use them as signposts for exploration of three approaches to care which may contribute to framing a new philosophy of care for people with complex, multiple LTCs.

Harm reduction

The findings showed ways both the clinician- and patient-participants developed patterns of working together that could be considered as compromises compared to clinical guideline recommendations. An example was Yvonne's clinician team using a "baby-steps" approach to negotiate with her to accept a suboptimal insulin dosage that, although possibly carried out unknowingly, is reminiscent of the harm reduction model.

Harm reduction is a strategy based on public health principles, that focuses on the reduction of the harmful outcomes of a behaviour, rather than the behaviour itself (Christie, Groarke, & Sweet, 2008; Hayhow & Lowe, 2006; Marlatt, 1996). It is a pragmatic approach that acknowledges the reality of people's lives whilst reducing adverse health, social and economic consequences (Collins & Marlatt, 2012; Inciardi & Harrison, 2000).

Harm reduction emerged from grassroots activism in the world of substance abuse in Rotterdam in the 1980s (Blume, 2012), where needle exchanges helped reduce the spread of HIV among drug users (Lee, Engstrom, & Petersen, 2011). Its main application continues in the area of substance abuse as well as HIV and Hepatitis C prevention. Its association with issues that are illegal or considered immoral has negatively affected its diffusion, particularly in the USA (Christie et al., 2008; DuPont, 1996; Fee & Krieger, 1993; Taylor & Caine, 2013).

Many public health measures successfully use the principles of harm reduction but are not explicitly named as such. These range from providing condoms for HIV, STD and Hepatitis C prevention, methadone for intravenous drug users, point of sale restrictions on the quantity of paracetamol in New Zealand to reduce overdoses (Freeman & Quigley, 2015) and e-cigarettes as an alternative to tobacco (Franck, Filion, Kimmelman, Grad, & Eisenberg, 2016). Organisations in New Zealand such as ACC practise harm reduction with their safe drinking and designated driver campaigns.

Within primary care, harm minimisation strategies are used in interventions that aim to decrease the harm from tobacco for those unable or unwilling to quit, to encourage flexible solutions such as smoking outside (Gould, 2014; Le Houezec, McNeill, & Britton, 2011; Stratton, Shetty, Wallace, & Bondurant, 2001). GPs and nurse practitioners work within this model when they prescribe combinations of medicines to people with hypertension or hyperlipidaemia who continue to smoke, so the ideas are familiar.

Although at first glance harm reduction seems focused just on the physical aspects of an individual’s life, the values that underlie it resonate strongly with the findings, where clinicians compassionately and pragmatically did what they could. The approach makes any manoeuvring overt and so is both more realistic and kinder than self-management, as it has diffused. The model acknowledges that overall patients are doing their very best in difficult circumstances, so reflects the humanistic values of dignity and respect. Christie et al. (2008) describe compassion as providing harm reduction with a strong ethical foundation, something that also comes through strongly in the findings. The aspects of the model, particularly compassion and pragmatic ways of addressing physical issues, will be further explored later in this chapter.

The recovery model

The problematic role of hope among the patient-participants showed an uneasy fit with the self-management approach, where the futility of goal setting sat in contrast to its message of compulsory hope. An alternative approach that has gained popularity in the mental health arena is the strengths-based recovery model, which arose as a grassroots approach from within the mental health survivors’ movement. The term ‘recovery’ is a misnomer, as recovery need not be the return to a previous state of health (Andresen, Oades, & Caputi, 2003). Individual’s goals are framed in terms of the achievement of things people value in everyday life (Brooks et al., 2015; Shepherd, Boardman, & Slade, 2008; Wand, 2013, 2015). It aims to support people to maximise their quality of life, living a satisfying life within the limitations of their current health status (Brooks et al., 2015; South London and Maudsley NHS Foundation Trust and South West London & St. George’s Mental Health NHS Trust, 2010).

Poole (2007) identifies several ways the biomedical discourse has also interpolated the recovery model, so decreasing its potential usefulness for this patient cohort. Familiar terms from the earlier critique of biomedicine’s effect upon self-management reoccur, such as self-efficacy, empowerment and self-determination (Bennett, Breeze, & Neilson, 2014; Lavallee & Poole, 2010; O'Hagan et al., 2012). Andresen et al. (2003) summarise the essential prerequisites of the model as finding hope and meaning, re-establishing identity and taking responsibility for recovery. The idea of a search for meaning and gaining some sort of enrichment within the illness experience permeates the recovery literature (Bennett et al., 2014; Repper & Perkins, 2003). Power (2014) describes this as a “discourse of overcoming” (p.62).

Poole (2007) and Weisser, Morrow and Jamer (2011) also highlight the familiar assumptions of capacity for agency within the model that laud the ideas of personal responsibility and individualism, without any acknowledgement of the social conditions that position someone as unable to embrace recovery. Despite the influence of biomedicine's shaping of the recovery model, the philosophy behind the approach can add to how hope is framed for people with several LTCs.

Palliative care

Another model that focuses squarely on quality of life, and offers a broader perspective of how hope could be framed for people with LTCs, is the palliative approach to care. The word palliative comes from the Latin pallium meaning a cloak and means to mitigate or reduce in severity. The principles of palliative care are about compassion, sympathy for another's suffering, kindness and understanding (Kellehear, 2004). The principles relate to the provision of comfort where cure is not necessarily the goal. Instead, the goal is the "relief and prevention of suffering and improvement of quality of life" (Pastrana, Jünger, Ostgathe, Elsner, & Radbruch, 2008, p. 223).

The pioneer of palliative care and the hospice movement was Dame Cicely Saunders, who worked in London in the 1960s (Clark, 1998). Saunders coined the phrase "total pain," to explain that the suffering of people who were dying included mental distress and social problems, as well as the more obvious physical symptoms (Clark, 1998; Richmond, 2005; Saunders, 1990). Her combined background and qualifications in social work, nursing *and* medicine gave her insights into the multidisciplinary potential for care that few others would have possessed. Her work spread internationally, and by the 1980s, the hospice movement was well established in New Zealand (Palliative Care Expert Working Group, 2003). Saunders' ideas focussed on the need for individualised care for people with all progressive illnesses (Richmond, 2005). She gave prominence to the importance of listening to patients' stories about their suffering and as such, her ideas have a clear synergy with the needs identified by the patient-participants.

Palliative care was originally synonymous with the hospice movement. The pressing needs in the first few decades of the hospice movement concerned the care of people with cancer, particularly their pain control. The strong association between palliative care and cancer has lessened but persists. Seventy-nine per cent of patients in hospice care have cancer, compared to 33% of overall deaths in New Zealand (Palliative Care Council of New Zealand, 2013). This has decreased from 90% in 2003

(Palliative Care Expert Working Group). The proportion is lower in the USA, where only 36.5% of hospice admissions are cancer related (National Hospice and Palliative Care Organization, 2014). Palliative care also tends to be associated with the very end of life (Mason et al., 2015). For example, the first line of New Zealand's Palliative Care Strategy refers to people as dying, rather than perhaps the more appropriate phrase life-limiting illness (Ministry of Health, 2001a).

Although people with LTCs have conditions that are progressive and life limiting, there is a much lesser uptake of palliative care by people with a non-cancer LTC (Burgess, Braunack, Crawford, & Bellby, 2013; Choudhuri, 2012; Johnston et al., 2015). Johnston et al. (2015) did suggest the uptake of palliative care is steadily increasing for people with non-cancer LTCs, but the engagement they refer to in their study is only in the last few weeks of life. The assumption that specialist palliative teams are the most appropriate people to offer care to people with non-cancer LTCs passes largely unchallenged (Burgess et al., 2013).

The timeframe associated with palliative care has been shaped by cancer's more predictable path of deterioration (Burgess et al., 2013). The local documentation includes the compulsory criteria that “the patient must have a … likely prognosis of 6 months or less.” The prediction of life expectancy for eligibility is both very narrow and impossible to apply. Warraich, Allen, Mukamal, Ship and Kociol (2016) found doctors to have limited accuracy in estimating life expectancy particularly for people with non-cancer LTCs. The patient-participants in this study have had many decades of living with their combinations of life-limiting illnesses and their needs endure throughout most of that time, certainly not in the last few weeks or months alone.

The evolution of palliative care

Today in New Zealand, multidisciplinary specialist hospice teams deliver palliative care both in the hospice and in patients' homes with this strong palliative philosophy (Ministry of Health, 2001a; Nichols, 2005). In addition to these teams, palliative care is also offered by specialist hospital teams and by general practice teams. Almost all general practice teams provide a level of palliative care to approximately 80% of palliative care patients (half of those include collaborative care with specialised palliative care teams). Despite this, there is insufficient data or research about palliative care originating in primary care and palliative care does not feature in the Primary Health Care Strategy (Ministry of Health, 2001b; Palliative Care Council of New Zealand, 2012, 2013).

The palliative care discourse is moving progressively towards more consideration of how people are living, rather than dying (Kelley & Meier, 2010). There are many examples of the benefits of palliative care beyond how it has previously been operationalised and the broader focus looks increasingly at quality of life (Kavalieratos et al., 2016; Palliative Care Expert Working Group, 2003). For example a randomised control trial in the USA offered early referral to the palliative care team for people with metastasised small cell lung cancer (Dahlin, Kelley, Jackson, & Temel, 2010; Temel et al., 2010). Alongside the not unexpected benefits of improved quality of life and reduced symptoms, far from hastening death, the intervention group lived longer. Kavalieratos et al.'s (2016) meta-analysis confirmed the impact of palliative care upon quality of life, although they found no difference in life expectancy. Stajduhar and Tayler (2014) describe a range of studies, albeit concentrating on cancer care, where an "upstream" orientation to palliative care occurred earlier in the disease trajectory. The idea of anticipatory palliative care is also gaining traction in the UK with the development of supportive care registers (Hansford & Meehan, 2007; Munday, Mahmood, & Agarwal, 2006). A Scottish study, which offered generalist anticipatory palliative care from the primary care team, showed significant improvement in the quality of life of the participants (Mason et al., 2015).

For palliative care generally, despite its holistic philosophy, the influence of biomedicine has once again meant that it "has become equated with service provision rather than its original intent as a philosophy and approach" (Stajduhar & Tayler, 2014, p. 144). Physical symptoms are awarded primacy as eligibility criteria in the local primary care palliative care funding stream and they are prominent in the literature (Beernaert et al., 2015; Choudhuri, 2012). In contrast, the findings of this study show most participants' anguish lies outside of the tinana cornerstone of the Whare Tapa Wha model.

The relevance of palliation for the patient-participants

The principles of palliative care seem entirely appropriate for people with multiple, complex LTCs. The patient-participants' overwhelming experiences of loss and grief over many years as their LTCs steadily worsen also suggests that aspects of a palliative approach to their care might be useful. Participants' experience of loss was more ambiguous and less overtly recognised than is typically understood in palliative care. However, although the principles of palliative care fit this cohort well, the findings contained no direct articulation of palliation from either patients or clinicians. Possible reasons for this are now explored.

Despite the life-limiting nature of LTCs, patient-participants rarely wanted to think in terms of palliative care as they understood it, even though they are ill served by the self-management approach. Neither did their clinicians seem to consider palliative care as an option, despite volunteering how the patient-participants' health was very fragile. In speaking with Tane, for example, I became profoundly aware of how very much he really needed the care, compassion and support accorded to people who receive palliative care. The solution was not entirely straightforward, as he personally may not have been ready to accept such a focus. Despite the discovery that he was not for resuscitation at the hospital, he felt he needed to believe he could get better. Yet, there is a space in which his care, if more palliative in approach, could meet his needs more directly.

The reluctance may also have been due to the clinicians' and patients' own understanding of palliative care. They may have considered acceptance of palliative services "giving up" (Garrett, 2001). Both groups may have felt it reflected failed clinical care and be therefore reluctant to contemplate palliation (Beernaert et al., 2015).

A palliative approach to care is entirely appropriate for people with incurable LTCs but it is not used. Some of the subterfuge and work-rounds that occur within self-management, something Demain et al. call "secret-acts" (2015, p. 14), are more overt in palliative care, as the focus on improvement that exists in the self-management approach has been lifted. Without palliative care, patients miss out on the much-needed psychological support and advance care planning that is typically offered to, and accepted by, people who are terminally ill.

Instead, exhausted patients are left to engage with the unrealistic goal setting and a constant strive for improvement of the self-management approach, an approach not designed for their severity of LTCs. The goal setting process and the almost inevitable subsequent sense of failure, hinder patients' acceptance of their LTCs and the unavoidable limitations their illnesses impose. The sense of failure increases shame and so can lead to further disengagement. Without a focus on acceptance, Tane was still looking for "a magic pill so I can do the things I used to do" and restricted his use of oxygen therapy to avoid becoming "addicted." Other patient-participants set goals that they intended to achieve when they were "better," saw using a walking-frame as an admission of defeat and looked forward to eventually stopping their medication.

The patient-participants were not ready to be classed as palliative in the way palliation is currently understood. Yet, what participants did want is clearly reflected in the intent behind palliative care. Palliation done properly is about working with the person's authentic agency. Agency that involves a focus on their unique needs and the mobilisation of what residual agency the patients *do* have in a direction of their choosing, to maximise their opportunities and enhance the patients' quality of life. The release of palliative care's implementation from its biomedical constraints could offer an opportunity for people with multiple LTCs to receive the support that they currently lack.

A new philosophy of care

The harm reduction, recovery and palliative movements all surface ways of thinking about care that have inherent value for the care of people with multiple LTCs. Aspects of their underlying philosophies have strong synergies with the sparks of valued care in the findings, particularly palliative care, which sits outside the self-management approach. For all three models, it is the underlying philosophies that truly resonate. The manner of diffusion into care has been distorted to differing degrees as initiatives bow under the weight of biomedical hegemony, which seems sufficiently dominant to capture all new agendas. The biomedical framing has pushed care towards the technical and developed in ways that "keeps wounds clean without asking patients what being wounded means" (Mol, 2002, p. 9). A refreshed approach to care could offset that.

The language used to describe any new approach is important. Although the intent of the original palliative philosophy does capture what I am going on to describe, the term palliative itself has a narrow meaning in both the public and clinicians' minds so is unsuitable. An incident recounted by Tane captured this, when he "panicked this month as when I saw [the podiatrist], he said he was doing palliative care on my feet. I thought he knew something I didn't!" For Tane, palliative was associated with dying or losing his feet, rather than the conservative foot care he was receiving.

Various overseas programmes that have expanded the boundaries of palliative care delivery have used terms other than palliative. These include directed enhanced service (Mason et al., 2015), an upstream approach (Stajduhar & Tayler, 2014), anticipatory and supportive care (Hansford & Meehan, 2007) and the gold standards framework (Munday et al., 2006). The new terminology appears to have gone some way to increase people’s acceptance of these services, possibly by avoiding the association with the end of life (Mason et al., 2015).

Care

Is there a need for a new term, or is there a need to re-awaken or re-invigorate one that is already in use that perhaps has been hidden under imposed agendas? Care is the common thread that resonated with both the patient- and clinician-participants and is reflected in the palliation, harm reduction and recovery models. Perhaps care can stand alone as an approach without being accompanied by an adjective?

Mol (2008) describes a logic or discourse of care that often sits in opposition to choice, where practices designed to foster choice often undermine care. Self-management fits this description. With the ideal of agency or choice largely irrelevant to the patient-participants, there is an opportunity to reframe an approach where an ethic of care replaces the choice or agency of the self-management approach. Care can be thought about as the “responsiveness to need with a view to the cared-for’s well-being” (O'Dowd, 2016, p. 795). This notion seems to echo what the patient-participants described as desirable.

The tradition of care ethics originated with the work of Gilligan (1982) and Nodding (1984), initially as a challenge to the unquestioned ethic of rights and obligations that dominated traditional ethical theory (Beauchamp & Childress, 2013). Nodding (1984) favoured the more practical ‘caring for’ over ‘caring about’ - the end result rather than the motivation behind the action (Sander-Staudt, 2006). However, patient-participants valued both. An ethic of care focuses on the particular needs of the individual and acknowledges that what works for one person, may well not work for another in seemingly similar circumstances (Engster, 2004; Nodding, 1984; Tronto, 1983). For people with multiple LTCs this may be more appropriate than the one-size-fits-all diffusion of self-management and offers a way to potentially optimise a person’s quality of life.

Mol (2008) identifies the tensions between choice and care, and claims good health care has little to do with patient choice. Agency, empowerment and patient choice in health care are accepted unquestioningly as desirable but challenge the idea of care. The goals of an optimal quality of life and learning to live with LTCs mesh well with the ethic of care and reflect data from both patient- and clinician-participants. These ideas are now organised in the familiar framework of the Whare Tapa Wha model.

Taha tinana

For people with significant LTCs, the pragmatic goal setting of harm reduction seems to hold promise. For the patient-participants, although hope for a cure is past, physical care remains important. Although this study has criticised the detrimental effect of biomedicine's perfusion of health care, there of course remains a need for biomedical solutions to the physical aspects of care that sit in the taha tinana domain. The patient-participants are likely to live independently for many more years and the findings show them suffering physical symptoms that are open to amelioration. There is a need to minimise the likelihood of LTC complications or further comorbidities in order to maximise their comfort and quality of life.

The patient-participants would benefit from care that is offered across a flexible continuum, where care can move from periods of active care, such as during an exacerbation of COPD, to symptom control and back, with an understanding that these are not mutually exclusive (Burgess et al., 2013). The decline of living with multiple LTCs may involve both intermittent exacerbations and "prolonged dwindling" (Murray, Kendall, Boyd, & Sheikh, 2005, p. 1008). The continuum would avoid the current barrier that formal referral onto a palliative pathway causes, as the principles of palliation would be always present.

The pragmatic lens borrowed from harm reduction means incremental goals can be set from 'where the patient is at,' with an acceptance that all people are not going to be able to comply and everyone's goals will differ (Blume, 2012). These goals are more realistic than expecting major changes in lifestyle. A refreshed focus subtly changes how care is offered to meet the needs of those experiencing the longer, more uncertain trajectory of LTCs alongside the complexities of chaotic lives.

Taha whānau

The findings show both cohorts valued the connection and relationships between them and the idea of knowing and being known and caring for and being cared about. Two key components here are compassion and whanaungatanga. The idea of compassion is a strong thread in the findings as something valued by both patient- and clinician-participants that is present in the harm reduction, recovery and palliative models of care. For the patient-participants, compassion is the connection they seek that includes kindness and thoughtfulness as well as clinical care, qualities often missing from the rational detachment of biomedicine (Youngson, 2011, 2014). The findings show multiple examples of overt compassionate intent that support rather than undermine patients' personal agency (Collins et al., 2012; Vakharia & Little, 2016).

Compassion resonates with the ideas of whanaungatanga described in the findings, which convey the idea of social connectedness and a sense of belonging (Cram et al., 2003; Durie, 1985; Wepa, 2015). Although whanaungatanga has traditionally concerned kinship relationships it has come to mean something that can be shared between people with a common purpose (O'Carroll, 2013). Patient-participants valued highly the sense of being known by their practice team over time, the sense of connection or belonging, the long-term relationships that characterise, and are identified as a strength of, primary care (Freeman & Hughes, 2010). Compassion and whanaungatanga set the scene for a powerful environment for care in an encounter where the clinician appears fully present and hears what the patient-participant is saying.

Care and partnerships

The principles of care framed this way can be incorporated into everyday primary care clinical encounters building on the enduring, compassionate relationships already in place. With multiple LTCs the norm, generalist primary care teams already in established long-term relationship are both the necessary and desirable way to offer this care, something identified by the WHO (World Palliative Care Alliance, 2014). The kind of care described should be considered as a routine part of the primary care offered to people with complex multiple LTCs (Beernaert et al.; Burgess et al., 2013).

The role of partnerships between clinicians and patients within this ethic of care possibly creates the space for patients to increase their capacity for agency, if both parties were released from the present futile struggle for improvement. For example, if a patient does not want to take their medicines, the clinician's responsibility would be to explain the range of possible outcomes of that course of action and perhaps discuss a compromise. Care offered in this way would foster honesty when patients do demonstrate rationalised non-adherence, which may ultimately lead to better health. A patient who feels cared for, listened to and respected would be more likely to engage in honest conversations and ultimately have their self-determination supported.

Care need not equate to passivity. The increased sense of being valued and supported may instead go some way to provide patients with what they need to supplement their depleted energy and ironically potentially increase their capacity for agency. Clinicians would also in turn be free to support the patient in that choice, reminiscent of Demain et al.’s (2015) secret acts made overt. This creates a different context for expertise and the palliation perspective gives clinicians permission to allow patients to make decisions that do not meet the best practice guidelines or targets that currently constrain clinicians.

The approach would allow the primary care clinicians to offer care that is respectful and responsive to patients’ values and delivered in mana-enhancing ways in contrast to the almost inevitable sense of failure patients currently experience. The approach promises the possibility of release from the present mutual entrapment experienced by clinicians and patients.

Taha hinengaro and taha wairua

The idea of hope, which relates to both the psychosocial context of taha hinengaro and the taha wairua domains, seemed both complex and often scarce in the lives of the patient-participants. The self-management approach resulted in people forced into unrealistic goal setting, which blocked their ability to focus on goals that were personally meaningful, as well as the acknowledgement of the chronic nature of their illnesses. Moreira and Palladino (2005) described this aspect of biomedicine as “riddled with the regime of hope” (p.67). The patient-participants’ needs had more in common with the palliative literature, where what people hope for changes over time, something Merrick (2016) described as “the potential for multiple objects of hope” (p.114).

The uncertainty of living with multiple LTCs occupies a more ambiguous territory for hope, as life is likely to go on for many years. There is a tension between hope for living and decisions around advance care preferences. Hope, as it is embraced by a new approach for people with multiple LTCs is not hope for a cure, as those days are long gone. With an uncertain future, living with hope despite multiple losses involves hope of meeting individual or very often whānau goals and is likely to be more about hope for today (Barilan, 2012; Bryant & Ellard, 2015). These goals are unlikely to overlap with the self-management approach but instead have more in common with the palliative philosophy that “allows hope to manifest by allowing space for the patient’s idiosyncratic values to be recognised” (Merrick, 2016, p. 115).

Care and goal setting

In contrast to the envisaged expert patient of the Chronic Care Model, patient-participants’ aspirations had more in common with survival and “getting by,” than thriving or gaining expertise. A refreshed approach would replace the current goal setting process with goals genuinely tailored to the individual's needs rather than striving for unrealistic goals that originate in a template.

A focus on care makes room for a different way to think about hope and personal agency, attaching values to patients' subjective experiences and personal priorities. For people with complex and significant LTCs, hope and personal agency need to be framed in ways that sustain people without disempowering, neither leave them with a sense of failure nor force them towards impossible goals. A reframed sense of personal agency restores an individual's sense of control, which is so often stripped away by the self-management framework.

Although the patient-participants' LTCs are inevitably progressive, there are still opportunities, and usually many years, ahead in which to optimise quality of life and have individualised realistic and meaningful goals. The patient-participant goals are likely to coincide with Mol's (2008) goal to make life "more liveable" (p.97). Good care for people with multiple LTCs would have the deceptively simple goal to make life better than it otherwise would have been.

For the patient-participants, their definitions of what a better life could be, will be as varied as their unique circumstances, with each person having different drivers towards their own ideas of mauri. The patient-participants spoke of their aspirations to simply have more "good days." Sadly, Aroha spoke of these good days as something she hoped for but no longer experienced. For Lou, a good day was when she "can get out and do my pots, and… go and sit in McDonald's with a cup of coffee and read my library book." Diane's wish was that "my health goal is to live until I die" and Eva's less ambitious wish for the strength to "be able to carry on." In contrast to a curative approach, an approach informed by palliative care attaches significance to personal priorities (Merrick, 2016). Goals can be negotiated between patient and clinician in a mutual decision-making process about achievable changes that are of importance to the patient.

A note of caution

The idea of an approach based on an ethic of care for people with multiple LTCs offers promise. However, the intent or underlying philosophies of all the models described, including the self-management approach, all hold great merit. However, the pervasive impact of a biomedical focus creates risk that the best intentions can go astray. As an example the UK's Liverpool care pathway, a clinical pathway developed to guide hospital clinicians in very-end-of-life care, was an innovation based on best practice from hospices disseminated internationally with substantive claims of efficacy from minimal evidence. Its diffusion into an existing biomedically framed health system led to it becoming channelled into a one-size-fits-all product. The pathway's diffusion process had led in many instances to a focus on 'box-ticking' with many clinicians losing sight of compassion and care and their capacity for critical thinking apparently disengaged (Di Leo et al., 2015; Neuberger, 2013). Distressed clinicians who did express concerns, felt unheard (Di Leo et al., 2015). The pathway was subsequently rapidly phased out after a damning report commissioned by the UK government (Billings & Block, 2013; Neuberger, 2013).

There are strong similarities between the Liverpool care pathway's diffusion and the findings of this study. The caveat is therefore, how can any vision of a new way of care avoid the colonisation by biomedicine that has constricted each of these? What would prevent clinicians being captured in the same way as happens with the self-management approach? The concern is captured well by Merrick (2016). Describing palliative care, she states, "it is not enough simply to replace the curative model of medicine with the palliative model because we may unwittingly retrench some of the values found implicitly in the curative model of medicine" (p.116). There is a need to reimagine care outside the biomedical framework, with those involved at strategy and clinical level alert to the need to resist the capture of the new approach by biomedicine.

The process of identifying recommendations from the findings of the thesis is difficult. The scale of the issue suggests it would be easy to trivialise by reducing this thesis to a number of recommendations. I will try to avoid that trap. Instead, there is a possibility for the potential of the new model to be explored.

Recommendations

Strategy documents

The ideas around what patient-participants want contain a clear synergy with the recently refreshed New Zealand Health Strategy, particularly the goals of people power and person centredness (Minister of Health, 2016). Once again, a key direction-setting document has been produced that is clearly appropriate. However, past history and the data presented suggest that this well-intentioned policy is likely to be another that is never fully implemented. There is a repetitive pattern of strategies, containing many of the same principles, never being realised with a continued gulf between the vision and operation.

However, as the health sector moves on relentlessly creating strategies, the part of the diffusion process where these strategies move into practice needs to be given more attention. Perhaps some reflection upon why, throughout the world, expensive policies are developed and yet never properly operationalised would be useful. As well as the missing voice of patients, clinicians have made it clear that the self-management approach is as inappropriate for them as it is for the patients, their perspective also needs to make its way into policy.

Reflections on the research process

The study gained strength from a number of factors particularly the long-term relationships with a mixed group of participants. The patient-participants offered rich data over a long period and so I was able to gain insights into their experiences. By their nature, long-term conditions deserve attention over as much time as possible. The research design allowed the achievement of the research aim to give primacy to the voices of people with LTCs by listening to their stories and the use of their kōrero.

Although qualitative research makes no claims about being representative or the findings generalisable, the cross-section of the population achieved with the patient-participants was valuable as the people who experience LTCs most are typically less involved in research. The numbers of Māori and Pasifika patient-participants, which are reflective of the numbers in the total population, was another strength of the study. These numbers were due to very early consideration of the importance of a diverse group of participants, particularly for a topic that affects minority groups disproportionately.

Ongoing engagement with my research whānau seemed to mitigate some of the difficulties experienced by other researchers, particularly recruitment and prolonged engagement with Māori participants. The ongoing relationships I had with my cultural advisors proved another strength of the study and an unanticipated pleasure. The result was participants who chose to engage with me for the duration of the study and willingly shared their experiences and insights. It is impossible to know definitively the effect of the consultation process on the decision of all the Māori patient-participants to continue their participation throughout the study. However, I suspect the research whānau's advice about initial engagement and building relationships with the participants was an important contributor to that outcome.

With primary health care for people with long-term conditions delivered by both GPs and PNs, another strength of the research design is the inclusion of both groups as clinician-participants. Additionally, these were the specific clinicians the patient-participants received their care from, so I gained a real sense of the relationship and heard about specific incidents from all perspectives. Care dyads or triads are far from universal in long-term condition research, which often instead involves either patients or clinicians (Carryer, Budge, & Francis, 2016). Where both groups are included, they may not be known to each other (Freeman & Hughes, 2010; Parker, Corden, & Heaton, 2011).

My initial intent was to focus almost exclusively upon the patient-participants and I sought clinician data with some vague idea of triangulating the data to check the 'truthfulness' of the patient-participant interviews. As I came to understand the chokehold that biomedicine has over the care offered to people with multiple LTCs, the revelation outlined in the introductory chapter flipped the purpose of the clinician interviews away from a confirmation or contradiction of patient-participant data. Despite my early shallow questioning, it was the clinician-participants' unanimous and uninvited determination to talk about the problems they encounter that added such value to the study. They showed me that, far from an approach built around the needs of clinicians, the self-management approach was equally ill suited to their needs.

A personal reflection

As is common during research, the process led to many changes in my thinking and a transformation of my understanding of the lives of people living with multiple LTCs. My previous unfailing faith in how self-management was offered to patients was called into question. During the early stages of the research, I had toyed with ideas of research with an emancipatory intent. I pondered on the possibility of how I could offer the patient-participants a way to achieve some sort of insight about how to self-manage their LTCs more effectively. However, I had concluded that it was beyond the scope of the study.

Once data collection was completed and I began to reflect upon the findings, aspects of care the patient-participants appreciated began to surface. These were about being listened to, cared about, understood and acknowledged. Patients valued clinicians saying, “yes, you have a heavy load and you are doing a good job” and examples of these exchanges pepper the findings. Clinician-participants had also identified both the need for a space where patients could be heard and its absence within the self-management paradigm.

It occurred to me that the research process had itself involved interactions with the patient-participants that mirrored the things they said they needed. Reflecting on that, I revisited many of the comments patient-participants had made about the research process itself. Diane complained that being involved in the research had “made me think too much about myself” - something she said made her uncomfortable. However, she continued, capturing Saunders’ (1990) idea of total pain, that it had instigated a process she described as starting to come to terms with “my physical, emotional and spiritual pain.” Aroha reflected, “you’ve helped me talk about things I never thought I’d talk about.”

Many participants spoke of how much they enjoyed having someone to talk to who understood them and cared, who “really listens,” which made me feel quite guilty because my motivation was data collection. Aroha said she looked forward to my calls and one month Wiremu telephoned me because he thought my telephone call was a few days late. He said once, “it is always good to talk to you, I look forward to it. You are a new friend I have made this year.” On one monthly visit, Wiremu persuaded me to help him try his new karaoke machine by singing along with him (very badly) to Neil Sedaka’s ‘Calendar Girl.’ For Wiremu, someone showing an interest in his hobby was valuable. The relationships that developed seemed important to the participants, as well as to me, and several participants expressed regret that the data collection was over.

My reflection is whether the research process itself was an intervention for the patient-participants? Were they any different because of the study? I did not ask the question of them, so there is no answer, but it is interesting to note.

Limitations of the study

The study was completed in New Zealand Aotearoa where the self-management innovation diffusion has been driven in a particular way at policy level. Primary care is delivered amidst a patchwork of policies and programmes. The results are a combination of co-payments (in primary care and not for hospital care, which differs from other countries), capitation funding and various funded programmes. These differences suggest that some of the issues patients encounter in New Zealand would be different overseas.

The patients recruited were enrolled with mainstream primary care providers. There may have been differences for those who enrol with Māori health providers. The patient volunteers were perhaps more likely to be already engaged in their health care than average and, for those who replied to the advertisement, possibly had relatively good levels of health literacy.

The patient-participants had significant, complex LTCs. There was no specific intent to recruit people with such severe illnesses and the reasons for the level of disease severity in the volunteers are unclear. Perhaps people with milder LTCs do not identify themselves as living with multiple LTCs or are still working so unable to volunteer for a study. Another possibility is that people with more significant LTCs are more likely to visit their health provider so more likely to see the poster in the waiting rooms. Alternatively, perhaps people like the participants are more prevalent than is widely believed.

Concluding statement

I want to be treated like an intelligent person who in spite of being an overweight, asthmatic, diabetic, arthritic, short sighted human, can, and have been, self aware and self caring for a long time. (Diane)

How can I describe it? You cope how you cope.
You just do what you can. (Aroha)

The diffusion of the chronic care and self-management models has emerged from within the biomedical frame of reference and so is underpinned by a set of assumptions that have shaped the way the models have developed. The health care offered takes no account of the social context of people's lives and virtually every aspect of living with LTCs undermines the agency that the self-management approach assumes is implicit. By subtle undermining of the patient, biomedically driven health care has become another structural determinant with the potential to increase health disparities, as Link and Phelan's work would predict (1995, 2010; 2013).

The approach focuses on getting people to help themselves through patient expertise. The inherent contradictions between the status of the exhausted patient-participants, the self-management approach and the underlying biomedical paradigm provide a poor basis for the assumptions of this agenda. A person depleted of energy by a succession of losses is poorly equipped to fill the idealised role. Instead, the self-management approach is unknown or irrelevant to the exhausted patient-participants while the clinician-participants describe how they work around it.

The findings do not challenge the LTC literature, which is a rich exploration of the issues facing people with LTCs. What they do challenge is the way a certain part of the literature, the part that corresponds with biomedical assumptions, is taken up disproportionately and dominates the way health care is delivered. Neither is the study a critique of the self-management approach. Self-management is something "organic and dynamic … naturally practised by consumers" (Kendall et al., 2011, p. 88) that is both inevitable and potentially helpful. The critique is around the unquestioned, unflinching funnelling of self-management into the shallow and constricted biomedical paradigm. Health care has taken a good idea and disabled it with the biases, language and behaviour of biomedicine. Many other models have been similarly constricted, with valuable ideas and philosophies disabled and their potential for helping patients lost. The study fills a gap in current knowledge for policy makers and health care professionals and may provide insights for them to better support the ever-increasing number of people with multiple long-term conditions.

A conclusion arising from the data is that to manage LTCs optimally, self-management needs to be conceptualised differently. The starting place is how best to maximise the quality of life of people with LTCs from their perspective. A revised view of self-management through an expanded, anticipatory, supportive re-awakened ethic of care would enable clinicians to better utilise their knowledge of the patient and their circumstances and their clinical expertise. As a PN said, “self-management is how they can manage best themselves within *their* health context.”

A reimagined care would wrap around the person with LTCs and support them within their unique circumstances and might liberate clinicians to offer compassionate, mana enhancing care.

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Appendices

Appendix one: Māori consultation process

From September 2011, I had regular meetings with the people below who named themselves my research whānau.

- **Potace Bennett,** RN. Tainui/Ngāti Kahungunu/TeArawa. Māori and Pacific Health Coordinator, Long-term Conditions Service.
- **Mathew Bennett**, Te Arawa/Ngāti Kahungunu/Tainui/Ngāti Raukawa. Māori Health Strategist.
- **Ann McCleland**, RN, MA, MN. Tainui. Experienced Nurse, Nurse Educator and Māori researcher.
- **Heather Te Au Skipworth,** QSM. Ngāi Tahu/Ngāti Kahungunu. IronMāori founder.
- **Tracee Te Huia**, Ngāpuhi/Ngāti Kahungunu. Director Māori Health.
- **Na Raihania,** Ngāti Porou.
- **Amber Logan-Riley**, BApSci, MSc, PGDipHlthPsy. Ngāti Kahungunu. Health psychologist and Māori researcher (Ao Marama Health Research).

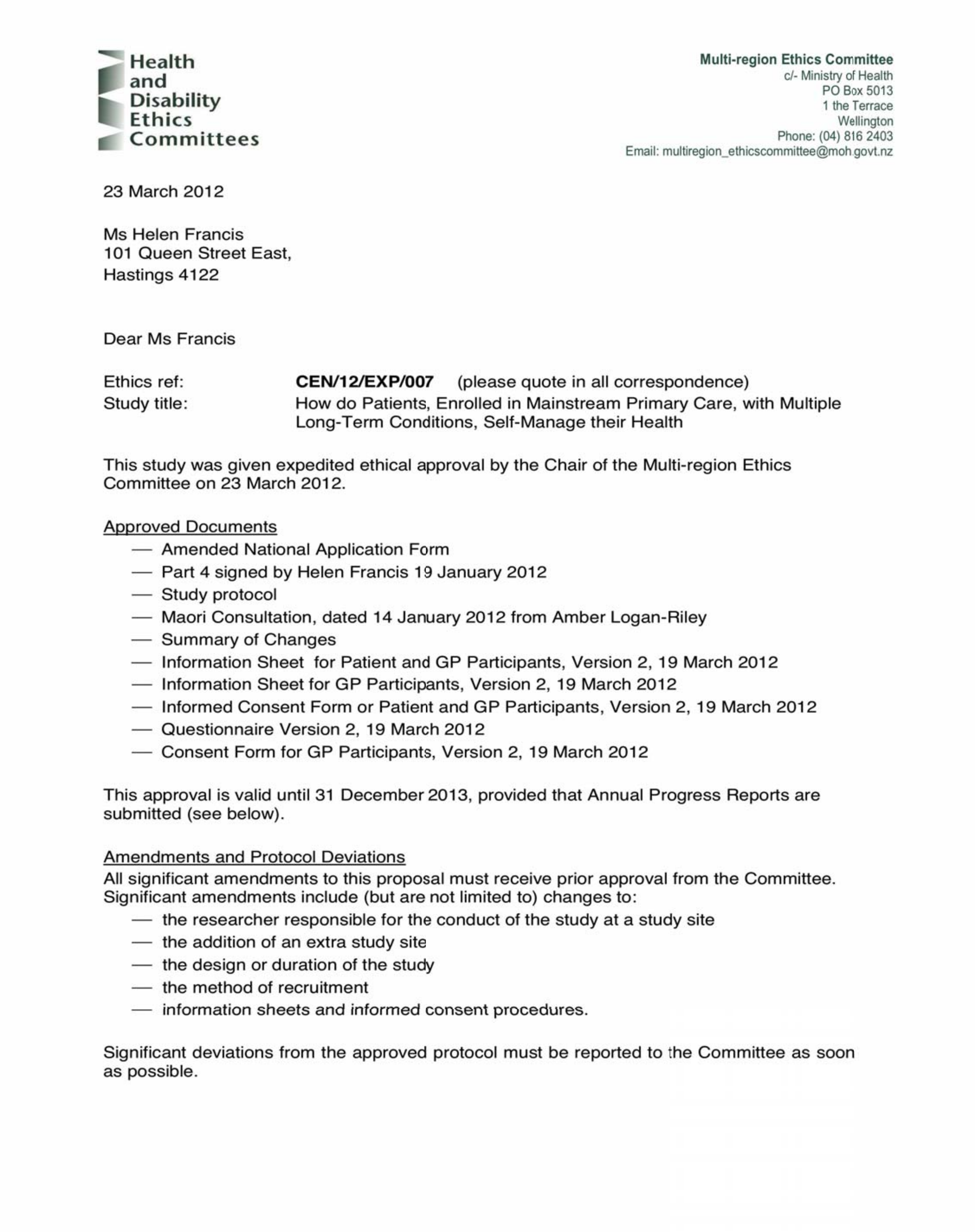
Their ongoing generous support, advice, aroha, help with recruitment and availability when I needed them, was invaluable. Their recommendations included keeping the local Iwi informed, so a letter was sent to both Iwi CEO and Chair.

During the planning, data collection and analysis, the membership of my research whānau changed due to their personal circumstances and because I felt the need for a more robust academic cultural lens during data analysis.

Potace and Mathew Bennett, my main cultural support team recommended a Māori academic who had a strong relationship with our local Iwi and who I had previously met more than once at health related hui. Many thanks to:

- **Dr Fiona Cram,** PhD, Ngāti Pahauwera. Director, Katoa Ltd.

Appendix two: Ethical approval



Health
and
Disability
Ethics
Committees

Multi-region Ethics Committee
c/- Ministry of Health
PO Box 5013
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Wellington
Phone: (04) 816 2403
Email: multiregion_ethicscommittee@moh.govt.nz

23 March 2012

Ms Helen Francis
101 Queen Street East,
Hastings 4122

Dear Ms Francis

Ethics ref:	**CEN/12/EXP/007** (please quote in all correspondence)
Study title:	How do Patients, Enrolled in Mainstream Primary Care, with Multiple Long-Term Conditions, Self-Manage their Health

This study was given expedited ethical approval by the Chair of the Multi-region Ethics Committee on 23 March 2012.

Approved Documents

- Amended National Application Form
- Part 4 signed by Helen Francis 19 January 2012
- Study protocol
- Maori Consultation, dated 14 January 2012 from Amber Logan-Riley
- Summary of Changes
- Information Sheet for Patient and GP Participants, Version 2, 19 March 2012
- Information Sheet for GP Participants, Version 2, 19 March 2012
- Informed Consent Form or Patient and GP Participants, Version 2, 19 March 2012
- Questionnaire Version 2, 19 March 2012
- Consent Form for GP Participants, Version 2, 19 March 2012

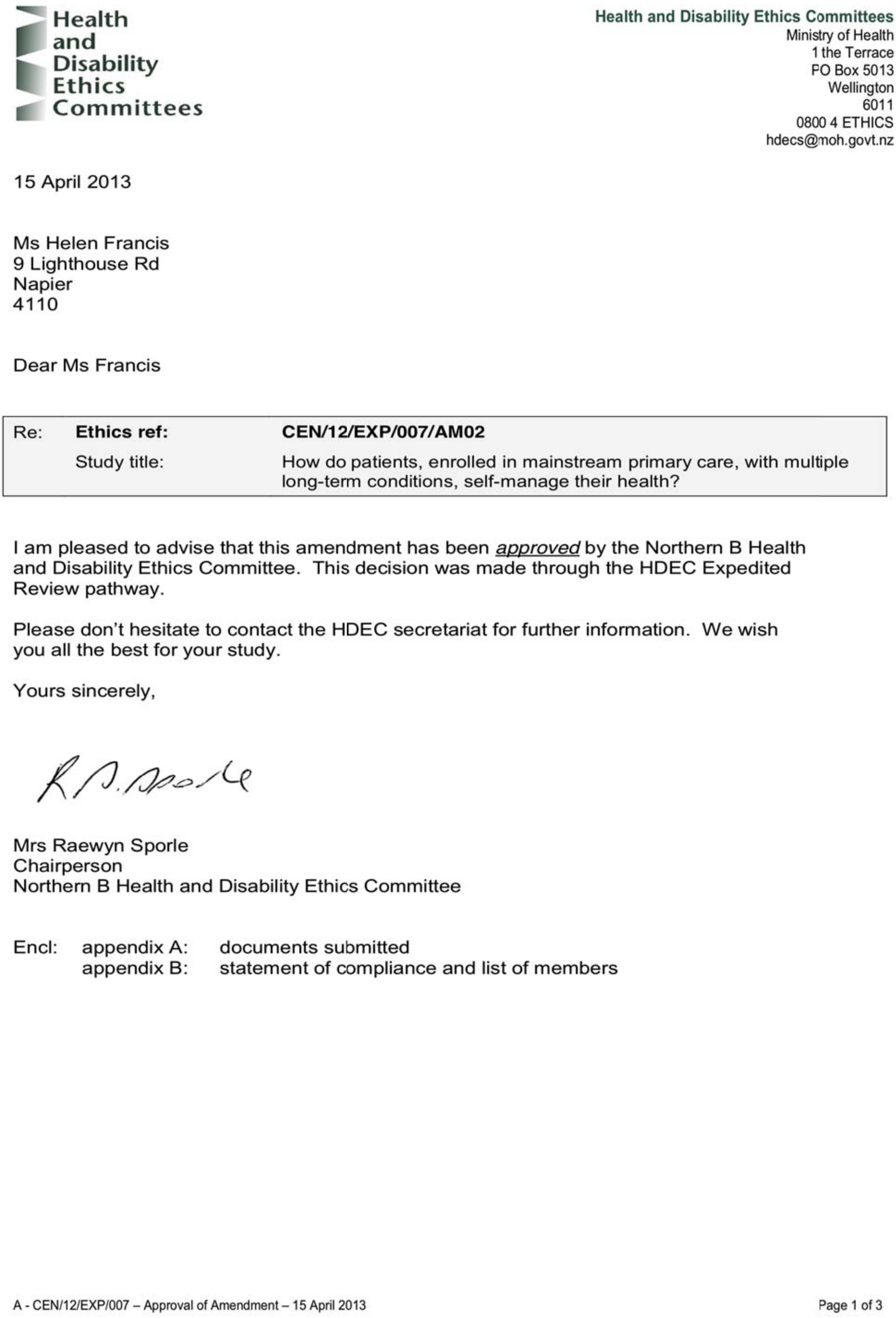
This approval is valid until 31 December 2013, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.



Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
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hdecs@moh.govt.nz

15 April 2013

Ms Helen Francis
9 Lighthouse Rd
Napier
4110

Dear Ms Francis

Re:	**Ethics ref:**	**CEN/12/EXP/007/AM02**
	Study title:	How do patients, enrolled in mainstream primary care, with multiple long-term conditions, self-manage their health?

I am pleased to advise that this amendment has been *approved* by the Northern B Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Raewyn Sporle
Chairperson
Northern B Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix three: Advertisement for patient-participants

Do YOU have more than one long-term health condition ?

Are YOU interested in telling someone what it is like?

Can YOU help with my research?

Many people are living with more than one long-term health condition which impacts on their lives significantly such as:

• DIABETES • STROKE • ARTHRITIS • GOUT
• CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)
• ASTHMA • HEART FAILURE • HEART ATTACK
• CHRONIC KIDNEY DISEASE.

I'm a registered nurse researching with Massey University into: what it is like living every day with several LONG-TERM HEALTH CONDITIONS; and how do you manage your everyday life along with all the things you are supposed to do to keep as well as possible.

If you think you might be interested in taking part there are a number of ways to get in contact. In the plastic pouch attached are cards with my contact details if you would like to contact me yourself. Otherwise, let the receptionist or your doctor or nurse know you are interested and they will send me a message to contact you. I can then explain more about what is involved, answer any of your questions and you can then decide if you want to be a part of this study.

Many thanks,

Helen Francis

MOBILE: **021 404 146** HOME: **835 4537**

Appendix four: Information sheets for patient, GP and PN participants

Massey University

Te Kunenga ki Pürehuroa

Information sheet for patient participants.

Living with multiple long-term health conditions

My name is Helen Francis and I am a registered nurse doing research in order to complete my doctoral thesis at Massey University. I am interested in finding out what it is like to live with more than one long-term or chronic health condition and so I am inviting you to take part in this study. I think this is worthwhile, as it may help doctors and nurses better support you and people like you, in the future if they understand more about what it is really like and how you juggle any health needs or restrictions with the rest of your life. I would like to tell you more about what I am hoping to do, so you can make an informed choice about whether you would like to take part.

How the study will be done

I would like to come and talk with you, in your home if that is convenient, about what it is like to live with more than one long-term or chronic health condition and how you manage that. The questions will be about your experiences of living with several health conditions, how you manage day-to-day, what things helps you and what is not so helpful. I would like to talk with you once in the near future and again in perhaps a year's time. Also during the interview I might make some observations about your general wellbeing and how you are managing.

I would also like to get some information from you about the number of hospital and GP visits and any other health care you receive. If you can't remember any of that exactly, I would like your permission to check that information with your GP who will have it all written down. At some point during that time I would also like your permission to go and talk to your GP about how they think your illnesses effect your everyday life and I would like your permission to do this. I will <u>not</u> tell the GP anything you have told me, apart from in the very unlikely event of you telling me something that might be dangerous to your health. If that should happen you and I would talk first about how best to let your GP know.

The first interview will probably take about an hour and I would like to digitally record it to help me remember what you have said. A professional typist will type up our conversations for me, and I will send you a copy of that so you can check it is accurate and your words have captured your meaning. Also during that year, I would like to hear about anything that has caused you to go to the emergency department or into hospital or to the GP with a health emergency. So I will phone you once a month to ask how you are. I will use this information in the study. The second interview will be like the first one and will be in about 12 months time. There will be no costs or risks to you, apart from you sparing the time to talk with me. I will send you a summary of the research findings at the end of the study and would be happy to talk to you about them as well.

Confidentiality

I will do my best to minimise the risk of you being identified in the study by changing your name and any identifying details. During the research, all recordings, transcripts and signed consent forms will be kept in a secure place. Their content will be seen by myself, the typist (who will have signed a confidentiality form) and my two Massey University PhD supervisors. When I have finished the research, all information will be kept securely for at least ten years and then destroyed.

What now?

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part, that decision will in no way affect you or your health care. I will phone you in the next week or two to see if you would like to take part in this research. I can answer any questions then, or if you prefer, you can contact me on the numbers below. If you agree to take part, you still have the right to:

- Refuse to answer any question(s).
- Ask any questions about the research at any time
- Read and check a copy of your interview transcript.
- Turn off the tape at anytime during an interview.
- Be free to withdraw at any time.
- Have someone with you during the interview if you prefer.

This study has received ethical approval from the Central Health & Disability Ethics Committee (CEN/21/EXP/007). If you have any questions, concerns, or want more information with respect to this please contact any of the following:

My contact details:
Helen Francis
021 404 146
835 4537
helen.francis@xtra.co.nz

My First supervisor
Professor Jenny Carryer,
School of Health & Social Services,
Massey University
Private Bag 11 222, Palmerston North 4442
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Phone +64 6 356 9099 extn 7719

My Second Supervisor
Dr Jill Wilkinson, Senior Lecturer,
School of Health and Social Services
Massey University
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Phone +64 4 8015799 ext 6639

Thank you for taking the time to consider participating

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

Free phone: 0800 555 050 Email: advocacy@hdc.org.nz

Massey University

Te Kunenga ki Pürehuroa

Information sheet for GP participants.

Title: Living with multiple long-term health conditions

Dear Doctor ,

My name is Helen Francis and I am a registered nurse undertaking research for doctoral study through Massey University.

As you will remember I recently approached medical centre, and you and your colleagues were kind enough to give me approval in principle to talk to your patients about living with multiple long-term health conditions.

My plan is to talk to patients with more than one significant long-term health condition about what it is like to live with these conditions how they manage them day-to-day, what things help and what is not so helpful. I plan to talk with them once in the near future and again in a year’s time, and during the interview make some observations about their general wellbeing. I will also be in monthly contact with them between these two interviews to discuss anything that has impacted on the their health that month.

Alongside this, I also want to talk to their GP once, for perhaps half an hour about what you think about how they manage their health, what things impact on their ability to do so and so on.

Please find enclosed an information sheet with more information and my contact details.

Thank you for taking the time to consider participating.

Warmest Regards,

Helen Francis

Living with multiple long-term health conditions Information sheet

Your patient………………………………… is keen to participate in this research, so before I arrange to talk with them I would like to ask you for your commitment to participate in this.

I will also be collecting some information about the number of hospital and GP visits and any other health services they receive. I will have their signed permission to ask your practice for any of those things that the patient can't recall.

I will also have their written permission to come and talk with you once about your thoughts on how they manage their illnesses and balance that with their everyday lives

How the study will be done

I would like to come and talk with you, at any time and place that is convenient to you, about this specific patient. I would like to arrange that between two weeks and a month after my first interview with the patient.

This is likely to take about half an hour and I would like to digitally record it to help me remember what you have said.

I would like to discuss your thoughts about what your patient understands about their various health conditions, how they mange their long-term health conditions when they are away from the practice, and what other things you think impact on their health and welfare.

There will be no costs or risks to you, apart from you sparing the time to talk with me. I will send you a summary of the research findings at the end of the study and would be happy to talk to you about them as well.

Confidentiality

I will do my best to minimise the risk of you being identified in the study by changing your name and any identifying details.

During the research, all recordings, transcripts and signed consent forms will be kept in a secure place. Their content will be seen by myself, the typist (who will have signed a confidentiality form) and my two Massey University PhD supervisors.

When I have finished the research, all information will be kept securely for at least ten years and then destroyed.

What now?

I will be in contact you in the next week or two to see if you would like to take part in this research or, if you prefer, you can contact me (details below) and I can answer any questions then.

Your participation is entirely voluntary and if you choose not to take part, I will thank your patient for volunteering but say I no longer need their participation.

If you agree to take part I will then arrange a time to interview the patient, and as soon as that has happened, be back in contact with you to arrange a time for our interview between two and four weeks after the patient interview. A professional typist will type up our conversations for me, and I will send you a copy of that so you can check it is accurate and your words have captured your meaning.

If you agree to take part, you still have the right to:

- Refuse to answer any question(s).
- Ask any questions about the research at any time
- Read and check a copy of your interview transcript.
- Turn off the tape at anytime during an interview.
- Be free to withdraw at any time.
- Have someone with you during the interview if you prefer.
- I will have a signed informed consent from your patient for all of the above.

I will not be telling you any information the patient has told me, or vice versa. The exception will be in the unlikely event of the patient telling me, or me observing, something that might be dangerous to their health.

This study has received ethical approval from the Central Health & Disability Ethics Committee (CEN/21/EXP/007). If you have any questions, concerns, or want more information with respect to this please contact any of the following:

My contact details:
Helen Francis
021 404 146 or 835 4537
helen.francis@xtra.co.nz

First supervisor
Professor Jenny Carryer, MNZM,
School of Health & Social Services,
Massey University
Private Bag 11 222, Palmerston North 4442
Email: J.B.Carryer@massey.ac.nz
Phone +64 6 356 9099 ext 7719

Second Supervisor
Dr Jill Wilkinson, Senior Lecturer,
School of Health and Social Services
Massey University
Private Box 756, Wellington
Email: j.wilkinson@massey.ac.nz
Phone +64 4 8015799 ext 6639

Thank you for taking the time to consider participating

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

Free phone: 0800 555 050 Email: advocacy@hdc.org.nz

Massey University
Te Kunenga ki Pürehuroa

Information sheet for Practice Nurse participants

Title: Living with multiple long-term health conditions information sheet

Dear ,

My name is Helen Francis and I am a registered nurse undertaking research for doctoral study through Massey University.

You may be aware that I have interviewed your patient …………… ………… about living with multiple long-term health conditions. After an initial interview with them, I have been in touch monthly about what it is like to live with these conditions how they manage them day-to-day, what things help and what is not so helpful. I will be conducting another interview with them within the next year, and I have also talked with their GP.

It would be really helpful if I could also talk with you for up to half an hour about what you think about how they manage their health, what things impact on their ability to do so and so on.

Please find enclosed an information sheet with more information and my contact details.

Thank you for taking the time to consider participating.

Warmest Regards,

Helen Francis

Living with multiple long-term health conditions Information sheet

Your patient………………………………… is participating in this research, and has given their written permission to come and talk with you once about your thoughts on how they manage their illnesses and balance that with their everyday lives.

How the study will be done

I would like to come and talk with you, at any time and place that is convenient to you, about this specific patient.

This is likely to take up to half an hour and I would like to digitally record it to help me remember what you have said.

I would like to discuss your thoughts about what your patient understands about their various health conditions, how they mange their long-term health conditions when they are away from the practice, what you think is their idea of self-management and what other things you think impact on their health and welfare. I would also appreciate your thoughts generally about how self-management does or doesn't work for patients with several long-term health conditions from your experience.

There will be no costs or risks to you, apart from you sparing the time to talk with me. I will send you a summary of the research findings at the end of the study and would be happy to talk to you about them as well.

Confidentiality

I will do my best to minimise the risk of you being identified in the study by changing your name and any identifying details.

During the research, all recordings, transcripts and signed consent forms will be kept in a secure place. Their content will be seen by myself, the typist (who will have signed a confidentiality form) and my two Massey University PhD supervisors.

When I have finished the research, all information will be kept securely for at least ten years and then destroyed.

What now?

I will be in contact you in the next week or two to see if you would like to take part in this research or, if you prefer, you can contact me (details below) and I can answer any questions then.

Your participation is entirely voluntary. If you agree to take part I will then arrange a time for our interview. A professional typist will type up our conversations for me. , and I will send you a copy of that so you can check it is accurate and your words have captured your meaning.

If you agree to take part, you still have the right to:

- Refuse to answer any question(s).
- Ask any questions about the research at any time
- Read and check a copy of your interview transcript.
- Turn off the tape at anytime during an interview.
- Be free to withdraw at any time.

- Have someone with you during the interview if you prefer.
- I will have a signed informed consent from your patient for all of the above.

I will not be telling you any information the patient has told me, or vice versa.

This study has received ethical approval from the Central Health & Disability Ethics Committee (CEN/21/EXP/007). If you have any questions, concerns, or want more information with respect to this please contact any of the following:

My contact details:

Helen Francis
021 404 146 or 835 4537
helen.francis@xtra.co.nz

First supervisor
Professor Jenny Carryer, MNZM,
School of Nursing
Massey University
Private Bag 11 222, Palmerston North 4442
Email: J.B.Carryer@massey.ac.nz
Phone +64 6 356 9099 ext 7719

Second Supervisor
Dr Jill Wilkinson, Senior Lecturer,
School of Nursing
Massey University
Private Box 756, Wellington
Email: j.wilkinson@massey.ac.nz
Phone +64 4 8015799 ext 6639

Thank you for taking the time to consider participating

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

Free phone: 0800 555 050 Email: advocacy@hdc.org.nz

Appendix five: Consent forms for patient, GP and PN participants

Consent form for patient participants

Living with multiple long-term health conditions

Massey University

Te Kunenga ki Pürehuroa

Consent form for patient participants: Living with multiple long-term health conditions

I have read the information sheet inviting me to take part in this study and understand the details of the study.

My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand taking part in this study is voluntary (my choice) and I understand that I have the right to withdraw from the study at any time, or to decline to answer any particular question and it will not affect my health care.

I give my General Practitioner (GP), Dr. ………………….. permission to talk to the researcher, Helen Francis, about my health conditions and how I cope with them, and permission to allow her to access data from my notes just about my number of hospital admissions and GP/nurse visits.

I agree to the use of a digital recorder but I have the right to ask at any time to have it turned off or to have any or all of the recording deleted if after further thought I am not happy.

I have had time to consider whether to take part.

I agree to provide information to the researcher on the grounds that it is completely confidential. The means of protecting my confidentiality has been explained to me: the only exception is that if I tell the researcher something that show's my health is in danger, she will discuss with me how to tell my GP about it, in the interests of my well-being.

I wish/do not wish to have a copy of the interview returned to me.

I …………………………………………………….. agree to take part in this research under the conditions set out in the Information Sheet.

Project explained by **Helen Francis**

Your signature ……………………………… Signature………………………………

Date…………………………………… Date……………………………………

Could you also please answer these few questions?, as I would like to get a mix of people taking part in my research.

Name	
Address	
Phone number	
Ethnicity	
Age	
Sex	**Male Female**
Which of these Long term health conditions do you have – please circle	
Diabetes	**Yes No**
Chronic obstructive pulmonary disease/ emphysema / chronic bronchitis	**Yes No**
Cancer	**Yes No**
Depression	**Yes No**
Arthritis or gout	**Yes No**
Have you had?	
A heart attack/angina	**Yes No**
A stroke?	**Yes No**
Anything else I've missed out?	
Who is your GP?	**Doctor**

Researcher's Contact number: 835 4537 or 021 404 146

Massey University

Te Kunenga ki Pürehuroa

Consent form for GP participants

Living with multiple long-term health conditions

I have read the information sheet for volunteers taking part in this study and understand the details of the study.

My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to the use of a digital recorder but I have the right to ask at any time to have it turned off or to have any or all of the recordings deleted if after further thought I am not happy.

I agree to provide information to the researcher on the grounds that it is completely confidential.

I wish/do not wish to have a copy of the interview returned to me.

I ………………………………………………………….. agree to take part in this research under the conditions set out in the Information Sheet.

Your signature …………………………   Project explained by **Helen Francis**

Date…………………………………… Signature………………………………

Date……………………………………

Researcher's Contact number: 835 4537 or 021 404 146

Massey University

Te Kunenga ki Pürehuroa

Consent form for Practice Nurse participants

Living with multiple long-term health conditions

I have read the information sheet for volunteers taking part in this study and understand the details of the study.

My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to the use of a digital recorder but I have the right to ask at any time to have it turned off or to have any or all of the recordings deleted if after further thought I am not happy.

I agree to provide information to the researcher on the grounds that it is completely confidential.

I wish/do not wish to have a copy of the interview returned to me.

I ………………………………………………………….. agree to take part in this research under the conditions set out in the Information Sheet.

Your signature …………………………   Project explained by **Helen Francis**

Date…………………………………… Signature………………………………

Date……………………………………

Researcher's Contact number: 835 4537 or 021 404 146

Appendix six: Data collection schedule

Month/ year ⇒ Name ⇓	3/12	4/12	5/12	6/12	7/12	8/12	9/12	10/12	11/12	12/12	1/13	2/13	3/13	4/13	5/13	6/13	7/13	8/13	9/13	10/13	11/13	12/13
Tane	PTIV1	GPIV PC1	PC2	PC3	PC4	PC5	PC6	PC7	PC8	PC9	PC10 PC11	PC12	PC13	PC14	PC15	PC16 PNIV	PC17	PC18	PTIV2			
Diane		PTIV1 GPIV	PC1	PC2	PC3	PC4	PC5	PC6	PC7	PC8	PC9	PC10	PC11	PC12	PC13	PC14	PC15 PC16	PC17	PC18	PTIV2		
Rawiri			PTIV1 GPIV	PC1	PC2	PC3	PC4	PC5	PC6	PC7	PC8	PC9	PC10	PC11	PC12 PNIV	PC13 PC14	PC15	PC16	PC17 PC18	PTIV2		
Beth			PTIV1	GPIV PC1	PC2	PC3	PC4	PC5	PC6	PC7	PC8	PC9	PC10	PC11								
Eva				PTIV1 GPIV	PC1	PC2	PC3	PC4	PC5 PC6	PC7	PC8	PC9	PC10	PC11	PC12 PC13	PC14 PNIV	PC15	PC16	PC17	PC18	PTIV2	
George					PTIV1	GPIV PC1	PC2	PC3	PC4	PC5	PC6	PC7	PC8	PC9	PC10	PC11	PC12 PNIV	PC13	PC14 PC15	PC16	PTIV2	
Yvonne						PTIV1 GPIV	PC1	PC2	PC3	PC4 PC5	PC6	PC7	PC8	PC9	PC10 PC11	PC12 PNIV	PC13	PC14	PC15	PC16	PC17	PTIV2
Huia							PTIV1 GPIV	PC1	PC2 PC3	PC4	PC5	PC6	PC7	PC8	PC9 PC10	PC11	PC12	PC13	PC14 PC15	PC16	PTIV2	

Key:
PTIV1: Patient participant first interview
PTIV2: Patient participant second interview
GPIV: General Practitioner interview
PNIV: Practice Nurse interview
PC#: Phone call and number

Month/ year ⇒ Name ⇓	3/12	4/12	5/12	6/12	7/12	8/12	9/12	10/12	11/12	12/12	1/13	2/13	3/13	4/13	5/13	6/13	7/13	8/13	9/13	10/13	11/13	12/13
Aroha						PTIV1	GPIV PC1	PC2	PC3	PC4 PC5	PC6	PC7	PC8	PC9	PC10 PC11	PC12	PC13	PC14	PC15 PC16	PC17 PTIV2		
Tamati						PTIV1	GPIV PC1	PC2	PC3 PC4	PC5	PC6	PC7	PC8	PC9 PC10	PC11	PC12	PC13	PC14 PC15	PC16	PC17	PTIV2	
Wiremu						PTIV1	GPIV PC1	PC2	PC3 PC4	PC5	PC6 PC7	PC8	PC9	PC10 PC11	PC12	PC13	PC14	PC15 PC16	PC17	PC18 PTIV2		
Losefo							PTIV1 GPIV															
Lou						PTIV1	GPIV PC1	PC2	PC3	PC4	PC5	PC6	PC7	PC8	PC9 PC10	PC11 PNIV	PC12	PC13 PC14	PC15	PC16	PC17	PTIV2
Margaret							PTIV1 GPIV	PC1 PC2	PC3	PC4	PC5	PC6	PC7	PC8	PC9	PC10 PNIV	PC11 PC12	PC13	PC14	PC15	PC16	PC17 PTIV2
Hayley							PTIV1 GPIV	PC1	PC2	PC3	PC4	PC5	PC6	PC7	PC8	PC9 PNIV	PC10 PC11	PC12	PC13	PC14	PC15	PC16 PTIV2
Paul								PTIV1	GPIV PC1	PC2	PC3 PC4	PC5	PC6	PC7 PC8	PC9	PC10	PC11 PC12	PC13	PC14	PC15 PC16	PC17	PC18 PTIV2

Key: PTIV1: Patient participant first interview
PNIV: Practice Nurse interview
PTIV2: Patient participant second interview
PC#: Phone call and number
GPIV: General Practitioner interview

Appendix seven: Musings from participant Diane

Diane started our first interview by telling me I was asking the wrong question. I was privileged to have her as a participant as her way of thinking about, and reflecting on, her lifetime of multiple significant long-term health conditions enhanced and challenged my data collection and my thinking. Here is one of her emails, which I felt more than worthy of reproducing in its entirety here.

How would I best be served in the health system?

That is not directly the question as first asked but I have reflected and thought and analysed my relationship with the health industry through the years. *I have realised*:

I have had health concerns since birth. My first remembered doctor's visit was when I was 3. The doctor came to our home on a Sunday afternoon so my parents must have been worried. My first hospital stay was at 5, in for three weeks with concussion caused by falling backwards on to a kerb in the school playground.

Many memories are painful; I had asthma and eczema together or separately all my life. As a child and right through to my early 30's my eczema could be infected. I have had severe allergic reactions, some life threatening. I realise now having these conditions affected my life and how ignoring them and trying to keep up with a normal life had equal effect. I have many times shouldered the blame for my conditions when it was not necessary to do so. The times when I think that and the stories I could tell are numerous but one must live in the present.

I have been hospitalised 11 times – plus giving birth to two babies. After the second child I suffered from post natal depression, however some of this was because my husband and I had our four parents die within two years, so there was some grief in there. Can't imagine how many doctors I have seen but when I went through the breast cancer year I counted the number of people who saw my naked chest. I got to 290 before I gave up. I had radio and chemotherapy part of which were together. Five hospital trips were with the cancer two for breast surgery, two were during chemotherapy. I had severe radiotherapy burns, treated with difficulty because of the chemo complications and one the following year with an arm infection. I have had three bone breaks, two hand traumas and one leg break, and I survive. I have had two near death experiences, one with asthma and one during surgery. I lost the sight in one eye as a result of undiagnosed keratoconus. I am seriously overweight and last year I was diagnosed with Type 2 diabetes. All this is why my health goal is to live until I die.

For thirty years I worked in not for profit development and volunteer roles at all levels. I was asked to take on a national resourcing and development role, work that involved travelling up and down New Zealand and on several occasions to Australia. It took its toll. I have just resigned after tutoring level 3 papers by distance after 18 years. All the time I was completing my own education part-time and by distance. I finished at Master's level.

I have been married for 44 years; have two adult children happily with partners and two grandchildren. Four and a half years ago we moved [here], to grow a garden and lead the simple life. For the most part it is working. Two magic things happened. Within three weeks of being here all my eczema was gone as a result of the water purity of the region. Secondly I went to an optometrist who had solutions to my sight problems and I have stronger sight in the one eye and can return to doing many activities I thought long gone. The clearer light … also helps. I am now 66 having lived longer than at times I have ever imagined possible.

Of course there is so much more to life than this. Health and daily work may be the warp threads of my life, but it is the weft threads, which make the cloth and the colour of life.

I have always been a reader and a book lover. When I was put to bed with asthma (how times have changed) my mother would organise a large pile of books to keep me quiet.

As a child I wanted to be a teacher, a florist or a writer. And in fact I have managed all three in different ways. My NGO work was in a training and education role, working with distance education and life long learning. I have a passion for reading and learning. I revel in the fact that there is a lot more to learn in life and in the gift to the world of internet, so I can be at home and have access the whole world. When my children were small I went to gardening and floral art classes and have continued my love of flowers and passion for the garden.

I have five key activities, which are my weft threads.

Family and Friends: We have family in Auckland and Wellington, two adult children with partners and three small grandchildren. We travel to see them and talk to them regularly. They are a key reason for keeping as well as we can. I believe in the importance of friends and in networking. It was very quiet when we arrived here but five years on we have good friends and in fact our phone goes more often here than it did in Auckland. I also keep in touch with lifelong friends by phone. We have had a number of friends come from out of town and spend the day, or sometimes a night or two with us. I am now engaging in writing and researching family history – the ultimate detective story.

Writing: I have written forever, ever since I read Little Women and Jo's Boys as a life beyond my bed. I freelanced for the local paper while the children were little. I took to academic work like a duck to water but it was always tempered by my health. Everything I did was by distance or piecemeal. Still I managed two degree papers from Massey and embroidery courses from Correspondence school as the start. My academic work culminated in a Masters Degree and in the writing of two distance study courses.

I discovered a love of poetry and began to write poetry. I now write a 500 word column monthly on spirituality "from my Backyard." My teaching has now morphed into writing. As well as writing family history I would like to put my poetry into a book, I published one in 1998. I have two other projects. I also draw and paint so plan illustrations. I have always loved photography, so taking, editing, storing and using photos is part of this. I love the catch of research.

Gardening: We came (here) to plant a new garden. We have a quarter acre of beautiful soil and make full use of it. We grow vegetables for the table and flowers because we love them and can grow many things we never did in Auckland. I grow herbs and dry them when I can. We have dahlias in mass and I enjoy propagating cuttings, which is something I can do when energy flags. We have fruit trees. We love the garden for working, sitting, resting and reflecting in and being an exciting but familiar place for the grandchildren to come on holiday. It has a deeper meaning for me, working to be self-sustaining and kind to the planet. It is a place of the spirit which is our small piece of the planet to treat kindly. Growing our own produce is a key part of our health and well-being.

Sewing and craft: I have sewn since I was 5. I embroider, sew clothes and make plain quilts, make rag dolls and whatever else takes my fancy. I knit and crochet. I gave up all of these things in the 1990's because of my eyesight but with good glasses and the good clear light I am thoroughly embracing the return to almost lost skills. I am now preparing for a craft stall.

Looking outward.

One cannot give up thirty years of community and professional development cold turkey, although coping with ill health means that some times seems how it must be. There are many things I would love to be involved in but turn my back on. At least I have come to see this sensibly. I could walk away knowing I have done well but the still small voice knows if I wanted it there would be another project. I have definitely decided I have spent so many hours in meetings in my life I have no desire to ever go to a business or committee meeting again. However, not being able to keep my hand off the community wheel, after a struggle I found two things which helped me enormously. I am a Caring Caller for St Johns, with two people to ring, one every morning at 9 and one once a week in the evening. It's a long term commitment of friendship. I also put out some feelers and began a neighbourhood support group in our street. That is going well and lots of volunteers have come forward to organise lunches etc.

The difference between the health service and the rest of life is very clear. Health stuff can be documented and itemised and categorised. But those aspects which serve as the weft threads can be described and discussed and some bits can put into a CV there is a style of living rather than events and as in a weaving the unhidden back bits are just as important.

What do I want from the health system currently geared to acute medicine?

- I want information.
- I want peer support.
- I want nurses trained in strategic questioning. Without a robust understanding of good questions by the practitioner an authoritative guilt creating relationship can develop with apparent non-compliance of the patient.
- I want to be treated like an intelligent person who in spite of being over weight, asthmatic, diabetic, arthritic, short sighted human, can and has been self aware and self caring for a long time.
- I want data based health care plans, that is based on my results and life style not community statistics.
- I want recognition that one cure doesn’t work for all and for recognition that multi chronic conditions brings its own challenges and do not always fit a basic plan or goal setting exercise.
- E.g. I have four conditions that interact

o Tell me to exercise and I have to take into consideration, asthma, allergies, eye sight and arthritis, and that is before one might flare up. Go for a walk – is the footpath even – no tripping and jolting no things I will not see, is the wind blowing, is there space to take a breather. These are not excuses they are the challenges I face. Sometimes I need to choose rest or exercise and some exuberant health worker will suggest the other without knowing the full person. Saying “yes, but” is not always a denial it is an invitation I give to help me find a solution.

- Last year I seemed to have so much health advice that had I followed it all I would have left no time for the activities, which excite and energise me and to some degree had money to the budget.
- I want a health system that does not assume. Just because I am designated retired it doesn’t mean I have free time for you all to fill. I have never been asked how much time I can give to any particular activity.
- I want some way in which my financial circumstances can be addressed sensibly

- I want recognition that the usual helpful systems may not work, I attend a COPD support group, but I am not able to attend diabetes or arthritis groups because of this, it’s a matter of time.
- I want recognition and, ideally, work done on the black holes of the multi chronic state. What happens in the spaces between each disease symptom? What plays against each other and what helps each other? Food and comfort are important but often “healthy diets” are full of allergy bombs.
- I want access to adequate health care based on personal situations not on demographics. I could not access free insulation or dietitian in spite of having a year of little income because we live in a better suburb.
- I want a change of language, ditch the pc words, and speak in a way which provides a grace filled service giving consideration to heart, mind, soul and strength. E.g. I decided to work on movement rather than exercise. There is significant work being done on spirituality in the health service.
- I am totally committed to scientific modern medicine but do you know in all the years I have had lung problems no one has ever said that the very best way to clear your lungs is by laughing and singing.
- I do not want to tell my story over and over again.

When I started to answer this question I swung into the classic community development mantra of analyse, educate, mobilise. I thought of a single unit to deal with the issues. From my research, my experience plus some reading I came to appreciate that the Care Plus scheme is a good model if well staffed.

There is significant research on the issue, a review of the Care Plus scheme in 2006 indicated that the heart of the programme was well trained nurse practitioners. I also discovered a scheme for patients to have a health passport which they would have with them at all times. I fully understand that these schemes are particular models with attached funding. Sometimes it is hard to see which comes first the care for the patient or the distribution of funds.

Two final thoughts.

Maybe Care Plus would work better if one of the year’s appointments was with a specialist nurse practitioner, bringing all those ‘black holes’ together. I am not surprised that Māori Health initiatives have been developed. I believe the items I have expressed as wanting are well represented in that setting. Traditional medicine starts with the science and in time will move to the lifestyle and not very often the spirit, Māori medicine starts in the opposite direction. Spirit, life and, if necessary, treatment.