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A Life Transformed: The Lived Experiences of Māori with Chronic Pain

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Abstract

Due to its subjective nature, pain can be a complex and difficult health issue to address; pain and pain experiences need to be better understood in order for improvements to be made in how it is responded to and managed. Although there is some international research exploring cultural issues in pain, very little research of this kind has been conducted in Aotearoa, where significant health disparities exist between Māori and non-Māori. Furthermore, there is a lack of research with a specific focus on the chronic pain experiences of Māori in Aotearoa. The aim of the present research was to fill this gap in the literature, by addressing the following research question: how do Māori talk about their lived experiences of chronic pain? The methodology used for this research included a Kaupapa Māori approach along with Interpretative Phenomenological Analysis. In-depth semi-structured interviews were conducted with seven Māori adults who were experiencing chronic pain or a chronic painful health condition. Analysis of the interview transcripts resulted in identification of four superordinate themes and thirteen subthemes. These were ‘A life transformed by the experience of chronic pain’ (four subthemes), ‘Experiences of chronic pain as Māori’ (four subthemes), ‘Evaluating treatment experiences’ (three subthemes), and ‘Negative perceptions, negative experiences’ (two subthemes). The major implications drawn from these results are a clear need to incorporate greater cultural consideration into consultations and treatment with Māori who have chronic pain, as well as a broader need to improve the treatment and care of people who have chronic pain. These needs are both informed and driven by commitments to Te Tiriti and health equity in Aotearoa.

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Mihimihi

Ngā mihi mahana ki a koutou

Ko Te Ūpoko o Tahumaata te māunga

Ko Ōkana te awa

Ko Uruao rāua ko Tākitimu ōku waka

Ko Tukuwaha tōku whaea tūpuna

Ko Kai Tahu tōku iwi

Ko Kāti Makō tōku hapū

Ko Wairewa tōku marae

Ko Te Awanga rāua ko Heretaunga ōku papa kāinga

No Te Whanganui-ā-Tara tōku kāinga ināiane

Ko Zoe McGavock taku ingoa

Nō reira, tēnā koutou, tēnā koutou, tēnā koutou katoa

Overview

Due to its subjective nature, pain can be a complex and difficult health issue to address; pain and pain experiences need to be better understood in order for improvements to be made in how it is responded to and managed. This need becomes even more pertinent in light of extensive evidence suggesting that culture plays a role in experiences of pain, including differences in how pain is expressed, how socially acceptable it is to express pain, pain thresholds and tolerance, and of particular concern, disparities in treatment and care for individuals experiencing pain. Although there is some international research exploring cultural issues in pain (mostly from the USA), very little research of this kind has been conducted in Aotearoa (New Zealand¹), where significant health disparities exist between Māori (the indigenous people) and non-Māori, sometimes referred to as Pākehā (New Zealanders of European descent). Furthermore, what little research there is on Māori and pain is inconsistent, perhaps due to the diverse range of methodologies used and types of pain that have been covered. What is also immediately apparent is the lack of research with a specific focus on the chronic pain experiences of Māori in Aotearoa.

As a contribution to addressing these research gaps, this thesis focuses on the broad research question:

“How do Māori talk about their lived experiences of chronic pain?”

I have taken a Kaupapa Māori approach, conducting in-depth qualitative interviews to capture the depth and breadth of the lived experiences of Māori with chronic pain.

Through the introductory sections of this thesis I demonstrate why in-depth qualitative research with Māori who have chronic pain is both important and necessary. In Chapter 1 I give a general introduction to chronic pain, highlight the significance and complexity of chronic pain as a health issue, and describe the current theories of pain. In Chapter 2 I outline the role that culture and ethnicity can play in chronic pain, specifically in the way pain is responded to and in the way that ethnic and cultural minorities with pain are treated. Turning to Aotearoa, in Chapter 3 I explore the context of colonisation and Te Tiriti o Waitangi (The Treaty of Waitangi; hereafter Te Tiriti), and the role that this context plays

¹ Translates literally as ‘land of the long white cloud’; I respectfully note that not all iwi accept this as the Māori name for New Zealand. Also note that Māori words are translated within the main text on their first use, and there is a glossary of Māori words to refer to on p. 124.

in the significant health disparities that exist between Māori and non-Māori. Māori perspectives of health and healing are also discussed. I then review the extant literature on Māori and pain. Chapter 4 focuses on the importance of conducting research with Māori about their experiences of chronic pain, research on the lived experience of chronic pain in both majority and minority populations, and the aims and research questions for the current research. In Chapter 5 I describe the methodology, including the Kaupapa Māori approach (Māori agenda/philosophy/rationale), Interpretative Phenomenological Analysis (IPA), and the research methods. Chapter 6 presents the analysis and results, which consisted of four superordinate themes and thirteen subthemes. These were ‘A life transformed by the experience of chronic pain’ (four subthemes: Causes and sources of pain; Pain embodied – living through the painful body; Restrictions imposed by the painful body: Change and identity; It’s not just physical), ‘Experiences of chronic pain as Māori’ (four subthemes: Māori identity and culture: Embedded in experiences of chronic pain; Experiences of rongoā Māori (general name for traditional remedies) and complementary/alternative treatment; Racism in the medical system; Restricted access to the medical system), ‘Evaluating treatment experiences’ (three subthemes: The decision to seek treatment; The medical system: Gatekeeper to treatment; The search for relief: Medication and other substances), and ‘Negative perceptions, negative experiences’ (two subthemes: Living with chronic pain: Stigma and isolation; Stoicism: I don’t want to be a burden). The conceptual relationship between the four superordinate themes is also discussed. Finally, in Chapter 7, reflexivity, implications, and research considerations are discussed, and conclusions are drawn.

Chapter 1: Chronic Pain

The aim of this chapter is to introduce the reader to the topic of chronic pain, beginning with a discussion of definitions. Information on the epidemiology of chronic pain at a global and national level is then provided, followed by a discussion of the significance and complexity of chronic pain. Finally, current theories of pain, and chronic pain in particular, are outlined.

Definitions of pain

Pain is a subjective experience and is therefore difficult to define (Meghani & Gallagher, 2008). The most common definition given is that used by the International Association for the Study of Pain (IASP): “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (IASP, 2011, para. 3). There are a number of caveats that come with this definition, however. The IASP specifies that pain is by its very nature unpleasant and is therefore also an emotional experience. They point out that, because of its subjective nature, people who report pain in the absence of physiological damage or pathology should be accepted as having pain in the same manner as a person who does have such damage. Accordingly, another definition of pain that has become increasingly popular is that of McCaffery and Thorpe (1998, cited in Davidhizar & Giger, 2004, p. 49): “Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does”.

Just as pain itself is difficult to define, differentiating between acute and chronic pain can be equally challenging. Acute pain usually occurs in response to a specific pain stimulus, and is generally considered useful, in the sense that it acts as a warning signal that something should be done in order to reduce the pain or get away from whatever is causing it (Sapolsky, 2004; Verhaak, Kerssens, Dekker, Sorbi, & Bensing, 1998). According to Sapolsky (2004, p. 187): “Pain is useless and debilitating, however, when it is telling us that there is something dreadfully wrong that we can do nothing about.” Enter chronic pain. Chronic pain can be associated with non-malignant progressive diseases (e.g., arthritis), or be present with or without tissue damage or injury (Ashburn & Staats, 1999). Chronic pain is generally considered to be pain that has continued beyond the expected time taken to heal, or pain that has continued for three months or longer, with some specifying that the pain must be continuous and others arguing that intermittent pain can

still be considered chronic (Elliott, Smith, Penny, Smith, & Chambers, 1999). The criterion for chronic pain varies considerably within the research context, ranging from three months (e.g., Elliott et al., 1999) to six months or longer (e.g., Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). These variations in definition contribute to the considerable variations in the prevalence rates of chronic pain used in the research literature.

Epidemiology

Estimated prevalence rates vary considerably for a number of reasons, including the above variability in definitions of chronic pain, differences in the population sampled, and differences in the specific types of chronic pain that are considered. UK figures suggest that approximately 60 to 80 per cent of the population will experience back pain at some point in their lives, and for 15 to 20 per cent, this pain will become chronic (Critchley & Hurley, 2007). The overall prevalence of chronic pain has been described as 50.4 per cent in a community sample from the UK (Elliott et al., 1999), 35.5 per cent in a community sample from the Republic of Ireland (Raftery et al., 2011), and between 17.1 per cent (males) and 20 per cent (females) in Australia (Blyth et al., 2001). A prevalence study of 15 European countries, as well as Israel, reports an average rate of 19 per cent, ranging from 12 per cent in Spain to 30 per cent in Norway (Breivik et al., 2006). Finally, a review of 15 prevalence studies from around the world gives the point prevalence of chronic benign pain as anywhere between 2 and 40 per cent (Verhaak et al., 1998).

In Aotearoa, the Christchurch Psychiatric Epidemiology study conducted in 1986 found a lifetime prevalence of 81.7 per cent of pain that was severe enough to significantly limit activity, led to medication being taken on more than one occasion, or led to medical consultation (James, Large, Bushnell, & Wells, 1991). More recently, the 2006/07 New Zealand Health Survey showed that 1 in 6 adult New Zealanders (16.9%) experience chronic pain of more than six months duration, with the prevalence increasing to 1 in 3 adults over age 65 (Ministry of Health, 2008). Further analysis of this data has also shown that almost two-thirds of those reporting chronic pain rated their recent experience of pain as moderate to severe, and one-fifth rated it as severe or very severe (Dominick, Blyth, & Nicholas, 2011). Although prevalence rates vary within and between countries, the overall picture is one of a significant health issue that deserves attention.

Significance and complexity of chronic pain as a health issue

Chronic pain has significant personal and economic costs; it is a source of disability for the individual affected, as well as being a burden on health care services, which is predicted to increase as the growing population ages (Gatchel, Peng, Peters, Fuchs, & Turk, 2007; Manek & MacGregor, 2005). For example, chronic pain has been estimated to cost 70 billion dollars each year in the USA alone (Gatchel et al., 2007). One of the economic costs is loss of productivity in the work force, which accounts for a substantial proportion of the total societal cost of chronic pain (Andersson, 1999). In terms of personal costs, chronic pain is associated with numerous negative experiences, including activity restriction, lost work days, disability compensation, job loss, financial stress, and chronic healthcare seeking (Andersson, 1999), sleep disturbance, personality changes, lack of energy, poor concentration, poor memory, and relationship difficulties (Ashburn & Staats, 1999).

Chronic pain is also associated with a range of psychological difficulties, including depression, anxiety, and anger, which can both predispose people to chronic pain, and augment the chronic pain experience (Gatchel et al., 2007). Anxiety generally stems from the unknown and unexplainable nature of chronic pain. For example, fear of movement or (re)injury is common and generally results in people restricting or reducing the amount of activity they do, which is known to contribute to further disability (Gatchel et al., 2007). There appears to be a mutually reinforcing relationship between having chronic pain and having depression; in fact, there is symptom overlap between the two (e.g., lethargy), which some suggest may be due to a common susceptibility factor (Gatchel et al., 2007). It is hardly surprising that some people with chronic pain experience anger at times, given the inherently unpleasant nature of pain, the frustration at it not remitting, and the stress of ongoing (and often difficult) interaction with the medical system (Gatchel et al., 2007).

Ongoing interaction with the medical system tends to occur because chronic pain rarely has a specific cause or medical diagnosis. For example, as many as 90 per cent of all cases of chronic back pain are thought to be non-specific and less than one per cent of back x-rays show a discernable cause of pain (Manek & MacGregor, 2005). The search for a cause can be all-consuming, as people with chronic pain look for a way of legitimating their experience of pain, which is often met with disbelief and doubt by medical practitioners, colleagues, family, and friends alike (Critchley & Hurley, 2007; Miles, Curran, Pearce, &

Allan, 2005). It is common for people with chronic pain to receive multiple and/or incorrect diagnoses from different medical professionals, which can contribute to psychological distress, and create risks when inappropriate treatment advice is followed (Critchley & Hurley, 2007).

More recent analyses of data from the New Zealand Health Survey have shown that chronic pain has a range of features, including associations with various socio-demographic factors (Dominick et al., 2011). For example, as economic living standards decreased, the prevalence of chronic pain increased. Adults who were unemployed or currently looking for work were more likely to report chronic pain. Over a quarter of adults who reported chronic pain had endured it throughout at least 40 per cent of their lifetime. Injuries or accidents, health conditions, or age were the most commonly reported causal attributions for chronic pain. Overall, over one-third of adults with chronic pain reported using no form of treatment, and alarmingly, a quarter of those reporting severe or very severe pain reported using no form of treatment (including both medical treatment and self-care or alternative strategies). Finally, poorer health related quality of life across all domains of the Medical Outcomes Study Short-Form (SF-36) was more likely in adults with chronic pain compared to those without, and was poorer still in those with more severe pain or multiple pain sites (Dominick et al., 2011).

In terms of treatment, chronic pain is complicated by poor prognosis with little chance of full recovery in many cases, and management rather than cure the accepted approach (Andersson, 1999; Ashburn & Staats, 1999). Due to the multitude of negative experiences which co-occur with chronic pain, singular treatment modalities are rarely successful, and multidisciplinary treatment is commonplace (Ashburn & Staats, 1999). At best, people with chronic pain can expect a reduction in pain, and improvements in the other areas of life affected (e.g., return to work, improved sleep, reduction in depressive symptoms, increased activity levels) (Ashburn & Staats, 1999). Multidisciplinary treatment is generally couched in a biopsychosocial approach, in which the influence of biological, psychological, and social factors is acknowledged (Gatchel et al., 2007). This approach is now highly influential in the field of chronic pain, due to these factors being incorporated into current pain theories (discussed below), and a general shift towards more holistic views of health (Gatchel et al., 2007). Current theories of pain incorporate its inherent complexity and subjectivity, and further contribute to developing a deeper understanding of the chronic pain experience. They will now be reviewed.

Current pain theories

Although theoretical understandings of pain have advanced significantly in the past two decades, they were developed out of theories from the past – in fact, the nature of pain has been debated for centuries (Melzack & Wall, 1965). The theories of the past will therefore be briefly reviewed in order to provide context and understanding for those of the present.

Specificity theory

Specificity theory originated in the 17th century work of Descartes but continued to be widely accepted until the 1950s, and appears to contribute to both medical and lay understandings of pain even today (Melzack, 1993). The basic principle of specificity theory was that there are specific peripheral pain receptors in the body, which transfer pain messages to a specific pain centre in the brain (Melzack & Wall, 1965). Proponents of this theory assumed there was a direct, invariant relationship between a pain stimulus and pain sensation. Although this has now been proven inaccurate, for centuries, anyone who reported pain in the absence of peripheral injury was not believed (Melzack, 1993). Sadly, this is still the experience of many people with chronic pain. Specificity theory was briefly replaced with pattern theory before more advanced theories were put forward.

Pattern theory

There were, in fact, a number of different ‘pattern theories’ that arose in the 1940s and 1950s. They were all based around the principal that spatial and temporal patterns of nerve impulses travel to the brain via the spinal column, creating intense stimulation of non-specific receptors that result in the experience of pain (Melzack, 1993; Melzack & Wall, 1965). However, proponents of this theory assumed that all receptors are passive and non-specific, which is not the case (Melzack & Wall, 1965). Despite this, aspects of pattern theory proved to be useful and were incorporated into the gate control theory, the most widely accepted and influential theory of pain to date (Melzack, 1993).

Gate control theory

Because of Melzack and Wall’s (1965) gate control theory, pain is now understood to be a process. The dorsal horn of the spinal column is seen as the mediator or ‘gate’ in this process, as it has been found to affect excitation and/or inhibition of nerve impulses, thus modulating pain output (Melzack & Wall, 1965). Afferent (incoming from the periphery)

nerve impulses activate various areas of the brain, including those associated with emotion, memory, attention, and experience, which can in turn send impulses through efferent (outgoing to the periphery) nerves that act to modulate the sensory output of pain (Melzack & Wall, 1965). Messages arrive at the gate in two different forms: via large slow-conducting nerve fibres that tend to be inhibitory (i.e., close the gate) or via small fast-conducting nerve fibres that tend to be excitatory (i.e., open the gate). When the nerve impulses reach a critical excitatory level the gate opens and a complex system of neural activity produces the various actions and behaviours that are associated with pain (e.g., yelling, moving, withdrawing from the pain stimulus, tears, visual and auditory attention) (Melzack, 1993; Melzack & Wall, 1965).

Through the gate control theory Melzack and Wall (1965) acknowledged that pain is not merely a physical phenomenon. The perception of pain is influenced by processes operating both within and outside the brain that influence whether or not a pain signal is transmitted (Melzack & Wall, 1965). Essentially, the brain plays a dynamic and active role in pain perception, or as Sapolsky eloquently puts it, "...the brain is not a mindless pain-ometer, simply measuring units of ouchness" (2004, p. 193). As a consequence of the wide acceptance of the gate control theory, and the vast amount of empirical support for it (Melzack, 1993), psychological, social and cultural factors are now seen as significant influences in the process of pain. Gate control theory also has a modern incarnation – the neuromatrix theory – which offers further insight into how these factors influence pain.

Neuromatrix theory

Neuromatrix theory was developed by Melzack and Casey (1986, cited in Melzack, 1999) in order to give credence to the idea that the brain plays a dynamic and interactive role in pain perception. The underlying principle of neuromatrix theory is that the brain contains a complex system of neural networks dubbed the 'body-self neuromatrix' that is developed by both learning and hereditary factors (Melzack, 1993). The subjective experience of the body is reflected within this neuromatrix and, although it is usually influenced by sensory inputs, the neural network is also able to produce subjective experience in the absence of sensory inputs (Melzack, 1993). This is also the case for pain. Sensory input influences the experience of pain but it does not cause it; the activation of complex neurosignatures (specific output patterns of the neuromatrix) in the brain produce the subjective experience of pain (Melzack, 1993).

The neuromatrix theory of pain can be used to explain why someone with complete spinal section can feel pain in their legs, and why many amputees experience phantom limb pain – the sensation of pain located in a limb that no longer exists (Melzack, 1999). Using this theory, chronic pain can be explained as the increased activation of the pain neuromatrix through a process of enhanced sensitisation, whereby little or no sensory input is required for neurosignatures to be ‘lit up’ and pain to be experienced (Moseley, 2003).

Neuroanatomical evidence supports the neuromatrix theory of pain. Brain activation studies have shown that no single area lights up in response to pain, but rather a number of different areas, for which there is enormous variation within and between individuals (Moseley, 2003). The areas that tend to light up most often during presentation of a painful stimulus are the premotor/motor cortices (organise and prepare movements), cingulate cortex (concentration and focusing), prefrontal cortex (problem solving and memory), amygdala (fear, fear conditioning, and addiction), sensory cortex (sensory discrimination), hypothalamus/thalamus (stress responses, autonomic regulation, and motivation), cerebellum (movement and cognition), and hippocampus (memory, spatial cognition, and fear conditioning) (Butler & Moseley, 2003; Moseley, 2003). Therefore, when this complex neurosignature is activated or ‘lit up’, it produces a pain experience that is influenced by a range of biological, psychological, social and cultural factors (Melzack, 1999).

It is easy to see how the biopsychosocial approach became so popular in the field of chronic pain (Gatchel et al., 2007). Not only do these factors influence the subjective experience of pain in the present, but they have also been formative in the development of the neuromatrix, and of the specific neurosignatures that it produces (Melzack, 1999). No one would deny that pain is a universal experience that applies to people from all cultural and ethnic groups but, as the neuromatrix theory highlights, it is by its very nature subjective. Therefore there needs to be consideration of cultural and ethnic influences on the experience of pain (Davidhizar & Giger, 2004).

Chapter 2: Pain, Culture and Ethnicity

The literature on cultural and/or ethnic differences in pain experiences and treatment has been reviewed thoroughly elsewhere (e.g., Bonham, 2001; Calvillo & Flaskerud, 1991; Davidhizar & Giger, 2004; Green et al., 2003; Shavers, Bakos, & Sheppard, 2010), however aspects of it will be briefly reviewed below in order to provide some context for the literature specific to Māori and pain that follows.

Defining race, ethnicity and culture

When discussing cultural aspects of pain, it is important to differentiate between the terms that are used in this research context, namely ‘race’, ‘ethnicity’, and ‘culture’ (Lasch, 2002). Race is the most contested term: it has a historical meaning as a biological or genetic basis to the grouping together of people with similar physical characteristics, but is now largely seen as a socially constructed term (Lasch, 2002). For example, it is widely understood that the genetic variation within any ‘race’ is characteristically wider than the variation between ‘races’ (see Cooper & David, 1986; Wald, 2006, for more on this). Ethnicity can be defined as “...a group of people within a larger society who share a common ancestral origin or social background, culture, and traditions that are maintained between generations and provide a sense of identity” (Lasch, 2002, para. 9). Finally, “Culture is shaped by the values, beliefs, norms, and practices that are shared by members of the same cultural group” (Davidhizar & Giger, 2004, p. 49). In this thesis, the focus is on people who identify with Māori ethnicity, within which aspects of Māori culture are incorporated, and who may or may not have the physical characteristics that have been aligned with the construct of Māori ‘race’.

Ethnic/cultural differences in pain

Culture and/or ethnicity has a relationship with a number of aspects of pain, including pain ratings and treatment, reactions to pain, pain tolerance, prescription rates for pain medication, and cross-cultural difficulties in the interpretation of pain. Research examples of each of these aspects will be reviewed. Note that terms used to refer to different ethnic and cultural groups vary; I have therefore chosen to use the terms provided by the author(s) of each item of literature reviewed, whilst acknowledging that some of them are contested.

Ethnic differences have been found in how severely pain is rated and what types of treatment are sought. In some of the earliest studies of cultural influences on pain, Zborowski (1969, cited in Goldberg & Remy-St. Louis, 1998) found that men of Italian or Jewish backgrounds expressed their pain more openly whereas Old American (i.e., third-generation Anglo) and Irish men were more stoic. Bates, Edwards, and Anderson (1993) also found that Hispanics and Italians with chronic pain in the USA were more likely to see the emotional expression of pain as acceptable, whereas Polish and Old Americans saw stoicism as a more acceptable way of dealing with chronic pain. Hispanics also experienced much more interference from chronic pain than Polish and Old Americans (Bates et al., 1993). These findings, and the ones that follow, are often described as perpetuating stereotypes; members of more expressive cultures are more likely to see communication of pain symptoms as acceptable, whereas members of more stoic cultures are not (Shavers et al., 2010). It is not always that simple.

In a sample of adults seeking treatment for chronic pain, McCracken, Matthews, Tang, and Cuba (2001) found that Black Americans were significantly more likely to report: higher pain levels, greater avoidance-related coping, greater fear and anxiety related to pain, and more physical symptoms compared to White Americans. Similar results were found by Riley (2002), however in this case there were no differences found between the pain intensity ratings of African Americans and White Americans with chronic pain.

Meghani and Cho (2009) found that minority ethnicities (i.e., Black, Hispanic, Asian) had higher ratings of pain severity than non-minority ethnicities (Whites), whereas no associations were found between ethnicity and receiving a chronic pain diagnosis, or between ethnicity and the type of treatment used. In contrast, comparing African American, Hispanic, and White university students in the USA, Hastie, Riley, and Fillingim (2005) found no difference in the frequency, intensity or duration of pain experienced. However, in this sample Whites were more likely than African Americans to use over-the-counter medications or apply heat or ice to reduce their pain, whereas African Americans and Hispanics were more likely than Whites to use prayer or spiritual approaches (Hastie et al., 2005). Similarly, Im et al. (2009) found that Whites with cancer pain tended to try to control their pain through seeking various treatments, whereas minority ethnicities were more likely to see religious factors as both a source of their illness and a way of treating it. Whites were also more likely to continually search for treatment for their cancer pain whereas minority ethnicities were more likely to see their

illness as a natural experience and therefore seek less medicalised treatments. Finally Whites tended to have individualistic approaches to cancer pain care as opposed to the family-based approaches more evident in minority ethnic groups (Im et al., 2009).

Despite conflicting evidence in terms of pain severity and intensity ratings, ethnic differences in pain tolerance are consistently found. Nayak, Shiflett, Eshun, and Levine (2000) found that expressing pain was less acceptable in university students from India than in American university students, and that, despite having similar ratings of pain intensity, Indians had higher experimental pain tolerance in a cold-pressor test (entails hands being submerged in ice-cold water) than Americans. Comparing African American and White American chronic pain patients, Edwards, Doleys, Fillingim, and Lowery (2001) found that African Americans experienced greater pain intensity and disability from their chronic pain than White Americans, and that White Americans had higher experimental pain tolerance in an ischaemic tourniquet test (entails clenching and unclenching fists whilst tourniquet is on arm). Dawson and List (2009) compared the experimental pain threshold and pain tolerance levels of Swedish and Middle Eastern adults, and found that, although pain thresholds were similar, Swedish participants had significantly higher pain tolerance levels than Middle Easterners on cold-pressor and pressure pain tests (entails a probe being applied to cheek with increasing pressure), but not on an electrical pain test (entails placing hands on increasing pulses of electrical current).

Although such differences are frequently reported, researchers often seem hesitant to make claims as to why it is the case. In experimental pain research, the focus tends to be on biological factors (e.g., endogenous opioid release) as opposed to the sensory or affective factors (e.g., negative emotional responses), which are more likely to have cultural origins or influences (Shavers et al., 2010). Shavers et al. (2010, p. 193) make four claims about the ways in which culture can influence the experience of pain:

- (1) individual pain-related behavior, sensations, emotions, and expectations;
- (2) interpersonal relationships and individual beliefs about pain and pain management (e.g., roles of family, health care professionals, support people);
- (3) inter-group relationships and the beliefs, expectations, and social meanings of pain of both the provider and the patient;
- (4) and the societal environment, which encompasses health culture, ideology, quality of life, and socioeconomics.

Ethnicity/culture and treatment of pain

Ethnicity or culture can also influence the treatment experience and interactions with health professionals. Heins et al. (2006) examined the medical records of adults over 18 who presented to the emergency department (ED) with musculoskeletal pain, specifically looking at prescription of analgesics and opioids (during the patients' time in ED and on release), and both patient and physician characteristics. No ethnic disparities were found for the prescription of analgesics, but White patients were 1.8 times more likely to receive opioids than Black patients. White patients were also twice as likely to be given an opioid prescription on discharge than Black patients (Heins et al., 2006). Similarly, Pletcher, Kertesz, Kohn, and Gonzales (2008) found that, although type and severity of pain was similar across ethnic groups, opioid prescription differed: 31 per cent of Whites were prescribed opioids, compared to 23 per cent of Blacks, 24 per cent of Hispanics, and 28 per cent of Asian/Other patients. Significant differences were maintained even when controlling for patient, visit, and hospital characteristics.

These differences in prescription rates may be due to cross-cultural difficulties in the interpretation of pain, but there are conflicting results in research of this type. Todd, Samaroo, and Hoffman (1993) found that 55 per cent of Hispanics presenting in ED with long-bone fractures received no analgesia compared to just 28 per cent of non-Hispanic Whites, even when controlling for a multitude of confounding factors. When investigating this issue further, Todd, Lee, and Hoffman (1994) found minimal differences in the pain ratings of patients and their physicians, which suggests that the disparity in rates of analgesia prescription was not due to a difficulty on the physicians' part in assessing pain in patients with a different ethnicity to their own. In contrast, Staton et al. (2007) compared the ratings of chronic non-cancer pain patients with those of their physicians. Examining the results by ethnicity, Black patients had significantly higher pain ratings than non-Blacks (White, Hispanic, Asian, etc.), and physicians were more likely to underestimate their pain (i.e., by two or more points) than the pain of non-Blacks, even when controlling for multiple confounding variables (Staton et al., 2007).

Again, there can be reluctance to make claims as to why these differences occur, however a wide range of suggestions have been made in a review of this literature by Shavers et al. (2010). These include: lack of awareness from providers of potential cultural variations in pain experience; practitioners interpreting the needs of their patient through the lens of

their own culture; inaccurate assessment or disbelief of symptoms of pain; assumptions about drug-seeking in minority ethnicities; language and communication barriers; environments that are not conducive to developing rapport (e.g., ED); reliance on stereotypes; personal bias; patient's negative past experiences with the healthcare system (for self or family); patient attitudes, beliefs, and behaviours (e.g., fear of addiction or side effects); legal scrutiny of prescribing controlled substances (i.e., opiates); access to appropriate care and medication; and health insurance coverage (Shavers et al., 2010). All of these have the potential to contribute to disparities in pain relief between majority and minority ethnicities, and are often present in various combinations, which merely exacerbates the situation.

In summary there is extensive – and sometimes conflicting – evidence to suggest that there are ethnic and/or cultural differences in pain experiences and also in the treatment of pain by health professionals, at least in the USA where the majority of this research was conducted. Could such differences exist in Aotearoa? The Aotearoa/New Zealand context will now be described before introducing the literature on Māori and pain.

Chapter 3: The Aotearoa/New Zealand Context – Māori and Pain

In this chapter the focus moves to Aotearoa – the location of the present research. The context of colonisation and Te Tiriti will be described, as will the role that this context plays in the significant health disparities that exist between Māori and non-Māori. Māori perspectives of health and healing will also be discussed. Following this, the literature on Māori and pain will be covered. This contextual information is vitally important when exploring a subject – Māori experiences of chronic pain – that has received little attention in Aotearoa to date. Not only does it highlight why this subject deserves attention, but it provides context to the topic, the research aims, the methodology employed, and the qualitative data that follows, aiding its analysis and interpretation.

Ethnic identity in Aotearoa

The terms used to describe the various ethnic groups in Aotearoa vary within the literature, as do the methods used to categorise them. For example, in some of the literature Māori are categorised as any person that identifies as such, even if they identify with another ethnicity as well, whereas in others they must identify solely as Māori to be in this category. The ethnic group/s that Māori are compared to also vary, from all non-Māori ethnicities in Aotearoa (called either ‘non-Māori or ‘Other’), to just New Zealand Europeans, to a combination of ‘New Zealand European/Other’. ‘Other’ tends to refer to Latin American, Middle Eastern, or African peoples, which are combined in order to avoid statistical problems with small numbers (Statistics New Zealand, 2006). Pacific peoples (from the Cook Islands, Western Samoa, Niue, Tonga, Tuvalu, Tokelau or Fiji), although distinct from Māori and from each other, are sometimes categorised with Māori. This appears to be because Pacific peoples in Aotearoa occupy a similar marginalised status to Māori in regards to health disparities (Ministry of Health, 2002). I will therefore use the terms provided by the author(s) of each item of literature reviewed.

Colonisation and Te Tiriti o Waitangi

Aotearoa has a history of colonisation, in which Māori have suffered significant discrimination and marginalisation by non-Māori (Nairn, Pega, McCreanor, Rankine, & Barnes, 2006), an experience believed by many to contribute to what are now vast socioeconomic and health disparities between the two ethnic groups (Harris et al., 2006a). Pākehā now make up approximately 80 per cent of the population, with Māori making up

15 per cent, and Pacific and Asian peoples making up 7 per cent each² (Harris et al., 2006a). Although Aotearoa may be considered a multicultural society, it has a bicultural context, specifically based on Te Tiriti – the founding document that was signed by representatives from Māori iwi (tribes), and representatives from the British Crown. Although the subject of some contention, three principles drawn from particular interpretations of Te Tiriti – participation (also known as *ōritetanga* or equal citizenship), protection (also known as *tino rangitiratanga* or self-determination), and partnership (also known as *kāwanatanga* or government) – have now been incorporated into the policies of all major health providers in Aotearoa (Herbert, 2002). In practice, the health disparities that exist between Māori and non-Māori demonstrate that these principles have not been upheld (Reid, Robson, & Jones, 2000; S. Walker, Eketone, & Gibbs, 2006).

Health disparities

Māori die an average of eight to nine years earlier than non-Māori in Aotearoa (Harris et al., 2006a). Māori are more likely to report poor or fair self-rated health, lower mental health, lower physical health, and higher rates of cardiovascular disease (Harris et al., 2006a). More specifically, Māori men and women aged 45 to 64 years have rates of ischaemic heart disease three to four times that of non-Māori (Kerr, Penney, Moewaka Barnes, & McCreanor, 2010). Māori experience an earlier age of stroke onset, and are more likely to be dependent on carers 12 months after onset (Dyall, Feigin, Brown, & Roberts, 2008). Māori are also disproportionately affected by cancer; they have an 18 per cent higher rate of diagnosis and a 93 per cent higher mortality rate than non-Māori (T. Walker, Signal, Russell, Smiler, & Tuhiwai-Ruru, 2008). Māori are also 7 per cent more likely than non-Māori to die from colon cancer, despite having a lower incidence of the disease (Hill et al., 2010). This list is not exhaustive.

There is also evidence to suggest that Māori have greater difficulty than non-Māori accessing healthcare and various treatments in Aotearoa. Māori women are less likely to receive a range of medical interventions during childbirth, including caesarean sections and epidural analgesia (Harris et al., 2007; Nelson, 2006; Sadler, McCowan, & Stone, 2002). Māori are also 1.35 times more likely than non-Māori to defer picking up prescription medication because of prohibitive costs (Jatrana, Crampton, & Norris, 2010). Tobias and

² The total exceeds 100% as respondents can identify with more than one ethnicity

Yeh (2007) found that 27.2 per cent and 34.2 per cent of the disparities between Māori and New Zealand European/Other males and females, respectively, could be attributed to amenable mortality, or deaths that were preventable and untimely. Davis et al. (2006) also found that Māori were more likely to experience an adverse event suggestive of inadequate care whilst in hospital than non-Māori/non-Pacific people.

Alongside access and quality of care, Māori also experience greater racial discrimination than non-Māori, which is thought to contribute to their poorer health (Harris et al., 2006a, 2006b). In the 2002/03 New Zealand Health Survey 10,377 New Zealanders (6,269 Europeans and 4,108 Māori) had face-to-face interviews about their health, which included five items relating to experiences of racial discrimination. Harris et al. (2006a) found that Māori were significantly more likely than Europeans to report experiences of racial discrimination. More specifically, they were 13 times more likely than Europeans to report discrimination when renting or buying a house, and 10 times more likely to have experienced three or more forms of discrimination. Māori were also more likely than European New Zealanders to report poorer physical and mental health. Using multivariate modelling, Harris et al. (2006a) found that these health disparities between Māori and European New Zealanders were reduced significantly by adding racial discrimination and socioeconomic deprivation into the model.

As well as these disparities in health status, Māori views on health and healing are different to the western biomedical views that dominate healthcare in Aotearoa at present. An introduction to these views will therefore contribute to understanding the chronic pain experiences of Māori.

Māori views on health and healing

Māori views on health and healing are generally described as holistic and multidimensional (Cram, Smith, & Johnstone, 2003; Mark & Lyons, 2010). In Durie's (1985) Te Whare Tapa Whā (the four-sided house) model, health is seen as the interaction between te taha tinana (physical health), te taha hinengaro (mental health), te taha wairua (spirituality) and te taha whānau (family). Another popular model of health is Pere's (1997) Te Wheke (the octopus), in which the head represents the child/family and each tentacle represents a dimension of their wellbeing: mauri (life principle/ life force), mana (prestige/power/influential qualities), wairua (spirituality), taha tinana, whanaungatanga (extended family), ranga whatumanawa (emotions), taha hinengaro, and hā, taonga tuku

iho (breath, treasures passed down from our ancestors). Further research and interpretation of Māori views on health have added the concepts of whānau/whakapapa (family/genealogy) and whenua (land) (Mark & Lyons, 2010), as well as te reo (language) and te ao tūroa (environment) (Cram et al., 2003), and mātauranga (knowledge/education) (Jones, 2000). Wairua is seen as particularly important, and is considered the aspect of health most commonly overlooked in western biomedicine (Cram et al., 2003; Jones, 2000).

These views of health inform the types of treatment that are traditional in Māori culture. Prior to colonisation, Māori had a well-established tradition of treating illness, usually carried out by tohunga (experts in traditional healing/chosen as leaders in their field) who had undergone extensive training and were highly respected members of the community (Jones, 2000). The Tohunga Suppression Act, passed in 1907, was used to discourage the use of rongoā Māori, as it was in conflict with western biomedical views. There was a significant loss of the knowledge and values that were related to health and healing but underground networks kept aspects of it alive until the Act was repealed in 1964 (Jones, 2000).

It appears that the use of rongoā Māori is still relatively popular even today. The National Board of Traditional Māori Healers was established in 1992 – there were over 600 members reported in 2002 (Bodeker & Kronenberg, 2002) – and there are standards of practice in place (Jones, 2000). In addition, a survey of patients in a provincial North Island hospital, found that 59 per cent of Māori sampled had used rongoā Māori (A. Evans, Duncan, McHugh, Shaw, & Wilson, 2008). Rongoā Māori treatments include the use of rongoā (plants, herbs and other items that have medicinal properties), romiromi (deep-tissue massage, often targeting pressure points), and mirimiri (massage targeting soft tissue), as well as the use of karakia (prayers or chants) (Mark & Lyons, 2010).

Unfortunately, a lack of understanding and acceptance of Māori views on health and healing within the dominant medical system in Aotearoa, is thought to contribute to the reported mistrust and unwillingness of many Māori to engage with the healthcare system (Cram et al., 2003). These attitudes are also related to historical events, such as whānau members being treated poorly or dying whilst in medical care (Cram et al., 2003). As well as these fears and suspicions, Māori also report a sense of whakamā (shame or shyness that is culturally bound) at having to see a doctor, or talk about certain health matters (Cram et

al., 2003). Furthermore, there is rarely acknowledgment within the medical system of the everyday needs of Māori who are experiencing poverty; for example, it is easy to see why some Māori would not prioritise a trip to the doctor if they were already struggling to provide their whānau with basic food, clothing, and shelter (Cram et al., 2003).

This research on views of health and healing, along with knowledge of the existing health disparities between Māori and non-Māori in Aotearoa, led me to question whether the experiences of chronic pain in Māori would be influenced by these contextual and cultural factors. In the following section I review the relatively small amount of research that has been conducted on Māori and pain.

Māori and Pain

A note on publications and review methods

Preceding my Masters research, I was granted a summer studentship in Māori health from the Health Research Council of New Zealand (HRC), which provided me with the opportunity to have a preliminary look at the literature on Māori and pain. Along with my summer studentship supervisors, a review paper based on that literature was written (McGavock, Moewaka Barnes, & McCreanor, in press), which is pending publication in 2012 with the journal *AlterNative* (<http://www.alternative.ac.nz>).

Some of the literature reviewed in this thesis was therefore gathered as part of that summer studentship. The literature search that was conducted used pain related terms³ along with ‘culture’, ‘ethnicity’, ‘race’, ‘Maori’ and ‘New Zealand’. Online databases were searched⁴, along with consulting He Kohikohinga Rangahau – a list of all published psychological research with Māori compiled by the University of Auckland (Hollis, Cooper, Braun, & Pomare, 2010). Once these searches had been exhausted, a scan of other literatures led to the inclusion of several Ministry of Health reports, a District Health Board study and a health psychology Master’s thesis.

³ Including: pain, pain experiences, chronic pain, intractable pain, analgesic, pain relief, pain medication

⁴ Including IndexNZ, Scopus, Web of Science, PubMed, CINAHL, Science Direct, PsycInfo, Academic Search Elite, and Google Scholar

As I began reviewing the literature on Māori and pain, it became immediately apparent that there was a lack of research with a specific focus on the pain experiences of Māori in Aotearoa, and chronic pain in particular. In addition, the literature that was found was inconsistent, perhaps due to the diverse range of methodologies used and types of pain that were covered.

Quantitative research covered topics from acute pain (Azariah, 1984; Mahmoud & Hill, 2006), pain associated with childbirth (Nelson, 2006), dental pain in children (Jamieson & Koopu, 2006), and prescription rates for analgesia (Crengle, Lay-Yee, Davis, & Pearson, 2005); to chronic pain (Dominick et al., 2011; Grace & Zondervan, 2004; Ministry of Health, 2008; Scott, McGee, Schaaf, & Baxter, 2008), fibromyalgia (Klemp, Williams, & Stansfield, 2002), and musculoskeletal pain associated with rheumatic diseases (Taylor, 2005; Taylor, Smeets, Hall, & McPherson, 2004). Qualitative research covered the topics of palliative pain (Penney, Fieldhouse, & Kerr, 2009), pain in physiotherapy patients (Bassett & Tango, 2002), and Māori views on the experience of pain (Fennell, 2005; Magnusson & Fennell, 2006, 2011).

Beyond the items listed above, the absence of Māori in other pain research in Aotearoa was also apparent. Three articles were found that were related to pain and had Māori participants, but did not examine the data by ethnicity or make any specific mention of the experiences of their Māori participants (Farquhar, Roberts, Okonkwo, & Stewart, 2009; Grace & Zondervan, 2006; Taylor, Dean, & Siegert, 2006). Furthermore, there were eight articles found that were related to pain experiences in Aotearoa but made absolutely no mention of Māori, with some not mentioning the ethnicity of their participants at all (Billis, McCarthy, & Oldham, 2007; Carron, DeGood, & Tait, 1985; S. Evans, Keenan, & Shipton, 2007; Grace & MacBride-Stewart, 2007; Huntington & Gilmour, 2005; James et al., 1991; Large & Mullins, 1981; Shaw & Lee, 2010). I will first review the quantitative research related to both acute and chronic pain in Māori, before turning to the three published qualitative studies.

Quantitative research

Acute pain

Much of the research located on Māori and pain focused on specific forms of acute pain. In an early study, Azariah (1984) noted the clinical impression among medical practitioners

that Māori men had a higher pain tolerance than European men in New Zealand. Azariah (1984) consequently conducted an experimental study in which 30 Māori and 30 European male volunteers complete an ischaemic tourniquet pain test. Māori males were able to tolerate this ischemic pain for longer than European males. This was the only study located that compared Māori experiences of pain with those of other New Zealanders, however only the abstract was available, and it would be premature to conclude that Māori have a higher pain tolerance based on this single example.

Continuing with the theme of clinical impressions, Māori and Pacific New Zealanders are thought to have higher rates of complicated appendectomies (i.e., the appendix has already burst), with anecdotes suggesting that medical practitioners believe this is due to delays in help seeking (Mahmoud & Hill, 2006). Mahmoud and Hill (2006) reviewed the patient records of 180 consecutive cases of appendectomy in a 16-month period, at a hospital in Auckland. Comparing Māori, Pacific, New Zealand European, and Other ethnicities, they found no significant differences in the median number of days in pain before help seeking or in the frequency of presenting within 48 hours of symptom onset (Mahmoud & Hill, 2006). This suggests that medical practitioners may have an inaccurate clinical impression of Māori pain tolerance in relation to help seeking for appendicitis. Note that the difference in range tells another story (0-18 days for Māori and Pacific patients, 0-7 days for New Zealand Europeans, 0-4 days for Other ethnicities) that could have clinical significance. It is also interesting to note that there were twice the rate of complicated appendectomies in Māori and Pacific patients than in New Zealand Europeans. However, these findings may have less to do with pain tolerance, and more to do with issues of access, treatment, or beliefs about the healthcare system.

Another form of acute pain is that experienced during childbirth. As already discussed, there are disparities between Māori and other New Zealand women in a full range of medical interventions during the labour and delivery process (Harris et al., 2007; Sadler et al., 2002). Nelson (2006) reviewed the literature on inequalities in pain relief during childbirth between Māori and non-Māori in Aotearoa. Ministry of Health reports on obstetric procedures and maternity were the main source of the review, and these showed that Māori and Pacific women had a rate of 15 per cent for epidural analgesia compared to 25 per cent in other New Zealand women. This is despite the fact that Māori and Pacific women are more likely to have pre-existing health conditions that would dictate a higher need for an epidural (Nelson, 2006). Some of this inequality has been attributed to Māori

being more likely to occupy the lower socioeconomic status (SES) demographic, because epidural rates also decrease with socioeconomic deprivation. Some of the suggestions put forward by Nelson (2006) for the remaining disparities are that Māori women: are more likely to be cared for by a midwife than an obstetrician; have a more positive approach to birth; are better able to tolerate labour pain; have better support from other women during labour; are less likely to have knowledge that an epidural is an option; and are less likely to know how to ask for or access an epidural.

Only one of the items reviewed focused on pain in children. Jamieson and Koopu (2006) conducted a study of the oral-health-related-quality-of-life in New Zealand children, as part of the National Childhood Nutrition Survey. Māori (37.4%), Pacific (32.3%), and New Zealand European/Other (30.3%) children under 14 years were interviewed in their homes alongside their parent or caregiver. Māori children were significantly more likely than New Zealand European/Other children to be kept awake by dental pain at night when adjusting for age, sex, and time spent living in New Zealand. However, when dietary factors, food security, or overall dental health were taken into consideration, there was no longer a significant difference. Jamieson and Koopu (2006) explain that the initial differences are a reflection of existing disparities in rates of dental disease. However, contrary to expectations based on these rates, Māori and Pacific children were less likely to have received a general anaesthetic for dental work than New Zealand European/Other children. This difference was significant for Pacific but not for Māori children. This has been put down to issues with access, such as living further from public hospitals, intimidating hospital environments, English as a second language, the inability of hospitals to accommodate large families, negative past experiences, or negative perceptions of the hospital environment (Jamieson & Koopu, 2006).

In contrast to the issues with dental-related general anaesthetic (Jamieson & Koopu, 2006), and with epidurals (Nelson, 2006), Māori were found to have higher prescription rates for analgesics than non-Māori (Crengle et al., 2005). This Ministry of Health report on Māori and non-Māori visits to doctors found that 9.0 per cent of all prescriptions given to Māori were for analgesics, as opposed to 7.6 per cent of all prescriptions given to non-Māori (Crengle et al., 2005)⁵. Importantly, there were also differences in overall prescription

⁵ Note that tests of statistical significance were not carried out for this report; comparisons between Māori and non-Māori should therefore be considered descriptive in nature.

rates, with Māori receiving more prescriptions than non-Māori (69.6% vs. 65.9%), but also having a slightly higher percentage of visits that resulted in no treatment (8.1% vs. 7.9%) and a slightly lower percentage of visits that resulted in non-pharmacological treatment (61.2% vs. 62.3%). Other important points to note from this report were that general practitioners (GPs) felt less rapport with their Māori patients, had shorter appointments with them, and had fewer appointments per year with them compared to their non-Māori patients (Crengle et al., 2005).

This research suggests that the experiences of Māori who are in acute pain may differ to those of other New Zealanders, whether in terms of tolerance, healthcare access, or treatment, including receiving pain relief medication. How or why it differs, in any qualitative sense, is unclear and requires further exploration.

Chronic pain

Research related to chronic pain in Māori, or chronic pain associated with specific health conditions (i.e., chronic pelvic pain, fibromyalgia, musculoskeletal pain from rheumatic disorders) in Māori, tended to focus on the prevalence of the condition or rates of healthcare seeking as opposed to lived experiences. In the New Zealand Health Survey conducted by the Ministry of Health (2008) researchers interviewed a total of 11,632 European/Other, 5,143 Māori, 1,831 Pacific, and 2,255 Asian people about various aspects of their physical and mental health, including questions about the presence of chronic pain in those over 15. More specifically, the researchers asked them whether they experience chronic pain (defined as lasting six months or longer), as well as questions about the location, cause and treatment of that pain. As previously mentioned, the overall prevalence of chronic pain was found to be 16.9 per cent. For European/Other adults it was 18.1 per cent, for Māori it was slightly lower at 17.3 per cent, with the prevalence 12 and 9 per cent for Pacific and Asian adults, respectively (Ministry of Health, 2008).

Further examination of this data has shown that European/Other adults are significantly more likely to report chronic pain compared to those without this ethnic identity, and Pacific and Asian adults are significantly less likely to report chronic pain compared to those without these ethnic identities (Dominick et al., 2011). When adjusting for age, Māori men were significantly more likely (age standardised rate ratio = 1.31) to have chronic pain than men in the total population (Ministry of Health, 2008). However, there is no difference in the likelihood of Māori adults reporting chronic pain compared to those

without this ethnic identity (Dominick et al., 2011). That is, the results varied depending on the comparison group used (Dominick et al., 2011).

Similar results were found in Te Rau Hinengaro: The New Zealand Mental Health Survey, which examined the relationship between mental and physical co-morbidity in Māori, Pacific, and Other New Zealanders (Scott et al., 2008). In face-to-face interviews, the researchers asked 12,992 people over 16 about a range of mental health conditions (e.g., anxiety, depression) and physical health conditions, one of which was chronic pain. Chronic pain could be in any form, including headaches, pain associated with arthritis, or back or neck problems; questions were posed in terms of lifetime prevalence. Adjusting for age and sex, Māori had significantly higher levels of chronic pain (42.2%) than Pacific (31.0%) or Other (38.4%) ethnicities. Although chronic pain was associated with higher levels of anxiety and depression, these co-morbidities did not differ by ethnicity (Scott et al., 2008). Important methodological features to note were that Māori were oversampled to increase accuracy, and that all mental and physical health conditions were self-reported. Also of note is that, in some current definitions, chronic pain is considered to be a condition in its own right; therefore including diagnosed chronic conditions in the definition would have increased the number of people identified as having chronic pain (Dominick et al., 2011).

In contrast to the results of the Ministry of Health (2008) and Scott et al. (2008), Grace and Zondervan (2004) found that Māori women had a significantly lower prevalence of chronic pelvic pain than New Zealand European women. They asked a sample of 1,160 New Zealand women aged 18 to 50 about their three-month and 12-month prevalence of chronic pelvic pain, which was pain not associated with dysmenorrhoea (pain from menstruation) or dyspareunia (pain from sexual intercourse). New Zealand European women had significantly higher prevalence of chronic pelvic pain than both Māori and Other New Zealanders, even after adjusting for age and education levels. However, pain ratings, severity, medical consultation rates, and diagnoses did not differ by ethnicity (Grace & Zondervan, 2004). Note that Māori women were underrepresented in this sample.

Klemp et al. (2002) looked at the population prevalence of fibromyalgia in 358 Māori and 331 European New Zealanders over 12 years of age from the Rotorua region. Fibromyalgia is a specific disorder characterised by chronic widespread pain (WP) and/or the presence of specific tender-points with scores greater than 11 (TPS>11) (Klemp et al., 2002). They

recruited European New Zealanders via electoral role sampling, but recruited Māori in accordance with ‘cultural protocols’, whereby elders from the surrounding iwi selected members of their community to take part who had at least 25 per cent Māori ancestry⁶. The prevalence of fibromyalgia in Māori, as diagnosed in the study, was 1.1 per cent, and 1.5 per cent in European New Zealanders. The age-adjusted prevalence for Māori was 9.8/1000 compared to 17.4/1000 in European New Zealanders. Although no statistical differences were found, in European New Zealanders, WP was more common than having TPS>11, whereas in Māori it was equally as common to have WP or TPS>11. However, in terms of the site of the pain, Klemp et al. (2002) found that Māori were significantly more likely to have it in their knee and European New Zealanders were significantly more likely to have it in their elbow or buttock. Cultural or genetic differences in pain are cited as the potential origin of these differences, however, the sample frames were different and the total number of respondents with fibromyalgia was low (1 Māori male; 3 Māori females, no European males and 5 European females).

Taylor et al. (2004) looked at how rheumatic cases (such as osteoarthritis and gout) presented in general practice, and whether that varied by ethnicity. They searched for cases from the Royal New Zealand College of General Practitioners database over a 12-month period, finding 5,940 adult New Zealanders who had consulted their GP about a musculoskeletal disorder. From these cases, they found that Māori were less likely than Europeans to be consulting their GP about back pain or regional pain disorders, but were 3.54 times more likely to be consulting them for gout. Although not reaching the level of significance, Māori were less likely than Europeans overall to consult their GP about any musculoskeletal disorder (Taylor et al., 2004). Although Taylor et al. (2004) oversampled Māori in order to increase accuracy, the sample is not representative of the New Zealand general population, as it is based solely on those who consult a GP. It is plausible that Māori in the general population have a higher prevalence of musculoskeletal pain, but are less likely to consult their GP about it, perhaps due to issues with access.

⁶ They describe this cut-off as ‘arbitrary’ and as a common way of differentiating between Māori and non-Māori. This implies a focus on ‘race’ rather than ethnicity and is problematic beyond any purported benefit of adhering to ‘cultural protocols’.

In order to see whether these differences in consultation rates for musculoskeletal pain between Māori and European New Zealanders were also present in the general population, Taylor (2005) conducted a feasibility study using an electoral role sampling frame. He used stratified sampling to ensure adequate representation of Māori and non-Māori under the age of 40, resulting in 289 respondents. Taylor (2005) included a variety of measures in the questionnaire, including the one-month prevalence of musculoskeletal pain lasting a week or more. However he did not analyse or discuss these results fully, focusing more on the response rate and other aspects of feasibility. Taylor (2005) suggests that Māori may have more disabling pain than non-Māori under age 40, but this difference was not apparent when compared to non-Māori over age 40. Without looking at the age of the Māori participants as well, this comparison does not add useful information. This study can therefore be said to be inconclusive in terms of contributing to understanding Māori and pain.

This research on chronic pain demonstrates that the experiences of Māori may differ to those of other New Zealanders, whether in terms of prevalence, type of chronic pain, or healthcare access. But again, how or why it differs, in any qualitative sense, is unclear and requires further exploration. Turning to the qualitative literature may provide more answers.

Qualitative research

Although the articles reviewed thus far give some insight into the prevalence of pain and certain painful health conditions in Māori, suggesting that differences may be at work, none of the researchers explored the lived experience of pain from a Māori perspective. Three qualitative studies were located that made a step in this direction.

In the first study reviewed the Northland District Health Board examined the experience of Māori patients in palliative care (Penney et al., 2009). Palliative care is the care of people who are dying, a large part of which involves pain relief and pain management (Penney et al., 2009). The research had both quantitative and qualitative components. In the quantitative component they looked at the routinely collected service utilisation data for Māori in palliative care from 2006 to 2008. This showed that Māori were being referred to palliative care in increasing numbers, although they were likely to have shorter stays in palliative care facilities than non-Māori, and were less likely to use inpatient services. In addition, Māori palliative care patients tended to die at home or in the hospice, whereas

non-Māori were increasingly likely to die in the hospice or hospital rather than at home (Penney et al., 2009).

The qualitative component of Penney et al.'s (2009) research consisted of hui (focus groups) and in-depth interviews with Māori palliative care patients (n=20) and their whānau (n=23) and non-Māori palliative care providers (n=27). Although this research was conducted on a small and specific sample from one area of New Zealand, it suggests that there may be disparities in palliative care, cultural assumptions made, and issues with stereotyping and miscommunication. More specifically, there appeared to be confusion and fear amongst Māori about the role of morphine, and whether it was to make the patient comfortable or contribute to their hastened death (Penney et al., 2009). Whānau members spoke of feeling guilty at having administered morphine to their dying relative, and felt that it was often used too soon and affected lucidity in the time leading to death. Because of this confusion some Māori refused to take morphine and suffered an enormous amount of pain as a result (Penney et al., 2009). There were also reports of whānau being stereotyped by health professionals as potential drug abusers, with a perceived risk that they might steal morphine for their own use (Penney et al., 2009). One woman felt that providers often misunderstood or misinterpreted her mother's pain symptoms, medicating her even when it was not clear whether or not she was in pain. In addition, because of the authority position that the providers occupied, she felt that her mother had a tendency to go along with whatever they said (Penney et al., 2009). Some also believed that assumptions were made about what Māori palliative patients would and would not want, largely based on cultural beliefs and stereotypes (Penney et al., 2009).

Another study that touched on Māori experiences of pain was the interpretive phenomenological work of Bassett and Tango (2002) on Māori experiences of physiotherapy. They conducted interviews with six Māori physiotherapy patients who were being treated currently or had been treated recently, and touched on various issues, including whether their cultural needs were being met. All participants felt that being respected as people was more important than having any specific cultural needs as Māori physiotherapy patients, and all felt that that had been achieved. In terms of pain, some of the participants alluded to pain being a necessary part of healing, and something that should be tolerated without complaint: "...participants did not think it was worth reporting to their physiotherapist, and endured the pain" (Bassett & Tango, 2002, p. 37). This 'no pain, no gain' theory is not physiologically accurate from a physiotherapy point of view,

and Bassett and Tango (2002) noted that physiotherapists should be vigilant to signs of their Māori patients enduring pain unnecessarily, and take steps to reduce this suffering.

Fennell's thesis (2005; Magnusson & Fennell, 2006, 2011) was the singular item of research located that had a specific focus on pain experiences in Māori. There were two aspects to the study: in the first she looked at the endorsement by Māori kaumātua (respected Māori elders) and Māori health care providers of 123 pain descriptors. These descriptors captured various aspects of the pain experience (i.e., sensory, emotional, cognitive, and social); as well as rating their suitability for use with Māori, participants were asked to provide alternatives in either English or Te Reo Māori (the Māori language) if they felt they were needed. Over 65 per cent of the participants endorsed 92 per cent of the descriptors. No alternatives were described in Te Reo Māori, but 58 additional and eight alternative descriptors were offered. It was concluded that the commonly used descriptors in pain questionnaires were appropriate for use with Māori.

In the second part of the study she interviewed a selection of kaumātua (n=24) and Māori health care providers (n=7) about Māori perspectives on pain. From the interviews, Fennell deduced that pain tended to be seen as a universal construct and that Māori did not have a specific perspective on it (Fennell, 2005; Magnusson & Fennell, 2006). The following are some examples from Fennell's (2005) thesis (with permission; some edited for brevity):

“What do you mean Māori pain? I've never heard of cultural pain, I thought pain was a human experience.” (kaumātua) (p. 53).

“...Māori patients tend to describe pain in relation to what they can't do with other people... how it affects their relationship with other people as opposed to how it affects them personally,... and probably internalize it more.” (healthcare provider) (p. 54).

“Māori express pain to those close to them mainly, and being private, you know we are private people, we don't like any Tom, Dick, or Harry to treat it, it's very hard to treat that, regardless even if they are doing a great job you know, we tend to find it much easier to work with one's own, to find a method to help with the pain.” (kaumātua) (p. 56).

“We withstand it, withstanding the pain as long as you can, that's, to me the reason we see [Maori] are so tolerant of pain.” (kaumātua) (p. 57).

“The word *mamae* is used a lot to encompass general physical pain, I’ve heard patients use that word, other ways in which Māori patients describe their pain might be in the context of the concept of *whakamā*, as having pain, and *whakamā* is a cluster of emotional feelings related to shame, loss of position, loss of hierarchy or a loss of ‘feeling ok’ about your place in the world, and I’ve heard patients describe pain around the losses associated with that, so I would probably call that an illness in the broader sense of the word from the Māori perspective.” (healthcare provider) (p. 55).

“[*Chronic pain*] kills the spirit, kills their *wairua*, kills their will to carry on, having put up with it for so long, and then for some of them, they get tired of being sore, tired of taking medication then depression comes in and then everything becomes bigger, ten times worse than what it really is, and spiritually that is the biggest.” (kaumātua) (p. 54).

Captured in these excerpts is the multidimensional view on health that is advocated by many Māori, whereby pain affects not just the physical aspect of health, but also affects spirituality, mental health (e.g., *whakamā*) and relationships with *whānau*. They also capture the sense of privacy that Māori have about health matters and an element of mistrust of the medical profession, suggesting that Māori would rather tolerate pain for as long as possible before seeking help⁷.

Another important feature to note about this research is that it used a small sample from a specific *iwi* in Aotearoa and as such presents a range of views that are not intended to represent a definitive viewpoint. Also the participants were *kaumātua* and healthcare workers offering their perspectives on Māori experiences of pain, and were not necessarily experiencing pain themselves. Magnusson and Fennell (2011) call for further research to be undertaken with Māori pain patients. However, the lived experiences of Māori in pain – and chronic pain in particular – have still been largely overlooked in the literature to date.

Summary and comparison to the international literature

In summary, I found very little research with a specific focus on Māori and pain, and in the literature that was located there were contradictory results and inconsistencies.

⁷ Note, however, that it is also possible that Māori seek help in other ways, such as going to traditional Māori healers or using complementary and alternative treatments (e.g., A. Evans et al., 2008).

Experimental evidence suggests that Māori men are more tolerant of experimental pain (Azariah, 1984), whereas equal tolerance to pain from appendicitis was suggested by Mahmoud and Hill (2006). Māori women are less likely than New Zealand European women to receive an epidural for pain relief during labour (Nelson, 2006), however, Māori are given more analgesic prescriptions than non-Māori by their GP (Crengle et al., 2005). Some studies found that Māori were more likely to have chronic pain (Ministry of Health, 2008; Scott et al., 2008) and other studies found that Māori were less likely to have chronic pain (Grace & Zondervan, 2004) or that there was no major difference between Māori and European New Zealanders (Dominick et al., 2011; Klemp et al., 2002; Taylor, 2005; Taylor et al., 2004). Māori are less likely than European New Zealanders to have a consultation with their GP that involves a musculoskeletal disorder (Taylor et al., 2004), which is a concern if Māori are in fact more likely to have chronic pain .

The literature on Māori and pain in the Aotearoa context shows some findings that are similar to the wider literature: broadly, that the minority ethnicity is more likely to be socioeconomically disadvantaged and have poorer health outcomes than the majority. This applies to pain too, at least in some cases, as inconsistencies were another commonality. Some of the research from the USA showed that, while the prevalence and intensity of pain or painful conditions did not differ between ethnicities, their experiences of and responses to the pain varied significantly (Hastie et al., 2005; Riley, 2002). Other research contradicted this by finding that minority ethnicities experienced greater pain intensity than White Americans (McCracken et al., 2001; Meghani & Cho, 2009). Such comparative research is yet to be conducted with Māori and other ethnicities in Aotearoa⁸.

The international literature showed that minority ethnicities are less likely to receive opioids and other medications for pain relief (Heins et al., 2006; Pletcher et al., 2008; Todd et al., 1994; Todd et al., 1993), and are more likely to have their pain underestimated or misunderstood (Staton et al., 2007). It is unclear whether this is the case with Māori in Aotearoa, however considering that Māori are less likely to receive an epidural during childbirth (Nelson, 2006), more likely to defer collecting prescription medication because of prohibitive costs (Jatrana et al., 2010), and have less rapport and fewer appointments with their GP (Crengle et al., 2005), it is a strong possibility. Fennell's (2005) research

⁸ Although I am aware of another health psychology Masters student doing cultural comparative pain research this year – watch this space!

also raised the idea that Māori are private about their health and may have a sense of shame or fear at having to see a doctor, which other research with Māori supports (Cram et al., 2003).

The qualitative research suggests that Māori have beliefs about health, medication use, and pain that are likely to affect their pain experiences. For example, the findings of Penney et al. (2009) and Fennel (2005; Magnusson & Fennell, 2006, 2011) demonstrate the importance of spirituality, family, and mental well-being for Māori, beyond physical health. This fits with Durie's (1985) Te Whare Tapa Wha model and Pere's (1997) Te Wheke model of Māori health. Similarly, several items from the wider literature demonstrated that minority ethnicities are more likely to have a holistic view of health, whereby spiritual/religious and family factors were seen to have a greater effect on their pain and the treatment that they sought, as opposed to the more medicalised, individually oriented approach of their majority counterparts (e.g., Im et al., 2009). Overall, the qualitative research supports the proposal made earlier; that contextual and cultural factors, such as traditional views on health and healing, could influence the experience of pain.

Chapter 4: Lived Experiences of Chronic Pain – The Present Research

I begin this chapter by arguing the importance of gaining an in-depth understanding of the lived experiences of Māori who have chronic pain. I then turn to existing research that has explored the lived experiences of people with chronic pain in the general population, and what little research has been conducted from the perspective of specific ethnic and cultural minorities. Finally I will outline the aims of the present research.

The importance of understanding the lived experience of Māori with chronic pain

The research review made it clear that there is next to no research on the lived experiences of Māori with chronic pain. It also suggests that there may be some differences at work in terms of Māori experiences of pain, but the nature and source of these differences is as yet unclear. By questioning and discussing possible sources of difference, I hope to further demonstrate why it is important to gain an in-depth understanding of Māori experiences of chronic pain.

Do healthcare practitioners have beliefs about Māori and how they tolerate pain that impact how they are treated, as has been suggested in the international literature? Several of the studies reviewed above suggested, or gave some evidence for, the idea that Māori are considered to have higher pain tolerance than other New Zealanders (e.g., Azariah, 1984; Mahmoud & Hill, 2006; Nelson, 2006). Furthermore, in a series of interviews held with Tauwi (non-Māori) GPs working with Māori in Auckland, McCreanor and Nairn (2002) found that disparities in health tended to be described by them in ways that downplay political or historical influences. Māori patients were seen as non-compliant, as interacting with the healthcare system symptomatically rather than preventatively, and as having a different view on health that few of the Tauwi GPs had formal knowledge of (McCreanor & Nairn, 2002). These views act to blame Māori culture and behaviour for Māori ill-health (McCreanor & Nairn, 2002), and could inadvertently guide the treatment decisions of healthcare practitioners working with Māori who are in pain.

Perhaps Māori who hold traditional views of health are better able to cope with and manage chronic pain, because current biopsychosocial approaches to pain fit well with their underlying health beliefs. The views on health outlined in models such as Te Whare Tapa Wha (Durie, 1985) or Te Wheke (R. T. Pere, 1997) bear some resemblance to the biopsychosocial approach that is so dominant in the field of chronic pain. However, the

biopsychosocial approach also adds another layer of personal responsibility, in which the patient is seen to have an active role in the management (or mismanagement) of their chronic pain (Kugelman, 1997). There is therefore potential for dual layers of victim-blaming in the treatment of Māori with chronic pain. In addition, culture is rarely considered within the biopsychosocial approach.

Do the underlying health beliefs of Māori influence their experience of chronic pain more generally? The qualitative research reviewed suggests that this may be the case (e.g., Penney et al., 2009), as does research on the use of the SF-36 with Māori, which contains a pain subscale (Scott, Sarfati, Tobias, & Haslett, 2000; Scott, Tobias, Sarfati, & Haslett, 1999). In the 1996/97 New Zealand Health Survey, Scott et al. (2000; 1999) found that New Zealand Europeans had higher self-rated health than Māori on all SF-36 subscales except vitality and bodily pain. However, Scott et al. (2000) have since contested the use of the SF-36 with Māori, due to differences in the factor structure in this ethnic group. Whereas young Māori (under age 45) show the same two-factor structure as New Zealand Europeans – namely the clear separation between mental and physical health – older Māori (over age 45) show only a single factor (Scott et al., 2000). This suggests that older Māori, who may have greater exposure to and endorsement of traditional Māori beliefs and values, may be more likely to see health as a single entity where the line between mind and body is blurred (Scott et al., 2000). Such beliefs may influence the experience of pain.

Some of the international research on ethnic disparities in the administration of pain medication suggests that the disparities are due to cultural differences in the expression of pain that are simply misunderstood (Shavers et al., 2010; Staton et al., 2007). Could this be the case with Māori in Aotearoa? There is no available evidence one way or the other. However, to say that differences in pain or pain experiences are ‘just cultural’ is inherently victim blaming, as it positions the individual as responsible for any miscommunication that may have occurred, and fails to consider wider social and structural issues that may be at work (Kerr et al., 2010; Nelson, 2006; Reid & Robson, 2007; Staton et al., 2007). Disparities between Māori and non-Māori have been normalised to the point where poor health is considered both a feature of, and a fault of, being Māori. This racist and deficit based thinking is the result of perpetuated colonialist values, such that Māori are marginalised and positioned as ‘other’ and Pākehā are the ‘norm’ against which they are compared (Reid & Robson, 2007).

It may even be the case that Māori are more likely to accept physical pain as just another one of the struggles that they experience as a marginalised ethnic group in Aotearoa.

According to Williams et al. (2003, p. 72):

“...decision making around disease is thought to be determined by the cultural group's expectations of what constitutes normal pain and illness during life. In other words, ethnic groups with consistently poor health status will accept pain and symptoms from disease as a normal part of life, rather than seek to have them treated.”

From a social justice perspective, a human rights perspective, and within the framework of Te Tiriti, such inequalities in experience are unacceptable and must be addressed (Commission on Social Determinants of Health, 2007; Reid & Robson, 2007).

Three of the major social and structural pathways that are known to work against Māori in Aotearoa/New Zealand are: “differential access to the determinants of health or exposures leading to differences in disease incidence”, “differential access to healthcare”, and “differences in the quality of care received” (Reid & Robson, 2007, p. 7). It is important to note, however, that ‘difference’ does not necessarily mean ‘inequality’. According to Meghani and Gallagher (2008), ‘disparity’ literally means difference and ‘inequality’ implies a sense of unfairness to do with that difference. However, Reid and Robson (2007) argue that ‘inequity’ is a more accurate term, as not even all inequalities are by their nature unfair. The differences in various aspects of pain found between Māori and other New Zealanders are not necessarily inequities; however, considering the context of health disparities in Aotearoa it is likely that at least some of them are.

Although it is important to look at the immediate causes of pain and painful health conditions, there must also be exploration of the “causes of the causes”, with a particular focus on the social determinants of health (Commission on Social Determinants of Health, 2007, p. iii). Brennan, Carr and Cousins (2007) argue that there has been a “global failure” (p. 207) to meet the challenge of adequate pain treatment. The Commission on Social Determinants of Health (2007) is championing a global movement towards the pursuit of health equity, arguing that, although technical medical advances are necessary for the improvement of health, they are by no means sufficient. Instead they advocate for empowerment at the material, psychosocial, and political level, pointing out that the effects

of disempowerment are most apparent in the poorer health status of indigenous populations (Commission on Social Determinants of Health, 2007).

The Commission should be viewed as a source of both information and inspiration in the pursuit of health equity in Aotearoa. In Aotearoa, New Zealand governments and the Ministry of Health have made similar commitments to reducing health inequalities, in documents such as He Korowai Oranga (the cloak of wellness) (King & Turia, 2002) and Reducing Inequalities in Health (Ministry of Health, 2002), although neither document makes specific mention of pain. Adding pain to the list of existing health inequalities between Māori and non-Māori should not reduce its significance as a health issue for Māori. There needs to be an examination of perpetuated colonialist values and the structural barriers that they create, particularly in terms of access to healthcare, of the treatment of Māori in pain, and how and why Māori may come to experience more pain and painful health conditions than other ethnicities in Aotearoa (Reid & Robson, 2007). Without an in-depth understanding of the lived experiences of Māori with chronic pain, the suggestions and queries above will remain mere speculation, and the task of addressing any inequalities that may exist cannot begin.

Exploring the lived experience of chronic pain

The lived experience of chronic pain has been explored in other populations in the past; this literature will now be reviewed in order to provide insight into the life-world of the chronic pain sufferer, and further highlighting the need to conduct such research with Māori. There are a growing number of qualitative research reports that explore the lived experiences of people with chronic pain. Note however, that 'people' in this case largely consists of white, middle class, middle aged people from the UK and USA. Much less research of this kind has been conducted with members of other ethnic groups and cultural minorities, other ages or other socioeconomic groups. Rather than discussing these reports at length on an individual basis, I will offer a sense of the themes that reoccur across many of them. Individual interviews or focus groups were the methods most commonly used, alongside a variety of analytical strategies, ranging from thematic analysis to grounded theory approaches.

People with chronic pain commonly experience a lack of understanding from the medical profession (J. Walker, Holloway, & Sofaer, 1999). Medical professionals were described as incompetent at understanding and treating chronic pain, and tended to operate from an

acute model of pain, with clear separation between physical and psychological influences (Dewar, White, Posade, & Dillon, 2003; Kugelmann, 1999). Accordingly, chronic pain patients were made to think that the pain was 'all in the head', and were not believed (Dewar et al., 2003; Jackson, 2005). The need for legitimacy often led to an extensive search for a label or diagnosis for chronic pain; some people even reported a sense of shock and sadness when tests continued to come back negative or labels could not be given (Toye & Barker, 2010; J. Walker et al., 1999).

Chronic pain is difficult to treat; people with chronic pain therefore tend to be seen as 'difficult' from the outset and there is a general dislike for them within the medical profession (Jackson, 2005). There also tends to be degrees of perceived entitlement (i.e., to treatment, to sympathy, to financial compensation), ranging from high sympathy for people who had tragic accidents (i.e., the pain is not their fault) to no sympathy for people who were perceived as malingerers (i.e., they are misrepresenting the extent of their pain) (Jackson, 2005). People with chronic pain often described their experience with treatments as ineffective and based on 'trial-and-error', side-effects from medication were common, and they felt the need for advocacy in the treatment process as they did not know about the resources and services that were available to them (Dewar et al., 2003).

Physical and mobility issues were also common experiences of people with chronic pain. Chronic pain infiltrates all areas of life, meaning a decrease in physical functioning and the ability to complete daily activities of living, and an increased reliance on others (Dewar et al., 2003; Miles et al., 2005). The activities that people engaged in often formed a significant part of their identity or sense of self; when chronic pain reduced the ability to engage in these activities there tended to be feelings of loss and grief for the pre-pain self (Hellstrom, 2001; Kugelmann, 1999; Lundberg, Styf, & Bullington, 2007). Identity was described as becoming one of a person in pain, and others (including medical professionals and peers) began to define them in this way also (Bullington, 2009; Hellstrom, 2001).

Unsurprisingly, emotional and psychological difficulties (including anxiety, depression, and anger) and difficulties with memory and concentration were common (Dewar et al., 2003; J. Walker, Sofaer, & Holloway, 2006). Accompanying these issues were fears of becoming, or being perceived as, mentally ill (Jackson, 2005). Although the influence of psychological factors on chronic pain was acknowledged by many, this was also seen as a threat to the legitimacy of their chronic pain, and therefore downplayed (Toye & Barker,

2010). Chronic pain reduced tolerance, patience and energy, to the point where some people with chronic pain felt like they had a mean, nasty side to their personality, which had not been there before (J. A. Smith & Osborn, 2007). This resulted in feelings of shame and self denigration, and considerable effort was required to keep up a happy facade in social situations (J. A. Smith & Osborn, 2007). Staying positive and motivated in the face of chronic pain was seen as the socially acceptable response, and victim-blaming was experienced when the person with chronic pain could no longer do so (Kugelmann, 1999).

Social issues relate to the overall impact that chronic pain has on the life of the person affected. The pain often resulted in huge changes in lifestyle, such as going out less, working less, and socialising less, which are accompanied by a decrease in quality of life (Dewar et al., 2003; Miles et al., 2005). Lifestyle changes affected relationships, and so too did stigma. Chronic pain was invisible, therefore friends and family found it hard to accept changes when they could not 'see' anything wrong with their loved one (Dewar et al., 2003; Kugelmann, 1999). The experience of chronic pain can be very isolating in this respect, as it is difficult to communicate to others who have not experienced chronic pain (Hellstrom, 2001).

Financial issues can also be experienced as a result of chronic pain. Numerous visits to doctors and health professionals for assessments, tests, and treatments were a financial burden, particularly if the person chose to seek complementary or alternative treatments that were not funded by the public health system or health insurance (Dewar et al., 2003). In addition, there tended to be a loss of income from reduced work hours, or complete cessation of work (Dewar et al., 2003). Accompanying this were related stresses and stigma, such as loss of social position, downward social mobility, or having to move to a smaller house or more deprived neighbourhood (J. Walker et al., 2006). Another form of stigma associated with chronic pain is the accusation of secondary gain, wherein medical professionals, health insurers, and even family members, suspect that the person is 'putting it on' or prolonging their chronic pain in order to receive financial or other compensation (Jackson, 2005; J. Walker et al., 1999).

The research outlined above further highlights the complexity and significance of chronic pain as a health issue, and the sorts of lived experiences that are common in those who have chronic pain. Far less research of this kind has been conducted with members of other ethnic groups or cultural minorities; what little there is will now be described.

Ethnic and cultural influences on the lived experience of chronic pain

There have been a small number of qualitative interview studies conducted with members of ethnic or cultural minorities about their experiences of chronic pain, or pain more generally. Most have been conducted from an ethnographic or grounded theory approach. In some instances healthcare professionals who work treating members of ethnic or cultural minorities with chronic pain have also been interviewed. These studies will briefly be described in turn, as their experiences often reflect cultural perspectives that would be difficult to try to describe more generally. The first few studies described represent the experiences of aboriginal peoples (Australian Aboriginals and First Nations people from the USA and Canada), who like Māori in Aotearoa, have experienced marginalisation within their native country.

A qualitative interview study on the post-operative pain experiences of Aboriginal women and their non-Aboriginal nurses in central Australia was conducted by Fenwick and Stevens (2004), who found cross-cultural difficulties with pain interpretation. There was cultural stigma reported around pain for the Aboriginal women, who tended to be silent about it, giving no verbal or non-verbal cues to the nurses. This may be because the nurses were viewed in the same manner as traditional Aboriginal healers; that is, that they would be able to 'see' or 'know' that the patient was in pain, making it unnecessary for the patient to express it. If the nurses made any suggestions about the pain level of the patient, the patient would simply agree, as to disagree with someone who 'knows' would be shameful and disrespectful. In addition a numerical pain rating scale from zero to 10 was used by the nurses, despite this particular group of Aboriginal people having no numbers above five in their dialect. Fenwick and Stevens (2004) concluded that the nurses had a knowledge deficit in terms of treating post-operative pain in Aboriginal women, and did not have the skills to interpret or manage their pain.

In interviews with First Nations women from a reserve community in Canada, Browne and Fiske (2001) found that their experiences of the dominant healthcare system had often involved a feeling of being dismissed or not taken seriously. This led to some of the women expressing reluctance seek help, but rather tolerating pain until their condition was severe, for fear that they would be dismissed yet again. Because of this, a stereotype had developed that First Nations people respond to health matters passively, which contributed to a sense of powerlessness.

In another study, rural dwelling American Indians⁹ were interviewed about their experiences of cancer pain, which is an often under-treated symptom (Haozous, Knobf, & Brant, 2011). The physical limitations of the pain were isolating in the rural setting, as the participants did not want to draw attention or shame to themselves or their families, and avoided being seen when the pain was disabling. Stoicism was highly valued, which meant that at times when they were unable to mask the symptoms of their pain, they withdrew from their community. In order to keep their sense of pride they told very few people about their pain, preferring privacy, although this was juxtaposed by the desire to make connections and remain a member of the community. There was also a distrust of outsiders (e.g., treatment providers) and sometimes an initial denial of even experiencing pain.

Similar themes were present in interviews with American Indians about the chronic joint pain experienced with arthritis (Kramer, Harker, & Wong, 2002). Pain complaints tended to be minimised; the participants did not readily ask for help or disclose the full extent of their pain. Fewer attempts to cope with or treat the pain were made as it became more chronic, with many choosing not to think about the pain, or to distract themselves from it. Over-the-counter pain relief was sought, as was advice from traditional healers, as well as mainstream medical care. However, pain relief options were often not used to their full capacity, or were discontinued due to side effects without further medical consultation.

Other research of this kind has focused on members of ethnic or cultural groups who have also been marginalised, either because of their minority status within a country, and/or because they have immigrated to the country. For example, Dickson and Kim (2003) interviewed older Korean women with osteoarthritis who had immigrated to the USA, but had limited integration into the dominant culture. Most of them had sought Western medical care for their symptoms of osteoarthritis, but found that language was a barrier to communication, and they often relied on family and friends to translate. As the illness progressed, these women increasingly felt that they were a burden to their family, and began using traditional or folk medicine such as acupuncture. This gave them a better sense of control and improved their self-esteem and they often ceased to complain to others about their pain. Many of these older women had gone through a process of reframing the meaning of their osteoarthritis pain as a part of ageing, which is revered in Korean culture.

⁹ Note that 'American Indians' is the term provided by the authors of this research; it is considered a contested and obsolete term, with 'First Nations' the preferred alternative

Katz et al. (2011) conducted focus groups with both Hispanics and Non-Hispanic-Whites who had either chronic back or knee pain, about their medical decision making processes. Hispanics were more likely than Non-Hispanic-Whites to express fear of seeking treatment for pain in case of negative outcomes. This was often influenced by the negative past experiences of friends or family members. Katz et al. (2011) also found that Hispanics were more likely to talk about the coping strategies that they use for their pain, such as the use of faith and religion, support from family and friends, and a positive attitude. Across both ethnic groups there was a reliance on medical professionals to make decisions regarding the treatment of their pain.

The cultural meanings of pain have also been explored in Black Caribbean and White British patients with cancer (Koffman, Morgan, Edmonds, Speck, & Higginson, 2008). The Black Caribbean patients were more likely to see pain as a test of their faith or a form of punishment, perhaps because of their strong religious ties and belief in God. Black Caribbean patients were also more likely to describe the pain from their cancer as unremitting and distressing despite the use of pain relief medication. There was no evidence for a disparity in pain treatment between these two ethnic groups, and in both the side effects from pain medication were very important and could sway the decision to discontinue taking them.

Rogers and Allison (2004) interviewed South Asian (i.e., Indian, Pakistani, and Bangladeshi) and African/Caribbean adults with musculoskeletal pain in the UK. Causes of widespread pain (e.g., fibromyalgia) and back pain tended to be seen as wear and tear due to hard physical work, with cold weather often mentioned in the context of working conditions. Whilst African/Caribbean respondents tended to refer to their pain in physical terms (e.g., joints), South Asian respondents tended to have a sense of a weakened or fragile body, leading to radiating pain throughout the body and restriction of movement. The South Asian respondents were more likely to cope with pain by taking time off work, praying or taking pain killers, whereas the African-Caribbean respondents were more likely to just think about something else. Pain was seen as something to bear by the African/Caribbean respondents and they tried not to burden others with their distress. In contrast the South Asians were more likely to have family involved because of the pain, having them help and share their roles. Older respondents from both groups were more likely to use home remedies or those that are traditional to their country of origin.

Health practitioners (both White British and South Asian) in the UK who have treated South Asian people with chronic pain have also been interviewed about their experiences (Patel, Peacock, McKinley, Carter, & Watson, 2008). South Asians were perceived as more likely to consult their GP about chronic pain, often repeating the same symptoms either with the same or different practitioners, in the hopes of receiving a different form of treatment. There was some suggestion that South Asians with chronic pain may be somatising (i.e., expressing psychological symptoms as physical) due to a lack of acceptance of psychological difficulties in their culture, although care was still taken not to make assumptions and overlook serious physiological diagnoses. Treating patients with chronic pain was seen as frustrating, often because of low adherence to medication and non-disclosure of additional or alternative treatments. These frustrations made GPs question their own skills and value; having cultural differences or language barriers just tended to compound frustration.

In summary, some of the broader themes that reoccurred throughout these studies were the different meanings that pain had to different groups, and the cause that pain was attributed to, the effect it had on social roles and responsibilities, concerns about pain medication, and difficulties with communication. This research highlights the value of exploring the lived experience of chronic pain in ethnic or cultural minorities, whose experiences may be coloured by layers of socio-cultural complexity.

Aim and Research Questions

The aim of the research was to conduct an in-depth exploration of the lived experiences of Māori who are currently experiencing chronic pain or a painful chronic health condition, based on the following broad research question:

“How do Māori talk about their lived experiences of chronic pain?”

More specific research questions drew on the following aspects of their experiences:

What was life like before the onset of pain?

How did it all begin?

What has changed?

What were your experiences when seeking treatment?

What do you do to manage your pain?

How involved are your whānau and friends in these experiences?

Do you feel that being Māori has influenced your experience of pain?

The answers to these research questions will aid conceptual and theoretical developments in the field of chronic pain in Aotearoa, as well as being invaluable in determining the next step in what is currently an underdeveloped and under-researched aspect of Māori health. It is hoped that this research will also be used to improve the practice of health professionals who are working with Māori who have chronic pain.

Chapter 5: Methodology and Research Methods

There is a need for research that is conducted from a Māori perspective; therefore a Kaupapa Māori approach has been used. In addition, to capture the depth and breadth of the lived experiences of Māori with chronic pain, the most appropriate methodology is one that is qualitative in nature and focuses on understanding individual experiences: IPA is arguably most appropriate. These methodological approaches will be described next, followed by the research methods.

Kaupapa Māori research

Kaupapa Māori research is research conduct by Māori, for the benefit of Māori, and with Māori (L. T. Smith, 1999). The approach began in response to years of research being conducted ‘on’ Māori, which was mostly based on dominant western, colonialist values (Bishop, 1998; G. H. Smith, 1997; L. T. Smith, 1996). The majority of this research was used to position Māori as inferior to their colonisers, positioned the (largely) non-Māori researcher as ‘expert’, focused on Māori as deficit, and misrepresented and misunderstood the Māori world-view (Bishop, 1998; G. H. Smith, 1997; L. T. Smith, 1996). By using a Kaupapa Māori approach, Māori worldviews, and Māori ways of being and doing, are legitimised (Moewaka Barnes, 2000). In other words, “Kaupapa Maori Research naturalises Maori epistemologies, methodologies and practices so that Maori are not articulated as the ‘other’” (Kerr et al., 2010, p. 2).

The work of Linda Smith (L. T. Smith, 1996; L. T. Smith, 1999), Graeme Smith (G. H. Smith, 1997) and Leonie Pihama (Pihama, 1993; Pihama, Cram, & Walker, 2002a, 2002b) has been integral in drawing the attention of the academy to Kaupapa Māori as both theory and practice (G. H. Smith, 1997). Although the struggle for recognition, legitimisation and validation of the place of Māori as tangata whenua (indigenous people of the land) in Aotearoa is not new (Pihama, 1993; Pihama et al., 2002a, 2002b), Kaupapa Māori became particularly prominent in the education sector in the 1980s, when the Kōhanga Reo (‘language nest’; Māori language preschool) and Kura Kaupapa Māori (school operating under Māori custom and using Māori language) movements began (G. H. Smith, 1997; L. T. Smith, 1996).

Kaupapa Māori is generally defined as an approach, philosophy, agenda or rationale, rather than a method, and as such there is no one right way to ‘do’ Kaupapa Māori research

(Pihama, 1993; Powick, 2003; G. H. Smith, 1997; L. T. Smith, 1996). There are, however, a number of principles and features that tend to be incorporated into this approach.

Kaupapa Māori research exercises Māori rights to tino rangitiratanga. Tino rangitiratanga is one of the principles of Te Tiriti, which has been loosely translated as self-determination (Bishop, 1998). Power, control, and ownership of the research rests solely with Māori (Bishop, 1998; Moewaka Barnes, 2000). In this manner Kaupapa Māori is closely aligned to critical theory in its examination of existing power relations, social structures and inequalities (Pihama, 1993). By giving Māori power and control over their cultural property and the knowledge that they produce, it can be actively protected for future generations.

Kaupapa Māori research involves a mutual relationship between the researcher and the researched. The relationship is open and reciprocal, the researcher offers full disclosure, and is not afforded status or hierarchy by nature of their position as the researcher (Bishop, 1998; Powick, 2003). Kanohi ki te kanohi (face to face) contact is sometimes cited as the preferred form of research contact, so that the researcher – who they are and what they stand for – is visible to the participants (Powick, 2003). However, the issue of methodology is secondary to that of ensuring all is tika (right/appropriate) with the research in terms of the kaupapa, as long it is appropriate for the purpose and intended use of the research (Moewaka Barnes, 2000, 2009; L. T. Smith, 1996). A continual process of negotiation and consultation takes place so that the research meets the needs and agendas of all Māori who are actively involved. This ensures that one of the major aims of Kaupapa Māori research is met; namely, that it will act to benefit the participants in some way (S. Edwards, McManus, & McCreanor, 2005). Kaupapa Māori research is also collectivist rather than individualistic, and therefore aims to benefit Māori as a people, rather than the individual needs of a select few.

Closely related to the collectivist principle is the concept of whānau or family, a critical component of Māori culture that permeates all areas of life (Mahuika, 2008). Hierarchy within and between whānau that are taking part in the research should be considered, as well as the researcher's own position within their whānau, and the 'extended whānau' that the research team can become (Mahuika, 2008). Therefore, an important process in Kaupapa Māori research is whakawhanaungatanga, which has been defined as "...establishing relationships in a Maori manner" (Bishop & Glynn, 1999, p. 169). In a

practical sense, this may involve a process of introductions before the research is to begin, in which the researcher greets and acknowledges their participants in a semi-formal manner, and works at establishing a connection with them (S. Edwards et al., 2005). Knowledge of whakapapa is therefore key in this situation (Mahuika, 2008). This process is often described as tapu (sacred/restricted), with the sharing of kai (food) traditionally used to lift the tapu from the research space and shift it into noa (neutral/unrestricted/free from tapu) (S. Edwards et al., 2005). Karakia may also be used in this process (S. Edwards et al., 2005).

Maintaining relationships is also important. In many cases of Kaupapa Māori research the participants are invited to remain actively involved throughout the research process, including the analysis and dissemination of results (Powick, 2003). This could include a process of conducting hui to discuss the results, including participants in the dissemination process, or ensuring that consultation has taken place in terms of when and how the results should be disseminated. Again, this process depends on the methodology being used and the overall purpose of the research, and may be limited by feasibility and cost particularly in large-scale quantitative research (Moewaka Barnes, 2000, 2009). Reciprocity is also acknowledged, whereby the researcher may be called upon in the future to engage with or support the participants or their whānau, hapū (sub-tribe), or iwi (Powick, 2003). Depending on the circumstances, guidance from a kaumātua is often desirable, as their knowledge of whakapapa, tikanga (customs) and kawa (protocol), as well as of the needs of their people, is unsurpassed (Bishop, 1998; Powick, 2003).

The use of Te Reo Māori is also seen as a key aspect of Kaupapa Māori research. Not only as a way of protecting and encouraging the use of Te Reo, but also under the understanding that there are certain ways of thinking or describing within Māori culture that are not easily translatable to English (Mahuika, 2008; Powick, 2003). As 42 per cent of Māori can speak Te Reo to some extent, this is an important consideration (Te Puni Kokiri, 2007). However, Mahuika (2008, p. 8) also points out that this argument “...raises issues of authenticity and challenges the identity claims and authority of those Māori who are unable to speak the language.” Essentially, the question is raised as to who is “Māori enough” (p. 8) to conduct Kaupapa Māori research, a question which can act to marginalise and disempower Māori from within their own culture (Mahuika, 2008).

The process of establishing validity/authority/truth within Kaupapa Māori research occurs within the cultural processes of the research whānau, where reality is an evolving and negotiated interaction between the researched and the researcher (Bishop, 1998). Validation is a process of acknowledging what is acceptable and what is not, in accordance with Māori tikanga, kawa, and overarching cultural values (Powick, 2003). According to Mahuika (2008, p. 4):

Unlike the dominant Western paradigms, kaupapa Māori does not make claims to universal truth or to superiority over other existing paradigms. Arguably the ultimate goal of kaupapa Māori research, like much of the scholarship from indigenous and minority peoples, is to challenge and disrupt the commonly accepted forms of research in order to privilege our own unique approaches and perspectives, our own ways of knowing and being.

Common criticisms levelled at the Kaupapa Māori approach include the argument that Māori are not a homogenous group – there is variation between iwi, hapū and individual whānau, and Kaupapa Māori research should not be seen as a unified, ‘one size fits all’ approach (Mahuika, 2008). Similarly, it has been argued that Kaupapa Māori has developed out of institutionalised research settings, meaning that some Māori in the community have little or no knowledge of what it is and what it means for them (Mane, 2009). However, Kaupapa Māori is in fact an ancient concept that has different meanings to different people, and has been applied in a myriad of ways that are not necessarily related to institutions or to research, including education, health, social services, justice, employment and training, and the housing sector (Pihama et al., 2002a). Despite these criticisms, Kaupapa Māori research continues to expand as a theory and as a philosophy: “Māori are striving to articulate their own reality and experience, their own personal truth as an alternative to the homogenization and silence that is required of them within mainstream New Zealand society” (Mahuika, 2008, p. 4).

Ko wai ahau? Who am I?

Given this context, reflecting on my identity as a Kaupapa Māori researcher is important, as transparency and disclosure on the part of the researcher contributes to a fuller picture of the process of research and analysis.

I am a 25 year old female of mixed Pākehā and Māori ancestry. I have brown hair, blue eyes, and fair skin, and you would be forgiven for not knowing, or understanding, that I

identify as Māori. I grew up in a Pākehā world with many of the privileges of being white (for further discussion of white privilege, see McIntosh, 1990; Robertson, 2004). Yet I was always told of my Māori whakapapa and held on to this knowledge with a sense of pride. It has only been as a young adult that I have had the chance to explore this side of my identity further, largely because the location of my undergraduate psychology studies at the University of Otago drew me physically closer to Wairewa (on the Banks Peninsula, Christchurch), the marae (communal meeting place) that I whakapapa to. This exploration also came about because of whakawhanaungatanga – the people who I met and established connections with – and the subsequent opportunities that this gave me to engage with this side of my identity.

This process of identity development coincided with a snowboarding accident that I had almost five years ago, in which I fractured one of my thoracic vertebrae, an injury that has left me with chronic pain. My interest in chronic pain largely stems from my own experiences, and I had always planned to focus on chronic pain for my Masters thesis. That decision was easy. My decision to focus on Māori experiences and to use a Kaupapa Māori approach was less so. It seemed daunting and I was plagued with feelings of self-doubt: am I “Māori enough” (Mahuika, 2008, p. 8) to undertake Kaupapa Māori research? I have a basic understanding of Māori tikanga, kawa and Te Reo Māori. I am by no means competent or fluent in any of these respects, and I do not claim to be. I do not hold any special position in the hierarchy of my whānau, marae, hapū, or iwi. My knowledge of whakapapa includes mine and that of my immediate whānau, but I can increasingly recognise the geographical locations and iwi that are spoken about in mihimihi (greetings) and pepeha (set verses that describe whakapapa links).

Beyond all of this, I have confidence and enthusiasm, and support from those more knowledgeable than me. The opportunity to incorporate two significant aspects of my personal development – chronic pain, and Māori identity – into my Masters research is too good to shy away from. I feel as though I have a level of insight and empathy for the experiences of my participants that allows for an in-depth understanding of the data that was produced, which an ‘outsider’ to the world of chronic pain, and to the world of Māori, would not have. Engaging in this reflexivity was an important step in the research process and has proven invaluable to me.

Interpretative Phenomenological Analysis

IPA was the methodology chosen for this research, as devised by Jonathan Smith (Eatough & Smith, 2008; J. A. Smith & Eatough, 2007; J. A. Smith & Osborn, 2003). The theories underlying IPA and its philosophical origins will be outlined, before clarifying my approach to IPA, the rationale for its use and applicability in the present research, and how it has been adapted for use with Māori who have chronic pain.

Theoretical background to IPA

IPA is philosophically and theoretically underpinned by phenomenology, which is essentially the study of human experience. As Eatough and Smith (2008, p. 180) describe:

Phenomenology is concerned with the way things appear to us in experience; the reality that we live is an experiential one and it is experienced through practical engagements with things and others in the world, and it is inherently meaningful.

Phenomenology began with the philosophical work of Husserl and has since had a range of proponents including Merleau-Ponty, Heidegger, and Sartre, who although have differing perspectives, all focus on humans and their relationship with the world (Giorgi, 2005). A phenomenologist sees consciousness as the mediator between humans (subject) and the world (object), a relationship that Husserl named 'intentionality' (Giorgi, 2005). Subject and object cannot be separated from our experiences of them, and the meaning-making that is an inherent part of that experience (Willig, 2001).

Originally, phenomenology was concerned with exploring the lived experiences of a phenomenon in order to get to the 'essence' of what it is (Creswell, 2007). In order to do this the researcher had to set aside their own experiences and views by placing them within parentheses, a process also called 'epoch' or bracketing, thus gaining a fresh perspective on the phenomenon of interest (Creswell, 2007). The catch-cry from Husserl was to return 'to the things themselves' (Eatough & Smith, 2008). This was traditionally an introspective exercise, in which the participant put aside their dominant understandings of a phenomenon and instead revisited the experience itself, with the hope of reaching a new and deeper understanding of it (Crotty, 1998).

This introspective practice lost favour, however, when psychologists began adopting principles of phenomenology (Crotty, 1998). Prior to this, psychological research had been limited to applying positivist, empiricist principles to human sciences (Giorgi, 2005). A

subgroup of psychologists realised that in order to understand human beings, it was necessary to study their experiences (Eatough & Smith, 2008). Qualitative, interpretative methods are most appropriate when examining the experience of a phenomenon of interest, because as Giorgi points out, “...experiential dimensions of phenomena do not have a quantitative structure that will support quantitative methods” (2005, p. 80). This is where the natural sciences and the human sciences differ – it is not possible to make the subjective meanings of someone’s experience objective – but this is essentially what psychology is tasked with (Giorgi, 2005). IPA was developed specifically in the field of psychology to meet this need for a method of analysis focused on the subjective meanings of experience.

In IPA, it is acknowledged that direct access to the experiences of others is not possible, which means there must always be some form of interpretation involved (Eatough & Smith, 2008; J. A. Smith & Eatough, 2007; J. A. Smith & Osborn, 2003). IPA has therefore been criticised for not being truly phenomenological; however, Smith argues that this was never his intention (Eatough & Smith, 2008). Although IPA borrows much from phenomenology, it does not try to discover the essence of a phenomenon in the broader sense, but rather to capture the lived experience of individuals (Eatough & Smith, 2008).

As well as the connection with phenomenology, IPA also has theoretical connections with hermeneutics and idiography (J. A. Smith & Eatough, 2007). It is hermeneutic in the sense that it involves interpretation or sense-making. The IPA process has been labelled the ‘double hermeneutic’: “The participant is trying to make sense of his/her world and the researcher is trying to make sense of how the participant is trying to make sense of his/her world” (J. A. Smith & Eatough, 2007, p. 36). It is idiographic in the sense that statements are made about the individual before moving to the group of participants as a whole (J. A. Smith & Eatough, 2007).

Clarification of the IPA approach and its appropriateness for the present research

IPA is becoming increasingly common in the field of health psychology as a way of understanding the lived experiences of various states of well-being or illness. It is considered to be appropriate when exploring a topic that is both complex and novel (J. A. Smith & Osborn, 2003), as is the case with the present research with Māori who have chronic pain.

Pain is fundamentally a subjective experience, and this is also the direct concern of IPA. Often people with chronic pain feel disbelieved – they (and others) question whether the pain is ‘real’ or ‘all in the head’. In phenomenology, reality is equated with the meaning of experience, and the researcher is asked to “...suspend all judgments about what is real” (Creswell, 2007, p. 58). The participants’ experiences of chronic pain are therefore positioned as valid, which may have positive implications for well-being. As Smith and Eatough state, IPA “...orients to an individual’s personal perception or account of an object or event as opposed to attempting to produce an objective statement of the object or event itself” (2007, p. 36).

In IPA it is assumed that “...the words participants employ when talking about a phenomenon can tell you something about the phenomenon itself” (Osborn & Smith, 2006, p. 218). Whilst the language used by participants constructs a particular version of their experiences, this is not in relation to any kind of external, objective reality – the focus on experience implies a relativist ontological position (Willig, 2001). Unlike social constructionist methodologies, IPA does not claim that language constructs reality, but rather that it adds meaning to experience (Willig, 2001). In IPA it is also acknowledged that language can ‘do’; it is action-orientated and by telling stories of our experiences we are making our lives, re-interpreting them, and even positioning ourselves in specific ways (Eatough & Smith, 2008).

The experience of chronic pain constantly draws the sufferer’s attention to their painful body (Bullington, 2009). It is therefore appropriate that IPA incorporates the concept of embodiment, defined as “the experience of both *being* and *having* a body” (Lyons & Chamberlain, 2006, p. 27, original emphasis). The phenomenologists Heidegger and Merleau-Ponty both refer to humans as living through the body or of ‘being-in-the-world’ (Eatough & Smith, 2008). The body is intrinsically bound in the relationship between subject and object, as it is the vehicle of consciousness, allowing for subjectivity or openness to the world (Giorgi, 2005). We live and experience the world through our bodies (Eatough & Smith, 2008). Psychology as a discipline has often been accused of ignoring the body, but IPA, by drawing attention to experience, draws attention to the body (Eatough & Smith, 2008).

Another aspect of phenomenology that is evident when using IPA is the importance of time. Merleau-Ponty refers to the influence of time on the life-world of a subject as ‘lived

temporality'; time is inextricably linked to the relationship between subject and object, and the subject's phenomenological experience (Hellstrom & Carlsson, 1996). Particularly with chronic pain, there can be a strong sense of change, and a comparison of life 'before pain' to life 'after pain' (Hellstrom & Carlsson, 1996). There can also be a sense of being trapped in the present by pain, and finding the future difficult to conceive (Bullington, 2009; Hellstrom & Carlsson, 1996). When experiences are described, time contributes to the sense that a narrative or story is being shared.

In IPA it is acknowledged that we are socially and historically bound – our understanding of the world is mediated by our existing knowledge and experiences of it (Eatough & Smith, 2008). Originally, a phenomenologist viewed culture with suspicion, as it was seen to impose some meanings on experience at the exclusion of others (Crotty, 1998). At the same time, it was acknowledged that as soon as experiences are thought about or described, language and culture are used (Crotty, 1998). This does not mean that we have to accept dominant cultural understandings; on the contrary, with IPA it is possible to take a more critical perspective (Crotty, 1998). Analysis moves from understanding the perspective and experiences of the participants, to a more critical interpretation in which the participants' perspective can be questioned, as the data is further theorised and a deeper understanding is reached (J. A. Smith & Eatough, 2007; J. A. Smith & Osborn, 2003). Both the views of the researcher, and the interaction between the researcher and participant, are therefore influential. This is why reflexivity on the part of the researcher is important, and was incorporated throughout the analysis process in the present research.

Adapting IPA to fit with the Kaupapa Māori approach

In using a methodology like IPA, it was important that the Kaupapa Māori approach was not lost in favour of methodological rigour. There are several aspects of IPA which make it particularly appropriate for Kaupapa Māori research, which will now be discussed, along with a description of how the principles of IPA were applied flexibly and adapted to ensure that they were appropriate for Māori who have chronic pain.

Phenomenological approaches have been argued to be particularly appropriate for use with populations that have a strong focus on oral history and transfer of knowledge (Struthers & Peden-McAlpine, 2005). In the past, Māori did not have a written form of knowledge transmission (as we know it today), but used a range of non-written forms of communication, which continue to be used (Lambert, 2009). These include the use of

visual forms of communication such as whakairo (carvings), pou (carved pillars or posts), and tukutuku (ornamental lattice-work), as well as the use of oral forms of communication such as whaikōrero (formal speeches) mōteatea (chants), whakataukī (proverbs), waiata (songs), pūrākau (myths) and pakiwaitara (legends). IPA can be seen as a way in which Māori can tell their story of chronic pain in one of the formats that is culturally valued, and has the potential to capture cultural understandings within descriptions of their experiences.

The idiographic nature of IPA was also felt to be appropriate for use with Māori, as each participant's story of chronic pain is respected and valued, rather than being ignored in favour of wider themes. The stories that the participants share can contain sensitive information that may be difficult for them to talk about, and may not have been shared before. By examining each participant as an individual the importance and 'wholeness' of their story is maintained, before any integration or wider interpretation takes place. In this sense, IPA takes a holistic view of the participant. The decision was therefore made to write a summary narrative for each participant as a first step in the analytical process. This was returned to the participant to ensure that the researcher had clearly represented their experiences.

IPA is therefore an appropriate methodology for this research, not only because the focus is on capturing complex experiences of chronic pain, but also because the mana of the Māori participants, and of their stories, can be upheld.

Research Methods

Ethics

Ethical approval for this research was granted by the Massey University Human Ethics Committee: Northern (file number MUHECN 11/034; see Appendix A). Ethical issues are not discussed separately here, but are incorporated and addressed throughout the methods sections, as well as in the description of the Kaupapa Māori approach.

Participants

Participants were seven adult Māori (five females, two males) who self-identified as having chronic pain. This self-identification process allowed for the participants' subjective understanding of their pain experience to guide their decision to take part, and did not rely on any formal diagnosis, which may or may not have occurred. Due to the qualitative, exploratory nature of the research the sample of seven allowed for sufficient time to be spent on detailed idiographic readings of the data, as well as a search for more generic themes. Table 1 contains a basic description of the participants' characteristics, including their pseudonym, gender, age, type and cause of pain, duration, average pain rating, and additional health issues (a mixture of both formally diagnosed and self-reported health issues recorded in the demographic questionnaire or reported in the interview).

As can be seen in Table 1, the participant characteristics fit with the purposive sampling methods of IPA; being Māori and having chronic pain were unifying factors. However, there was diversity in terms of age, gender, and cause, duration and intensity of chronic pain. In addition, Māori are not a homogenous ethnic group. Some of the participants specified their iwi affiliations and other ethnicities that they identify with however they have not been listed in the table in order to preserve anonymity. These included (in their own words): Ngāti Ngāpuhi, Kai Tahu, Kati Mamoe, Ngāti Kahungunu, Tūwharetoa, Ngāti Tainui, Te Aupōuri, Waitaha, Ngā Rauru, 'white as Māori', Scottish, Shetland Islands Welsh, French, Scandinavian Viking (Normandy/Danish), English and Jamaican. Four of the participants were from the Wellington region, two were from the Auckland region, and one was from the Hawke's Bay region. The participants had a range of skills in Te Reo Māori, and all used at least one Māori word during their interview.

Table 1: Participant Gender, Age, Type of Pain, Duration, Average Pain Rating, and Additional Health Issues

Pseudonym	Gender	Age	Type of pain	Duration (years)	Average pain rating (0-10)		Additional health issues
Hoani	Male	52	Back pain	25	Today:	0	Depression, brain injury, hearing loss
					At its worst:	9	
					On average:	2	
Kate	Female	26	Intestinal/ digestive pain from medical condition	5+	Today:	8	Celiac, inflammatory bowel condition
					At its worst:	8	GERD, anxiety, anaemia, low blood pressure
					On average:	5-6	
Jake	Male	37	Back pain	20	Today:	5	Liver disease, depression, post traumatic stress, head injury, ADHD (undiagnosed)
					At its worst:	8	
					On average:	6	
Teresa	Female	47	Migraine and associated neck/shoulder pain	5	Today:	2	Depression and anxiety
					At its worst:	8.5-9	
					On average:	4-5	
Delia	Female	39	Pain from kidney disease/ dialysis	22	Today:	2	Associated health issues incl. fatigue, general aches and pains, and episodes of shingles
					At its worst:	10	
					On average:	3	
Sarah	Female	45	Back pain	3	Today:	6	Lung disease, liver damage associated with extensive pain medication
					At its worst:	10	
					On average:	7-8	
Makareta	Female	37	Widespread pain originating in the back, plus migraines	11	Today:	7	Hay-fever, depression, anxiety disorder, chronic fatigue syndrome, tinnitus and schizophrenia
					At its worst:	8.5	
					On average:	6	

The participants were recruited via Māori networks that are available to myself and my supervisors (Dr Helen Moewaka Barnes and Dr Antonia Lyons), including connections at Whariki Research Group, Massey University, and personal connections to Kai Tahu iwi. More specifically, I drafted an email based on the information sheet that was sent out to potential participants by my supervisors and I, with those who were interested in taking part asked to contact me directly. This method of recruitment relates to the Kaupapa Māori principle of whakawhanaungatanga, as existing connections were used, and new connections were made. Five participants were recruited in this manner, two of whom were known to me previously, but who I did not know were experiencing chronic pain. The recruitment protocol was expanded further to include the use of a number of emailing/network lists available to people I had made contact with about the research, and the use of a one page advertisement that was circulated via these lists and placed on local community notice-boards (see Appendix B). Revised ethical approval was granted for these additions. Two participants were recruited in this manner.

Four of the potential participants first made contact via email, one via text message, and two via a phone call. A variety of emails, phone calls, face-to-face discussions, and text messages then took place in order to arrange the interview, and in the period leading up to it. During these exchanges I checked that the potential participants were eligible to take part, ensured that they understood what participation would entail, and had read the information sheet. I also did my best to begin the process of whakawhanaungatanga with the participants, by making connections and being interested, engaged and friendly, so that the participants began to feel comfortable with me before the interview took place. Interviews were generally scheduled at the participant's earliest convenience.

Materials

The participants were given an information sheet (see Appendix C) to read along with a consent form (see Appendix D), and a brief questionnaire asking for their age, sex, any other ethnic or cultural origins (i.e., other than Māori; this allows for bicultural or multicultural identities to be acknowledged), length of time with chronic pain, average pain rating on a numerical rating scale, and a checklist of any other co-morbid health conditions (see Appendix E). They were allocated an anonymous study code number that was used to identify their questionnaire and audio files, and were later allocated pseudonyms to identify quotations included in the results. Interview responses were audio-recorded using

an Olympus WS-450S digital note-taker on conference setting so that it could be placed a short distance from the participant. The resulting audio files were downloaded onto a password protected university computer and stored as digital Windows Media Audio sound files, again identified using the participant's anonymous study code number. Headphones were used in the transcription process, which was carried out using playback on the Express Scribe software programme.

Interview processes

Interviews were conducted at a location that was mutually decided upon. The first option offered, if it was feasible for the participant to travel there, was a room on the researcher's university campus. Alternatively, any other location that was convenient for the participant was offered, in which case I transported myself to that location. The environment was always one that both the participant and I felt comfortable and safe in. Although I tried to arrange quiet, private and distraction-free locations, at the request of the participants, two were held in relatively noisy dining spaces. Three participants were interviewed at home, two at their workplace (one in an office, the other in the staff dining area), one in an interview room at the university campus, and one in a public restaurant. Therefore the interviews all took place *kanohi ki te kanohi*.

When the participant and I met, I greeted them and began by continuing the process of *whakawhanaungatanga*, chatting to them semi-formally so that they felt at-ease. Where appropriate, I related aspects of my *whakapapa* to them, where I am from, and briefly explained my personal story with chronic pain and why I was interested in theirs. Openness and disclosure on my part was an attempt to ensure that I was not afforded any hierarchy, and contributed to the sense of collective responsibility for the research. The participant and I usually shared refreshments during this process, which sometimes carried on through the interview, or took place after the interview. Sometimes this was just a coffee or tea, other times biscuits or cakes were shared, and on one occasion we had burgers! On this latter occasion I was asked to bless the food with a *karakia*.

Once the participant was ready to begin, I asked them to complete a consent form. I checked that the participant had understood the consent form and its contents, and responded to any questions. The participant then completed the brief demographic questionnaire.

I then reiterated a number of points from the information sheet and consent form. First that, although the interview was to be conducted in English, the participant was welcome to describe things in Te Reo Māori at any point, and that if I needed clarification or interpretation I would simply ask. Second, that they were able to decline to respond to any of the questions, request the audio-recorder to be switched off, or discontinue the interview, particularly if they became uncomfortable or upset. Third, that I understood that having chronic pain meant that they were already in physical discomfort, but that I did not want the interview to elevate their pain levels. I told them they were welcome to stand or lie down while they are interviewed, take a break, stretch, take a walk, or do whatever they need to do to make themselves more comfortable. Finally, I reminded the participants that the information gathered or discussed in the interview was not a form of diagnosis or treatment for chronic pain, and would not be passed on to medical professionals or health-related organisations. I also explained that I could not offer any advice or give any promise of pain alleviation.

I positioned the audio-recording device between the participant and myself to ensure optimum recording quality, but not so close as to impose on the participant. I then commenced the in-depth, semi-structured interview, following the interview schedule (see Appendix F) but allowing for flexibility of topics and order. In accordance with IPA methodology, the interview schedule was designed to guide rather than dictate the interview, and started with broad, general questions before more specific prompts were used, when necessary. Questions were phrased and responded to in an empathic and sensitive manner.

The interviews ranged from 34 minutes to 75 minutes in duration. Although all of the participants appeared to find the interview a reflective and cathartic process, one person became emotionally distressed and needed to take a break from the interview. I had a list of support resources and options available to people with chronic pain on-hand (see Appendix G), which I offered to four of the participants who requested further information. All of the participants were currently in the medical system with regards to their chronic pain and could access further help if needed.

At the end of the interview, I thanked the participant, gave them the opportunity to ask questions, and offered a \$40 credit card voucher as a koha (gift/contribution), to compensate for their time and thank them for their valued contribution to the research. This

was usually received with surprise but gratefully accepted, particularly by those participants who had expressed financial concerns. One participant chose to accept the koha but pass it on as a gift to a friend.

Transcription, review and feedback

After the interview I explained the purpose of the transcript release authority form indicating that the participant agrees that the edited transcript and extracts from this may be used in reports and publications arising from the research (see Appendix H) and arrangements were made if the participant wanted to meet with me to review their transcript for accuracy, or whether this process would be conducted by post or email. Four of the participants took the opportunity to review their transcripts: Hoani, whose interview was the shortest, spent considerable time reviewing his transcript and added a wealth of information, Kate removed some information that she felt was identifying and clarified a few terms (in both cases we met again to discuss the changes), and Teresa and Makareta did not make any changes. The other three were happy for me to use their transcripts without reviewing them and signed the transcript release authority after the interview.

Arrangements were also made to give the participant the (optional) opportunity to discuss the results further and have input into the analysis process – again, I offered the options of having a further kanohi ki te kanohi meeting or consultation via telephone or email. All of the participants expressed interest in being involved in the initial analysis process via email. I therefore summarised each participant's experiences into a three-page narrative, including a message of personal thanks, and a whakataukī that was felt to be appropriate: Ahakoa ngā ueue, kia kaha, kia toa, kia manawanui (When you find things that are difficult in life, stand strong, stand tall and be of great heart). This opportunity for further participation was designed to support the principle of tino rangitiratanga, so that participants knew that they shared the ownership of the research, and that their needs and agendas could be met. It was also to gauge the acceptance and accuracy of my interpretations and ensure that they were not solely imposed by the researcher. Three participants responded to these narratives – one saying she was confident that I would take the analysis the right way, one saying she did not feel the need to be a part of it and was sure I had understood her experiences well, and another thanking me for giving him a record of events in his life that he had thought forgotten. I can only hope that the silence of

the other four participants was indicative of agreement. Participant involvement in the analysis process was therefore minimal.

Finally, I explained to the participants that they could receive a summary of the final results if they wished, and suitable arrangements were made (i.e., via post, email, *kanohi ki te kanohi*, at a *whānau* or community hui). All of the participants requested a copy of the final results via email or post, which was sent out in the form of a three-page summary.

I transcribed the audio-recordings verbatim (with the exception of any identifying information) into Microsoft Word documents. Transcription in IPA does not require the detail given in conversation analysis or discursive methods; however certain notation was used for the sake of clarity (see Appendix I). Transcription took place one by one (in all but one case; Sarah was interviewed the day after Delia), so that I could reflect on how the interview went, and incorporate additional topics or questions into subsequent interviews.

Analysis

I followed the series of steps that are recommended for conducting IPA (Eatough & Smith, 2008; J. A. Smith & Eatough, 2007; J. A. Smith & Osborn, 2003), which were carried out ideographically before moving towards a cross-case analysis and narrative account.

The first step took place during the transcription process, as it is acknowledged that the researcher is already forming thoughts and impressions about the participants' experiences. The summary narratives were written for each participant at this point, as previously described. The analysis process continued with the repeated reading and re-reading of the transcript, during which detailed, line-by-line notes of significant points were made in one margin. These processes allowed for reflection on the individual life-world and experiences of each participant.

The detailed notes were then transformed into themes, which were recorded in the other margin. There was a strong emphasis on retaining a close connection between the themes and the original data. The next step was to cluster the themes by looking for relationships between them. Conceptual or descriptive labels were chosen for these clusters, or higher-order themes. A table was then produced containing the higher-order themes, themes, short quotes which exemplify each theme, and the line numbers needed to identify the location of the quote. The analysis of the first transcript informed the analysis of subsequent data; comparison naturally occurred and similarities and differences were noted. I also

attempted to look at each subsequent participant's transcript anew and took care to represent the themes that were specifically important to them.

A cross-case analysis was then completed, during which a final table of superordinate themes was constructed. This involved a move to more conceptual analysis, including the prioritizing and reduction of the data in accordance with the original research questions and overall focus. This entailed looking across all cases to get a more general understanding of the phenomenon of interest, while remaining well-grounded in the data. To do this, I spread out the individual tables and looked across them, noting superordinate themes and their sub-themes in mind-map form. In order to ensure that the sub-themes were still well grounded in the data, I created files containing lists of quotes that exemplified them.

Chapter 6: Results and Discussion

This chapter begins with a brief description of the participants, followed by the description, interpretation and discussion of the IPA results.

Results

Chronic pain had had an impact on all of the participants' lives, although the ways that this manifested in experience varied. Kate, Teresa, and Sarah were currently employed despite their chronic pain, Delia and Jake had returned to study, and Hoani, Jake, and Makareta were receiving the Work and Income New Zealand (WINZ) Invalid's Benefit. Experiences of mental health in relation to chronic pain also varied; Hoani, Kate, Jake, and Teresa had been affected by symptoms of depression and/or anxiety, Makareta by schizophrenia and Jake by attention deficit hyperactivity disorder (ADHD) and post-traumatic stress. Delia and Sarah did not report any mental health difficulties. In addition, Kate, Teresa, Delia and Sarah appeared to be managing their pain reasonably well on a daily basis themselves with the help of pain relief medication and/or Complementary and Alternative Medicines (CAM), whereas Hoani, Jake and Makareta had either experienced repeated treatment failures, or lacked support from, and/or access to, the medical system and/or pain relief medication. Social support and relationships also varied, with Kate, Teresa, Delia and Sarah largely maintaining their usual forms of social contact, and Hoani, Jake and Makareta experiencing a breakdown in relationships and/or social support from family, partners, and friends. Despite this diversity, there were also commonalities and a sense of unification across their experiences, which make up the IPA results described.

IPA Results

Four distinct but interrelated superordinate themes were apparent in the cross-case analysis. These were: 'A life transformed by the experience of chronic pain', 'Experiences of chronic pain as Māori', 'Evaluating treatment experiences', and 'Negative perceptions, negative experiences'. They are presented in this order because the first superordinate theme offers general insight into participants' experiences of chronic pain and gives context to the experiences described in the following three superordinate themes, and are illustrated in Table 2 along with the 13 subthemes.

Table 2: The Four Superordinate Themes and their Thirteen Subthemes

<i>Superordinate Themes</i>	A Life Transformed by the Experience of Chronic Pain	Experiences of Chronic Pain as Māori	Evaluating Treatment Experiences	Negative Perceptions, Negative Experiences
<i>Subthemes</i>	Causes and sources of pain	Māori identity and culture: Embedded in experiences of chronic pain	The decision to seek treatment	Living with chronic pain: Stigma and isolation
	Pain embodied – living through the painful body	Experiences of rongoā Māori and complementary/alternative treatment	The medical system: Gatekeeper to treatment	Stoicism: I don't want to be a burden
	Restrictions imposed by the painful body: Change and identity	Racism in the medical system	The search for relief: Medication and other substances	
	It's not just physical	Restricted access to the medical system		

It is important to note from the outset that, whilst the second superordinate theme makes explicit the aspects of chronic pain that participants experienced in relation to being Māori, the other three superordinate themes demonstrate that all of the participants' experiences are embedded within their Māori identity: we do not stop being Māori when we are in pain.

Each superordinate theme and its subthemes are described and discussed in turn, followed by a discussion of the relationships between them. Note that a basic description of each of the participants can be found in Table 1 (p. 52). For the sake of clarity, interviewer interjections that did not add meaning or change the course of the participants' descriptions (e.g., mm, yeah, uh huh) have been removed. The sources of the quotations are indicated by the participant pseudonym and the line number the quote started on. Also note that on reviewing his transcript, Hoani added a series of dates in brackets (e.g., (1990)) in order to make sense of and remember his experiences of chronic pain across 25 years, which have been kept in his quotes.

A Life Transformed by the Experience of Chronic Pain

This superordinate theme encompasses the ways in which the participants made sense of how the embodied experience of chronic pain had transformed their lives. They engaged in a process of sense-making about what caused or exacerbated their pain, described their experiences of bodily symptoms, and talked about pain in a way that suggests that their experiences were deeply embodied. The restrictions imposed by the painful body contributed to a sense of change in the participants' lives, particularly in regards to performing activities that were a part of their identity, and new identities that had formed. Time was often used to make sense of this transformation and change. Considering these transformations and the ongoing nature of their chronic pain, it is not surprising that the participants also experienced negative feelings and difficulties with mental health.

Causes and sources of pain

This subtheme captures the various ways in which the participants made sense of the factors that they described as causing or exacerbating their experience of chronic pain. All of the participants engaged in this process of sense-making. The two male participants talked about accidents or events that had caused their pain: for Hoani it was a car accident in his 20s when he had been drinking, and for Jake it was a motorbike accident in his

teenage years. Although these accidents were described as the original cause of injury, it was later physical activity that appeared to trigger their back pain:

Hoani, L39: one of the doctors sent me to a fellow, who bends you and twists you and all that and he said go and do weight-lifting or running you will not be able to play rugby or league again. In remembering this about the man telling me that, I cannot play those games again, I must have had back problems before I started running. The running must have brought the back pain on more

Jake, L26: I didn't really notice the back so much for a year or two um and then I was digging and it was a lift and a twist motion which um, which I still can't do to this day um when I was 18 or 19 which first got my back registered with the with the medical professions

There was a strong physiological relationship between the mechanism and the chronic pain, and neither of these participants talked much about the influence of psychological or emotional factors on their pain, but rather about physical activity being an exacerbating factor. The belief that physical activity increases pain levels can lead to people restricting or reducing the amount of activity that they do for fear of exacerbating the problem, however this tends to in fact contribute to further disability (Gatchel et al., 2007; Osborn & Smith, 1998).

Sarah and Makareta also talked about physiological mechanisms for their pain but had both experienced events in which someone else had inflicted pain, for Sarah from a Chinese masseuse who perforated three discs in her spine, and for Makareta from domestic violence:

Makareta, L12: I think the um main reason for my back pain is um a domestic violent incident that I was involved with um with an ex partner back in (11 years ago)? Yeah um he, stomped on my shoulder and stomped on my back on the right side and um, yeah, I've had problems ever since then

Sarah also described physical activity as an exacerbating influence on her pain, whereas for Makareta, strong emotions and difficulties with mental health were described as factors affecting her experience of chronic pain.

The two participants who had a diagnosable medical reason for their pain experienced both advantages and disadvantages for having a label; for Kate it was Celiac disease, inflammatory bowel syndrome (IBS), and gastroesophageal reflux disease (GERD), and for Delia it was kidney disease. Having a label was useful in terms of making sense of their

symptoms, but for Kate it also meant that all bodily sensations were put down to her medical condition, rather than being addressed as new concerns by medical professionals:

Kate, 308: okay this is the way I see it I like the fact that they know what's wrong with me? But whenever something happens they're just like oh that's just a flare-up

This led to feelings of self-doubt and uncertainty about the origins and seriousness of bodily symptoms. For example although there was little doubt about the original source of their chronic pain, Kate and Delia drew strongly on the influence of psychological factors to make sense of symptom flare-ups or treatment failures:

Kate, L321: it's just like am I doing myself in my head um, or is the doctor just being blasé and just, I think you know, just treating it as my normal con a part of my normal condition like I do see where the doctors are coming from because I do have times when I'm like, I have real bad um heart burn under my, shoulders and I was like oh fuck I've got chest pain then you know is that chest pain, if I don't think about it, it's gone

Delia, L528: at the first transplant I hadn't dealt with a lot of the reasons why the sickness had turned up in the first place, um hadn't hadn't done a lot of healing on that those issues, so my first transplant failed because I was under a lot of stress from my partner at the time, and that stress plus the fact that I hadn't um gotten rid of the root of the cause of the illness, um contributed to me losing the kidney

Finally, it was not surprising that Teresa used mental exertion to make sense of the cause of her migraines, as 'head work' has a natural association with 'head aches':

Teresa, L10: Well I went back and studied and I suppose it was my brain got a fright {laughs} having to work again and you know having to think and stay up, you know I don't know whether it was a combination of, late nights and you know just constantly, and reading a lot 'cause you know but they they just started then basically when I start about half a year after I started studying

The participants also engaged in a process of sense-making about the different factors that could trigger or exacerbate their pain. Some of these were strongly physical in nature:

Hoani, L88: I just twist or bend the wrong way in my back and it gets me, pain pain pain

Jake, L449: without warming up or anything I tried to ah reach in ah move all my tools out of the boot which are quite heavy and ah felt my back go

Whilst some participants had a clear understanding of the cause or a direct physical relationship between an event and their pain, others were not as certain and drew on psychological and emotional concepts as well:

Teresa, L780: Well in in, in retrospect I think that a lead up of a lot of emotional pain building up, I don't, and maybe that's why and then, this is just going back to me um, as to why I started, these headaches started coming on well for a start hitting forty, but then the years, the few years leading up to that with a lot of intense {clears throat} yeah emotional sort of suffering

Delia, L363: my actual thinking is that um, a lot of my sickness comes from um for me as a child they were ways of dealing with what was going on with being sexually abused and and having no one to talk to

The search for an explanation often continues as various causal models, both psychological and physical, fail to adequately explain the symptoms (Osborn & Smith, 1998). In the face of such uncertainty, there tends to be a 'common sense' approach whereby people with chronic pain use their everyday understandings of health, the body, and pain – particularly 'stress' – to inform or create a theory for its existence (Osborn & Smith, 1998):

Kate, L720: Yeah it's like a cycle it's like the, is my stress and anxiety making my symptoms worse or am I making my symptoms worse because of my stress and anxiety? It's like it's like {laughs} which one's causing causing each other

Delia, L397: my sickness has been a big huge part of my learning as a child to, I used it as a way to cope as a child, and then as a young adult especially in my 20s I didn't quite connect up that when I get stressed I get sick

Some have argued that the term 'stress' has become a discursive object, whereby it can be used to explain anything – physical or psychological – that could increase bodily tension, and therefore increase pain (Kugelmann, 1999). Pain therefore becomes a problem to be solved with the polarity of stress – relaxation – which again encompasses both physical and psychological concepts (Kugelmann, 1999). Discourses of stress as something that we can control also increase the level of responsibility that people with chronic pain have for their wellbeing; stress is viewed as something that can, and should, be reduced (Kugelmann, 1999).

Pain embodied – living through the painful body

This subtheme captures the ways in which participants described their lived experiences of pain and other symptoms, and how these experiences were deeply embodied – they

experienced a sense of both being in, and having, a painful body. Although all of the participants described their pain as something that was chronic, in the sense that it was ongoing, they also experienced fluctuations in intensity:

Jake, L532: Yeah someone, a doctor said does the pain ever go away and I was like no, and that was mm you know and I hadn't thought about it like that at all it was just it was just how sore is it today

Makareta, L385: The chronic pain is always there, it's just where it is on the scale

Some of the participants even used the 10-point rating scale of pain to describe these fluctuations:

Teresa, L240: when it's sort of, a six or like seven I mean you can do things but it's like a, a real effort it's just like, you know oh my God, even hanging out the washing or like when it's up to a nine or whatever I just nah, I just yep pretty much stop

Sarah, L169: Yeah I only take it if I'm having a real bad day where the pain is at a 10, 10 plus? Then I'm left with no choice because by that time I also get the sciatica come down my legs?

The use of the 10 point rating scale made sense in context of the questionnaire that the participants had completed prior to the interview, when they were asked to use that scale to describe their average levels of pain at its worst, that day, and on average. Bearing in mind that we rely on subjective descriptions to know about and understand pain, the use of a number may be useful in the sense that it is a numerical rather than a verbal indicator of intensity, and may therefore be easier to convey to others. It is important to note that such scales only measure perceived intensity, and do not capture diverse pain experiences adequately, particularly in cultures different to the population that the scale is developed for, as is often the case with Māori and the pain questionnaires used in the New Zealand medical system (Magnusson & Fennell, 2006).

These periods of pain flare-up were often described using references to markers of time:

Delia, L308: Yeah {laughs} so that was a bad year, so what happens with me is that, I'll have a year or so that I'm good I'm not too bad and then something will happen and I'll um have the transplant or lose a transplant or something or other, and then I'll be ok for a few years and then I'll be back into it again

Teresa, L855: I thought oh my God, am I, am I that bad or, but then I when you put it to me I think yeah yeah I mean you know, those bad days are just yeah, just unbearable

These were the times that pain was experienced as overwhelming, debilitating, or something that literally stopped them in their tracks, meaning they had to rest or sleep:

Hoani, L417: If it gets bad, well I'll just go and lie down, slow down all of my physical movements that brings on the pain more, go and suss out someone with some marijuana yeah (2) just physically stop moving

Makareta, L161: The medication that the psychiatrist gave me would knock me out for sixteen hours, I could sleep for sixteen hours, day after day after day after day, that's how much pain I was in

Fluctuations in pain intensity can be made sense of using Melzack and Wall's (1965) gate control theory of pain, as there are a number biological, psychological and social factors that can affect excitation and/or inhibition of nerve impulses, thus modulating pain output. This fits with the participants' experiences of the various physical and psychological factors that they believed could cause or exacerbate their pain. Neuromatrix theory also tells us that there need not be sensory input for pain to be experienced, as neural networks or the 'body-self neuromatrix' can be activated in the brain without such input, and still produce the subjective experience of pain (Melzack, 1993). This theory can explain why some of the participants experienced an increase in pain that was not related to a physical mechanism.

Pain was also experienced as something that could move around, radiate and have different qualities:

Kate, L164:

K: = Yeah so it's like a stabbing it's like a burning gnawing pain?

Z: Uh huh =

K: = and you feel like you feel this gurgling gnawing sort of thing

Delia, L69: you get to the stage where just everything, feels like, um, painful, just maybe like breathing and getting up feels painful? But so it's more of a gradual decline rather than a sharp um, sharp pain

The words that the participants used to describe their experiences of pain (e.g., sharp, stabbing, burning) fit with descriptors within the pain questionnaires that are commonly used in medical practice in New Zealand (Fennell, 2005; Magnusson & Fennell, 2006, 2011). Previous research has suggested that the commonly used descriptors in pain questionnaires are appropriate for use with Māori (Fennell, 2005; Magnusson & Fennell, 2006, 2011), and these examples appear to support that conclusion.

Descriptions of symptoms at times suggested that the body was experienced in a unified manner; the participant was very much a part of their body, and described their pain in ways suggestive of occupying it or ‘being’ it. For example, Teresa felt weak after her migraines:

Teresa, 561: But um generally it will last for a day, to a day and a half, and then after it you just feel like you’ve been, like you’ve had the stuffing like knocked out of you so you feel quite weak, still get up and do stuff but like really slowly

And Makareta closely monitored her body, her thoughts and her feelings, making her tired:

Makareta, L129: I become very wary of you know and suspicious, which affects me physically because I kind of get all tensed up and, you know if I stay on that track for too long then it could result in an anxiety attack so, yeah I kind of have to monitor how I’m feeling and how I’m thinking and um what my body’s like and, it’s really tiring

When they described what it felt like to be in a painful body, they did so in ways that suggested that notions of the self (e.g., ‘you just feel’, ‘I’m feeling’) were closely bound to the embodied experience of pain. The self was an occupant of the body and the two were unified – the mind and the body were one.

However, there were also times when symptoms were described as if the body was an entity in and of itself, an ‘it’ or a ‘thing’ that was capable of doing things. For example, Delia felt powerless over her body:

Delia, L167: what’s coming to me at the moment as I’m thinking about that is it makes you feel very powerless? Because you you can’t do anything it’s your body doing this to you whereas I mean like you know, if you get drunk and you get a hangover well you did that to yourself, but with my body and my kidney disease, making me to be on dialysis, and then you’re on dialysis and then you’re getting these infections, and you can’t do anything about it?

And Hoani experienced his back as a separate object that could tell him when he was doing too much physical activity:

Hoani, L97:

H: I learnt up to a certain stage {laughs} probably 99 per cent but yeah I always still get carried away and then [my my back

Z: [Easy to do

H: warns me yeah yeah], increase of pain that I am doing it wrong again

This was in stark contrast to the experiences of the body as unified with the self, and suggested that the participant had little control over their body. Perhaps another way of looking at this would be as an experienced dualism – the mind was willing, but the body

was not – which therefore makes it feel as though the two are separate entities (Miles et al., 2005). This very experience was described by Teresa:

Teresa, L572: I get annoyed and I just think I want to do this I want to you know get in the garden or I want to, need to, you know go somewhere and you just, like they say the spirit is willing but the flesh is, weak and all that, you know

Embodiment was also evident in the participants' use of visual imagery, describing their bodies in ways that conjured up incredible visual images of what they were experiencing:

Jake, L62: yeah like you know they say slipped discs and stuff but I don't even know if such things exist in reality, but um definitely got um swollen um swollen discs I suppose you can call it? Or you know bits sticking out where they, possibly you know it should be lined up but it's not quite kind of you know it's compressed or enlarged or or something um, the lower few vertebrae don't move?

Makareta, L329:

M: And, um, it's hard because I can feel all the um, I don't know what they are, but it's like muscles twitching in my body?

Z: Uh huh

M: Yeah so I lie there and it's like someone is inside my body with their finger prodding at my skin?

Z: [Mm that must be a weird sensation huh

M: [Yeah it's horrible

Teresa, L256: it feels like your brain's exploded and it's all sort of running down the inside {laughs} of my skull

These visual images appear to be used as a way of making sense of the bodily sensations that the participants experience, and highlight how chronic pain can draw attention to the body (Bullington, 2009).

Dualism between mind and body, and the way that pain draws attention to the body, has been described in other qualitative research on chronic pain in non-Māori New Zealanders (Crowe et al., 2010). In addition, Osborn and Smith (2006) also describe how their participants with chronic pain from the UK were "...living with a body separate to the self" (p. 216). Rather than use mind body dualisms to describe the experience of embodiment, Bullington (2009) approaches the issue in a more holistic manner, using phenomenology:

Human beings exist and we know that we exist. We can wonder about our own existence and be aware of ourselves in a way that gives rise to a dimension of existence that can neither be explained by nor reduced to the material level. The human being is both mind and body (p. 101).

Merleau-Ponty conceptualised the ‘body that I have’ as the ‘object body’ and the ‘body that I am’ as the ‘lived body’ (Bullington, 2009). The manifestation of the object body can be understood as the way in which chronic pain causes the person to “...pay attention to the body in a way that we experience as unnatural” (Bullington, 2009, p. 105), creating a split between the self and the painful body. Bullington (2009) argues that when someone is healthy, they are their body, but that when someone is ill or in pain, the two become separate, and the objective body comes into focus – the body is referred to as an ‘it’ that needs fixing. Although the ‘object body’ was present in the participants’ experiences, this was contrasted with times when their body was experienced as unified with the self, which tended to be during times of intense pain and fatigue. These experiences of a unified mind and body demonstrate the uniquely human ability that the participants have of reflecting on themselves (Bullington, 2009). Therefore pain or illness does not necessarily result in separation between the ‘lived body’ and the ‘object body’, and may indeed shift between the two depending on the situation.

Restrictions imposed by the painful body: Change and identity

This subtheme captures how the participants’ lived experiences of chronic pain were used to make sense of the ways in which their lives – and their identities – had been transformed by the restrictions imposed by their painful body. There was a strong sense of change in the participants’ lives:

Hoani, L105: Yes, life is now different to how I remember it was, that has changed a lot of things that I for me

Jake, L251: things are different and, I don’t, I don’t really appreciate how much different I guess

Sarah, L215: I don’t um, just you know it’s just trying to change my perspective on life and changing the ways I do things?

Time was used as a reference point and a marker of change in the participants’ experiences of living with chronic pain. There was a tendency to make comparisons using terms like ‘before’ and ‘after’, ‘then’ and ‘now’ and ‘prior to’ and ‘since’. Words like ‘change’ and ‘different’ also contributed to the general sense of a life that had been transformed by pain.

The very word ‘chronic’ has a strong relationship to time and the participants were very aware that pain was something that they had either lived with for a long time, or would live with for a long time to come:

Delia, L45:

D: basically that's the start of my kidney dialysis and transplant career
I call it [{laughs}]

Z: [Career right I like that {laughs}]

D: Yeah yeah I've often said to people um, that um I consider it it's
it's the thing in my life that's been the most constant

Kate, L55: it's something you live with for the rest of your life you know

There was a real sense that time had passed some of the participants by:

Makareta, L548: Yes, um because I've been dealing with chronic pain,
within my immediate family group I've kind of been left behind when it
comes to moving on with my life? So my siblings are working, they've
got children now you know, they're involved with family groups and I'm
kind of left here lying on my bed on a benefit watching telly! And feeling
like I'm still 16 when I'm 37 and I've been dealing with this pain for 11
years

Jake, L834: Yeah so when I say I've I've been dealing with chronic pain
for five years or whatever it's probably you know it might be a bit longer
than that

These findings fit with the New Zealand Health Survey, which found that over a quarter of adults who reported chronic pain had endured it throughout at least 40 per cent of their lifetime (Dominick et al., 2011).

The experience of time has been described by phenomenologists such as Merleau-Ponty as 'lived temporality' (Hellstrom & Carlsson, 1996). Notions of 'lived temporality' help us to understand how time is used to make sense of change due to chronic pain, the direct phenomenological experience of time within symptoms of pain and their relationship to treatment, and the sense of an everlasting present and uncertain future (Hellstrom & Carlsson, 1996). Learning about pain and how it responds in various situations and to various treatments, can also be thought of as a temporal process, whereby earlier experiences are used to inform later decisions (Hellstrom & Carlsson, 1996). Although it was clear that time was being used to make sense of the experience of chronic pain, this did not occur in a linear or unidirectional fashion, but was rather a complex and dynamic process, as found by Hellstrom (2001) who also considered time in relation to chronic pain.

The experience of restrictions imposed by the painful body were embedded in changes in identity, as the participants found that they could no longer carry out the activities and roles that had once defined who they were. This was particularly true of physical activity:

Hoani, L495: Well it has slowed me down in various activities I wanted to do, because before I had my accident I was a very physical type of person, and yeah just the afterwards it's just kind of limited my access to, what I want to do

Kate, L70: I was quite healthy I was real real sporty real fit real sporty um um, I'm a happy-go-lucky person anyway, um but then once I had a label I was like oh shit, I've got a so called medical condition you know?

An ideal self from the past was often described with a sense of nostalgia, using terms like 'fit', 'healthy', 'strong', and 'fast', as was also found in Osborn and Smith's (1998) IPA research on chronic pain. According to Lundberg et al. (2007), the more 'enmeshed' the experience of pain is with aspects of identity, the greater impact pain will have on identity change. It was noticeable that the participants whose pain-restricted activities were more closely connected to their sense of identity experienced a greater impact, particularly in the case of the men, Hoani and Jake.

Work was another aspect of identity affected. Three of the participants were on a WINZ Invalid's Benefit, and the remaining participants felt that the chronic pain was affecting their working life, and had concerns about letting their employers down:

Sarah, L622: the thing that scared me the most was um them saying that I might have to go to a what do you call it a sickness benefit, I've never been on a benefit on my life! And for that I was like oh over my dead body that's going to happen! But um yeah that was, I think that was another thing of my biggest fears um, losing control of my identity I've always worked you know

Kate, L918: Um I feel it affects my work, so I feel like, am I, how do they perceive me? At work, am I still professional?

The painful body also restricted the way that the participants socialised, which was also experienced in terms of identity, for example Makareta had become more reclusive:

Makareta, L408: Um and I'm not really the kind of person that likes staying home, I would rather be out doing things but this is just the way I have to um, this is the way it has to be for now

These restrictions imposed by the painful body had a strong impact on identity – there was either a loss – or a fear of loss – of the pre-pain identity. Phenomenologists have made sense of the impact of pain on identity by describing pain as a way of 'being-in-the-world' (Kugelmann, 1999). That is, the 'lived body' consists not only of the mind and the body, but also of their relationship to the world, as Bullington (2009, p. 104) wrote:

Pain is not merely a question of adverse sensations in the body. Pain entails a way of thinking, a way of feeling, a way of perceiving, a way of experiencing and way of acting. It pervades the ambiance of the world. Chronic pain, when persistent and severe, radically alters the way in which we are in the world.

By disrupting the harmony between mind, body, and world, pain is no longer a physical problem, but an existential one (Kugelmann, 1999).

Pain as a way of 'being-in-the-world' can also be understood as an experience of "alienation from ones pre-pain self" (Bullington, 2009, p. 105). Experiencing a loss of identity can be just as debilitating, if not more so, as experiencing pain (Bullington, 2009). Previous research on chronic pain has also suggested a strong relationship between pain and identity, whereby restricted access to the activities that form a significant part of one's identity or sense of self, leads to feelings of loss and grief for the pre-pain self (Crowe et al., 2010; Hellstrom, 2001; Kugelmann, 1999; Lundberg et al., 2007; J. A. Smith & Osborn, 2007).

Some of the participants also described a new identity that had developed – one of a sick person, or a person with pain:

Delia, L379:

D: So I really, so I guess it really has been a huge part of my identity as a person, is being sick

Z: Yeah [that's interesting]

D: [Which sometimes] I look at and I think that's not really a nice way to {laughs} be, I'm a sick person that's who I am but it does actually feel that way, sometimes it feels like my illness is my life, um depending on what, what type of year I'm having

These participants tried to make sense of who this new person was, and several of them expressed reluctance about the using the term chronic pain, and did not want to be labelled with it:

Kate, L955:

K: I don't like calling it chronic pain

Z: What, if you [were, what what would you, refer it, refer to it as

K: [I don't know, just Kate's life! {laughs}]

Z: if you were to say =

K: = um they call it like they call it they've labelled it disease

Z: Yeah

K: Um (2) I just have a medical condition

Z: Yeah

K: That does cause chronic pain {laughs}

Sarah, L228:

S: But even now I still don't class myself as having chronic pain?

Z: Uh huh

S: I just have pain every day

Z: Yep, yeah you don't like seeing it as being chronic =

S: = Labelled =

Z: = the label, yeah yeah sure that's fair enough

A mismatch between the chronic nature of pain, and reluctance to accept the term as a part of identity, has been interpreted as due to the lack of closure created by ongoing pain and the reluctance to accept that it may indeed never remit (Corbett, Foster, & Ong, 2007). There tends to be a sense of uncertainty about the future and hopes of a solution get repeatedly dashed (Corbett et al., 2007). Furthermore, the perception of chronic pain as a negative, stigmatised, and untrustworthy phenomenon can also contribute to identity in relation to that label (Crowe et al., 2010). Previous research has also found that people with chronic pain describe their identity as becoming one of a person in pain (Bullington, 2009; Hellstrom, 2001).

Notions of a new identity were also evident in some of the participants' descriptions of the association between pain and ageing:

Jake, L354: I've always had empathy you know for for older people who you see hob you know hobbling around I you know which is, you know it's ah a it's kind of funny that I'm going to be like that now ay I guess, you know

Teresa, L594: it's ['it' being the pain from her migraines] probably just telling me oh you're getting old, yeah I don't know, which I don't like {laughs}

It was interesting how much the experience of pain had contributed to their identity as people that were 'getting old', despite the fact that these two participants were in their 30s and 40s. Chronic pain appeared to be speeding up the experience of the ageing process, and Kate was already thinking about her future with her chronic condition, despite being only in her 20s:

Kate, L503: we both know, when we're probably about 60, we'll be like {laughs} with a colostomy bag, and like being wheeled around

These comparisons to those older, or acknowledgements of ageing, make sense when considering the parallels between chronic pain and ageing: just like chronic pain, ageing is experienced as a process that leads to physical restriction, a shrinking social world, and changes in identity (Miles et al., 2005).

It's not just physical

This subtheme captures how chronic pain was embedded in the participants' experiences of mental health, emotions and feelings. It was clear that the experience of chronic pain was not just physical. In general, chronic pain was described as something that had an impact on feelings and emotions:

Jake, L329: your patience is probably less than what it would be without the pain?

Delia, L81: you get to a point where it starts getting to your, psychologically so that you start feeling like you just can't be, can't be bothered, you don't care, you know you don't get up to do regular things you know you just lose interest? And so, part of it is the physical disease that brings the gradual decline but then the other part is the psychological?

Previous research has also found that people with chronic pain experience reduced tolerance, patience and energy, which could explain these general changes in mood (J. A. Smith & Osborn, 2007). If we return to the concept of embodiment, phenomenological understandings of pain that suggest it is a way of 'being-in-the-world', could also explain why pain can manifest as, or create, a range of negative feelings or emotions (Bullington, 2009). Fennell (2005) also found that Māori talked about more than the physical aspects of pain.

Living with chronic pain was also embedded in how some of the participants felt about themselves:

Kate, L590: It made me feel like I was a head-case I was like, I'm a nutter and I'm making these symptoms up

Or their sense of self-worth:

Hoani, L571: Yeah yeah the pain yeah like I said I just wanna be away by myself. I love being in with the normal life mixing with people, but with the pain, depression and hearing problems, I have learnt that I am the bad apple in the pack of good apples. That is how it feels to me

All but two of the participants (Sarah and Delia) also talked about specific mental health problems, such as depression and anxiety, and how their experience of chronic pain was embedded within their mental health:

Kate, L126: I've built up the anxiety about it? You know normally I'm fine it's just like yeah all good but, um, just those little things those little wee things that I need to worry about you know

Hoani, L286: over the years now I've learnt how to handle it I know when my depression is coming and that's not always due to back pain just depression in itself. Yes, depression was brought on from my accident and is caused from my back pain, and also other things happening in my life

Makareta, L220: Sometimes I feel suicidal that's how bad the pain gets because how are you supposed to run away from pain? {She becomes upset and is crying}. You can't run away from pain you have to live with it

For some participants the terms depression or anxiety were used to describe their experiences, and for others they were used to describe a diagnosed mental illness. It is widely recognised that depression and anxiety can both predispose people to chronic pain, and augment the chronic pain experience (Gatchel et al., 2007). The prevalence of anxiety and depression is greater in the chronic pain population than in the general population (Demyttenaere et al., 2007; Scott et al., 2008). Depression has also been found to be undertreated in the chronic pain population, as the overlap between symptoms creates confusion and a lack of diagnosis, and therefore treatment (Bair, Robinson, Katon, & Kroenke, 2003). The long-term prognosis is also poorer for people with chronic pain who have a co-morbid mental illness such as depression (Bair et al., 2003).

Experiences of pain as more than just physical sat alongside experiences of being doubted by medical professionals. Some medical professionals implied that the participants' symptoms were 'in the head' or psychosomatic in some way:

Kate, L349: He would look at my history and he'd be like oh that's just a part of your symptoms you know you're just being hypersensitive, you're being anxious about it, but then it's like well is this a new symptom or is this in my head, you know?

Sarah, L114:

S: Yeah because they sent me to a pain specialist and then um, the first lot of drugs he he issued me were to basically tell my brain it was all in my head? The pain was in my head?

Z: Uh huh

S: They always try that to ensure that it's not in your head

Previous research has also found that people with chronic pain, particularly women, feel 'checked out' by their doctor for mental factors when they present with physical pain, making them feel like a less credible patient (Werner & Malterud, 2003). This shows a lack of trust towards the person with chronic pain in a situation where there is often no source of information other than the symptoms that they report (Biro, 2011a).

This is evidence that dominant understandings of pain within the New Zealand medical system are acute, despite the growing popularity of biopsychosocial approaches to health. Toye and Barker (2010) point out that the mismatch between a person's experience of chronic pain and the pervading explanatory model within the medical system, can contribute to a sense of illegitimacy and stigma. In acute, biomedical understandings of pain there is a strong polarity between mind and body, and thus between the real and the unreal: "real relating to the body, medical, rational, fact and visible, and unreality relating to mind, psychosocial, irrational, belief and invisible" (Toye & Barker, 2010, p. 1729). This can lead people to question the validity of their own experiences, as they struggle to either accept a biomedical understanding that does not fit their experience, or accept a biopsychosocial understanding and accept a level of responsibility for their pain (Toye & Barker, 2010).

Summary

The participants had experienced a transformation in their lives through their experiences of chronic pain. When physiological mechanisms for pain could no longer offer a valid explanation for pain, the participants talked about their experiences of psychological difficulties or stress. Their experiences of pain and other bodily symptoms fluctuated in intensity, and were often made sense of using markers of time. Experiences of chronic pain were strongly embodied, and suggest that the painful body was at times separate, and at times unified, to the self. The participants had experienced change, particularly in regards to identity, due to the restrictions imposed by the painful body. Finally, chronic pain was not just described as a physical problem, indeed it appeared that some of the physical symptoms were easier to deal with than the participants' experiences of mental health difficulties.

Experiences of Chronic Pain as Māori

Now that the participants' experiences with chronic pain have been described in a general sense, this superordinate theme encompasses the participants' experiences of chronic pain that were more specifically related being to Māori, or to Māori worldviews. Making these aspects of experience explicit is a way of valuing the worldviews that Māori have, and ensuring that these worldviews can be incorporated into the future treatment of Māori with chronic pain. There were aspects of Māori identity and culture that were embedded in the

participants' experiences of chronic pain, including notions of what it means to be Māori, the value of whānau and collective identity, and holistic views of health. Holistic views of health informed the participants' experiences of using CAM and rongoā Māori treatments. Experiences of racism within the medical system were also apparent, and access to treatment appeared to be restricted, an experience that was particularly applicable to Māori who have low SES.

Māori identity and culture: Embedded in experiences of chronic pain

This subtheme captures how the participants' Māori identity and cultural perspectives were embedded in their experiences of chronic pain. The participants were asked directly about whether, and if so how, they felt that being Māori had influenced their experiences of chronic pain. The participants' varied responses reflected variation in their connections to the Māori worldview. Māori are, after all, a heterogeneous group of people (Mahuika, 2008). Some of them did not feel that their experience of pain was any different because they were Māori. Jake felt that this was because he did not have brown skin:

Jake, L906: Oh, well, probably possibly not that much because of the way I look you know um but yeah I think that um that well yeah it's hard to it's hard to work out with the chronic pain as such I I don't think that there's been any, one moment where I could suggest that it would have been, different at all um to to anyone else

Whereas Sarah responded with regards to the likelihood of Māori experiencing chronic pain compared to others:

Sarah, L691: {shakes head} nah, I reckon all walks of life will get it, mm it's just how they, deal with it, manage it, and go forward and that that's what will determine their outcome, and also um, how I suppose how headstrong they are and what what what road they want to go down

Some of the participants felt that their cultural identity was not Māori in the 'traditional' sense, which meant that their experiences of pain were less influenced by it:

Teresa, L686: So although I wasn't brought up like Māori particularly, it was quite Eurocentric really, the people that I grew up with had that sort of understanding, so I can't say, maybe it's sad maybe it's not, whether being Māori has, you know, affected my, the way I am, or my outlook on, yeah

Delia, L919: Perhaps, for whānau who might be more um steeped in um Māori cultural customs and beliefs such as being brought up speaking Māori, or being brought up in rongoā healing families you know um you'd have a different way of dealing with the pain, than if you were brought up in the cities which is mostly what I was?

Time was used in this process, in reference to ways of the past or ways of the ancestors, as well as in reference to age, as older Māori were seen to endorse cultural perspectives that were considered more 'traditional':

Hoani, L438: Yes, being Māori has influenced my experience of pain, and handled my threshold of pain. Looking back to our ancestors and to our warrior race status, we had a very different life style before Pākehā arrived, to what we live in at this point of time. Ngā hapū ngā whānau /hunter gatherer living out in nature, living with nature, living with ngā atua/gods, living with ngā mate/dead, our thought process was totally different then, to what it is now

Kate, L860: yeah Māori beliefs this is not me but the older people ay! What is the medical doctor going to do to me I'd rather go see some someone and get a rongoā or like there's a there's a Māori, mākutū [curse] or something on me, therefore I'm sick you know?

Indeed, Scott et al. (2000) found a different factor structure on the SF-36 for older (over age 45) Māori which suggested that they are more likely to see health as a single entity within which the line between mind and body is blurred. Such talk demonstrates a dominant discourse in New Zealand that Māori culture is a thing of the past, rather than a 'living culture' that is continuing to change with its people (Nairn et al., 2006). Delia, however, identified that Māori are now more individualised (as opposed to collective):

Delia, L906: I wonder if (2) everyone has their own way of dealing with, of of coping with life and sickness and illness and pain, and I wonder if, each individual's viewpoint or perspective, is more important than their identity as a Māori, and I don't know I'm just wondering, but for me, um, while I, you know I definitely am proud to be Māori and love my Māoritanga [Māori culture, practices and beliefs] and culture, because of the way our lives are structured now um being more individualised in our own little houses and, doing our own little jobs and things and not so, connected as we were before, that we have more um, um, individualised way of doing things now?

Delia talked about this even further as she tried to make sense of the sexual abuse that had occurred in her childhood and the impact it had on her experiences of pain:

Delia, L747: all of that influenced a lot of the way I act in my illness and pain, um experiences such as um sometimes blocking off and numbing from the pain and ignoring it and or withdrawing into myself so that I don't bother anybody else with it, that came from the sexual abuse, because as a as a child it was drummed into me that I needed to keep it a secret?

She also tried to make sense of whether or not this meant that her way of dealing with pain was Māori, as she had a perception that sexual abuse was more common in Māori families:

Delia, L757: whether I consider that a Māori belief that the sexual abuse was handed down and that my way of dealing with pain is Māori, I don't really know, I think it's definitely an individual thing in my personal case that is what happened

Although there was a general sense of uncertainty about how or whether being Māori had influenced their experiences of chronic pain, the participants did engage in a sense-making process using their understandings and experiences of Māori identity. These findings fit with the assertions of Shavers et al. (2010), that an individual's identification with their cultural group and endorsement of culture-specific worldviews can have an impact on their experiences of pain, but that it can depend on factors such as age, SES, or isolation from the cultural group. References to these factors can be found throughout the examples used above.

In addition to the responses to this direct question, the participants talked about their experiences of chronic pain in ways that suggest they were embedded in Māori cultural perspectives. Involvement of whānau and collective wellbeing are important concepts in Māori perspectives of health, and in Māori culture more generally (Mahuika, 2008). The whānau as a whole was described as a priority over individual health:

Delia, L894: So I think it's um definitely part of the collective nature of um Māori thinking and then um prioritizing the whānau above your individual needs, however if there are no whānau needs then my individual needs can take priority

Kate, L752: it's that kei te pai attitude? Like for example you see it with cervical cancer and stuff like that, oh she'll be right you know I'll be alright I've just got to plod along with it I've just got to look after the whānau I've just got to go to work um I can't take the day off work I can't lose a half days pay to go go to the doctor or even to pay for a doctor um, I'll be alright give it a week you know or they sort of don't put themselves, first?

This collective way of thinking appeared to be a source of strength, in terms of tolerating or pushing through pain for the sake of others, but also a reason why steps towards seeking treatment or caring for themselves were sometimes delayed or not taken at all. This has also been reflected in other research with Māori patients, who would rather put the community or whānau needs ahead of their own, particularly in regards to spending money on their health or to drawing attention to themselves (Jansen, Bacal, & Crengle, 2008).

Makareta also talked about the Māori concept of whakapapa. She felt that she would have been better able to deal with her experiences of chronic pain and mental illness if she had engaged in the process of whakapapa:

Makareta, L578: I didn't whakapapa, I relied on people that I knew people that I'd been introduced to um people that I ah had met and or the knowledge that I had learned along the way, without remembering where I came from and what my place is within my family group, within my hapū, within my iwi, and within this country

However, whakapapa in some forms is privileged knowledge, and her father had passed that knowledge onto another sibling, thus limiting her access to it. These examples highlight the importance of concepts such as taha whānau, whanaungatanga, and whakapapa discussed in Te Whare Tapa Whā (Durie, 1985) and other Māori health models (Mark & Lyons, 2010; R. T. Pere, 1997), for the experience of chronic pain.

As well as the importance of whānau, the participants also talked about health using further concepts related to Māori culture, such as a holistic view of the person and of wellbeing, and the influence of spirituality and religion:

Teresa, L681: growing up at (place-name removed) they recognise you know the different um, our our different, the way we're made up it's not only the physical but they also believe in the spirit and the soul and and all that sort thing so it, which is kind of similar to our our the Māori way of thinking anyway?

Delia, L941: yeah and things like having a belief in God is very um strong with Māori, um belief in God, whānau um, having a more holistic view on health such as you know mind body spirit family and land, that um impact on everything

These views are consistent with the literature which generally describes Māori views on health as holistic and multidimensional (Cram et al., 2003; Durie, 1985; Jones, 2000; Mark & Lyons, 2010; R. T. Pere, 1997) and acknowledges that spirituality is particularly important, but commonly overlooked in western biomedicine (Cram et al., 2003; Jones, 2000). These views may well have implications for their understandings of chronic pain.

Experiences of rongoā Māori and complementary/alternative treatment

This subtheme captures the participants' experiences of using rongoā Māori treatments for their chronic pain, and how their Māori cultural perspectives on health informed the use of CAM. The use of rongoā Māori practices, either self-administered or practiced by rongoā

healers, was something that was utilised by several of the participants, but particularly Kate and Delia:

Kate, L462: yep my sister-in-law um does mirimiri and stuff like that she's done stuff my Mum's a real God-squad so she's always praying for me {laughs} you know

Delia, L555: Yep I saw a spiritual healer spiritual healers, I saw a um, chakra healer, I went to a homoeopathist, um I think I went to a naturopath once, um, and um I would have massage, as well as um Māori healers, oh and as well I used a technique called The Journey um so that's around um processes of forgiveness, and as well as using a healing technique called Quanta Healing, so I counted eight just then so, there was those as well as I read a lot a lot a lot of books about different um perspectives on diet exercise, health illness and spirituality so, I um, and um, had some mirimiri as well?

Note that spiritual beliefs and a holistic understanding of health are strongly imbued in these experiences, and that rongoā were used alongside other CAM treatments. Several of the other participants talked about rongoā Māori as an option, but it was not necessarily something they had pursued as a treatment for their chronic pain:

Sarah, L684: I haven't done the Māori side – if my Dad was alive, because he was a witch doctor he'd more than likely try something some Māori things and stuff

Teresa, L287: And I actually hadn't thought of going to some old medicine, medicine man you know from the Māori community I I don't know who I would go to actually anyway

The participants in this study were also cautious about their use of rongoā, for example Sarah saw little point in taking an internal remedy for a problem that she associated with bone:

Sarah, L665:

S: Yep and then they were saying about drinking um have you heard of kūmarahou [native shrub used in rongoā]?

Z: Uh huh I have yeah

S: Drinking all that, I was like that stuff's disgusting {laughs} I'm not drinking that! But um, because I said kūmarahou is supposed to clean you out from the inside, so I don't think it's going to help with my bones {laughs}

And Kate did not want to take anything internal that might upset her IBS:

Kate, L469: I haven't actually tried any medicinal, ones, like there was this like mushroom thing it smelt like fungi or mushrooms sitting in the boiler cupboard at my parents' house {laughs} it was just like drink some of this and I'm like nah no way no not with knowing what's going to happen with me and, because that stuff's not regulated as well

As well as having tried some rongoā, Hoani had experienced the healing properties of nature:

Hoani, L443: Yes, I do have a different view on pain, because there is stuff out there in nature that can make the pain go away or slow the threshold of pain down, that is good. When you have to handle the pain without the help of that stuff out there in nature, it changes your whole way of thinking and makes you do things so that you can mentally numb out the continuous surge of pain

The use of rongoā has proven to still be relatively popular with Māori (A. Evans et al., 2008), but there is little knowledge of it within the mainstream medical system (Poynton, Dowell, Dew, & Egan, 2006) as well as a reported lack of understanding and acceptance of Māori views on health and healing (Cram et al., 2003). This was evident in some of the participants' experiences of CAM as a point of contention with medical professionals:

Delia, L630: he doesn't know what I am trying to achieve by using alternative treatments he doesn't know you know what my beliefs are and he doesn't care either, so um, I will just say whatever I say to them and then I'll go and do whatever I feel like doing

Teresa, L277: Um well in some ways, I've got a lovely lovely doctor but she doesn't, she's not open to alternative medicine, anything even the name Arnica [homeopathic remedy for muscle aches and bruises] she'll probably just sort of raise an eyebrow you know, which which kind of goes, you know, clashes with me a bit

CAM is seen to contradict the pervasive culture of science and evidence-based treatment typically endorsed by medical professionals in New Zealand (Poynton et al., 2006). This is despite the fact that many New Zealanders, particularly Māori and Pacific Islanders, regularly use CAM and may benefit from being able to discuss its risks and benefits openly with their GP or other medical professional (Poynton et al., 2006).

Despite the lack of understanding of CAM or rongoā in the medical system, all of the participants had either experienced using CAM:

Kate, L729: medically, when I do have a flare-up it's like okay I've got to take medication now um but, when I'm feeling good I keep up with those complementary sort of stuffs stuff because it keeps me well, you know

Or, like Jake, wanted to try more CAM, and identified the benefits of holistic approaches:

Jake, L737: although it's hard to explain to a scientific community you know, um as a holistic approach I don't see any any harm in it, and it I'd suggest there's actually benefits to be gained, whether or not they're actually directly physically attributed to the area concerned or whether it's more a general well-being approach

Experiences with CAM were described as useful for general wellbeing, treating the person as a whole, and treating not just physical but psychological, emotional and spiritual aspects of living with chronic pain. Again, the use of this type of treatment fits with general understandings of Māori views on health, such as those exemplified in Durie's (1985) Te Whare Tapa Whā.

Some have argued that the gate control theory, in which a biopsychosocial approach to pain is advocated, provides a sense of legitimacy to the use of CAM for treating chronic pain (Ashburn & Staats, 1999; Kugelmann, 1997). Furthermore, CAM use in people with chronic illness has been described as a way of taking individual responsibility for health and wellbeing, and trying to be as 'well as possible' under the circumstances (Thorne, Paterson, Russell, & Schultz, 2002). However, such notions of individual responsibility again leave the person with chronic pain open to blame when attempts at self-management are not successful (Kugelmann, 1997).

Racism in the medical system

This subtheme captures the participants' experiences of being treated differently within the medical system in Aotearoa, evidence of racism, and how they made sense of this through their Māori identity. Although the participants generally reported being treated well within the medical system, several did experience differential treatment that could be construed as racism:

Sarah, L518: the other thing that really makes me laugh is um, I don't know if you come across it but I come across it a lot is um, just because you're brown right, they think you're dumb

Kate, L636: it's like oh my God I'm a educated person I'm going to a doctor you're supposed to be, educated as well don't treat me first of all, like a dumb, Māori or some hypochondriac who's been Googling diseases I think I have? Yeah. Sorry I'm getting angry even talking about it {laughs}

It is interesting to note that in both these examples and the one below, the participants talk about these experiences with a sense of sarcasm and humour ('makes me laugh', {laughs}). Hoani also experienced racism, but pointed out that Māori also treat each other differently, depending on iwi affiliations and abilities such as speaking Te Reo:

Hoani, L466: Yeah I think they kind of um yeah as soon as they take one look at you and notice that you're Māori, um, their attitude changes and yeah they come in from, a totally different angle, than what a what a normal {laughs} what the normal doctor does like what I've got down in (place-name removed). I have lived with these Pākehā thoughts that downgrade Māori, yes I have lived with it for 40 years now. But in saying that I have had Māori downgrade me because of my not being able to talk the Māori language, or because I am Ngāi Tahu

Note that experiences of racism were particularly related to the visible features associated with being Māori (i.e., 'brown', 'notice that you are Māori'), which was also evident when Jake – who described himself as a 'white as Māori' – reported being treated badly by a Māori health organisation because he did not have brown skin:

Jake, L875: because I um come to light as a Māori in various aspects when like um with ADHD for instance I I went to a specialist Māori unit, and because I wasn't Māori enough I got treated quite badly

Racist treatment was a difficult issue for some of the participants to make sense of, and some of them appeared reluctant to make such accusations. Kate felt that the attitudes she brought into the medical consultation were part of the experience of being treated differently as well:

Kate, L669: I don't think I feel necessarily it's because I'm, Māori but there has been cases, where I think they've undermined me. Definitely undermined me where, oh, well, let me think about that it's more that I refuse to take medication like don't give me antibiotics because it's just not going to do anything for me. Um, yeah so that's hard I don't I kind of I can't I cannot make a definite call on that actually I can't make a hundred per cent call yes they are um or no they're not because it maybe it's my attitude going in there saying you know me, if you're going to give me stupid antibiotics, why am I here if you're going to give me my ten minutes, and then try and wham bam thank you ma'am, I'm out, you know?

Previous research has found that Māori feel treated with disrespect by health providers because they are Māori, and that lack of information, clear explanations, or support to pursue further treatment, were just other forms of this prejudice (Jansen et al., 2008).

Racist treatment was also apparent in experiences with government departments such as the Accident Compensation Corporation (ACC), which people who have chronic pain often have to deal with in order to access the medical system:

Sarah, L418: the first thing she goes to me is oh you know um we'll only cover you for so long? Then you're expected to go back to work or go on the, sickness benefit, and I'm like oh you know that's really nice to know, I said so do you think all brown people come in here just to go on ACC just to try and milk it do you? And she's going oh I didn't imply that I said oh you didn't need to, I said 'cause I ain't flippin' dumb, so I was just really annoyed

Government departments, as representatives of the crown, have the greatest responsibility to the principles of Te Tiriti, yet there was evidence of interpersonal racism from their employees. Whereas interpersonal racism refers to discriminatory actions between individuals that can be directly perceived, institutionalised racism refers to embedded organisational structures that are less visible (Harris et al., 2006b). Experiences of racial discrimination, whether interpersonal or institutional, could have a negative impact on the participants' health beyond that already being experienced through their chronic pain (Harris et al., 2006a, 2006b).

Institutionalised racism in Aotearoa has been described as both a driving force and a continuing by-product of colonisation, whereby the dominant cultural group puts in place structures, policies and procedures which systematically disadvantage the minority, in this case Māori (Nairn et al., 2006). Notions of equality are bound up with the idea that Māori would, or should, simply assimilate into the dominant culture so that everything was 'fair' and nobody need be treated any differently (Nairn et al., 2006). Kate specifically mentioned institutionalised racism:

Kate, L818: Then there's also like changing the medical, professions, attitudes towards Māori as well? Which sometimes it's in it's ingrained it's that institutionalised racism, where they, actually don't know they're acting racist?

Such notions are evident in Tauwiwi GPs' reluctance to treat Māori differently to any of their other patients, and failure to acknowledge cultural or historical influences on their health (McCreanor & Nairn, 2002). Note that although Tauwiwi GPs are reluctant to treat Māori differently (i.e., give them more/better attention than others) there is evidence in the participants' experiences that they are in fact treating Māori differently – but worse – although perhaps as Kate points out they may not be aware they are doing it.

Victim-blaming was also described by Kate as an issue for Māori in the medical system, but she acknowledged that Māori themselves can perpetuate these attitudes:

Kate, L800: it's always very victim-blaming for Māori it's always very Māori's fault, you've put yourself in that position you choose to smoke you choose to drink you choose to gamble you choose to have more kids/unprotected sex, um so it's that very, deficit, victim-blaming approach towards Māori, and sometimes I feel we perpetuate that institutionalised racism as Māori as well it's like with oh just a typical Māori, what is a typical Māori you know?

Victim-blaming posits that the problem or deficit – whether health-related or otherwise – lies with Māori, thus ignoring structural and systematic bias (Reid & Robson, 2007). Individual responsibility for health has long been a feature of the western medical system (Kugelman, 1997). For example, McCreanor and Nairn (2002) found that Tauwiwi GPs viewed their Māori patients through notions of compliance – Māori were seen as difficult patients who do not take their medication, do not take it as prescribed, do not attend follow-ups, present late, do not attend frequently enough, are apathetic and react to health symptomatically rather than preventatively. Individual responsibility and victim blaming could be doubly problematic when combined with the 'morality of responsibility' that people with chronic pain have to manage their symptoms, arguably produced by the biopsychosocial approach (Kugelman, 1997).

Restricted access to the medical system

This subtheme captures how the participants' negative, and sometimes racist, experiences in the medical system had an impact on their access to treatment; it appeared that the participants were sometimes restricted in their access to the medical system. Difficulties with access were compounded by financial difficulties, which were seen to be particularly applicable to Māori who have low SES.

Negative experiences of treatment, such as those described in the previous subtheme, sometimes led participants to undertaking treatment elsewhere. For example, Hoani's wife and her friend decided to care for him at home after his accident:

Hoani, L58: They felt that they weren't looking after me in the hospital and that they could look after me better in their, home

And Kate had changed treatment providers:

Kate, L628: I went and told Mum and Dad that I'm never going back to that effing doctor again you know radiradirah and Mum was like change, you're paying for a service at the end of the day and if they're gonna be like that

Negative experiences also appeared to contribute to attitudes towards the medical system, as Kate suggested when asked whether she felt that Māori were more staunch or tolerant when it comes to pain:

Kate, L760: I don't know if that's Māori are necessarily staunch or have a higher pain tolerance but more about Māori experiences that they've had, with the doctors that influences their attitudes and beliefs of western medicine but I think it could be both you know?

There also appeared to be a sense of mistrust of western medicine – access went beyond a simple matter of appointment costs:

Teresa, L724: aside from the expense say say if you talk to them and say you can come for free or you know, reduced price, why they still wouldn't come, so it's, yeah, whether it's distrust of white man medicine you know that sort of thing or, I don't know

Ongoing or repeated discussion of negative experiences may contribute to a sense of mistrust towards the medical profession and towards the utility of treatment on the whole, as has been found in previous research on Māori perspectives of healthcare (Cram et al., 2003). Negative experiences can also change the expectations that Māori have of the healthcare system. As Jansen et al. (2008, p. 59) found, Māori have "...an expectation that care will be provided to them at a lesser quality, of a lesser intensity and by people who are either disrespectful, do not understand Māori or provide understandable information to Māori". In previous research with First Nations women in Canada, such experiences and expectations were a major factor in delayed treatment seeking (Browne & Fiske, 2001). However rather than acknowledgement of this by the medical system, First Nations people were stereotyped as passive in response to health concerns (Browne & Fiske, 2001). Similar stereotypes have been expressed by Tauwiwi GPs about their Māori patients (McCreanor & Nairn, 2002).

Access to treatment for chronic pain usually occurs through the medical system, with GPs generally being the first port of call for treatment or further referral. For some participants being Māori had an impact on their experiences of seeking treatment, for example, Jake felt that being Māori meant he was more likely to get an appointment at a health provider designed to serve Māori and other low SES groups:

Jake, L915: Um I think that um the slight um, right at the beginning of processes with the GPs um I think that they they um, they they do actually have more opening um yeah I I think it's actually probably slightly advantageous, slightly um just to get in the door

But that using health providers designed to serve Māori also meant that the treatment he received might not be as good quality, as someone who goes to a full-cost, mainstream provider:

Jake, L924: I end up going to this health provider and someone else would probably go to this health provider now this other health provider um may may charge more money for their service, but at the end of the day, they've actually got better equipment and better better resources and you know better doctors basically

Being Māori was also had an impact on experiences of referral:

Kate, L847: for example, a doctor will think, I won't refer them on to a specialist because they won't turn up to the appointment, you know why should I bother my time with this type of person, it's those type of perceptions on access as well?

Previous research has shown that Māori have greater difficulty than non-Māori accessing healthcare and various treatments in Aotearoa (Davis et al., 2006; Harris et al., 2007; Tobias & Yeh, 2007). In addition, follow-ups, referrals, and tests, are ordered at lower rates for Māori compared to non-Māori (Jansen & Smith, 2006). The examples above suggest that chronic pain is no exception. Taylor et al.'s (2004) finding that Māori are less likely than Europeans overall to consult their GP about musculoskeletal disorders, also demonstrates this. Previous research has also found that Māori perceive non-Māori as having more knowledge about the services available to them and how to access them, and also believe providers are more likely to service the needs of non-Māori (Jansen et al., 2008).

Finally, being Māori was seen to have an impact on access to treatment via the pathway of lower SES. Kate described the multitude of ways this can happen:

Kate, L789: you see Māori living in a low decile area, three kids at school, um they've got no car, so first of all the mother for example needs to get the kids to school, she needs to somehow get to and from her appointment, or even get an appointment, maybe take time off work, then she's got to get the money, from the money to go there for a doctor to prescribe her antibiotics it's like, well, you know?

Makareta also pointed out that there are complex processes involved in the allocation of iwi or marae financial resources for health, and felt that the issues important to her – experiences of domestic violence, chronic pain, and mental illness – were not prioritised:

Makareta, L509: because of the tikanga like it's a process and, to get that process going requires not just people but it requires resources which cost money, and having a lower socioeconomic status means that we don't always have access to, you know, well maybe we do, we just don't want to dish it out I don't know

Finally, Jake felt that it was really important that there were medical systems in place that specifically help Māori, particularly in recognition of the years of marginalisation that Māori have suffered in Aotearoa. He expected improvements to be seen in the health disparities between Māori and non-Māori via these services:

Jake, L961: Um and it just so happens that you know oh Māoris in cities are generally overrepresented in in those statistics which, you know is is unfortunate but I mean you know what can you really expect you know it's only you know without going into the whole the whole Treaty of Waitangi and everything the you know it's you can't really expect too much over the 150 years um you know and the more generations that go through the bigger and bigger improvement there will be

The fact that Māori are overrepresented in deprived living areas and low SES statistics was known to these participants, several of whom had experienced this first hand. The experiences of these participants highlight how access to treatment for chronic pain can be restricted for Māori at different levels, right from the individual level (Kate), through to the community level (Makareta), and the level of healthcare policies and Te Tiriti (Jake).

Summary

There were a range of experiences with chronic pain that were related to the participants being Māori. The participants' experiences of chronic pain were made sense of in the context of their Māori identity, and embedded within Māori cultural perspectives of whānau and health. Their experiences of using rongoā and CAM for treating chronic pain were imbued with Māori perspectives of health and wellbeing. However, there was also evidence for racism towards the participants and Māori more generally, from both medical professionals and government employees. In addition, the process of victim blaming may add another layer of personal responsibility for their chronic pain. Finally, the participants' experiences suggested restricted access to treatment, which was compounded by financial difficulties.

Evaluating Treatment Experiences

This superordinate theme encompasses the participants' experiences of seeking a solution to their chronic pain. These experiences go beyond the issues of racism and treatment access already described in 'Experiences of chronic pain as Māori'. First, the decision to seek treatment was embedded within the participants' experiences of symptoms and the efficacy of their own pain management strategies, as well as financial factors and access to ACC and WINZ. Experiences of the medical system suggested that it acts as a gatekeeper to treatment for people who have chronic pain. These experiences were evaluated in regards to their expectations of treatment and care, with most evaluations being negative, but some notable positive exceptions. Finally, the participants described their experiences of taking pain relief medication or other substances, as they searched for something that would take the pain away, or at least reduce it.

The decision to seek treatment

This subtheme captures the participants' experiences of seeking treatment, and the different factors that were taken into account in those decisions. The decision to seek treatment was generally tied to experiences of different or worsening symptoms, or a feeling that the participant's own strategies for managing their pain were no longer effective:

Kate, L316: when a different symptom happens I'm like oh fuck there's something else wrong with me I need to go to the doctor

Teresa, L301: oh it's just when I, when I get kind of desperate and I just need anything to to get rid of it, that's initially why I decided to go to her because I I, prior to that I'd tried to manage it myself

The financial situation of some of the participants was also a factor in their decision to seek treatment:

Hoani, L490: Myself, I have tried to seek treatment, from a lot of Doctors / Specialists, but they have all said no. Because of having not enough money to see more doctors and specialists, I have accepted pain and symptoms from my accident. But I have been able to go out, and found stuff on the black market to help me with my pain. That was ok until I ran out of money

Makareta, L344: I run out of money so I can't get my medication

The cost of medical treatment appeared to be weighed up with how useful it was perceived to be, based on previous experiences when seeking treatment had not helped:

Delia, L217: I've been to the doctors and the hospitals so many times and they've just said go home, go home and have some Panadol I'm so sick of hearing that I'm paying four, paying 40 bucks just to hear go home and have some Panadol and go to bed, so I won't go to the doctors unless I'm in chronic, you know really bad pain and I know I need to do something

Kate, L577: I know I'm not spending 70 dollars to be told the same story even though she's really supportive I know what makes me feel better, you know unless I'm dying on the floor, then I'm going to A and E [accident and emergency] where it's free

If there was an alternative option to going to an expensive doctor's appointment, only to be told that they cannot help, it appeared to be taken. Note that the severity of the situation was taken into account in these decisions. Previous research has found that Māori see little value in a brief consultation, particularly if it does not lead to any improvement (as is often the case with consultations for chronic pain; Ashburn & Staats, 1999) or just leads to even further costs such as prescriptions (Jansen et al., 2008).

Access to financial compensation such as ACC or WINZ also had an impact on the decision to seek treatment. Because of relying on ACC or WINZ, several of the participants experienced living conditions which prevented them from managing their chronic pain on a daily basis, as well as preventing them from seeking treatment:

Makareta, L242: I don't do as much exercise as I could, like swimming would probably be the ideal option for me but seeing as I don't have a car I don't actually um, I can't get there at the moment but I'm working on that with Work and Income, to try and get more money for my disability allowance so that I can get travel assistance to get to the swimming pools

Hoani, L345: But due to me being on the Invalid's Benefit, I cannot afford to go to the doctor all the time as the bill rises up very fast

Although these systems were perceived as necessary and useful, they were not currently meeting the needs of these participants for treating their chronic pain. The decision to use CAM or more natural treatment alternatives was also hampered because of financial restrictions and burdens that the participants experienced:

Jake, L726: Yeah well I would have acupuncture I would have liked um I still would actually, um, um, yeah the the cost is somewhat because it's not really a government sponsored thing? So yeah so um, so again because of, because of, not working or not having a lot of disposable income um it that puts a stretch on on that side of things

Kate, L434: also I'm labelled a high earner which I'm not {laughs} um I've got to pay for services full and because I intend to go down the alternative treatment path, I can't get anything subsidised?

Although previous research has also described difficulties with the cost of CAM in those with chronic pain (Dewar et al., 2003) and more generally (Bodeker & Kronenberg, 2002), the problem is likely to be compounded for Māori. Māori are not only more likely to occupy a lower SES position, but are also more likely to be personally invested in the use of CAM treatment particularly if holistic views about health are strong.

The medical system: Gatekeeper to treatment

This subtheme captures experiences that suggest that the medical system acts as a gatekeeper to treatment for people with chronic pain, and how experiences within the medical system were evaluated by the participants. Gate-keeping occurred in terms of the participants' access to diagnostic tools such as x-ray and MRI, and to the results of tests:

Jake, L554: um ah back specialists orthopaedic surgeons all the rest ah ah two of them never got back to me? You know they went to all the effort to stick me in an MRI machine and then never, ever rung me back even though I went in and talked to the receptionist and everything and I and I've never got the results from them

Makareta, L309:

Z: did you ever have any investigations like x-rays or MRIs or anything like that? [No

M: [No], I asked for an MRI but the psychiatrist didn't think it was necessary

Medical professionals were also gate-keepers of information and knowledge that could be beneficial to the participants. Makareta's experiences of physical symptoms were dismissed by her psychiatrist, who only focused on her schizophrenia even though the two were closely related:

Makareta, L332:

Z: with those um symptoms you get, does the psychiatrist ever discuss that with you? Like what's his kind of explanation in terms of when those symptoms kind of, sort of move around a bit?

M: {Moving around to make herself more comfortable} Sorry, um, the psychiatrist doesn't focus on the physical

Z: Oh that's right yeah so he's more focusing on that that mental side

And a lack of information had led Hoani to doing his own research:

Hoani, L70: um, I think at some stage there I started looking through books because the doctors and various other people weren't giving me, any good information, on what had happened in my injuries to me and, what I could expect so I started reading lots of medical books

Effective communication can be hindered when there is a mismatch between the cultural background of the patient and the provider, leading to misunderstandings, less listening, less discussion, and ultimately poorer healthcare (Jansen & Smith, 2006). Traditional power relationships between doctor and patient still abound, whereby the patient's input is not valued or requested (Monsivais & McNeill, 2007). In fact, research from the USA shows that doctors are less likely to be collaborative, empathic, or interested, in their interactions with patients from lower SES or ethnic minority groups (Frantsve & Kerns, 2007). There has also been some suggestion that Māori have a culturally bound reluctance to question the doctor, to ask for further information, or to have to be forceful or demanding (Jansen et al., 2008), which could also influence the transfer of knowledge and information.

ACC was yet another gate-keeper within the medical system that had the power to dictate whether or not several of the participants would be receiving treatment. ACC was trying to claim or prove that their chronic pain had been caused by some kind of degenerative or ageing process rather than an accident or injury:

Jake, L560: ACC they just want to get their way out of anything related to backs they just, basically they start erring on the side of it's a degenerative condition how can we prove that it's a degenerative condition

Sarah, L448: ACC turned around and said well you've we need another, we need a third party to see if it's related to your accident or if it's due to old age, and I was like, far out I try to do the right thing and they still try and slap you in the face. So I had to go through that rigmarole for three months with that um before that third party said no it's related to your injury, and I said well, I knew that!

Sarah had the social and financial resources to fight these claims however Jake did not and had to accept the downgrade to WINZ compensation. Complex systems such as ACC and WINZ tend to be evaluated negatively by Māori for a number of reasons, such as information (forms, booklets) not being presented clearly, dealing with multiple staff members and having to repeat the story, or feeling like they were being given the 'run-around' when services were not providing what they needed (Jansen et al., 2008).

Experiences within the medical system were evaluated by the participants in regards to their expectations of treatment and care. For some participants their experiences of particular aspects of the medical system had been extremely negative, producing strongly emotive accounts:

Jake, L606: they've got a team of workers there um, you know a couple of physios couple of different specialists from each area including a you know the equivalent of a of a doctor um and the doctor person walks around quite upright um hasn't suffered a day of pain in his fucking life and tells, basically tells me that that I'm, I'm just there to get drugs

Hoani, L448: But being Māori at times is a downer in this Pākehā world, only when you meet ignorant Pākehā that are stuck up themselves, living in their tunnel vision, ignorant world. They [Doctors/Specialists] do not give you the right time of day or treatment medicine to numb the pain, so you can live a normal comfortable life in an everyday non pain society

Note that these experiences suggest a strong sense of having the right to effective treatment for pain. Relief from pain is, in fact, a fundamental human right (Brennan et al., 2007). However, Brennan et al. (2007) have argued that the under-treatment of both acute and chronic pain is an international issue, particularly influenced by political and legal restrictions on the use of opioid analgesics (they term this 'opiophobia'), and a lack of specific pain management knowledge in the medical system (they term this 'opioignorance'). Notice that difficulties accessing pain relief medication were exemplified in both Jake and Hoani's experiences.

The participants' experiences within the medical system were not always negative, and several of the participants described a GP or other medical professional who had been helpful and central to their care:

Delia, L601: I've got a GP now who's awesome, she's great because um she because she knows me so well I can just walk in and say I've got this and I need this, and she'll just write me out the script she she trusts that I know, been around the block so many times that I know exactly what I need and I won't come in unless I really really need to because it costs me

Kate, L396: went to the acupuncturist she was honestly the awesomest lady, real calm made me feel real comfortable and, we went through all these things and she explained everything to me

Makareta was asked what it was that made experiences with some medical professionals good:

P6, L503: Oh they're just straight up and tell you where you're at, they don't, they don't try and um (5) like, I I don't know about other cultures but I know about Māoris especially females, they don't like being, oh I don't know, this I know this female doesn't like being dictated to {laughs}

In the wider literature on chronic pain, providers who communicate well, take the time to explain things and provide information, trust their patients' accounts of pain experience and show general respect, are evaluated more positively than those who do not demonstrate such care (Parsons et al., 2007).

The search for relief: Medication and other substances

This subtheme captures the participants' experiences of taking pain relief medication or other substances, as they searched for something that would take the pain away, or at least reduce it. Concerns about the addictive properties of pain relief medications were expressed:

Teresa, L83: I just found that I didn't want to have to rely on those so I'd have to try not to, unless it was really really, sort of, you know, unbearable I wouldn't take them until then

Sarah, L333:

S: I've always maintained to the doctors I don't want to get addicted um, to Oxycontin because it's a synthetic morphine

Z: Yep

S: And, um, he was saying I'm not addicted I'm reliant

Z: Right {laughs}

S: I said to him well reliant and addicted is the same thing as far as I'm concerned

However, concerns about pain medication appeared to be balanced with an even stronger desire to have complete or partial relief from chronic pain, and how able the participant felt to cope without some form medication or substance use:

Sarah, L133:

S: It's hard depending on drugs, when I never used to depend on drugs to do what I wanted to do

Z: Yeah

S: But now it's like, I've got to depend on it to get ah from A to B?

Z: Yep

S: Like if you asked me can I go a day without drugs, I can't (2) that's the sad thing about it is I can't

Teresa, 697: all of the medicines we had were Weleda [brand of homeopathic medicine] or you know sort of natural remedies and all that sort of thing {clears throat} yeah so, for me to suddenly you know resort to this stuff you know it's, that's how bad it is!

Concerns about pain relief medication are common in people with chronic pain, particularly in regards to side-effects and dependence (Campbell & Cramb, 2008), and have also been expressed in previous research with Māori (Penney et al., 2009). Misperceptions or misunderstandings can influence whether or not the medication is taken as prescribed, or taken at all, as can cultural beliefs about inherent harm in taking medication (Monsivais & McNeill, 2007).

The participants also described being 'palmed off' by treatment providers who saw pain medication as the only solution, and experiencing side-effects:

Hoani, L197: Not long after the accident, ah, yeah, I ah I didn't think they helped me much at all, they only just kind of gave me pills and shunted me off and, kept me happy on my pills for a while until I got sick of them because they would just blob me out make me sit down and do nothing and I started putting on weight I can remember being up to 17 stone, where before the accident I was a fast swift mean player of sports, my weight being between 12-13 stone (1987)

The strong focus on the use of pain medication may well have links to the biomedical understanding of health that still dominates the medical system, or to medical professionals having acute understandings of pain (Monsivais & McNeill, 2007).

The search for something to take the pain away had led at least three of the participants to self-medicate with drugs or alcohol:

Makareta, L225: You have to find something that's going to take it away, and I do that with drugs and I do that with alcohol and I do that with sex

Hoani, L243: I suppose the only medication would be, marijuana? I do remember asking different doctors for pain killers but what they were giving me was useless

Whereas for other participants, it was a matter of using over the counter or prescription medications in a way that provided the most pain relief for them:

Delia, L491: Sometimes when I feel like um you know I just feel a bit seedy I feel a bit off, or you know I just don't feel motivated or whatever, or I've got a bit of a headache and it's all just sort of on top of me I'll take a codeine and feel better and get the thing that I need done, and I won't carry on with it, so so I'm not like addicted to them but um, I use them for more than just pain?

Jake, L30: at one stage there I was, I was getting um, six 60 milligram codeines a day um, but I because I was picking them up weekly I could have whatever I wanted basically, and the doctor was very understanding about that so you know I basically just, you know, I basically just take them until, you know, I ah until I fell asleep happily

The overuse or abuse of alcohol and illicit drugs, as well as the misuse of prescription drugs (e.g., opiates), has been found to be greater in the chronic pain population than in the population as a whole (Demyttenaere et al., 2007; Manchikanti et al., 2007). Past illicit drug use, alcohol abuse, multiple pain sites, depression, having a car accident as the cause of pain, or having previous drink driving convictions have all been identified as risk factors (Manchikanti et al., 2007). Note that at least one of these risks factors applied to each of the three participants who described drug and/or alcohol use in response to chronic pain.

Summary

The participants had a range of experiences when seeking treatment and care for their chronic pain. The decision to seek treatment was influenced by experiences of symptoms and self-management, as well as by financial factors, such as the perceived value of treatment in relation to cost and the high cost of CAM. Experiences suggest that the medical system acts as a major gate-keeper to the treatment of Māori who have chronic pain. Experiences within the medical system were evaluated both negatively and positively. Finally, the participants had had a range of experiences taking medication and other substances, as they sought relief or reduction in their symptoms of pain.

Negative Perceptions, Negative Experiences

This final superordinate theme encompasses the participants' experiences of living with a chronic condition that tended to be perceived negatively by both the participants themselves, and the people around them. Chronic pain was a stigmatised condition that was difficult for people who were not experiencing it, or 'outsiders', to understand. This left some of the participants isolated and lonely, breaking down relationships, and restricting the amount of social support that they had. In addition, the participants' own reluctance to burden others with their chronic pain manifested in stoic responses and the downplaying of symptoms.

Living with chronic pain: Stigma and isolation

This subtheme captures the participants' experiences of living with a stigmatised chronic condition that was difficult for 'outsiders' to understand. This left some of the participants isolated and lonely, breaking down relationships, and restricting the amount of social support that they had. Notions of stigma tended to be bound to the invisible nature of chronic pain; 'outsiders' found it difficult to understand how the participants were in pain when there were no visible symptoms:

Hoani, L384: Yeah yeah I think that they don't believe it's still there, should be gone after so many years or they just forget. On the outside of my frame I look too healthy to suffer from injuries on the inside of my body

Teresa, L515: especially because you can't see it it's different if you've got a broken arm or you know you've had an amputated limb or something you know people can see it and think oh you poor thing and although that may not be painful to that person any more it just looks worse so internal things and mental, um, what am I trying to say, mental health sort of problems um, yeah people find it a lot harder to understand

This 'invisibility' was associated with suggestions that people with chronic pain might be making it up. This has a strong influence on the stigma of chronic pain, and the tendency towards disbelief from people in the participants' lives. In these cases people with chronic pain can be conceptualised as having 'liminality' – being 'in between' the worlds of mind and body – which is seen as threatening the social order (Jackson, 2005). In Sarah's instance, this contributed to her reluctance to be labelled with the term chronic pain:

Sarah, L224:

S: I used to think people who had chronic pain were, sick in the head!

Z: Right, that's a that's a common perception actually yeah

S: Yeah well, yeah I thought it was a easy way out

Z: Yeah

S: But even now I still don't class myself as having chronic pain?

Z: Uh huh

S: I just have pain every day

Z: Yep, yeah you don't like seeing it as being chronic =

S: = Labelled =

Z: = the label, yeah yeah sure that's fair enough

Whereas for Hoani and Teresa, it meant they were reluctant to talk about their chronic pain with 'outsiders', for fear of being seen as weak or in an inferior state:

Hoani, L365: Well they know but um (2) I suppose if I complained more often they they'd know that it's still happening yeah yeah yeah I'm not very vocal about it to them as I do not want to sound like a useless weakling really yeah

Teresa, L492: that's also another reason why I don't really talk about it that much is thinking oh well, you know, like when you were younger you thought it would never happen to you you never talk about you know, you thought it was an, inferior state {laughs} I don't know I think oh my God I can't admit to having pain

Sometimes, the reluctance to talk came from people in the participants' lives, for example Makareta wanted to talk to her family about it, but they did not:

Makareta, L479: my family have experienced a lot of pain and they do expect me to put up with it, and they don't like me complaining about it, and they think that I'm weak when I do that and basically all I get from you know the people that I do talk to about my pain is, why don't you talk to a psych a counsellor about it?

Notice that in this case, although her family have experienced pain themselves, this made them less rather than more empathetic. Previous research has found that openly talking about chronic pain with family and friends was perceived as 'complaining' and as a source of frustration (Campbell & Cramb, 2008).

Stigma and disbelief have been commonly discussed in the wider literature on chronic pain (Dewar et al., 2003; Jackson, 2005). Stigma has been described as a form of categorical inference, whereby the unexplainable – and thus negative – features of chronic pain have come to be associated with fundamental character flaws in the individual experiencing it (Jackson, 2005). The features of chronic pain that are unexplainable are those that contradict dominant cultural understandings of pain as an acute problem (i.e., one that is visible and time-bound): "we have all had pain, but our pain went away" (Jackson, 2005, p. 340). To the stigmatiser, these features have become more salient than any other aspects of that individual, even though they are often aware of evidence that contradicts their negative impression (Jackson, 2005). Therefore, as R. A. Hilbert puts it, people with chronic pain 'fall out of culture' (1984, cited in Jackson, 2005).

This stigma or 'fall out of culture' meant that chronic pain was a socially isolating experience:

Makareta, L406: I tend to be very reclusive and stay home a lot, um and that makes me lonely

For Hoani, this isolation was affecting his ability to learn Te Reo Māori, which was important for his sense of Māori identity:

Hoani, L562: Yeah yeah well the language, I find it difficult because, I don't have anyone to kōrero [talk] in Te Reo Māori with yeah I I have people in class and all that but it's a very short period of time to kōrero in Te Reo, but after that yeah I, (2) I'm more of a loner too since the accident

Experiences of isolation and loneliness were also evident in the loss of relationships with family members, partners and children:

Makareta, L381: during that time I lost custody of my son and had two mental breakdowns, I entered into a relationship with (name removed) who is now living here as, yeah my partner, and, um (2) I've had that to manage as well as the chronic pain?

Hoani, L532: (4) Yeah yeah well (2) it pretty much broke up my relationship, after living together for 13 years. I was not there with the bringing up of my two sons, the oldest boy at that time was five and the pōtiki/youngest of the whānau was three. I remember when I visited them, my youngest said, Dad you can live here and sleep on the couch! Sob sob sob, that makes me sad, my two boys are young men now and do not have or want to have contact with me, that makes me even sadder sob sob (1990)

Social withdrawal, isolation, loneliness, and decreased social functioning have been reported in other research with people who have chronic pain (Biro, 2011b; Jamison & Virts, 1990; J. A. Smith & Osborn, 2007). Reasons given for social withdrawal include fear of being judged or pitied due to chronic pain, or a sense of shame or embarrassment (J. A. Smith & Osborn, 2007). This in turn could have serious consequences for the mental wellbeing of the participants, as the ability to fulfil valued social roles is reduced, and sources of social support become fewer (Campbell & Cramb, 2008; Osborn & Smith, 1998).

Indeed, because chronic pain was described as an experience that an 'outsider' would not understand, the social support that people offered often seemed to fall short of what was needed:

Makareta, L180: my friends drifted away because I'd moved home with my Mum and they knew I was having problems and they gave me my privacy and, so I felt isolated, and my family didn't know how to talk about it with me um, so they left me alone as well, and basically I was left to talk to the psychiatrists {laughs} so, I've been doing that now for like eleven years

Teresa, L522: unless you've suffered you you cannot, there's no way you can empathise

Friends, family members or colleagues who had experienced chronic pain or chronic health conditions were seen as the only people who could understand, which therefore limited the number of social support options available. When social support was present it was viewed as helpful, as experienced by Kate, who has a restricted diet due to her IBS:

Kate, L933: the fact that I've got such a support network that they people go out of their way to make me things I can eat they don't like me not eating when I'm around them or oh sorry can I eat this around you, and um can you eat these certain things, I've I've saved all the packets so you can read them, um, so I do have a really good support network

Having good social support is associated with a range of positive outcomes in people with chronic pain, including decreased depression, positive treatment outcomes, lower perceived pain intensity, better quality of life and functional status, and less use of pain medication (Jamison & Virts, 1990). In comparison, having an unsupportive family was associated with continuing searches for different medical treatments, lower likelihood of returning to work, and greater interference from pain (Jamison & Virts, 1990).

Stoicism: I don't want to be a burden

This subtheme captures the participants' reluctance to burden others with their chronic pain, and their experiences of downplaying their pain or being stoic. The participants' experiences of isolation, loss of relationships, and inadequate social support described in the previous subtheme were present alongside their own reluctance to burden others with their chronic pain. Perhaps the stigma and lack of understanding from 'outsiders' contributed to this reluctance:

Delia, L822: maybe there's some some shame and embarrassment about it because oh I'm sick again you know just like repetition {laughs} the poor people must be sick of my texts or sick of hearing I'm in hospital again, you know people have got other lives to live, you know you don't want to be burdening them with your problems

Kate, L914: Um, and I hate bringing other people down, with my pain especially my friends and stuff and it's like ooh can't drink today or, nah I really just want to stay home today

Keeping pain to oneself may be a way of maintaining positive relationships with family and friends (Campbell & Cramb, 2008). It may also be a way of maintaining a form of social identity as a 'healthy' person, despite private experiences of a painful body (Osborn

& Smith, 1998). Research with African/Caribbean immigrants to the UK found similar results, namely that pain was something to bear and not to burden others with (Rogers & Allison, 2004).

Perhaps because of this reluctance, the participants described incidents where they had downplayed their pain in order not to draw attention or undue sympathy to themselves:

Jake, L103: a lot of people say things like harden up and you know that kind of thing and and it's really easy to do that I mean I I did that for a long long time because I knew that if I told anyone about it I wouldn't get the good jobs

Delia, L232: I got up in the morning and put on my 'I'm ok' face which I often do, um and I said to Mum oh I'm feeling a bit sick I might go to the doctors and I'll you know I'll just see what happens but all the whole time I was feeling like I was about to die

This appeared to be a pattern that they saw with other Māori whom they knew, who were often in role modelling positions:

Delia, L792: oh I've heard tonnes and tonnes of examples of kuia [female elder] or kaumātua who are in massive pain but they'll sit through a whole pōwhiri [welcome ceremony] and you know they're sick they're tired they're hungry but they'll sit there for the whole tangi [funeral] or whatever it is and um, aches and pains you know people, Māori in particular just carry on regardless, um while sickness or or um you know stress or whatever

Teresa, L411: like with my Dad I mean he's he's older now but, you know, and he he's very like staunch, he can be in the most intense pain, and you'll say are you ok Dad – oh fine! And he's done that in the past, and then, like one night we were there and he just collapsed into his, like did a face-plant into his dinner and we had to get the ambulance and they said well did he not complain was there no, and I said nah he's fine, he always says he's fine!

Pain was something to be endured privately, not something to complain about, and there seemed to be social pressure to deal with it 'well':

Makareta, L436:

M: my Mum deals with it a lot better than I do {laughs}

Z: Does she [{laughs} what what are her ways of dealing with it

M: [Yeah well she doesn't complain] she doesn't moan she doesn't try to understand it and she doesn't use things to cover it up she just gets on with what she has to do

Z: Uh huh

M: So she's a very good example of you know um someone that is dealing with her pain successfully within society um me myself I kind of um I'm not that advanced so I'm still learning as I go

There has been reference to similar understandings of pain in the wider literature, whereby it is seen as a weakness that can, or should, be controlled by positive thinking or psychological strength (Kugelmann, 1999). The onus is on the individual to be positive or motivated in the face of pain, leading to blame when this level of coping is no longer possible (Kugelmann, 1999). Indeed, sometimes the chronic pain became too much, and stoicism was no longer possible:

Jake, L413: I tried it for years just hiding it but then sooner or later it would just be enough's enough you know

Makareta, L449: you don't just get over pain like that! You hold on to it, you feel it, you understand it, you know it, you try to um let it go if you can um, you know if you can't then you have to take it with you

Bassett and Tango's (2002) research with Māori physiotherapy patients also alluded to the idea that pain was something to be tolerated without complaint, as did that of Fennell (2005). Stoicism has also been found to be highly valued in previous research with American Indians experiencing painful symptoms, who expressed a preference for privacy and a desire to keep a sense of pride (Haozous et al., 2011; Kramer et al., 2002).

Stoicism can be understood in a number of ways, for example Delia described stoicism as a way of "trying to grab some self worth back from the powerlessness" (L814) imposed on her by chronic pain. Other research with Māori patients has conceptualised stoicism as a form of the 'wait and see' attitude, whereby Māori wait until it is clear that their health problem is not going to resolve itself before seeking treatment (Jansen et al., 2008). Furthermore, stoicism has been described as a response to the Māori belief that it is inappropriate to draw too much attention to oneself or to 'make a fuss' about individual needs (Jansen et al., 2008). This belief does not fit well within a healthcare system that values individualism and self-advocacy (Jansen & Smith, 2006).

Summary

Chronic pain tends to be perceived negatively, which meant that many of the participants' experiences of chronic pain had been negative. Stigma was embedded in the participants' experiences, particularly with regards to visibility and belief. Living with chronic pain was an isolating experience, associated with a breakdown in relationships, and limited social support from 'outsiders' to chronic pain. The participants themselves did not want to be a burden to others, and appeared to approach and deal with their chronic pain with a sense of

stoic resolve. This is not to suggest that Māori may have a greater tolerance to pain, but rather that pain was treated as something to be endured.

The Relationship between the Four Superordinate Themes

The four superordinate themes identified in the IPA were distinct but interrelated. The first superordinate theme ‘A life transformed by the experience of chronic pain’ is the most central to the participants’ experiences and provided a context and general background for the other three superordinate themes. All of their experiences – those more specifically related to being Māori, their treatment experiences, and negative perceptions and experiences of chronic pain – were viewed through the lens of a painful body. The very nature of chronic pain means that it is ever-present in the participants’ lives, and central to their world. This understanding fits with phenomenological perspectives which position chronic pain as a way of ‘being-in-the-world’ (Bullington, 2009; Kugelmann, 1999). ‘Experiences of chronic pain as Māori’, ‘Evaluating treatment experiences’, and ‘Negative perceptions, negative experiences’, were therefore embedded within this ‘pain-full world’ (see Figure 1).

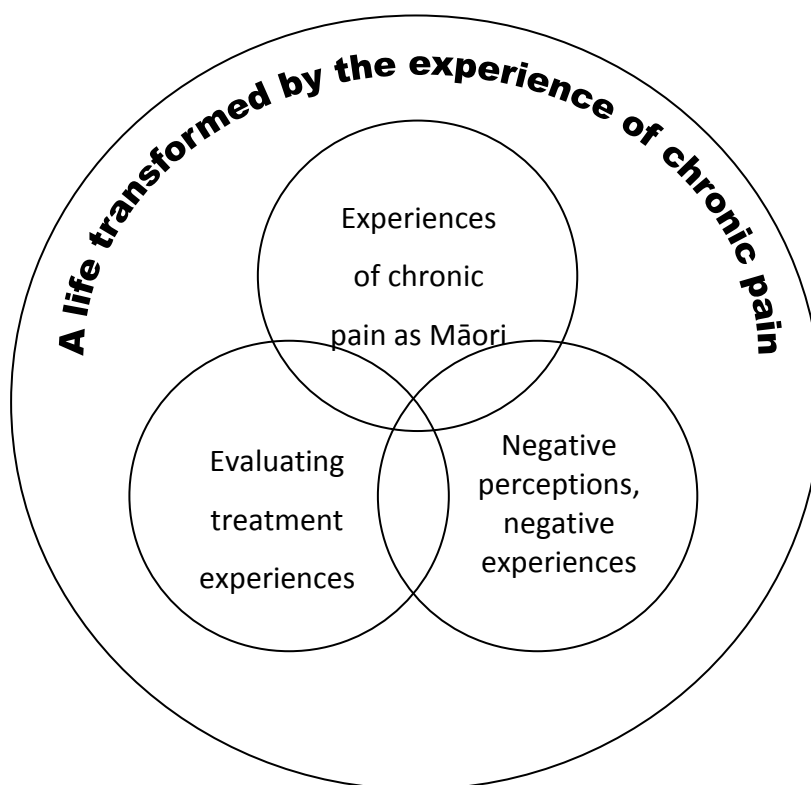


Figure 1: A conceptual model of Māori experiences of chronic pain - the 'pain-full world'

The importance of these three aspects of the chronic pain experience varied considerably between the seven participants, and can therefore be conceptualised as shifting and malleable depending on the individual person and their situation. Compare the experiences of Delia with those of Jake in Figure 2 and Figure 3.

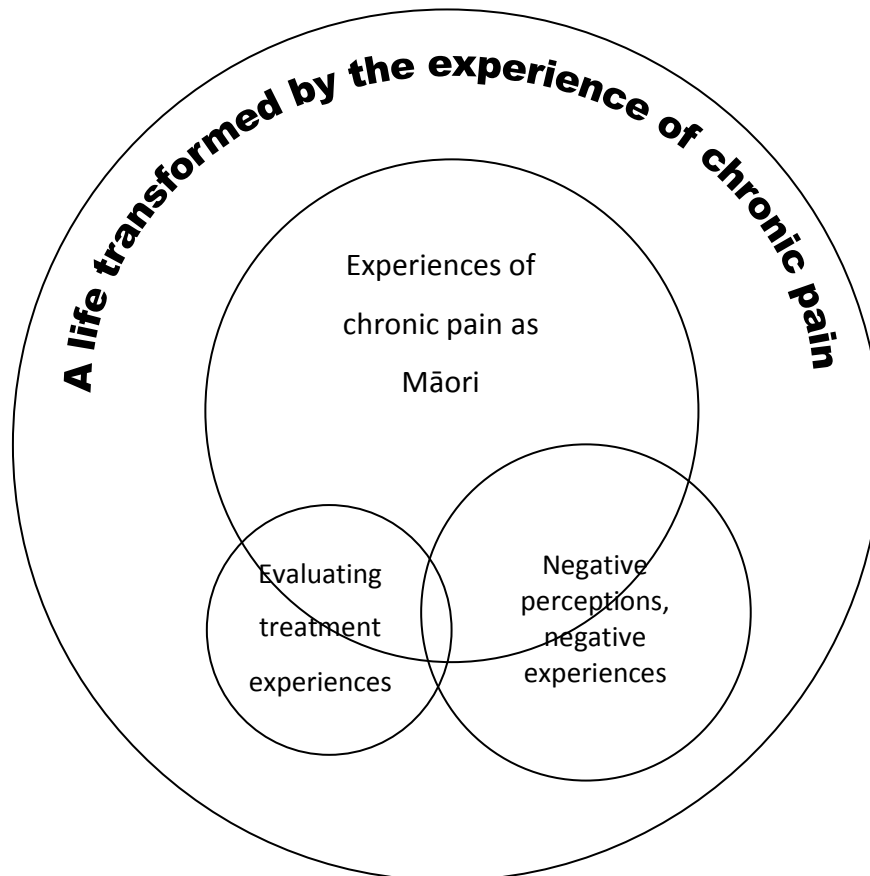


Figure 2: Example - Delia's 'pain-full world'



Figure 3: Example - Jake's 'pain-full world'

These examples show that chronic pain experienced as a Māori were more important and central to Delia's 'pain-full world', whereas evaluating treatment experiences was more important and central to Jake's 'pain-full world'. By using this conceptual model of Māori experiences of chronic pain, we may be better able to understand the issues that are of primary importance to them, and offer treatment and care that is more specific to their individual needs.

Chapter 7: Reflexivity, Implications, Research Considerations, and Conclusion

This chapter starts with reflexivity with regards to my background and the influence this had on the analysis. Implications and recommendations are then discussed for: Māori who have chronic pain; friends, whānau and partners; medical professionals; government and policy; theoretical development; and future research. A series of general research issues will then be considered, followed by those specific to conducting IPA, and conclusions.

Reflexivity

Due to the interpretative focus of IPA, and the central role that the researcher plays in that interpretation, an important feature of IPA is reflexivity (Eatough & Smith, 2008; J. A. Smith & Osborn, 2003). The researcher must engage in a process of examining their pre-existing knowledge and perceptions of the subject, and the various ways that this may have impacted the analysis and process.

My own knowledge and experiences

Having had an interest in chronic pain for a number of years I have read widely about the topic in general and the experiences of people with chronic pain specifically. The analysis therefore took place through the lens of my background knowledge, undoubtedly influencing the outcome. For example, much of the research that I have read is based on treatment trials that test outcomes using quantitative questionnaires. I therefore found it difficult to look at the data with a purely experiential focus; because my understandings of causal relationships and influences on the experience of pain were so strong, I had to resist describing the participants' experiences in this way. In addition, I spent eight weeks earlier in the year completing a practicum at a chronic pain clinic, during which time I had extensive exposure to people (mostly non-Māori) with chronic pain and the sorts of issues that were important to them. I was supervised by a clinical psychologist and observed multiple patient interviews where the aim was to gather information about how chronic pain was affecting their lives. The questions that I asked in the interview were similar to those used in a clinical interview setting like a chronic pain clinic, other than those that had a specific focus on Māori. I therefore may have unwittingly omitted questions that could have more relevance to Māori.

Before the interviews began I disclosed my status as a person with chronic pain. Sharing this insider status made the participants more relaxed and comfortable – there was a sense of relief at knowing that I would understand and empathise with their experiences. It is possible that the participants did not feel the need to elaborate on their experiences to someone who knew what it was all about, as opposed to sharing their experiences with an ‘outsider’ to chronic pain, particularly because they felt that ‘outsiders’ do not understand. Having ‘insider status’ in research has been discussed by Nielson (2007), who also conducted research on chronic pain, whilst experiencing it herself. Being an insider in chronic pain research can be seen as valuable in the sense that a deeper understanding is likely to be reached (Nielsen, 2007). This is particularly so in minority groups who have not yet had a chance to voice their experiences (Nielsen, 2007), as was the case here with Māori who have chronic pain.

However, having chronic pain meant that I analysed the participants’ experiences through the lens of my own ‘pain-full’ world, picking out the issues that – although important to the participants – were important to me. My own experiences provided an informal validation process, using logic such as ‘if it has happened to me too, it must be an experience worth describing’. There were also times when my own pain was so overwhelming that I could not sit and write about it; not only because sitting for long periods tends to exacerbate my pain, but also because the experiences and emotions of the participants resonated so strongly with my own. I found the analysis process particularly difficult during such times, as my own negative experiences began to seep into the way I saw the data, perhaps producing a more pessimistic account.

The same was true of my insider status as a Māori: although I did not have a strong upbringing within Māori cultural perspectives or worldviews, I came to view all of the participants’ experiences as being embedded within these perspectives. However, I became conscious that not all Māori would agree with this viewpoint, and further, that non-Māori – particularly those who provide treatment and care for Māori with chronic pain – would benefit from having Māori experiences made explicit.

Insider researchers have been accused of being biased by their subjectivity, however Nielsen (2007) argues that a number of processes can be used to quell such accusations (which tend to come from those who conduct quantitative and therefore ‘objective’ research). The processes that I applied were: transparency about insider status, the use of

semi-structured interview methods, reflexivity, and a process of checking interpretation and understanding with participants. A further disadvantage may be that of “overlooking the familiar” (Nielsen, 2007, para. 18), where extensive experience with the phenomenon may lead the extraordinary to be viewed as ordinary, or assumptions of meaning to occur. However, awareness of this issue, and a thorough process of ‘checking’ the interpretations reduces this likelihood. Overall, I felt that being an insider to both chronic pain, and Māori identity, was an advantage to the present research and analysis process, and this insider status was well-received by the participants as well.

Researcher intervention

It appeared that participating in the research was a valuable and positive experience overall; several participants expressed afterwards that they ‘felt better’ or had found it useful to talk about their chronic pain. These comments led me to reflect on my role as a researcher and whether the interview had been a form of intervention. Considering that all participants expressed a reluctance to talk about their chronic pain with friends and family members, would there have been a benefit to my giving them permission to speak freely about their experiences of chronic pain for an hour? My instincts tell me ‘yes’. Although my intervention in the lives of the participants was brief, there was a sense that it had been of some benefit to them, however small that may have been. In addition, previous research has found that brief courses of talking therapy, based on principles of cognitive behaviour therapy, can be conducted over the telephone with people who have chronic pain, with noticeable improvements in ratings of overall health, and ratings of ‘feeling better’ (Medical News Today, 2011).

Implications and recommendations

There are a number of implications that can be taken from the findings of the present research, which I will address in the form of a series of recommendations for the different stakeholders involved in chronic pain.

Māori who have chronic pain

The first point to make for the participants of this research, for other Maori who have chronic pain, and for people who have chronic pain in general, is: you are not alone. Despite variation, diversity and complexity in the participants’ accounts there were also

commonalities of experience, many of which related to wider qualitative research with people who have chronic pain. Living with chronic pain is not easy, at times it is debilitating, and considering the all-encompassing effects that it has on the life of the sufferer, a degree of psychological distress is understandable. What you are experiencing is real and you have the right to be taken seriously. It is clear that chronic pain needs to be reconceptualised or indeed acknowledged as a chronic disabling physical condition (Crowe et al., 2010).

Several of the participants expressed uncertainty about the cause of their pain, factors likely to exacerbate it, why it was persisting, and why certain forms of testing and treatment are unlikely to be useful. Information about the relationship between physiological processes that occur in the brain and body, and how they are influenced by psychological, social, and cultural factors would be useful, and can even reduce the threat value associated with the pain (Butler & Moseley, 2003; Meeus, Nijs, Van Oosterwijck, Van Alsenoy, & Truijen, 2010). Books such as 'Explain Pain' by Butler and Moseley (2003) are specifically designed to inform those living with chronic pain in a simple and accessible format, as well as the people around them, such as family members or medical professionals. Creating a booklet or pamphlet in consultation with Māori, that is specific to their experiences and needs, would be even better.

As discussed at several points in the analysis and discussion, the notion of individual responsibility for health is strong in the dominant biomedical system, and although biopsychosocial approaches to health are helpful in terms of understanding the multiple interacting factors that have an impact on chronic pain, they can also act to increase individual responsibility (Kugelmann, 1997). However, concerns about individual responsibility and victim-blaming should not outweigh the value of the participants' efforts at managing their chronic pain. They were clearly taking responsibility for their own wellbeing: many of them acknowledged the importance of keeping active despite being in pain, a strategy that has been found to be effective and particularly important in cases of chronic back pain (Critchley & Hurley, 2007). They also employed strategies (e.g., CAM use, rest) to keep themselves 'well' more generally, perhaps as a way of ensuring that they were better able to deal with the pain. I encourage them to continue with these efforts.

I also encourage the participants, and other Māori with chronic pain, to engage in greater consultation with their GPs about the resources that are available to people who have

chronic pain, such as referrals to ACC-funded providers like physiotherapy, chiropractic, acupuncture and osteopathy (where possible), or publicly funded services such as multidisciplinary chronic pain clinics. Multidisciplinary treatment is considered to be the most effective for chronic pain (Ashburn & Staats, 1999), addressing many aspects of life with chronic pain, not just physical concerns. Addressing mental health concerns such as depression or anxiety can even have a positive flow-on effect on the pain itself (Bair et al., 2003). However, it is acknowledged that this may not be easy for those who are experiencing co-morbid mental illness, financial concerns, or perhaps even the culturally-bound reluctance to question the doctor, to ask for further information, or to have to be forceful or demanding (Jansen et al., 2008). Medical professionals therefore need to take responsibility for this consultation too.

Friends, whānau and partners of Māori who have chronic pain

There was a clear need for more social support and opportunities to talk about chronic pain. It may be the case that chronic pain is difficult for friends, whānau and partners to understand simply because it has never been explained to them. Considering the participants' reluctance to talk about chronic pain and the desire not to burden others, important people in their lives may need to take the first step by offering their support or asking about how they are doing. These conversations may be difficult but they need to happen; otherwise people with chronic pain may become increasingly socially isolated, potentially impacting their mental health and physical wellbeing (Jamison & Virts, 1990). The use of a neutral third party or facilitator may be necessary, particularly if there is a general reluctance to talk about chronic pain from both parties. Information sessions or discussion sessions could be arranged within whānau circles, at marae, or at wider hapū or iwi events, if deemed appropriate. This could have implications for the allocation of funding within various health organisations, which may not yet recognise chronic pain as an important health issue for Māori.

Medical professionals working with Māori who have chronic pain

It was clear that the participants were not getting the information, support, and treatment that they needed from the medical system, although trusted GPs were a notable exception for some. GPs and other medical professionals, particularly those who act as gatekeepers for further treatment, have a responsibility to better educate themselves about chronic pain

and its various correlates and consequences in a person's life (Parsons et al., 2007). Acute, biomedical understandings of chronic pain, with clear separation between mind and body, and an inherent suspicion that the pain might be 'in the head' were all beliefs apparent in the participants' experiences within the medical system, and are supported in a literature review of patient-provider interactions about chronic pain (Parsons et al., 2007). There is a need for greater compassion for, and validation of, lived experiences of chronic pain from medical professionals (Dewar et al., 2003).

There has been a general shift internationally towards using shared decision making to improve patient experiences in the healthcare system (Frantsve & Kerns, 2007). The patient and provider often have different perspectives on the cause, consequences, and best treatment of their chronic pain, resulting in lower patient satisfaction and poorer treatment outcomes (Parsons et al., 2007). Finding ways to foster a shared understanding of the patients' experiences of chronic pain is therefore paramount. For example, provider training in communication has been found to enhance outcomes in patients with chronic pain (Frantsve & Kerns, 2007).

Not only do medical professionals need to take greater responsibility for understanding and developing shared understandings of chronic pain, but also for understanding cultural conceptualisations of health that are different to their own, so that Māori and members of other cultural minorities in New Zealand feel more comfortable talking about their experiences, and experience greater participation in their own healthcare (Mark & Lyons, 2010). Most of the participants expressed having a holistic view of health and wellbeing, specifically the importance of spirituality and whānau, which meant that they were drawn to rongoā Māori and/or CAM for their treatment and self-care. These findings are similar to previous research on Māori views of health (Cram et al., 2003; Jones, 2000; Mark & Lyons, 2010). Evidence of racism and restricted access to the medical system are also urgent indicators that improvements need to be made in the care of Māori who have chronic pain, and are unacceptable within the context of Te Tiriti in Aotearoa and in relation to human rights.

There needs to be greater understanding of Māori views of health and forms of treatment within the medical system in Aotearoa, perhaps facilitated through education or compulsory professional development (Poynton et al., 2006). The medical professionals or treatment providers that the participants had the most positive experiences with were those

that took their concerns seriously, seemed to care, took an interest in them as a person, helped them access needed treatment and information, talked to them in a straight forward manner that was not patronising, and in general, had a more holistic view of wellbeing (e.g., acupuncturists, naturopaths, homoeopaths, healers). These experiences should be taken into account when planning education or professional development.

Government and policy level

At the government and policy level, there needs to be lobbying and dissemination of information regarding the importance of chronic pain as a health issue and, more specifically, the need to better support Māori with chronic pain. Publicising the issue may be a way of reducing the stigma associated with chronic pain, and breaking the association between visibility and belief (Dewar et al., 2003). An example that comes to mind is the 'Like Minds, Like Mine' campaign that has been running for several years in Aotearoa, which is aimed reducing the stigma of mental illness and has resources specific to Māori (Like Minds Like Mine, 2009). As mentioned previously, disseminating a book such as 'Explain Pain' (Butler & Moseley, 2003) or material of a similar nature specific to Māori, could be useful in educating both the person with chronic pain, and those around them. In addition, considering how health professionals respond to Māori who have chronic pain, change at the policy level (training requirements or professional development for medical professionals, for example) may be necessary – particularly with regards to addressing racism.

Several of the participants were reliant on government-run sickness benefits that were not meeting all of their needs or had been a source of distress and burden as opposed to support. Experiences with ACC suggest there may be a reluctance to help people with back injuries, and to challenge the condition as degenerative, rather than the result of accident or injury. This was literally adding 'insult to injury' for the participants who were already struggling with a medical system and social environment that doubted the existence of their pain. Racist treatment by ACC employees was also suggested. There needs to be a system in place to support Māori seeking ACC compensation, particularly in instances where they perceive unfair treatment or when their condition is challenged and they do not have the financial resources to deal with the situation.

None of the participants who were eligible for ACC compensation at the time of their injury or accident remained on it for long, forcing some of them to seek an Invalid's

Benefit from WINZ. This generally resulted in a significant loss of income associated with negative lifestyle changes and difficulties with paying for needed treatments. The Invalid's Benefit appeared to be insufficient to support some Māori who have chronic pain. Another suggestion that has been made in previous research is to offer government subsidies to support employers who are willing to accommodate and support employees with chronic pain (Dewar et al., 2003). In light of the government's commitment to Te Tiriti and to equality in health (King & Turia, 2002; Ministry of Health, 2002), it is clear that a number of changes need to be made before the needs of Māori with chronic pain can be met.

Theoretical development

IPA, with its underlying theoretical constructs of phenomenology, hermeneutics, and idiography, appeared to be a useful methodology for understanding the lived experiences of Māori with chronic pain. Although many of the experiences described are similar to those found in previous qualitative research with people who have chronic pain, both in Aotearoa and beyond, there were also experiences related to being Māori which add to conceptual and theoretical understanding. The participants talked about chronic pain in ways that suggest that their whole lives had been transformed by their embodied experiences of it. Experiences related to being Māori, experiences of treatment, and experiences of stigma were embedded within this central transformation experience, and it was evident that chronic pain had become a way of 'being-in-the-world'. Using a conceptual model of the 'pain-full world', these three aspects of experience can be represented, in the hopes of gaining a better understanding of the issues that are particularly important to Māori who have chronic pain.

Although the biopsychosocial approach appeared to be a good fit with the participants' experiences in general, it did not take culture into account. This research demonstrated the importance of considering culture in experiences of chronic pain; the participants' experiences were deeply embedded within their culture, as evidenced in their talk of Māori identity, the importance of the whānau or collective, holistic views on health, experiences of racism, and access to the medical system.

The way that the biopsychosocial approach draws attention to the individual and responsibility, specifically in the case of chronic pain, is also something that deserves further attention. Here is a theoretical perspective that simultaneously helps us to understand a chronic illness whilst placing responsibility for recovery from it firmly within

the individual (Kugelmann, 1997). This downplays wider societal, political and structural influences on Māori experiences of chronic pain and on the health of Māori more generally, and continues to blame Māori when they are unable to deal with their pain in a way that is socially acceptable.

Future research

Although there is now a significant amount of research that addresses concerns about disparities in health outcomes between Māori and non-Māori, there was none that focused on the experiences of Māori who have chronic pain. Note that a review article based on the existing literature on Māori and pain (McGavock et al., in press) is pending publication in 2012 with the journal *AlterNative* (<http://www.alternative.ac.nz/>). Along with the review article, this research contributes to filling a significant gap in the literature. It is, however, a growing area of interest in Aotearoa; during the course of completing my Masters, I made contact with three other researchers covering topics related to Māori and pain.

Where to from here? I believe there needs to be further research conducted in relation to the medical system as a gatekeeper to effective treatment for Māori and others who have chronic pain. What beliefs do GPs and other medical professionals in Aotearoa hold about chronic pain? What have been their experiences of treating Māori who have chronic pain? Are they aware of the need for improvements in practice with people who have chronic pain, and with Māori specifically? Such research would ground the findings of the present research in practice and lead to the identification of specific points of change and improvement for the treatment of Māori who have chronic pain.

Research considerations

These Māori participants came from different iwi, hapū, and whānau contexts, reflecting the diversity of Māori as a group. This research captures both the differences and commonalities in their experiences with chronic pain and as such should not be viewed as a definitive Māori viewpoint that would apply beyond the participants themselves.

The participants were interested and willing to talk about their experiences of chronic pain and may therefore reflect a subset of experiences that would differ from Māori who were not willing to take part in the research. Finding seven participants was a long process, and despite the different channels and connections that I used, Māori with chronic pain were an

elusive population to reach. Indeed, several of the people who I asked to help me recruit participants knew Māori who fitted the criteria, but said that they were not willing to talk to me about it.

There are several reasons why this may be the case, first being the stigma and stoicism that was reflected with the present participants. Some people just don't want to talk about their chronic pain. The other reason may be that, as someone new to research with Māori, and new to the geographical area, I was not well known or visible in the communities where I was trying to recruit. It is well known that Māori are more comfortable engaging in research when it is conducted by a member of their community or someone known to them (L. Pere & Barnes, 2009). Two of the participants in the present research were known to me and volunteered their help almost immediately following my request. A further reason may be the language that I used in the recruitment process, as several of the participants expressed a reluctance to identify themselves using the term 'chronic pain'; perhaps if I had explained the criteria using alternative terms, I would have had a better response.

Research quality

Although it is not generally considered appropriate to apply positivist notions of research rigour (i.e., validity, reliability, generalisability) to qualitative work (Chamberlain, 2000), there were a number of processes engaged in that contributed to the present research being of sound quality and conducted in a manner that was respectful and in line with Kaupapa Māori principles. Before the interviews began, I attempted to explain who I was, aspects of my whakapapa, and my reasons for undertaking the research. I believe openness and disclosure on my part contributed to developing rapport and to the participants feeling comfortable. I also used the practices of sharing food and giving of koha which were well-received. The processes of transcription review and sharing narratives in the initial stages of analysis were also felt to be valuable, although only three participants responded to the request for feedback from the narratives. Finally, I engaged in reflexivity throughout the research process, gaining some valuable insights into aspects of my experience that were influential on the analysis and research process as a whole.

Some have argued that IPA relies too much on the abilities of the participants to articulate their experiences in an interesting and insightful manner (Brocki & Wearden, 2006). Perhaps because chronic pain was an issue of significant personal importance to the participants, and they appeared to have had little opportunity to discuss it openly prior to

the interview, all of them produced accounts of their experiences that were interesting and insightful. However, I did find that the participants varied in their levels of ‘chattiness’ (and thus how much I prompted them as an interviewer), and that the participants who were more comfortable being interviewed or had strong communication and language skills produced accounts of experience that were both clearer and richer, than those who did not.

Smith has published criteria for what constitutes acceptable and good quality IPA, following a review of IPA research on illness experience (J. A. Smith, 2011a, 2011b). To be acceptable: the paper must clearly subscribe to the theoretical principles of IPA – it is phenomenological, hermeneutic, and idiographic; the paper must be sufficiently transparent so the reader can see what was done; it must have a coherent, plausible, and interesting analysis, including theme summaries and interpretation of extracts. As well as meeting the acceptable criteria: the paper should have a clear focus; the paper will have strong data; the paper should be rigorous; sufficient space must be given for elaboration of each theme; the analysis should be interpretative not just descriptive; the analysis should be pointing to both convergence and divergence; and the paper needs to be clearly written (J. A. Smith, 2011a).

Further markers of quality IPA research have been suggested in response to Smith’s (2011a) review. Todorova (2011) argued for the importance of socio-cultural contextualisation. More specifically, that the analysis needs to be deeply embedded within the cultural, political, and historical situation or context, after all it is not just the person at the centre of the analysis, but the ‘person-in-context’ (Todorova, 2011). Similarly, Kaptein (2011) argued that IPA focuses too much on the individual, and continues to ignore political and social determinants of health. I agree with Todorova and Kaptein’s critiques, and found that at times the focus on experience detracted from contextual factors that were highly important to the participants. By presenting a review of literature that highlighted the cultural, political and historical context of Māori in Aotearoa, it is hoped that some of that contextual information has been made clear. The use of a Kaupapa Māori approach was also a step towards considering broader or more structural determinants.

Overall coherence is another criterion suggested by Todorova (2011) – do the epistemology, methodology, and methods match? There may even be situations where the context dictates that an interpretative epistemology is no longer appropriate, and that a

constructionist epistemology, for example, may provide better coherence (Todorova, 2011). Indeed, there were times when dominant discourses, which are usually discussed within constructionist epistemologies, were referred to in order to interpret the participants' lived experiences.

Maintaining consistency of methodology for the sake of it – a phenomenon which Chamberlain (2000) refers to as 'methodolatry' – is also an issue that has been raised in regards to IPA. Chamberlain (2011) argued that there should be consideration of the ways that IPA may be adapted for certain research projects. I admit that, being new to IPA, I did 'blindly follow' the step-by-step analysis process recommended for the most part, although it was adapted slightly to fit with the Kaupapa Māori approach, by starting with narrative summaries that were returned to the participants.

Despite these limitations and considerations, IPA was an appropriate methodology for research with Māori who have chronic pain, producing a rich account of their lived experiences. It was also conducted with attention to process, coherence, context, quality, and adaptation to Kaupapa Māori principles.

Conclusion

In conclusion, the participants talked about their lived experiences of chronic pain in ways that suggest a life transformed by chronic pain, becoming one of a 'pain-full world'. Cultural perspectives related to being Māori were embedded in these experiences, as were evaluations of treatment experiences, and notions of stigma and limited understanding from 'outsiders' to chronic pain. There is a need to incorporate cultural considerations into consultations and treatment with Māori who have chronic pain, perhaps by using a conceptual model such as the one presented here. We also need to move beyond the use of the biopsychosocial approach, which ignores culture, and places responsibility for managing chronic pain firmly within the individual. Addressing racist treatment and restricted access for Māori in the medical system is another urgent matter. These needs should be both informed and driven by commitments to Te Tiriti and health equity in Aotearoa.

Ahakoā ngā ueue, kia kaha, kia toa, kia manawanui

Glossary of Māori terms

Translations have been taken from the literature sources referred to in-text, from Te Aka – the Māori dictionary (Moorfield, 2005), or from my own knowledge, interpretations or understandings.

Ahakoā ngā ueue, kia kaha, kia toa, kia manawanui = When you find things that are difficult in life, stand strong, stand tall and be of great heart

Ahau = I

Awa = river

Ao tūroa = environment

Aotearoa = New Zealand; 'land of the long white cloud'; I respectfully note that not all iwi accept this as the name for New Zealand.

Ehara taku toa, he taki tahi, he toa taki tine = My achievement should not be bestowed onto me alone, as it was not an individual achievement, but that of a collective

Hā = breathe / breath

Hapū = sub-tribe / pregnant

He Korowai Oranga = the cloak of wellness

Hui = meeting (can mean 'focus group' in research setting)

Ingoa = name

Iwi = tribe

Kai = food

Kāinga ināianeī = current home

Kanohi ki te kanohi = face to face

Karakia = prayers or chants

Kaumātua = respected Māori elder (male or female)

Kaupapa = agenda/philosophy/rationale

Kawa = protocol

Kāwanatanga = government or partnership (article of the Treaty of Waitangi)

Koha = gift/contribution

Kōhanga Reo = 'language nest'; Māori language preschool

Kōrero = talk

Kuia = elderly woman, grandmother, female elder

Kūmarahou = a native shrub, also known as gumdiggers' soap. Used as a treatment for coughing, asthma, bronchitis, chest congestion. Also a blood purifier, general tonic, and is good for the liver. It has been reported to aid bladder issues and arthritis. The flowers can also be wet and rubbed in the hands as you would use soap.

Kura Kaupapa Māori = school operating under Māori custom and using Māori language

Mākutu = curse

Mamae = pain

Mana = prestige/power/influential qualities

Māori = the indigenous people of New Zealand

Māoritanga = Māori culture, practices and beliefs

Marae = communal meeting place

Mātauranga = knowledge/education

Māunga = mountain

Mauri = life principle/life force

Mihimihi = speech of greeting

Mirimiri = massage targeting soft tissue

Mōteatea = chants

Ngā mihi mahana ki a koutou = warm greetings to you all

Noa = neutral/unrestricted/free from tapu

Ōritetanga = equal citizenship or participation (article of the Treaty of Waitangi)

Pākehā = New Zealanders of European descent

Pakiwaitara = legends

Papa kāinga = original home

Pepeha = set verses that describe whakapapa links

Pōtiki = youngest family member

Pōwhiri = welcome ceremony

Pou = carved pillars or posts

Pūrākau = myths

Ranga whatumanawa = emotions

Rongoā / Rongoā Māori = remedy - plants, herbs and other items that have medicinal properties / general name for traditional remedies

Romiromi = deep-tissue massage, often targeting pressure points

Taha hinengaro / hinengaro = mental health / mind

Taha tinana / tinana = physical health / body

Taha wairua / wairua = spirituality

Taha whānau = family wellbeing

Tangata whenua = indigenous people of the land

Tangi = funeral

Taonga tuku iho = “treasures passed down from our ancestors” / customs which dictate how we are to behave

Taonga = treasure

Tapu = sacred/restricted

Tauīwi = non-Māori

Te = the (singular)

Tēnā rāwā atu koutou = many thanks to you all

Te reo / te reo Māori = the Māori language

Te Whare Tapa Whā = the four-sided house (Durie's model of health)

Te Wheke = the octopus (Pere's model of health)

Tika = right/appropriate

Tiriti o Waitangi = Treaty of Waitangi

Tikanga = customs

Tino rangitiratanga = self-determination or protection (article of the Treaty of Waitangi)

Tohunga = experts in traditional healing/chosen as leaders in their field

Tukutuku = ornamental lattice-work

Wai = who

Waiata = songs

Waka = canoe

Whaea tūpuna = female ancestor

Whaikōrero = formal speeches

Whakairo = carvings

Whakamā = shame or shyness that is culturally bound

Whakapapa = genealogy

Whakataukī = proverbs

Whakawhanaungatanga = establishing relationships in a Māori manner / making connections

Whānau = family

Whanaungatanga = extended family

Whāriki = floor mat

Whenua = land / placenta

Appendix A: Ethics Approval



MASSEY UNIVERSITY
ALBANY

26 May 2011

Zoe McGavock
c/- Dr H Moewaka Barnes
College of Humanities & Social Sciences
Massey University
Albany

Dear Zoe

HUMAN ETHICS APPROVAL APPLICATION – MUHECN 11/034
The Experiences of Maori with Chronic Pain

Thank you for your application. It has been fully considered, and approved by the Massey University Human Ethics Committee: Northern.

Approval is for three years. If this project has not been completed within three years from the date of this letter, a reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Dr Ralph Bathurst
Chair
Human Ethics Committee: Northern

cc: Dr H Moewaka Barnes & Associate-Professor A Lyons
College of Humanities & Social Sciences
Massey University

Te Kunenga
ki Pūrehuroa

Research Ethics Office
Private Bag 102 904, Auckland, 0745, New Zealand Telephone +64 9 414 0800 ex 9539 humanethicsnorth@massey.ac.nz

Appendix B: Request for Participants to Take Part in an Interview



Request for participants to take part in an interview:

“The experiences of Māori with chronic pain”

Kia ora koutou! My name is Zoe McGavock (Kai Tahu iwi) and I am a Health Psychology student studying towards a Master of Science at Massey University. If you are a Māori adult between the ages of 18 and 65 who has chronic pain, or experiences pain as the result of a chronic health condition, then I am interested in talking with you.

I would like to invite you to talk to me about your experiences of chronic pain. If you are interested in taking part or wish to know more about the research, please email me at zcmcgavock@gmail.com or phone me on (04) 801 5799 extension 62528 (office hours).

Or please feel free to contact one of my supervisors if you have any questions:

Supervisor 1: Dr Helen Moewaka Barnes, Whariki Research Group, Massey University, Auckland H.Moewakabarnes@massey.ac.nz, 09 366 6136

Supervisor 2: Dr Antonia Lyons, School of Psychology, Massey University Wellington A.Lyons@massey.ac.nz, 04 801 5799 extension 62164

Appendix C: Information Sheet



The experiences of Māori with chronic pain

INFORMATION SHEET

Thank you for taking the time to consider participating in my research. The information below is designed to give you all the details that you need to make an informed decision about whether or not to take part.

Researcher profile

Kia ora koutou, my name is Zoe McGavock (Kai Tahu iwi), and I am a student at Massey University in Wellington, currently working towards my Masters in Science (MSc) with an endorsement in Health Psychology. My supervisors for this research are Dr Helen Moewaka Barnes (Whariki Research Group, Massey University, Auckland) and Dr Antonia Lyons (School of Psychology, Massey University, Wellington).

What is the nature of the study?

I am interested in the experiences of Māori who currently have chronic pain. Chronic pain is an underdeveloped and under-researched aspect of Māori health, and it is hoped that this research could be used to improve the practice of health professionals who are working with Māori who have chronic pain.

Who can take part?

In order to take part, you must be a Māori adult between the ages of 18 and 65 who self-identifies as having chronic pain (preferably living within the Wellington or Auckland Region, but other locations are possible). Chronic pain can arise from an injury, a painful health condition, or have no apparent cause at all. You do not have to have been diagnosed as having chronic pain by a medical professional, or have received treatment for your chronic pain. The interviews will be conducted in English, therefore English competency is another requirement. However, should you wish to use Te Reo Māori at any point during the interview you are very welcome to.

What is involved in participating?

If you agree to take part, you will be invited to be interviewed by the researcher, who will ask you a range of questions about your experiences with chronic pain. The interview will be held at a jointly agreed upon time and place. Should you decide to come to the Massey University campus for your interview, public travel or parking costs will be reimbursed. The interview process is likely to take up to an hour and a half of your time, allowing time for you to fill out a consent form and a brief demographic questionnaire at the beginning, and to discuss any issues or questions at the end. The interview will be audio-recorded and later transcribed by the researcher (i.e., the interview will be typed up word-for-word, with the exception of any identifying information). A \$40 credit card / gift voucher will be given to those who take part as a koha. This is to compensate for your time and thank you for your valued contribution to the study.

You will be given the option of meeting with me again shortly after the interview has taken place, in order to read and amend the transcript of the interview, or of doing so by post. This is expected to take one hour or less, and is optional. You will also be asked to sign a transcript release form, agreeing that the edited transcript and extracts from this may be used in reports and publications arising from the research. A few months later, after I have written up the results, I will contact you again to see if you would like to discuss the results further and provide input into the analysis.

How will confidentiality be assured?

Anonymous study code numbers will be used to identify your demographic questionnaire, your audio files, and the transcripts. Any information that could be used to identify you will be removed from the transcripts and the final report. The only people who will have access to the data are the researcher and the supervisors, and all information that you share in the interview will be treated in confidence.

What will happen to the data when it is obtained?

All raw audio data and the resulting transcripts will be stored securely on a computer that is password-secured. Because the data collected includes some information about your health, it will be stored securely for 10 year with the School of Psychology, Massey University, and then disposed of.

Participants will be given the opportunity to view the transcripts and make changes or comments, should they wish to prior to analysis. They will then be asked to sign a transcript release authority form. They will also be invited to engage in further discussion of the results, should they wish. The findings from this study will be written up in a Masters thesis, and a summary of the results will be made available to all participants who request it.

How will the information from the study be used?

The information from this study will be used for publication in a Masters thesis, academic, and professional journals. Dissemination at international and national conferences is also possible. All of the information from the study that is used in subsequent publications or other dissemination forms will be anonymous and participants will not be able to be identified.

Are there any risks involved?

There are no significant risks predicted to taking part in this study. However, having chronic pain can be a difficult experience to talk about: not only does it affect you physically, but it can affect how you feel and what you think too. Therefore, you would not be under any obligation to answer a question that you were not comfortable with, and would be free to stop the interview or recording at any time, without consequence.

Please also note that the information gathered or discussed in this interview is not a form of diagnoses or treatment for chronic pain, and will not be passed on to medical professionals or health-related organizations. No advice or promise of pain alleviation will be given to the participants.

What are your rights? You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- contact me prior to the interview with any questions about the research;
- decline to answer any particular question or talk about any particular topic;
- withdraw from the study at any time, including prior to, during, or up to two weeks after the interview;
- ask any questions about the study at any time during participation;
- be given access to a written copy of the your transcribed interview, and have the opportunity to revise or delete any particular comments within the transcript;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded.
- ask for the recorder to be turned off at any time during the interview.

What do I do next? Anyone who is interested in taking part can contact the researcher directly either by email, phone, or text message (see contact details below). Due to the exploratory nature of this research only a small number of up to 10 participants will be required. These will be recruited on a “first come, first served” basis. You are welcome to contact the researcher and/or supervisor(s) if you have any questions about the project.

- Researcher: Zoe McGavock, School of Psychology, Massey University Wellington
 - zcmcgavock@gmail.com, 0274288842 or 04 801 5799 extension 62528 (office hours)
- Supervisor 1: Dr Helen Moewaka Barnes, Whariki Research Group, Massey University, Auckland
 - H.Moewakabarnes@massey.ac.nz, 09 366 6136
- Supervisor 2: Dr Antonia Lyons, School of Psychology, Massey University Wellington
 - A.Lyons@massey.ac.nz, 04 801 5799 extension 62164

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 11/034. If you have any concerns about the conduct of this research, please contact Dr Ralph Bathurst, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 9570, email humanethicsnorth@massey.ac.nz.

Appendix D: Participant Consent Form



The experiences of Māori with chronic pain

PARTICIPANT CONSENT FORM - INDIVIDUAL

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

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me.

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

Signature:

.....

Date:

.....

Full Name - printed

.....

Appendix E: Brief Demographic Questionnaire



The experiences of Māori with chronic pain Brief demographic questionnaire

How old are you?

Which sex are you? Male / Female (Please circle)

If there are any other ethnicities or cultural origins that you identify with, other than Māori, you are welcome to record this information in the space below:

.....

How long have you had chronic pain? (Please tick the one box closest to your situation)

- Six months or less
- 12 months or less
- Between one and three years
- Between three and five years
- More than five years
- Cannot remember how long

Please score the severity of your pain using a scale from 0 to 10, 0 having no pain and 10 having the worst pain imaginable.

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

Today, I would rate it as a

When it was at its worst last week, I would rate it as a

On average, I would rate it as a

Are you suffering from any of the below health conditions? (Please tick all boxes that apply unless you would rather not disclose this information, in which case you are free to leave any item blank)

- A cold, cough or the 'flu
- Hayfever
- Lung disease (e.g., asthma)
- Liver disease (e.g., hepatitis)
- Kidney disease (e.g., kidney stones)
- Stomach or bowel disease (e.g., irritable bowel syndrome)
- Cancer (including being in remission)
- Acquired immune deficiency syndrome (AIDS) or human immuno-deficiency virus (HIV) infection
- Anaemia or other blood disease
- High blood pressure
- Heart disease (e.g., angina)
- Diabetes
- Depression
- Anxiety disorder (e.g., panic attacks)
- Eating disorder (e.g., bulimia nervosa)
- Rheumatoid arthritis
- Osteoarthritis
- Chronic fatigue syndrome
- Other condition (please give details)

Appendix F: Interview Schedule

Key topics to cover (share with participant)

- How this chronic pain started – what happened
- Your experience if/when seeking treatment for your chronic pain
- What does it feel like to live with chronic pain – your experience as a Maori

How this chronic pain started – what happened

- I see here that you have had chronic pain for, can you start by telling me a bit about when the pain started?
 - Did you have an injury or illness, or did the pain just start?
- What was your understanding of what happened?
- Do you have any ideas or theories about why the pain is still there?
 - i.e., your own, or from what others have told you?
- Has anything changed? Is life with chronic pain different to what it was before?
 - In what ways?

Your experience if/when seeking treatment for your chronic pain

- Have you sought any form of treatment for your chronic pain?
 - Why? What made you seek help?
 - Why not? Have you/your whānau/your community got your own ways of managing chronic pain?
- What was this experience of seeking help like?
 - Have you seen a doctor, been to the hospital, physiotherapy, chiropractor, acupuncture, rongoā Māori treatments, anything else?
- How did they respond to you?
 - Were you taken seriously? How did they respond?
- Did you ever feel you didn't get the treatment you needed? In pain unnecessarily or under-medicated?
- What did you find useful/not useful for your pain?
- Did you feel that the cause of your pain was thoroughly investigated?
 - E.g., did you have any x-rays or scans?
- Do you take any pain killers or medications for your pain?
- What about smoking/drinking as a form of pain relief/distraction?
- If you haven't sought any form of treatment – why not?
 - E.g., was it just a personal choice, was it an issue with access/cost, fears/mistrust of medicine/hospitals?
- Health service/health provider access/ history?

- i.e., if they have other health issues, who do they usually seek help from?
- Have they had any issues with access in the past?

What does it feel like to live with chronic pain – your experience as a Maori

- Apart from all those treatments, what helps you to cope with or manage your pain?
 - i.e., do you take rests, keep active, talk yourself through it?
- Who knows about your chronic pain?
 - i.e., do you talk about it with whānau, friends, colleagues?
- What sorts of things do you tell them about your pain?
- Do you know anyone else who lives with chronic pain too?
 - Friends, whānau?
- What does it feel like to live in a body that is in pain all of the time?
- Do you feel like being Māori has influenced your experience of pain in any way?
 - The way you think or feel about your pain? Your treatments? How you have been treated by doctors?
- Do you think Maori see pain differently to Pakeha?
- Do you feel like having this pain is a normal part of life/expectations about how life is?
 - At what point did you feel like it was no longer normal, or when would you see this pain as being abnormal?
 - Do you think Maori are more tolerant of pain? How exactly?
- Do you feel like your experiences of chronic pain have changed you?
 - i.e., how you think of yourself? Your role in the family/relationships? Your roles at work or at home? How you feel about your culture/identity?
- Anything you would like to add that would add to us gaining a deeper understanding of what it is like to live with chronic pain, as a Māori in New Zealand?
- Do you have any questions for me?

- | |
|--|
| <ul style="list-style-type: none"> - Allow for silence, at least 5 seconds – don't interrupt - Don't be tempted to repair (as in conversations) - Can you think of any reasons why that might have happened? - Narratives: what was positive/negative? What led up to that/followed that? - Can you give me an example? - What happened then? - What happened before/after/at that time? - Uh huh, can you tell me a bit more about that? - Can you explain that a bit more? - What was that like? - How did that make you feel? - Ok / Really - That's interesting |
|--|

Appendix G: List of Resources Available for People with Chronic Pain



List of resources available for people with chronic pain in the Wellington Region (If the participant is from outside the Wellington Region, a list of resources specific to their geographical location will be compiled prior to the interview).

- First: consult your general practitioner. They are also the primary source for referring you for further help
- Physiotherapists who specialise in chronic pain
 - **Habit physiotherapy (referral not necessary, \$15 with ACC)**
 - Majestic Centre, Podium 3, 100 Willis St, Wellington City P 04 499 9940
 - Level 1, 24 Johnston St, Wellington City P 04 499 9037
 - Cobham Drive Retail Centre, 50 Tacy St, Kilbirnie, Wellington City P 04 387 2888
 - **TBI Health (The Back Institute) 0800 824 432**
 - Level 1, ANZ Business Centre, 21-23 Andrews Avenue, Lower Hutt P 04 570 2639
 - Level 1, 107 Mana Esplanade, Mana P 04 233 0754
 - 112 Rimu Road, Paraparaumu P 04 902 6017
 - Level 5, 111 Customhouse Quay, Wellington P 04 499 4564
 - Level 4, Wakefield Hospital, 99 Rintoul Street, Newtown P 04 381 8690
- Psychologists who work with people who have chronic pain
 - Anja Kaehmzow-Ferguson (psychologist) 027 6515264
 - Fran Hurnen (psychologist) 027 2839581
 - Roz Walker (psychologist) 021 1216435
- **CCDHB Pain Management Clinic:** The service is a multidisciplinary service and is engaged in the various aspects of pain management, including multidisciplinary assessments and treatment, medication reviews, pain management programmes, functional assessments and interventional procedures. Their aim is to facilitate both physical and emotional wellbeing and a return to a healthy and functional role in the family and community. Their team members include: Doctors, A Clinical Psychologist, Occupational Therapists, Physiotherapists, and Specialist Nurses.
 - Wellington Hospital, Riddiford Street, Newtown Wellington, P 04 385 5344
 - Kenepuru Community Hospital, Raiha Street Porirua P 04 385 5344
 - Kapiti Health Centre, Warrimoo Street, Paraparaumu P 04 385 5344
 - Level 4, Levin House, 330 High Street Lower Hutt P 04 385 5344

Appendix H: Transcript Release Authority



The experiences of Māori with chronic pain

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: **Date:**

Full Name - printed

Appendix I: Transcription Notation

- [] Indicates overlap between speakers. Also clarifies points within quotes
- = Indicates rapid speech exchange without breaks
- , Indicates short pauses
- (2) Indicates timed pauses in seconds
- Yes Indicates stress in terms of pitch or amplitude
- YES Indicates particularly loud speech or sounds
- { } Indicates significant behaviour such as laughter
- () Indicates information that was omitted for anonymity, or added by the participant in transcription review
- ! Indicates excitement or emphasis
- ? Indicates questions or rising inflection

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