Exploring the meaning of cardiovascular disease with Māori men

A thesis presented in partial fulfilment of the requirements for the degree of

Master of Science

in

Health Psychology

at Massey University, Albany,

New Zealand

Samantha Lisipeki

2019

Abstract

Ethnic disparities in health outcomes are an ongoing concern in Aotearoa/New Zealand. These disparities are particularly pronounced between Māori and non-Māori, and are especially apparent for cardiovascular disease (CVD). Despite these well-known disparities, research into how the social determinants of health manifest in the context of Māori people's everyday lives and experiences of CVD is limited. Using a narrative approach, this research documents Māori male patients' experiences of CVD within the context of everyday life. Four Māori males who have experienced cardiovascular care were recruited through the Waikato District Health Board secondary prevention service. The patients and their whānau (family) who wished to participate were engaged in three separate semi-structured interviews which explored topics involving their CVD diagnosis, experiences of CVD, their steps to accessing care and experiences of care. Overall, the cases revealed three key findings. First, various factors work in concert to influence participant access to cardiac care, which extend beyond individual decision making (such as structures of everyday life and resources). Second, there is considerable diversity in participant life circumstances, which are related to their experiences of care and its outcomes. Third, CVD impacted the lives of my participants differently and contributed to varying levels of illness disruption to their life narratives. This study contributes to a growing body of knowledge for addressing disparities in health outcomes between Māori and non-Māori.

Acknowledgements

Firstly, I would like to express how grateful I am for my academic supervisors Professor Darrin Hodgetts and Dr Bridgette Masters-Awatere. Darrin, thank you for making sense of my drafts, your constructive feedback, always challenging my thinking and providing some humour along the way. Bridgette, thank you for walking alongside us in this project and for providing important cultural guidance and ongoing support. I also want to thank Byron Perkins for sharing your heart story with me and providing cultural feedback in support of this research.

I would also like to thank the partners in this project, the Waikato District Health Board. I want to especially thank Dr T.V. Liew for helping craft this project and your collaborative approach to this research. I want to thank the Cardiac Rehabilitation Nurses for your enthusiasm and assistance in recruiting participants. Cate Shepherd, thank you for your ongoing support in this project despite your busy schedule, and sharing your stories and knowledge with me.

I would like to thank Betty (mum) and Mike, for providing a place for respite and a home-cooked meal throughout this journey. Thank you to my siblings and wider family and friends for your unwavering support. Your collective words of encouragement mean the world to me. To my husband Jay Lisipeki. I am very fortunate to have such a supportive and accepting husband like you. You have been there every step of the way and I appreciate you more than you know.

Lastly (and certainly not the least), I want to express my gratitude to the Māori men and whānau who welcomed me into their homes and shared their stories of illness with me. This thesis would not have been possible without you. You have not only shaped this thesis but have also contributed to my understanding of myself as a researcher. You have taught me much that is not documented in this thesis and I am forever grateful for these learnings.

Table of contents

Table of figures

CHAPTER ONE

Introduction

Ethnic disparities in health outcomes are an ongoing concern in Aotearoa/New Zealand and other countries subjected to colonisation (Fariba, Forouz, Kyoung, & Sangita, 2015; Gracey, 2014; Miner-Williams, 2017). The developments associated with colonisation varies across countries however, it often involves the arrival of a new group that subsequently leads to the suppression and dislocation of pre-existing indigenous peoples (Hodgetts et al., 2010). The related processes of colonisation have generated a long withstanding impact on indigenous peoples and their health. The adverse impact is evident today by the persistent health disparities between indigenous and non-indigenous peoples (Gracey, 2014). Disparities in health outcomes refer to the disproportionate burden of disease across certain ethnic groups where indigenous peoples appear to be overrepresented in negative health outcomes (Zambas & Wright, 2016). These trends are evident across nation states for example, Aboriginal and Torres Strait Islander health in Australia has worsened in areas over recent decades with an increase in chronic diseases such as diabetes, cardiovascular disease and kidney disorders (Gracey, 2014). In Canada, First Nations people experience life expectancy twelve years below the national average and are documented as having a higher rate of preventable chronic diseases than non-indigenous Canadians (Fariba et al., 2015). The impact of colonisation on Māori health has been vast and will be discussed further in my thesis (Miner-Williams, 2017; Pool, 2016).

As discussed by Durie (1998), various health reports began to surface from the 1950s which illuminated the state of Māori health. In 1980, Eru Pomare, a grandson of Māui Pomare who was the first Māori medical officer in New Zealand, compiled a health report from hospital sources which provided an overview of Māori health (Durie, 1998; Pomare, 1980). The report underlined the fact that although Māori life expectancy had dramatically improved between the years 1955 to 1975, significant disparities between Māori and non-Māori existed across most disease categories. Additionally, the pattern of disease was changing with a reduction in infectious diseases and an increase in degenerative diseases (Pomare, 1980). Eru Pomare's second report which examined statistics between 1970 and 1984, showed further improvements in Māori health though, disparities were growing in other areas including psychiatric admission and chronic illnesses (Pomare & de Boer, 1988).

Similar trends were noted in the 'Decades of Disparity' report released by the Ministry of Health in 2003 (Ajwani, Blakely, Robson, Tobias, & Bonne, 2003). The report presented the mortality rates and life expectancies during the 1980s and 1990s and pointed out concerning disparity patterns. For instance, the report noted the only slight (if any) decline in mortality rates for Māori and Pacific peoples over these two decades despite a continual decline in non-Māori and non-Pacific rates. Moreover, despite a rapid decline in cardiovascular mortality for non-Māori and non-Pacific groups, the decline in Māori and Pacific rates were much slower (Ajwani et al., 2003). The discussed reports highlight disparities in health outcomes between Māori and non-Māori is not a new issue in New Zealand and has remained constant.

As touched on previously, these health disparities are keenly apparent when examining particular conditions such as cardiovascular disease (CVD) (British Heart Foundation, n.d.). CVD is an umbrella term encompassing all heart and circulatory diseases. It includes (however is not limited to) angina, congenital heart disease, ischaemic heart disease, heart attack, hypertension, stroke and vascular dementia (British Heart Foundation, n.d.). The different CVDs pertain to various areas of ailment in the body and associated processes which are often linked. Several terms can be used to describe the same ailment for instance; coronary heart disease, coronary artery disease and ischaemic heart disease are terms used interchangeably (Dr T.V. Liew, personal communication, May 09, 2018). These various terms have been used across the current literature. In New Zealand, ischaemic heart disease (IHD) accounts for a high rate of CVD mortality (OECD, 2015). IHD is when the coronary arteries supplying the heart with oxygen become narrowed by a gradual build-up of atheroma (fatty deposits) on the inside of artery walls, which can restrict the delivery of oxygen-rich blood to the heart. IHD is often a precursor to other CVDs including angina and heart attacks (British Heart Foundation, n.d.).

The ongoing issue of health disparities between Māori and non-Māori provides the purpose for the current study. The following sections offer further context surrounding the focus of this research in CVD and Māori men in particular. Within the last two decades, the evidence suggests disparities in CVD outcomes have remained persistent overtime in New Zealand. For instance, Tobias and colleagues (2009) examined the burden of coronary heart disease (CHD) in Māori by making population-based estimates for the period 2000-02 using various sources of hospital and public data. The analysis revealed Māori had higher CHD incidence rates, prevalence, case fatality and mortality than non-Māori (Tobias et al., 2009). More specifically, Māori males had a substantially higher case fatality rate than non-Māori males whereas, the difference in case fatality between Māori female and non-Māori female was moderate (Tobias et al., 2009). Relatedly, a data-linkage study examined ethnic differences in case fatality following an acute IHD event in 35-84-year-olds between 1 December 2008 and 1 November 2010 (Grey et al., 2016). A total of 26,885 IHD events were recorded and the results illustrated Māori had higher death rates than non-Māori groups. The study showed a higher rate of Māori people died within 28 days of an IHD event compared to non-Māori. In addition, the odds of death for Māori was still higher than non-Māori after adjusting for potential confounders (Grey et al., 2016).

In succeeding years, Ministry of Health (2015) statistics from the period 2010-2012 also illustrate disparities in CVD outcomes. For adults over 35 years of age, the mortality rate of IHD per 100 000 was 154.6 for Māori compared to 72.1 for non-Māori (Ministry of Health, 2015). The rate for stroke mortality and heart failure per 100 000 was 48.2 and 5.2 for Māori, compared to 30.9 and 2.2 for non-Māori respectively. The total cardiovascular mortality per 100 000 for Māori was twice as high with a rate of 286.8 compared to 132.4 for non-Māori (Ministry of Health, 2015). Further, available statistical evidence indicates that Māori males fare worst in cardiovascular outcomes than other groups. The rate of CVD mortality per 100 000 for Māori males over 35 years of age was 346.9, compared to 168.2 and 232.3 for non-Māori males and Māori females respectively (Ministry of Health, 2015). Moreover, despite their visible need, there are concerns Māori may not be accessing healthcare services for cardiac concerns.

Māori are underrepresented in terms of hospital presentation for treatment of acute coronary syndromes (ACS). The study by Grey et al. (2016) found Māori formed only 11.3 percent of the ACS population from 2008 to 2010, whilst during this period the Māori population according to 2006 and 2013 census data ranged between 14.6 percent and 14.9 percent respectively (Grey et al., 2016; Statistics New Zealand, 2006, 2013b). More recently, in the Waikato District Health Board (DHB) during 2016-2017, only 8.9 percent of patients being referred onto the secondary prevention service identified as Māori, whilst according to DHB data, the population of Māori in the Waikato DHB catchment was 22.9 percent for the same period (Dr T.V. Liew, personal communication, March 27, 2018; Statistics New Zealand, 2013a). The same DHB data also indicated, Māori were likely to have more advanced disease at presentation with a higher proportion (28.8 percent) requiring bypass operations than Europeans (20.2 percent) (Dr T.V. Liew, personal communication, March 27, 2018). The underrepresentation of Māori in hospital treatment and presentation with more advanced disease suggests there may be significant inequities faced by Māori in accessing cardiology services. These inequities may operate at different levels of both the service and personal life.

The differential access to material and structural resources imperative for health such as housing, income and education can be connected to CVD risk factors including smoking, dietary intake, obesity, diabetes and high blood pressure (Curtis et al., 2010). The study by Grey et al. (2016) highlighted the uneven distribution of socio-economic determinants of health among IHD patients. The study found 20 percent of non-Māori patients resided in the most deprived neighbourhoods compared to over 50 percent of Māori and Pacific patients. The study illustrated interesting patterns between higher case fatality of IHD and economic deprivation (Grey et al., 2016).

With majority of research focussed on ‘indicators’ of deprivation, less is known about the experiences of material and structural constraints and how such social determinants of health manifest and interact with Māori people’s everyday lives. These constraints may not only be contributing to worse CVD outcomes for Māori. They maybe influencing access to care. Considering the broader factors potentially impacting Māori people’s access to cardiology care invokes the need to turn our attention to understanding illness within people's everyday lives. The need to shift our attention is because experiences of illness do not occur in isolation or separate from one's situation or circumstances. In actuality, certain actions such as seeking healthcare services may need to be considered and negotiated with other aspects of everyday life (Radley, 1993).

To improve CVD outcomes for Māori, some attention must be paid to the perspectives of Māori who have experienced CVD and related cardiology services. In particular, the high mortality rate of CVD for Māori males supports the need for research focussed on this group (Ministry of Health, 2015). Upon examining the available research, there appears to be a gap in our knowledge surrounding Māori male experiences of CVD and access to related services in the context of their everyday lives. This thesis takes steps to address this gap by examining the understandings Māori male patients have about CVD and taking into consideration the perspectives of whānau (family). Attention will be given to the narratives Māori have created for their experiences of CVD and how this informs their responding actions to cardiac events and their engagements with health services. Central to this thesis will be the meaning of CVD and its related consequences and constraints in the context of conducting everyday life. Exploring the 'meaning' of CVD involves going beyond strictly medical terms and extending the focus to how CVD enters the lives of patients and their families (Radley, 1993). The described focus reflects the importance of understanding responses to illness in the context of personal circumstances and cultural background.

For the remainder of this chapter, I delve into the background material leading to the focus of my thesis. I briefly consider the history of colonisation and draw links to how various events during the nineteenth century impacted Māori health. Exploring the history will provide some context surrounding how health disparities materialised between Māori and non-Māori. I then consider tensions between various understandings of health and how indigenous understandings align more so with concepts of illness than disease. I introduce theories of illness as an experiential and inherently social response to disease within everyday life. I then discuss how disparities in health outcomes are maintained in the form of barriers to accessing healthcare for indigenous peoples, where I draw on research from Aotearoa and abroad. The discussion of various barriers leads to the realisation the available literature pays limited attention to accessing healthcare services within the context of everyday life, which is the focus of the current study. Before continuing to the discussion of colonisation, I want to establish that when I refer to 'Māori' in discussion, I do not intend to discuss Māori as a homogenous group. I understand much diversity exists within and across Māori communities and some topics of discussion may not be applicable to all Māori (*cf.*, Durie, 2001).

A history of colonialism and Māori health

The importance of discussing colonisation and its significance towards health disparities lies in the need to acknowledge the changing conditions Māori peoples have experienced across generations and how this has impacted their health. Discussing the historical connections to health disparities is key as these connections are not often shared within public domains. Instead, stories shared by dominant outlets such as the media can become taken-for-granted knowledge and these perspectives can be misleading and ill-represented (Hodgetts, Masters, & Robertson, 2004). Settler society corporate news media have been implicated for some time in the framing of Māori health as more the product of a lack of personal virtue amongst Māori people in taking care of their own health than as a product of continued processes of colonisation (Hodgetts et al., 2004). I hope to share with others that disparities in health outcomes involves more than individual action and direct one's attention to the historical events which have helped shape the current climate.

It is crucial that in working to address disparities in health faced by Māori, that we foreground how with colonisation, the introduction of diseases, the effect of human activities, the loss of land and ongoing political struggles have all impacted Māori health (Durie, 1998). The colonisation of Aotearoa by the British is embroiled within a complex history entailing many events to which I only provide a small snippet. I draw mostly from Durie (1998) because of his focus on historical developments and its impact on health. I also recognise other historical perspectives exist (Oliver & Williams, 1981; Pool, 2015), some of which may not be formally documented as of yet. In this context, particular nineteenth century developments had significant health consequences for Māori that continue to impact people today. Let us begin with the introduction of foreign diseases.

Infectious diseases existed in New Zealand before European contact. Such infectious diseases were often managed by Māori communities through practices of isolating the ill to reduce the spread of disease, and to protect the health of other tribal members (Durie, 1998). However, when viral diseases that were considered minor ailments in Britain, including measles, mumps and influenza were introduced into New Zealand, they had devastating impacts on Māori (Parsonson, 1981). In addition, Māori had trouble accessing European healthcare services which were predominantly designed to cater for European settlers. A lack of healthcare access forced Māori to cope with diseases for which they had no previous knowledge (Timu-Parata, 2009). Accompanying the impact of disease, certain developments over the nineteenth century dismantled the economic and social life of Māori which increased Māori people's susceptibility to illness and mortality (Durie, 1998). I outline several of these developments in the following sections.

Utilising traditional forms of knowledge and skills is important to health for Māori and their conduct of everyday life. Acknowledging this also avoids us considering issues of health and illness in isolation from the wider cultural, social, intergroup, and economic environments

(Durie, 1998; Lyons & Chamberlain, 2006). With the arrival of British settlers, Māori traditional forms of knowledge were beginning to be replaced and challenged as opposed to enhanced, which impacted how they conducted daily activities within their communities (Durie, 1998). For instance, the strategic location of pā sites (fortified villages and stockades) in the hills was important for the Māori public health system. In the 1820s, many Māori relocated from the hills to coastal areas to gain better access to trading opportunities with the settlers and to reduce their vulnerability to gunfire (Durie, 1998). Evidently, new pā sites were established that contradicted Māori ways of managing health (Timu-Parata, 2009). Many amenities often essential to pā sites including clean water, sanitation and drainage were absent (Durie, 1998). There were also issues with new homes being poorly ventilated, damp and overcrowded, and often residing in swampy areas (Timu-Parata, 2009). Such moves also involved a lifestyle change for Māori of less physical work from not residing in the hills and eating different foods including sugar, tea, flour and potatoes (Durie, 1998). In this context, the new pā sites created various health risks for Māori and reveals how developments surrounding colonisation stimulated Māori to defy well-established forms of knowledge to the detriment of their health. Furthermore, moving away from hinterlands and various forms of land alienation had consequences for Māori health and development (Pool, 2015).

At the end of the nineteenth century, the extent of land owned by Māori had diminished to less than twelve percent of what they possessed in 1840 (Durie, 1998). Tribes who decided to sell land or lost land through colonising processes suffered a precipitous decline in numbers. The loss of land contributed to the Māori population fluctuations during the nineteenth century (Pool, 2015). Moreover, certain law changes including the Native Lands Act (1865) along with the amended Native Land Act (1873), worked in favour of the settlers and to the detriment of Māori through individualising land processes (Ministry of Culture and Heritage, 2016). Consistent reports advocate the law was fabricated to support quicker land sales by avoiding the resistance of collective Māori groups (Ministry of Culture and Heritage, 2016; Pool, 2015).

The political processes and practices to remove land from Māori impacted their health. Transferring land to settlers meant the loss of imperative resources of cultivated land; uncultivated land used for hunting and birding; and limited access to swamps and lakes for fishing and collecting water species (Pool, 2015). The transferring of land resulted in Māori losing key assets that underpinned the Māori economy and inevitably contributed to their underdevelopment (Pool, 2015). Moreover, the disconnection of Māori from their land was significant as land was essentially part of one's internalised identity. Land provided people with a material past, a tūrangawaewae (a place to stand), and a place for people to feel secure and supported, indicating land alienation extended beyond material effects (Durie, 1998). Moreover, these negative processes were permitted to occur with little effective intervention from the government (Pool, 2015).

The signing of the Treaty of Waitangi in 1840 represented British officials and Māori chiefs entering a political agreement or pledge to found a nation state and form a government in New Zealand to manage the pressing new conditions (Ministry of Culture and Heritage, 2017a). The Treaty is a founding document in New Zealand and involves a broad statement of principles and an exchange of promises between two parties. The translation of the Treaty of Waitangi from English to Māori language resulted in the interpretation and use of terms encompassing different meanings which created dissimilar expectations between the settlers and Māori (Ministry of Culture and Heritage, 2017a). The misinterpretation and plain disregard of the Treaty principles by settlers has had implications for Māori health. Part of the Treaty's intentions was to protect and maintain the wellbeing of all peoples through processes of good government, equity and participation (Ellison-Loschmann & Pearce, 2006). The rising disparities in health outcomes show the failure of the British government to uphold the rights of Māori and provide the protection they were guaranteed under the treaty (Ellison-Loschmann & Pearce, 2006).

The brief overview of certain historical developments over the nineteenth century provides some context to the emerging health disparities in New Zealand. The introduction of infectious diseases was not the only destructive occurrence. Colonisation also induced a loss of land, spiritual disconnection and unjust political processes which impacted the health of Māori (Durie, 1998; Pool, 2015). The disparities in health outcomes are entrenched within our history, and the affliction on Māori from the arrival of European settlers is still felt today (Miner-Williams, 2017). Similar patterns have been noted for Aboriginal Australians where indigenous customs and behaviours were suppressed through the introduction of unfamiliar and ill-understood regulations by settler society (Gracey, 2014). The imposed changes on Aboriginal Australians has too, had a detrimental impact on health outcomes.

In accounts devoid of this history of colonisation and its compounding effects, Māori are often accused of making poor lifestyle choices in relation to the development of CVD. However, lifestyle choices such as physical activity cannot explain the health disparities between Māori and non-Māori (Ross & Hamlin, 2007). Instead, processes of colonisation underlie the present precarious position of many Māori (King, 2017). For instance, the loss of land and associated resources has had economic repercussions for Māori. Many people were driven into urban areas in the 1950s with lower prospects and irregular working opportunities amid the changing economic environment (Durie, 2001). The limited opportunities afforded to Māori influenced their higher representation within the low-income group and a higher rate of Māori living within deprived areas (Durie, 1998, 2001).

Having low socio-economic status increases one's prospects of being exposed to added risk factors for a range of ailments, including CVD (Ellison-Loschmann & Pearce, 2006; Miner-Williams, 2017). The day-to-day living patterns comprised of inadequate exercise and poor diet are well known predisposing factors to CVD and dominant assumptions insinuate engaging in these activities are a matter of individual choice. However, although Māori and other indigenous peoples may understand the importance of a healthy diet and exercise, they may be unable to access or afford healthy foods and safe exercising environments (Durie, 2001; Gracey, 2014). The disparities in CVD outcomes between Māori and non-Māori is not easily explained by individual choice and action only. A number of inequities may exist that underline the unequal opportunities afforded to Māori to maintain their health. Such issues raise the importance of how we understand and conceptualise health and illness. This is key as it determines what factors are contemplated and reflected upon as influencers and imperative to health. Next, I consider the tensions over different understandings of health between Māori and the settler society. This will not only make clearer the impact of colonisation on Māori health. It will underline the importance of considering 'CVD as illness' for this study.

Some conceptual work: Understandings of health, disease and illness

In understanding the contemporary health experiences of Māori in the historical context outlined above, it is important to look beyond the plight of individuals and notions of 'disease'. A good place to start is with the important distinction between disease and illness (Lyons & Chamberlain, 2006). This discussion also needs to extend to Māori models of health that encompass personal, relational and contextual factors.

Notions of disease refers to the disorder or ailment within areas of the body and associated symptoms. Biomedical understandings often reduce explanations of ill-health to biochemical or physiological processes within the body (Lyons & Chamberlain, 2006). This Eurocentric approach has been criticised for some time as being overly reductionist, mechanistic, and for being narrowly focused around individual bodily functions. It has not gone unchallenged by those seeking broader and more contextually inclusive orientations to illness. For example, in New Zealand during the 1970s, some Māori health professionals began to openly contest biomedical understandings of health that were individualistic and paid little attention to the broader environment and history (Durie, 1998). Health became a topic of discussion in the 1980s on marae and at a series of hui throughout the country, the concepts of taha wairua (spiritual health), taha hinengaro (mental health), taha tinana (physical health) and taha whānau (family health) became widely recognised and favoured as conceptual elements of Māori health (Durie, 1998). These concepts have since been used in Māori models of health such as Te Whare Tapa Whā (Durie, 1998), where notions of interdependency and balance are equally vital and necessary to health. This multi-dimensional view of health made sense to Māori as it reflected what Māori valued in terms of relationality and wellness (Durie, 1998). Māori understandings of health not only makes clearer how acts of colonisation impacted Māori health with its emphasis on interdependency. It also moves away from notions of disease towards the concept of 'illness'.

Although the terms are often used interchangeably, the concept of illness differs from notions of disease outlined earlier. Illness acknowledges disease of the body occurs within a wider social and cultural context, which influences how people experience their ailment (Radley, 1993). Illness relates to the socio-cultural responses, the subjective feeling associated with disease, and these feelings are determined by how people understand and interpret their illness within the context of their everyday lives and cultural milieu (Radley, 1995). Accordingly, the holistic Māori perspective of health is more in line with notions of illness than disease. This orientation embeds the contrast between the biomedical focus on disease and indigenous health focus on illness as a broader conceptualisation that encompasses disease, human experience and context. The concept of illness emphasises disease of the body and experiences of illness do not occur in isolation from people's 'everyday life'.

The concept of everyday life is difficult to delineate when it is seen as both routine and repetitive, and both unpredictable and changeable. As outlined by Hodgetts and colleagues (2010), everyday life can be considered a 'catchphrase' to refer to the mundane actions typically carried out each day. However, the routine and flow of everyday life can sometimes be disrupted by 'extraordinary' events such as illness, job losses and exclusion, which shifts people from the ordinary and normative basis of their lives (Hodgetts, Rua, King, & Te Whetu, 2014). For some groups, living extraordinary lives that can be damaging to health is the norm. As such, engaging in mundane and ordinary activities can provide respite for those living lives perturbed with continual disruption. This is apparent for colonised groups whose everyday practices have been disrupted and reworked amidst the conditions of a settler society (Hodgetts et al., 2010). It foregrounds the importance of understanding how disruption can form the normative basis of one's life as opposed to being an acute event (Hodgetts et al., 2014).

For Māori, everyday life is often conducted in conditions not fully of one's own making and that have been established through processes of colonisation (Rua et al., In Press). The phrase 'the conduct of everyday life' originated in the work of Weber (1952), and was developed in psychology by Holzkamp (1995/2016), as an attempt to overcome the criticism that dominant approaches in psychology focus overly on individuals and did not engage adequately with how people actually go about their lives everyday beyond the laboratory. Central to this evolving approach are the relationships between persons and the broader societies within which they take shape as they actively construct their lives, often through engaging in shared everyday practices such as going to the doctor or exercising to prevent illness (Højholt & Schraube, 2016). What often seems like the engagement in mundane everyday activities, such as brushing one's teeth, preparing 'healthy' food or going for a walk contain broader significance in the reproduction of narratives regarding maintaining one's health (Stolte & Hodgetts, 2015)**.** The focus is often on such practices as reflections of broader social structures, intergroup relations and public narratives that are reproduced through these micro level practices (Teo, 2016). In other words, people's everyday acts or practices are implicated as manifestations of broader socio-political relations (King, Hodgetts, Rua, & Te Whetu, 2015). It highlights the need to acknowledge the complex and interconnected nature of everyday life and people's health.

Appreciating people inhabit different and diverse lifeworld's alludes to the significance of understanding illness in the context of people's inhabited situations (Hodgetts et al., 2010). In consideration of this, more attention is being paid to perspectives of the ill as their experiences can indicate how they understand their illness, what it means to them and how this informs various actions (Radley, 1993). To expand on the concept of illness, Bury (1982) and Radley (1993, 1995) offer useful approaches to understanding how one's experiences of illness do not occur in isolation from people's everyday lifeworld's and collective understandings.

Bury (1982) offers an understanding of chronic illness as contextualised 'biographical disruption'. This concept draws from Giddens (1979) belief that "we can learn about day-to-day situations in routine settings from analysing the circumstances in which those settings are radically disturbed…" (p. 123). Meaning, illnesses such as CVD are a major disruptive event in people's lives that emerge from the contexts of lived group histories. Illness is a type of experience where the structures of everyday life and systems of knowledge underlying these structures are disrupted (Bury, 1982). The theory acknowledges that illness causes individuals, their families and broader social networks to confront the nature of their relationships in which the normal rules of support and reciprocity are disrupted (Bury, 1982). People are said to mobilise resources and respond to the disruption. Illness as biographical disruption considers how the taken-for-granted spheres of everyday life suddenly becomes a burden of purposeful and conscious action (Bury, 1982).

Further, Radley (1993) recognises illness as a condition that often calls for a re-negotiation of one's social identity and not only something people suffer. When faced with illness, people employ various ways of coping, develop responses to illness, and pathways through it (Radley, 1995). How a person works through such situations is said to be determined by the social positioning of people and their resources. Thus, 'lay perspectives' or common, everyday understandings of illness and experiences are shaped in concert with other spheres of life (Radley, 1993). Different positionings in society may equate to the engagement and expression of particular cultural practices and necessitates situating experiences of illness within a given context (Radley, 1993; Shahid, Finn, Bessarab, & Thompson, 2009). Conceptualising illness in this way suggests that CVD may hold different meanings to people and this is influenced by their lived social, cultural and political context.

Acknowledging people live within diverse realities suggests a plurality in experiences and understandings of illness. Radley (1993) promotes understanding illness in relation to a person's own interpretations of what a disease poses to them within the context of their everyday situations. Meaning, we must recognise certain questions surrounding the experience of CVD, various actions to seeking treatment, and how it impacts everyday life, must be asked in terms of how people comprehend it as part of their own life conditions and aspirations. Ultimately, experiences of CVD are not restricted to personal interpretations of bodily sensations. They are also formed in relation to various domains of one's life (e.g., will I be able to work?) and relationships (e.g., what will happen to my children?).

Focussing on CVD as illness, enables an examination of the effects of CVD to aspects of one's 'whole' (social and emotional) life (Wissen et al., 2017), and how this influences actions such as accessing healthcare services. As mentioned previously, there are concerns Māori may not be accessing healthcare services for cardiac problems (Grey et al., 2016), or may not gain the same positive outcomes when they do access services. We now turn to understand how disparities in CVD outcomes are maintained at present through modern day practices and conditions. More specifically, I will focus on the research showing that indigenous peoples experience barriers to accessing healthcare services.

Access to healthcare services

Inequalities in access to healthcare for Māori has emerged as an important concern for health researchers seeking to address inequalities in health outcomes (Curtis et al., 2010; Davidson et al., 2012; Jeremy et al., 2010). As stated by Jeremy and colleagues (2010), the best healthcare delivery system will still fail to be effective if patients cannot access its services. Access within this context can be described in two ways of 'access to' and 'access through' healthcare services. Describing access in this respect pays attention to both whether people have the opportunity or means to access services and the quality of services being delivered (Ellison-Loschmann & Pearce, 2006). Accessing healthcare for cardiac problems is crucial since receiving prompt treatment can often determine CVD outcomes (Dracup & Moser, 1997). However, accessing treatment may not be equitable between Māori and non-Māori where Māori can experience barriers to care. Below, I briefly consider some of the available literature to provide some insight into the barriers Māori may experience to accessing cardiology services. I will engage with research within and outside the CVD context and Māori as a distinct indigenous people to draw attention to certain issues potentially relevant to Māori peoples. Important to note that where there are gaps in the literature focused specifically on Māori, I will draw insights from research with other indigenous groups facing similar inequalities in health. Our discussion here spans the personal, institutional and structural domains of society, and I begin by discussing personal barriers to care.

Personal barriers to care have been associated with a person's beliefs regarding the nature of illness and its severity as well as the efficacy of services. For example, perspectives from Māori patients with ischaemic heart disease (IHD) revealed delays in seeking healthcare due to their interpreting cardiac symptoms as other conditions, including asthma, indigestion, and ageing in general (Kerr, Penney, Moewaka Barnes, & McCreanor, 2010). Additionally, having certain expectations of cardiac symptoms was found to be a barrier towards Māori accessing care. When certain cardiac symptoms were not present, the exhibiting symptoms were believed to be non-cardiac in origin (Kerr et al., 2010). Furthermore, one’s knowledge of CVD such as identifying symptoms influenced the utilisation of healthcare services among Aboriginal Australians (Artuso, Cargo, Brown, & Daniel, 2013). Health provider perspectives have identified other personal barriers including everyday ‘whānau crisis’, patient whakamā (reticence), and the health literacy of patients (Cram, 2014).

A range of experiential factors can act as personal barriers to care. When experiencing symptoms of IHD, Māori participants reported having feelings of fear, disbelief and thoughts of not wanting to waste health professionals time, resulting in patients initially avoiding healthcare services (Kerr et al., 2010). In addition, Aboriginal Australian patients have reported feelings of fear towards healthcare services and their possible prognosis (Artuso et al., 2013). This contributed to their refusal to utilise healthcare for cardiac problems. Personal barriers provide some perspective at an individual level. However, looking beyond the individual is important to gain a fuller picture of the factors influencing access to care.

The socio-economic disparity between Māori and non-Māori is well known where Māori are over-represented in low-socioeconomic categories (Durie, 2001). Income is one factor influencing how Māori can participate healthily in everyday life where Māori families have discussed economic factors in relation to accessing healthcare services. Whilst certain disability allowances have aided access to healthcare services for some Māori families (Bolitho & Huntington, 2006), research with Māori sole mothers has highlighted even subsidised healthcare can still be too expensive to access (Lee & North, 2013). Furthermore, previous research suggests Māori can also experience environmental obstacles beyond their control to accessing healthcare. In New Zealand, structural barriers such as transport difficulties and the location or scheduling of services can work as barriers for Māori (Lee & North, 2013; Penney, Barnes, & McCreanor, 2011). Moreover, indigenous people who reside in rural areas can often be distanced from specialist cardiology services which has been documented as creating barriers for indigenous Australians (Davidson et al., 2012; Jeremy et al., 2010).

Interpersonal communication can also present barriers to accessing care. In a study with Aboriginal and Torres Strait Islander people with chronic illness (heart failure or chronic obstructive pulmonary disease), participants discussed their experiences of the negative and discriminatory treatment they had received from healthcare and public services (Aspin, Brown, Leeder, Jowsey, & Yen, 2012). These negative interactions led to feelings of frustration, sorrow and distrust. Additionally, poor communication between health providers and indigenous Australians has been noted as an impeding factor towards patients receiving good care and support

(Artuso et al., 2013; Aspin et al., 2012). Similar findings have been documented in New Zealand where health professional practices of explaining conditions using complex medical terms and not discussing medical decisions with wider whānau were considered as barriers to care for Māori patients (Kerr et al., 2010). Moreover, the study by Reid, Cormack, and Crowe (2016) found the relational continuity of care to be important to Māori patients engaging with non-Māori doctors. The study found accessing a familiar general practitioner (GP) was essential to some participants to avoid discriminatory treatment (Reid et al., 2016). It emphasises the importance of contemplating the design and delivery of healthcare services and the need to consider broader systems when understanding barriers to care.

Institutional barriers in this context refers to the policies or practices within healthcare systems and related organisations influencing access to care (Jeremy et al., 2010). As reported in Sandiford, Bramley, El-Jack, and Scott (2015), although ethnic differences in revascularisation procedures had reduced since the 1990s, when their analysis of revascularisation procedures were linked to expected need for intervention, large disparities were found between Māori and non-Māori. The findings of Sandiford and colleagues (2015) suggests the 'inverse care law' (Hart, 1971) still applies in IHD, at least for Māori. The inverse care law postulates that those who need healthcare the most often consume the least and those who consume the most healthcare tend to need it the least (Hart, 1971). Sandiford and colleagues (2015) questioned the adequacy of the healthcare system in meeting the needs of Māori and Pacific peoples.

Healthcare systems designed within a Eurocentric framework can generate barriers to care for indigenous peoples. For example, Jeremy and colleagues (2010) report from a conference centred on talking through ways to improve cardiovascular care for indigenous populations in Australia and New Zealand. Consultation with indigenous communities in Australia found the lack of Aboriginal staff, non-Aboriginal staff members being 'unfriendly' or treating Aboriginal patients poorly, and patients being unable to identify with anything at healthcare service sites were factors impeding access to cardiology services. The study reflects the recognition by health professionals that healthcare systems can be inadequate for indigenous peoples and could be contributing to their underutilisation of healthcare (Jeremy et al., 2010).

The discussion thus far has illuminated important thoughts surrounding the barriers indigenous people may face towards accessing healthcare services. The barriers have shown Māori and indigenous peoples may experience barriers to care at different levels of the person, institution and macro levels of society. However, little research appears to explore barriers to accessing healthcare services within everyday life and especially for Māori peoples. I could not find research that explored Māori men's everyday experiences of CVD. Understanding CVD for this group within the context of their everyday lives is important because experiences of CVD do not occur in isolation from people's lifeworld's and related social structures that impact Māori health (Hodgetts et al., 2010). Theorising experiences of CVD and access to related services within the context of everyday life can advance our understanding of the barriers Māori people face when accessing cardiology services. An effort to understand Māori men's experiences of CVD within the context of everyday life and with a view to shaping responses to Māori needs is central to the present study.

The present study

This opening chapter has directed our attention to a contextualised account of ethnic disparities in CVD outcomes between Māori and non-Māori. The exploration of certain nineteenth century developments underlined how processes of colonisation have played a key role in the development of health disparities. This led to exploring tensions between understandings of health to make clearer the impact of colonisation on Māori health, and to stress the need to shift our understandings of CVD as strictly a disease process occurring within the individual. Considering notions of 'CVD as illness' assists with understanding Māori experiences of CVD and within everyday realities.

Current literature in this area provides some insight to the barriers indigenous peoples may encounter when accessing healthcare services and illustrates how health disparities are maintained through modern day conditions and practices. In particular, the previously discussed study by Kerr and colleagues (2010) overlaps with my current research. However, the Kerr study was conducted in the Northland region where the service provision varies significantly to that of the Waikato DHB (Dr T.V. Liew, personal communication, April 29, 2018). The scarcer cardiology resources in Northland impacts the ability for health professionals to deliver IHD services with a lack of regular doctors and locum coverage. The insufficient resources within the Northland catchment may lead to poorer engagement and confidence in services by Māori patients (Dr T.V. Liew, personal communication, April 29, 2018). Thus, the experiences of patients in Northland may well differ to the patient experiences we will be collecting in the current research. There is a need for further research in the Waikato into how the conduct of everyday life can impact Māori engagements with and experiences of healthcare and related outcomes. To understand these idiosyncrasies further requires engaging with Māori people about their experiences of CVD as illness.

What limited research there is on Māori within CVD (Curtis et al., 2010; Kerr et al., 2010), provokes the need for the proposed study. As outlined earlier, there appears to be a gap in understanding Māori perspectives and the 'meaning' of CVD within the context of everyday life. My thesis takes a step in the direction of addressing this knowledge gap and additionally informing the development of services in the Waikato DHB. My aim is to gain an understanding of the perspectives of Māori males diagnosed with CVD and their whānau, including their experiences and understandings of CVD and associated medical care in the context of their everyday life. Participant accounts can shed further light on how we might better target cardiac care to meet the needs of Māori. Ultimately, this focus reflects my embracing of the idea illness does not occur in a vacuum and the need to understand CVD and subsequent actions among broader aspects of everyday life. By extending knowledge of the meaning of CVD and care for Māori patients, we can inform the efforts of the Waikato DHB Cardiology Unit regarding how best to respond to patient needs.

In chapter two, I will offer further context for this study as part of a growing collaboration between the Cardiology Unit at the Waikato DHB and the Massey University Health Psychology program designed to inform the evolution of care. I also outline the theoretical basis for this study that focuses on Māori men's experiences of CVD and related services with the complimentary experiences of whānau members who were involved in their care. This is then followed by four chapters (3 to 6), each focused on the single case of a Māori man who has undergone medical treatment for CVD. The thesis concludes in chapter seven with a general discussion of the findings and its related implications for care.

CHAPTER TWO

Method

After exploring the background to this research in chapter one, this chapter outlines my theoretical orientation and methodology for the thesis. My approach to investigating the current topic was based on the key aims of the research and also brings a sense of awareness towards working with Māori people as a non-Māori researcher. The first section of this chapter outlines my research orientation based in narrative research. The following section discusses the importance of incorporating Māori cultural concepts and practices to my research orientation and reflects on how such cultural aspects were integrated into this project. I also touch on how my own cultural background helped inform my research approach. Sections three and four discuss the research design of the current study. Here, I discuss the groundwork involved in preparing for the research as a wider collaboration with staff from the Cardiology unit at the Waikato DHB. I describe the participants, recruitment process and briefly introduce the four participants. I then recount my engagements with participants and offer further detail regarding the semi-structured interviews and use of visual techniques. In section five, I cover the ethics approval process and foreground key considerations for the conduct of this research, including consultative processes. Lastly, I outline my approach to narrative analysis and the presentation of my participants' experiences in the form of cases.

Narrative research orientation

To understand the inequities and injustices that result in illness that many Māori people experience in everyday life requires engaging in kōrero (talk) with those affected and actively listening to their perspectives. A qualitative approach aligns with such an orientation towards valuing and gathering some of the experiences of participants and for conceptualising illness in everyday life (Chamberlain, 2015). As a non-Māori researcher, it was also important to develop an orientation that resonates with Māori (Ware, Forster, & Breheny, 2018). Below, I outline the narrative orientation to this research which is informed by Kaupapa Māori theory and methodology. Later in this chapter I consider the importance of a case-based analytic strategy for engaging with participant narratives (*cf*., Hodgetts & Stolte, 2012).

Although interests in narrative within psychology can be traced back to the nineteenth century to the work of Wilhelm Wundt (1832-1920), narrative approaches have historically been side-lined in relation to ruling positivist orientated approaches to psychology (Murray, 2003; Murray & Sools, 2015). With a growing interest in qualitative approaches in the 1980s, a renewed interest in the study of narratives surfaced within psychology as a way for scholars and practitioners to access and make sense of personal experiences (Murray, 2003; Murray & Sools, 2015; Riessman, 2008). Narrative approaches made a comeback because they speak to the storied nature of human existence.

Telling lives through narrative forms is central to human meaning-making processes (Hiles & Čermák, 2008), and the conduct of everyday life (Hodgetts et al., 2010). Work in this area foregrounds the importance of human agency in not only making meaning of one's existence through storytelling. But how such practices occur within the social and material conduct of one's life, and often in concert with others (Højholt & Schraube, 2016). In conceptualising narratives, we must recognise that many of the structures used to construct personal stories extend beyond the level of specific persons (Hiles & Čermák, 2008). As Riessman (2008) notes, narratives are 'speaker's connecting events' that weave persons into particular cultures and social milieu, and in many respects the story structures employed in these processes are shared to varying degrees by speakers and listeners.

It is through the storying of events that people often assign meaning and causality to experiences such as illness (Murray & Sools, 2015). As Radley (1993) notes, chronic illness encompasses more than the ongoing management of symptoms where illness carries much broader effects. Allowing people to story themselves enables listeners to understand the impediments that come with illness at a much broader level where the meanings people associate with their experiences of illness and corresponding actions may highlight the everyday issues, struggles and disruptions people face (Radley, 1993). For instance, presenting late to healthcare services for cardiac problems may not be solely related to the recognition of symptoms. A range of circumstances including what CVD means to people's ability to work and a person's sense of self as a productive worker in their story of themselves can also shape responses to illness, including efforts to access healthcare. Thus, through the adoption of a narrative approach, particular issues relating to illness that patients experience in everyday life can be considered and addressed.

Moreover, as noted by Young (1981, 1982), lay stories or accounts of illness do not necessarily form into logical and coherent schemas ordered around causal attributions. Instead, people can also draw on the stories and experiences of others and broader public illness narratives to make sense of their own experiences and corresponding actions (Groleau, Young, & Kirmayer, 2006). Young suggests that people can make use of representational schemas or public narratives that populate their wider social milieu to produce their own illness narratives. The employment of these representational schemas highlights that the stories told by others, such as family and friends, can inform how one makes sense of their own condition (Groleau et al., 2006). As such, narrative researchers assert that stories are constructed in both personal and social contexts (Murray, 1997, 2003; Murray & Sools, 2015).

In terms of structure, narratives are said to provide a particular shape, form, or plot to a chain of events and in so bringing a sense of orderliness and meaning to layers of detail or happenings from people's lives (Murray, 2003). The structure of narratives can be influenced by an array of factors including the narrator, audience, and the broader social and cultural context from which stories of illness emerge. Thus, when considering any illness story, one cannot detach the story content from the context within which it is expressed (Murray, 1997). Stories tell us a lot about how people understand their worlds and the factors that shape their situations and social interactions. This is why I spent time considering the context of colonisation and its links to Māori illness trends in Aotearoa/New Zealand.

Central to research on narratives of illness is the assertion that illness often comes as a disruption to people's life stories that people then work to repair by making sense of the illness within the context of their larger life narratives (Frank, 1995). Specifically, an illness event may not fit easily into one's life story and status as a healthy person. This results in a loss of coherence in one's life narrative and may induce feelings of uncertainty and anxiousness (Murray, 2003). To overcome such feelings, people engage in efforts to revise their personal stories in order to bring about a sense of coherence that encompasses an illness within a broader story about themselves, their health status, and their place in the world (Frank, 1995; Murray, 2003). Such re-storying aids people in refamiliarizing themselves within bodies that may have been rendered strange and untrustworthy by illness. This is also a process of encompassing any physical limitations that come with chronic conditions that may invoke changes in how people see themselves in relation to others, and how they conduct everyday life (Frank, 1995). Narrating a personal illness story in this context can comprise an attempt to acquire a sense of agency or control over a crisis and contemplate options for action to restore normality as a person with health. As such, illness narratives encompass processes of personal identity reconstruction as narrators share and tell stories to themselves and others in order to work through, make sense of, and share illness experiences in forms that are understandable to listeners (Murray, 2003).

In research contexts, narratives are often elicited through techniques such as interviews. These narratives are not restricted to talk alone and are also evident in visual materials from artworks, to participant photographs, drawings and maps. In engaging participants verbally about their stories of CVD, I also drew on visual techniques to help open the liminal space for dialogue in which participants could openly narrate their illness experiences. Using an integrated approach of talk and visual methods offered a pathway of exploring the complexity and multifaceted nature of human experience (Guillemin, 2004). As outlined by Hodgetts and colleagues (2019; 2019), drawings can be considered 'visual artefacts that are produced and used by participants in research as 'mimetic objects' that speak to human experiences that are never fully disclosed. Mimetic visual objects created during research reflect the 'human inclination to create artefacts as aids to communication that mimic aspects of their circumstances, experiences and everyday practices', but which never fully captures what it is like for narrators or the full emotional complexities of their lived experiences of illness (*cf.*, Hodgetts, Stolte, Groot, & Drew, 2018).

Tying together my narrative approach to the illness experiences of Māori men is Bhaskar’s (1975) work on critical realism that has also informed the work of critical health psychologists such as Murray (2000) and Radley (2009). The critical realist stance adopted combines a social constructionist epistemology with a realist ontology to acknowledge the physical realities of disease whilst focusing on the social construction of associated illness experiences. Meaning, I do not deny the physical reality of biological processes (disease), whilst focusing on working with the constructions that come through the narration of associated experiences of illness (Bhaskar, 1975; Yucel, 2018). Drawing from the concepts outlined above, my approach to narrative research orientates around providing opportunities in the formation of ‘liminal spaces’ (Watkins & Shulman, 2008) for participants to recount their storied experiences of CVD. As discussed below, I worked to create spaces in my encounters with participants for four Māori men to story and share what CVD means to/for them and their whānau.

Informing narrative research with Kaupapa Māori theory and research

It is important to acknowledge that narratives are shaped at personal and collective levels. People are both storied and enculturated beings. As such, the generation and interpretation of the narratives must be seen as cultural artefacts in their own right. For research with Māori, this means relating people’s accounts to broader understandings of health and illness. It also requires us to consider the relational nature of illness as understood from within Māori culture (Durie, 1998).

As mentioned earlier, Murray (1997) posits, a key premise in studying narratives is that stories are created in both personal and socio-cultural contexts. He suggests these entwined personal and collective elements need to be contemplated when interpreting illness narratives (Murray, 1997). Thus, when working with Māori, taking into consideration their ways of ‘being’ and ‘doing’ health is focal (Durie, 2017). Therefore, my narrative approach is somewhat eclectic in that I draw on narrative theory from Europe as well as elements of Kaupapa Māori Theory (KMT) and methods in order to manifest a more ‘Māori-centred’ research orientation (Hudson, Milne, Reynolds, Russell, & Smith, 2010; Smith, 2017). KMT orientates towards Māori forms of knowledge production and ways of conducting research (Smith, 2017). This orientation informs my engagements with the stories of illness constructed by Māori participants. It attunes me to some of the Māori cultural concepts and practices that form an integral part of the construction and interpretation of my participant’s illness narratives.

Correspondingly, it is important to state my position as a non-Māori woman of colour. I identify as Chinese and was born and raised in New Zealand. I have learnt overtime that maintaining my Chinese cultural heritage within a European dominant society takes effort, and I thank my mother (Betty) for engaging in efforts to keep important Chinese traditions alive within our family. Although informing my research with KMT and related methods as an outsider, I do have some affinity culturally as a Chinese-New Zealander with the more collectivist orientations to illness. Thus, I bring my own cultural understandings and practices to this research. For instance, my mother often makes particular Chinese dishes for myself and my siblings when we visit her home. This is not only to satisfy our appetites. Making such dishes is my mother's way of caring for us. I have adopted such practices in my own everyday life and used my understandings of the sharing of food within this research process. I used food to create a mutual ground that allowed for strangers to meet, build trust, and converse openly.

Further, I have grown to understand 'humour' as aiding the process of talking about topics and issues in a non-confrontational manner within my own family. In recognising one's illness can be a sensitive topic to discuss, humour was used sensitively with these Māori men throughout our interviews. The use of humour helped to foster a connection with these Māori men and reflects my efforts to open up a space for them to communicate their experiences in ways that felt comfortable. Thus, I also became attuned to the way these Māori men communicated in which I adjusted my own interaction style to suit. This included sometimes sitting with longer silences and adopting certain language to help our conversations flow. These actions illustrate my bicultural approach to this research and much of which is underpinned by Ritchie (1992). Ritchie asserts that biculturalism involves working to understand 'one's own' and also the 'other' person's culture (Ritchie, 1992). This is reminiscent of my approach to this research of engaging in practices that were familiar within my own cultural heritage however, always in relation to, and in synergy with these Māori men.

In essence, bringing my own cultural understandings and practices to this study was to support the processes of prioritising the voices of Māori people and privileging their experiences and lived expertise (Ware et al., 2018). In doing so, I was able to co-create a liminal space with my four Māori male participants (and whānau who wished to participate) in which to openly discuss their understandings of CVD and engagements with the healthcare system. In this space, we identified and examined particular issues Māori faced in everyday life with CVD and towards accessing cardiology services. This in turn provoked the consideration of ways to addressing these issues moving forward with their lives (*cf.*, Eketone, 2008). Thus, KMT can be seen as shaping the interpersonal practices I drew from within my own cultural background to support my engagements with Māori and undertaking this research in a culturally respectful manner. It fostered a sense of 'consciousness' (Bishop & Glynn, 1999), in which I was not only acutely aware of my own actions, but how these actions were reflecting and impacting on others throughout this research process.

In emphasising the importance of shared understandings of illness among Māori, I do not wish to homogenise Māori understandings or experiences of CVD. Although Māori may share similar experiences and values, each personal story is significant in and of itself. Non-Māori researchers have been warned of the need to resist the temptation of viewing Māori as a homogenous group (Durie, 2001; Ware et al., 2018). This is, at least in part, why I selected to engage with four participants and to present their stories in their own right as personal case studies (discussed later in this chapter), rather than as extracts in a decontextualized composite thematised analysis. Valuing each personal story in this way is especially important for Māori considering research processes have previously omitted their experiences, marginalised their voices, or homogenised their understandings into an overly generalised pattern (Ware et al., 2018). Having an awareness of the negative experiences Māori have endured through research processes with non-Māori prompted me to develop a research strategy for the māhaki (respectful conduct) of this study, and reflects my efforts to engage in a positive manner with Māori participants.

Moreover, my research was informed by Māori cultural concepts and relational practices. For example, I worked to support tino rangatiratanga (self-determination) where participants were encouraged to exercise their autonomy in reconstructing their illness narratives during our conversations. Within the limits of my own knowledge and with the support of my supervisors, I worked to recognise the importance of a Māori worldview and the need to engage in whakawhanaungatanga (establish and maintain meaningful and supportive relationships) with each participant. Understanding the role of whānau in the health of their loved ones (Masters-Awatere et al., 2017), I encouraged opportunities for whānau to join us in the interview process if they so desired (Walker, Eketone, & Gibbs, 2006). This is because I recognised whānau may offer a different perspective that may well be useful in responding to the needs of Māori. Interviews were conducted kanohi ki te kanohi (face-to-face) and encompassed manaaki ki te tangata (taking care of people) (Cram, 2001), to engage in processes that reflect a KM approach. These processes were particularly relevant for this research and express my intentions of establishing a partnership with participants and Māori communities through actions of aroha (care). As such, throughout the project, I emphasised the notion of conducting research 'with' Māori as opposed to 'on' Māori. This required my engaging in reflective processes throughout to ensure that these processes were enacted in my engagements with participants and research strategy more generally.

Overall, through conducting interviews that explore Māori narratives of CVD through kōrero and drawing techniques, this research documents how Māori male patients and their whānau make sense of CVD in the context of their everyday lives. Acknowledgement of the health inequality backdrop (Reid, 2015) drove the need to provide context for patient engagements with healthcare services. Undertaken here with a view to enhancing the responsiveness of services to the needs of this population group who face considerable inequalities in healthcare outcomes (see chapter one). The following sections elaborate on how this research focus was carried out in practice.

Groundwork: Access and participant recruitment

Prior to conducting this research, I engaged in important groundwork. This included advice seeking from Māori scholars, meetings surrounding the conduct of the research, and shadowing one of the cardiology nurses at the Waikato DHB during community outreach visits. Because I am part of a larger emerging project between the Cardiology unit staff (intervention cardiologist and cardiac rehabilitation nurses) and my academic supervisors, engaging in such groundwork is intended to address inequalities in outcomes from cardiac care. Thus, important to this study was developing cohesive partnerships. Meetings were conducted between the research team (myself and supervisors) and Cardiology unit staff to establish responsibilities and determine logistics. For instance, advice was sought from the intervention cardiologist involved in the current study regarding the focus of the study and recruitment of participants. As participants were being recruited from the Waikato DHB database, it was important for Waikato DHB staff to be involved and provide input on the most ideal process. Most importantly, these meetings were about building positive and reciprocal relationships. The intervention cardiologist allocated a cardiac rehabilitation nurse (CRN) to assist with fieldwork and the recruitment process.

Before recruiting participants, I engaged in some fieldwork with the CRN to become familiar with the research context. This included my attending several cardiac rehabilitation outreach clinics run by cardiac nurses, including an educational session, physical activity session and community home visits. The purpose of this fieldwork was to gain an understanding of the research context, discuss recruitment and learn more about CVD and recovery. Another key aspect of this fieldwork was whakawhanaungatanga. Building relationships with the nurses who were assisting with the study. I document my fieldwork experience further in appendix 1.

Given the exploratory and qualitative nature of this thesis, I recruited four Māori male patients. Their whānau were also invited to participate. I use the term patient in referring to the person diagnosed with CVD and whānau when referring to family members. Patients were recruited via the cardiology unit at the Waikato DHB and a purposeful sampling approach was used. Purposeful sampling is ideal for research such as this which focuses on a specific social group (Cozby & Bates, 2011).

More specifically, I employed a pre-determined criterion to select participants. A search was made of the Waikato DHB secondary prevention service database for patients that were referred to the service following an acute coronary syndrome (ACS) event by the CRN. The database contains approximately 95 percent of patients referred to and treated by the Waikato DHB cardiac service and are domiciled within the Waikato DHB catchment. Patient ethnicities are recorded in DHB clinical records which is a critical aspect of identifying target participants. Patients within the cardiac secondary prevention service from the previous six months (January 2018 to June 2018) were identified, and totalled 150 patients. Potential participants were identified from this list as per the selection criteria. The first key criterion included patients with a previous ACS event who identified as Māori (including multi-ethnic backgrounds). The second criterion relates to how patients presented to the healthcare system. Patients who were noted as presenting ‘late’ and/or with ‘severe’ disease were included. ‘Late’ refers to patients who were noted as having delayed treatment from the onset of symptoms and ‘severe’ refers to patients presenting with more advanced CVD. These factors were key to identifying patients who may have experienced issues towards accessing healthcare services.

The patients who fit the pre-determined criterion were listed as potential participants to be contacted and invited to the current study. Excluded patients included those residing outside the Waikato catchment (71), female (33), different ethnicity recorded (3), incorrect National Health Index (NHI) number (2), non-ACS event (3) and deceased patient prior to June 2018 (1). After examining patient clinical notes and talking with colleagues involved in their care, the CRN phoned potential participants to gauge their interest in participating. Interested patients were initially mailed the participant information sheet (see appendix 2), and asked if they were comfortable with being contacted by the research team. Patients who agreed to further contact were phoned several days later by myself where I discussed the research further and offered to meet patients kanohi ki te kanohi. Potential participants were met by myself and their respective CRN kanohi ki te kanohi in order to explain the project more fully, outline what participation involves and discuss how the information they provide will be used. Having the CRN present during the initial meetings recognised the established relationships they already have with these Māori men. Thus, I was ‘introduced’ to potential participants by someone familiar to them. The introductory meetings were followed with a phone call to confirm their involvement. After meeting with potential participants, the CRN and I met to ensure we both felt comfortable that potential participants had the information required to make an informed decision regarding participation. The recruitment process reflected a concerted effort by both Waikato DHB staff and the research team to work collaboratively together to identify, recruit and fully inform participants.

Since respective whānau members were invited to participate in this study, it was important to define ‘whānau’ (Masters-Awatere et al., 2017). For the purpose of this study ‘whānau’ are defined as family members who are part of the patient’s everyday life, and/or who have shared the experience of CVD with the patient. In this context, whānau included anyone identified by the person diagnosed with CVD. This inclusive approach is consistent with KMT (Masters-Awatere et al., 2017), and enabled me to include people identified as whānau members who are non-Māori. Although whānau were encouraged to be involved in the study through discussions with the patients, the decision to involve whānau was left to the patients. One participant decided to include whānau in the interviews. Reasons for whānau not participating across the other three participants relate to personal reasons important to my participants, whānau being too busy and some whānau not wishing to participate in research.

The recruited participants are briefly mentioned here in the order I present them in succeeding chapters. Pseudonyms were chosen by my participants for the write up of this thesis. I introduce the participants in more detail at the beginning of each chapter. The first participant Akul is 60 years of age and was approximately six months out of hospital since his latest medical intervention at the time of recruitment. The second participant TH[1] is in his mid-50s, and his partner DM also participated. At the time of recruitment, TH was approximately sixteen weeks out of hospital following his *"triple bypass surgery"* and was awaiting further treatment. The third participant Henry is 65 years of age and was approximately five-weeks out of hospital since his heart attack where he received medical intervention of one stent fitting. The fourth participant Noah is in his early 50s and was approximately twelve weeks out of hospital since his heart surgery to repair his *"leaky valve"*.

Prior to recruiting and interviewing the participants, I sought cultural advice regarding the recruitment and interview process with a Māori academic staff member who had recently undergone treatment for CVD. This enabled me to gain feedback on how I was relating culturally, any practices that may not work and to also gain a sense of the type of response I might elicit from participants. Having such feedback from a cultural insider with knowledge of conducting research with Māori was key towards developing a culturally responsive approach towards engaging with my participants. This practical feedback complimented the advice of my academic supervisors and also worked to build my confidence in engaging in these research processes.

Engagements with participants: Semi-structured interviews and drawing exercises

After initially engaging with participants regarding participation, three semi-structured interviews involving drawing techniques were conducted with each patient and whānau, and usually spread over two to three weeks. The two to three-week timeframe was to keep the interviews relatively close together to evolve the conversation over a series of interactions and build on previously discussed topics. Further, it was important that the research be conducted in a setting familiar and comfortable enough for participants to narrate their experiences. Correspondingly, interview sites were decided upon by participants where all the interviews, except one (in a café), occurred in the participants homes and were sound recorded. Participant interviews ranged from 48 minutes long to 1 hour, 47 minutes. One interview was 28 minutes long as something arose for the participant unexpectedly. However, we continued this interview from where we left off at the following interview. Prior to commencing interviews, the issue of informed consent was discussed with participants and documented via consent forms (see appendix 3).

Engaging in three interviews with each patient and whānau was important as, conducting a series of interviews can help with building rapport with participants, and gaining fuller and rich

---

[1] TH and his partner DM requested their initials be used instead of a pseudonym

descriptions of participant experiences (Lyons, 2015). Additionally, a semi-structured approach is ideal to generate conversation about the focus of the research project, whilst allowing participants to formulate their own path to their story (Riessman, 2008). As described by Riessman (2008), the aim of narrative interviewing is to produce detailed accounts as opposed to brief answers. Therefore, the questions in the interview protocols were mostly open ended to encourage more in-depth responses from participants (Lyons, 2015). The interview protocols were adapted from the McGill Illness narrative (Groleau et al., 2006) where questions were modified to suit the aims of the current research (see appendix 4,5,6). Moreover, I remained flexible towards engagements with participants and attempted to work around their schedules and at their pace.

Upon meeting participants for interviews, participants were engaged in talk about their day where our interactions often began with me offering kai (food) and participants offering to make a hot drink. As mentioned earlier, the sharing of food is a common practice within my own cultural heritage when engaging with others and I included such practices in the conduct of this study. Making food and sharing it with others shapes part of my understanding of caring. It provided an opportunity to build a bridge with participants and establish a sense of trust. Sharing food before engaging in interviewing reflects my efforts at prioritising the building of relationships. I often saw such processes as paving the way for our interviews to occur naturally. In addition, I checked in with participants regarding any unanswered questions before commencing interviews. These were important processes of whakawhanaungatanga and manaakitanga (engaging with respect and care) and reflects a cultural protocol I engaged in at each interview. It also reflects my efforts to create a warm and friendly environment to avoid participants feeling like they were part of an information extraction process with an outsider.

In conducting interviews with participants, I adopted a conversational and interactive approach where I used the interview protocol as a guide to cover certain topics, but allowed the conversation to flow. The protocols were used flexibly and other questions were generated based on the conversations with each participant. Generally, the first interview involved the patient’s medical history, experiences of their first cardiac event and subsequent actions by participants. The second interview focussed in more depth on participant experiences of care and how CVD impacted their broader everyday lives. The third interview drew on aspects of the first two interviews, exploring key issues further, and offering an opportunity to close of the conversation. These interviews also involved the use of visual methods including drawing techniques where appropriate, to help participants articulate their experiences in the interviews.

As the current study is orientated towards understanding the meaning of CVD to everyday life, visual methods offered participants a useful way of expressing what CVD means to them and how they have experienced healthcare services. Participants were encouraged to bring objects such as images or possessions they felt were important or meaningful to their experience and were invited to share their significance. Such objects have been found to hold much more meaning than their physical appearance or function, and assists with understanding human experiences within everyday life at a broader and deeper level (Hodgetts, Chamberlain, et al., 2019). I also acknowledge these experiences of illness maybe incomplete where visual artefacts and associated dialogue may ‘hint at’ but may not fully explicate experiences of illness (Hodgetts, Stolte, et al., 2019). Thus, drawings and other visual objects are not considered as ‘hard data’ and solid evidence of reality. Instead, they are most helpful in formulating *impressions* (Hodgetts, Stolte, et al., 2019) of what everyday life with CVD is like. I present these various visual artefacts in the following chapters.

Engaging in separate interviews opened up a space for participants to ponder the research topic further between our engagements. It also allowed me to reflect upon the previously gathered information to either clarify or expand on particular points in subsequent interactions with participants (Lyons, 2015). To encourage ongoing participation from participants in the research process they were partaking in, each interview ended with a debrief so participants could feedback possible changes for future engagements. At the end of the interview process, participants were given a koha (gift - $150 voucher) to thank them for their participation.

Ethical considerations and consultation

Ethics approval was initially sought from the Waikato DHB. The intervention cardiologist involved in the current study co-ordinated the ethics process while the research team were responsible for providing key information about the research. This research has undergone a peer review process at the Waikato DHB through their Quality and Safety Committee. The Quality and Safety Committee were given a full outline of the research for their consideration to assess the possible ethical issues. A core ethical consideration for this study was that I am a non-Māori researcher conducting research with Māori participants. For this reason, I stated my intentions of drawing on cultural advice on the focus and conduct of this study from my university supervisors, cultural advisor(s) and participating staff from the Waikato DHB. The Waikato DHB deemed the project to be ‘low risk’ so from their perspective, did not need to involve the Health and Disability Ethics Committee (HDEC). The outcome of the Waikato DHB ethical review was shared with Massey University. When applying for Massey University Ethics, I described the peer review process and parties involved such as academic supervisors and Waikato DHB staff. I outlined the ethical considerations for the current study surrounding the protection of participant identity and the experiences I gather, ensuring the safe storage of participant information, cultural considerations and using aliases in the write up of the thesis. The current study was assessed as low risk via peer review process and received Massey University ethics approval. Notification number 4000019378.

From the early stages of formulating the current study it was important for me to have Māori involvement in the research since I am a non-Māori researcher conducting research with Māori participants. Bringing on a Māori academic supervisor was essential for cultural advice as well as community approaches to research, and for Māori to have input into the appropriate processes surrounding this study. For instance, I sought advice from our Māori supervisor regarding informed consent processes surrounding individual and collective consent when engaging with Māori whānau. I also considered and sought advice surrounding participants conducting interviews in te reo Māori since I cannot speak te reo myself. From conversations with my supervisors and taking into consideration my own capability, participants were informed via participant information sheets and reiterated verbally that interviews would be conducted in English. However, Māori terms would be welcomed in our interactions. As noted earlier in this chapter, prior to interviewing participants I also sought cultural advice and completed a run through interview with a Māori male Massey academic staff member who had experienced his own heart event. This was to gain feedback regarding my approach to working with Māori and to ensure I was engaging with participants in a culturally respectful manner. These were more confirmatory processes to understand if my strategy would likely work with the participants. I also sought advice regarding participant pseudonyms from supervisors. I raised the issue of one whānau requesting to use their initials for the thesis write up which was checked for potential ethical issues with my academic supervisors. As a non-Māori researcher in this study, seeking cultural advice and consulting with others prior to undertaking certain actions was key.

In practice, I adopted an ethics of care where actions to the conduct of this research were often determined by the best interests of participants. For instance, the CRN and I shared concerns a participant had agreed to participate in the study without fully understanding all the information. After discussing our concerns, the CRN phoned the participant and had an extensive conversation with the participant about the research. Following this conversation, the CRN felt comfortable the participant understood the research and related processes where we felt their consent to participate was based on a fully informed decision. Similar discussions took place with academic supervisors regarding the impact of the study on participants who have had adverse experiences of CVD and related care. These discussions demonstrate the wellbeing of participants were a key priority. Such processes reflect a person-centred approach and ensuring ethical matters were actively attended to and managed with care.

As part of the cultural responsiveness of my research, I adopted a reciprocal approach in feeding back to the groups involved in the study and shared knowledge gathered with Māori communities (Smith, 1999). My reference to 'Māori communities' refers to various groups such as participants and organisations. It seemed appropriate to share the findings back to various Māori communities in which the study was conducted otherwise it reinforces processes of knowledge extraction which I was inherently trying to avoid. I made contact and visited my participants to share and explain the findings. This was an important part of my ethical obligations to ensure I was upholding an inclusive process with my participants and for participants to see the outcomes of the research. The key findings from the analysis were initially presented to the Cardiology unit at the Waikato DHB to inform ways in which their services can better respond to Māori whānau needs. The sharing of this research created an open discussion about the delivery of cardiac care to Māori. The presentation (see appendix 7) and related open discussion enabled the Cardiology unit staff to reflect on their practice and service. I discuss the key implications for care and future directions that have resulted from this research and related conversations with the Cardiology unit at the Waikato DHB in chapter seven. I have also been invited (at time of writing) to share the findings with Te Puna Oranga at the Waikato DHB. I have also been invited to present this research at various forums in the future, including meetings with various cardiology groups. The lead cardiologist involved in this study has recommended the findings be shared to the wider cardiac and health provider networks, and emphasises the ongoing collaboration within which this research is situated. This study provided an opportunity to establish, build, and strengthen relationships between groups who share common goals and aspirations of addressing disparities in health outcomes and improving outcomes for Māori. Feeding back to all of these groups is consistent with my aspirations of conducting a project of some benefit to a significant health issue and making a contribution to improving Māori health.

Narrative analysis and the presentation of cases

My analysis approach is drawn from insights offered by Murray and Sools (2015) who provide a dynamic five-part process and associated steps to narrative analysis informed by the levels of narrative analysis outlined by Murray (2000). Briefly, Part I involved focussing on the story as a whole to provide context for the analysis of particular elements in more detail. Part II involved storyline analysis, the focus here was on both the form or structure and overall content of each participants story. Part III concerned dialogical and interactional narrative processes involving the positioning of storylines, storytellers and key characters such as doctors, nurses and whānau members. Part IV built on previous parts and employed insights from narrative, KM theory and previous research. This was to unpack storyline patterns and to relate these where appropriate to the functioning of the wider social, cultural and societal context in which healthcare is being provided, and illness is being experienced by my participants. Part V involved comparative work to look at similarities and differences across the four cases (Murray & Sools, 2015; Small, 2009).

These steps offered a bottom-up strategy for making sense of participant narratives that began with an examination of distinct words and images provided by participants and progressively moved to situate their accounts systemically (Murray & Sools, 2015). This was very much a text in context approach. The different steps in the analysis process were employed flexibly and reflected an iterative process of going back and forth between steps as the need arose. I embraced the notion of using this general narrative analysis process as a guide to be used dynamically. In short, I employed a case-based and comparative analysis strategy that was informed by the work of both Murray and Sools (2015) and Small (2009). This strategy enabled me to keep participants experiences intact and to present their stories of CVD in a coherent and contextually informed manner.

In terms of the specific mechanics involved in applying this analytic strategy, my analysis began by my taking some notes regarding key issues raised after each interview. I then transcribed the interviews taking further notes for issues to follow up as I went. Through the iterative process of re-reading the transcripts, I had a good grasp of each participant’s story in its own right and in relation to the narratives of the other participants. In addition to using the overall strategy of Murray and Sools (2015), I adopted a somewhat eclectic orientation and also incorporated my own techniques of making sense of participant experiences. I created an ideas map surrounding the key topics after reading the interview transcripts for each participant. I arranged these ideas into linear storylines of events for each participant in the form of flow charts. I then constructed a plan of the key ideas for discussion in each case and created section headings accordingly. Throughout this process, I revisited the transcripts frequently to ensure my interpretation was grounded within participant experiences. Undertaking this systematic approach assisted with organising the cases and to avoid the cases being too repetitive. I also sought advice from academic supervisors about findings as these emerged, other ways of interpreting participant accounts and key cultural considerations. The result is what I consider to be four coherent case studies and each dealing with a major substantive issue.

In the following chapters, I present the four cases in separate analysis chapters. This proved a useful strategy in that the study of cases has been advocated repeatedly in the methods literature as an important component of research in critical health psychology and the health sciences more generally (Radley & Chamberlain, 2001, 2012). This orientation towards casing enabled me to capture some of the varying experiences of my participants and to not lose the uniqueness of their illness narratives. As outlined by Radley and Chamberlain (2012), a person with illness does not automatically comprise a case. We create cases when treating or offering support to patients or when engaging them in case-based research (Hodgetts & Stolte, 2012). Adopting a narrative orientation to each case, I present each participant’s experiences in a sequentially ordered story form with a beginning, middle and end, which encapsulates how they recounted specific events and interactions in their illness journeys into, through and, out beyond the health system. Although there are overlaps in the experiences and stories, I have focussed on taking particular angles with each case to cover material relevant to understanding key issues surrounding these men’s access to and experiences of care. Importantly, readers of these cases should not take the descriptions of Māori terms as translations that can be applied across multiple contexts. The Māori terms I have used within these cases are related to the context within which they were experienced or described by my participants. Overall, the examination of several cases offers the opportunity to extend our understandings of four substantive issues, each of which a particular case has been orientated (Radley & Chamberlain, 2012; *cf.*, Small, 2009). The purpose here is to understand the person within each case and the processes, mechanisms and circumstances that help shape their experiences of CVD and the care they received with a view to informing future efforts to ensure the best possible health outcomes for Māori men (Small, 2009). Let us begin with Akul.

CHAPTER THREE

Akul and his heart attacks

Making sense of repetitive heart events

Akul resides in a small town in North Waikato. When we met, Akul shared his history and talked about fond memories of growing up in this small town with six siblings and his parents: *"We had the river out the back door there. Dad brought us a canoe when I was like 12, so we were up and down the river in the canoe. Spent most of my time playing down there"*. Akul shared an extensive history of undertaking an upholstery apprenticeship in the early 1970's, spending much of the late 1970s to late 1980s travelling back and forth to Australia, and settling back into New Zealand in the mid-1990s. He reflected on the difficult times of employment and observing the political changes occurring in New Zealand at certain points in history, which are relevant to his illness experience. Engaging in kōrero about his illness essentially involved his attempts to explain: *"Why I ended up here and how I felt about it"*. At times, Akul found it difficult to discuss his experiences of CVD, particularly during his narration of the origins of his illness. Akul's story entangles his heart attacks within a history of traumatic life events.

In the context of his broader lifeworld and processes of colonisation, Akul recounts his moving through a cyclic process of diagnosis, medical intervention and recovery three times. Akul's first heart attack came on suddenly and was medically treated with no further need for intervention. Subsequently, Akul's heart condition worsened and he reported misinterpreting heart attacks for angina. Akul's CRN identified further heart issues and Akul had another angiogram and one stent fitted during the second cycle. Akul went through a process of recovery again. During the treadmill test to receive clearance to resume his usual role at work, health professionals identified further heart issues. Akul returned to hospital for a third angiogram which involved having two more stents fitted. At the time of interviewing, Akul was discussing another potential heart issue with his CRN relating to *"A-type defibrillation"*. This new development appeared to cast further doubt into Akul's mind regarding his health. Such repetitive processes of moving between being ill and recovery were reported to take a toll on him.

Akul's experiences of care differs across the three events. He reflected on particular inconsistencies surrounding how medical professionals interacted with him and conducted certain procedures. Although Akul expressed an appreciation for health professionals as - *"I was grateful to be alive"* - some experiences of care contributed to his unsettling experiences of illness and treatment. More broadly, experiencing multiple heart attacks and subsequent medical interventions has impacted Akul immensely. Each heart event seems to have eroded his confidence and undermined his ability to work and autonomy in conducting his everyday life. Thus, Akul appears to be uncertain about his heart condition moving forward and is in a state of "*limbo"* between illness and recovery, and regarding the future.

I have framed Akul's case around the above issues and to exemplify some of the uncertainties and complications that come to a person with recurring heart events. The focus of the current case is to understand Akul's more unsettling experiences of CVD and the impact of repetitive heart events on his everyday life. As previous literature indicates, those experiencing cardiac events reported being physically and mentally affected by the disease and faced additional challenges of recovery and resuming their everyday lives (Simonÿ, Dreyer, Pedersen, & Birkelund, 2015). Akul's unsettling experiences of CVD is also exacerbated by less satisfactory experiences of cardiac care. Previous research has reported the mixed feelings of Aboriginal patients receiving cardiac care and particular negative experiences relating to system failures and engagements with healthcare professionals (Worrall-Carter et al., 2016). Akul's case featuring multiple cardiac events exemplifies a greater disruption to my other three participants that is characterised with an experience of 'liminality' (Bruce et al., 2014). Liminality is a term often used to denote the experience of being caught in-between states and uncertainty regarding where one is headed in the future, if in fact one has a future (Bruce et al., 2014; Smith, Frazer, Hyde, O'Connor, & Hall, 2017).

I have opted to present Akul's narrative first because of his references to colonisation and his narration of more unsettling experiences of illness and the healthcare system in comparison to the other three cases. This chapter first explores Akul's understanding of the source of illness and how he associates CVD to the social processes and the accumulative effect of certain life events. I then discuss the challenging time Akul has undergone of experiencing an acute event and suffering recurring heart problems. We then consider Akul's varying experiences of care, paying particular attention to several positive aspects of care. I also present Akul's account of where the conduct of his care could have been done differently to minimise the impact of the unsettling experience of CVD. I then discuss the impact of suffering multiple heart events on Akul's employment, social life and confidence. Lastly, Akul appears to be in a state of *"limbo"* where his moving forward with life is now characterised by indecision surrounding his employment and uncertainties about his future.

Heart attacks represent more than physical disease

Becoming ill can often provoke people to search for explanations to their illness and to make sense of their situation (Murray, 1999; Radley, 1995). Although Akul states: *"Smoking cigarettes didn't help"*, smoking is not considered the source of his ill health. For Akul, his heart attacks are embroiled with meaning that stems from his past and in particular, he eludes to the stress that comes with being located (as a Māori man) in the lower socio-economic strata of society: *"My heart condition that I have now is due to a lifetime of being placed in very*[2] *stressful situations and being put under a great deal of stress constantly!"*. In this section, I discuss certain events that will illustrate how Akul's heart attacks mean more than physical disease to him. These are manifestations of broader inequities in society that emerged in his everyday life as interpersonal racism and stress. I discuss notions of interpersonal racism, the stress of being involved in processes relating to colonisation and stressful experiences of everyday life.

Although colonisation forms an inherent part of the history of Aotearoa/New Zealand, it has since manifested in Māori people's lives in various ways (Pool, 2016). Particular manifestations include various stressors such as racism and other social processes which are reported to negatively impact the wellbeing of Māori (Harris et al., 2012; Moewaka Barnes, Taiapa, Borell, & McCreanor, 2013). Interpersonal racism (sometimes referred to as personally mediated racism) is defined by Jones (2000) as encompassing both prejudice and discrimination. Prejudice involves the differential assumptions about the motives, abilities and intentions of others based on their race, and discrimination denotes the differential actions towards others based on their race. Interpersonal racism can be both intentional and unintentional, and can manifest as a lack of respect, devaluation, and suspicion (Moewaka Barnes et al., 2013). Notions of interpersonal racism are apparent within various extracts from Akul's account:

> *It's this compounded stress of where I'm always having everything questioned all the time and have to justify. For instance, as soon as I got my first wages, I started keeping my receipts because I knew I would be asked by a policeman if I had paid for that. Yes! So yes, I kept my receipts right up until I was 30 years-old so I had boxes and boxes of receipts. And yes, I did have to pull them out to say, "Yes I'd bought that. Yes, I have paid for that" ... So yeah, definitely long-term stress.*

Akul's account emphasises the stressors of being considered suspect and a potential criminal as a Māori man in past interactions with police. His account speaks to issues around the racial profiling of Māori by police (Smith, 2014), and the stress this creates for those being stopped and questioned. Akul demonstrates his awareness of the assumptions of Māori held by some institutions and groups within society. Akul's report outlines his attempts to defend and justify himself as an honest person and how people such as Akul learn to manage being rendered suspect in everyday life. Akul emphasises the impact of having to live with incessant accusations: *"You just get tired of being accused of being a thief and having to justify your every waking moment of the day"*. Akul's account aligns with previous research where Māori have reported feelings of harassment, being under surveillance and being subject to accusations of dishonesty (Moewaka Barnes et al., 2013). The participants reported the pervasiveness of racism in everyday life where

---

[2] Words underlined is to show the emphasis placed on these words in talk.

mundane tasks for most people, such as grocery shopping were fraught with confrontation and tension for Māori. Such instances function as metonymic reminders of dysfunctional intergroup relations in our society that adversely impact Māori health.

Akul also attributed his illness to processes relating to colonisation and particular experiences of being involved in the land claims process. The Waitangi Tribunal was created in October, 1975 to hear Māori claims of the breaches of the Treaty of Waitangi (Ministry of Culture and Heritage, 2017b). Certain breaches relate to land claims and the unjust processes surrounding land purchases between European settlers and Māori. In the context of talking to me about his CVD, Akul expressed his responsibility to help and aid others through the land claims process:

> *I couldn't justify thinking of myself and going back to Australia when there was so much work to do here. As a Māori, I felt a burden of responsibility to protect those that could not defend themselves and it was very blatantly obviously going on in New Zealand at the time… Carried that burden and it was a burden for 30 years.*

Here, Akul interweaves the burden of colonisation on Māori into his account with the overwhelming work involved in land claim processes. Akul's account emphasises his interconnected self and valuing of the collective through his need to protect and support others. Akul identifies the burden he felt to engage in the claims process on behalf of others and the criticisms he faced for acting:

> *How many times do you think I was asked about the land claims or Waitangi Tribunal? Everyone I talked to wanted to know about it and I had to answer… And the right answers… They weren't interested in my answers they were just looking for opportunities to criticise me… They were just looking for opportunities to attack.*

In this excerpt, Akul emphasises how the land claims process spreads into his everyday social interactions and conversations with others. His account underlines the incumbrance of being an educator and source of knowledge for these processes. Being a source of information appears to expose him to confrontation and disparagements. Akul recalled his experiences of being provoked and then having his voice marginalised during interactions with Pākehā: *"It's very difficult to communicate, to have a conversation with someone who says they wanna have a conversation, but they actually don't. They're just looking for opportunities to have a go at you"*. Here, we can also see aspects of the reproduction of dysfunctional intergroup relations between Māori and Pākehā through tense interpersonal interactions. This reflects the wider narrative of colonial dominance in which the voices of minority groups can often be marginalised (Nelson & Prilleltensky, 2010). Akul's accounts underline the stress of managing the ongoing effects of colonisation at the interpersonal level in everyday life.

Akul recounted his experiences of several traumatic events leading up to his first heart attack and attributed these events to his first heart attack occurring at the time. The following extract accentuates the role of stressful events in his life and how he makes sense of his illness:

> [Partner's] *bi-polar event which I believe was part of the stressors. Then of course the events that happened around here* [home] *which were major stressors has led to it* [heart attack]. *I mean, I've been a physical man all my life… Very active and really enjoyed being active. I've never had to bother to try and get fit because I always have been fit… I don't do gyms and stuff ya know. I just don't need that stuff cos I'm so active.*

For Akul, certain stressful events are considered as triggering the first heart attack. To reinforce the salience of stressors in his life, Akul presents himself as an active person in order to disassociate himself from being an obvious candidate for a heart attack. References to healthy lifestyles and staying active places responsibility for health within the individual and to a certain extent, Akul adopts this subject position in recounting his responses to his partners health concerns. This varies from his adoption of a more structural position that places responsibility for illness in colonisation. Akul highlights the inevitable nature of becoming ill in light of his ongoing stressors that are outside of his control whilst projecting an image of himself as morally worthy by accepting responsibility to maintain his health through being an active person (Hodgetts, Bolam, & Stephens, 2005). As a result of this framing, becoming ill with CVD is presented as the product of unrelenting pressure that overcame his ability to maintain his health: *"Something had to give and it was my heart"*. His assertion emphasises the compounding stress of these events on his body and his relational view of illness.

To recap, Akul's storying of the relationship between life stressors and his heart attacks illustrate how he has come to understand the sources of his illness. Most importantly, his account demonstrates how heart attacks have become representations of what he has endured as a Māori man in life and the much deeper meaning of CVD. In doing so, Akul highlights the social processes surrounding illness. Akul is the only participant who expressed such structurally informed explanations for the source of CVD.

Challenging times

For Akul, his illness reflects a turbulent time of moving between diagnosis and recovery several times. This has contributed to his more unsettling illness disruption where I focus on several challenges, he has experienced through his heart condition. I first discuss the manifestation of his symptoms and his understandings of a close encounter with death. I then discuss Akul's experiences of suffering multiple setbacks.

Akul reflected on his first heart event and the manifestation of his symptoms. Akul reports his symptoms as coming on suddenly and portrays a critical situation of needing to cope with, and respond to an existential threat (Jensen & Petersson, 2003):

> *I was getting ready for work, put my clothes on and then um, that's when the event happened. That's when the heart attack happened and I was unable to move. I ended up collapsing on the floor… I was still trying to breathe… I lay down on the floor in that foetal position... I'm lying there and I'm just thinking about going to sleep cos I've already said goodbye to* [his partner]. *We were staying at a friend's place. When* [his friend] *saw me in the morning she recognised that I was having a heart attack… Because she had watched her husband have a heart attack. So, she responded very well and she rang the ambulance.*

Here, Akul's account outlines the sudden disruption of illness to his life and the severity of his symptoms. His account emphasises how his friend responds appropriately having witnessed a heart attack previously and facilitates prompt access to care. The act of saying 'goodbyes' reflects Akul's grave understandings of his situation. His account resonates with previous research where participants reported their first heart attack as a close encounter with death (Jensen & Petersson, 2003). Participants reported the grave fear and despair they felt during the acute phase of the existential threat. This extract conveys how the more pervasive and debilitating signs of illness initiated a prompt response to accessing care.

Akul recounted the experience of suffering setbacks during recovery with the identification of further heart issues requiring medical intervention. This often resulted in the process of comprehending a diagnosis, medical intervention and recovery several times and such repetitive and cyclic processes appear discouraging for Akul. For instance, Akul describes how he looks forward to receiving medical clearance to return to work however, suffers a further setback in the process:

> *We've progressed to where they're finally gonna do the physical test on me where I actually do the physical walking on the treadmill… I'm looking forward to it because if I pass this test and I pass it okay, the doctor will give me a clearance* [to work]. *So, I do the test and that's when they realise that I'm not even close to being well… I get the phone call the next day. "We've spotted something here and we need you to come in" and that's when the treatment took over. By this stage I'm not doing too well mentally. I didn't do too well mentally when I went in for the second time.*

Here, Akul emphasises the importance of the treadmill test towards regaining his work duties and returning to the familiarities of everyday life. His account illustrates how his progression with moving forward is once again disrupted with the identification of further heart issues. The reference to 'treatment taking over' denotes the invasion of medicine into his everyday life once again (Radley, 2009). His account emphasises the psychological impact of suffering these setbacks and how such situations can be upsetting for patients.

To recap, this brief section has outlined Akul's experiences of a critical event and his understandings of being close to not making it through. The discussion of Akul's setbacks emphasises the challenging times patients can experience when their return to everyday life is disrupted by disease once again. In the next section, I delve into Akul's experiences of care.

Varying experiences of care

The challenging times Akul has experienced is accompanied by his accounts of varying experiences of care. This is reflected in Akul's drawing (figure 1), which also depicts his journey through the healthcare system. In relation to figure 1, the box in the centre represents Akul, and the lines extending out to various healthcare facilities depicts the relationships Akul perceives to have with health professionals (the meaning of each line is positioned in the top right-hand corner of figure 1). Additional arrowed lines reflect Akul's movements across facilities and relationships. The time elements reflect the approximate period between each heart event Akul experienced. Figure 1 provides some perspective surrounding Akul's experiences of care where he depicts strong relationships with some health professionals, and not so good relationships with others. His drawing tells us that such varying experiences occurred within and across healthcare facilities.

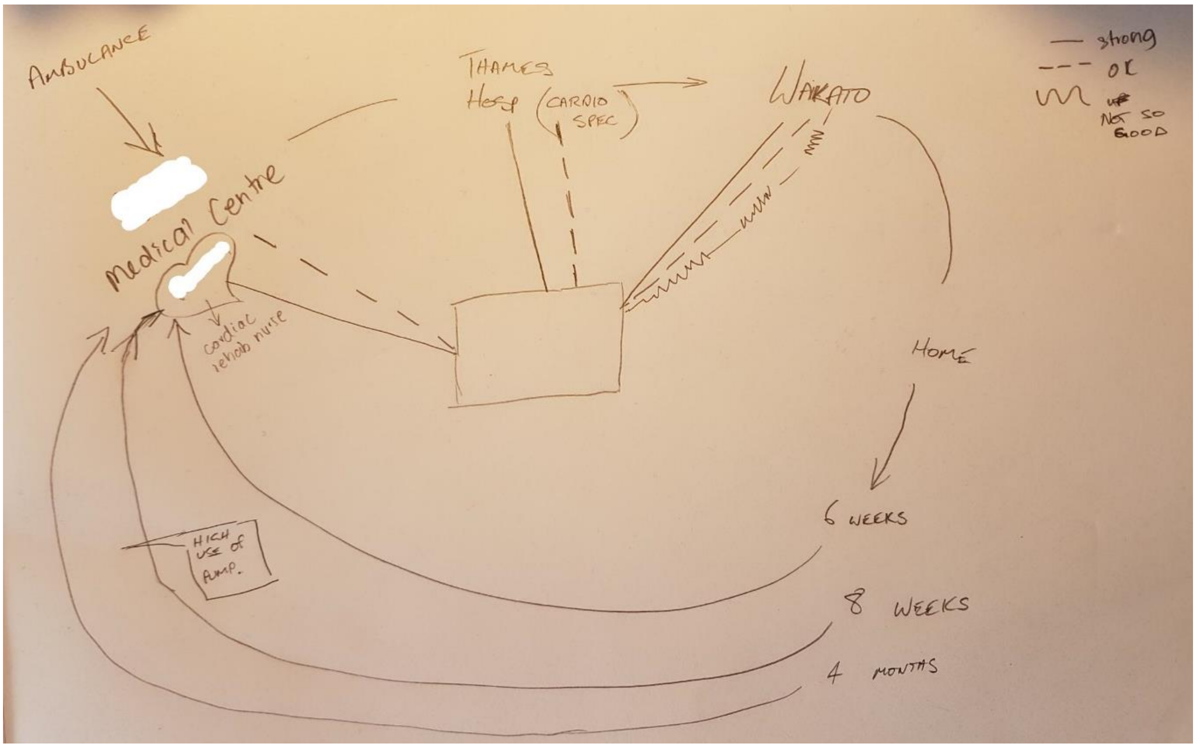


Figure 1. Akul's drawing of health professional relationships, and movements through the healthcare system.

In this section, I provide further context to figure 1 by discussing Akul's varying experiences of care. I begin with the positive aspects relating to hospital nurses and his CRN. Correspondingly, there are aspects of care that Akul questions could have been done differently. I discuss his experiences of being left to confirm his own heart attack, communication issues surrounding his condition, and his experiences of inconsistent treatment during medical interventions. Lastly, I discuss Akul's experiences of follow up care.

Consistent with other participant accounts, Akul reports positive experiences with hospital nurses. Throughout Akul's heart journey, the hospital nurses are reported to provide consistently good care. This is represented by the strong lines in figure 1. Akul states:

> *Nurses, ya know, are the heroes in the hospitals because we see more of them, their behaviour is really consistent, they're always nice and available... I say the nurses do a lot more for you than just change your blumin stuff ya know. They're there and they're good company and ya know, they do a lot more for you.*

Here, such statements call upon perceived common tropes of nurses as the glue that bonds hospitals as is evident in 'you know' or in this case 'ya know' statements. His account suggests nurses go beyond the practical aspects of caring and provide support and companionship during his stays in the hospital. This consistently good care is also evident with his CRN.

Akul reflected on the importance of the CRN through his heart events. This is also reflected in figure 1 with Akul drawing a heart around her name. Akul reports his CRN as taking on a dynamic role in his care. Akul emphasises how his CRN is involved in identifying further heart issues, facilitating access to care and providing ongoing medical and social support. In relation to his drawing he states:

> *She* [CRN] *really does deserve that* [the heart]. *Because I could go directly to* [his CRN] *and* [his CRN] *would invite me in and then* [his CRN] *would look at me and start going for it without me really knowing what was going on. And then saying "well* [Akul] *you're going to hospital" and that's what literally happened. "Oh, am I, why?" "Oh, ya know, just noticed something". "Oh, have you?".*

Here, Akul recounts the proficiency and thoroughness of his CRN in identifying further heart issues through his recovery. His account suggests she identifies these issues prior to him realising the seriousness of his condition and she initiates the next steps of accessing the hospital. For Akul, his CRN is an advocate towards ensuring he receives the required medical intervention: *"She has a discussion with the medical doctor about admitting me and this is where* [his CRN] *really comes to the party. She manages to tell this doctor in no uncertain terms exactly how ill I am. And he books me in straight away".* Such advocation and proactiveness contributes to Akul's positive experiences of care. When I asked Akul who or what supports him through his heart journey his reply was his CRN: "*The end. Start to finish".* The frequent mention of his CRN throughout his narrative underlines the integral part she plays in his heart journey where notions of whanaungatanga (having good relationships) is apparent. Despite such positive references to the efficacy of hospital nurses and his CRN, Akul raises concerns surrounding other aspects of his care and whether it could have been managed differently.

It is common practice for people to seek care upon feeling unwell to have some resolution to what is ailing them. However, responses from health professionals are not always what a person might expect or need. This is evident in Akul's case where the response of ambulance officers during his first event is reported to differ to his expectations:

> *I really didn't know I'd had a heart attack until I got to the doctors, but I had! And it was blatantly obvious according to* [his friend] *who's not a friken ambulance officer… They* [ambulance staff] *really talked me out of getting into that ambulance… They put it all back onto me as I need to go and get tested and checked to see if I'd actually had an event like that. Which is not what I expected… And if you even think it's a heart attack, what the hell are you doing leaving it up to me? Might I have another one on the way? I mean, I don't know what they were thinking!*

In this extract, Akul expresses his dissatisfaction with the ambulance officer's response to his likely having had a heart attack. The account of this experience suggests the officer overlooked the signs of a heart attack and how this conflicted with Akul's expectations of how he should have been treated. Akul discusses the difficult time of managing his condition himself following the initial interaction with ambulance officers: *"I was just falling asleep on the couch and I can barely move… Why did I have to drag my very sorry arse to the doctors to be barely be able to walk in there and get tested?"*. Essentially, the response of the officer left Akul in a state of ambiguity about having had a heart attack or not, which he had to again initiate the resolution of by taking himself to the doctors when barely able to walk. He also experienced communication issues during some interactions with health professionals.

Information exchanges between both doctors and patients are central to establishing diagnoses (Lyons & Chamberlain, 2006). Based on tests and what patients tell them, doctors often provide information to patients relating to their condition and a plan of action. This often helps patients make sense of their situations and what a diagnosis and prescribed course of action means for them. Such communication is presented as lacking at times in Akul's narrative:

> *It's the lines of communication here so yeah, my cardio specialist right. And this is really important because I don't know the questions to ask about myself to find out what position I'm in… I would have liked a full diagnosis of where I was at and have that full diagnosis explained to me. So, I'll get things like, "*[Akul] *you've had a heart attack you need to give up smoking",* [Akul] *says "what do you mean a heart attack what has actually happened?" "Well you've had a heart attack". And that's not good enough. Ya know, I have some sort of education…I mean a heart attack what does that mean?*

Akul reports being offered a general diagnosis without specific detail from a specialist. He reads this as reflecting a lack of adequate care. Akul's account underlines how providing information is central to reassessing one's current state of health and understanding the repercussions of a heart attack. Providing instructions to 'quit smoking' appears irrelevant without information regarding what has evidently happened. Akul is also frustrated in not feeling that he knows the right questions to remedy the situation. The importance of communication and how health professionals provide information is a consistent matter across all four cases and I discuss this in succeeding chapters.

Adding further dissatisfaction to his experiences of care, Akul reports undergoing the same medical procedures several times inconsistently. He appears to realise the inconsistencies following his third event in hospital, which seemed more skilful than the first two: *"He had the skill set I was looking for the first time around! Not the third time".* A particular inconsistency Akul discusses is the time spent examining his heart across the angiograms. He questions why examinations on the first two occasions were not as thorough as the third intervention:

> *On the second angiogram, they did not do another thorough check of my heart because if they had of, they would have picked up that I needed two more stents on the other side... Because the first stent was a major indicator that there was something going on. And there's another three heart attacks I could have avoided had they looked at my heart... They never bothered and didn't actually canvas the heart. I wouldn't know they needed to do that until the next two stents were fitted. Because when the next two stents were fitted, I stayed there for another 10-15 minutes as he really went over my heart... When those last two stents were fitted, he actually examined me, and I knew he was examining me. And that's when my confidence in Waikato came back. Cos now, he's fitted two.*

Akul uses his own experience to substantiate the emphasis he places on the consequences for patients of inadequate examinations. His account of inconsistencies across examinations invokes the frustration and disappointment he feels about these experiences. Akul has concluded rightly or wrongly that his third heart event was avoidable if the initial two examinations were more thorough. As a result of his experience with the third examination, he was able to restore his confidence in the healthcare system. Akul's reported inconsistencies underline the ways in which patients can make sense of varying experiences of examinations.

Complicating the situation, at the time, Akul questioned his having trainee doctors work on him and the uneasy feeling this invoked. Reference to trainee doctors enabled Akul to deepen his contrast between examinations one and two, and the third examination. Akul warrants his concern as reasonable in acknowledging that student doctors need experience, although perhaps not with patients such as himself and not twice in a row: "*We all realise that doctors have to be trained, but there's actually a living organism that they have to train on and that's the human".* Akul recounts his unnerving experience of the second angiogram and his sense of being experimented on as doctors learned their trade:

> *I have no idea what that was but it was bloody unnerving… I'm lying there, staying still, with my arm all opened up and that, and the first guy has trouble. And then I'm looking at the main surgeon coming in and he's not happy that he's having trouble. And then the first guy sort of "I got it. Its good". I'm going shit, I'm just thinking, oh I'm an experiment at the moment. Ya know so, as a training tool, I couldn't lie there and say 'hey hey I want the best guy in the world to do this job', because that's what I wanted to say… After that one yeah, I definitely felt like a lump of meat… The lack of eye contact or communication with either of the surgeons.*

Akul paints a disconcerting situation of being a training tool and his discomforts during the process. His account reminds us of the attentiveness and sensitivity of patients during procedures where signs of technical difficulty with little reassurance can be unsettling. Akul's report emphasises how the care of medical professionals can inadvertently induce anxiety and worry in patients. It also illuminates the power imbalance that can occur between health professionals and patients through Akul's reports of 'holding back' in relation to voicing his concerns. Akul's statement suggests notions of dehumanization occurred during interactions with trainee doctors (Haque & Waytz, 2012), and this appears to be a contrasting feature between trainee doctors and the *"professional"* service he received from a qualified cardiologist for his third angiogram.

Akul's account underlines how a lack of communication and even coaching of patients through such procedures by doctors can impact negatively on patient perceptions of the quality of care they are receiving. This point is supported further in Akul's account of his third angiogram during which he felt that he was treated as a *"human being"*: *"The surgeon looked me in the eye and said "Are you okay? How did we go? Are you alright? And I got the opportunity to thank him… I'm grateful he acknowledged that I was a human being. I hadn't had that before.* This quote illustrates notions of manaaki (care and respect) and how small acts of acknowledgement during medical procedures has humanizing functions.

Akul also recounted varying experiences of medical technology in relation to his care. He reports an unsettling experience when being unable to follow what was happening during medical procedures. In the following extract, he emphasises further inconsistencies in his care through the discussion of medical technology:

> *Things that worried me about the first stent being fitted was that I couldn't actually see my heart as I could in the first angiogram. The difference between the first two students and the last professional was the amount of dye used to highlight my heart because I could actually see, literally see what was going on the last time. The first time I had an idea, the second time I couldn't see anything, and the third time I could actually see the blockage. I could see where it was going. I watched it disappear for goodness sake.*

For Akul, the act of 'not seeing' during medical procedures invokes worry and concern, whereas 'seeing' appears to demystify the heart and provide some clarity to one's condition. A patient being able to witness what is occurring inside them seems to be linked to a sense of participation and cooperation in the procedure. Akul's account emphasises how understanding what is happening is important to comprehending the state of his heart. In this way, medical technology can provide a sense of relief, reassurance and inclusion to patients. As Akul states: *"The angiogram and looking at the screen… Really helpful for my mind to understand what was going on"*. Akul's report illustrates how medical technology becomes part of his meaning making process.

Akul reflected on his follow up care from his general practitioner (GP) after being discharged from hospital and through recovery. Akul reports being less satisfied with his follow up care and emphasises the trying times of achieving some stability:

> *The doctor that was assigned to me… He's a cardiologist and he's the only doctor I haven't* <u>*seen*</u> *from the medical centre. So yeah, I've had, since the incident the initial one* [doctor] *who got me the tests… Then after that I've dealt with two other doctors. And I've seen one of those doctor's twice… I've asked for my case to be transferred to him cos he's consistent and he's there. So yeah, definitely intermittent. They're very very busy. I tried them in the middle of winter. Honestly its two weeks to get into see them.*

Here, Akul depicts a lack of continuity with his follow up care through his description of various encounters with doctors, and none of which were with his original doctor. His account suggests he prefers some continuity by his actions of transferring his case to a specific doctor. He also makes reference to the busy nature of the premises and the difficulty in obtaining prompt appointments. For Akul, having a CRN assigned to him is crucial to him receiving follow up cardiac care in light of his busy local GP practice: *"I think based on having a cardiac nurse assigned to me has kept healthcare at the forefront of my mind… It's very fortunate that someone's identified that there is a need for a specialised cardiac nurse"*. His account demonstrates some clear inconsistencies in his follow up care and the importance of the CRN in his ongoing recovery.

Briefly, Akul reports very positive experiences of care from the nurses and his CRN. Other reports convey his questioning of certain instances of care. Drawn from his account, Akul appears to question his treatment by an ambulance officer, trainee doctors and what he perceives to be the inadequacies of communication between himself and these health professionals. Although Akul appreciates the work of medical professionals, he questions the handling of his first and mostly his second heart event. Akul's case raises questions regarding medical procedures being unnecessarily unsettling experiences, and the importance of engaging patients as people in their care. His account also raises concerns of fragmented follow up care with his GP where his

CRN is portrayed as more accessible. In the next section, I discuss the impact of enduring repetitive heart events on Akul more broadly.

The impact of suffering repetitive heart events

As mentioned previously, Akul has repeated experiences of cardiac symptoms, seeking care, undergoing medical treatment and then working through recovery. Such repetitive experiences have impacted Akul immensely and particularly in his employment and sense of confidence. Such repetitive events have also impacted his social life. I elaborate on these issues in the current section.

Akul discussed the meaning of CVD to his employment of working for the Department of Conservation (DoC). In particular, he recounted the impact of repetitive heart events on his ability to 'perform' his work. Akul's account of how CVD has affected his employment also illuminates the embodiment of illness through reports of his efforts to 'keeping up' with the pace of his job:

> *All of these occasions* [heart events] *have really affected my employment now... I mean like, I was gonna be not so good for approximately a year and I was never gonna have another heart attack according to the doctors... But it's really affected my work now. There's so much stress and stuff lying around. I just can't keep up at the pace they need me to keep up to do the job. I was keeping up, I was more than keeping up before. But, on the medications I am on now, I'm forgetting things and things are falling away and running out of. I just don't have the bottle to do it.*

Evident in this account is Akul's effort to test his ability to conduct everyday activities, including his previous role at work. Such testing has proven discouraging for Akul who now realises the new limits of his body. Although Akul presents himself as being fully competent prior to his heart attacks, he now depicts himself as in a diminished physical and psychological state employee. This situation challenges Akul's ability to make a living and also to his very sense of self. When he attempts to work and cannot keep up, he experiences a loss of respect as a worker: *"Each time I went back to work to say I was fit and capable and ready to go and I wasn't, I'd lose respect"*. On this issue, Akul's narrative is congruent with previous research where participants reported having less strength and energy to perform regular work tasks (Simonÿ et al., 2015). Participants also reported their employment being jeopardised as a result and feeling less secure in their work. Additionally, the repetitive heart events have negatively impacted Akul's confidence.

Experiencing a heart attack can be a shocking experience for patients faced with the onset of life-threatening symptoms and associated uncertainties (Fors, Dudas, & Ekman, 2014). Such events have the ability to impact people's confidence in their body, and their ability to conduct their everyday lives with continuity (East, Brown, Radford, Roosink, & Twells, 2004). The fact Akul has suffered three heart events appears to take a toll on his confidence:

> *I've gotta get it in my mind that I'm okay… Yeah, that's gotta be reinforced that I'm okay and I keep seeing things like this 'defibrillation' and stuff, that might mean I'm not okay. But really, I'm so gun shy after having to do it three times.*

This extract illustrates how each heart event progressively erodes Akul's sense of confidence in his body. The importance of confidence to Akul is evident in how he attempts to regain his confidence by engaging in physical activity to test his body again. Figure 2 depicts the hut Akul had started building prior to his first heart event although, building the hut became a process of confidence-building thereafter. Following his third event, he questions whether confidence building is more damaging:

Figure 2. Akul's hut he built through his illness experience.

> *I was trying to get my confidence back about my body and stuff. I needed a hand, but I didn't accept anyone's help. I just needed to get the confidence cos I'd had a hell of a shock after that first heart attack... And of course, it was so disappointing when I had to go for that second angiogram. So, I tried the same thing again after the angiogram, the second one... Once again, I tried to rebuild that confidence in me to go forward. That I can manage to actually be able to do this ya know? But after the third time I just stopped. I just stopped. Is what I'm doing trying to rebuild this confidence again good for me?*

Akul's account emphasises the setbacks he experiences to his confidence and his attempts to persevere through trying times. In this extract, engaging in acts of physical activity provides a way of building confidence and overcoming the shock of suffering a heart attack. This act represents Akul's way of moving forward and reaffirming to himself that he is 'okay'. Such acts represent particular styles of recovering and reclaiming something important in life prior to a serious illness (Radley, 2009). Radley (2009) discusses how several men in his earlier research engaged in 'digging a garden' and 'chopping wood' following bypass heart surgery. These mundane activities were an expression of the men's recovery and state of the health to themselves and others in their lives. This aligns with Akul's story in how he attempts to regain his confidence and sense of health through the building of his hut. Though, there appears to be a threshold in which such activities provide some benefit to Akul. For Akul, confidence-building means setting oneself up for more disappointment when another heart event occurs. Akul eventually finished the hut however, reported employing other important reasonings in addition to confidence-building to sustain his motivation to continue on. This extract illustrates how repetitive heart events can disrupt people's sense of certainty and confidence in their body, and the difficulties patients face in regaining their confidence again.

Akul reflected on the changes to his social life and relationships throughout his heart events. In line with Akul's understanding of stress as causing his illness, he emphasises the importance of adjusting his life to avoid stressful situations while recovering. Akul discusses notions of needing to withdraw temporarily from social endeavours as a way of recovering:

> *Social life is gone.* [His good friend] *is very important to me because that's my social life and that's maybe two days a week at the most. Social life is gone and um, I love my girlfriend very much but I can't be with her every day at the moment. I'm just not strong enough... She has ups and downs and all-around towns and I can't cope with all that... Um, so social life is gone and that's because I'm on the mend... So that's just something I'm stepping back from until I'm really good or until I understand that I'm really good now.*

Here, Akul notes the changes to his social life with illness and the difficulty he experiences managing social relationships through these events. He depicts himself as being weaker and fragile during this time and emphasises the need to circumvent social relations that may be overdemanding for his body. His account brings to light how patients may understand recovery and engaging in social life again. For Akul, he is not convinced about handling the usual social engagements of everyday life and disengages from such activities to preserve his efforts at recovery.

To recap, Akul's account illustrates how he is confronted with the new limited capacities of his body. The mundane activities of working become a source of concern as Akul realises the changes in his abilities to perform his work. Each heart event also appears to erode Akul's confidence. Although he demonstrates agency and determination to regain confidence in his body, the third heart event appears to interrupt such efforts. His account of the changes to his social life adds to the disruption of illness to Akul's life. Next, I discuss how Akul envisions his moving forward.

In a state of *"limbo"*

Akul's outcome differs to the other three cases to be discussed where he appears to have the least favourable outcome. His account emphasises the impact of experiencing multiple heart events where he experiences notions of 'liminality' (Bruce et al., 2014). I will discuss this issue through Akul's indecisions surrounding work, uncertainties about the future and how he understands his state of health.

Although Akul was put on lighter duties following his coronary events, the notion of 'lighter' means less physical work within his work context. Akul reports this 'lighter' work as stress provoking: *"Although they were offering me what they thought was lighter work, it was actually more work and it was <u>heavy</u> work... It was like really really stressful".* Akul's understanding of the relational connection between stress and CVD prompts him to question the impact of working for DoC on his body. As a result of this, Akul finds himself in a state of limbo surrounding his work situation:

> *I'll just have to seriously think about what I'm gonna do to make a living. And I just don't know if I can make a living anymore so, that's the situation I'm in... Having to choose leaving work not because I want to go but because I can't really cope with it. That's why I'm having to leave work... It's because I just can't cope with it. It's just so dam stressful... Yeah, so for the future as far as working career goes, I don't know.*

In this extract, Akul presents illness as a life development that disrupts his identity as a productive worker. Akul presents his aspirations of continuing to work and being frustrated by the bodily limitations that have accompanied his living with CVD. This extract demonstrates how Akul re-evaluates certain aspects of everyday life, such as work and likely negative impacts on his health moving forward. Such re-evaluation appears to invoke ambivalence and doubt in Akul's future to earn a living as he constructs new meanings surrounding his work. Although Akul ponders leaving DoC, such actions come with a great sense of loss and underlines the complex decision Akul faces: *"It took a very long time to get into DoC, a lot of sacrifices and a lot of <u>really</u> big sacrifices to get into DoC... I put so much effort into that job to watch it all evaporate away like that it's just cruel it's just friken cruel".* Akul's quote emphasises his indecision surrounding work and the subsequent state of limbo in which he finds himself.

Although Akul is now in recovery, a sense of uncertainty exists where illness appears to disrupt his planning for the future. This uncertainty stems from Akul not knowing how his body will respond to coming off certain heart medications. Akul expresses a sense of life being on hold as a result:

> *I'm getting more and more concerned about what's going to happen to me when I come off the medicine. So, in January 2019 I finish. Literally counting it down. The big mystery with the medication and all the rest of it. I've tried to describe my next move to you, but I don't know if literally what that's gonna be. So, I'm very up and down with my um, where I'm at. It's really unnerving and I certainly do put a lot of effort into planning things and I just can't plan anything. Totally limbo! So yeah, I can't make a decision on what my future's gonna be.*

Here, although Akul envisions a future, it remains tentative and contingent on his illness. This extract emphasises how patients may feel uncertain regarding the course of CVD and subsequently, the future moving forward. This aligns with previous research that reported patients and their partners adopted a 'wait and see approach' to life following a heart attack (Eriksson, Svedlund, & Asplund, 2010). The participants reported not planning for the future and being in a more vulnerable position. The worry and concern invoked by Akul emphasises how patients may require further reassurance to counteract the uncertainties and feelings of liminality illness cultivates.

Akul also appears to question his health moving forward where notions of mortality have come to the fore. Akul's more upsetting experiences of several heart attacks and medical interventions that he considered sub-standard appears to raise his awareness to his own mortality:

> *Before the heart condition, I felt that I had a lot of potential. That even though I was older that with my ability and good planning, I could still achieve long-term goals. After the heart attacks and because of the nature of my work, that's not going to be possible. I'm a temporary citizen. I can see my own demise… I always envisioned making it to 80 in reasonable health and then I'd be satisfied with that… That's all I ever planned for. But it doesn't look like I'm gonna make that.*

Akul's account emphasises how illness disrupts people's thoughts of achieving future goals and living a long prosperous life. His report emphasises the embodying experience of illness through its limitations and restrictions it imposes on Akul's way of being. This extract illuminates how patients question their health moving forward and must manage the loss of future prospects as a consequence of serious illness (Radley, 1999). Akul appears to make sense of his illness in a manner that centralises his: *"…need to get this confidence about myself that I can live the way I'd like to"*. Akul appears to be searching for a way to live with illness and meet his own personal expectations for himself.

To recap, Akul's story emphasises how he experiences being in *"limbo"* following numerous coronary events. Akul appears to seriously re-evaluate his employment situation where his hopes of working for DoC is clouded by the stress and demands it provokes. The various unknowns relating to his medication has created some uncertainty in his future. Akul has become increasingly aware of his own mortality where his illness experience appears to change his views surrounding his health. Overall, the account emphasises how Akul moves through a period of disrupted normality. I discuss and bring the chapter to a close in the next section.

Chapter discussion

Akul's story of illness illuminates an upsetting experience of CVD. This is evident through Akul's vivid and emotional passages of illness. His narrative portrays the immense disruption of illness to his everyday life. Akul's account regarding the source of illness illustrates how occurrences in the past are profoundly etched on the present (Riessman, 2015). Akul's experiences of racism and discrimination, the participation in political processes surrounding colonisation and particular traumatic events reflect particular stressors of the past that give meaning to his illness. His account points to stress as a stimulus where stress is viewed as something external to the individual and located within the environment (Lyons & Chamberlain, 2006), which emphasises notions of interdependency. Akul's story advocates the need to explore people's social relationships and how stress emerges and exists in people's daily social interactions and encounters (Hodgetts et al., 2010). It emphasises the importance of paying attention to lay understandings of the source of illness and the meanings that come with CVD.

Although Akul made some positive references to his care, he equally feels disappointed in some instances of care. This brings to light the spaces that are produced in people's lives from the exposure to medicine and related professionals. Radley (2009) considers how medicine creates spaces in people's lives and how these are not always comforting and promising spaces. Instead, these spaces can reflect chasms of 'doubt and relief, anxiety and hope' and correspondingly invoke people to respond in various ways to medical help (Radley, 2009). This is reflected in Akul's case where he responds by storying these experiences of care in an attempt to render these problems of care graspable (Radley, 2009). By rendering his accounts graspable, Akul creates an opportunity for certain issues of care to be addressed.

Akul's storying of the impact of repetitive heart events to his capacities to perform his work tasks, his confidence and reduced social life conveys the damage CVD has inflicted on his life. Akul's account encompassing these issues emphasises how his life story continues although, changed by illness (Frank, 1995). The act of storying enabled Akul to take stock of what survived the 'storm of disease' (Frank, 1995), where the discussion of his employment, the future in general and his state of health reflects his future outlook and subsequent state of *"limbo"*. This storying reflects how he attempts to understand his current position and where he might be going in the future (Frank, 1995). Akul’s account illustrates how he experiences a sense of loss in various areas of life moving forward. Certain elements of life have lost their ‘aesthetic qualities’, which Radley (1999) terms as the persons dreams, wishes and fancies in the future. Although storying affords Akul the opportunity to repair the damage illness has inflicted, he is still in a process of redrawing maps and finding alternative destinations of where he is going in life (Frank, 1995).

Overall, Akul’s understandings of the source of illness, the varying experiences of care, the impact of experiencing repetitive heart events and the state of being in *“limbo”* collectively contribute to a more unsettling experience of illness and disruption to everyday life. His case shows there is a strong need to consider the emotional wellbeing of patients who experience such journeys. Conversely, in the following case, I discuss TH’s experiences of CVD. TH has experienced a long and involved journey through the healthcare system after suffering setbacks and complications with his heart condition. Such ‘up and down’ experiences resonate in some respects with Akul’s case. In particular, TH’s case highlights how particular social conditions contribute to, and compound the disruption of illness in people’s lives.

CHAPTER FOUR

TH and his ‘playing up heart’

An ongoing journey of “up and down”

TH and DM (his partner) live in a very small South Waikato community consisting of basic amenities including several basic stores, a café and a General Practice. Larger healthcare facilities, supermarkets and key amenities for living are located approximately forty kilometres away. TH and DM’s story reflects a co-construction of their heart journey. This co-construction was evident in the manner in which during our interviews, TH and DM prompted one another regarding the sequence of events, sometimes pondering together and swapping views before continuing with their story. Evident in the interviews with this couple was how intimate partners can co-create illness narratives and memories dialectically together.

Conveying the enduring and perpetual journey through illness is important to TH and DM. They clearly stated how their heart journey began four years ago: *“It wasn’t just a one-year thing. Nah, it’s been going on four years!”*. TH and DM’s journey begins with TH experiencing signs of illness whilst he was working that evolved into a crisis situation over a 48-hour period. Initially, TH was misdiagnosed with kidney problems. This diagnosis was later changed to a heart condition of a *“leaky valve”*. His heart condition added to his already diagnosed Type 2 diabetes (T2D), and he reported being diagnosed with sleep apnoea through his heart journey. During our interviews, TH provided a succinct explanation to the cause of his illness as ‘lifestyle’ factors in the context of the social determinants of health: *“Working heaps and heaps of alcohol”*.

Since TH’s heart diagnosis, both he and DM have been working through an ‘up and down’ journey of illness. This journey is shaped by the sudden disruption of CVD to their lives, TH’s inability to work, overcoming setbacks relating to various heart related events, and TH needing to undergo significant medical interventions. Following numerous ‘up and down’ experiences, TH is uncertain regarding the outcomes of medical interventions moving forward. TH and DM’s long journey through the healthcare system is reflected in their narrative which features processes of accessing care and many encounters with health professionals. Their story presents more positive experiences with hospital nurses than with hospital doctors, which leads them to believe: *“I reckon that they* [nurses] *would make better doctors”*. Although technical aspects of caring seem important, the manner in which health professionals engage with TH and DM is most prominent within their narrative and often facilitates positive and negative experiences of care.

The social determinants of health are interwoven through the account of TH and DM's experience which features economic hardship. Illness has also called into question the nature of their relationships and their story exemplifies the stressors of illness on particularly the partner. The account of these issues foregrounds how illness has disrupted many aspects of their everyday life. Despite the presenting challenges of illness, they also show their ability to adapt and adjust. In this way, they have begun to repair the 'unexpected rupture' (Watkins & Shulman, 2008) of illness to their lives by engaging in processes that are representative of moving them forward through their illness journey. These processes of repair are still ongoing as their heart journey continues. TH states: *"Yes it's not over yet"*. This overview provides a general picture of the current case.

According to previous literature, particular coronary conditions can pose long-term disruptions to people's lives due to the physical realities of the disease and delays in treatment (Fitzsimons, Parahoo, & Stringer, 2000). Research suggests people's lives can change as everyday life is disrupted with managing a more pervasive heart condition and the need to access healthcare on a frequent basis (Östman, Ung, & Falk, 2015). In addition, researchers have documented how patients and their families can be confronted with particular social consequences of illness, such as financial concerns and its related negative repercussions to the conduct of everyday life (Jan, Essue, Jeon, Wells, & Whitworth, 2009). Furthermore, Knowles and colleagues (2016) reported the roles within the family unit and life circumstances for families can change as coronary patients become unable to carry out the usual tasks of managing the household, work, and family life. Partners of coronary patients assuming caring roles can also experience considerable stress and feel isolated (Knowles et al., 2016). The case of TH and DM presented in this chapter personifies many of these issues that form the focus of the current chapter. This case will emphasise how illness can pose considerable disruption to the lives of patients and their immediate whānau. In particular, how certain social conditions of illness must be considered within the context of healthcare experiences.

In this chapter, I first discuss TH and DM's experience of moving through the *"up and downs"* of illness and then discuss particular issues surrounding access to care. This is followed by an exploration of TH's experiences of care and how TH and DM present 'good' and 'bad' characters in their co-constructed illness narrative. I also explore how CVD has impacted their broader everyday lives and attend to the economic strain and the impact of illness on various relationships. This is followed by an exploration of how TH and DM show signs of adapting to, and incorporating illness into their everyday lives in ways that mitigate aspects of the disruption they have experienced.

The ups and downs of illness and experiences of accessing care

TH and DM's story emphasises a more "*up and down*" experience of illness. In the first part of this section, I focus on how TH and DM experienced a crisis situation and an unexpected rupture to their lives. I then discuss how their journey involves setbacks and uncertainties surrounding TH's condition and proposed medical intervention. In addition, access to care forms an important part of TH and DM's story of their heart journey, which was constructed as a compulsory and persistent process of active engagement: "*I don't think we had any barriers in front of us at all. It's just been full on just go go go".* Despite their perceived ability to access care, their story highlights particular factors that influence their access. In the latter part of this section, I discuss how effective communication can influence access to care and how everyday circumstances can influence such access, particularly for patients living in rural areas.

TH and DM reflected on how CVD unfolded in their lives through the portrayal of a crisis situation and sudden 'rupture' (Watkins & Shulman, 2008) to everyday life. Here, a crisis constitutes a sudden onset of medical impairment and/or disability, a life-threatening diagnosis, a loss of valued function and being highly traumatic (Livneh & Antonak, 2012). Such elements are evident within TH and DM's account. DM describes the initial crisis situation when TH is taken to Tokoroa hospital and *"went straight into the re-suss room"*:

> **DM***: They said they want the ambulance to Waikato… That was a P1* [priority 1] *at the time… That was the panic of our lives… I didn't go. I was that tired I ended up coming home and sleeping. The next day me and my daughter shot up. But at the time, his oldest daughter was up in Hamilton… Yes, she was staying there so she went up to the hospital and our son shot through from here… They thought his kidneys were going… And because he was drugged up most of the time ya know, he couldn't tell us what was going on with himself ya know? How he was and what not… Yeah no, he pulled himself out of it. He showed them "nah that's not what's wrong with me".*

In this extract, the demands of TH's heart condition are highlighted where critical events appear exhausting for loved ones. DM's account illustrates her attempts to respond to the demands of illness by organising logistics and mobilising the resources of whānau to collectively share the load of supporting TH. Moreover, her account emphasises TH's determination and willpower to convey to doctors that his kidney diagnosis is incorrect. TH's actions forced doctors to re-examine the source of his critical event as DM states: *"He got himself all better and started being independent… Everything started healing and then, yeah, they realised it was his heart instead"*. TH's cardiac event and being diagnosed with a 'leaky valve' meant he was therefore designated as being unable to officially drive a truck. His account conveys the effects of having his truck license suspended: *"The finances have dropped quite badly… I've lost my truck license and everything"*. TH and DM's simultaneous mention of: *"That was the start of everything"*, suggests this crisis event represents the sudden rupture to their lives. TH's abrupt onset of life-threatening symptoms, DM's sudden need to act, and having to comprehend and manage numerous matters within a short period of time represents their 'crisis' situation (Livneh & Antonak, 2012). Following this crisis situation, TH experiences further complications with his heart.

TH and DM discuss returning to hospital on multiple occasions for complications relating to TH's heart condition. TH reports suffering setbacks and undergoing numerous processes of medical testing and monitoring. He states being fortunate to be alive: *"It's like every time we go somewhere and they check through the files and they* [health professionals] *go why are you standing in front of us? You shouldn't even be here".* Their story illustrates the experience of more severe disruption with being exposed to ongoing interruptions to their lives and several critical situations. In the following account, TH and DM emphasise the 'up and down' process of their heart journey through experiencing critical setbacks and surviving through them:

> **TH**: *Cos they* [health professionals] *reckon I've died twice.*
>
> **DM**: *Yeah, he ended up in ICU* [intensive care unit] *and this, it was the second time when he collapsed. He died on the way to Waikato but they* [emergency staff] *didn't tell me that… They were really good they didn't tell me that. And even when I was in the emergency centre and I was just down from him in the waiting room… They had re-sussed him and here's me thinking he was just sleeping… Even they* [doctors] *were frightened that he might not come out of it* [his coma]. S*o, it ended up being an awesome morning because he did end up coming out of it.*

Here, TH states his close encounter with death and his survival of multiple critical situations. DM emphasises her unawares to TH's critical situation at the time and expresses her gratefulness to being oblivious. This extract emphasises the unpredictable forces of CVD and how it can induce multiple crisis situations for patients and their families. The account reflects an emotionally turbulent time for whānau as notions of fear and happiness are conveyed in this situation. DM's account highlights her relief of TH coming out of his coma and such events reflect the 'triumphs' of illness (Frank, 1995). This extract emphasises how TH and DM have worked through severe setbacks in their heart journey and have overcome very serious events. Though, his up and down journey has created some uncertainty.

A diagnosis of one's illness can often provide some relief to patients as they are given some perspective about their future. Not having a clear or reliable diagnosis can leave people in an ambiguous situation (Radley, 1999). This ambiguity is evident within TH's case where notions of uncertainty exists surrounding his heart condition and the outcomes of medical intervention:

> **TH**: *Oh, at the first time I didn't really know and I still don't really know what was going on… They* [doctors] *said this, they said that, and then they said, ya know, 'kidneys'… Then all of a sudden there's nothing wrong with that… Well they are hoping it's the defibrillator… Hopefully that'll do it they reckon, but you never know*

> *it might be something else… Same as the bypass, that should do it! But six weeks later, I'm back in hospital again… And one of the bypass parts that they put in is buggered! A bit of up and down.*

Here, feelings of uncertainty are apparent with the identification of what ailed TH. His account emphasises a changing and evolving condition overtime where he still remains unsure of his diagnosis. The next treatment plan of "*defibrillator*", is approached with a sense of hesitancy and caution. The need to return to hospital following bypass surgery now casts doubt regarding future plans for intervention. Previous reports have also highlighted the frustration and uncertainty patients experience when suffering setbacks following a coronary event and treatment (Forslund, Jansson, Lundblad, & Söderberg, 2017). Participants reported how the setbacks of new disease following intervention impeded their progress forward which appears to resonate with TH's case (Forslund et al., 2017). Within the context of these up and down times are considerations surrounding access to care.

As outlined in chapter one, there are a range of personal, situational and structural factors that may influence how indigenous peoples access healthcare, including symptom recognition and expectations (Kerr et al., 2010), and the orientation of healthcare services (Jeremy et al., 2010). This couple's story brings to light the importance of understanding access to care alongside the demands of conducting everyday life:

> **DM**: *He* [TH] *rang me and said he was sick, and he was actually working driving a logging truck… When he called, it* [the truck] *was loaded at the time… And it took you how many hours to get back to* [home]*?*
>
> **TH**: *Oh, about three or four hours…*
>
> **DM**: *From Taumaranui, yeah from Taumaranui which is unusual.*
>
> **TH:** *I just couldn't walk… I knew there was something wrong, wasn't sore or anything… I just had to sit there a bit longer… None of the boys was on the radio and couldn't get a hold of despatch so just carry on.*

This extract demonstrates how signs of illness can compete with the activities and responsibilities of everyday life. TH's report illustrates the disruption he feels at the time and his uncertainty surrounding his symptoms. TH's account expresses his attempts to persevere with driving as a consequence of not obtaining help from others or seeing any other option. DM then indicates how unwell TH was feeling at the time, which is reflected in his reported extra ordinary action of ringing his GP: *"I remember that day very well because he rang me and said he had already made the doctor's appointment"*. At this appointment, TH is offered some perspective relating to his condition.

Communication between health professionals and patients is documented as having an impact on access to healthcare for cardiac patients (Artuso et al., 2013). The importance of communicating with patients using understandable language to support their comprehension of the situation and the importance of prompt access to cardiac care is illustrated through the following extract:

> **DM**: *At the time it was just his heart. His heart was like up to 200… Well virtually the doctor gave him two options. How much does it cost for a hāngī* [food cooked in the ground] *or go to hospital? So, we took the hospital.*
>
> **Samantha**: *What does that mean, how much does it cost for a hāngī?*
>
> **DM**: *See we understand it being Māori. But it's the food going into the ground to feed everyone coming to his funeral.*
>
> **TH**: *Yeah cos I've died. So, do that or do I go to the doctors.*

Here, the seriousness of TH's situation is communicated in culturally relevant terms relating to the importance of going to the hospital to avoid dying and being buried in the ground. The benefit of speaking to patients using lay terms (Lyons & Chamberlain, 2006) is emphasised in the above extract and exemplifies how a culturally-located metaphor can aid patients in comprehending the nature of their situation. TH's condition is rendered meaningful to him by his GP and facilitates his responding actions of accessing care. DM states: *"He* [GP] *had to put it in a way because he knew TH doesn't like going to hospitals at all. So, that's the only way he knew he would understand"*. This can be especially crucial when patients and their families must access care beyond where they usually live.

The push to centralise care has given rise to various specialist care being available at different hospitals across the varying DHBs. This means patients may often be transferred, or they must travel to locations outside of their usual residence (Masters-Awatere et al., 2017). This situation is prominent in TH and DM's story related to the added expense of travel:

> **TH**: *I do all that, work it out whether we got enough money to get up there* [hospital] *and back… Or if we have to stay up there, I just make the phone call… And they set it* [accommodation] *up for me… They normally ask you how long, how many days and you just tell them.*
>
> **DM**: *Lucky he's a good saver… If it wasn't for him, we probably wouldn't have gotten anywhere. It's been hard.*

Here, TH takes on the responsibility of ensuring the funds are available to visit the hospital for various appointments. The extract highlights the issues such as financial strain patients experience in accessing care. Such processes can involve the use of both personal and social resources. TH's account illustrates how he makes use of the travel assistance resources (Ministry of Health, 2013) to lessen the financial strain of accessing care. He also foregrounds the importance of people knowing about such services and how beneficial they are: *"A lot of them* [patients] *they gotta find out what's out there for them… Like the supports from the hospital… They've got some big support"*. Moreover, the significance of these supports is understood through DM's assertion that such services can make accessing the hospital more comfortable: *"They are a good asset they're* *real helpful, saved me from sleeping in the back of the car"*. This co-constructed account illustrates how accessing care is a process for some rural patients and the importance of having particular resources to facilitate the process, which despite the availability of resources was constructed as an 'up and down' or mixed experience.

To recap, TH and DM's account conveys how they experienced a sudden disruption of CVD to their lives through the way it invoked a crisis situation and changed their conceptions of everyday life. Their story does not reflect a process of moving steadily through access to care, diagnosis, treatment and recovery. Instead, their story is comprised of unpredictability, setbacks, emotionally unsettling times and a lot of stress. TH's expression of uncertainty brings into consideration the impact of suffering ongoing heart related setbacks. In addition, their story raises important concerns surrounding access to care and what can delay and facilitate the process. I now turn to explore TH's experiences of care.

"A lot of the nurses were pretty good…Some doctors were good"

TH and DM's experiences of care form a large element of their co-constructed illness narrative. Complementary to their storying is figure 3, which depicts the relationships TH and DM perceive to have with certain professionals in TH's care (the meaning of each line is positioned to the bottom left of figure 3). TH and DM depict a 'strong' relationship with most health professionals using the straight lines in figure 3. However, they perceive the relationship with hospital doctors to be 'up and down' as shown with the curvy line. I elaborate on such distinctions in the current section and provide further context to the lines pictured in figure 3. I will focus on the importance of relationships, the importance of 'knowing' and the value of the CRN in his care. I begin by discussing the issues surrounding relational continuity of care in the hospital setting and beyond.

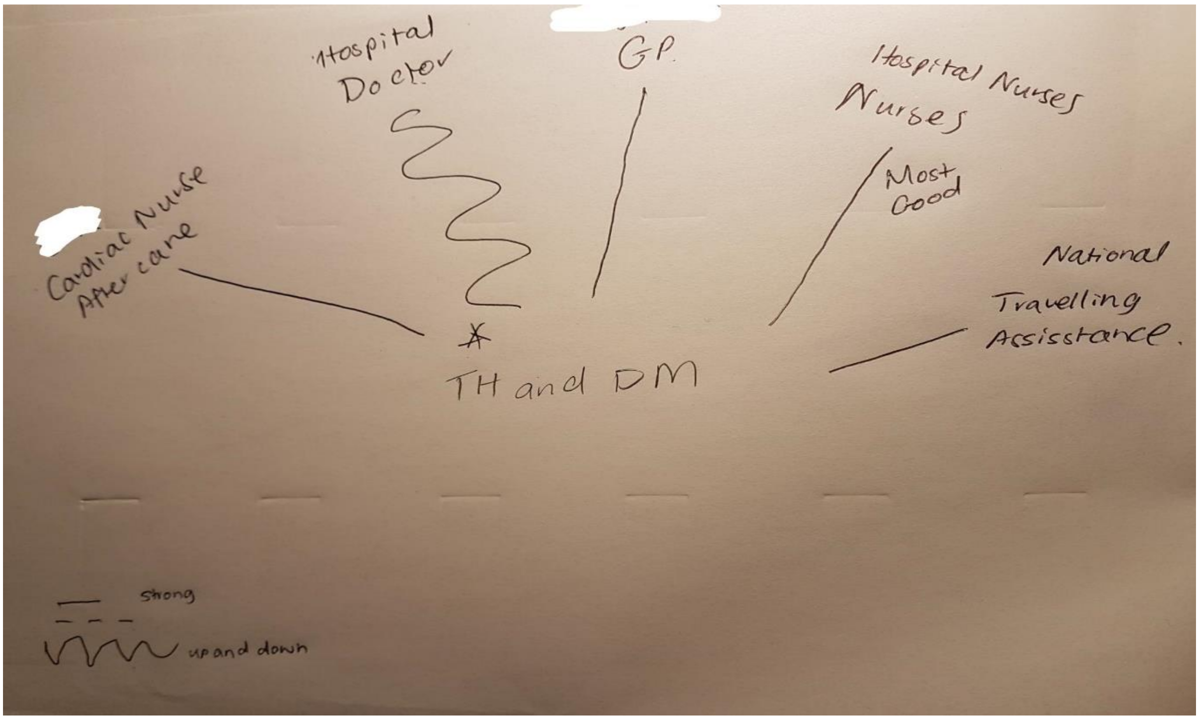


Figure 3. TH and DM's drawing of health professional relationships.

It is important to reiterate that TH resides in a small town and has a strong relationship with his GP that is depicted as being central in figure 3. TH and DM often emphasised their GP's proactive and consistent involvement in TH's follow up care: *Our family doctor up here was really good when it came to that* [follow up care]. *Ringing through to Waikato and finding out what had happened. What needed to be done and follow up appointments*. TH's GP is given a strong line in figure 3 because "*they know their patients"* and are central to continuity of care (*cf*., Reid et al., 2016). However, coronary care can often involve various health professionals interacting with patients (Giuliano et al., 2017). Having multiple professionals involved in one's care can sometimes induce a fragmented experience and this is evident in DM's account:

> ***DM:*** *You never know who you're getting. Like a GP, you know, you expect to see your doctor. I mean, when you go to the hospital, you're given this one doctor right, and then not long after that you've changed to another doctor. And then next minute, they're changing things on you and then you're wondering what the heck's going on… Yeah, there's never an assurity that that's actually gonna happen that day… That's the reason why they're up and down.*

In this extract, the lack of relational continuity of care is presented as an unsettling hospital experience. DM's account suggests the changing of doctors is a disruptive and confusing process as it naturally comes with the shifting of plans and style. Although treatment plans may be subject to change, the importance of communicating this to patients in effective ways is evident in DM's statement: *"One minute you could be going for an ECO, and then next minute they're gonna* *change it to the next day, and there's another doctor coming in and going oh nah, you going at this time*". DM's statement suggests the interactions between TH and the doctors are not informed by manaakitanga. For her, the lack of continuity of care induces an 'up and down' experience with hospital doctors. This also brings to light the importance of relationships as a foundation for caring.

TH and DM reflected on the close relationships and bonds they have formed with the nurses throughout their heart journey. Their account advocates the nurses' engagement in processes of whakawhanaungatanga as an important part of caring. The couple invoked the importance of informal greetings between themselves and nurses as: "*it's like first name basis".* This seemingly mundane gesture highlights the importance of some informality for developing bonds of care. Whakawhanaungatanga is also evident through the social practices enacted between TH and the nurses:

> ***TH****: The nurses down there knew I was playing up, fair enough. And from the first one* [heart event] *I was playing up. I was asking for certain stuff and they ended up just getting it and I calmed right down. Like a fan, or when I'm staying there moving too much, they put earphones on me and put music on… Put a radio on and when I went back in, they go, "oh that's so and so. Yep. Oh well we can get him a fan".*
> ***DM****: They set his whole area up for him cos they, ya know, remembered him from last time… They were really good.*

TH and DM's account points to an appreciation of nurses treating TH as a person with certain needs as opposed to a patient with an ailment. The mundane practical actions of nurses emphasise how forming culturally responsive connections with patients can facilitate positive experiences of co-operation and care (Levack et al., 2016). It also reflects the nurses' efforts at creating a 'home space' for TH by personalising his small part of the hospital environment (*cf*., Gilmour, 2006). For TH, engaging in processes of whakawhanaungatanga is important and can be achieved through mundane though, significant actions. Levack and colleagues (2016) have previously highlighted the importance of whakawhanaungatanga in the uptake of health-related services. Interactions that involved establishing and building culturally meaningful connections with others was considered to be a successful approach for engagements in rehabilitation services by patients.

The importance of positive relationships becomes particularly salient when it is deficient in particular interactions. TH reports a particular instance with a doctor that exemplifies how important relationships are to TH: *"He* [the doctor] *walked in and that's the first thing that come out of this mouth, wasn't even to go hi! He goes, "you're going on dialysis" and that's the end of the story*. TH's account indicates there is no sense of establishing a connection or relationship before being provided with his diagnosis and treatment plan, which was later found to be incorrect. TH's proposition that: *"he wasn't the best",* illustrates how interactions that lack simple acts of acknowledgement can contribute to less favourable experiences of care.

The uncertainties of illness can be somewhat unsettling and gathering information and being engaged with in decision-making provides a means of reducing or resolving feelings of uncertainty and helplessness (Radley, 1995). TH reflected on his lessons learned through his heart journey and especially in relation to processes within the hospital. In particular, he attributes this learning to the engagements with nurses:

> *I learnt a lot from them* [nurses] *because they told me "oh why have you got those* [pills] *for?" And I said "that's what the doctor said". "No, you don't take them unless, you know, what they're for".*

TH's account emphasises how the nurses engage in efforts to encourage him to exercise his autonomy. Their providing TH with the knowledge surrounding hospital processes and his rights aid him to be self-determining and remain actively engaged in his own care. TH asserts: *"You learn what they can do, what they can't do… So, every time they gave me a new medical, I wanted to know why".* His assertion demonstrates how his experiences enabled him to question certain elements of care for which he is unsure. Relatedly, a sense of trust appears to exist between TH and the nurses. TH perceives the nurses to be more reliable in providing the necessary information to him and conveyed in relevant terms: *"When you couldn't understand the doctor at least the nurse was there to tell you".* In contrast, such information providing is depicted as lacking at times with doctors: *"That's all the doctor had to do, was tell him* [TH] *the whole procedure, how long it was going to take, and that it wasn't a big operation... But they just went this needs to be done, blah blah blah and that was it".* Despite this, the CRN in TH's care is also considered as having similar affirmative qualities to the hospital nurses.

As eluded to in Akul's case, the CRNs at the Waikato DHB enact a valuable role by attending to, and caring for cardiac patients in the community. Such community services can help overcome the barriers of patients receiving cardiac rehabilitation care (Shepherd, Battye, & Chalmers, 2003). Cardiac rehabilitation encompasses a primary focus on reducing risk factors, improving patient prognosis and providing support towards recovery (Simonÿ et al., 2015). What is particularly salient within TH and DM's account is how such work is conducted:

> **DM**: *I think it's just the way she talks. She's on the same wave length as us. She doesn't put herself above anybody else… We understood ya know when she was talking about like a hospital term or health term or something, we understood what she was talking about… And she just explained things where we could understand. We weren't sitting there five minutes later going oh, didn't understand what you said.*

In this extract, the CRN approaches caring for TH and DM with notions of manaaki (care). The sense of appreciation invoked in this extract underlines how patients may value health professionals devoting time to explain health-related information to them. This aligns with previous reports of Fry and colleagues (2016) where participants reported more appreciation towards health professionals who spent a greater amount of time explaining heart related information to them. Moreover, the CRN is seen as a support person and a key character in the progression of their illness narrative: *"She's come right through it with us since then… She tries to help"*. The nurse is depicted as walking alongside them since coming into their lives. Their account provides some perspective to the strong line given to their CRN in figure 3. This does raise the question of how such support did not appear sooner than TH's bypass surgery in March to aid them through the 'up and downs' over the last four years.

To recap, this section has highlighted how caring not only involves technical aspects of repairing the body. For TH, caring also involves notions of whakawhanaungatanga, manaaki and keeping patients well informed. TH and DM's account of their CRN and GP illustrate how these professionals can be important partners in the care of patients within the community. The next section focuses on how CVD has impacted everyday life for this couple.

Illness and the impact on everyday life

In the previous chapter, I discussed the significant impact of illness on Akul's everyday life of work, his confidence and social life. TH's case also reflects a significant impact of illness on everyday life however, reveals other issues. In this section, I explore the economic impact and implications of TH's CVD for this couple. The key point to take from this section is that such ailments are not experienced by, and do not only impact individuals. As such, I discuss the impact of illness on various relationships.

As noted in chapter one, processes of colonisation underlie the present precarious position of many Māori (King, 2017). In particular, the loss of land and its associated economic resources has had significant repercussions for Māori as they were driven into urban areas with irregular working opportunities and lower prospects (Durie, 2001). This has contributed to Māori having less economic security and being collectively overrepresented in lower socioeconomic groupings when compared to non-Māori (Pool, 2016). For patients like TH, a CVD diagnosis with the related restrictions on working can have a significant financial impact. This is because becoming ill does not occur in isolation from the demands of everyday life (Schott & Badura, 1988). Accordingly, being ill can pose additional stressors for those with fewer economic resources for whom financial strains can feature prominently within their illness experiences:

> ***DM****: Having to make ends meet… You go from financially set to un-financial. You know, you're going backwards in those kinds of things.*
> ***TH****: Financial, pulling money out of thin air with a bill coming up, or if something happens to the car… You go through and see what you can sell… Make sure we got enough money for the next week, get us some bread and butter and that.*

Here, the account illustrates the economic burdens of illness and the precarious position patients may face. The social determinants of health are interwoven through this extract and underlines the relational nature of health and illness (Cornish, Murray, & Campbell, 2004). TH and DM's story emphasises the material effects of illness in which providing the basic needs of daily living requires more conscious effort and activity. TH and DM report having to ask themselves key questions prior to undertaking activities or making purchases including: *"where's the money gonna come from?"* Their account has similarities to previous research where participants reported the limiting discretionary spending on more expensive healthier food, reduced participation in exercise programs and the limited financial capacity to engage in recreational activities (Jan et al., 2009). It highlights the importance of considering how experiences of illness are intricately tied to the circumstances and conditions of everyday life (Hodgetts et al., 2010). Experiencing financial pressure may also compel people to return to work despite still being ill.

Patients with a chronic illness can still experience economic hardship despite accessing social welfare and other government services (Jan et al., 2009). Such situations are reflected in TH and DM's account where they often discussed the financial struggles associated with illness and despite them receiving social welfare payments. Furthermore, TH's insurance does not cover or provide reprieve to the financial strain caused by his heart condition and has actually created more stress for him: *"All the insurance was a waste of time, me paying all the insurance... So that was another big stress on me"*. Being able to provide appears very important to TH where the financial pressures and not working have had a considerable impact on him. In this context, illness has interrupted his sense of self as a provider, even though he now engages in work locally out of financial necessity despite being advised by medical professionals not to work:

> ***TH**: Well, I can't live on what they give me, what social welfare gives me... That's why even now, even though I'm not meant to be at work... Couple of the boys might call me up for a day's work or something. Couple of days so I'll go to work... Just to make a couple of dollars...Ya know, when they call you don't turn it down especially with the money we make.*

In this extract, the support of social welfare is presented as limited, and the resulting financial hardship requires TH to generate additional funds. Engaging in such work constitutes an effort to reduce the level of disruption his illness has brought to their lives. TH appears to manage the possible accusation of being medically irresponsible by emphasising how he is mindful about his work and does not endanger other road users: *"It's not on the road. In the paddock or something. Just driving the tractor. Not doing physical work. Just driving cos that's all I know now"*. The account illustrates how TH negotiates the restrictions of driving imposed on him to continue working. Nonetheless, his account raises broader issues of what financial support is available to patients towards managing their illness and everyday life (Jan et al., 2009).

In addition to financial stressors, illness has also adversely impacted whānau. TH's whānau have been moving through his heart journey alongside him and most poignantly, DM has shared this stressful time with him. In doing so, she has experienced the 'stress of caring' (Schott & Badura, 1988):

> **DM:** *You go from doing everything to doing nothing. And then you go from being able to be everywhere to me personally, being nowhere. You have to make him your first priority regardless. So, you know regardless of, right now I'm sick. But he'll always be the first priority because he's got more of a chance of just saying goodbye anytime than I have ya know? He could check out anytime where I'd be probably still standing later who knows. But it does take a toll on the family. Takes a toll on me.*

For DM, life is now lived differently where illness has imposed limitations on her very way of being. Her contributions to our discussions foreground TH's more vulnerable position where her needs are positioned as comparatively minor in comparison. Although her account presents her own illness struggles, she also reiterates her need to continue supporting and caring for TH. This not only shows her aroha for TH. It also reflects DM's collectivist focus towards whānau and putting other people's needs before her own needs. The above extract illustrates how illness, relationships and identities are interwoven together in complex ways and how partners must also make sense of illness and finding their place in the world (Radley, 2009).

More broadly, when I asked TH and DM what aids them through their journey, their response of: *"family"*, suggests whānau support is crucial. TH states: *"I gotta say, I'm lucky I got a lot of family"*. TH's whānau help them with the matters of everyday life including the upkeep of the home: *"Comes back and does some work around the house for me… Hates mowing the lawns, but he* [son] *loves the ride on"*. However, whānau also offer a type of support that is not apparent in the other three cases. The following excerpt is DM's response to a question regarding what is helpful about having family around:

> **DM:** *A sense that I can let go, ya know. That I don't have to sit around and be there all the time. Just to be able to have some 'my time' having them around. And then it makes it easier for him he's got someone else to talk to… But yeah, when his daughter started coming back and helping out it was awesome. I had that feel of belief, ya know, that I could just take off and not worry.*

In this except, having whānau involvement is presented as enabling DM to find an ordinary space among extra ordinary circumstances often accompanying serious illness. Relinquishing the responsibilities of TH's illness is somewhat freeing and her report suggests she finds comfort in knowing TH is left in the hands of whānau. The relief of having whānau around illustrates how whānau offer a type of respite. DM's assertion that: "*We go to Ngatea where I don't have to do nothing. I just kick back and be me. He* [TH] *goes fishing"*, supports this notion of whānau offering respite, which enables DM and TH to regain their sense of selves. Their account resonates with Bury's (1982) assertion that illness brings individuals face to face with the character of their relationships and how rules of reciprocity and mutual support can often change.

To recap, this section has explored the greater disruption of illness to everyday life through the discussion of the economic impact of illness on TH and DM. Additionally, DM's account highlights how illness impacts the lives of partners and is essentially life changing. Their report illustrates how the meaning of family can change. I have discussed how TH and DM have endured much through their heart journey and how illness has significantly impacted their lives. Despite these impacts, they display signs of making sense of illness and re-working CVD management into everyday life.

Adjusting to a life with illness

Despite their long journey through illness and the healthcare system, TH and DM demonstrate an ability to adjust to the circumstances of illness and this agency forms the focus of the current section. I elaborate on TH and DM's ability to adapt and TH's re-working of medication into everyday life. We also consider how storying becomes a way of re-fashioning illness into an experience that makes sense and which is manageable.

Illness can often involve processes of adjusting to the changes it brings to one's everyday life (Radley, 1999). In responding to illness, TH portrays himself as being stoic in the face of adversity and he emanates a sense of agency through illness: "*A lot of it just depends on yourself, what chu going to do about it ya know, that's all it is".* His own actions in adjusting to illness are positioned as being central to him moving forward with his life. They respond to the challenges of illness by adjusting to the circumstances imposed on them:

> ***DM**: But like with everything else you know, you learn to adjust as you go along. Ya know, you have to make adjustments in your life because if you don't, you're not gonna get anywhere. We've had to cut back on a few things, but at the end of the day we realised it wasn't a necessity… You learn what you need, you learned between needing something and wanting it and for the first time we've ever made do with what we got. Normally, there was a time when we were working, we would just update everything… Yeah, we had to go back to square one and learn to make do.*

Here, DM invokes the need to adapt one's life to the demands of illness in order to move beyond being encumbered by it. DM's account suggests they have re-worked actions of differentiating between 'needs' and 'wants' in their everyday life. Other families of chronic illness sufferers report similar needs for adjusting and re-working illness into their lives (Anderson & Bury, 1988). The account demonstrates DM and TH's resilience and strength by their attempts to incorporate new perspectives to support their moving forward. In particular, DM shares her perspective of needing to appreciate what is presently available to them: *"You need to appreciate it more ya know, what you have and that's it*". Moreover, THs ability to adjust and adapt is illuminated through his medication management.

TH currently takes medication for his heart condition and his medication is changeable in relation to his condition and medical intervention: *"It depends on what they give you. They gave me a fair bit this time. About eleven I think".* Many patients with a heart condition must adjust to taking a substantial amount of medication every day. TH's 'medication lunchbox' is depicted in figure 4 and reflects an object that often travels with him for overnight stays:

Figure 4. TH's medication lunchbox.

> *If we go away for the weekend, I take the container. Everything's in here and I just take it with me. This book is for my Warfarin. Tells me how many I gotta have a day cos you can't get that one wrong. Otherwise you overdose and swallowing rat poison well… I've gotta take* it [medication container] *to hospital too, and I'll take that so the doctors know what I've been on. Or the nurses they'll ask me and I said, "just go and check my lunchbox".*

In this extract, TH has integrated the practice of medication taking into his everyday life where the medication lunchbox reflects a constant travelling companion. He presents himself as a proficient medication user by his awareness of the stringent nature of some medications. Not only does TH incorporate medication taking into everyday life. He also adopts certain practices to aid the process: *"Sometimes it's a complete new wardrobe of medication and all I've done, I've just* *gone back to all my old stuff I got lying around with the exact same medi and I'll just use them. Saves going to get another one"*. TH presents himself as practical and tactful by adopting a strategy to reduce the economic impact of medication regimens. His account aligns with previous reports of Māori men adopting strategies to reduce the cost of accessing and procuring medication (Hodgetts, Nikora, & Rua, 2011). When I asked TH if he experiences difficulty managing these treatments he stated: *"Nah, it's just an ongoing thing"*. This quote emphasises how medication taking is now a routine social practice that populates his everyday life (*cf.*, Hodgetts, Nikora, et al., 2011).

TH discussed particular interactions with other patients during his stay in hospital. He described these interactions as involving the sharing of one's respective heart condition and related medical intervention. Such sharing enables TH to reflect upon his enduring heart journey and he appears to find some use in his own experiences of illness. TH employs narration as a way of utilising his experiences in a positive fashion to aid fellow patients:

> **TH**: *Everybody thinks like when the last time we were in there* [hospital], *there were these fellas in there. They go, "going in for an op". I say "Oh yeah?" And its minor. And I look at them and go "you'll be right ya know yeah". And they look at me "oh what are you in for?" "Oh, I just come in for, I just had my bypass and all that" and they're like "oh hell! And you're standing in front of us?" I say, "I've been here for ages, I've just come in because its blocked up again. I can't win".*

In this extract, TH attempts to relieve the nerves of patients undergoing heart operations. He stories himself as a stoic veteran of medical intervention who is still somewhat in battle with disease. His account reflects the social nature of illness and how patients may seek confidence and reassurance in others (Junehag, Asplund, & Svedlund, 2014). DM's following proposition suggests that TH provides a form of caring through his storying of experiences to others: *"He was like their inspiration…being able to talk to someone who has already been through it made it easier for them"*. This aligns with the study by Hodgetts and Rua (2010), which highlighted men can engage in more subtle ways of caring as opposed to overt displays of affection. TH's ability to engage in such activities emphasises his efforts to come to terms with his ongoing illness by re-fashioning it in alternative ways more meaningful to him (Radley, 2009). Storying is a way for him to become familiar with his sense of self with illness.

To recap, TH and DM appear to come to terms with their situation and engage in processes of adjusting to life as an essential part of moving forward with illness. In this way, they attempt to exert control over certain areas of life disrupted by disease. TH's account of his medication regimen exemplifies how he has re-worked medication taking into everyday life and has personalised such practices. Moreover, TH's willingness to provide some comfort to others emphasises how one's experiences of illness can be refashioned into stories of endurance and survival. I next bring the current chapter to a close.

Chapter discussion

TH and DM's story underlines the 'ups and downs' of illness many patients and their families endure, with illness complicating and disrupting aspects of their everyday lives (Radley, 2009). Their account emphasises how experiences of CVD do not form a linear progression to a state of health. Instead, it can involve a more changeable and unpredictable journey that can be compounded by the social conditions and particularly the economic consequences of illness. Their story highlights the broader issues of the current supports in place to aid patients with ongoing health conditions (Jan et al., 2009).

Based on their narrative, we see how illness also has significant meanings and consequences for people close to persons who are ill. Most notably, how partners enter a process of readjusting and incorporating a caring role into everyday life. A challenging time is presented as DM is confronted with having to construct new aspects of being in relation to TH's illness and sometimes at odds with her sense of self. In addition, whānau now form an important mechanism to manage the disruption illness has brought to TH and DM's lives. Managing this disruption is not only evident at the practical level. It includes support that reflects whānau taking care of the overall wellbeing of TH and DM through their illness journey. The stress of caring and how the meaning of whānau has changed highlights how relationships are examined and re-worked in light of illness (Bury, 1982). Their up and down journey is also intricately tied to the health professionals that populate their story.

The co-constructed story offered by TH and DM illuminates how the nurses attempt to 'know the person' (MacLeod, 1993), by engaging in notions of whakawhanaungatanga and having frequent communication with TH and DM. Their account demonstrates how the nurses situate the patient within their everyday lived social and cultural context and realised through the comprehensible language employed by nurses. Conversely, their reports suggest the interactions with hospital doctors are more biomedically focussed with common actions of providing a diagnosis and plans for treatment (Haque & Waytz, 2012). What their narrative emphasises is that spending time with patients can be important towards building a sense of trust. This is seen through the way a sense of trust exists between TH and the nurses with their more prominent presence in his care.

Through storying their ups and downs of CVD, TH and DM are afforded the opportunity to acknowledge the implications of CVD, and consider the meaning of CVD in their lives (Radley, 1999). Acknowledging the difficulties appear to enable TH and DM to become witnesses to what they have undergone and acknowledge what has been displaced (Radley, 1999). This is important as the repairing of illness ruptures encompasses acknowledging what 'was', to find a new way of being in the world (Radley, 2009). Thus, through this process, TH and DM re-story themselves as adaptable and interconnected beings who find some comfort in helping others. TH's report of offering some confidence to other patients illustrates how the challenges of illness can be transformed into ‘aesthetic practices’ and refashioned into more meaningful representations (Radley, 2009). In this way, TH’s enduring journey through illness and the healthcare system becomes an ‘artefact’ that is used positively to aid others through their illnesses.

Overall, this chapter has explored TH and DM’s up and down journey through illness and the healthcare system. A prominent issue within TH’s case is the nature of TH’s condition which has impacted his ability to work for a long period of time. TH’s situation and circumstances are key to his illness experience where particular economic issues has added more stress and worry to their lives. This forms a clear distinction in comparison to the two cases I will discuss next in turn. We now move into the two cases which reflect a lesser disruption of illness to one’s everyday life. I first discuss Henry’s case which encompasses a very brief disruption of illness to everyday life. His case will emphasise how patients can enter hospital for an acute event and feel they have returned to a state of health following medical intervention. Henry’s story of illness focuses more on notions health as opposed to ‘being ill’ where he emanates a sense of resistance to such labels.

CHAPTER FIVE

Henry and being ‘all good’

“…I still didn’t think I had a heart attack…”

Henry lives in a small rural town in North Waikato with his wife. Key amenities such as supermarkets, medical centres and healthcare facilities are located in neighbouring rural towns with the closest being approximately nine kilometres away. Henry owns his own trucking business and reported commuting to Auckland several days a week to drive trucks and manage his employees. He presented a socially-enriched lifestyle of working, playing golf, playing Masters League, watching the mokopuna (grandchildren) sports games and being involved in the community. These are the important activities that populate and shape his understanding and the conduct of his everyday life. My conversations with Henry were light-hearted and sometimes filled with laughter, which reflects his easy-going nature.

Henry’s illness narrative is strongly centred in ideas of health. Being healthy is important to Henry and his conceptualisations of health are central to understanding how he responded to signs of illness and interpreted the need for accessing care. Henry considered himself as healthy prior to being diagnosed by doctors as having a heart attack and despite his reportedly having pre-exiting conditions of high blood pressure and T2D. Such a diagnosis created confusion for Henry as a clear discordance existed between the medical diagnosis, his experience of a heart attack and his beliefs surrounding what constituted a heart attack. This discordance was often expressed through the way he identified the inconsistencies across these elements. In response to Henry’s claims of not experiencing a heart attack, I often tiptoed around the label of a ‘heart attack’ by using alternative terms in our interviews. My tiptoeing represents my attempts to whakaute (show respect for) Henry’s expression of his illness experience. Thus, the term ‘heart event’ has more meaning in this case. It reflects my efforts of trying to find a more accurate representation of what Henry experienced.

Henry’s story illustrates how he experienced some disruption of illness with the conditions imposed on him following a heart attack. He also had to manage the reactions of others among his social networks which challenged Henry’s thoughts of returning to his sense of being healthy. Nevertheless, Henry’s story emphasises how he considers his heart event as something he experienced and correspondingly moved on from. This is because Henry engaged in repairing the rupture of CVD to his life soon after his heart event occurred. His narrative emphasises a ‘brief’ disruption of illness to everyday life and he subsequently moves forward being relatively unchanged by the event, although with an improved understanding surrounding medication taking towards maintaining his health.

The current case will illustrate how some people who experience an acute myocardial infarction (AMI), or a ‘heart attack’ in lay terms, may have very brief encounters with the healthcare system. Patients may receive medical intervention, remain in hospital for monitoring and return home for recovery within four days if not earlier (Kaul et al., 2004). These experiences can be fleeting and fast-paced as medical professionals work swiftly to reduce or prevent damage to the heart (Thuresson et al., 2007). Pervious research indicates that some patients experiencing an acute event can return home for recovery and experience little disruption of illness to their lives (Smith, Banwell, & Rakhit, 2017). Although patients may consider a heart attack to be a shocking experience initially, they can also recover quickly and consider themselves unchanged from the event (Smith, Banwell, et al., 2017). In Henry’s case, the manifestation of his heart event and brief experience with the healthcare system contributes to his understandings of not having actually experienced a heart attack. The focus within this case is to understand how illness can be experienced as a brief disruption to everyday life and can be resisted.

This chapter documents Henry’s experiences of CVD and the importance of him regaining his sense of ‘being healthy’. The first section focuses on Henry ‘being healthy’ which includes his understandings of health and associated implications towards accessing care. The second section attends to Henry’s reaction to the diagnosis of a heart attack and how he attempts to reassert his state of health after a very brief experience of care. I also consider how Henry experiences some disruption of illness to everyday life through his inability to undertake certain activities and being reminded of his heart event through social interactions. The last section touches on the important implications of Henry returning to everyday life as a way of coping. I discuss how Henry has learnt the importance of medication taking. However, I discuss how Henry maybe unaware of other ways towards managing his heart condition ongoing.

‘Being healthy’: Implications for Henry accessing care

Previous research offers some insights into the complexity and sophistication of lay understandings of health (Bury, 2005). It has shown that lay concepts of health can be pluralistic (Blaxter, 1990; Bury, 2005). Henry’s case includes understandings of health as the absence of symptoms that are considered serious, being able to do what you want (functionality), and being relationally connected and active. These understandings inform Henry’s experience of, and responses to CVD. In this section, I elaborate on Henry’s understandings of ‘being healthy’ and foreground the implications of such understandings for his accessing care.

Important to Henry’s understandings of health is how one ‘feels’ as an indicator of being healthy. Such ideas are reminiscent of a biomedical perspective fixated on bodily signs and symptoms of illness (Lyons & Chamberlain, 2006). He states: *"Just the way you feel I suppose um yeah, just the way you feel, you feel healthy, you're feeling good".* His statement indicates, if symptoms are absent or considered minor and do not disrupt his sense of regular bodily functioning, then Henry considers himself to be healthy. In addition, Henry reconciles other aspects of his life and incorporates this into his conceptions of health. Below, he draws on the classic functionality trope of health as being un-encumbered and able 'to do what you want':

> **Henry**: *I think being healthy is… Doing all the things you normally do in everyday life. Um, that's what I think health is. If you can't do those things, you're not healthy.*
> **Samantha**: *Being able to do activities is important to your health?*
> **Henry**: *Yeah everything, everything you do in a normal day life. Get up go to work, get up go and play golf, get up and play masters* [Rugby League]. *Yup if you can't do that well yeah, somethings happening.*

In this extract, health encapsulates the ability to function and engage unencumbered in everyday life. Health, as presented as a functional resource (Blaxter, 1990), is interwoven into the broader activities that constitute his very being and such activities form an expression of his health. His constant use of 'get up go' to engage in certain activities suggest these activities are the mundane happenings in everyday life that shape his conceptions of the 'ordinary' embodiment of health. Henry's account also reflects Māori cultural understandings of health in the way he values an integrated perspective of health and its relational and contextualised nature. His understandings of health are evidentially holistic as he situates himself within his wider social and cultural context (Durie, 1998).

Henry's functional and relational understandings of health appear to be connected to how he responded to signs of illness. Although enabling him to stay calm and cope with disease, Henry's ability to still function and carry out everyday life meant medical care was not sought promptly for his heart. He talked about experiencing chest pains for *"about three or four months"* previous to his heart event at which point he accessed a doctor. Although, initially attributed his symptoms to more mundane health concerns:

> *I was getting sorta chest pains few and far between… Ya know, I just thought it was just heart burn sorta pain nothing serious. Then it goes away for weeks on end… Maybe four to six weeks and you have another one, nothing major just an odd pain for a little while, then it goes away so you just don't think about it… The last couple of months it was starting to get more frequent… This time it might happen once every three days and then it might happen about three times a day when it was getting closer… Oh, I better go and see someone about this.*

In this extract, Henry reflects on his initial normalising of symptoms and the explaining of chest pains as being something ordinary and non-threatening. In light of Henry's ability to still function, his 'heart burn like symptoms' did not initially seem serious enough to warrant his seeking care.

In recounting his experience, Henry presents himself as calm, relaxed and composed over bouts of pain and is unperturbed by the irregular nature of his symptoms. He expresses the lack of worry over his pain through how he manages himself: *"Ya know, you get the itch and you just rub your heart and it goes away. You don't see it again for another two or three weeks"*. Henry's story is comparable to other stories told by men who have experienced chest pains that they do not consider to reflect a serious ailment and who are later diagnosed with coronary disease (Radley, 1995).

Following the increased frequency of chest pains, Henry sought care at an emergency clinic in Hamilton. In the following extract, he describes the interaction between himself and health professionals and how he responded to the instructions they provide. In particular, the account outlines the complexities of how particular understandings of health can contribute to the responding actions of accessing care:

> *I think they said, your arteries were blocking or something and the blood was finding it hard to get through... So, they gave me some pills and I don't know what kind of pills they gave me, and then they told me to go to the hospital... They signed and filled in all these papers and said I had to go to the hospital, that's straight away... But I didn't take it seriously cos it had stopped and nothing was happening. I was all good and walked out of the emergency clinic feeling all good so I told my wife we go home.*

In this excerpt, although Henry is provided with directives from health professionals towards accessing the hospital for further cardiac care, these instructions are at odds with his sense of 'feeling good'. His account illustrates how the subsiding of symptoms negates the need for further action towards seeking care. In this way, Henry only warrants accessing care when signs of illness are more pervasive, unexplainable and disrupt his functioning in everyday life. This extract also invokes the potential issue surrounding the discordance between health professional and lay understandings of health and when medical intervention is warranted. The advice by the health professional that Henry 'should' visit the hospital appears to contribute to Henry reading the situation as less serious or immediate than is actually the case: *"They didn't make it sound like I* <u>had</u> *to go to the hospital. They said I 'should'. They told me to just go to the hospital but you know me. But they didn't make it sound serious enough I think"*. This account reflects a communication breakdown in that advice that he should go to hospital is interpreted by Henry as meaning such a visit to the hospital is not crucial. Henry did eventually access the hospital which I discuss next following the recap of the current section.

Briefly, this case highlights how important patient understandings of health are for how men such as Henry access care and interpret subsequent medical advice. There appears to be a persistent discrepancy between the medical diagnosis Henry received and his own understanding of his health status. In the next section, I discuss how Henry experiences a brief disruption to his sense of health.

A brief disruption to Henry’s health and related experiences of care

This section explores Henry’s experiences of CVD as a challenge to his health, and his engagements with the healthcare system. I first discuss Henry’s initial reaction to being diagnosed with a heart attack and the process of his making sense of the diagnosis and its challenges to his health. Considered are Henry’s attempts to resist being ill by claiming to be well following medical intervention, and the practices he employs in the hospital to facilitate this self-perception. Despite minimising the seriousness of his cardiac event, disruption is most acute for Henry in his account of his return to everyday life after his hospital stay. He stories his illness relationally through an account of modified interactions with his work colleagues and his efforts to convince others that he is healthy. In doing so, he conveys some of the implications of CVD for the conduct of everyday life, which I discuss in the latter part of this section.

A cardiac event can be a shock to patients and especially for those who consider themselves as healthy and who do not experience life-threatening symptoms leading up to the event (Hutton & Perkins, 2008). This is apparent in Henry’s case where the sudden revelation of a ‘heart attack’ creates a sense of disbelief at the thought of his heart failing him or that he might not be as healthy as he thinks:

> *Well my reaction was holy shit! But my hearts good! The heart attack was the last thing on my mind… When they diagnosed me as having a heart attack, that was when I said I mightn’t be that healthy after all… It took that heart attack to, maybe I’m not that healthy. I still think I, well they said I did, I don’t know I suppose I did. But it didn’t feel like a heart attack. Cos it* [the pain] *comes and then it goes ya know. So, when it* [the pain] *goes it’s all good. So, go and do normal things and then comes <u>again</u> it’s just a well. I dunno what a heart attack is, its I just had a pain in the chest that was it. No other symptoms.*

In this extract, being diagnosed as having a heart event means being unable to claim the status of being healthy. The diagnosis produces feelings of shock where CVD is constructed as disrupting Henry’s claims to health. The extract emphasises how Henry attempts to work through the shock by making sense of the chasm between his experience of health, a heart event and corresponding diagnosis. Henry has the expectation that a real or serious heart event should entail more than what he experienced. As a result, he maintains some uncertainty surrounding what a heart event is or should feel like and whether or not he actually has a heart condition. The presenting symptoms did not match Henry’s understandings of a heart attack at the time where he thought that such events were fatal: *“I thought when you have a heart attack that’s it!... Ya know, died!”*.

Henry now understands there are varying degrees of heart attacks: *"Ya know, like some people die like my nephew, he died of a heart attack. He must have had a real bad heart attack… I'm lucky I didn't have that one"*. The account also emphasises how his grave understandings of a heart attack are informed through social relations. This social world also includes other outlets such as the media that Henry also mentioned as informing his understandings of a heart attack.

Henry reflected on the swift process of examination and related medical intervention for patients experiencing a heart event. Patients who experience a rapid recovery and resolution of symptoms following medical intervention can often experience not feeling as though they have actually had a heart attack (Dullaghan, Lusk, Donnelly, McGeough, & Fitzsimons, 2013). This is apparent in Henry's case where he attempts to return to a state of 'being healthy' again following medical intervention:

> *They put me straight into the stent doctor or whatever they do and put a stent in that night. Yeah, it was within a couple of hours of me going in I had the stent in. They move that fast! Yeah, I was ready to come out* [of hospital] *again after that. It was yeah, everything was, after I had the stent in, I was fine. I was fine. And I'm no, it's still fine now. It's been fine. That's why I still ya know, I didn't think I had a heart attack.*

For Henry, the repairing of his ailment within a matter of hours is surprising. He emanates a sense of resistance to being ill despite undergoing medical intervention, and he remains stoic despite his felt identity of a healthy person being threatened. Such stoicism is corroborated through his claim of being healthy following medical intervention and not believing he suffered a heart attack. This reflects his attempts to protect himself from the connotations associated with being positioned as a man with a defective heart or who is ill. Further, Henry resists being ill by engaging in practices during his stay in hospital to maintain his sense of 'being heathy'.

Henry had not frequented the hospital often prior to his heart event and *"it was sort of a culture shock for me staying in over the weekend"*. Reflecting on this stay in hospital, Henry reports feeling *"locked up"* and *"stuck there"*, and most notably whilst being wired up to the heart monitors following his medical intervention. Although the hospital is constructed as a restrictive and limiting place in comparison to the freedoms of everyday life at home, Henry describes how he engages in certain activities during his stay more representative of his usual self:

> *Met a few friends in there… Oh a couple of times we went for a walk to the café up the road. About ten to fifteen minutes away. Went out to the foyer cos they had some live groups there singing so, no they were entertaining. So, we went down there and then yeah that's about all we did... Me and my mate next to me, that's that car guy from coromandel… Come back and have our lunch and off again. I dunno if we were allowed to go but we disappeared anyway.*

In this extract, although distanced from his everyday life, Henry engages in efforts to enact his identity as an active and healthy person despite the extra ordinary circumstances of being in hospital. His everyday self as a social and functional being is re-fashioned somewhat in alternative ways that work to buttress notions of being ill. Accordingly, Henry attempts to repair the discontinuity of self he felt in hospital by engaging in practices and activities that enable him to present a more preferable version of himself as not 'ill'.

In the context of seeming to struggle with the imposition of a new identity as an ill person, Henry presents his experiences of care in hospital only briefly in comparison to the other three participants. In the following extract, Henry discusses his positive experiences of care that he seems to not really accept as being necessary:

> **Henry:** *They were really good the nursing staff and the doctor, the doctor was really good. And um, I didn't see him again until the Monday and that surgeon that put the stent in me… But the nurses were good over the weekend. I thought they were really really good.*
>
> **Samantha:** *What was 'good'?*
>
> **Henry**: *Well nothing really, I suppose… I didn't really need them cos I was very good ya know, I never had a problem but yeah, they just were there just to give us our pills and whatever, take my sugar count levels check on those, check my cos I was on the monitor the night before and the day and so they just checked all that.*

In this extract, Henry expresses his contentment surrounding his care. Although several health professionals are reported to be involved in his care, his account underlines the more frequent and helpful contact with nurses. In his account, Henry reinforces the notion of being healthy by claiming to not really 'need' the assistance of others. He disassociates himself from being an ill person which warrants only brief encounters with health professionals.

Both Henry and Akul underwent similar medical procedures and they both reported the role of medical technology in their awareness of their conditions. Interestingly, the participants account regarding the 'necessity' of such resources differ where Henry seems less concerned about its use:

> ***Henry**: Oh, I was very aware, I was watching everything ya know, or so I thought I might have been watching everything but really, I was just looking at the monitor… Yeah, I think they explained it, what they were doing to me and why and that's all I needed to know… Well, I probably didn't even need to know that but that's what they told me anyway. What they were doing.*
>
> ***Samantha**: If they didn't have the screen, what do you think it would have been like then?*
>
> ***Henry**: Well I probably wouldn't even have a clue what's going on. I probably wouldn't have known a thing… It probably wouldn't have bothered me.*

Henry discerns between 'watching' and 'looking' where the account conveys notions of inattentiveness implicitly. The account emphasises Henry's preference to distance himself from the procedure through the reports of being provided with more information than what he needed to know. This extract illustrates Henry's more relaxed approach to understanding and participating during medical procedures. The remainder of this section now turns to the disruption Henry experiences within his everyday life following his discharge from hospital.

The conditions imposed on those who have experienced a heart attack often involves not working and driving temporarily (C. Shepherd, personal communication, July 7, 2018). For instance, Henry is a truck driver. Upon returning home, he could not revert to driving a truck for six weeks and until medically tested and deemed fit to drive. As such, his illness made this aspect of his life somewhat unfamiliar (Radley, 1999) and lead him to question his being prevented from participating in such previously taken-for-granted everyday activities when he feels healthy:

> *That was really hard for me because I was so used to being so active and work wise and ya know, for all my life I've been doing that… It was quite hard, I sort of sitting here, what the hell do I do now ya know. I mean there's a lot of things you can do around the house but you don't really do it… And you can't really go anywhere without somebody taking you cos you're not allowed to drive, that's hard too… Just being idol, I don't like being idol… That sucked!*

In this extract, the challenges of returning home are illuminated as the interim conditions imposed on Henry disrupts his ability to carry out everyday life. Everyday routine contains the things of importance to Henry and in turn shapes his sense of self. Being prevented from engaging in such activities appears to create a sense of confusion. Through his account, we can see how particular social practices such as driving a truck are important markers of his understandings of health and response to illness. As outlined by Radley (2009), people can engage in certain activities as a way of expressing their state of health and level of recovery. Thus, Henry's inability to work and perform certain activities reflects the disruption of illness. In addition, having to rely on whānau to be driven places proved difficult for Henry and he often avoided asking for assistance to avoid disrupting others routines: *"You gotta ask somebody can you take me here, take me there. And then nine times out of ten, you don't even bother… I sort of didn't really want to interrupt them I suppose".* Henry experienced being marooned within an illness state at home despite feeling healthy.

As mentioned previously, Henry understands heart attacks to be critical situations with severe and grave consequences, although has not fully adapted such seriousness to his own situation. As such, aspects of public narratives regarding heart attacks drawn on in the reactions of others towards him are at odds with Henry's sense of feeling well. He presents himself as having to manage such tensions within his everyday social interactions:

> *All you hear is other people saying "how are you, how are you, are you all good?" "Yeah I'm great" ... "Take it easy". I said, "but I'm good" ... I just keep saying "I'm all good, I'm all good..." Maybe because they don't know how I feel. They just think I had a heart attack so I'm not all good and that's what they must be thinking.*

Here, the worry and concern of others demonstrates how a medical diagnosis can follow one into their social world and produce a range of reactions requiring active management. Henry's account suggests he must contend with the dominant ideas and assumptions of a heart attack and potential negative connotations attached to it. He shows resistance to such negative connotations and engages in repair work to restore his image that the label of a heart attack had tainted. He presents himself as committed and staunch regarding his level of health and reasserts he knows his body. Although Henry appreciated the concern expressed by members of his social networks and whānau, he experienced this as a questioning of his level of health and continual reminder of an event he was hoping to move on from.

In everyday social interactions, Henry works to present himself as someone who is not ill or incapacitated despite the meanings that people in his social network draw upon in responding to him. His account speaks to how particular illnesses have stigmatising elements in which people are subjected to the social repercussions of illness (Bury, 1997; Radley, 1993). Such stigmatisation of health issues can induce whakamā (shame/embarrassment). Henry states: "*Well I think I was more embarrassed than anything... Oh I just think um ya know it's a health issue and ya know health issues ah, you don't want to talk about to other people I suppose".* Additionally, Henry reported his reluctance to initially tell extended whānau of his heart event because he understood the worry and concern it would invoke. He did not consider this warranted after considering his heart event as not reflective of a heart attack: *"I was all good ya know, everything was fine and I still felt that I didn't have a heart attack so, I didn't think it was worth the hassle of worrying them* [whānau]*".* Henry's account demonstrates his awareness of certain assumptions surrounding health issues that in turn creates apprehension in his sharing the event with whānau.

To recap, Henry's diagnosis of a 'heart attack' briefly disrupted his sense of self as a healthy person. In subsequently questioning whether or not he actually had a real heart attack, he quickly repairs this narrative rupture. Henry's account of his hospital stay invokes his resistance to understanding himself as an ill person. However, Henry felt some disruption of illness upon returning home for recovery through not being able to undertake the mundane and taken-for-granted activities of everyday life. We see how dominant narratives regarding a 'heart attack as serious illness' was experienced as a challenge to Henry's sense of being healthy and his position as someone who had merely had a minor health scare. The next section explores the importance of Henry returning back to the routines of everyday life as a means of overcoming illness.

“I’m fine, I’m all good”: Further denial of illness and incapacitation

Henry regularly emphasised his status as a healthy person despite having CVD. Such claims appear to enable him to situate his heart attack as a minor interruption to his everyday life, which has been resolved. In this section, I discuss how Henry’s narrative repair of the minor disruption of CVD involved regaining continuity in everyday life. I consider how this may have implications for managing his heart condition ongoing.

It is important to dwell on the importance of Henry returning to everyday life a little more because he stressed the significance of moving on from his heart event as quickly as possible. Most notably, returning to everyday life for Henry provides a means of coping and self-protection, and to avoid CVD defining him:

> *Well the quicker I get back into the things the less I worry about what’s happened to me… If I start thinking about my heart attack all the time, it probably has an impact on what I would do so if you don’t think about these things and just carry on with your normal day life, it’s all gone… The only thing that I know that I had all those things is all the pills I’m taking now. Before I wasn’t taking the pills at all and now I gotta take them… So that’s the only thing that’s reminding me.*

In this extract, slipping back into everyday life reflects Henry’s attempts to overcome the threat of illness to his personal narrative and the importance of functionality in demonstrating health. Henry’s account suggests illness has the potential to change the landscape of how he conducts his everyday life in which the very contemplation of his heart event presupposes disruption. Henry’s attempts to engage in previously mundane everyday practices smooths over the disruption of illness and forms a pathway to normality associated with a sense of health. In this way, a return to the conduct of his everyday life appears to offer a safe haven for Henry in which he can regain a sense of security and respite from illness. However, this transition from illness back to everyday functionality and health remains incomplete. The pills Henry must now consume hold particular meaning in reminding him of his heart condition. The medications are not simply absorbed into his body physically. These objects are also absorbed into his life psychologically as reminders of his illness (Hodgetts, Chamberlain, et al., 2011). To complicate the matter further, Henry is also reminded of the importance of medication consumption in order to prevent another adverse heart event, and as such a reminder of the tenuous nature of his health is now ever-present in his everyday life.

Medication taking is not completely new to Henry with his pre-existing health conditions. As a ‘passing comment’, Henry disclosed not routinely taking his blood pressure and diabetes medication in the past. Through the process of suffering a heart event, Henry realises the importance of medication taking:

> *So, all this has made me realise what my pills are for, why I take these pills. Ya know, before I was only taking um high pressure pills* [high blood pressure] *or something*

> *and my diabetes pills but I never used to take them… Well I thought I was feeling good yup, didn't worry me. But now that I know all this, shit I better take my pills… I just well cos, I didn't know much about these pills and what actually they do. I didn't bother about it but now, I know Aspirin's a blood thinner aye. I gotta take that for the rest of my life yeah, and I gotta take these um, some plaque pills that… clears the plaque in your arteries. So, I gotta take those for at least 12 months so, now because I know what they actually do inside you, you do take them. But before it's alright, I'm alright.*

Henry now articulates the importance of taking his prescribed medications to maintain his sense of 'being healthy' and thus incorporates this into everyday life. His account emphasises his initial sense of uncertainty surrounding certain medications and their purpose where taking medication is depicted as being at odds with Henry's sense of 'feeling good'. His account aligns with previous research conducted with Aboriginal and Torres Strait Islander peoples (Swain & Barclay, 2013), which found that people often grapple with accepting why they need to take certain medications when they felt good and their health checks reflected a good state of health. Such experiences raise the importance of ensuring patients understand the preventative measures and the meaning and purpose of medication taking.

Despite a heart attack being a shocking and sudden experience for some, patients can also move forward from the experience reporting being unchanged and making a positive adjustment to living with the threat of further heart problems (Smith, Banwell, et al., 2017). This is apparent in Henry's case where his heart event is not considered to have impacted him negatively in relation to his thoughts regarding his heart and general health. In particular, Henry discusses why his outlook on his health has not really changed:

> *But what really sort of made me say I'm all good cos when they had that photo of your heart, they reckon my heart is in real good shape. So yeah, everything all the valves are all working well and so oh yeah, I'm good! So that really put me in another frame of mind about my health… Yeah it was all good… Just carry on with your normal life. I'm just doing the same things I was doing before… Just carrying on.*

Henry's account emphasises how the feedback from doctors has a lasting effect on how he understands his heart health moving forward. Such feedback offers a new perspective to Henry regarding his health that counteracts the impact of suffering another negative heart event. The account emphasises Henry's adaptable and malleable nature through the way he reports moving on with his 'normal' everyday life. However, Henry's report of returning to his usual everyday life may have repercussions for the future.

Patients are often encouraged to manage their CVD once diagnosed to reduce or prevent further issues. This may involve making particular lifestyle adjustments including eating habits work situations, and physical activity (to name a few). For Henry, feeling good following medical intervention does not warrant any future changes and he prefers returning to the familiar and predictability of everyday life: *"If I feel good, I'm all good and I haven't thought about changing".* This should not be interpreted as Henry's 'disinterest' in looking after his health. He reports having little knowledge on how to prevent a subsequent heart event: *"Looking after my heart, I wouldn't have a clue how to do that".* This uncertainty reinforces the educative value of having the CRNs working in the community who remain in dialogue with patients following their discharge from hospital (C. Shepherd, personal communication, June 26, 2018).

To summarise, Henry places importance on reaffirming his sense of being healthy by elaborating on the importance of returning to everyday life and moving beyond the disruption of illness. Undertaking the activities of everyday life forms an essential part of Henry's strategy to overcome his heart event despite being reminded of it through his daily consumption of medications. By embedding the routine of medication consumption into his everyday social practices, he is able to manage the threat of a repeat event. Although Henry has a positive outlook of his heart and health moving forward, I have highlighted possible issues of his reluctance to accept and manage his ongoing heart condition.

Chapter discussion

This chapter has explored the meaning of CVD as a brief disruption to Henry's sense of being healthy. What is clear through Henry's account is the strong motivation towards feeling healthy and also being seen to be healthy by others (Bury, 2005). In previous research, Blaxter (1990) demonstrated that health, disease and illness are not mutually exclusive within every day or 'lay' understandings. Participants in her study frequently stated that they saw themselves as healthy despite being diagnosed with serious conditions, such as diabetes. Such research not only resonates with Henry's case. It underlines how health can be taken-for-granted as a normal state of being in everyday life that is threatened by the advent of illness (Bury, 2005; Radley, 1995).

Henry's narrative not only tells us about his personal experiences of illness. It also exposes some of the shared meanings evident in public understandings of CVD specifically, and health and illness in general (*cf*., Lyons & Chamberlain, 2006). His account illustrates how the contentions across the shared meanings of a heart attack and his own experiences actually created a space for Henry to realise new understandings and insights regarding heart attacks. In many respects, Henry (like the other participants in this study) re-crafts his own self-narrative against the backdrop of broader public narratives. In doing so, he was able to not only develop an account of CVD that is intelligible to others, but to also challenge dominant ideas regarding heart attacks and how one must respond (Radley, 2009; Watkins & Shulman, 2008).

To reiterate, heart disease is a chronic illness that requires ongoing management. Their condition presents people such as Henry (and other participants in this study) with the prospect of living with disease and adjusting to a life rendered different (Radley, 1993). However, Henry's case tells us how he chooses to keep adjustments to a minimum such as taking the necessary medication. Henry does not appear to engage in adjusting everyday life excessively because this means accepting, he had a heart attack. From looking at Henry's response, it seems important to take into consideration how patients understand their illness. Previous literature has highlighted that the illness experience (symptom manifestation and treatment) can influence how patients interpret their heart conditions as 'serious' (Dullaghan et al., 2013). Such interpretations were found to adversely impact the participants motivation for lifestyle and behaviour changes to support their condition. Thus, understanding the patient's perception of their illness may be useful in cardiac rehabilitation to develop approaches that better cater to the needs of patients (Dullaghan et al., 2013).

In the process, Henry storied himself as having a fleeting experience of illness. He can be viewed as constructing his normal everyday identity in which he positions himself as moving from the temporary extraordinary circumstances of illness to the 'ordinary' of everyday life (Radley & Billig, 1996). The need to legitimate such a position is to reconcile his understandings of not having actually had a heart attack and substantiate his claims of being healthy. Overall, Henry's account of the brief disruption of illness provides another diverse perspective of the meaning of CVD. We can see how Henry's case differs significantly from Akul's and TH's case discussed previously. Henry's disruption of illness was very brief and appeared to be more manageable than what Akul and TH have experienced. In the following case, I discuss Noah's experiences of CVD. Noah's case differs somewhat to the previous three cases I have discussed with the foregrounding of his somewhat positive experience of CVD and the healthcare system. His case will emphasise his experience of a more minor illness disruption within the context of everyday life.

CHAPTER SIX

Noah and the 'Zipper Club'

"For what it was… it was a positive experience"

Noah lives in the Northwest Waikato region with his wife and five tamariki (children). Noah is a familial and social person whose everyday life is occupied with work, family and various social activities. Noah is a keen surfer and shared his fond memories of spending his formative years in Raglan surfing. He works in Hamilton for a dairy factory often driving forklifts and has done so for the past eighteen years. Despite our conversations being serious at times, they were also comprised of light-hearted humour.

Although our conversations focused on Noah's heart story, he also recounted experiencing other significant health conditions, which he interweaves throughout the account. His is a multi-ailment illness narrative. Noah reports having undergone two major operations on his back after contracting an infection in his vertebrae: "[The infection] *started eating away at my vertebrae and they were collapsing*". He also reports having to undergo another operation to support this spine after the infection returned: *"To put titanium rods and things in there* [spine], *straighten it all back out*". It is important to acknowledge Noah's spine condition as it not only featured in his heart-related illness experience. It contributed to his account of CVD.

Similar to Akul, Noah also considered what may have caused his heart condition. He employed various public narratives to make sense of his heart condition within the context of his everyday life. Moreover, Noah progressed through a relatively different process in comparison to the other three participants in this study. A heart murmur was identified by his GP at the time of his spine condition and prior to him feeling symptoms of CVD. Such early detection and subsequent ongoing monitoring resonated positively with Noah. As such, Noah's story offers a positive experience of accessing care and engagements with the healthcare system. He states: *"I think it's just been a really, for what it is, it's really been a good experience really. Overall, a positive one. And most people yeah, they were all really helpful. I'm just grateful for all their help.* These positive references are also evident within Noah's account of his recovery in which a number of factors appear to ameliorate the stressors that illness can often invoke. These factors, which exist at both the personal and interpersonal level appear to reduce the sense of illness disruption to his everyday life. The way Noah tells his story suggests he has much for which to be grateful. He positions himself as a person who is moving forward having learned something from his illness experiences and having woven these lessons into his sense of self and place in the world.

The focus of the current case is on how Noah experienced a minor form of illness disruption through his somewhat positive experience of CVD and the healthcare system. Previous research invokes the importance of narrative disruption in people's lives with the onset of illness (Bury, 1982; Murray, 1999; Radley, 2009). Such disruption can bring notions of uncertainty to the fore (Radley, 1995), and may force men to reflect on their health and lives. This may not always be discouraging, where there can be positive consequences of such disruption and related thoughtful processes (Nadarajah, Buchholz, Wiegand, & Berger, 2017). This case provokes the need to consider the multiplicity of illness narratives in which patients may not only story the adverse impacts of illness. They can also consider the affirmative changes it invokes within one's everyday life (Nadarajah et al., 2017).

I have elected to present Noah's case last as he emphasised the early detection of his condition and positive access to care which differs to the other three participants. I begin the analysis with Noah's understandings of the cause of his heart condition and the explanations he has constructed to make sense of his illness occurring at the time. I consider how the process of being monitored and having some awareness of future illness avoided a crisis situation. This leads to an exploration of factors that facilitated Noah accessing care. I then explore certain aspects of care and discuss how these experiences of care had a positive impact on his overall experience of illness. Correspondingly, I consider several factors buffering the impact of CVD in Noah's everyday life and ongoing recovery. To conclude, I tie together this participant's positive experiences and discuss how he is moving forward with his life.

Contemplating the cause of illness

Exploring the cause of one's illness is often central to the meaning making process of illness narratives (Murray, 1999). Both Noah and Akul (chapter three) spent time contemplating the cause of illness and both participants came to varying conclusions of explaining their heart condition. In this section, I discuss how Noah attributes his illness to individual factors, heredity factors and other health related issues however, still remains uncertain regarding the cause.

People can often assign the cause of illness to factors external to the person and beyond one's control, including the broader environment, uncontrollable events and heredity factors. Additionally, people can also consider personal behaviours as health determining (Radley, 1995). Noah considers such factors in the following account though, he ponders over how his heart condition developed with an overt level of uncertainty:

> *Might have been born with it or something like that… Could have been lifestyle… Fitness and stuff like that… Playing up when you're younger and doing things you're not supposed to… Yeah playing up drinking too much and indulging in other things… You don't realise what you're doing to your body because you're invincible then.*

Here, Noah explores a range of factors to explain his heart condition. He refers to causalities as mere possibilities and remains unsure of how his heart condition arose. Earlier in his life, Noah acted as if his body was infallible and as such he could ‘play up’. It was the recognition of illness that called into question his stoicism and lead to him reflecting on his actions and how these may be linked to illness (Bury, 1982). Noah emphasises his own behaviour through his acknowledgement of a lifestyle change and thus becoming less active over the course of his life to date: *“I was sorta pretty active. Like we could be surfing for hours a day and just running around diving and stuff. But when the kids come, we sorta moved away from that”*. Despite acknowledging personal factors, Noah also considers the family history of heart disease which also emphasises the role of heredity factors: “*I think there is a bit of heart disease in dad’s family cos he’s lost about three of his brothers to heart attacks and stuff like that. Yeah so must be a defect there somewhere”.* These conflicting statements reinforce the uncertainties surrounding the cause of Noah’s illness in the narrative process.

Although Noah remains unsure of the cause of his illness, he displays more certainty of why his heart problems arose at the time they did. He emphasises how his heart condition is related to other health issues and draws connections to his spine condition as responsible for multiple parts of his body failing:

> *I think when my back problems started yeah, just had a lot of trouble with my lungs as well. Cos one of my lungs collapsed at the same time and my heart beat was just going something like 300 beats. So, they all sorta came together and I was really sick then. Must have been stressing the heart out as well… Like those three things* [heart, lung, spine] *came all at the same time and they couldn’t really pin down what was the matter. But I think that infection that actually got in there* [spine], *that was a big part of it.*

For Noah, multiple ailments appear to strain his heart and contribute to his heart problems arising at the time. Noah’s account indicates he experiences some level of uncertainty as health professionals try to understand his ailment. This extract expresses how Noah attempts to find some meaning in the chain of events that eventuated. His report emphasises how his spine condition provides an explanation that aids him in making sense of his health issues. This provides some context surrounding why Noah’s back condition features in his heart story and how the two illnesses are interconnected within his lifeworld and understanding of himself.

To recap, Noah’s account emphasises how he ponders a range of factors to the cause of his illness with notions of uncertainty. Although Noah attributes his illness to many personal factors, he also considers the role of family history. His account emphasises how his spine condition is intertwined and an important feature of his heart story. Most notably, he did not link his illness to the structural factors such as the stress of colonisation which was a key feature within Akul’s narrative (chapter three). Next, I consider Noah’s early detection process.

Early detection, monitoring and little illness disruption

Noah's story differs to the other three participants through the early detection of his heart condition. I outline how early detection contributes to Noah's more positive experience of illness by discussing the initial detection, and how his symptoms manifested gradually in which he eventually accesses care. I discuss how Noah believes he avoided a crisis situation through the early detection process.

The presence of chronic disease is often confirmed when a person has felt unwell and sought medical advice (Radley, 1995). In other cases, disease can be detected before the person begins to feel any of the signs. Such early detection can equate to quite a different experience where a doctors' knowledge becomes the primary guide in the first instance of a person grappling to make meaning of the ailment (Radley, 1995). This is evident in Noah' case:

> *Yeah just um, when the GP heard the murmur in my heart yeah, he just um well sent me up to the hospital to get the test done and yeah that's when they found that it was a 'leaky valve'. But it wasn't bad enough then to operate on it. So, they* [doctors] *thought yeah, cos they said I've probably been living with it for years before then. Forever probably.*

For Noah, the revelation of a heart problem does not pose a serious issue within the context of everyday life. The extract illustrates the involvement of health professionals prior to him feeling symptoms of CVD where his diagnosis of a 'leaky valve' does not appear threatening or intimidating. The reports from doctor's aid Noah in understanding one can still conduct everyday life with a heart condition. Further, the early detection of Noah's heart condition leads to a process of ongoing monitoring. Ongoing monitoring does not appear onerous to Noah and instead, he emphasises the notion of various people watching over his heart condition and never being alone in the process: "*Just said they'll keep an eye on it* [heart condition] *and do I think tests or whatever they do... Just get the GP to keep an eye on it as well. It's like they were there the whole time, just a check-up every once a year or something"*. His account demonstrates his relaxed approach to the heart-related processes.

Noah's symptoms appeared gradually several years following the initial detection of his heart condition. Noah states: *"Might have been about two or three years probably more like three"*. Noah recounted how his symptoms unfolded and how CVD gained more meaning in his life. What is particularly evident in his account is the complexities and interconnected nature of illness and everyday life:

> **Noah**: A*fter a few years it just got worse and worse and just getting breathless at times. But mostly at work going up the stairs and stuff. I thought I was getting really unfit or something and just getting really tired as well... Yeah, I couldn't keep up with the kids... couldn't play with them as much and stuff... I thought I better tell someone I suppose.*

> **Samantha**: A*nd could you relate it* [symptoms] *to your heart?*
>
> **Noah**: *If they hadn't of found it* [his heart condition] *yeah nah. I don't think nah.*

Here, Noah's account depicts the progressive disruption of illness to everyday life where common explanations can no longer explain his worsening heart condition. Noah's report illustrates his more overt awareness to his heart condition through feelings of breathlessness and tiredness. For Noah, CVD has become meaningful over-time through its relationship to other activities and practices central to the conduct of his life. Symptoms are not only labels for bodily changes (Radley, 1995). Symptoms are also intertwined and embedded within the happenings of everyday life. For Noah, being ill means being unable to engage in everyday activities which signals the need to seek care. Noah's report indicates prior knowledge of a heart condition can assist a person with drawing connections between symptoms and a worsening condition; although only when everyday explanations have been exhausted. This prior knowledge also contributed to Noah's sense of avoiding a crisis situation.

Noah expressed his relief for the early detection of his heart condition and his understanding of avoiding a 'crisis' situation, which I outlined earlier as occurring in TH's case (chapter four). Below, Noah reflects on his thoughts surrounding a heart attack and how his own heart process appears more manageable than other situations:

> **Noah**: *Yeah, I was lucky. Yeah, I was really lucky that they found it* [heart condition] *way back yeah. So, I didn't have to go through a heart attack or anything like that. It's a bit scary.*
>
> **Samantha**: *What you've experienced can be scary as well?*
>
> **Noah**: *Yeah but, I don't think it's that not too bad really yeah, I'm just glad I didn't have to go through an event like a heart attack or anything… I think it's just really scary yeah. Pain would be pretty bad I'd say. I'm just like yeah, I'm just glad I didn't have to go through that. Experience it... Ya know your heart could stop or, you could die from it ya know… I'm just glad I didn't have to go through that yeah, and put my family through it as well ya know.*

In this extract, Noah's understandings of a heart attack lead him to appreciate the process of early detection and him not having to experience the crisis that a heart attack may invoke. Noah perceives a heart attack to be an unpredictable situation of losing control of the body with more significant consequences, including death. The downplaying of his own heart process stems from Noah's understanding that his situation could potentially be worse. Moreover, Noah's comparison of a heart attack and what he experienced suggests different CVDs can invoke different levels of disruption to people's lives. Noah constructs a heart attack as a severe disruption to one's life and something he is grateful to not have experienced.

Noah reported being unsure of where his thoughts of a 'heart attack as scary' originated from. Correspondingly, it is useful to consider here how Noah has lost several whānau members to heart attacks and his father has also suffered a heart attack, which I mentioned in the previous section. Thus, Noah's 'scary' perceptions of a heart attack may be informed by the relational context (Conrad & Barker, 2010) in which he resides and the health experiences of whānau. Such social influences on understandings of illness were also evident in Henry's case. This emphasises how Noah's social world maybe important towards his understanding of avoiding a crisis situation.

To recap, Noah emphasises the benefits of early detection and monitoring to surviving CVD. His account emphasises how he remained calm and relaxed over his *"leaky valve"* diagnosis and continued on with everyday life. Although Noah's symptoms gradually worsened overtime, he understands himself as avoiding a crisis situation for which he is grateful. I next discuss Noah's experiences of accessing care and positive experiences of the healthcare system.

Accessing care and riding a "good wave" through healthcare

As mentioned previously, Noah reported having a positive experience of the healthcare system for his heart condition. His positive experience is conveyed in his drawing (see figure 5) of the relationships between himself and health professionals by his use of 'strong' or 'okay' lines to describe these relationships (the meaning of each line is positioned in the top left-hand corner of figure 5). Interestingly, Noah's drawing indicates his understandings of care as not confined to those directly concerned with physical treatment and recovery. Instead, his drawing depicts multiple agents of care or characters in his illness narrative that shape his experiences of care. In this section, I discuss Noah's positive experiences of care and provide further context to figure 5. I first begin by exploring the facilitating factors contributing to Noah's accessing care and then the contributions of caregiver characters.

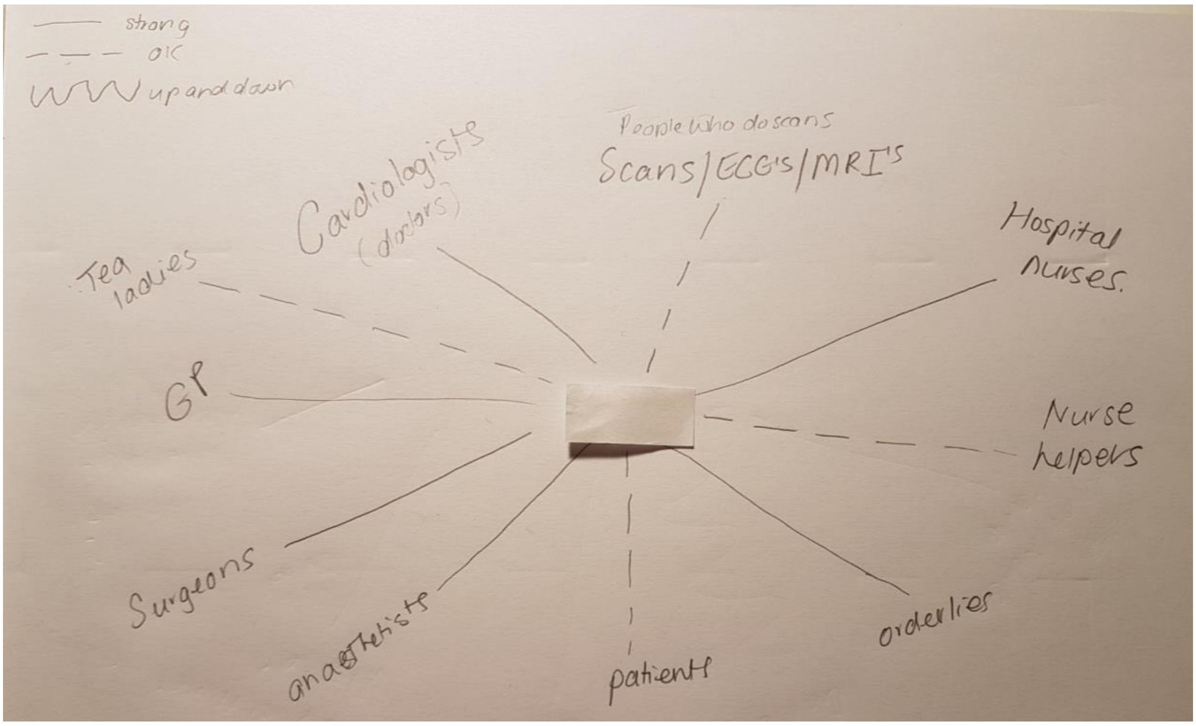


Figure 5. Noah's drawing of health professional relationships.

Noah recounted his experiences of accessing care for ongoing monitoring and in preparation for his surgery to repair his leaky valve. He described how he managed this within the context of his everyday life. Importantly, the following account illustrates how accessing care is not an individual process and can involve employing various resources:

> **Noah**: *If I had an appointment yeah, I'd just make sure I'd be there and keep everything rolling along how it was supposed to be I suppose and yeah nah.*
>
> **Samantha***: So how would you do that?*
>
> **Noah***: Well pretty much,* [mother-in-law] *was mostly here all the time so if I knew I was gonna be away um she'd be here… And if it was during work time yeah, work would just let me take a couple of hours off or the rest of the day off. And so yeah, it wasn't too hard. Yeah, and most of the times were pretty good anyway so.*

Here, Noah's account emphasises how he engages in efforts to prioritise and arrange other matters of everyday life to attend appointments. His account suggests he is supported through this process with whānau and an understanding employer. This extract emphasises how the process of seeking care can be made easier for patients through the collective support and help of others. Such support is important as having the resources and flexibility to attend these appointments contributes to Noah's ability to access care. The account illustrates how he is cared for by certain characters within his broader social context through being able to focus on monitoring and treatment. Attending these appointments are essential for Noah to learn about his heart condition.

Noah discussed making regular trips to the hospital prior to his operation as his heart condition worsened, which necessitated a new plan for intervention. He states: *"It* [his operation] *got put off a couple of times cos they kept on finding other things so they had to make different plans… Talk about it* [his heart] *a bit more and come up with a different plan".* An important part of the process of making new plans involved Noah understanding his condition through the use of medical technology and discussions with health professionals. In the following account, the usefulness of scans and images becomes apparent as these visual aids help Noah to make sense of his ailment:

> *I thought it was really interesting actually seeing all the scans and things and how your heart and body works… Watching the computer screen and whatever else… You could see it actually not working… The shut off valve or something and it's not closing down properly… Get a bit of an understanding.*

In this extract, Noah presents himself as an interested and active agent in his treatment. The account also reflects the efforts of health professionals to ensure Noah was informed of what was happening. In the process, Noah maintains his embodied humanity despite seeing his body reduced to parts on a screen where he gains a deeper understanding of his body, and is given a new perspective. As outlined in Haque and Waytz (2012), mechanization of the body can be necessary for diagnostic and therapeutic purposes. Technology can be used to depict the source of symptoms in the body to pinpoint and objectify the cause of disease (Good, 1994). Noah's account illustrates that such processes can be useful for patients to understand their condition and need for medical intervention. The communication that accompanies these informative meetings also appears to put Noah's mind at ease regarding his surgery.

For Noah, an important part of caring relates to the communication between himself and health professionals with regards to his CVD and related medical intervention. In particular, the time spent by professionals explaining information to Noah contributed positively to his experiences of care. The following account relates to the 'strong line' given to the cardiologist in figure 5:

> *I'd say it's a pretty good one too really* [strong line in the drawing]. *Cos they're pretty good at explaining what's wrong. Yeah and explaining what they have to do. It's good to get feedback from them... They knew their jobs and, just puts your mind at ease I suppose… Yeah, I just um, I think they just come across like they know their job I suppose… Cos I wouldn't have a clue… Yeah, I think they are just pretty confident people in what they gonna do.*

In this extract, the explaining of information reduces notions of uncertainty surrounding one's CVD and treatment plan. For Noah, the emanation of confidence from the cardiologist invokes a calming effect surrounding having to undergo an operation. As a result of this, Noah reports less concern and anxieties over his operation and more concern for his whānau: *"I was just worried* *about the kids and* [his wife] *and everyone else like that. But like I say, we had confidence in all the doctors and medical staff".* His more collective concerns reflect a central aspect of Māori values (Durie, 1998).

Noah reflected on the health professionals drawn in figure 5 and discussed how they contributed to his care. Whilst he elaborated on several positive experiences, he foregrounded the conversations held with various people involved in his care. As outlined by Radley (1995), 'as a person', a patient can often be shifted to the background or their subjectivity becomes eclipsed by an ailment when doctors and those around them fixate on linking "physical intrusions with abstract classifications of disease" (p. 26). Such understandings are not consistent with Noah's positive story in which various interactions with health professionals aided him in characterising himself as a person with an illness, rather than being reduced to a body with a disease. He was able to maintain his humanity across a range of interactions in the healthcare system. For instance, Noah recounts a particular interaction with an orderly:

> *They're* [orderlies] *all different people and good to hear their stories and where they're from and whatever they do and it would pass the day away as well... I just try and strike up a conversation with them while they're pushing you around... Yeah shaking hands and stuff like that. Stories usually come out after that yeah. Like one guy asks me where I was from. I said "oh* [North Waikato]*" and he says "Oh* [North Waikato] *that's awesome town". And then he said "yep that's the only town in New Zealand that umm* [rock band] *has ever played at"... I thought yeah that's right! I remember that happening yeah. "Oh yeah I went to that concert" and stuff like that yeah just real random but it was awesome.*

In this excerpt, Noah presents himself as an interconnected human being who enjoys connecting with others. A *"handshake"* reflects the beginning acts of whakawhanaungatanga and such acts create a space for the mutual exchange of stories. Noah's account reflects particular expressive stylizations of caring where mundane acts of a *"handshake"* and discussing common interests represents acts of caring more commonly found among men (Hodgetts & Rua, 2010). This extract demonstrates how Noah is afforded the opportunity to be present in the healthcare system and to re-story himself as someone with an illness who is being supported in a humanly way by health professionals. Noah's account demonstrates that the small and brief conversations between hospital staff and patients should not be underestimated in terms of maintaining the humanity of patients at times when their very selves and being are at threat. The conversations with the 'zipper club guy' has similar affirmative qualities.

Noah shared the story of being a 'prospect' and recruited into the 'zipper club' during his stay in hospital. He described the 'zipper club' as a club for patients who have undergone open heart surgery. Noah's account suggests one is selected and initiated into this exclusive club: *"He must have a list of everyone that's had a heart operation... Comes around looking for you".* Noah discusses the helpful ‘zipper club guy’ who provides him with useful and constructive information to incorporate and support his recovery:

> **Noah**: *Just little tips they gave me to ya know look after the pain and handle the pain a bit better and manage it… Just things like having a tri pillow up in the hospital… Cos the other pillows are just normal pillows yeah just a bit harder…Stuff like that… He come around and just talk to you and he was really good. Good value. Well he’s been through it before as well so, it’s good to get another perspective from him.*
>
> **Samantha**: *Like sharing stories?*
>
> **Noah**: *Yeah cos it was something that was happening to us. Yeah and find out that they’ve been through it just takes the worry away from ya sorta thing… Seen that people have been through it and come out the other side.*

The ‘zipper club guy’ is considered a facilitator towards Noah’s goal of recovering and returning from the extra ordinary state of hospital care to the ordinary state of his everyday life. The zipper club guy is seen as an ‘assistant’, and enters into Noah’s heart journey at a critical time by instilling confidence in Noah that recovery is possible. Noah and the assistant are connected through shared narration by invoking the common ground of the ‘zipper club’, which facilitates the cultivation of a sense of kotahitanga **(**unity) that one’s own heart journey is not a solitary venture. It is one that can feature solidarity. Noah’s positive experiences of the ‘zipper club’ member aligns with previous research where participants reported good experiences of having a mentor during their cardiac recovery (Junehag et al., 2014). Participants reported the benefits of having contact and sharing stories with someone with previous experience of a coronary event. Such resources in the hospital appear very helpful for Noah.

To recap, as opposed to experiencing barriers to accessing care, particular facilitators including his mother-in-law and his employer aided his subsequent engagements with the healthcare system. Moreover, Noah’s positive journey through the healthcare system is shaped by the constructive use of medical technology and effective communication with health professionals regarding his CVD and treatment. His account emphasises how practices that centralise the person of the patient can facilitate positive experiences of care. Noah’s discussion of the ‘zipper club guy’ underline how such hospital resources can contribute to patient recovery constructively. I next discuss the factors buffering the impact of illness in Noah’s heart journey.

Buffering the impact of illness

Noah’s ‘somewhat’ positive experiences of illness and treatment appears to be associated with several key factors that reduced his sense of narrative disruption and assisted his recovery. In this section, I discuss how a supportive employer and presence of whānau collegial support conspired to reduce any major disruption to his everyday life. Despite having these supports, some disruption remained as he recounted his efforts to return to the normality of an everyday life already populated by other ailments. I also consider how his broader social networks of work colleagues also contribute to his narrative. I first discuss how in a sense, Noah was already socialised to managing serious illness due to previous experiences of severe health conditions.

As mentioned previously, Noah considered his spine condition as more severe than his heart condition. The more severe experience of his spine condition appears to have a desensitising effect on Noah as is evident through the way he recounts his heart related illness experience. The following interview extract is Noah's replies to a question I posed regarding whether and how he compares the two health conditions:

> *I think you do* [compare conditions]. *It's sort of cos, you've been through big operations as well ya know. Doesn't really phase me anymore I suppose. But yeah, I think you do end up comparing things. But they are two different, really different recoveries and operations… Cos I don't think there was as much pain in the recovery after the um heart operation… Yeah just a lot more pain killers with the other ones* [spine operations]. *Yeah, a bit harder stuff but I didn't like taking them.*

Here, Noah's experiential knowledge of other health conditions reduces the worry and concern of his heart related medical intervention and recovery process. For Noah, illnesses that he considers minor to his back condition are less concerning since he has already physically and psychologically worked through and re-storied himself in relation to ailments that he understands as being much worse. In light of his back ailments, Noah positions himself as being 'experienced' through the healthcare system by having previous knowledge of various procedures: *"Like I say, been through it before with my back and stuff so it wasn't anything new to me"*. Previous experience of procedures means Noah's heart condition and recovery is rendered less overwhelming. He is already well practiced at illness narration and is able to transfer his knowledge of one ailment to his understanding of another and in doing so reduce the level of disruption that often comes with illness. He knows how the health system works and his role in it. Although not all patients will have prior experiences of illness, it is important to acknowledge in Noah's case how his back-condition contributes to the meaning of CVD as minor illness disruption to everyday life. These factors buffering the impact of illness extend beyond Noah himself and into a well-established support network at work and within his whānau.

TH's case (chapter four) clearly highlighted the economic consequences of illness through his narration of losing his truck license and subsequent financial struggles following his cardiac event. Such socioeconomic consequences of illness are not something Noah has endured as he reportedly took leave from work for appointments and treatment on full pay. In the following extract, Noah discusses how the economic support of his employer contributes to his recovery:

> *Didn't have to worry about the money sorta thing… Yeah, that was really good cos it was peace of mind that ya know, all the bills were gonna be paid and there's gonna*

> *be food on the table. Stuff like that yeah, it's really a load off your mind. Yeah, don't have to worry about that and just concentrate on getting better. Cos you don't wanna be worrying about ya know, when the next loaf of bread is coming from or whatever and don't have any money and power bills coming up that need paying.*

Noah's account emphasises the lack of economic stress and anxiety he experiences through his recovery with having the *"special sick leave"* from his employer. Such resources enabled Noah to recover while still keeping up with the financial demands of everyday life. Noah is afforded the opportunity to still enact the provider function of contributing to the bills and covering the basic needs of his whānau. The provider role in his personal narrative is storied as being shared with his wife who also works and Noah considers this a necessity in the current day: *"Most families if you don't have a really good paying job ya know, you do need two wages. It's not ideal but yeah, especially when you got five kids that you gotta look after"*. Here, Noah touches on the idealised view of having one parent stay at home with the children. In reality for many families including himself, two wages are essential to look after the whānau which further emphasises the crucial support from his employer.

Noah's ability to contribute to providing for the whānau means his identity is not disrupted through illness to the same extent if he was employed elsewhere. He realises his current position and shares his impressions of how things may have been different: *"Probably be pulling my hair out... Yeah it would be really hard... Yeah, bills still need paying ... And probably have to get back to work quicker and probably not ready to go back"*. Noah's employer buffers such negative impacts of illness by providing Noah with a sense of financial stability that illness can often disrupt. Not all the participants in this study have such resources available to them and this forms an important distinction across the cases. Additional to financial support, Noah's social supports play an important role.

Noah reflected on the presence of social support through his heart journey. An array of supports comprising of whānau and work colleagues form a large part of the social capital he relies upon to respond to illness. The term social capital has been used to refer to such "access to social resources, such as family members and networks of friends and others who can provide social support" (Hodgetts et al., 2010, p. 227). Such capital is known to have a positive association with health (Hyyppa & Maki, 2003). In the following account, Noah discusses the importance of whānau to the running of everyday life during his recovery through processes of providing practical support:

> *Yeah just good having* [his wife's mother] *ah, the kids just really love hanging out with her and everything. So, she was taking them to practices and picking them up after school and stuff like that. Her mum and dad would bring around meals every now and again just things like that yeah. Or else we would go around to the brother*

> *and laws for dinner and our kids would go around to his place as well. So yeah, just taking the load off with the kids really… Hanging out the washing and stuff like that.*

Noah 's account emphasises how recovering from illness is not simply an individual process. Rather, it involves many helping hands and folding one's self back into the relationships and routines of everyday life. Whānau members collectively contributed to the smooth running of everyday life in an attempt to create little disruption as possible to Noah's wife and children. As outlined in chapter one, whānau is considered an essential element in Māori understandings of health where whānau have supported Noah through his recovery by eliminating the pressures of everyday life (Durie, 1998). Noah asserts: *"Yeah you probably wouldn't be able to get through without everybody".* His assertion emphasises the importance of whānau throughout his illness. Importantly, Noah still engages in his own efforts to slip back into everyday life.

The support offered from whānau meant that Noah's illness had less impact on the routines of his children and wife and enabled him to experience not being a dependent burden on others. This does not suggest Noah removes himself from everyday life. Instead, Noah's minor illness disruption is mediated through his own efforts to maintain his participation in ordinary everyday routines that are central to his recovery: "*We just pretty much the same as always… It's always busy and um yeah, like even though I was recovering I was still pretty busy looking after the kids and stuff as well at the same time".* Noah's account demonstrates how he maintains some sense of responsibility within the whānau and remains an active contributor to familial life. Carrying out his role as a father during his recovery shows the transitioning into everyday life 'with' illness. This can be central to one's recovery as enacting such roles can enable life to become familiar again (Radley, 2009).

Noah's social connections with work colleagues is also central to his network of supportive relationships that are aiding his effective response to CVD. As outlined by Hodgetts et al. (2010), the supportive relationships people establish with one another can facilitate people towards taking care of themselves and engaging in more positive health behaviours. Such support is apparent in Noah's story where he underlines a genuine concern and need to support each other as he and his work colleagues age:

> *I'm pretty close with quite a few of the guys from work and just talk about a lot of things like that I suppose. Just worried about each other ya know. Getting to that age where we have to take care of ourselves now… And there are some people there that have um gone through the same sorta operations. There's a lot of older people there and yeah, I sorta found that really helpful to talk to them and get their thoughts on it… Yeah some of them things yeah, they told me I was going through but because I was a bit younger, I think that it wasn't as hard as it was on them. Cos um, one guy said that recovery for him up here in his chest took over six months to really get over it. But I'm feeling really, it feels really good actually.*

The extract above invokes a sense of aging and vulnerability that appeared at various points in Noah’s illness narrative. His account reflects notions of entering a stage in life where his body is no longer invulnerable and now requires attention and care. ‘Worrying about each other’ demonstrates how Noah and his colleagues have established a social connection. These social connections are a type of social resource which may help people cope with adversity and other life stressors (Lyons & Chamberlain, 2006). As Steptoe and colleagues (2008) highlight, “happier individuals do not necessarily experience reduced levels of enduring adversity throughout life. Instead, possess greater protective resources to manage problems effectively and flexibly in concert with better mental health” (p. 223). Reflecting the relational nature of illness recovery and Māori ways of being (King, Hodgetts, Morgan, & Rua, 2017; Rua, Stolte, & Hodgetts, 2017), Noah is positioned to manage illness better by remaining positive through being loved by others and having people to depend upon.

Furthermore, the social connection between Noah and his colleagues appear to buffer the impact of illness by providing a liminal space in which he can normalise his illness experience with others (Watkins & Shulman, 2008). The sharing of illness stories amongst work friends can create a sense of togetherness and facilitate the positivity currently advocated as important towards managing illness (Hodgetts et al., 2010). It also illustrates how experiences of illness are also shaped through processes of storying with others (Groleau et al., 2006). The factors buffering the impact of illness play an important role in Noah’s heart story. In the following section, I consider how Noah is moving forward with a sense of gratitude following the recap of the current section.

To recap, this section has illustrated how certain factors can buffer the impact of CVD and reduce the illness disruption in people’s lives. Noah’s prior health conditions appear to have a desensitising effect and contribute to the meanings he makes of his heart journey. Noah’s account emphasises how he is well supported in various domains of his life and how certain supports aid him towards making sense of his illness and recovery. Importantly, his recovery also involves his own efforts to slip back into everyday life also.

Moving forward

Noah reflected on his illness and what this means for the future moving forward. He appears to re-story himself as gaining insights from his experiences of CVD that contribute to an existing illness narrative that is anchored in his existing conditions. His is very much a multifaceted illness narrative in which CVD is only one focal point. In this section, I discuss how Noah considers making lifestyle adjustments and how his awareness to his mortality invokes a positive outlook moving forward. I first discuss how Noah considers a proactive approach to his whānau health.

Noah's experience of CVD prompts him to think of his whānau health moving forward. He reflected on a past memory of whānau encouraging the tāne (men) in the family to get checked for potential heart problems. At the time, Noah did not take this seriously: *"The aunties, when the uncles passed away, they said you boys have to get checked out and stuff like that. So, you thought oh nah you'll be right but we were all younger then"*. Noah's views on being checked have evidently changed in light of his positive experiences of early detection and avoidance of a crisis situation:

> *Yeah that's what I think now about my son. I wonder if he will need to get checked later on as well... Yeah that's what I sorta been thinking about lately even getting my brothers and sisters check their kids as well sorta thing. Cos you don't wish anything like this on anybody.*

Here, we see some of the relational consequences of illness experiences surfacing. Although Noah presents a relatively positive experience of CVD, he hopes other whānau can avoid this illness. From his own experiences, Noah can now vouch for the benefits of early detection whereby his story has become a cautionary tale or resource to encourage other whānau to have their tamariki checked. It illustrates how Noah uses his experiences of illness constructively, as something others within his whakapapa (genealogical descent) line and beyond can learn from.

To reduce the risk of future cardiac events, patients with CVD are often encouraged to make lifestyle adjustments following medical intervention (Nicolai et al., 2018). Noah considers such lifestyle changes where his experiences of CVD appear to raise his awareness of looking after his health more:

> *I think just have to start walking quite a bit... Get out on the bike as well so that's a really good one. Cos the kids like walking around and riding bikes. But yeah, just general fitness always helps... I think we have to change ya diet a bit. Not so much cream and stuff like that. I never used to drink too much but just every so often but yeah, I probably won't even do that anymore. But um yeah diets a big one. Just to eat a bit healthier and not so much... Yeah, I think just trying to take the healthy option.*

For Noah, the meaning of CVD is invoked as an ongoing health condition that must be managed through lifestyle changes. His account makes references to notions of health as a matter of personal responsibility (lifestyle change) at one level, and collective responsibility (encouraging others to undergo medical checks) at another. The consideration of certain foods and drinking patterns demonstrates Noah has some awareness of exploring healthier options. Although Noah considers these changes, he mentions the challenges of changing embedded everyday habits: *"It's pretty hard I suppose after you've been doing it all your life. Just have to have more yum cha or something like that.* Noah's awareness of lifestyle changes is also reflected in how he contemplates his health in general and life moving forward.

Patients suffering a heart event can often change their outlook on life moving forward (Nadarajah et al., 2017). Such occasions can force people to confront their mortality where they can become more aware of the temporality of life. This is evident in the following account where Noah invokes the positives of becoming aware of his mortality:

> *Just saying that you only got one shot at life and yeah, trying to live it to the fullest I suppose. You have to look after yourself when you get older. Yep, not immortal like you used to think you are when you were younger and you just think yeah. Ya know, just people you knew and they're all passing away sorta thing and you think oh they're the same age as you, could happen to you and I thought that, yeah just makes you aware of your mortality I suppose it is… Make sure you have a good time with the family I suppose and make sure it's a good positive one so there's nothing you regret someday.*

Noah moves forward with the view that life is not be wasted and it is important to take opportunities to look after oneself. His report of people passing away around him demonstrates his relational thinking and the social influences through which Noah comes to understand his own health. Being confronted with one's mortality appears to invoke a positive outlook on life moving forward where he expresses certain meanings of spending quality time with whānau and engaging in life with a sense of purpose. I next bring the chapter to a close.

Chapter discussion

Noah's case demonstrates that men can have positive experiences of CVD and the healthcare system. His positive experiences were not fostered by his psychological disposition alone. They were facilitated through the complex interaction of factors relating to the person, social conditions, resources and the provision of care. Understanding the broad range of factors involved underlines the complexities in how we understand one's illness experience and what factors and events are contemplated in relation to it. It centralises notions of relationality and interdependency that underpin Māori understandings of health and illness (Durie, 1998). Noah's case exemplifies how he exists within a wider social milieu shaped by people, structures and institutions, which all appear to influence his somewhat positive illness experience.

As a chronic illness, CVD can mean patients are designated to be 'chronic patients' or 'sufferers' who have to live with a disease that is incurable within a world of health (Radley, 1995). Being illness free is considered the normative basis within society where illness is often confined to the "subordinate opposite of health" (Radley, 1995, p. 6). However, as mentioned earlier in Henry's case, health, disease and illness are not mutually exclusive. People can still live what they perceive as healthy lives with illness (Blaxter, 1990). This is apparent within the current case where Noah does not appear to construct himself as 'sufferer' as such. Instead, he constructs himself as a person of whom is managing a heart condition as part of living out a ‘normal’ everyday life. In consideration of such constructions and within the context of the previous three cases, we need to think about illness disruption as existing along a continuum of severity in responses. Understanding illness disruption in this way invokes us to look at the underlying mechanisms that contribute to such varying responses. For instance, the early detection of a heart condition within Noah’s case and associated positive responses which was not seen across the other three cases.

Radley (1993) asserts that, despite people regularly sharing their own illness stories with others and creating shared understandings, there is no universal response to illness. Radley proposes that this is because people have access to different resources in society and there is a wide variation in domains of everyday experiences of illness (Radley, 1993). This is an important insight as it is clear within Noah’s case that personal and social circumstances have a large bearing on his healthcare experiences and response to CVD. Also important within Noah’s story, is the fact Noah is aided by considerable previous experiences of illness and existing supports that make his storying of illness more straightforward than is apparent in the other cases. He is well practiced at storying his ailments and this helps him cope with, and respond effectively and positively to CVD. Such cases also raise the importance of looking in detail at each person as a case and considering their life circumstances in understanding their responses to conditions such as CVD.

Overall, we have moved progressively through the four cases that began with Akul’s more unsettling experience of CVD and the healthcare system, and has concluded with Noah’s more positive experiences. In the following chapter I discuss key findings from across the four cases at a more general level. I also attend to the outcomes from this research and discuss key implications for care and future directions.

CHAPTER SEVEN

Discussion

This thesis was undertaken in the context of health disparities between Māori and non-Māori in general, and CVD in particular (Ministry of Health, 2015; Tobias et al., 2009). Chapter one contextualised the issue of health disparities between Māori and non-Māori through the exploration of the history of colonisation and its impact on Māori health. A wealth of existing literature documents how processes of colonisation dismantled and disrupted many aspects of the Māori way of being through unjust political processes and practices that impacted the health of Māori negatively (Durie, 1998; Pool, 2015; Timu-Parata, 2009). More specifically, links have been drawn between the reverberating effects of colonisation and CVD through the emphasis on the overrepresentation of Māori in lower socioeconomic groupings (Durie, 2001), and its associated effects on health (Ellison-Loschmann & Pearce, 2006; Miner-Williams, 2017). In reviewing this material, I emphasised the need to understand the contemporary conditions contributing to the health disparities between Māori and non-Māori today.

According to the available evidence, Māori have been underrepresented in relation to hospital presentation for treatment of acute coronary conditions in New Zealand (Grey et al., 2016; Statistics New Zealand, 2006, 2013b). More specifically, during the period 2016-2017 within the Waikato DHB catchment area, Māori were underrepresented in the treatment of coronary conditions and were more likely to present with more advanced disease (Dr T.V. Liew, personal communication, March 27, 2018; Statistics New Zealand, 2013a). The current literature has provided some insight into the possible barriers Māori experience in accessing care for their health concerns. After reviewing the available literature, I argued for the need to understand accessing care within the context of everyday life by exploring the meaning of CVD with Māori. To do this, I highlighted the need to shift our understandings of CVD as purely a disease process and to adopt the notion of ‘CVD as illness’. Illness is a broader concept acknowledging disease of the body occurs within a wider cultural and social context which can shape how people experience their ailments (Radley, 1993). A focus on illness enables us to understand how patients understand their illness, what it means to them and how this informs various actions.

The purpose of this study was to document the experiences of four Māori men diagnosed with CVD, regarding their access to care, associated medical treatment and experiences of the disease within the context of their everyday lives. Using a narrative approach, my aim was to engage with participants in a culturally respectful manner that allowed them to share their illness narratives with me. This involved multiple and repeat interactions of semi-structured interviews with participants in which I worked with them to create liminal spaces (Watkins & Shulman,

2008) through the enactment of the core cultural values of whakawhanaungatanga and manaakitanga. This approach enabled participants to story their experiences of illness, their movements through the healthcare system and the impact of illness for their broader everyday lives. By identifying certain issues patients experience with illness and ‘access to’ and ‘access through’ healthcare services (Ellison-Loschmann & Pearce, 2006), this thesis contributes to the body of knowledge that can inform efforts to improve how healthcare services respond to the needs of Māori diagnosed with CVD and their whānau.

This chapter focusses on several key findings from the research at a more general level. The first key finding discussed is *accessing care as complex process within everyday life*. Here, I emphasise the varying factors involved in my participants accessing care. The second key finding is *Māori men’s experiences of care as diverse*. In this section, I elaborate on the participants experiences of moving through the healthcare system and particular aspects of care reported by the participants. The third key finding is *varying levels of illness disruption within the context of everyday life*. In this section, I discuss the illness experience of participants and what was made particularly salient through their narratives. I then discuss these findings at an applied level in the section of ‘implications for care’ before concluding the thesis.

Accessing care as complex process within everyday life

All the participants in this study reported being able to access healthcare for their respective heart conditions. However, certain factors appear to facilitate or hinder the process. The manifestation and interpretation of symptoms, the structures of everyday life, particular interactions with health professionals and the issue of ‘resources’ represent the factors that have shaped my understanding of ‘accessing care as complex process’. I elaborate on these factors further and provide some context to the current key finding.

Earlier in my thesis, I discussed the notion of personal barriers in relation to accessing care. Personal barriers were theorised as one’s beliefs and thoughts as delaying or impeding one’s access to care (Artuso et al., 2013; Kerr et al., 2010). In the current study, various factors including particular understandings of health, and the manifestation and related interpretation of symptoms influenced the participants responding actions of accessing care. Generally, the less concerning and non-threatening signs of illness that did not disrupt everyday life or one’s sense of health meant care was not sought promptly. Alternatively, the more pervasive and debilitating signs of CVD prompted a shift to illness and the act of accessing care more swiftly. Their narratives illustrate how they make meaning of their situations and respond accordingly.

My participants stories align with public narratives of illness and specifically relating to how they recount becoming ill. In particular, Noah and Henry’s stories speak to narratives of individual’s initially interpreting the signs of illness as something ordinary and less threatening until later confirmed as being symptoms of disease (Radley, 1995). The interpretation of symptoms as a factor delaying access to care for Māori patients with ischaemic heart disease has been previously reported by Kerr and colleagues (2010). Noah's and Henry's narratives suggest that signs of heart disease are not always easily identified by the lay person. Especially when symptoms can be rationalised by relevant explanations within one's everyday life. Noah and Henry's actions of seeking care align with earlier research by Stewart and Sullivan (1982), where chronic illness sufferers shared accounts of often seeking care when particular signs of illness became recurrent or more severe. In contrast, TH and Akul's stories reflect the narratives of those more abruptly disrupted by disease. Their narratives emphasise the level of discomfort they suddenly experienced that emanated a sense of urgency and rendered accessing care necessary.

My participants stories reinforce that physical discomforts can form part of our everyday existence (Radley, 1995). This means the matter of becoming ill cannot be comprised of only the perceptual recognition of a sign as an indicator of disease. It also involves a distinction between states where one can dynamically cope with discomfort, and those where one cannot. This concept of coping within this context suggests that people can attempt to live with discomforts so as to continue 'normally' for as long as possible (Radley, 1995), and until accessing care is deemed necessary or achievable as reflected within my participants narratives.

Further, my participants narratives demonstrate some heterogeneity within an overall pattern of accounting for illness. This is apparent through various contextualised accounts that positioned becoming ill within a backdrop of everyday life. It highlights the interconnected nature of health and illness (Hodgetts et al., 2010), and the importance of considering people's everyday context to understand how one might conclude a shift in status from health to illness. In other words, health and signs of illness were intertwined with the participants relationships and undertakings of everyday life and adds to the complexities of how people understand and make meaning of the signs of illness and responding actions of accessing care (Bury, 2005). Essentially, this study demonstrates how the participants understood themselves to be ill and how they responded accordingly. Conversely, there is more to the matter of accessing care than individual level factors.

As described earlier, 'everyday life' can be conceived of as the ordinary and mundane activities that shape our very existence (Hodgetts et al., 2010). It relates to the regular and also unpredictable happenings that we live out each day. TH's narrative provides insight into how the structures of everyday life such as work can influence, and in this case, delay the accessing care process for heart issues. We were unsure at the beginning of this thesis as to how certain structures of everyday life interact and influence the accessing care process for cardiac concerns. TH's narrative provides insight into this issue and supports how the responding actions of accessing care is not isolated from the context of everyday life. Instead, it can be negotiated and contemplated in relation to it. His narrative has aroused questions surrounding certain occupations and delays to accessing care. This could be an area requiring further investigation to understand the mechanisms currently in place to support employees in isolated occupations who suddenly fall ill.

Adding to these complexities, accessing cardiac care is not always a direct process. In many cases, patients may access healthcare providers including one's GP, and later be referred onto specialised cardiac services (Artuso et al., 2013). This means various health professionals can be involved in the process of accessing care. My participants narratives revealed that health professionals can play a key role in the accessing care process. Health professionals were particularly important figures for identifying further heart issues and facilitating access to cardiac care within Akul's and Noah's stories. Alternatively, Henry's and TH's stories illustrate how certain 'communication patterns' between themselves and health professionals (Lyons & Chamberlain, 2006) influenced the responding actions of accessing care. Henry's story in particular raises concerns surrounding differing approaches to understandings of health and the influence this has on communication patterns.

This divergence between medical and lay perspectives of health and illness and its effect on the commmunication between health professionals and patients is not a new issue (Lyons & Chamberlain, 2006). Mishler (1984) has contended that the communication between doctors and patients can be distorted when doctors used a scientific and rational voice, which was incompatible with the voice of the 'life-world' during interactions. The 'voice of medicine' serves to decontextualize certain events and attempts to remove them from particular persons and social contexts. In contrast, the voice of the 'life-world' denotes the contextually located experiences of patients (Mishler, 1984), which foregrounds the divergence between these approaches to communication during consultations. Further, Wilson, Heaslip, and Jackson (2018) have discussed the dominance of biomedical worldviews within healthcare services and the discordance this has with indigenous worldviews. As a result of this, miscommunication, variations in understandings and responding to intervention and treatment can emerge. The authors highlighted the need to attend to this issue through person-centred approaches in order to reduce the health inequity currently experienced by minority groups such as Māori (Wilson et al., 2018). Henry's narrative supports such a need as his story exemplifies the miscommunication that occurred which influenced his response of accessing care.

The importance of considering the communication patterns between health professionals and patients is reinforced through the culturally-centred communication TH experienced with his GP upon initially seeking care. The use of culturally-situated metaphors and lay terms was an important factor towards TH grasping the seriousness of his situation and accessing cardiac care. This finding adds to previous research of the effect of communication patterns on healthcare utilisation among indigenous patients by providing a positive account (Artuso et al., 2013). It also adds to earlier research that reported the favourable nature of GP's predominantly speaking in the voice of the ‘lifeworld’ during interactions with patients (Barry, Stevenson, Britten, Barber, & Bradley, 2001). TH’s narrative has demonstrated how communicating with patients using terms reflective of one’s everyday lived social and cultural context can enhance the likelihood of a person accessing further care.

Overall, my participants narratives position health professionals as both facilitating and hindering the accessing care process. Their narratives revealed health professionals can potentially contribute to the inequities in accessing healthcare for cardiac concerns for Māori people. The men’s narratives not only broaden our understanding of the process some patients undergo to seek cardiac care. The narratives also deepen our understanding of ‘who’ is involved in such processes and related significance. This importance of ‘who’ is involved also extends beyond health professionals.

My participants narratives suggest the availability of resources can also influence the process of accessing care which adds to the complexity of this issue. As I discussed earlier, this is because accessing care can sometimes involve particular activities of taking time out of work, organising familial life and considering issues of travel (Artuso et al., 2013; Bolitho & Huntington, 2006; Lee & North, 2013). My participant’s stories reveal how particular social and economic resources based on the participants respective needs are important towards accessing care which aligns with other health related research involving Māori (Bolitho & Huntington, 2006; Lee & North, 2013).

The discussion and importance of particular resources relative to accessing care differed across my participants narratives. Such diversity between the participants promotes the central point that everyday life is not always ‘equitable’ (Hodgetts et al., 2010). The insights from these men invoke us to examine people’s broader social worlds when understanding such processes. People must overcome certain challenges towards accessing care by the employment of particular resources whilst for others, this can form a taken-for-granted process. This finding makes us more aware of the situations and circumstances of patients and I elaborate on particular social issues later in the chapter.

Generally, this finding of *accessing care as complex process within everyday life* supports earlier research that has identified barriers to accessing cardiac care at various levels beyond the individual (Artuso et al., 2013; Davidson et al., 2012; Jeremy et al., 2010). My participants ascribed certain meanings to particular experiences and situations relative to their social and cultural context, which influenced the responding actions of accessing care. Additionally, their narratives demonstrate that accessing care was not an individual process and has embedded the importance of looking beyond the individual when examining such issues. This study has provided a more in-depth understanding of the factors that can facilitate, delay and support such processes. I next expand on my findings by looking at the men’s experiences of care.

Māori men's experiences of care as diverse

My participants highlighted their experiences of moving through the healthcare system and discussed the quality of care they received (or are receiving). In particular, the participants narratives illustrate some diversity in the reported level of care they received in relation to their heart conditions where inconsistencies exist. These men also took a constructive stance and illuminated certain aspects of care they found helpful or essential which reflects the changes within the healthcare context that have occurred overtime. I elaborate on these ideas in the current section.

In the process of telling their stories, participants constructed health professionals as important 'characters' for the advancement of the plot, and within their illness and treatment journeys. These characters were often portrayed in a positive or negative light and characterised within a context of how they contributed to the men's story. This supports the assertion of Murray and Sools (2015) that illness stories can be comprised of particular 'helpers' that are considered as helpful or hindrance in achieving the goals or intentions of the story. Particular characters include 'nurses as heroes' and 'CRNs as champions'. Such characters were constructed as being 'helpful' across the narratives. Other health professionals were constructed as helpful or hindrances to varying degrees and these constructions did not always align across the participants stories. Instead, the participants accounts have revealed some inconsistencies across the hospital care they received for their heart conditions.

The diverse experiences of care found across my participants narratives can be understood through the inconsistent accounts of care. Whilst Noah and Henry reported more positive experiences of care, TH and Akul reported more irregular and 'up and down' experiences of care. TH's and Akul's accounts also highlighted inconsistencies in the delivery of care across health professionals. Literature within the area has also reported variations in experiences of cardiac care where both positive and concerning aspects of care were raised by participants (Hutton & Perkins, 2008; Worrall-Carter et al., 2016). This suggests the finding of the inconsistencies across experiences of care is not isolated to this research context and also exists elsewhere.

The issue of inconsistencies in care found among my participants accounts does not only provide insight and a general overview of their perspective of care. My participants narratives have created a space for discussion into how these inconsistencies have eventuated. Whilst the current study has found not all experiences of the healthcare system are negative, the cases have highlighted certain issues worth examining if we are to respond to the needs of Māori. Narratives such as Akul's exemplify how patients can lose confidence in the healthcare system following what they believe as instances of sub-standard care. As outlined in Radley's (2009) 'works of illness', stories can stimulate examination and dialogue concerning "matters in the world beyond the frame" (p. 78). This means these works including the narratives and related drawings constructed by my participants provoke actions of thought and questioning. In this way, narratives can be viewed as 'active' where they offer the possibility for change and ongoing critical examination (Radley, 2009). The importance of considering the potential changes from the participants narratives is because these inconsistences in care appeared to translate into the participants broader everyday lives.

Noah and Henry who both reported positive experiences of care experienced the least illness disruption to their lives. Alternatively, TH's and Akul's account of more 'up and down' and unsettling experiences of care were consistent with a greater illness disruption. This relationship supports the research of Östman et al. (2015), who found the encounters with health professionals created continuity or discontinuity in patient's lives with an ongoing coronary condition. The authors argued that brief encounters with health professionals had a lasting effect on patients and the need to foreground individual needs through responsive practice (Östman et al., 2015). As the theory of 'interconnected self' suggests, "people's lives are interwoven into relationships and situations and is not independent of context" (Hodgetts et al., 2010, p. 140). A 'Māori sense of self' is deeply interconnected in nature and Māori often understand themselves in relation to their broader environment (Rua et al., 2017). Thus, we can understand how this study supports the notion that encounters with health professionals can impact a patient's broader everyday life and contribute to one's experiences of illness (Östman et al., 2015). Elaborating on this, my participants went into more detail regarding aspects of their care.

Participant narratives also reveal certain aspects of care that they found valuable or central to the delivery of cardiac care. These men discussed the importance of being well-informed and communicated with in responsive ways by health professionals, the use of medical technology, and the importance of follow up care with respective GPs and CRNs. The accounts also indicate the value of health professionals engaging in processes of whakawhanaungatanga and manaakitanga. Essentially, the participants accounts reflect the importance of certain practices that reinforces the 'person of the patient' (MacLeod, 1993). The participants made reference to these processes in diverse ways and placed varying levels of emphasis on these processes. The diversity in accounts suggests certain acts and practices of care have different meanings and levels of importance.

The elements of care raised by my participants supports the research by Browne and Fiske (2001) who reported the clinical competence of health professionals was not the sole factor shaping experiences of cardiac care. In the current study, the manner in which health professionals engaged with patients was found to be particularly salient. The narratives suggest this is an important matter considering when processes of manaakitanga, whakawhanaungatanga and humanly acts of care were lacking during interactions between my participants and health professionals, this contributed to less positive experiences of care. On the most part, my participants narratives reflect the changes in the context of healthcare that have occurred overtime.

There have been considerable changes in the ideology and practices relating to the process of delivering health care over recent decades (Bury, 2005). Many of these changes attempt to challenge notions of ‘medical dominance’ where concepts of ‘partnership’ and ‘shared decision making’ between health professionals and patients have gained prominence. These changes in relations within the healthcare context denote a shift away from paternalistic approaches and instead, the foregrounding of approaches that foster a sense of agency and autonomy within patients (Bury, 2005). My participants appear to appreciate such inclusive and ‘patient-centred’ approaches to care (Bury, 2005; Lyons & Chamberlain, 2006). I do not suggest paternalism is no longer an issue within the healthcare context. Instead, I acknowledge how the wider shift to more joint processes between health professionals and patients contributed to more positive experiences of care as evident within my participants accounts. This finding also reflects how my participants position themselves within the process of receiving care. Most participants can be viewed as positioning themselves as active agents as opposed to passive individuals within the healthcare context. Even the act of my participants constructing their narrative represents how they wish for the ‘subjective’ (Bury, 2005; Radley, 2009) to be heard to improve how we respond to their needs.

The key finding of *Māori men’s experiences of care as diverse* recognises that these men not only reported varying experiences of care. They also constructed their accounts in diverse ways by emphasising certain issues, discussing particular health professionals and discerning between positive and negative experiences of care. Participant narratives demonstrate how these men are not only receivers of care. They engaged in efforts to position themselves as active participants in their own care. Such positioning centralises the support for more joint and patient-centred approaches within the healthcare context. Overall, accessing care and experiences of care formed only part of my participants illness narratives. Their narratives also revealed how CVD had impacted broader everyday life and the meaning this held for my participants. I explore this issue next in my discussion of the third key finding.

Varying levels of illness disruption within the context of everyday life

It became evident through engaging in kōrero with these men that illness did not disrupt their lives to the same extent. I will elucidate this diversity through the following discussion of various narrative types and the social conditions and circumstances of illness. To begin, I discuss the general concept of illness disruption.

What was particularly salient across my participants narratives is that patients can experience varying levels of ‘illness disruption’. As described earlier, the notion of illness disruption refers to the extent in which illness disrupts one’s sense of everyday life (Bury, 1982; Radley, 1993). This finding of varying levels of illness disruption reinforces Radley’s (1993) assertion that people live in diverse realities and may construct different worlds of illness. Radley

(1993) has previously argued that illness must be understood in relation to a person’s own interpretations of what a disease means to them and within the persons’ everyday lived context. This finding suggests that CVD invoked different meanings across these Māori men in which CVD meant a minor, brief, significant and unsettling disruption to everyday life. These meanings were often generated through the participants examination of the relationships, activities, routines and practices of everyday life. In particular, the cases have shown the extent in which CVD manifested and disrupted everyday life and one’s very sense of self, and to a certain degree, how participants attempted to deal and resolve such disruptions. Resolving these disruptions was explicated through the ways in which the participants attempted to make adjustments and adapt, and also revise and re-work one’s sense of self in relation to one’s illness. Further, this sense of illness disruption can be seen through the type of narrative my participants constructed.

My participants narratives were comprised of how illness unfolded in their lives, medical processes, illness trajectories and their sense of recovery. Underlying the accounts were general ‘narrative types’ (Frank, 1995). A “narrative type is the most general storyline that can be thought of as underpinning the plot and tensions of particular stories” (Frank, 1995, p. 75). For instance, Frank (1995) offers three narrative types of the restitution narrative, the chaos narrative and the quest narrative. People can narrate their own distinct stories. However, Frank (1995) suggests people construct these stories by reconciling and merging “narrative types that cultures make available” (p. 75). For instance, Noah and Henry narrated a story comprised of becoming ill, undergoing medical intervention and returning to a sense of ‘being healthy’, although comprised of different details and nuances. Their stories reflect elements of ‘restitution stories’ and are the most desired and accepted narratives by society (Frank, 1995). People regularly learn this narrative from institutional stories that shape how illness is to be told. In these stories, medicine is often depicted as providing some restoration to the ill person in that where there is suffering there is some remedy (Frank, 1995). This narrative offers a return to a state of health following illness.

On the contrary, TH’s and Akul’s illness stories were conveyed as more temperamental. Both participants storied the sudden onset of symptoms and the need to manage an acute situation. Their accounts align with previously reported research underlining the overwhelming experience of acute situations (Fors et al., 2014). They both storied ‘up and down’ experiences of medicine alongside the unpredictable nature of their heart condition, and ongoing repair of disruption to their lives. Thus, dissimilar to Noah and Henry, TH and Akul had not moved ‘beyond illness’. Meaning, TH and Akul’s narratives suggest they were still managing their illness condition, its related effects and intrusions to everyday life, and determining their passage through its course (Radley, 1993).

TH and Akul’s stories of illness can be placed in other narratives to that of restitution. They can be located in narratives that exemplify the patient ‘in’ treatment or ‘affected’ by treatment (Frank, 1995). What TH and Akul's narratives have made present for us is the more discomforting and uneasy journeys of illness that some patients experience in everyday life. As outlined by Radley (2009), as medicine becomes more pronounced in a patient's life either through investigation or treatment, this raises questions over the effects of diagnosis, prognosis and intervention in the lives of patients and significant others. The participants narratives have revealed the need to consider such questions moving forward. This is understood through the way TH and Akul storied more severe impacts to everyday life within the context of their heart conditions.

Understanding participant stories can be placed within existing public narrative forms illustrates how they draw on multiple narrative structures or tropes in crafting their own personal narratives (Murray, 2000). This supports the assertion of Groleau and colleagues (2006) outlined earlier, that lay experiences of illness do not necessarily form into logical and coherent schemas arranged around causal attributions. Instead, people can draw on particular public narratives or communal representational resources from their wider social context to make sense of their illness (Groleau et al., 2006). The use of representational schemas is apparent through the way my participants made sense of illness through interactions with medical professionals, sharing stories with others, drawing on experiences of family and friends and exposure to certain social outlets such as the media. This emphasises how personal narratives are also shaped by broader socio-cultural understandings which reinforces the complexities of the meaning making process (Frank, 1995; Murray, 1999). Thus, the participants narratives also reflect strong cultural and personal preferences in the telling of stories. It raises the importance of situating people within their everyday context when understanding experiences of illness (Radley, 1993).

Whilst each participant's illness trajectory was important to the varying levels of illness disruption, their narratives have emphasised that the 'social conditions and circumstances' in which illness occurs is of core significance. The participants drew on notions of the social and economic resources available to them. Additionally, they narrated certain personal and social circumstances of their broader everyday lives relative to their illness experience. In terms of resources, most participants found social support at the interpersonal level to be useful or helpful. This is consistent with previous research that reported positive experiences of support (Hutton & Perkins, 2008), and the importance of social support from relatives (Junehag et al., 2014), or speaking to peers following a cardiac event (Junehag et al., 2014; Merritt, Zoysa, Hutton, & de Zoysa, 2017).

Alternatively, Henry's account emphasises how not all support has positive effects. This is consistent with reports that certain types of support can intensify the disability and suffering experienced by people who are ill (Lyons & Chamberlain, 2006). For instance, Itkowitz, Kerns, and Otis (2003) found that solicitous responding, including expressing sympathy to symptoms of coronary heart disease, was linked with increased disability, symptom severity and depressed mood. This demonstrates the diversity in how social support at the interpersonal level can be experienced by patients.

Arguably more importantly, social support at the interpersonal level represents only part of the circumstances and the 'social' of people's lives (Hodgetts et al., 2010). The social also comprises societal structures that shape everyday life of individuals experiencing illness. Although social support is important, it can do little to change the material circumstances and broader structures which can impact those experiencing illness (Hodgetts et al., 2010). For instance, TH's narrative tells us of the economic burdens of illness and the related impact and adjustment this created within his whānau life. Jan and colleagues (2009) have provided insight into this issue previously where the authors underlined the economic stressors of illness. The authors found that economic hardship required households to make difficult decisions between basic living expenses and care, which at times, compromised necessary healthcare and treatment (Jan et al., 2009). Henry and Noah did not recount the economic burden of illness whereas, Akul shared concerns of his future employment. A disproportional level of additional stressors appeared to exist across the narratives relating to this issue and most evident within TH and Akul's accounts.

Materially, this study reveals that the participants had varying levels of resources and differing circumstances which either reduced or compounded their experiences of illness. Importantly, the CRNs reported being aware of the socio-economic conditions and circumstances of particular participants. They expressed the difficult circumstances some patients must manage and the issues they faced within their everyday lives with illness (C. Shepherd, personal communication, July 4, 2018). These issues appear to exist at a much broader level beyond the healthcare system. For instance, TH reported the inadequacy of his social welfare payments and the lack of insurance support that prompted him to engage in working against medical advice. This alone raises questions regarding the sufficiency of the current economic supports for patients to manage and cover the demands of everyday life (Jan et al., 2009). This provides an example of the need to consider the social conditions of illness.

Considering the social conditions and circumstances of illness means we must situate people within their everyday lived social and material context, and pay attention to the social determinants of health influencing patient outcomes (Hodgetts et al., 2010). There is consistent and continuing evidence depicting a negative relationship between socioeconomic status (SES) and health (Smith, Bartley, & Blane, 1990). Those of higher SES often experience far greater health than to those of lower SES which has been described as working in a stepwise gradient (Lyons & Chamberlain, 2006). Understanding the impact of lower SES on health outcomes suggests the need to understand how individual social conditions and circumstances may impact patient recovery or journey through illness. The issue of varying social conditions and circumstances of patients is not an issue the healthcare system alone can address. Such broader issues require particular governing bodies to recognise the disparities in CVD outcomes is also a social issue. A social issue that much of which is linked to colonisation and its reverberating effects as outlined in chapter one.

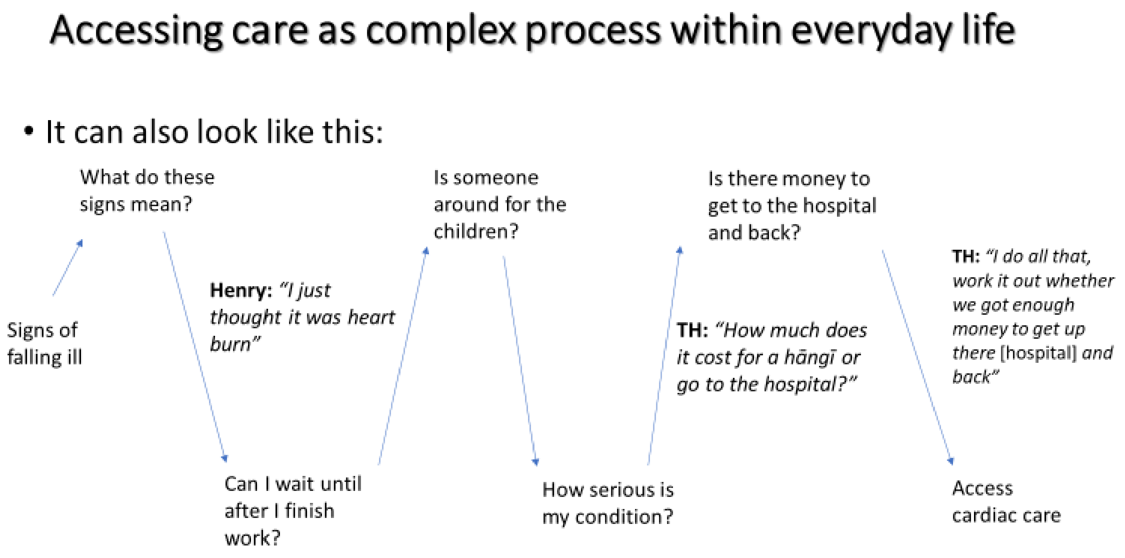
Essentially, my participants convey what CVD means to them within the context of their everyday lives. They make sense of illness in varying ways in which they storied about the past, present and future. This enabled us to understand how past events such as colonisation can manifest both overtly and implicitly within one's illness narrative and in some cases (such as Akul's), can form an important part of how one understands their illness. Akul was the only participant who explicitly drew on colonisation as the cause of his illness. Blaxter (1997) has previously reported that people of lower SES tended to neglect the structural causes of ill health which may account for why such structural explanations were lacking within TH and Noah's narratives.

As outlined by Murray (1999), one's story can be shaped by material from one's life history, tied with information from our current situation and future outlooks. My participants narratives are reflective of this dynamic construction and reinforce how particular aspects of one's life can invoke new meanings when they are examined in the relation to one's illness (Murray, 1999). Overall this key finding raises our awareness to how patients understand, manage, adjust and attempt to adapt when a rupture such as illness occurs in everyday life. The narratives have highlighted particular issues and dilemmas the participants faced with illness and have identified areas in which we can better respond to their needs.

The issue of *varying levels of illness disruption within the context of everyday life* is important in aiding recognition CVD can invoke different meanings across patients. In this study, these meanings relate to varying levels of impact to everyday life and disruption to one's very sense of self. The participant narratives highlight the 'repairing of one's life' was a matter they were confronted with alongside the repairing of one's ailment which encompassed both a personal and social process. Such repair involved the process of tying together and connecting the past, present and future to bring some coherence to the life disrupted by disease. Upon comparing the cases, this study has found that there are certain inequities that exist within the context of my participants everyday lives that have contributed to the experience of illness. This suggests the issue of disparities in CVD outcomes may also exist at a much broader level that extends beyond the healthcare system. I next discuss the implications for care and future lines of direction that have come from this research and related discussions with the Cardiology unit staff at the Waikato DHB.

Implications for care and future research

The key findings from this study should broaden one's understanding regarding the complexities' patients may face towards accessing cardiac care. The diagram depicted in figure 6 (taken from the presentation slides, see appendix 7) provides a visual 'impression' of what accessing care within the context of everyday life may look like for some patients. Figure 6 illustrates how accessing care is not solely related to the personal attitudes and perceptions of patients. Such processes can involve everyday situational and structural factors that shape access to care. It highlights that accessing care may not be a straightforward process where some patients may be confronted with various challenges in the process of accessing care. The complexities conveyed in figure 6 emphasise the need to understand how accessing cardiac care does not occur in isolation from one's everyday life. It is often negotiated and contemplated in relation to it.



Accessing care as complex process within everyday life

- It can also look like this:

Signs of falling ill

What do these signs mean?

Henry: *"I just thought it was heart burn"*

Can I wait until after I finish work?

Is someone around for the children?

How serious is my condition?

TH: *"How much does it cost for a hāngī or go to the hospital?"*

Is there money to get to the hospital and back?

TH: *"I do all that, work it out whether we got enough money to get up there* [hospital] *and back"*

Access cardiac care

Figure 6. Depicting complex process of accessing care

The findings from this research suggest the clinical competence of health professionals is not the only important factor that can shape experiences of care and patient perspectives of the healthcare system. 'How' health professionals engage with patients in their care is also fundamental to care. Practices that foreground relationships, engaging patients as persons in their care and fostering a sense of continuity may be key towards facilitating more positive experiences of cardiac care. Such practices may help to build a sense of 'trust' in health professionals and thus, the healthcare system in general. Overall, it is important to understand that health professionals can play a key role in not only a patient's journey through the healthcare system, but also how they experience illness within the context of their everyday lives. This means paying attention to particular strategies that support positive social relations between health professionals and patients within the context of cardiac care.

The findings from this study demonstrate how patients can be affected by their heart conditions in different ways. Relatedly, the illness trajectories and the circumstances in which CVD and care is experienced should be considered as key in relation to understanding the extent of illness disruption to the lives of patients and their whānau. Acknowledging patients may be impacted by their heart conditions in different ways emphasises the importance of more patient-centred approaches that focuses on certain needs of patients.

The outcome of the discussion between the research team and Cardiology unit staff suggests some further work needs to be conducted in this area to build on the findings of the current study. Potential further lines of research may involve exploring patient understandings of having a chronic condition and ongoing management, or further research may explore the social circumstances of illness to understand the impact on patient recovery. Not only this, these discussions have invoked some thought regarding establishing, building or strengthening relationships with other services such as primary care and other support/allied services. Such relationships and collaborative efforts may be key to better support patients receiving cardiac care. Overall, the findings from the current study has provided staff at the Waikato DHB with information to inform their efforts to maintain and lift current standards of care and respond to the needs of Māori in cardiac care.

Concluding statement

To conclude, foundational to this thesis is the assertion that people live within particular social and material contexts that are reproduced through particular, often mundane, social practices that shape everyday lifeworld's. Falling ill does not occur in isolation from these features and how people respond, and experience illness is interconnected with and related to one's broader everyday lived context. This study demonstrates the importance of understanding access to care within the context of everyday life. It has shown various factors extending beyond the individual can influence one's responding actions of accessing care and how such processes are complex. Despite my participants being able to access care, the findings suggest certain factors can facilitate and delay access.

Studies such as mine provide diverse patient perspectives on healthcare systems, and in this case, the functioning of cardiac care. The findings suggest not all my participant's experiences of the healthcare system are negative although, some areas of cardiac care can be viewed as requiring some consideration and thought. This study also offers an insight into Māori men's experiences of CVD within the context of everyday life. The findings indicate that patients can experience varying levels of illness disruption which is determined by a range of interrelated and complex factors. Importantly, this study has identified the personal, interpersonal, material and structural constraints of everyday life may not only exist at the level of access to care. These work in concert in everyday lives to shape people's experiences of and responses to illness. It necessitates further consideration of issues that have traditionally resided outside the healthcare system and which contribute to the disparities in CVD outcomes. Overall, the narratives presented here have shown that Māori are not a homogenous group and CVD can invoke different meanings within the context of everyday life. It embeds the importance of case-based approaches that allow such differing meanings to be recognised and examined (Radley & Chamberlain, 2012).

Illness narratives offer a way of exploring the experience of patients suffering from certain diseases such as CVD. This study demonstrates that illness narratives offer great insight into one's experiences of illness that extends beyond the processes of falling ill, diagnosis, treatment and recovery. Illness narratives also offer the opportunity for patients to story about how oneself and their families have been affected by illness and what meaning this has to broader everyday life (Radley, 2009). As this study has shown, the meanings of illness may differ and vary across patients where narratives enable the uniqueness of personal narratives and public narratives to be analysed (Murray, 2000; Murray & Sools, 2015). Most importantly, constructing illness narratives can afford people the opportunity to engage in processes of reflecting on, and repairing the disruption of disease to one's life narrative (Radley, 2009). The employment of visual methods such as drawings and photos can aid such processes. Thus, in the process of constructing one's illness narrative, such processes can also bring some coherence to one's life.

Overall, this study has contributed to the body of knowledge working towards reducing the health disparities between Māori and non-Māori. The men's narratives have provided important insights for consideration of how we respond to Māori needs with heart conditions in the future. These insights can be useful in supporting and facilitating positive patient outcomes and determining lines of further investigation.

References

Ajwani, S., Blakely, T., Robson, B., Tobias, M., & Bonne, M. (2003). *Decades of Disparity: Ethnic mortality trends in New Zealand 1980-1999*. Wellington, New Zealand: Ministry of Health and University of Otago.

Anderson, R., & Bury, M. (Eds.). (1988). *Living with Chronic Illness: The experience of patients and their families*. London, United Kingdom: Unwin Hyman Ltd.

Artuso, S., Cargo, M., Brown, A., & Daniel, M. (2013). Factors influencing health care utilisation among Aboriginal cardiac patients in central Australia: A qualitative study. *BMC Health Services Research, 13*(1), 1-13. doi:10.1186/1472-6963-13-83

Aspin, C., Brown, N., Leeder, S., Jowsey, T., & Yen, L. (2012). Strategic approaches to enhanced health service delivery for Aboriginal and Torres Strait Islander people with chronic illness: A qualitative study. *BMC Health Services Research, 12*(143), 1-9. doi:https://doi.org/10.1186/1472-6963-12-143

Barry, C. A., Stevenson, F. A., Britten, N., Barber, N., & Bradley, C. P. (2001). Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. *Social Science & Medicine, 53*(4), 487-505.

Bhaskar, R. (1975). *A realist theory of science*. London, United Kingdom: Verso.

Bishop, R., & Glynn, T. (1999). Researching in Māori Contexts: an interpretation of participatory consciousness. *Journal of Intercultural Studies, 20*(2), 167-183. doi:10.1080/07256868.1999.9963478

Blaxter, M. (1990). *Health and Lifestyles*. London, United Kingdom: Routledge.

Blaxter, M. (1997). Whose fault is it? People's own conceptions of the reasons for health inequalities. *Social Science and Medicine, 44*(6), 747-756. doi:10.1016/S0277-9536(96)00192-X

Bolitho, S., & Huntington, A. (2006). Experiences of Māori families accessing health care for their unwell children: A pilot study. *Nursing Praxis in New Zealand, 22*(1), 23-32.

British Heart Foundation. (n.d.). *Cardiovascular disease*. Retrieved from https://www.bhf.org.uk/heart-health/conditions/cardiovascular-disease

Browne, A. J., & Fiske, J.-A. (2001). First Nations Women's Encounters With Mainstream Health Care Services. *Western Journal of Nursing Research, 23*(2), 126-147.

Bruce, A., Sheilds, L., Molzahn, A., Beuthin, R., Schick-Makaroff, K., & Shermak, S. (2014). Stories of Liminality: Living With Life-Threatening Illness. *Journal of Holistic Nursing, 32*(1), 35-43. doi:10.1177/0898010113498823

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4*(2), 167-182.

Bury, M. (1997). *Health and illness: In a changing society*. London, United Kingdom: Routledge.

Bury, M. (2005). *Health and illness*. Cambridge, United Kingdom: Polity Press.

Chamberlain, K. (2015). Epistemology and qualitative research. In P. Rohleder & A. C. Lyons (Eds.), *Qualitative research in clinical and health psychology*. Hampshire, United Kingdom: Palgrave Macmillan.

Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior, 51*, 67-79. doi:10.1177/0022146510383495

Cornish, F., Murray, M., & Campbell, C. (2004). Making 'context' concrete: A dialogical approach to the society-health relation. *Journal of Health Psychology, 9*(2), 281-294.

Cozby, P. C., & Bates, S. C. (2011). *Methods in behavioral research* (11 ed.). New York, NY: McGraw-Hill.

Cram, F. (2001). Rangahau Māori: Tona tika, tona pono - The validity and integrity of Māori research. In M. Tolich (Ed.), *Research ethics in Aotearoa New Zealand: Concepts, practice, critique*. Auckland, New Zealand: Pearson Education New Zealand Limited.

Cram, F. (2014). *Improving Māori access to cancer, diabetes and cardiovascular health care: Key informant interviews*. Auckland, New Zealand: Katoa Ltd.

Curtis, E., Harwood, M., Riddell, T., Robson, B., Harris, R., Mills, C., & Reid, P. (2010). Original article: Access and society as determinants of ischaemic heart disease in indigenous populations. *Heart, Lung and Circulation, 19*(5), 316-324. doi:10.1016/j.hlc.2010.04.129

Davey Smith, G., Bartley, M., & Blane, D. (1990). The Black Report On Socioeconomic Inequalities In Health 10 Years On. *BMJ: British Medical Journal, 301*(6748), 373-377.

Davidson, P. M., MacIsaac, A., Cameron, J., Jeremy, R., Mahar, L., & Anderson, I. (2012). Original article: Problems, solutions and actions: Addressing barriers in acute hospital care for indigenous Australians and New Zealanders. *Heart, Lung and Circulation, 21*(10), 639-643. doi:10.1016/j.hlc.2012.07.005

Dracup, K., & Moser, D. K. (1997). Beyond sociodemographics: Factors influencing the decision to seek treatment for symptoms of acute myocardial infarction. *Heart & Lung: The Journal of Acute and Critical Care, 26*(4), 253-262. doi:https://doi.org/10.1016/S0147-9563(97)90082-0

Dullaghan, L., Lusk, L., Donnelly, P., McGeough, M., & Fitzsimons, D. (2013). Communicating with people who have experienced heart attack. *Emergency Nurse, 21*(6), 33-36. doi:10.7748/en2013.10.21.6.33.e1203

Durie, M. (1998). *Whaiora: Māori Health Development* (2 ed.). Auckland, New Zealand: Oxford University Press.

Durie, M. (2001). *Mauri ora: The dynamics of Māori Health*. Auckland, New Zealand: Oxford University Press.

Durie, M. (2017). Kaupapa Māori: Indigenising New Zealand. In T. K. Hoskins & A. Jones (Eds.), *Critical Conversations in Kaupapa Māori*. Wellington, Aotearoa/New Zealand: Huia Publishers.

East, L., Brown, K., Radford, J., Roosink, S., & Twells, C. (2004). 'She's an angel in disguise' The evolving role of the specialist community heart nurse. *Primary Health Care Research and Development, 5*(4), 359-366. doi:10.1191/1463423604pc204oa

Eketone, A. (2008). Theoretical underpinnings of Kaupapa Māori directed practice. *MAI review (Online), 1*, 1-11.

Ellison-Loschmann, L., & Pearce, N. (2006). Improving access to health care among New Zealand's Māori population. *American Journal of Public Health, 96*(4), 612-617. doi:10.2105/AJPH.2005.070680

Eriksson, M., Svedlund, M., & Asplund, K. (2010). Couples' thoughts about and expectations of their future life after the patient's hospital discharge following acute myocardial infarction. *Journal of Clinical Nursing, 19*(23-24), 3485-3493. doi:10.1111/j.1365-2702.2010.03292.x

Fariba, K., Forouz, N., Kyoung, J. Y., & Sangita, S. (2015). Understanding the social determinants of health among Indigenous Canadians: Priorities for health promotion policies and actions. *Global Health Action, 8*(0), 1-16. doi:10.3402/gha.v8.27968

Fitzsimons, D., Parahoo, K., & Stringer, M. (2000). Waiting for coronary artery bypass surgery: a qualitative analysis. *Journal of Advanced Nursing, 32*(5), 1243-1252.

Fors, A., Dudas, K., & Ekman, I. (2014). Life is lived forwards and understood backwards-Experiences of being affected by acute coronary syndrome: A narrative analysis. *International Journal of Nursing Studies, 51*(3), 430-437. doi:http://dx.doi.org/10.1016/j.ijnurstu.2013.06.012

Forslund, A. S., Jansson, J. H., Lundblad, D., & Söderberg, S. (2017). A second chance at life: people's lived experiences of surviving out-of-hospital cardiac arrest. *Scandinavian Journal of Caring Sciences, 31*(4), 878-886. doi:10.1111/scs.12409

Frank, A. (1995). *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago, IL: The University of Chicago Press.

Fry, M., McLachlan, S., Purdy, S., Sanders, T., Kadam, U. T., & Chew-Graham, C. A. (2016). The implications of living with heart failure; the impact on everyday life, family support, co-morbidities and access to healthcare: A secondary qualitative analysis. *BMC Family Practice, 17*, 1-8. doi:10.1186/s12875-016-0537-5

Giddens, A. (1979). *Central Problems in Social Theory*. London, United Kingdom: Macmillan.

Gilmour, J. A. (2006). Hybrid space: Constituting the hospital as a home space for patients. *Nursing Inquiry, 13*(1), 16-22. doi:10.1111/j.1440-1800.2006.00276.x

Giuliano, C., Parmenter, B. J., Baker, M. K., Mitchell, B. L., Williams, A. D., Lyndon, K., . . . Levinger, I. (2017). Cardiac Rehabilitation for Patients With Coronary Artery Disease: A Practical Guide to Enhance Patient Outcomes Through Continuity of Care. *Clinical Medicine Insights: Cardiology, 11*, 1-7. doi:10.1177/1179546817710028

Good, B. J. (1994). *Medicine, rationality, and experience. An anthropological perspective*. Cambridge, United Kingdom: Cambridge University Press.

Gracey, M. (2014). Why closing the Aboriginal health gap is so elusive. *Internal Medicine Journal, 44*(11), 1141-1143. doi:10.1111/imj.12577

Grey, C., Jackson, R., Wells, S., Marshall, R., Mehta, S., & Kerr, A. J. (2016). Ethnic differences in case fatality following an acute ischaemic heart disease event in New Zealand: ANZACS-QI 13. *European Journal of Preventive Cardiology, 23*(17), 1823-1830. doi:http://journals.sagepub.com/doi/pdf/10.1177/2047487316657671

Groleau, D., Young, A., & Kirmayer, L. J. (2006). The McGill Illness Narrative Interview (MINI): An interview schedule to elicit meanings and modes of reasoning related to illness experience. *Transcultural Psychiatry, 43*(4), 671-691. doi:10.1177/136346150607079

Guillemin, M. (2004). Understanding illness: Using drawings as a research method. *Qualitative Health Research, 14*(2), 272-289.

Haque, O. S., & Waytz, A. (2012). Dehumanization in medicine: Causes, solutions, and functions. *Nurse Researcher, 12*(2), 14-17.

Harris, R., Cormack, D., Tobias, M., Yeh, L.-C., Talamaivao, N., Minster, J., & Timutimu, R. (2012). The pervasive effects of racism: Experiences of racial discrimination in New Zealand over time and associations with multiple health domains. *Social Science & Medicine, 74*(3), 408-415.

Hart, J. T. (1971). The inverse care law. *The Lancet, 297*(7696), 405-412. doi:https://doi.org/10.1016/S0140-6736(71)92410-X

Hiles, D., & Čermák, I. (2008). Narrative psychology. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage Handbook of Qualitative Research in Psychology*. London, United Kingdom: Sage Publications Ltd.

Hodgetts, D., Bolam, B., & Stephens, C. (2005). Mediation and the Construction of Contemporary Understandings of Health and Lifestyle. *Journal of Health Psychology, 10*(1), 123-136. doi:10.1177/1359105305048559

Hodgetts, D., Chamberlain, K., Gabe, J., Dew, K., Radley, A., Madden, H., . . . Nikora, L. W. (2011). Emplacement and everyday use of medications in domestic dwellings. *Health and Place, 17*(1), 353-360.

Hodgetts, D., Chamberlain, K., & Groot, S. (2019). Impressionist reflections on visual research in community research and action. In P. Reavey (Ed.), *Visual Methods in Psychology* (2nd ed.). London, United Kingdom: Routledge.

Hodgetts, D., Drew, N., Sonn, C., Stolte, O., Nikora, L. W., & Curtis, C. (2010). *Social psychology and everyday life*. London, United Kingdom: Palgrave Macmillan.

Hodgetts, D., Masters, B., & Robertson, N. (2004). Media coverage of 'Decades of Disparity' in ethnic mortality in Aotearoa. *Journal of community & applied social psychology, 14*(6), 455-472.

Hodgetts, D., Nikora, L. W., & Rua, M. (2011). Māori men and the indirect procurement and sharing of prescription medications. *AlterNative, 7*(2), 152-162.

Hodgetts, D., & Rua, M. (2010). What Does it Mean to be a Man Today?: Bloke Culture and the Media. *American Journal of Community Psychology, 45*(1/2), 155-168. doi:10.1007/s10464-009-9287-z

Hodgetts, D., Rua, M., King, P., & Te Whetu, T. (2014). The ordinary in the extra-ordinary: Everyday lives textured by homelessness. In E. Schraube & C. Højholt (Eds.), *Psychology and the Conduct of Everyday Life*. London, United Kingdom: Routledge.

Hodgetts, D., & Stolte, O. (2012). Case-based Research in Community and Social Psychology: Introduction to the Special Issue. *Journal of Community & Applied Social Psychology, 22*(5), 379-389. doi:10.1002/casp.2124

Hodgetts, D., Stolte, O., Groot, S., & Drew, N. (2018). Homelessness, mimesis, and the flânerie. *International Perspectives in Psychology: Research, Practice, Consultation, 7*(2), 91-106.

Hodgetts, D., Stolte, O., King, P., & Groot, S. (2019). Reproducing the general through the local: Lessons from poverty research. In C. Højholt & E. Schraube (Eds.), *Subjectivity and Knowledge: Generalization in the Psychological Study of Everyday Life*. New York: Springer.

Højholt, C., & Schraube, E. (2016). Introduction: Toward a psychology of everyday living. In C. Højholt & E. Schraube (Eds.), *Psychology and the Conduct of Everyday Life* (pp. 1-14). New York, NY: Routledge. Retrieved from http://ezproxy.massey.ac.nz/login?url=https://www.taylorfrancis.com/books/9781315746890.

Holzkamp, K. (2016). Conduct of everyday life as a basic concept of critical psychology. In C. Højholt & E. Schraube (Eds.), *Psychology and the Conduct of Everyday Life* (pp. 65-98). New York, NY: Routledge. Retrieved from https://www-taylorfrancis-com.ezproxy.massey.ac.nz/books/9781317599708.

Hudson, M., Milne, M., Reynolds, P., Russell, K., & Smith, B. (2010). *Te Ara Tika: Guidelines for Māori research ethics: A framework for researchers and ethics committee members* New Zealand: Health Research Council of New Zealand on behalf of Pūtaiora Writing Group

Hutton, J. M., & Perkins, S. J. (2008). A qualitative study of men's experience of myocardial infarction. *Psychology, Health & Medicine, 13*(1), 87-97.

Hyyppa, M., & Maki, J. (2003). Social participation and health in a community rich in stock of social capital. *Health Education Research, 18*, 770-779.

Itkowitz, N. I., Kerns, R. D., & Otis, J. D. (2003). Support and coronary heart disease: The importance of significant other responses. *Journal of behavioral medicine, 26*(1), 19.

Jan, S., Essue, B., Jeon, Y.-H., Wells, R., & Whitworth, J. A. (2009). Economic hardship associated with managing chronic illness: A qualitative inquiry. *BMC Health Services Research, 9*(1), 182-193. doi:10.1186/1472-6963-9-182

Jensen, B. O., & Petersson, K. (2003). The illness experiences of patients after a first time myocardial infarction. *Patient Education and Counseling, 51*(2), 123-131. doi:10.1016/S0738-3991(02)00196-9

Jeremy, R., Tonkin, A., White, H., Riddell, T., Brieger, D., Walsh, W., . . . Kritharides, L. (2010). Original Article: Improving cardiovascular care for indigenous people. *Heart, Lung and Circulation, 19*(6), 344-350. doi:10.1016/j.hlc.2010.02.015

Jones, C. P. (2000). Levels of Racism: A Theoretic Framework and a Gardener's Tale. *The American Journal of Public Health*(8).

Junehag, L., Asplund, K., & Svedlund, M. (2014). A qualitative study: Perceptions of the psychosocial consequences and access to support after an acute myocardial infarction. *Intensive & Critical Care Nursing, 30*(1), 22-30. doi:10.1016/j.iccn.2013.07.002

Kaul, P., Newby, L. K., Fu, Y., Mark, D. B., Califf, R. M., Topol, E. J., . . . Van de Werf, F. (2004). International differences in evolution of early discharge after acute myocardial infarction. *Lancet, 363*(9408), 511-517.

Kerr, S., Penney, L., Moewaka Barnes, H., & McCreanor, T. (2010). Kaupapa Māori action research to improve heart disease services in Aotearoa, New Zealand. *Ethnicity & Health, 15*(1), 15-31. doi:10.1080/13557850903374476

King, D. (2017). *How Māori precariat whānau navigate social services.* (unpublished master's thesis), Massey University, Palmerston North, New Zealand.

King, P., Hodgetts, D., Morgan, M., & Rua, M. (2017). Disrupting being on an industrial scale: Towards a theorization of Māori ways-of-being. *Theory and Psychology, 27*(6), 725-740. doi:10.1177/0959354317733552

King, P., Hodgetts, D., Rua, M., & Te Whetu, T. (2015). Older men gardening on the marae: Everyday practices for being Māori. *AlterNative: An International Journal of Indigenous Peoples, 11*(1), 14-28.

Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N., & Sanders, C. (2016). Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health & Social Care in the Community, 24*(2), 203-213. doi:10.1111/hsc.12207

Lee, R., & North, N. (2013). Barriers to Māori sole mothers' primary health care access. *Journal of Primary Health Care, 5*(4), 315-321.

Levack, W. M. M., Jones, B., Grainger, R., Boland, P., Brown, M., & Ingham, T. R. (2016). Whakawhanaungatanga: the importance of culturally meaningful connections to improve uptake of pulmonary rehabilitation by Māori with COPD – a qualitative study. *International Journal of COPD, 11*(1), 489-501.

Livneh, H., & Antonak, R. F. (2012). Psychological adaptation to chronic illness and disability: A primer for counselors. In I. Marini & M. A. Stebnicki (Eds.), *The psychological and social impact of illness and disability*. New York, NY: Springer Publishing Company.

Lyons, A. C. (2015). Approaches to collecting data. In P. Rohleder & A. C. Lyons (Eds.), *Qualitative research in clinical and health psychology*. Hampshire, United Kingdom: Palgrave Macmillan.

Lyons, A. C., & Chamberlain, K. (2006). *Health psychology: A critical introduction*. Cambridge, United Kingdom: Cambridge University Press.

MacLeod, M. (1993). On knowing the patient: experiences of nurses undertaking care. In A. Radley (Ed.), *Worlds of illness: Biographical and cultural perspectives on health and disease* (pp. 179-197). London, United Kingdom: Routledge.

Masters-Awatere, B., Boulton, A., Rata, A., Tangitu-Joseph, M., Brown, R., & Cormack, D. (2017). Behind the label: Complexities of identifying Māori whānau in an away from home hospital transfer. *New Zealand Journal of Psychology, 46*(3), 20-29.

Merritt, C. J., Zoysa, N., Hutton, J. M., & de Zoysa, N. (2017). A qualitative study of younger men's experience of heart attack (myocardial infarction). *British Journal of Health Psychology, 22*(3), 589-608.

Miner-Williams, W. (2017). Racial inequities in cardiovascular disease in New Zealand. *Diversity and Equality in Health and Care, 14*(1), 23-33.

Ministry of Culture and Heritage. (2016). *Obtaining land*. Retrieved from https://nzhistory.govt.nz/politics/treaty/the-treaty-in-practice/obtaining-land

Ministry of Culture and Heritage. (2017a). *The Treaty in brief*. Retrieved from https://nzhistory.govt.nz/politics/treaty/the-treaty-in-brief

Ministry of Culture and Heritage. (2017b). Waitangi Tribunal created. Retrieved from https://nzhistory.govt.nz/waitangi-tribunal-created

Ministry of Health. (2013). *Travel Assistance*. Retrieved from https://www.health.govt.nz/your-health/services-and-support/health-care-services/hospitals-and-specialist-services/travel-assistance

Ministry of Health. (2015). *Cardiovascular disease*. Retrieved from https://www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/cardiovascular-disease

Mishler, E. G. (1984). *The discourse of medicine: dialectics of medical interviews*. Norwood, NJ: Ablex.

Moewaka Barnes, A., Taiapa, K., Borell, L., & McCreanor, T. (2013). Māori experiences and responses to racism in Aotearoa New Zealand. *MAI journal, 2*(2), 63-77.

Murray, M. (1997). A narrative approach to health psychology: Background and potential. *Journal of Health Psychology, 2*(1), 9-20. doi:10.1177/135910539700200102

Murray, M. (1999). The storied nature of health and illness. In M. Murray & K. Chamberlain (Eds.), *Qualitative Health Psychology: Theories and Methods* (pp. 47-63). London, United Kingdom: Sage Publications Ltd.

Murray, M. (2000). Levels of narrative analysis in health psychology. *Journal of Health Psychology, 5*(3), 337-347.

Murray, M. (2003). Narrative psychology and narrative analysis. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design*. Washington, DC: American Psychological Association.

Murray, M., & Sools, A. (2015). Narrative research. In P. Rohleder & A. C. Lyons (Eds.), *Qualitative research in clinical and health psychology*. Hampshire, United Kingdom: Palgrave Macmillan.

Nadarajah, S. R., Buchholz, S. W., Wiegand, D. L., & Berger, A. (2017). The lived experience of individuals in cardiac rehabilitation who have a positive outlook on their cardiac recovery: A phenomenological inquiry. *European Journal of Cardiovascular Nursing, 16*(3), 230-239. doi:10.1177/1474515116651977

Nelson, G., & Prilleltensky, I. (Eds.). (2010). *Community Psychology: In pursuit of liberation and wellbeing* (2nd ed.). London, United Kingdom: Palgrave Macmillan.

Nicolai, J., Müller, N., Noest, S., Wilke, S., Schultz, J.-H., Gleißner, C. A., . . . Bieber, C. (2018). To change or not to change – That is the question: A qualitative study of lifestyle changes following acute myocardial infarction. *Chronic Illness, 14*(1), 25-41. doi:10.1177/1742395317694700

OECD. (2015). *Mortality from cardiovascular disease*. In Health at a Glance: OECD indicators, (pp. 50-51). doi:http://dx.doi.org.ezproxy.massey.ac.nz/10.1787/19991312

Oliver, W. H., & Williams, B. R. (Eds.). (1981). *The Oxford History of New Zealand*. Wellington, New Zealand: Oxford University Press.

Östman, M., Ung, E. J., & Falk, K. (2015). Health-care encounters create both discontinuity and continuity in daily life when living with chronic heart failure—A grounded theory study. *International Journal of Qualitative Studies on Health & Well-Being, 10*(0), 1-12. doi:10.3402/qhw.v10.27775

Parsonson, A. (1981). The pursuit of mana. In W. H. Oliver & B. R. Williams (Eds.), *The Oxford History of New Zealand*. Wellington, New Zealand: Oxford University Press.

Penney, L., Barnes, H. M., & McCreanor, T. (2011). The blame game: Constructions of Māori medical compliance. *AlterNative, 7*(2), 73-86.

Pomare, E. W. (1980). *Māori standards of health: A study of the 20-year period 1955-1975* (No. 7 Special Report Series). Auckland, New Zealand: Medical Research Council of New Zealand.

Pomare, E. W., & de Boer, G. M. (1988). *Hauora: Māori standards of health- A study of the years 1970-1984* (No. 78 Special Report Series). Wellington, New Zealand: Medical Research Council and Department of Health.

Pool, I. (2015). *Colonization and Development in New Zealand between 1769 and 1900: The Seeds of Rangiatea*. Cham, Switzerland: Springer.

Pool, I. (2016). Māori health, colonization and post-colonization: Aotearoa New Zealand, from 1769. *Journal of Northern Studies, 10*(2), 19-43.

Radley, A. (1993). *Worlds of illness: Biographical and cultural perspectives on health and disease*. New York, NY: Routledge.

Radley, A. (1995). *Making sense of illness: The social psychology of health and disease*. London, United Kingdom: Sage Publications.

Radley, A. (1999). The aesthetics of illness: narrative, horror and the sublime. *Sociology of health & illness, 21*(6), 778-796.

Radley, A. (2009). *Works of illness: Narrative, picturing and the social response to serious disease*. Ashby-de-la-Zouch, United Kingdom: InkerMen Press.

Radley, A., & Billig, M. (1996). Accounts of health and illness: Dilemmas and representations. *Sociology of Health and Illness, 18*, 220-240.

Radley, A., & Chamberlain, K. (2001). Health psychology and the study of the case: from method to analytic concern. *Social Science & Medicine, 53*(3), 321-332.

Radley, A., & Chamberlain, K. (2012). The Study of the Case: Conceptualising Case Study Research. *Case studies in Community and Social Psychology, 22*(5), 390-399.

Reid, J., Cormack, D., & Crowe, M. (2016). The significance of relational continuity of care for Māori patient engagement with predominantly non-Māori doctors: Findings from a qualitative study. *Australian and New Zealand Journal of Public Health, 40*(2), 120-125. doi:10.1111/1753-6405.12447

Reid, P. (2015). Promoting health equity. In L. Signal & M. Ratima (Eds.), *Promoting health in Aotearoa New Zealand* (pp. 146-161). Dunedin, New Zealand: Otago University Press.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. California, CA: Sage Publications, Inc.

Riessman, C. K. (2015). Ruptures and sutures: time, audience and identity in an illness narrative. *Sociology of health & illness, 37*(7), 1055-1072. doi:10.1111/1467-9566.12281

Ritchie, J. (1992). *Becoming bicultural*. Wellington, New Zealand: Huia Publishers.

Ross, J., & Hamlin, M. (2007). Māori physical activity: A review of an indigenous population's participation. *Health Promotion Journal of Australia, 18*(1), 73-76.

Rua, M., Groot, S., Nikora, L. W., King, P., Masters-Awatere, B., & Hodgetts, D. (In Press). Decoloniality in being Māori and community psychologists: Advancing an evolving and culturally-situated approach. In G. Stevens & C. Sonn (Eds.), *Decoloniality and Epistemic Justice in Contemporary Community Psychology* New York, NY: Springer.

Rua, M., Stolte, O., & Hodgetts, D. (2017). Māori men: An indigenous psychological perspective on the interconnected self. *New Zealand Journal of Psychology, 46*(3), 55-63.

Sandiford, P., Bramley, D. M., El-Jack, S. S., & Scott, A. G. (2015). Original article: Ethnic differences in coronary artery revascularisation in New Zealand: Does the inverse care law still apply? *Heart, Lung and Circulation, 24*(10), 969-974. doi:10.1016/j.hlc.2015.03.013

Schott, T., & Badura, B. (1988). Wives of heart attack patients: The stress of caring. In R. Anderson & M. Bury (Eds.), *Living with Chronic Illness: The experience of patients and their families*. London, United Kingdom: Unwin Hyman Ltd.

Shahid, S., Finn, L., Bessarab, D., & Thompson, S. C. (2009). Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. *BMC Health Services Research, 9*(132), 1-9. doi:10.1186/1472-6963-9-132

Shepherd, F., Battye, K., & Chalmers, E. (2003). Improving access to cardiac rehabilitation for remote Indigenous clients. *Australian and New Zealand Journal of Public Health, 27*(6), 632-637.

Simonÿ, C. P., Dreyer, P., Pedersen, B. D., & Birkelund, R. (2015). Empowered to gain a new foothold in life—A study of the meaning of participating in cardiac rehabilitation to patients afflicted by a minor heart attack. *International Journal of Qualitative Studies on Health & Well-Being, 10,* 1-12. doi:10.3402/qhw.v10.28717

Small, M. L. (2009). 'How many cases do I need?' On science and the logic of case selection in field-based research. *Ethnography, 10*(1), 5-38.

Smith, D. (2014). *Criminal Injustice: Māori, racisim and mass incarcertaion*. Wellington, New Zealand: International Socialist Organisation Aotearoa.

Smith, F., Banwell, E., & Rakhit, R. (2017). 'I was in control of it from the start': A qualitative study of men's experiences of positive adjustment following a heart attack. *Journal of Health Psychology, 22*(10), 1345-1354. doi:10.1177/1359105315627000

Smith, G. H. (2017). Kaupapa Māori Theory: Indigenous transforming of education. In T. K. Hoskins & A. Jones (Eds.), *Critical conversations in Kaupapa Māori*. Wellington, Aotearoa New Zealand: Huia Publishers.

Smith, L. T. (1999). *Decolonizing methodologies: Research and indigenous peoples*. Dunedin, New Zealand: University of Otago Press.

Smith, R., Frazer, K., Hyde, A., O'Connor, L., & Hall, P. (2017). 'Betwixt and between health and illness': Women's narratives following acute coronary syndrome. *Journal of Clinical Nursing, 26*(21-22), 3457-3470. doi:10.1111/jocn.13711

Statistics New Zealand. (2006). *Quickstats about Māori: Māori ethnic population/ Te Momo Iwi Māori*. Retrieved from http://archive.stats.govt.nz/Census/2006CensusHomePage/QuickStats/quickstats-about-a-subject/maori/maori-ethnic-population-te-momo-iwi-maori.aspx#

Statistics New Zealand. (2013a). *2013 Census quickstats about a place: Waikato region*. Retrieved from http://archive.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-about-a-place.aspx?request_value=13631&tabname=

Statistics New Zealand. (2013b). *2013 Census quickstats about Māori*. Retrieved from http://archive.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-about-maori-english.aspx

Steptoe, A., O'Donnell, K., Marmot, M., & Wardle, J. (2008). Positive affect and psychosocial processes related to health. *British Journal of Psychology, 99*(2), 211-227. doi:10.1348/000712607X218295

Stewart, D. C., & Sullivan, T. J. (1982). Illness behavior and the sick role in chronic disease. The case of multiple sclerosis. *Social Science and Medicine, 16*(15), 1397-1404. doi:10.1016/0277-9536(82)90134-4

Stolte, O., & Hodgetts, D. (2015). Being healthy in unhealthy places: Health tactics in a homeless lifeworld. *Journal of Health Psychology, 20*(2), 144-153. doi:10.1177/1359105313500246

Swain, L., & Barclay, L. (2013). They've given me that many tablets, I'm bushed. I don't know where I'm going. *Australian Journal of Rural Health, 21*(4), 216-219. doi:10.1111/ajr.12053

Teo, T. (2016). Embodying the conduct of everyday life. In C. Højholt & E. Schraube (Eds.), *Psychology and the Conduct of Everyday Life* (pp. 111-123). New York, NY: Routledge. Retrieved from https://www-taylorfrancis-com.ezproxy.massey.ac.nz/books/9781315746890.

Thuresson, M., Jarlöv, M. B., Lindahl, B., Svensson, L., Zedigh, C., & Herlitz, J. (2007). Thoughts, actions, and factors associated with prehospital delay in patients with acute coronary syndrome. *Heart & Lung, 36*(6), 398-409. doi:https://doi.org/10.1016/j.hrtlng.2007.02.001

Timu-Parata, C. (2009). May the dreams of the past be the reality of the future: Reflections on the Māori health journey. *Whitireia Nursing Journal*(16), 38-46.

Tobias, M., Li-Chia, Y., Wright, C., Riddell, T., Wing Cheuk, C., Jackson, R., & Mann, S. (2009). The burden of coronary heart disease in Māori: population-based estimates for 2000-02. *Australian and New Zealand Journal of Public Health, 33*(4), 384-387. doi:10.1111/j.1753-6405.2009.00412.x

Walker, S., Eketone, A., & Gibbs, A. (2006). An exploration of Kaupapa Māori research, its principles, processes and applications. *International Journal of Social Research Methodology, 9*(4), 331-344. doi:10.1080/13645570600916049

Ware, F., Forster, M., & Breheny, M. (2018). Kaupapa Kōrero: a Māori cultural approach to narrative inquiry. *AlterNative, 14*(1), 45-53. doi:10.1177/1177180117744810

Watkins, M., & Shulman, H. (2008). *Toward Psychologies of Liberation*. London, United Kingdom: Palgrave MacMillan.

Weber, M. (1952). *The Protestant ethic and the spirit of capitalism*. New York, NY: Scribner.

Wilson, D., Heaslip, V., & Jackson, D. (2018). Improving equity and cultural responsiveness with marginalised communities: Understanding competing worldviews. *Journal of Clinical Nursing, 27*(19/20), 3810-3819. doi:10.1111/jocn.14546

Wissen, K., Thunders, M., McBride-Henry, K., Ward, M., Krebs, J., & Page, R. (2017). Cardiovascular disease and prediabetes as complex illness: People's perspectives. *Nursing Inquiry, 24*(3), 1-9. doi:10.1111/nin.12177

Worrall-Carter, L., Daws, K., Rahman, M. A., MacLean, S., Rowley, K., Andrews, S., . . . Arabena, K. (2016). Exploring Aboriginal patients' experiences of cardiac care at a major metropolitan hospital in Melbourne. *Australian Health Review, 40*(6), 696-704. doi:10.1071/AH15175

Young, A. (1981). When rational men fall sick: An inquiry into some assumptions made by medical anthropologists. *Culture, Medicine & Psychiatry, 5*(4), 317-335.

Young, A. (1982). Rational men and the explanatory model approach. *Culture, Medicine & Psychiatry, 6*(1), 57-71.

Yucel, R. (2018). Scientists' ontological and epistemological views about science from the perspective of critical realism. *Science & Education, 27*(5), 407-433.

Zambas, S. I., & Wright, J. (2016). *Impact of colonialism on Māori and Aboriginal healthcare access: A discussion paper* (Vol. 52).

APPENDICES

Appendix 1 – Fieldwork experience notes

As outlined in Chapter two, I initially engaged in fieldwork for the current study by shadowing a cardiac rehabilitation nurse (CRN). The purpose of this fieldwork was so that I could develop an understanding of what cardiac rehabilitation involves and to extend my knowledge of cardiac events and recovery. Shadowing the nurses also facilitated the recruitment of participants. In one case, I met a potential participant through the community visits. This time with the CRN was also used to discuss other potential recruits. From my experiences of attending cardiac outreach services, I found these services to be much more than their titles of 'educational session' or 'exercise training session.' More specifically, I noticed how the creation of communicative and caring liminal spaces facilitated several activities that appeared to be important for patients to make sense of their illness and ongoing recovery. There may be some variation across the groups of people who attend these sessions as I attended each different session only once. Thus, my experiences I discuss here can be considered as related to a certain time and place.

Creating liminal spaces

To provide some context, cardiac rehabilitation outreach services are often run in community settings such as halls or churches. These locations are often determined by the cost, locality and whether they meet the needs of the session the nurses are conducting. These community locations essentially provide a 'place' and 'space' for care. However, I use the expression 'creating spaces' because I believe these community locations are more than places for educational and exercise training sessions. Other important liminal and relational spaces are fostered, facilitated and produced here that collectively support patients towards moving forward and recovering after their cardiac event.

From my fieldwork experiences, it appears these community locations and patient homes are transformed into communicative spaces for care that are liminal in character and which bring more meaning to cardiac outreach services. These community spaces are transformed into caring spaces that appear to open up and encourage communication between health professionals and patients. Cardiac outreach sessions fostered a communicative and caring space where patients could ask for specific information as well as receive general information to make sense of their illness and postoperative health. For instance, educational sessions not only involved the delivery of information to patients. The nurses created a communicative space which enabled patients to ask questions regarding medical abbreviations and personal clinical notes they felt apprehensive in questioning during their stay in hospital. A patient's partner stated: *"I don't feel like asking too* *many questions because they* [doctors] *are always so busy"*. Such statements highlight the importance of these educational sessions for patients to make sense of, and comprehend their cardiac event after leaving hospital.

I understand that experiencing a cardiac event and undergoing medical treatment can involve processing a wealth of information related to one's presenting illness and potential changes in their future. The processing of information can be overwhelming where outreach cardiac sessions appear to provide a slower paced environment for people to seek information and grasp what their chronic illness means to them. Thus, such services are essential when patients can be confused about their postoperative health after leaving hospital. As one patient expressed: *"Kind of starting to make sense"*. Although sessions may vary, the particular educational session I attended reflected a negotiated space shared between the CRNs and patients. Patients did not attend this educational session as passive listeners only. They came with a sense of 'information seeking' which nurses had to manage amongst their own agenda. Such spaces that facilitate interaction and enables patients to ask questions shifts from notions of impersonal care to care that benefits and meets the needs of patients.

Cardiac outreach sessions also involved transforming community places into spaces that helped patients realise where they are at now and to provide hope for the future. The post exercise training session I attended created a caring space that not only included asking patients how they were going and observing their physical progress. It also involved providing a space in which patients could learn to trust their body again through discussions with cardiac nurses and by actively testing how their body works within the safety of nurses overseeing activities. Such discussions and corresponding activities have been described by a cardiac nurse as *"really important towards allowing patients to feel confident again. To know that everything still works"*. I learnt from the nurses that patients who have suffered a cardiac event can often have feelings of not trusting their body. This highlighted to me the significance of experiencing a heart event for patients and how understandings of the body can change. The exercise training sessions I attended appeared to provide a safe space for patients to test the limits of their body and for patients to 'show' and 'tell' the cardiac nurses and more importantly themselves how they were progressing post their cardiac event.

Moreover, exercise training sessions also reflected a 'space' where patients came to the same place over a six-week period that was familiar and known to them when their cardiac event had created so much unknown in their lives. Coming to these sessions created some routine and something patients could rely and depend on among extraordinary circumstances. The exercise training sessions was a place of social interaction and for patients to talk about the extraordinary in their lives within an ordinary space among company who understands and listens. From my experience, I believe these exercise sessions were a nurturing environment that held much more meaning to patients than purely a site of physical exercise. The warm embrace from patients to

CRNs as they were leaving the last post exercise session with one patient stating *“thanks for everything”,* illustrates the significance of coming along to these exercise sessions for patients. This could be because although this was a site for monitoring physical recovery, it was also a space to process the psychosocial consequences of their recent heart procedures. In these ‘spaces’, patients had the time to express how their cardiac event had impacted their life. It also provided a place for storytelling where the telling of stories was an often occurrence throughout my attendance at various outreach services and it emphasised that these sessions often opened a space for identity re-working.

At cardiac outreach sessions, patients often shared their personal stories with other patients, cardiac nurses and myself. The telling, sharing and exchange of personal stories at the outreach services appeared to reflect processes of re-constructing a sense of self and re-working one’s identity. The cardiac outreach sessions demonstrate how the self can be constructed through the engagements and interactions with others whether it be through the illness stories of other patients or the cardiac information nurses provide. Through engaging in dialogue with others, the patients could re-construct their sense of self.

What I noticed is that people often storied their experiences of their heart event and how the experience had changed them. Most notably, I noticed a shift in the characters people presented before and after a cardiac event. A patient who deemed themselves to be a ‘hard-worker’ that ‘works hard, plays hard’ was now ‘taking it easy’ and a ‘negotiator of work conditions’ post their cardiac event. To me, this embedded how illness can invoke people to reconsider their sense of self with illness and related identity. An important part of this identity re-working can come from learning about what has physically happened to the body to understand and comprehend one’s new everyday routine of taking medication and lifestyle adjustments. Therefore, I noticed the important role the cardiac nurses play in helping patients understand CVD within their everyday lived context. It also highlights that the cardiac rehabilitation nurses are concerned with notions of illness more so than disease.

Notions of illness and care:

Through my fieldwork experiences with the cardiac nurses I have noticed their work aligns more so with notions of illness. This is apparent in the way the nurses consider patients within their wider everyday context in delivering care. For instance, the language used within interactions between the nurses and patients reflected the use of everyday language with medical terminology used as the ‘alternative’ term. The importance of such practices is exemplified from my experiences of being at a cardiac outreach session where I noted a patient commenting on how helpful it would be to have clinical notes written in ‘lay terms’. The comment highlights the difficulty patients can have in making sense of their CVD when they have trouble understanding the medical terms used to describe what has happened to them.

On a number of occasions, I noticed how the cardiac nurses played an important role in reprocessing medical terminology into lay terms for patients and in so doing reflects their awareness of the context in which they are delivering information. Using lay terms appeared to open up a space to humanize medicine. The use of lay terms and corresponding pictures to show patients the site of disease and associated medical intervention during community home visits demonstrates how the nurses engaged in efforts to work with patients to ensure they understood their ailment and what it meant. Additionally, the cardiac nurses attempt to rehumanize patients by presenting these same pictures with a story and one that is relevant to the patient. At a community home visit, the cardiac nurse used phrases such as *"can you see here where it looks like someone has taken a bite out of your artery? That's where the blockage was".* Then with a post-operative picture explaining *"can you see how that bite mark is gone so there is no more blockage there, and everything looks ok".* Such processes not only help patients understand what has changed within their body. It also helps patients understand the outcomes of medical intervention. An important part of this process as outlined by the cardiac nurse is to show patients that *"things are going to be ok"* and *"to provide some reassurance to patients"*. Some patients may require more assurance than others where the cardiac nurses often take into consideration the unique characteristics of patients and implement practices to suit.

CVD is a chronic illness and the cardiac rehabilitation nurses highlight the importance of ongoing management to prevent and reduce the advancement of CVD. These cardiac outreach services provide an opportunity for participants to understand what CVD now means for their lives moving forward. The sessions cardiac nurses provide extend the meaning of CVD beyond medical terms to the meaning of CVD in terms of everyday life conditions such as (and not limited to) the change in lifestyle, change in diet, adjustments in routine and medication taking. It demonstrates a shift away from focussing on CVD as a disease occurring within the individual to the wider implications of CVD within the context of people's everyday life. It reinforces the notion of cardiac rehabilitation nurses being more concerned with notions of illness than disease.

Contextualising the fieldwork:

Conducting the fieldwork was an important part of this study for several reasons. Firstly, attending the various cardiac outreach services has given me first-hand experience of the kind of care the cardiac rehabilitation nurses provide. I found this to be an interesting experience and I saw how their cardiac outreach sessions entailed much more than their given titles. The fieldwork experience has given me a line of inquiry for future interviews in terms of understanding whether patients distinguish between experiences of healthcare services and the characteristics that may set them apart. Secondly, the fieldwork gave me an opportunity of how to conduct myself within the research context. I became very aware of the relationships the cardiac rehabilitation nurses have with their patients and wished to continue such relationships if not enhance them. I used the cardiac nurses as a model for my interactions with participants to ensure I preserved the relationships already established by the cardiac nurses.

This fieldwork process was also about building relationships. The CRNs were important in the recruitment of participants and as such, it seemed important to build relationships with those I would be working closely with.

Appendix 2 – Participant information sheet

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
Te Kura Pūkenga Tangata

Exploring experiences of cardiovascular disease with Māori whānau

Participant Information Sheet

You have been invited to take part in a study involving Māori whānau and their experiences of cardiovascular disease. Taking part in this study is voluntary. This information sheet outlines the purpose of the study, what participation involves, your rights as a participant, how the information collected will be used and the consent process.

What is the purpose of the study?

The purpose of this study is to gain a better understanding of cardiovascular disease as part of everyday life for Māori whānau. The study is also designed to inform efforts to improve how healthcare services can better respond to Māori whānau needs.

What will my participation in the study involve?

Participation in this study will involve three kanohi ki te kanohi (face-to-face) interviews with the researcher. Each interview will be approximately one hour in duration and will involve questions surrounding your experiences of cardiovascular disease and accessing cardiology services. Although interviews will be conducted in English, the use of Māori terms will be welcomed by the researcher. We acknowledge that talking about experiences of health and healthcare can be sensitive. If you do find this upsetting, the researcher will pause the interview so that you can regather your thoughts or choose not to continue. Interviews will ideally be carried out over a 2-3-week period. Interviews can be one-on-one between the researcher and person who has received cardiology care. Interviews can also include whānau members. All interviews will be audio recorded. At the completion of the interview process you will be provided with a koha ($50 voucher).

How will my information be used and managed?

The information collected from the interviews will be used for a Master's degree research project. This information will be kept confidential and in safe storage to ensure it will only be accessed by the researchers. Although there are limits to confidentiality, all steps will be taken to protect the identification of your information. An alias will be used when referring to your experiences in the write up of the project and in any presentations of the findings from the research. For example, the information will also be presented in an anonymized form to the cardiology unit at the Waikato DHB. The reason for presenting the results to the cardiology unit is to inform efforts to improve the services they provide to Māori and their whānau. Anonymized findings from the research will also be shared with the Iwi Māori Council and Te Puna Oranga.

What are my rights?

- Māori whānau have the right to make a decision on whether to participate in this study and are welcome to seek guidance or support in making this decision.
- You do not have to answer every question asked by the researcher.
- At any stage of the interviews, you can ask for the audio recorder to be turned off.
- Although I would like participants to engage in all three interviews, I understand there are unforeseen circumstances that can mean participants can no longer take part in this research. If issues such as this arise please do not hesitate to approach the researcher.
- It is your right to ask any questions relating to the research throughout the whole research process.
- Once the interviews have been transcribed, participants will be provided with a copy of the conversations.
- You will be informed of the research findings where the researcher will provide an overview of the findings and will explain the outcomes to your participating whānau.

Providing consent

After considering the information in this participant sheet and having any questions answered by the researcher, each whānau member who chooses to take part will be asked to provide informed consent to participate. The researcher will provide consent forms for each whānau member to consider and sign. Alternatively, your consent to participate can be given verbally and audio recorded by the researcher.

Who can I contact?

Below are the contact details of the research team. Please feel free to contact any of the below team if you have any questions or queries:

Researcher: Samantha Lisipeki (Student Master of Science, endorsement in Health Psychology program at Massey University. Albany Campus), [redacted] samantha.lisipeki.1@uni.massey.ac.nz

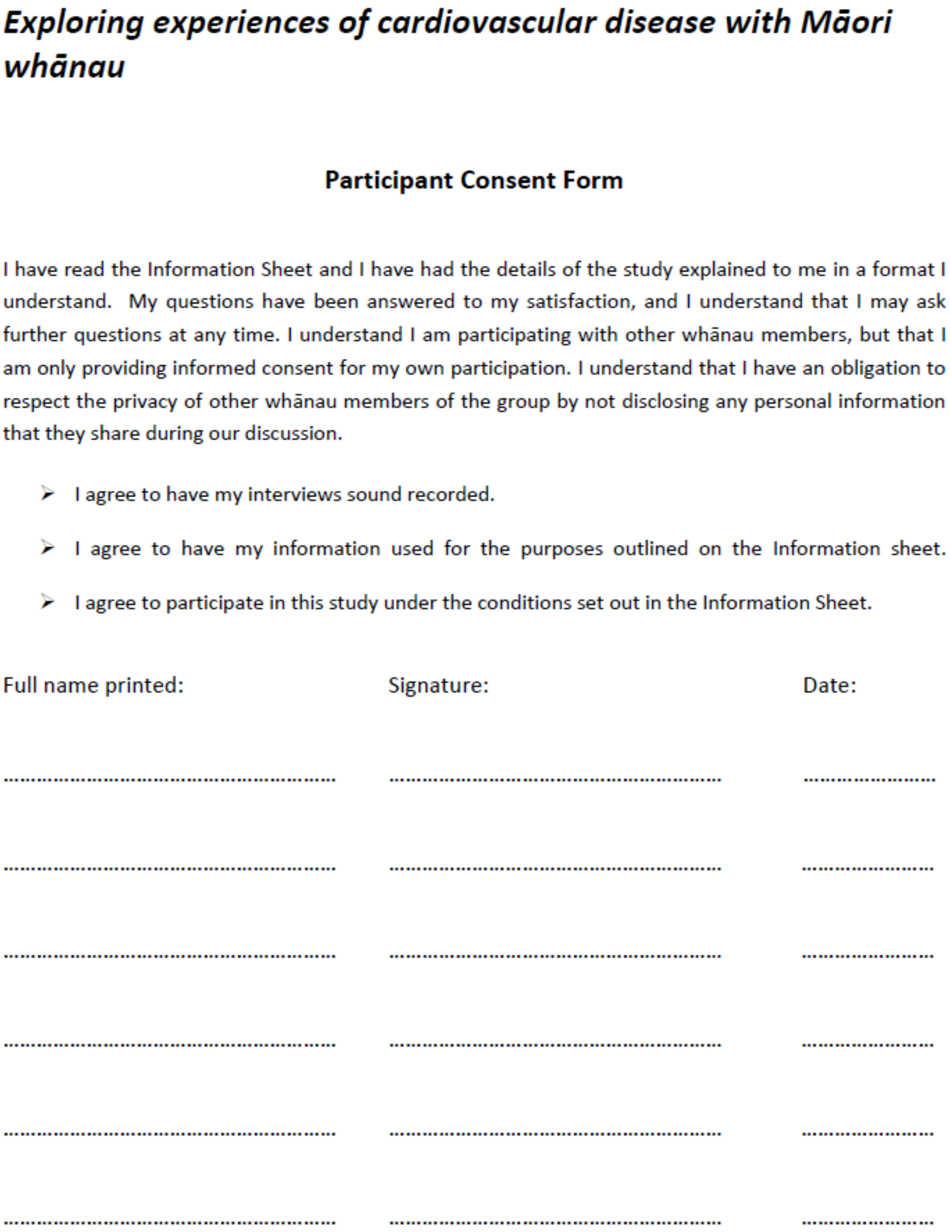
Research Supervisor: Darrin Hodgetts (Professor at Massey University) d.j.hodgetts@massey.ac.nz

Research Supervisor: Bridgette Masters-Awatere (co-Director Māori & Psychology Research Unit, Waikato University, bridgette.masters-awatere@waikato.ac.nz)

Ethics information:
This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.
If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact A/Prof Tracy Riley, Acting Director, Research Ethics, telephone 06 356 9099 x 84408, email humanethics@massey.ac.nz

Alternatively, you are welcome to contact Te Puna Oranga Māori Health Service who have been involved in the Māori consultation process. Phone: 07 834 3628

Appendix 3 – Participant consent form



Exploring experiences of cardiovascular disease with Māori whānau

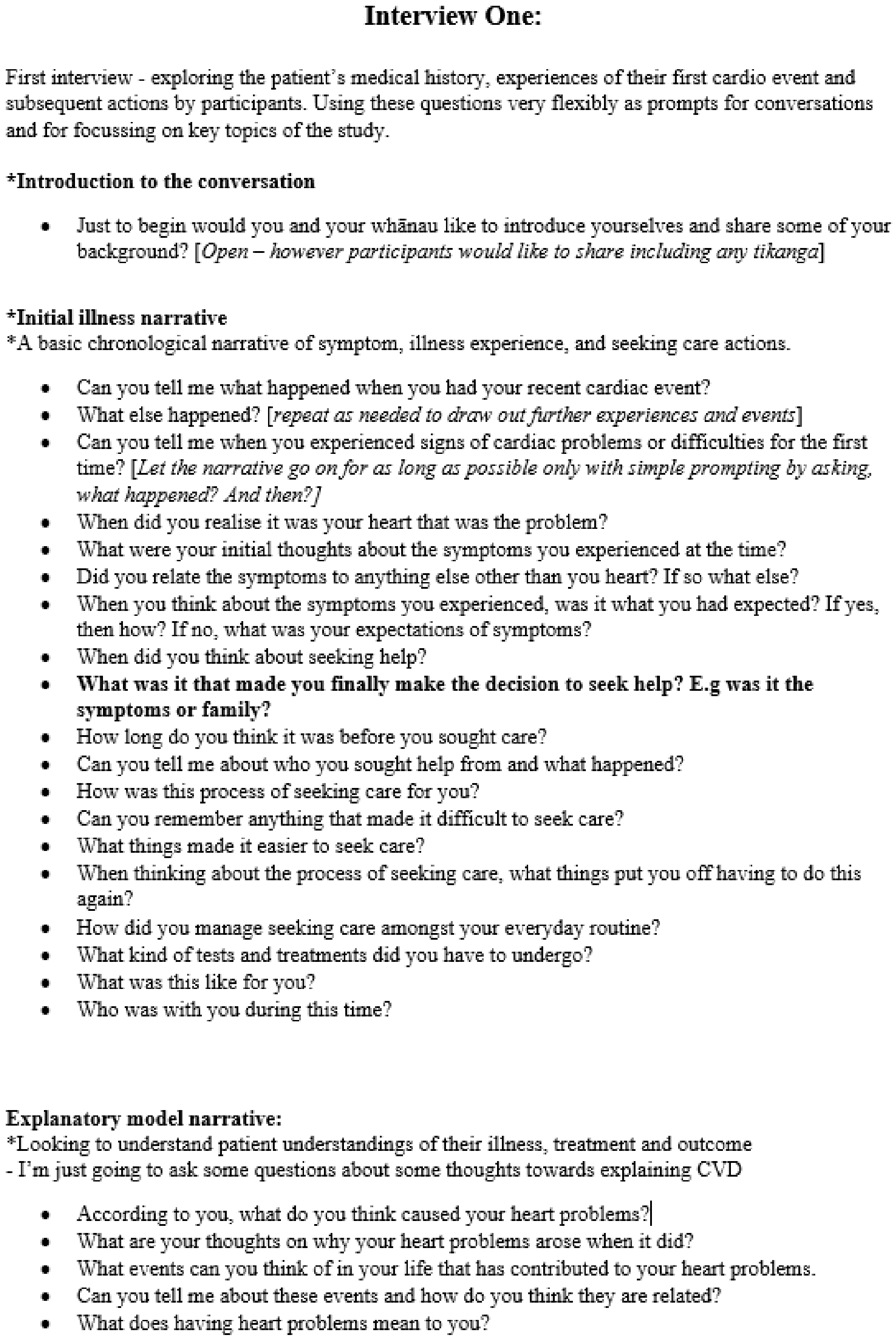
Participant Consent Form

I have read the Information Sheet and I have had the details of the study explained to me in a format I understand. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I understand I am participating with other whānau members, but that I am only providing informed consent for my own participation. I understand that I have an obligation to respect the privacy of other whānau members of the group by not disclosing any personal information that they share during our discussion.

- ➢ I agree to have my interviews sound recorded.
- ➢ I agree to have my information used for the purposes outlined on the Information sheet.
- ➢ I agree to participate in this study under the conditions set out in the Information Sheet.

Full name printed:	Signature:	Date:
…………………………………………………	…………………………………………………	……………………
…………………………………………………	…………………………………………………	……………………
…………………………………………………	…………………………………………………	……………………
…………………………………………………	…………………………………………………	……………………
…………………………………………………	…………………………………………………	……………………
…………………………………………………	…………………………………………………	……………………

Appendix 4 – Interview protocol (Interview one)



Interview One:

First interview - exploring the patient's medical history, experiences of their first cardio event and subsequent actions by participants. Using these questions very flexibly as prompts for conversations and for focussing on key topics of the study.

***Introduction to the conversation**

- Just to begin would you and your whānau like to introduce yourselves and share some of your background? [*Open – however participants would like to share including any tikanga*]

***Initial illness narrative**
*A basic chronological narrative of symptom, illness experience, and seeking care actions.

- Can you tell me what happened when you had your recent cardiac event?
- What else happened? [*repeat as needed to draw out further experiences and events*]
- Can you tell me when you experienced signs of cardiac problems or difficulties for the first time? [*Let the narrative go on for as long as possible only with simple prompting by asking, what happened? And then?]*
- When did you realise it was your heart that was the problem?
- What were your initial thoughts about the symptoms you experienced at the time?
- Did you relate the symptoms to anything else other than you heart? If so what else?
- When you think about the symptoms you experienced, was it what you had expected? If yes, then how? If no, what was your expectations of symptoms?
- When did you think about seeking help?
- **What was it that made you finally make the decision to seek help? E.g was it the symptoms or family?**
- How long do you think it was before you sought care?
- Can you tell me about who you sought help from and what happened?
- How was this process of seeking care for you?
- Can you remember anything that made it difficult to seek care?
- What things made it easier to seek care?
- When thinking about the process of seeking care, what things put you off having to do this again?
- How did you manage seeking care amongst your everyday routine?
- What kind of tests and treatments did you have to undergo?
- What was this like for you?
- Who was with you during this time?

Explanatory model narrative:
*Looking to understand patient understandings of their illness, treatment and outcome
- I'm just going to ask some questions about some thoughts towards explaining CVD

- According to you, what do you think caused your heart problems?
- What are your thoughts on why your heart problems arose when it did?
- What events can you think of in your life that has contributed to your heart problems.
- Can you tell me about these events and how do you think they are related?
- What does having heart problems mean to you?

Prototype narrative:

- Are you aware of any family members who have experienced something similar to CVD? How do you think it's the same or different?
- What about your friends, do you know any friends who have experienced something similar to CVD? How do you think it's the same or different?
- What about work colleagues, do you know any friends or work colleagues who have experienced something similar to CVD?
- Have you heard about people having CVD in any type of media outlet such as T.V, newspaper radio etc? What kind of experiences have you heard about through these outlets? How do you think your experience is the same or different?

***Understandings of health and illness**

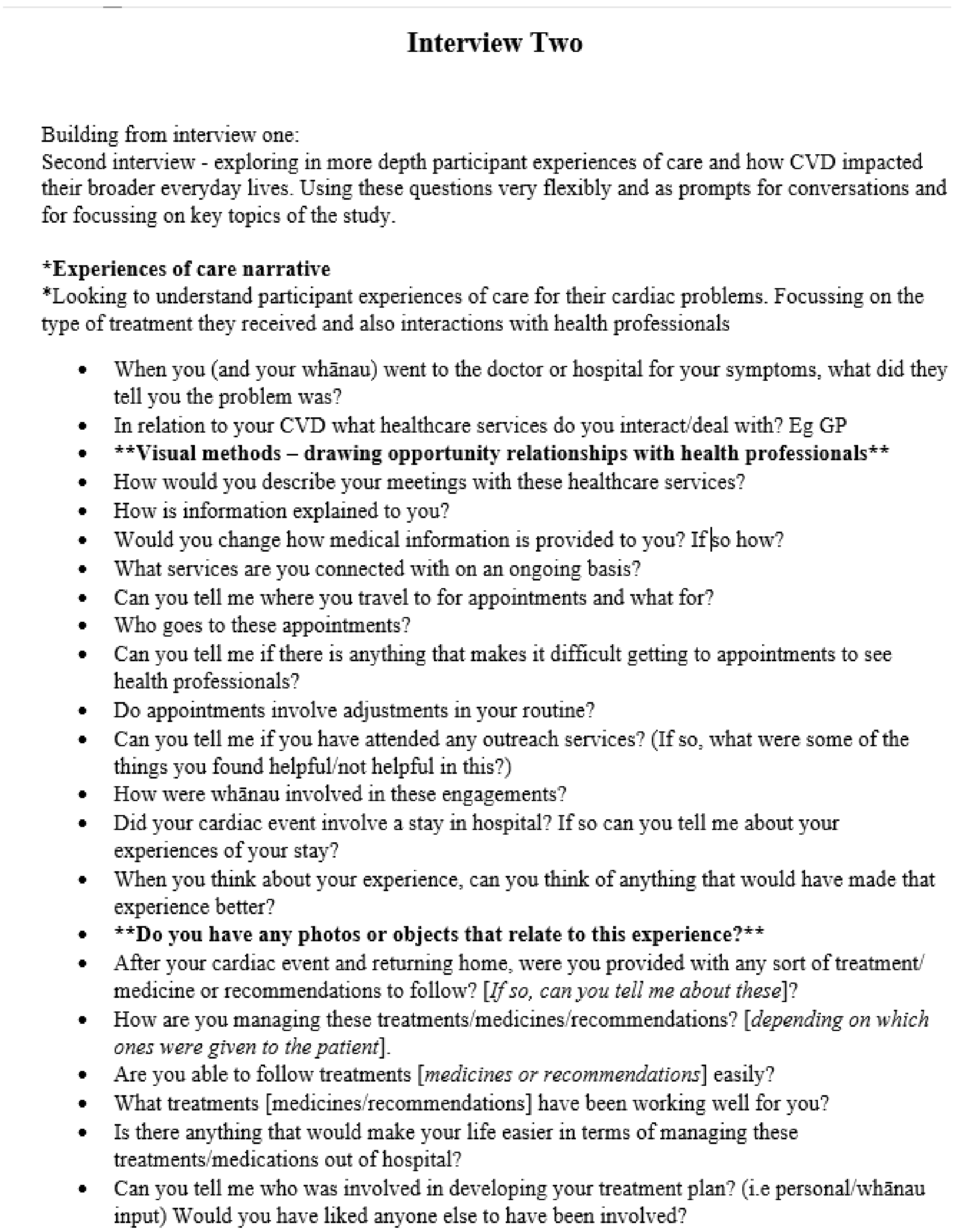
*What does health mean and how do participants understand it?

- Can you tell me your understanding of 'being healthy'?
- What things (if any) do you (and your whānau) do to maintain your health?
- Since you can remember, how do you think your level of health has been?

*****At the end of interview, ask them if they would like to bring anything a long for the next interview that they would like to share with me. For example, photos, or is there something that was important to you in the hospital?**

***** Check in with participants regarding the interview process and offer space for feedback**

Appendix 5 – Interview protocol (Interview two)



Interview Two

Building from interview one:
Second interview - exploring in more depth participant experiences of care and how CVD impacted their broader everyday lives. Using these questions very flexibly and as prompts for conversations and for focussing on key topics of the study.

***Experiences of care narrative**
*Looking to understand participant experiences of care for their cardiac problems. Focussing on the type of treatment they received and also interactions with health professionals

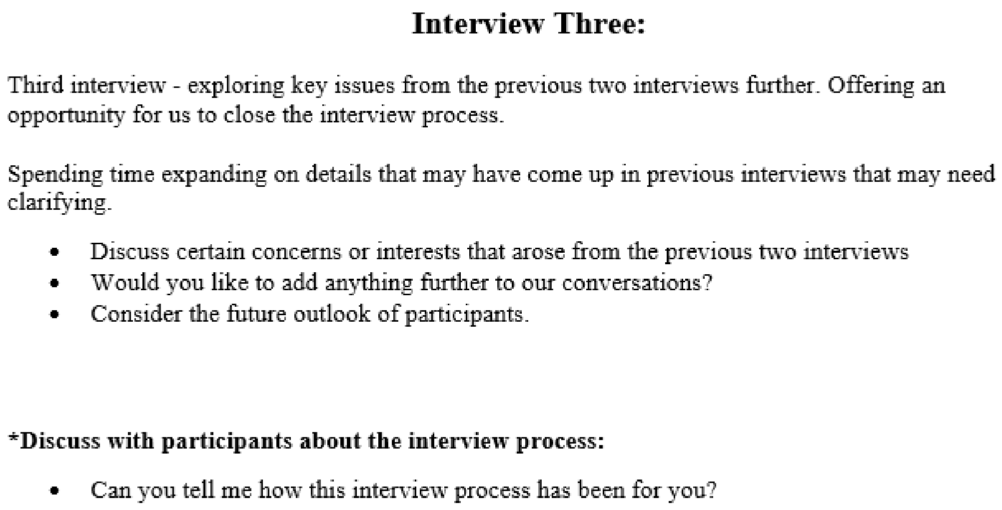
- When you (and your whānau) went to the doctor or hospital for your symptoms, what did they tell you the problem was?
- In relation to your CVD what healthcare services do you interact/deal with? Eg GP
- ****Visual methods – drawing opportunity relationships with health professionals****
- How would you describe your meetings with these healthcare services?
- How is information explained to you?
- Would you change how medical information is provided to you? If so how?
- What services are you connected with on an ongoing basis?
- Can you tell me where you travel to for appointments and what for?
- Who goes to these appointments?
- Can you tell me if there is anything that makes it difficult getting to appointments to see health professionals?
- Do appointments involve adjustments in your routine?
- Can you tell me if you have attended any outreach services? (If so, what were some of the things you found helpful/not helpful in this?)
- How were whānau involved in these engagements?
- Did your cardiac event involve a stay in hospital? If so can you tell me about your experiences of your stay?
- When you think about your experience, can you think of anything that would have made that experience better?
- ****Do you have any photos or objects that relate to this experience?****
- After your cardiac event and returning home, were you provided with any sort of treatment/ medicine or recommendations to follow? [*If so, can you tell me about these*]?
- How are you managing these treatments/medicines/recommendations? [*depending on which ones were given to the patient*].
- Are you able to follow treatments [*medicines or recommendations*] easily?
- What treatments [medicines/recommendations] have been working well for you?
- Is there anything that would make your life easier in terms of managing these treatments/medications out of hospital?
- Can you tell me who was involved in developing your treatment plan? (i.e personal/whānau input) Would you have liked anyone else to have been involved?

***Impact on life**
*Looking to understand how CVD has impacted everyday life.

- Going back to when you returned home after your cardiac event, what was that transition like for you?
- Can you tell me how life/things may have felt different?
- How has CVD changed the way you (and your whānau) live?
- **How do you think your heart problems has impacted you and your whanau?**
- How did your family react to your heart event?
- Is there anyone else you can think of that has been affected by your experiences of heart problems?
- How do you think CVD has changed or disrupted your everyday routine?
- Can you tell me about any adjustments you have had to make after your cardiac event? What has been most difficult for you? Can you tell me how?
- Can you give me some examples of how you have to manage your ‘normal’ life stuff on top of your heart problems?
- In what ways has experiencing a cardiac event changed the way you think about yourself and your health?
- How has CVD changed the way you look at life in general?
- What or who helped you through the period during your cardiac event?
- What or who is currently helping you now through your heart problems?
- How have friends, family, work colleagues been involved in this period?
- How has CVD impacted your work-life?
- In what ways has CVD impacted your social life?
- What does CVD mean to you within your life?

***** Check in with participants regarding the interview process and offer space for feedback**

Appendix 6 – Interview protocol (interview three)



Interview Three:

Third interview - exploring key issues from the previous two interviews further. Offering an opportunity for us to close the interview process.

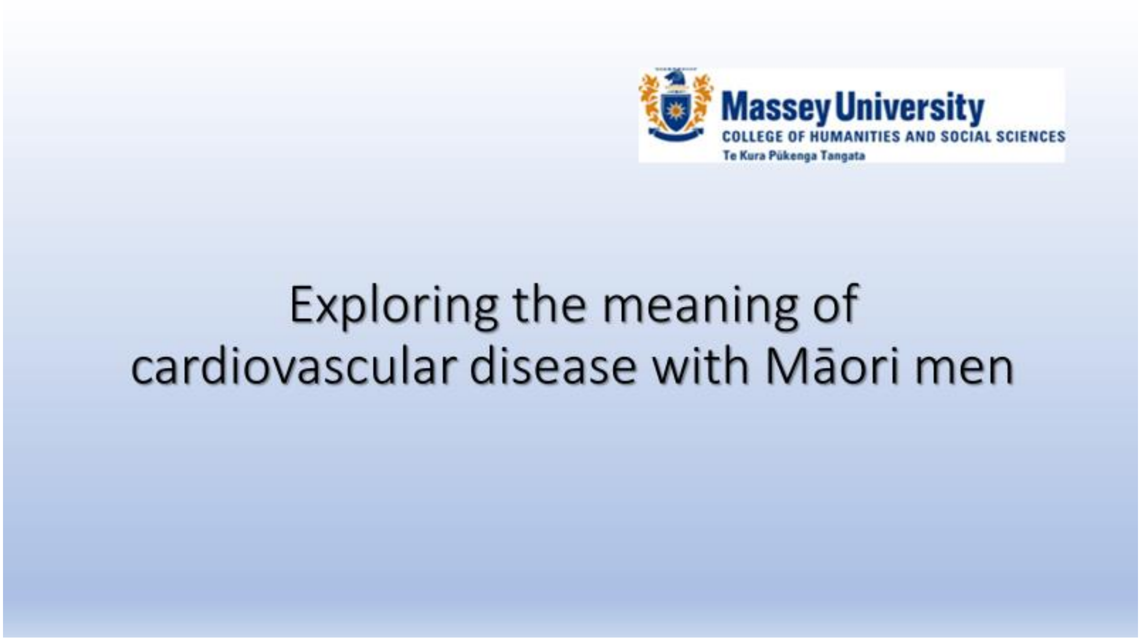
Spending time expanding on details that may have come up in previous interviews that may need clarifying.

- Discuss certain concerns or interests that arose from the previous two interviews
- Would you like to add anything further to our conversations?
- Consider the future outlook of participants.

***Discuss with participants about the interview process:**

- Can you tell me how this interview process has been for you?

Appendix 7 – Copy of presentation for Waikato DHB

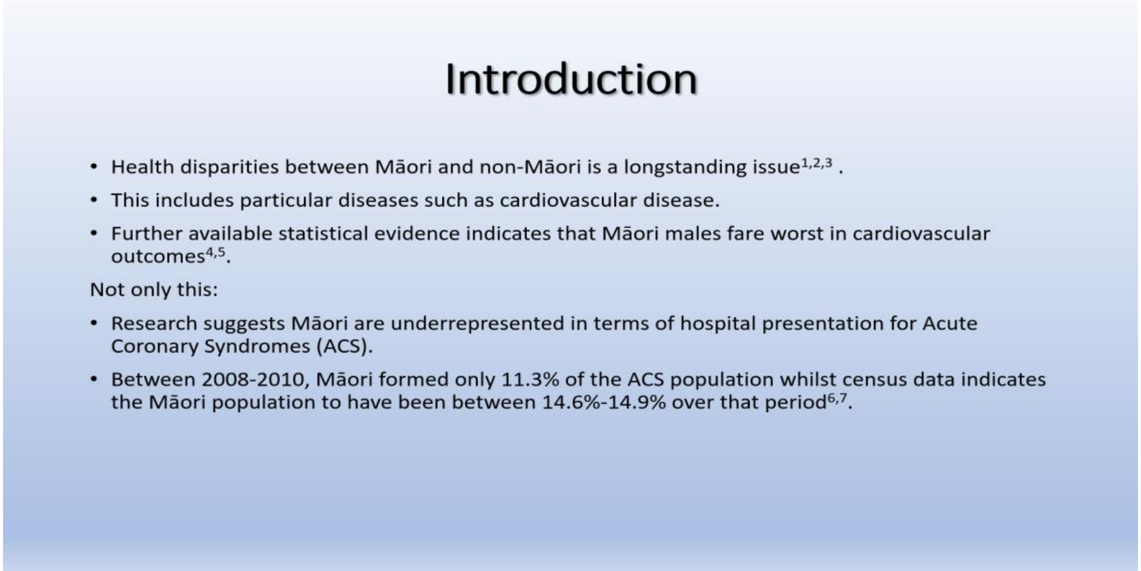


Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
Te Kura Pūkenga Tangata

Exploring the meaning of cardiovascular disease with Māori men

Acknowledgements

- Professor Darrin Hodgetts – Massey University
- Dr Bridgette Masters-Awatere – University of Waikato
- Waikato District Health Board
  - Dr T.V. Liew
  - The Cardiac Rehabilitation Nurses
  - Cate Shepherd
- The participants

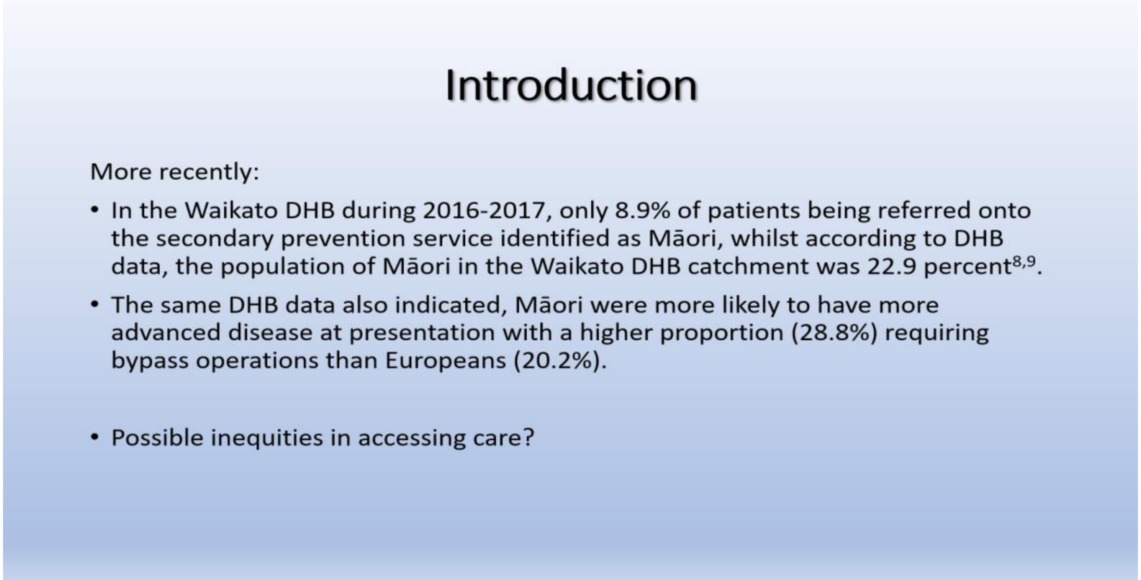


Introduction

- Health disparities between Māori and non-Māori is a longstanding issue[1,2,3] .
- This includes particular diseases such as cardiovascular disease.
- Further available statistical evidence indicates that Māori males fare worst in cardiovascular outcomes[4,5].

Not only this:

- Research suggests Māori are underrepresented in terms of hospital presentation for Acute Coronary Syndromes (ACS).
- Between 2008-2010, Māori formed only 11.3% of the ACS population whilst census data indicates the Māori population to have been between 14.6%-14.9% over that period[6,7].

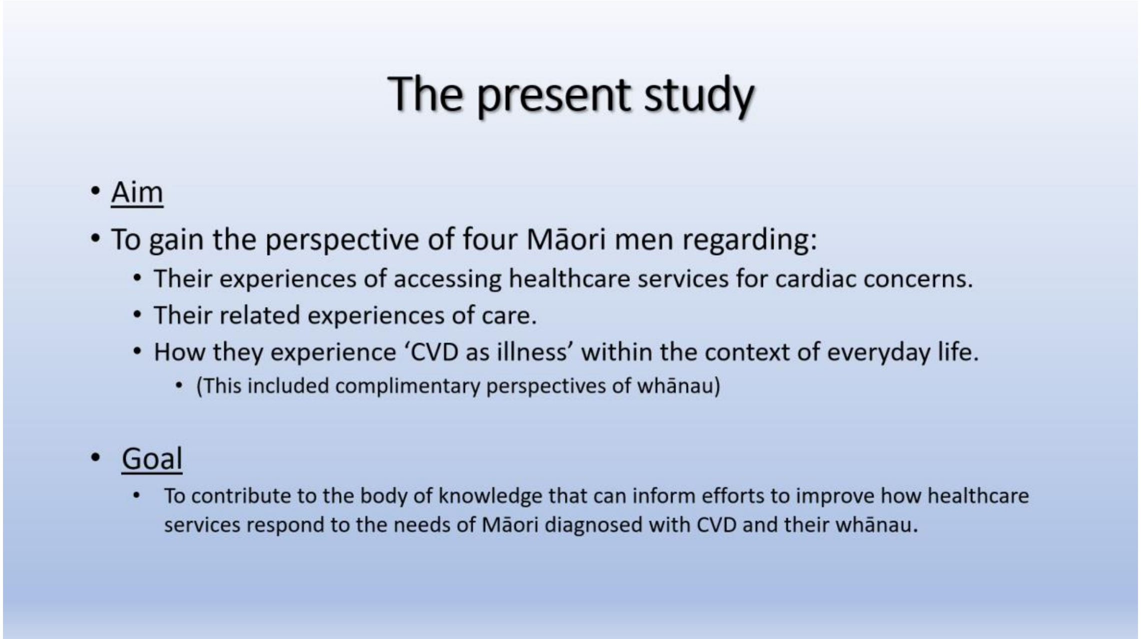


Introduction

More recently:

- In the Waikato DHB during 2016-2017, only 8.9% of patients being referred onto the secondary prevention service identified as Māori, whilst according to DHB data, the population of Māori in the Waikato DHB catchment was 22.9 percent[8,9].
- The same DHB data also indicated, Māori were more likely to have more advanced disease at presentation with a higher proportion (28.8%) requiring bypass operations than Europeans (20.2%).

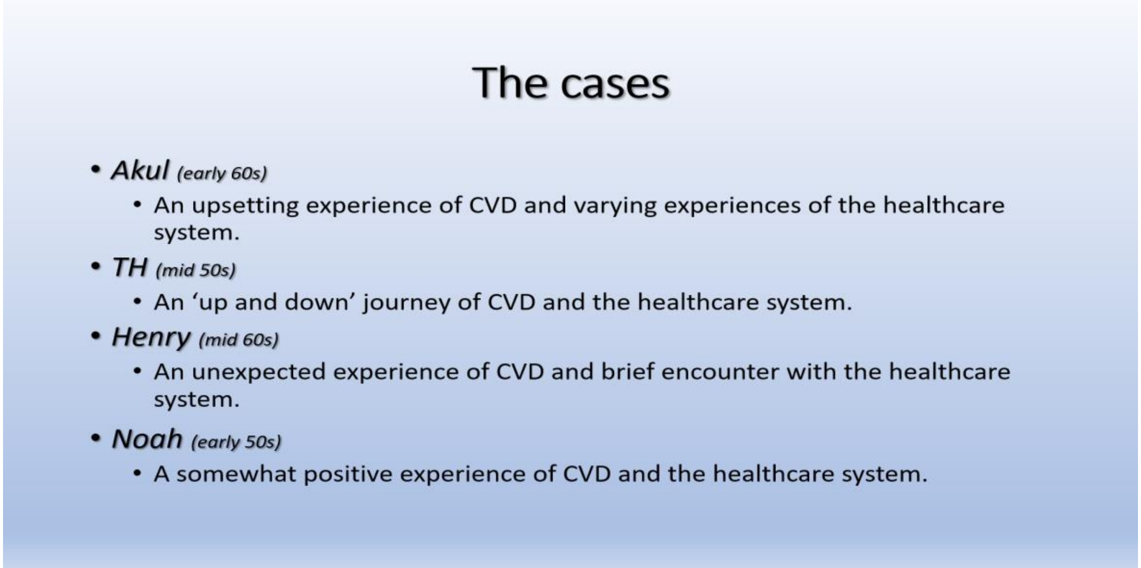
- Possible inequities in accessing care?



The present study

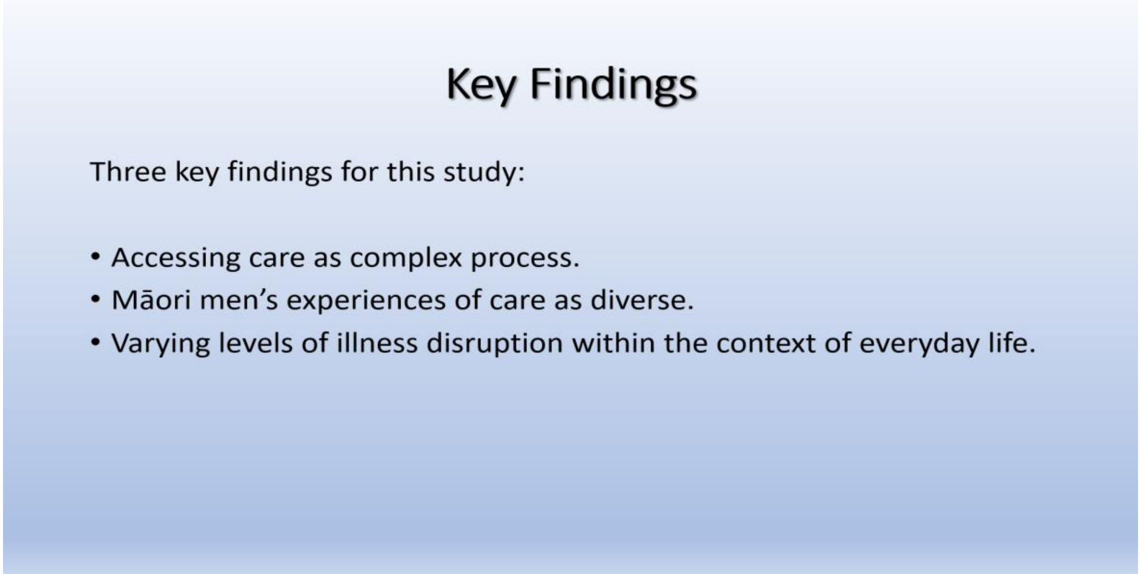
- Aim
- To gain the perspective of four Māori men regarding:
  - Their experiences of accessing healthcare services for cardiac concerns.
  - Their related experiences of care.
  - How they experience ‘CVD as illness’ within the context of everyday life.
    - (This included complimentary perspectives of whānau)

- Goal
  - To contribute to the body of knowledge that can inform efforts to improve how healthcare services respond to the needs of Māori diagnosed with CVD and their whānau.



The cases

- ***Akul*** *(early 60s)*
  - An upsetting experience of CVD and varying experiences of the healthcare system.
- ***TH*** *(mid 50s)*
  - An ‘up and down’ journey of CVD and the healthcare system.
- ***Henry*** *(mid 60s)*
  - An unexpected experience of CVD and brief encounter with the healthcare system.
- ***Noah*** *(early 50s)*
  - A somewhat positive experience of CVD and the healthcare system.



Key Findings

Three key findings for this study:

- Accessing care as complex process.
- Māori men’s experiences of care as diverse.
- Varying levels of illness disruption within the context of everyday life.

Accessing care as complex process within everyday life

- **Individual factors**
  - The manifestation and interpretation of symptoms.
- **Structures of everyday life**
  - This includes certain routines and practices such as work.
- **Available resources**
  - Personal and social resources.
- **Health professionals**
  - The identification and monitoring of heart conditions by health professionals
  - The communication between participants and health professionals.

Accessing care as complex process within everyday life

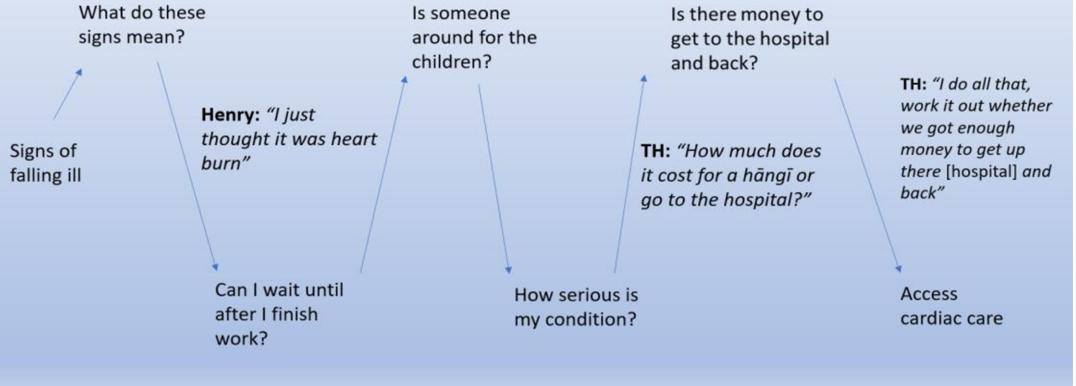
- Although accessing care may look like this:


Signs of falling ill

Access care

Accessing care as complex process within everyday life

- It can also look like this:


Signs of falling ill

What do these signs mean?

Henry: *"I just thought it was heart burn"*

Can I wait until after I finish work?

Is someone around for the children?

How serious is my condition?

TH: *"How much does it cost for a hāngī or go to the hospital?"*

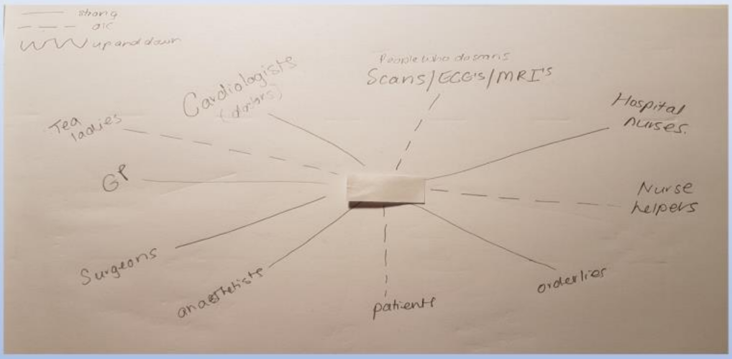
Is there money to get to the hospital and back?

TH: *"I do all that, work it out whether we got enough money to get up there* [hospital] *and back"*

Access cardiac care

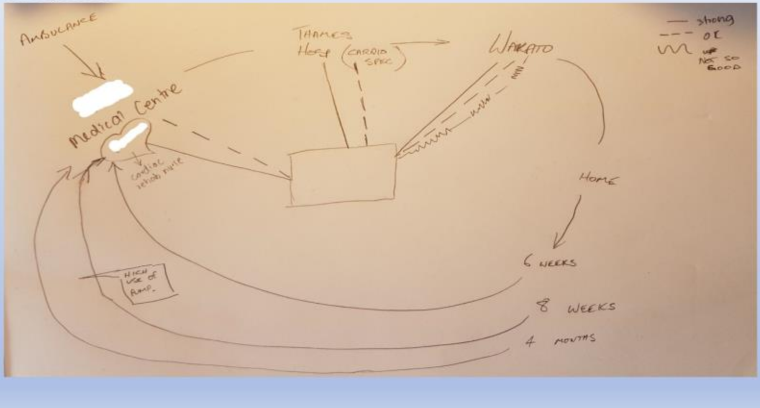
Māori men's experiences of care as diverse

- Noah's drawing of the relationships between himself and the health professionals involved in his care:



Māori men’s experiences of care as diverse

- Akul’s drawing of the relationship between himself and health professionals and movements through the system:

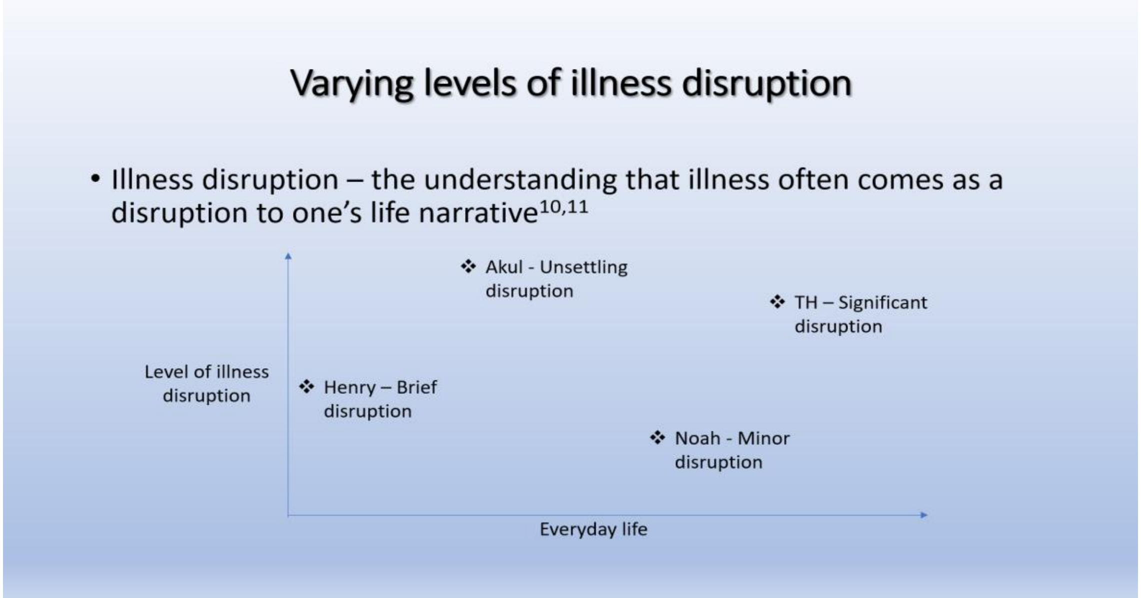


Māori men’s experiences of care as diverse

- The accounts suggest some inconsistencies in care
  - Inconsistencies across the cases
  - Inconsistencies in care across health professionals
    - **TH:** *“I reckon that they* [nurses] *would make better doctors”.*
    - **Akul**: *“I’m just thinking, oh I’m an experiment at the moment. After that one* [second angiogram] *yeah, I definitely felt like a lump of meat… The lack of eye contact or communication with either of the surgeons”.*
    - *“The surgeon <u>looked</u> me in the eye and said “Are you okay? How did we go? Are you alright? And I got the opportunity to thank him… I’m grateful he acknowledged that I was a human being and because I hadn’t had that before”.*

Māori men’s experiences of care as diverse

- The clinical competence of health professionals is not the only element that shapes experiences of care:
  - Being well-informed
  - Communicated with in responsive ways
  - Using tools to increase understanding (e.g. medical technology, scans, images)
  - Whakawhanaungatanga (establishing and building relationships)
  - Manaakitanga (engaging with respect and care)
  - Recognising the ‘person’ of the patient



Varying levels of illness disruption

- Illness disruption – the understanding that illness often comes as a disruption to one's life narrative[10,11]

Level of illness disruption

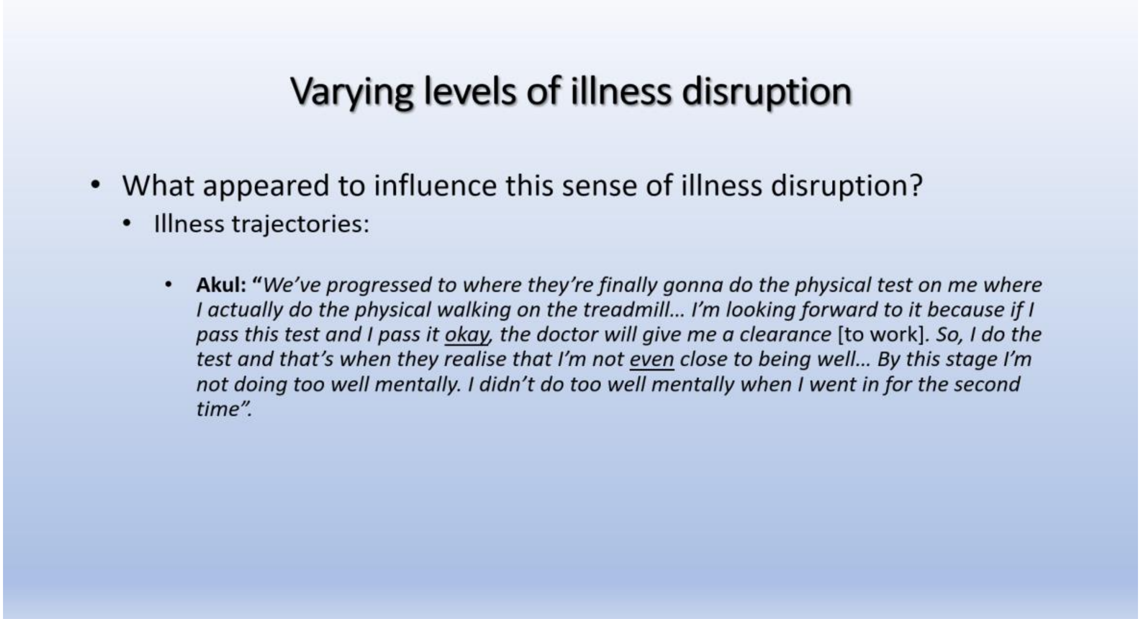
❖ Akul - Unsettling disruption

❖ TH – Significant disruption

❖ Henry – Brief disruption

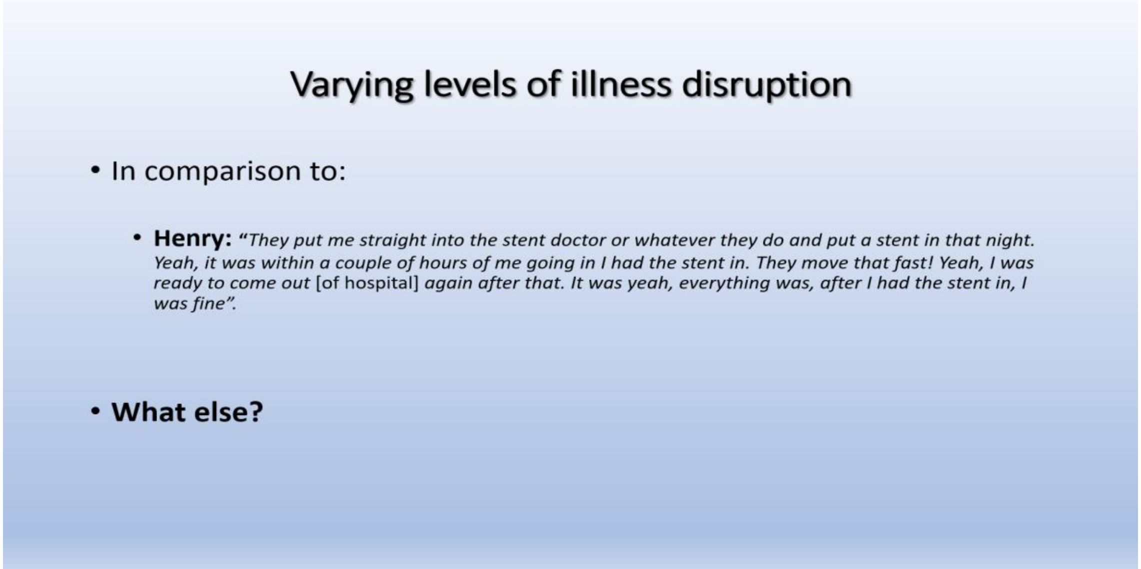
❖ Noah - Minor disruption

Everyday life



Varying levels of illness disruption

- What appeared to influence this sense of illness disruption?
  - Illness trajectories:
    - **Akul: "***We've progressed to where they're finally gonna do the physical test on me where I actually do the physical walking on the treadmill… I'm looking forward to it because if I pass this test and I pass it okay, the doctor will give me a clearance* [to work]. *So, I do the test and that's when they realise that I'm not even close to being well… By this stage I'm not doing too well mentally. I didn't do too well mentally when I went in for the second time".*



Varying levels of illness disruption

- In comparison to:
  - **Henry:** **"***They put me straight into the stent doctor or whatever they do and put a stent in that night. Yeah, it was within a couple of hours of me going in I had the stent in. They move that fast! Yeah, I was ready to come out* [of hospital] *again after that. It was yeah, everything was, after I had the stent in, I was fine".*

- **What else?**

Varying levels of illness disruption

- What does this mean?
- It provokes us to consider how patients and their families are affected by ongoing heart conditions and medical intervention.
- The importance of acknowledging peoples' everyday broader context in understanding illness and recovery.

Concluding remarks

- This study:
    - Demonstrates the importance of understanding access to care within the context of everyday life. It has shown various factors extending beyond the individual can influence one's responding actions of accessing care and how such processes are complex.
    - Suggests some areas of cardiac care can be viewed as requiring some consideration and thought however, not all experiences of the healthcare system are negative. Importantly, how patients are engaged with by health professionals is considered key.
    - Illustrates that patients can experience varying levels of illness disruption that can be shaped by an array of interrelated and complex factors.
    - Importantly…

References

1. Durie, M. (1998). *Whaiora: Māori Health Development* (2 ed.). Auckland, New Zealand: Oxford University Press.

2. Pomare, E. W. (1980). *Māori standards of health: A study of the 20-year period 1955-1975* (No. 7 Special Report Series). Auckland, New Zealand: Medical Research Council of New Zealand.

3. Ajwani, S., Blakely, T., Robson, B., Tobias, M., & Bonne, M. (2003). *Decades of Disparity: Ethnic mortality trends in New Zealand 1980-1999*. Wellington, New Zealand: Ministry of Health and University of Otago.

4. Ministry of Health. (2015). *Cardiovascular disease*. Retrieved from https://www.health.govt.nz/our-work/populations/Māori-health/tatau-kahukura-Māori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/cardiovascular-disease

5. Tobias, M., Li-Chia, Y., Wright, C., Riddell, T., Wing Cheuk, C., Jackson, R., & Mann, S. (2009). The burden of coronary heart disease in Māori: population-based estimates for 2000-02. *Australian and New Zealand Journal of Public Health, 33*(4), 384-387. doi:10.1111/j.1753-6405.2009.00412.x

6. Grey, C., Jackson, R., Wells, S., Marshall, R., Mehta, S., & Kerr, A. J. (2016). Ethnic differences in case fatality following an acute ischaemic heart disease event in New Zealand: ANZACS-QI 13. *European Journal of Preventive Cardiology, 23*(17), 1823-1830. doi:http://journals.sagepub.com/doi/pdf/10.1177/2047487316657671

7. Statistics New Zealand. (2013). *2013 Census quickstats about Māori*. Retrieved from http://archive.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-about-Māori-english.aspx

8. T.V Liew, personal communication, March 27, 2018

9. Statistics New Zealand. (2013). *2013 Census quickstats about a place: Waikato region*. Retrieved from http://archive.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-about-a-place.aspx?request_value=13631&tabname=

10. Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4*(2), 167-182.

11. Radley, A. (1993). *Worlds of illness: Biographical and cultural perspectives on health and disease*. New York, NY: Routledge.

Image – Tea and cookies retrieved from https://weheartit.com/entry/44470013
Image – Puzzle and people retrieved from http://www.esparter.com/workingtogether/

Glossary

Aotearoa – New Zealand
Aroha – care
Hāngī – food cooked in the ground
Kai - food
Kanohi ki te kanohi – face to face
Koha – donation, gift
Kōrero – talk, conversation
Kaupapa Māori – Māori philosophy
Kotahitanga – unity
Māhaki – respectful conduct
Manaaki – care and respect
Manaakitanga – engaging with respect and care
Manaaki ki te tangata - taking care of people
Mokopuna – grandchildren
Pā sites – fortified villages and stockades
Pākehā – New Zealander of European decent
Taha hinengaro – mental health
Taha tinana – physical health
Taha whānau – family health
Taha wairua – spiritual health
Tamariki – children
Tāne - men
Te reo Māori – Māori language
Te Whare Tapa Whā - Māori model of health developed by Mason Durie
Tino rangatiratanga – self determination
Tūrangawaewae – a place to stand
Whakamā – reticence, shame/embarrassment
Whakapapa – genealogy descent, lineage
Whakaute – show respect for
Whakawhanaungatanga – establish and maintain meaningful and supportive relationships
Whanaungatanga – having good relationships
Whānau – family, extended family