"I like to be treated like a person, a little smile never costs a thing"

Weaving kaumātua experiences of living with osteoarthritis in Hawke's Bay, Aotearoa New Zealand into a collaborative Osteoarthritis-Management Toolkit

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He Mihi: Acknowledgements

Mihi mihi

Tēnā koutou	Greetings
Ko Hikurangi te maunga	My mountain is Hikurangi
Ko Waiapu te awa	My river is Waiapu
Ko te whānau a Uepohatu raua	My hapū is Uepohatu and
Hinetapora oku hapū	Hinetapora
Ko Ngāti Porou te iwi	My iwi is Ngāti Porou
Ko Mangahanea raua Ko Hinemauri oku marae	My marae are Mangahanea and Hinemauri
Ko Awatere te whānau	My whānau is Awatere
Ko Sharon Aroha taku ingoa	My name is Sharon Aroha
No reira, tēnā koutou, tēnā koutou, tēnā koutou katoa	Greetings to you all

To the research whānau: for sharing your stories

To my supervisors: for your support
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Dr Mere Kēpa: for mentoring from afar

To my whānau: for your unconditional love and support

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Kia ora. Thank you.

Abstract

The global burden of osteoarthritis has major ramifications for societies and governments around the world. Despite a high rate of osteoarthritis, there is a low level of osteoarthritis-management knowledge and awareness in the Māori community. Numerous studies of Māori health have identified a need for new health communication approaches to osteoarthritis-management, in order to close the disconnection between Māori and non-Māori disease rates.

Positive health management is the topic of the present thesis, as viewed through Māori eyes. It has been informed by the memories and aspirations of kaumātua who have lived through the challenges of living with osteoarthritis, but have emerged with qualities that enable them to enjoy older-age and to contribute to their own whānau, the Māori world, and wider society. These factors have been brought together into a Māori-centred toolkit, appropriate to modern health promotion, as they apply to Māori health perspectives of kaumātua in Hawke's Bay.

The present research was undertaken within the interpretivist paradigm using qualitative methods and Māori principles, aligned to a tīkanga (cultural principles) base. It is argued that Western science and a Māori-centered approach are relevant to research concerning osteoarthritis-management in the contemporary context, and reflect the realities of kaumātua with osteoarthritis, who live in both the Māori world, and wider society. The study drew upon the experiences, attitudes and beliefs of 20 kaumātua with osteoarthritis, employing interviews and group hui, to inform constructing an osteoarthritis-management toolkit, process and outcome appraisal.

The research found that osteoarthritis-management for kaumātua, can be characterised by a two dimensional concept that incorporates a process dimension and an interpretive appraisal dimension. The process dimension is consistent with a values perspective. The appraisal dimension can be described in terms of complementary Māori specific outcome indicators of osteoarthritis-management.

The outcome indicators are encapsulated by the idea that kaumātua, family and whānau know what issues deserve their attention and what is needed to address local problems. The Māori-specific outcome indicators for optimal osteoarthritis-management identified in the present study are: 'Manākitanga' (kind support); 'Tino rangatiratanga' (self-determination, and; 'Oritetanga' (equity and assessment). The overarching indicator is 'Manākitanga-ā-tinana' (culturally relevant approach to osteoarthritis-management and relationship-based care).

Preface

It is a particularly great honour for me to introduce the subject of such important effort. Precisely, to understand the lived experience of osteoarthritis-management for kaumātua. If my personal practitioner experience of working in Hawke's Bay as a registered allied healthcare practitioner since 2002 had not already given me such strong feelings about the disparities in my region and around the countryside, I would not have dared to attempt the awesome task that I have been entrusted.

Over the course of the past five years, I have learnt that there are not many studies that have started by asking kaumātua, not only what do they want to see, but what self-management initiatives do they want to engage with? In the chapters that follow, I will detail, how I collaborated with Māori living in Hawke's Bay, New Zealand to enable kaumātua to tell their story about osteoarthritis in the Māori community, through the experiences of those who live with their condition everyday. In telling the story of kaumātua, I do not wish to intellectualise the experiences of kaumātua, but seek an understanding as a heathcare practitioner, doctoral researcher and life-long community member.

In asking the question, 'why me' (why should I explore the kaupapa concerning osteoarthritis self-management with kaumātua?), I am an example of a healthcare practitioner who sits within purposeful networks of practice. That is, networks that are central to the development of knowledge building, from within my community, having worked consistently in my clinical practice and research over the years. Yet the present study (project) has enabled me an opportunity to carefully organise argued texts that offer compelling evidence for an integrated approach to managing osteoarthritis, healthcare practice, research and evaluation.

Although the project is conducted in Hawke's Bay, the learning surely extends to healthcare practitioners across the globe. There is much in the present work that will appeal to, and be identified by healthcare practitioners in a range of contexts, not least Osteopathy or traditional Chinese Medical Acupuncture. I commend the voices of kaumātua for drawing our attention to the issues that they face, and draw on my professional leaning in the hope that the project really does make a difference.

To conclude, I have positioned myself in the present specific section as an insider (active voice), there are various sections and chapters within the thesis where I have positioned myself from an outsiders' perspective (passive voice). The current section has required me to use an active voice, because the purpose has been to provide background knowledge of myself (as researcher-healthcare practitioner), in order to highlight the reasons for undertaking the project.

I have also discussed, the reasons which led me to undertake the present PhD and focus on Māori hauora (wellbeing) and to recount my experience as an emerging health researcher. Correspondingly, in other sections of the thesis I am positioned as an outsider to kaumātua as 'they', or 'kaumātua', these terms have been used sometimes, to indicate older-Māori from times past and/or Māori who are of a different iwi than my own. At other times I have referred to the participant or participants, as, 'we' together as a group, within the context of the past and the future.

Although researcher positioning throughout the thesis can appear inconsistent, I have chosen a position for that section or chapter especially, to give some authority to what is being written, whether that be in an active or passive voice. The pēpeha at the opening of the present thesis, is a form of introduction that establishes identity and heritage, signifying where I come from in terms of kinship, whenua (land), iwi (tribe), hapū (sub-tribe) and whānau and I position myself within these structures as I navigate the field researching within Māori development and public health. Accordingly, I have included the use of Māori terms when applicable, and the glossary at the end of the document provides suitable translations for those terms.

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Chapter 1: Real-world contexts (Introduction)

Introduction

There are many persuasive pieces of evidence and statistical studies that can be used to illustrate, why there was a compelling need to create a culturally appropriate osteoarthritis-management toolkit for kaumātua with osteoarthritis. Yet it was a simple statement, “Well we would never be asked that [preferences for osteoarthritis-management support] as kaumātua” (Journal entry 10/4/14), which lies at the core of the present thesis for provoking the question, ‘why not? To understand the magnitude of the potential that impact rising osteoarthritis rates through real-world contexts will have on Māori communities, the aim of the present chapter is to provide a critical review of health promotion and osteoarthritis-management literature.

In the current introductory chapter, I outline through reference to the relevant literature, an argument that a locally-based approach to osteoarthritis-management is appropriate. Notably because, initiatives that are designed by these principles, are more likely to reflect the experiences, preferences, cultural values and environmental context of the participating community (Cram, 2014a) A review of the literature that follows, explores the real nature of osteoarthriritis, offering lessons on how to generate an appropriate health management resource for Māori with osteoarthritis.

Real nature of osteoarthritis

Over the past 20 years, with the ageing of the population and increasing obesity throughout the world, studies have documented secondary osteoarthritis is on the rise. Notably, the overrepresentation of the world’s indigenous people in the majority of chronic disease statistics, in comparison with non-indigenous groups. For example in Australia, obesity which is the greatest modifiable risk factor for secondary osteoarthritis (Karssiens, Kulkarni, Kumar, & Pandit, 2016), is one and a half times more common among Aboriginal and Torres Strait Islander peoples than among other Australians (Australian Bureau of Statistics, 2013).

The essential characteristics or nature of secondary osteoarthritis, commonly refers to the long-term condition that causes the breakdown of cartilage (the firm rubbery substance that covers the ends of bones and acts as a cushion or shock absorber between the boney ends). The condition causes the progressive breakdown and wearing away of cartilage, resulting in the boney ends (forming a joint) to become unprotected, painful, stiff, difficult to move and prone to swelling. Further, secondary osteoarthritis is the destruction of cartilage from a known cause such as joint injury, obesity, gout, infection, congenital abnormalities (at birth), or joint surgery (S. Bullock & Hales, 2012; Southern Cross Healthcare Group, 2018), and commonly noted in indigenous groups (Australian Institute of Health & Welfare, 2017).

The Australian Institute of Health & Welfare (2017) noted that osteoarthritis was present in over half of all indigenous people with co-morbidities[1] (Australian Institute of Health & Welfare, 2017), higher (10 percent) than the Australian non-indigenous group (Australian Bureau of Statistics, 2011). There are multifarious explanations for the higher rates among Aboriginal and Torres Strait Islander peoples, including diet and socioeconomic factors (Australian Bureau of Statistics, 2013). Environmental changes connected to the transition from customary to westernised living have also been identified as pretexts for the development of osteoarthritis in indigenous groups (O'Dea, 1991).

In New Zealand, arthritis[2] is more common (1.2 times higher) in Māori than non-Māori, across all community health settings (Ministry of Health, 2016a). Female mobility and ambulation is commonly known to be most affected by osteoarthritis of the knee (Alexander & Hame, 2013), although data pertaining to Māori females has yet to be presented (Ackerman et al., 2014), it is known that two in three people who have osteoarthritis in Australia will be female (Australian Institute of Health and Welfare, 2017)[3]. Māori adults are diagnosed younger and are two to three times more likely to develop chronic conditions than non-Māori adults (Ministry of Health, 2016b; P. Reid & Robson, 2007).

Similarly in 2015, the Hawke's Bay District Health Board published the most recent comprehensive profile of Māori health (Māori making up 25 percent of the district's total group) in Hawke's Bay (Hawke's Bay District Health Board, 2016a; Purdie et al., 2015). A known consequence of advanced ageing and osteoarthritis, 'frailty[4]' was associated with the most common age-related musculoskeletal conditions, including hospitalisations for falls (Åkesson, Bartosch, & McGuigan, 2017). According to the Hawke's Bay District Health Board Māori Health Profile 2015 (Purdie et al.,

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[1] Co-morbidities refers to two or more health conditions (for example, cardiovascular disease, back problems, mental health problems, asthma, diabetes, chronic obstructive pulmonary disease and cancer) occurring at the same time (Australian Institute of Health & Welfare, 2017).

[2] The term, 'arthritis' refers to adults who reported that a doctor had told them at some time in their life that

[2] The term, 'arthritis' refers to adults who reported that a doctor had told them at some time in their life that
they had any type of arthritis (i.e., osteoarthritis, rheumatoid arthritis, gout, lupus and psoriatic arthritis) (Ministry of Health, 2016a).

[3] Mobility refers to the abilty to move, such as the arms in space whereas ambulation is about walking.

[4] Frailty refers to a state where an individual is independent but at high risk of developing disability. Common characteristics are weight loss, tiredness or exhaustion, low energy expenditure, slow gait and weak grip strength. Frailty can lead to decreased function, where good correlation with survival is based on walking speed, with good correlation on a scale of frailty with institutionalisation and deaths within a year (Bolzetta et al., 2016; Choe, Lim, Merchant, Seetharaman, & Tan, 2017).

2015), the data revealed that from 2011 to 2013, the rate of hospitalisation due to injury such as falls was 36 percent higher for Māori than for non-Māori.

The findings concerning age-related falls is considerable, given that the Hawke's Bay Māori population aged 65 years and over is expected to increase by 41 percent between 2013 and 2020 (Purdie et al., 2015). In terms of chronic conditions generally, from 2011 to 2013, the prevalence of gout (a known risk factor for increasing the risk of developing secondary osteoarthritis (Bryant, Raina, & Te Karu, 2013), was estimated to be 7 percent (compared to 4 percent in non-Māori). The rate of hospitalisations over the period for gout were nearly double in Māori as for non-Māori indicating a higher rate of flare-ups, and increased need for self-management (M. Doherty, Nuki, & Richette, 2017; Purdie et al., 2015).

As the prevalence of osteoarthritis increases with age, the coexistence of other chronic diseases is common (Costal et al., 2011), such as circulatory system diseases (nearly five times higher for Māori than non-Māori in Hawke's Bay) (Purdie et al., 2015). Similarly, diabetes was higher (five times) for Māori, as was having a lower limb amputated, or being admitted to hospital for chronic obstructive pulmonary disease (over three times higher than non-Māori) and hospital admissions for a mental disorder during 2011 to 2013 was higher (68 percent than non-Māori). Overall the data reiterating that chronic conditions among Māori, characterised by co-morbidities, are placing a greater burden on individuals, communities and healthcare services.

Although these are sobering statistics, the real nature of secondary osteoarthritis[5] (osteoarthritis) is largely preventable (Balanda et al., 2013; Carruthers, Guillemin, & Li, 2014; Colditz, 1999). Actually, the risk of osteoarthritis can be reduced by controlling obesity and increasing physical activity (Duclos, 2016). Although, prevention, detection and management of osteoarthritis have yet to become a health priority in New Zealand (Bagg, Baldwin, Briggs, & Larmer, 2017; World Health Organisation, 2014). It is likely that having no national priority for an osteoarthritis model of care in New Zealand will become a challenge (Bagg et al., 2017) for Māori with arthritis, (Gibbons & Merriman, 2017), requiring a shift toward healthcare, in which healthcare practitioners and patients work together as 'ushers' for self-management.

Ushering in self-management

Self-management is important to living well with a chronic condition, because

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[5] Secondary osteoarthritis is caused by another disease or condition, such as gout (Frampton, Hooper, Lee, & Rothwell, 2014), obesity (W. Doherty, Roddy, & Zhang, 2007; Lefèvre-Colau, Nguyen, Poiraudeau, & Rannou, 2016) and accidental trauma (Ministry of Health, 2015a), increasing the risk of developing osteoarthritis (secondary osteoarthritis) (Bryant et al., 2013). In contrast primary osteoarthritis has no known cause, thought to be related to ageing.

people have a better chance of a rewarding lifestyle, when they are educated about their condition and take part in their own care (Bodenheimer, Macgregor, & Shafiri, 2005). Self-management has been reported as enabling people to minimise pain, share in decision-making about their treatment and reduce the frequency of visits to healthcare practitioners, gaining a sense of quality and control over their lives (J. Barlow, 2010; J. Barlow, Williams, & Wright 1999; Holman, Lorig, & Sobel, 2013). Although, despite there being evidence of cost-benefits and improved health outcomes for those that participate in established initiatives, purportedly self-management is only reaching a small number of people with chronic conditions (De La Barra, Doolan-Noble, Gauld, & Waters, 2013; Eakin, Bull, Glasgow, & Mason, 2002; Ministry of Health, 2014a).

Even so, there is evidence that self-management initiatives are being embraced by healthcare policymakers, as a way of reducing costs, by having empowered and healthier patients accessing health services with less frequency (Ministry of Health, 2012b, 2014a). When turning to the literature, rise of the self-management movement is noted throughout (Access Economics Pty Limited, 2018; J. Barlow, Hainsworth, Sheasby, Turner, & Wright, 2002; Chen et al., 2015; Holman & Lorig, 2004; Laurent, Lorig, Moreland, & Ritter, 2015), and a national statement from the The Treasury of New Zealand (2013) flagging the urgency of tackling chronic condition self-management, relative to age-related conditions becoming an increasingly important contributor to rising healthcare costs. On the other hand, close analysis of the health literature uncovers widespread usage of a prescriptive medical approach to self-management, emphasising adherence to directions provided by healthcare practitioners (Grey, Knafl, & McCorkle, 2006; Jaser et al., 2012; Jenkin, Koch, & Kralik, 2004)

The health literature also demonstrates there being prescriptive approaches to self-management, which Bagg et al. (2017) suggested must change. Bagg et al. (2017) recently called for osteoarthritis to be made a national priority toward a longer view, with planning being the guidance of future action throughout New Zealand. Similarly, Brembo et al.'s (2016) study of 13 patients with hip osteoarthritis, detailed a care continuum with a longer view, suggesting that addressing the burden of osteoarthritis will require system-wide approaches involving public policy responses for targetting primary prevention, and new models of self-management.

What is self-management in the real-world?

Brembo et al.'s (2016) suggested that the rise of new models of self-management are ushering healthcare into a world where knowledge, power and capability are dispersed. The same is true of self-management with varying definitions, roles and the types of relationships occurring between patients and providers, becoming more dynamic and persistently disruptive (Brembo et al., 2016). So it is worthwhile understanding what is meant by the term, 'self-management' in patients with chronic conditions, and in real-life (real world) situations that matter to patients.

Self-management has been referred to as, "methods, skills and strategies by which individuals can effectively direct their own activities toward the achievement of objectives" (Ncama & Omisakin, 2012, p. 1734). There are various definitions of self-management in public health policy. The Ministry of Health's (2016c) best practice paper for the primary and community health sectors defines self-management as:

> any way in which a person with a long-term condition manages their condition by themselves … a continuum of learning experiences and opportunities, where a person with a long-term condition and their family and whānau work in collaboration with carers and health professionals (p. 5).

The definition emphasises a number of ambiguities and also raised questions from my perspective as a healthcare practitioner. The Ministry of Health's (2016c) definition commences with a noun, the word "person" which may refer to an individual person, imparting the idea of 'individuality'. The use of "person" is reiterated again, and followed with reference to 'family, whānau, carers and health professionals', implying collective group involvement. The definition also uses the words, "continuum of learning experiences and opportunities", possibly suggesting that the process is dynamic, over a period of time and requires opportunities for learning experiences and the right circumstances to develop (p. 5).

The Ministry of Health's (2016c) definition also uses the words "work in collaboration", possibly suggesting that people do not currently have enough participative collaboration with services. Otherwise, the definition of self-management appears to suggest that self-management involves more collaborative partnerships with carers and healthcare professionals. In any manner, these words acknowledge that the bulk of the management of a long-term condition is undertaken by the individual, at home or away from the direct guidance of a healthcare practitioner (p. 5).

Returning to the Ministry of Health's (2016c) definition of self-management, raises the question of the dynamics that influence the patient-practitioner interaction, that act as obstacles to collaboration working between equal partners. Connecting these two ideas of individual and collaboration is the verb, "work" meaning to be engaged, in order to achieve a result. Also of interest is the choice of words, "long-term condition" used to align which, "person" is being talked about (p. 5).

Use of the word, "long-term condition" is suggestive of an attempt to create a ‘blanket-term’ that potentially seeks to incorporate a range of understandings of chronic conditions, in order to appeal to different audiences and related issues. The additional phrase “and their family and whānau work in collaboration with carers”, seems to indicate that self-management engages an individual who manages their condition on their own and with the help of, “family and whānau”. Carers and health professionals as resources, are incorporated into the definition through the use of the word, “collaboration” (Ministry of Health, 2016c, p. 5).

The reference made of “collaboration” in the Ministry of Health’s (2016c, p. 5) definition, suggests some sort of appropriate ‘match’ between people that facilitates the process, and leads to trust (Ministry of Health, 2016c). The process of facilitating trust precedes empowering outcomes for those involved, such as goal ownership and perceived utility of change, through credible aspects of the interaction (Hou, Leske, & Strodl, 2012). The explicit process that precedes the patient developing trust with the practitioner relationally in the Ministry of Health’s (2016c) definition, is left to the reader to determine.

Pared-back, the Ministry of Health’s (2016c) definition appears to suggest that self-management lies within the context of coordinated networks, that are located within the health and social support system of an individual (Ministry of Health, 2016c). The aforementioned definition implies there being a link between between positive health outcome indicators and primary healthcare for indigenous communities, although much of thel evidence linking the two to outcomes, is anecdotal. For example, one of the areas of primary healthcare in New Zealand most heavily criticised by the Organisation for Economic Co-operation and Development’s (2010) study of health policy and value for money in health spending, is in the area of intersectoral collaboration, as well as the general absence of explicit approaches to equity in primary healthcare initiatives.

Another implication regarding individual self-management in the Ministry of Health’s (2016c) definition, is the inference that the individual with a long-term condition is responsible, and will have some knowledge of risk and therefore knows what to do. In accordance with Lupton (1994), reducing long-term conditions to individual responsibility and choice, ‘brackets’ individuals into those who are at risk or pose a risk, obligating them to choose how they will manage risk (Lupton, 1994). Ultimately for the individual an obligatory choice is made resulting in solutions that are based on risk and moral duty, to do the ‘right thing’ by and for themselves, their family and the wider society (Lupton & Petersen, 1996).

Green (2009) argued that within the sociological health field, a ‘risk’ focus generated theory that linked and framed understandings, of how people dealt with, “uncertainty and misfortune” (p. 1). While acknowledging the inherent problems of focusing mainly on changing risk factors, Green (2009) argued that the prominence of risk aversity in self-management policy and underlying rationale of encouraging risk-management was problematic, requiring change towards a different perspective. Precisely that the solution may be to adopt a nuanced view of ‘risk' and self-management.

Adopting new views of self-management has potential for ushering healthcare into a world where knowledge, power and capability are dispersed with definitions of self-management, its role, and the types of relationships occurring between patients and healthcare practitioners, becoming more dynamic and persistently disruptive. For example in the patient living with a chronic condition, self-management may be interpreted as the availability of information regarding underpinning factors such as physical mobility, social support, economic and cultural conditions, than focusing mainly on changing risk factors. In short, the focus will be attuned to addressing the underlying health determinants (J. Green, 2009).

Bos-Touwen et al.’s (2015) assessment of self-management in patients with chronic conditions noted that social support and illness perception were important determinants, explaining 16 percent of variance in activation for self-management. As well, that the very same variance made up a proportion of chronic condition patients, that did not respond to mainstream self-management initiatives. In short, indicating that definitions and models of self-management needed to change and adapt to the requirements of each patient, reiterated in more depth throughout the section that follows.

Three models of self-management

The predominant use within self-management of the medical model, was noted by Jenkin et al. (2004). Jenkin et al. (2004) studied chronic condition self-management over nine months from in-depth interviews with 24 older participants, an open-ended questionnaire and two mixed-gender action research groups. ‘Unpacking’ what ‘self-management’ constituted, Jenkin et al. (2004) proposed that there were three major self-management models in operation namely, the medical model of self-management, collaborative model of self-management and self-agency model of self-management.

Medical model

Reference to self-management principles in the literature appear as early as 1916 with the Principles of Health Control, written by Francis M. Walters (1916), a professor of physiology. The book espouses that the expertise of the patient should be guided by the physicians' care and advice, required for the control of conditions such as osteoarthritis with remedies that first, "must do no harm" (1916, p. 21). Ideas about self-management began to evolve critique about healthcare in the 1960s, in response to power imbalance of the patient-practitioner relationship and medicalisation about aspects of life, that had previously remained non-medical (Bury, Kennedy, & Rogers, 2009).

The first of these, the 'Medical model of self-management' is what most participants in Jenkin, Koch, and Kralik's (2004) study identified with, evident in those older-people with chronic conditions, that appeared to be taking prescribed medications. Most often when participants were first diagnosed with a chronic condition, they found themselves in the medical management model, which usually meant following the healthcare practitioners' (practitioners) orders, resulting in most taking responsibility for the management of their medications. Generally, practitioners held authority about the patient's condition and by way of the medical management model, the practitioner did all the managing and monitoring of the condition process.

Issues raised by participants of Jenkin et al.'s (2004), study concerning aspects of medical management for instance, perceived that practitoners can become complacent over a period of time, putting all ensuing symptoms down to arthritis for example, rather than searching for pathology. Other participants felt that medical management consistently headed down a narrow condition-specific pathway, rather than viewing their life in context. Finally, participants noted a fear of being labelled as non-compliant or being, "objectified as, 'the patient'" (p. 485), which is in contrast to individualising the explanation of illness (Yadavendu, 2014) or the holistic Māori view of health and healing (R. Jones, 2000).

Collaborative model

The second predominant model of use in the literature of chronic condition self-management was identified by Jenkin et al. (2004) as the collaborative model, that combined the use of biomedical and experiential terms to describe a chronic condition. Collaborative models insisted that, when people living with a chronic condition are provided with support, education and care in partnership with healthcare practitioners, that self-management was enhanced (J. Barlow, 2010; J. Barlow et al., 2015; Holman & Lorig, 1993, 2003, 2004; Holman et al., 2013).

Jenkin et al. (2004) noted that some participants with a chronic disease, combined biomedical and experiential terms to describe their condition. Some merged their biomedical understandings with the effect that their condition had on other people, who were often assisting their self-management, something which Bodenheimer, Grumbach, Holman, and Lorig (2002) discussed represented the patient-practitioner partnership, involving collaborative care and self-management education.

Under a collaborative model, self-management would engage much more than medical advice alone. In addition to medication information, involving patients in their care, so that they would be in a better position to make informed decisions about their management as a result, enabled them to bring their own intelligence into the relationship through their input. Practitioner acknowledgment of the patient's expertise and input was found by Jenkin et al. (2004) to be conducive to self-agency in managing one's condition, particularly when patients were valued.

Personal-agency model

The final self-management model was a theoretical contribution articulated by Jenkin et al.'s (2004) study, describing the way that people with chronic disease, identified their responses to illness. For example, constructing a daily routine as a way of bringing order into their lives, self-management was as much about reclaiming the self and regaining full human identity, which can mean attaining recognition and support for their self-monitoring practices. Some took control, almost becoming self-determining in the manner by which they ignored biomedical language, and focussed on the impact of their condition with relevancy, according to their own personal agency (self-agency).

Self-agency which requires monitoring one's actions in a self-directing manner, has been argued for being related to better health and social integration (Bandura, 1989). For instance, the ability to be self-determining in one's self-care, is also concerned with the motivation behind the choices that are made, without external influence or interference. In contrast, Bandura (2000) later argued collective efficacy as a mechanism of human agency, collective agency and shared beliefs, all produced effects by collective action, fostering group motivation, commitment and resilience to adversity.

As a theoretical construct a collective efficacy approach to adaptation and resilience, attempts to understand the role of groups to empower personal action. However the theory is limited for understanding the impact of the historical, cultural environment on indigenous resilience (McIntosh & Mulholland, 2011). Rather than transplanting an international concept onto local aspirations of 'tino rangātiratanga' or self-governance that are culturally bound, Aspin, Green, Penehira, and Tuhiwai-Smith (2014) promoted more beneficial resources required Māori to design and lead their own initiatives, aimed at promoting these understandings for Māori.

With the aim of promoting Māori leadership, Brougham, Haar, and Roche

(2015) interviewed 18 Māori leaders from various leadership positions within their community. Brougham et al. (2015) found that incorporating a number of values and cultural protocols[6] was beneficial to the wellbeing of Māori leadership. In so far as indigenous positionings on self-determination, similar to N. Denzin, Y. Lincoln, and L. Tuhiwai-Smith (2008b), Brougham et al. (2015) argued, that the use of a cultural and self-determination lens was integral to wellbeing of Māori leadership, where individuals determined their own goals and made sense of the world in their own culturally generated manner.

In sum, through the process of articulating these models, self-management appears to be a broadly defined concept, referred to by Ncama and Omisakin (2012) as, “methods, skills and strategies by which individuals can effectively direct their own activities toward the achievement of objectives” (p. 1734). As evident in the growth of self-management of chronic condition management concerning older-people, the concept is used to describe the confidence and ability to manage health conditions, and maintain an active and fulfilling life (Breckman et al., 2008; Gilbert, Hayward, Lai, Saibil, & Yip, 2008). In the section that follows, unlocking paternalistic practitioner-patient relationships (relationships that are based on compliance with medical advice) are discussed and the shifting models of relationship that are based on different expectations of self-management.

Unlocking real ownership

Gilbert et al. (2008) suggested that healthcare has generally moved away from the traditional stage of paternalism, through the stage of the educated, evident in the questioning patient of the present day. Gilbert et al. (2008) discuss for instance, that many patients were ready to take real ownership of their chronic conditions and participate in the therapeutic decision-making process. Similarly, Bury, Newbould, and Taylor (2006) noted that we were in an age of self-management and the growth of self-management models, toolkits and strategies within healthcare.

A main priority area within healthcare concerning self-management, has seen growth in interest by policy-makers, to encourage lay-led self-management approaches (Bury et al., 2006). Besides, growth has resulted out of patient demand, of wanting to control their chronic condition on their own or with the assistance of others, alongside the belief that helping people to manage potentially disabling conditions can boost their quality of life. Also, the demography of population ageing and epidemiologic

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[6] Largely, the values and cultural protocols in Brougham, Haar, and Roche’s (2015 study were: ‘tino rangātiratanga’ or autonomy and self-determination; ‘mana’ or respect and influence; ‘whānau’ or extended family; ‘whakapapa’ or shared history, and ‘whānaungatanga’ or kin relations, consultation and engagement, were united into a model of leadership wellbeing.

transition to chronic conditions in developing countries and new attitudes to healthcare delivery, have been the main drivers of self-management and self-care in healthcare (Bury et al., 2006).

From the present review of the health literature, it is clear that self-management has potential benefits for both patients and healthcare practitioners. From the indicated analysis, Jenkin, Koch, and Kralik's (2004) theoretical contribution of self-agency and self-determination to discussions concerning self-management, have potential. Expressly, for recognising that people who have lived with a chronic condition over a period of time, will have become self-determining experts to varying degrees.

As a result, the argument for locating the 'self' within self-management emerges (Jenkin et al., 2004). As does my personal (healthcare practitioner) experience of chronic condition self-management, that osteoarthritis does not exist in a clinical framework of gait analysis and medication management alone. Hence my use of the term 'osteoarthritis-management' in the present thesis, seeks to represent the complexity of, osteoarthritis 'self-management'.

What is more, while I recognise that for patients and healthcare practitioners alike, to grow and learn is essential. Yet the way to do so may require new tools which promote a partnership that facilitates patient control over 'what' is offered and 'how' these tools are initiated, than assuming that as the healthcare practitioner that we know what patients want to learn. There is an argument for appropriate tools, that enable healthcare practitioners not only to partner with their patients effectively, but raise patient confidence and awareness of their condition.

Real face of awareness

For some older-people with a chronic condition, their osteoarthritis affects everyday life. Their activities may be limited and in some cases when dealing with healthcare practitioners, lead some to hesitate from asking questions (Hafeez-Baig, Soar, & Yusif, 2016). They may hold anxieties about taking too much valuable time, sounding unintelligent, fuelled by a desire of wanting to 'fit-in' with the society (Kart, Metress, & Metress, 1992), representative of the 'real face' and reality of living with a chronic condition (World Health Organisation, 2017b).

Raised awareness in the real face of reality was evident in a 2008 study of Māori attitudes to chronic joint inflammation in Manukau, which found that there was a lack of knowledge and awareness in the Māori community, about what gout (arthritis) was, what caused it, and how to treat it (Gibbons & Merriman, 2017). For example, knowledge of arthritis was based on jokes about overindulgence and of arthritis being an 'old man's disease', with many putting their symptoms down to a strain or injury and therefore not seeking out appropriate treatment. Normalisation of arthritis was occurring in the Māori community, with most having a family history leading them to think that their condition was something they had to 'put up with' (inevitable), than controllable.

Similarly overseas, a study with older-railway workers (over 50 years) in Malaysia, documented that over 50 percent of participants had low levels of knowledge of osteoarthritis, pointing to an urgent need for information to be disseminated, to foster primary prevention and self-care management (Alabsi et al., 2014). The need for self-care management to be occurring with Māori was highlighted in the report 'Kōrero Mārama: Health literacy research in 2006, where around four out of five participants were less likely to be managing their long-term chronic condition, due to poor health literacy skills[7]. Commonly, Māori were found to have poorer literacy skills than non-Māori, regardless of age, gender, level of education, labour force status, household income or rural/urban location, which was likely to be having a negative impact on their health status (Ministry of Health, 2012b).

Older Māori (50 to 65 yrs age group), were also found to have the poorest health literacy compared to all other age groups, which is particularly concerning, considering older age groups have higher levels of health need and are generally higher users of healthcare services (Ministry of Health, 2012b). On top of that, Māori with lower health literacy were less likely to use preventative services, recognise the first signs of medical problems, manage their long-term condition, or communicate concerns to a health professional. Consequently they were more likely to be hospitalised due to a chronic condition, and need emergency services (S. Reid & White, 2017).

As noted by Reid and Robson (2007), Māori and non-Māori health profiles are different also, with respect to health determinants (education, employment, housing, income, income support, literacy, engagement with the criminal justice system, and deprivation). Reid and Robson (2007) suggested that these profiles provided patterned exposure to a number of risks and realities (poor nutrition, substandard housing, and unsafe employment conditions (more blue-collar, low-paying employment. In addition, differential access to healthcare and quality of care were thought to attribute to Māori experiencing longer, slower pathways through the healthcare system.

A systematic review of literature from 2004 to 2011, identified real need for improvement in health literacy for kaumātua around functional, technical, interactive,

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[7] Health literacy refers to the ability to find, read and use health-related information to make decisions about one's own healthcare.

and critical literacy[8] (Rauawaawa Kaumātua Charitable Trust Research Project Team, 2013). Rauawaawa Kaumātua Charitable Trust Research Project Team (2013) identified the need for improvement in health literacy for healthcare practitioners in cultural health literacy[9]. They also recommended that kaumātua with existing knowledge, networks and whānau connections, were better able to navigate the healthcare system and access care, resources and services.

These findings are consistent with subsequent research findings, that appropriate osteoarthritis-management initiatives will need to promote the importance of social networks (Kennedy, Koetsenruijter, Rogers, & Vassilev, 2014). Additionally, that learning about care before it is needed, would most benefit kaumātua, family and whānau (Rauawaawa Kaumātua Charitable Trust Research Project Team, 2013). All of which is not too dissimilar to recommendations in the literature concerning ethnic minority populations internationally (Browne-Yung, Ziersch, & Baum, 2013; Kennedy et al., 2014).

Real-world knowledge

Shifting from a health literacy perspective in the previous section ('Real face of awareness'), the present section is concerned with local understandings about kaumātua wellbeing and wellness. Waldon's (2004) Oranga Kaumātua study, showed that many kaumātua derived their wellness knowledge from a number of sources. The most common being cited as informal sources from family and whānau, peers, the media and personal experience.

Family and whānau

In so far as informal sources of information, kaumātua are known to often prioritise a clear preference for talking with whānau (family, extended family) to find out about health and disability and related matters (Te Puni Kokiri, 2013; Te Puni Kōkiri, 2013). However, older-people do not always find family members easy to talk to and the aforementioned uneasiness may in part, arise from not wanting to complicate the busy lives of adult children (Barg, Bogner, Cahill, & Lewis, 2009). Otherwise, older-people at odds with discussing issues, can withhold information out of fear, that their

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[8] Functional health literacy refers to the ability of individuals to get hold of or acquire, process and understand health facts and services to make appriate choices, while technical literacy refers to the use of medical or technical terms with words that people use in their conversations with one another, interactive literacy incorporates ability to ask questions and identify one's own knowledge gaps, versus an individual that has difficulty explaining heir health problem or talking about these with their healthcare practitioner, and finally critical literacy seeks to improve control over personal decisions, enabling people to participate actively in political and social decisions concerning one's own health (DeVoght, Gould, & Mogford, 2010).

[9] Cultural literacy is culture-specific and refers to the ability to understand and participate fluently in a given culture (Hirsch, Kett, & Trefil, 1988).

family will become overly worried about the care required of their older family member, and impact upon their independence (Barg et al., 2009).

All the same, older-people whose family talk more openly about their health and disability tend to have more accurate information about osteoarthritis-management, and are more likely to develop lifestyle attitudes and values similar to that of their family, than those who speak less with their family about their health and wellbeing (Arai & Yamada, 2017; Yamazaki, Hayashida, & Yontz, 2017). However, physical ability and cognitive understanding between younger generations and older-people can widen, resulting in reduced effective communication about disability concerns and osteoarthritis-management support (Dobbs et al., 2017). Katene (2010) noted that even in the face of changing social structures within whānau, that Māori leadership was imperative for supporting whānau wellbeing, noting that whānau is where values are taught, as well as extended whānau lending support when needed.

Katene (2010) noted that when the whānau is strong, positive leadership is imperative to whānau, hapū and iwi being strong too (Katene, 2010). Providing quality health information and resources for whānau to facilitate and engage in appropriate conversations about the health of their older-members may also contribute to, and encourage more informed health discussions. For example, the attitude of whānau can assist the normalisation of physical activity, purposeful movement of the body (mobility), strengthening muscles and controlling physical balance, to improve activities of daily living (Ministry of Health, 2017; Te Puni Kōkiri, 2017).

Older-Māori also tend to seek out friends and peer relationships with members of the same community that are not expert driven (peer support), for information on safety precautions such as falls prevention (Ministry of Health, 2017; Te Puni Kōkiri, 2017). Although Alea, Bluck, Davis, James, and Shafto (2015) suggested that knowledge gained from peers, may be inaccurate and cannot necessarily be relied upon (Alea et al., 2015). Nevertheless, older people may consider close friends and peers to be more accessible, easier to talk to, and more likely to listen in a non-judgmental way (World Health Organisation, 2017a).

Peer support groups are one way of enabling older-people to gain access to these informal social networks, to connect older-people with health information and professional support (World Health Organisation, 2017a). In that regard the term ‘self-management’ can suggest an holistic interdependent focus. For example, that gives priority to kaumātua with osteoarthritis within their wider social context, than focus on the ‘self’ as an individual at the expense of important social contexts, particularly family and whānau (Ministry of Health, 2016c).

Peers

New Zealand studies in the community setting, often cite that older people are a major resource and source of health information exchange (C. Doughty, Kahi, & Scott, 2011; Dyall, Hayman, Kēpa, Kerse, & Skiller, 2013; Kites Trust, 2012). Peer-to-peer support refers to social friendship groups or constructed groups, such as kaumātua ora rōpū (organised community wellness groups for kaumātua) for the purpose of peer health education (Te Kupenga Hauora, 2017)[10]. The latter, often falling under the banner of peer education has been described as a, "method in search of a theory" (Shepherd & Turner, 1999, p. 235) [11], that is focussed on 'health behavioural change[12]', for example, increased physical activity for improved chronic condition management.

Although, following K. Berryman, Iti, Oetzel, Reddy, and Simpson (2016), it does appear that healthcare agencies have been taking a 'one size fits all' approach to health behavioural change. In the process, agencies have been failing to address the needs of diverse groups of older people, such as kaumātua and whānau. In so far as supporting a tailored approach to Māori health literacy and communication, Rauawaawa Kaumātua Charitable Trust Research Project Team (2013) recommended the implementation of kaumātua led models and peer-to-peer resources.

One such programme is the, 'Kahungunu Hikoi Whenua', a Māori-led ("by Māori for everyone"). The healthy lifestyle initiative that has been showing positive indicators with nearly 80 percent of participants reporting change as a result of engagement (Hawke's Bay District Health Board, 2012, p. 7). Peer-led initiatives have also gained increased recognition as an effective means of influencing older-people's attitudes and behaviours (Barker et al., 2016).

Recently, Hale, Waters, and Wurzer (2016) developed the 'Steady As You Go' (SAGO) peer-led fall prevention exercise classes in Dunedin, by drawing on existing peer networks. That the programme was delivered by older-people who receive training to provide social support, played an important role in promoting and maintaining behaviour change. A process evaluation concluded that the SAYGO approach was effective for older-people, for sustaining less severe injuries following a fall than previously (Hale et al., 2016).

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[10] Kaumātua ora rōpū are government funded programs that offer wellness, wellbeing and Access to healthcare promotion, education and a fitness stream (Te Kupenga Hauora, 2017).

[11] Based on the scant empirical work at that time of peer education, Shepherd & Turner (1999) described it as a method that was in search of a theory, than the application of theory to practice.

[12] Health behavior change for improved chronic condition-management refers to: "promoting the adoption of skills, behaviours and coping strategies to enable patients to actively participate in their healthcare and decision-making, and to maintain health and wellbeing" (New Zealand Guidelines Group, 2012, p. 6). For example in the case of osteoarthritis-management, increased physical activity, improved diet and managing weight, improving self-efficacy, self-monitoring, medication adherence, decreasing health resource use etc.).

The integration of peer and family support strategies into osteoarthritis-management programmes, have been found to play an important role in promoting and maintaining lifestyle changes. Although the peer-led approach is useful, it should not be relied upon as the sole conduit for the dissemination of health information in a community (World Health Organisation, 2008). Similar to mass media initiatives, peer led initiatives need to be a component of a comprehensive configuration of health education and programme initiatives (World Health Organisation, 2008).

Mass media

Similar to peer led initiatives, mass media targeted campaigns and programmes aim to increase awareness of osteoarthritis-management that promote health and person-environment interactions. Such as outdoors exercising in safe community spaces, that may pose threats and opportunities. On the one hand, the media could educate and inform older-people about osteoarthritis-management, using the popular appeal of television and web-based tools of social communication.

On the other hand, commentators have remarked on the limited range and portrayal of stereotypical characterisations of mass public health campaigns (World Health Organisation, 2008). In another context of other mediums of mass media, the fourth New Zealand survey of the World Internet Project New Zealand, investigated the usage of and attitudes to the internet of a sample of 2006 New Zealanders' (Bell, Crothers, Gibson, Miller, & Smith, 2013). A significantly higher proportion of Māori participants' rated 'other people' as an important source of information.

Over 90 percent recognised television, radio and news as important sources of information, although the influence on kaumātua and their management of chronic conditions has been difficult to ascertain. In so far as publicity on television, "Osteoarthritis Awareness Campaign" (or the "Broken Glass" advertisement) was broadcast to educate the public about the condition. Campaigning the same television commercial, a website and associated publicity, led to a surge of calls to an 0800 number and website visits, resulting in national and international cut-through for Arthritis New Zealand's annual appeal (Arthritis New Zealand, 2012). The results of follow-up research to the osteoarthritis awareness campaign found that more than 60 percent surveyed remembered the advertisement on television, recalled osteoarthritis as a form of arthritis, and visited their doctor about osteoarthritis after seeing the advertisement (Arthritis New Zealand, 2012).

Additionally, after watching the osteoarthritis awareness campaign on television, one in six people told the survey that the television was their main source of information about arthritis. Although knowledge about kaumātua and osteoarthritis-management was not documented (Arthritis New Zealand, 2012), research is warranted to ensure that these are well-suited for Māori with osteoarthritis. Determining how widely accessible television is as a medium of communication, will need to be incorporated into a comprehensive strategy, to promote osteoarthritis-management, and understand factors supporting greater reach into the Māori community.

Even less is known about the influence of new technology, such as email, the internet, mobile phones, or the effect text management strategies may have on older-people's concepts of osteoarthritis-management. Matamua's (2010) review of social marketing campaigns that were aimed at Māori, revealed that most publicity was concerned with obesity, alcohol, drugs, crime, and educational underachievement, as opposed to encouraging positive behaviours such as Māori language and culture. After watching television advertisements Māori participants believed that the designers should have consulted with Māori iwi, to ensure that the message contained positive cultural indicators, cultural markers in language, and humour, which was said to be a really great way of "selling the message" (Matamua, 2010, p. 37).

Similarly, osteoarthritis awareness through media campaigns requires research, to examine the experiences of kaumātua of new media, on their cultural values. Many websites are dedicated to promoting older-people's health. For example the Health Navigator New Zealand (2017) (healthnavigator.org.nz); Arthritis New Zealand (2017) (arthritis.org.nz), and; Taiaho Trust (2017) (tiaho.org.nz), are all focussed on raising awareness, advocating for literacy in arthritis, providing advice and support. Although, despite the availability of web-based information, there is little evidence to suggest that kaumātua are accessing it.

Encouragingly, in Hawke's Bay just over 68 percent of Māori had access to the internet with a high usage reported at free internet access points in community spaces and facilities such as marae, education, outside of the home (Ministry of Business, 2015). It is also known that of all New Zealanders who have access to the internet, two-thirds of people browse to obtain information on health and healthcare services, and to find information prior to visiting a doctor (Boyd et al., 2014). Correspondingly, it is conceivable that a relatively small number of kaumātua would access health information via the internet, yet there is a remarkable lack of published literature discussing osteoarthritis-management initiatives with ethnic minority groups (Boivin, Denis, Hébert, Lehoux , & Roncarolo, 2017; Fernandez-Orgega et al., 2016).

A real opportunity

Although there is a wealth of information available on management of chronic conditions on the web and elsewhere, its appropriateness and accessibility to older-Māori with osteoarthritis in Hawke's Bay has not been explored. As there is not a large body of work, it has been challenging for me to identify osteoarthritis-management strategies, laying bare a real opportunity for the growth of strategies. Namely, strategies that have demonstrated the most positive effects and outcomes with kaumātua.

In 2002, an American report found that most osteoarthritis initiatives developed for the mainstream, were not culturally suitable for minority groups (Jordan, 2012). Nearly a decade later, authors' of a separate study similarly noted, the paucity of research on how to meet the educational needs of minority patients with osteoarthritis (K. Allen, 2010). Nearly a decade later, the same issue was reported, even though systematic review and meta-analysis of osteoarthritis patient education programs (such as weight reduction, coping strategies, and exercise programs for the management of knee osteoarthritis) demonstrated that these improved patient knowledge and were beneficial in the management of osteoarthritis (Alghadir, Anwer, & Brismée, 2016).

Similarly, Conaghan et al.'s (2014) review of patients diagnosed with osteoarthritis and their conservative management, identified the same issue. Conaghan et al. (2014) suggested that osteoarthritis provided a promising opportunity for healthcare initiatives to improve, as mainstream services were poorly perceived by patients, there being uncertainty regarding when care was required. Conaghan et al. (2014) recommended that rather trivialising osteoarthritis, healthcare practitioners should enthuse patients towards the principles of osteoarthritis-management, accordingly promoting an improved perception of osteoarthritis-management using non-surgical (operative) treatment forms.

In the same way, the Ministry of Health (2016c) argued that effective osteoarthritis-management initiatives were needed. In effect to address a disconnection between medical professionals' (biomedical) perspectives on chronic disease, and experience based cultural beliefs, that influenced how ethnic groups understood their condition. Similarly, Bury, Newbould, and Taylor (2005); Jinks, Morden, and Ong (2011) recommended respecting and incorporating lay perspectives, beliefs, and experiences of chronic disease, rather than simply adopting a mainstream, medical approach to osteoarthritis-management, care and education.

Lay knowledge of the real world

Internationally, very few studies have focussed on the perception and lay understandings or bodies of knowledge concerning osteoarthritis in indigenous groups, or social and cultural meanings of the condition (Darmawan, Minaur, & Parker, 2004;

García-Ferrer, García-Kutzbach, Iraheta, Mejia, & Obregón-Ponce, 2012). The situation is similar in New Zealand, and notable, as Māori understandings of health often do not always follow the mainstream model that distinguishes between the mental and the physical (Durie, 2001; M. Henare, 1988b; Mead & Mead, 2003). Rather than adopting a biomedical perspective for instance, Māori health has been conceptualised as a four-walled house, describing a 'Whare Tapa Whā model' (M. Durie, 1998b) (the Māori concept of health).

The Māori concept of health (Māori model) encompasses not only the physical (taha tinana) but is also balanced with the spiritual (taha wairua), mental (taha hinengaro) and familial (taha whanau) (M. Durie, 1998b). Incorporated in Māori health and culture are conceptions of te whenua (land), te reo (language) and whānaungatanga (extended family, sense of family connection) (Durie, 1999b). The importance of a Māori model is reiterated throughout the present thesis, being that of holistic integration and within the context of kaumātua with osteoarthritis, may be applied to all areas of health and wellbeing.

In addition, the present research adopts the terms 'health and wellbeing', based on the holistic idea of health, in line with 'Te Whare Tapa Whā'. In contrast the terms, 'adaptability' and 'adjustment' reference Western psychological definitions of wellbeing, all focusing on the psychological health of the individual (Badley, Cott, & Gignac, 2000). Also, kawa (cultural practices) and tīkanga (cultural principles) are key elements in the health and wellbeing of Māori (Durie, 2011; Hodges, 1994; Mead & Mead, 2003), related to understanding osteoarthritis-management, these are commonly associated with cultural values and beliefs.

Several studies concerning health and wellbeing have identified the need for models and approaches that understand Māori and chronic-condition management, to reduce the disparities of disease rates between Māori and non-Māori (Beaton et al., 2017; Howard et al., 2017; McGavock, 2011). Beaton et al. (2017) identified the need for communicating in a culturally appropriate way, that reflected Māori beliefs and practices. Their report recommended more and better Māori specific educational resources, that were acceptable and appropriate for use with the Māori community (Beaton et al., 2017).

Simmons and Voyle (1999) proposed that mainstream approaches to healthcare for Māori were insufficient, and that increased consideration needed to be given to the settings in which services were being offered, as these influenced chronic disease prevention and earlier diagnosis. Simmons and Voyle (1999) suggested that settings in which Māori identity, values and cultural practices were affirmed, potentiated and enhanced emphasis on cultural identity. In turn generated self belief, trust and confidence, creating more supportive environments for sustainable osteoarthritis-management.

In contrast, environments where Māori have low levels of knowledge about their condition, have been recognised for not providing information adequately. As an illustration, reflecting Māori cultural practices in ways that are appropriate for use in Māori communities (Beaton et al., 2017). Even so, in the advent of availability of the best initiatives, positively affecting osteoarthritis-management, is a formidable challenge (Briggs et al., 2014). Not only do osteoarthritis-management initiatives need to motivate, but they also need to sustain the interest for change in daily habits pertaining to eating and exercise, even if the risk factors for osteoarthritis are well known (De Vlam et al., 2016).

Acknowledging issues concerning long-term conditions, chronic care and self-management, the Ministry of Health (2012b, 2016c) argued for establishing locally-based initiatives in New Zealand, emphasising that these should be based on a collaborative partnership and include on-going evaluation. All the same, there have been no locally-based osteoarthritis-management initiatives that have been published through the direct experiences of kaumātua with osteoarthritis that are living in Hawke's Bay. As will be demonstrated, it has been difficult to establish what processes were used for creating osteoarthritis-management resources or levels of community involvement, resulting in a clear disconnection within the literature concerning how to best implement culturally appropriate osteoarthritis-management with kaumātua.

Making empowerment real in design

Historically, few mainstream chronic condition management initiatives have been especially designed with culturally appropriate strategies (Auckland District Health Board & Waitemata District Health Board, 2015; Islam, Kwon, Park, Nadkarni, & Trinh-Shevrin, 2015; Russell (Pere), Smiler, & Stace, 2013). Similarly, Islam et al. (2015) using a case study approach, emphasised the need for a framework that included culturally relevant strategies for underserved, culturally diverse groups. Islam et al. (2015) found that disease prevention and health promotion had largely focussed on mainstream groups (white, middle-class), arguing the need for culturally tailoring health education, outreach materials and initiative strategies across group specific health initiatives.

Culturally relevant strategies for diverse groups according to Löfström, Örtenblad, and Sheaff (2015) emerged from the 1990s decade of, "blossoming of empowerment research" that mainly focussed on cross cultural and multi-country comparative studies of ethnicity. Research studies and popular health education text books, began to explore aspects of empowerment that worked in specific cultures, contexts and groups. Patient empowerment toward sel-management, and social movements focussed on preventative health, helped to establish that it is not possible to presume that health promotion approches which are working well for one ethnic group, will be as effective with others.

Durie (2011) suggested that research had been moving since the 2000s, to develop and test different strategies and approaches for effective initiatives with ethnic minorities (Durie, 2011). More recently, literature on osteoarthritis-management support has continued to emphasise the importance of spotlighting the unique qualities of these groups, the purpose being to address persistent health disparities (Bach et al., 2017; Institute for Healthcare Improvement, 2017a; Stairmand, 2014).

Barron et al. (2016) argued that a neglected area of osteoarthritis-management, was critical analysis and documentation of the main drivers behind the health issue that initiatives intended to address. Barron et al. (2016) advised that for osteoarthritis-management initiatives to be more accessible, the theoretical basis needed to be brought up to the standard of scientific scrutiny. What is more, monitoring and feedback from the target community would have to be included into the rationale of a chosen theory of osteoarthritis-management, as well as suitability of the initiatives within the culture and context of the targeted group.

Remarkably, multiple authors' have not identified their use of theory, particularly with regards to osteoarthritis-management initiatives with ethnic groups. Even so, a number of recent studies have shown that effective health osteoarthritis-management initiatives utilise theory, toward developing and shaping initiatives and ideally to ensure favourable lifestyle changes (D. Barton, Jiang, Harris, & West, 2017; A. Bullock, Davies, Edwards, Wallace, & Wood, 2018). For instance Carrol et al.'s (2014) research of key mechanisms operating in chronic condition osteoarthritis-management initiatives.

Carrol et al.'s (2014) research among disadvantaged groups noted the importance of considering the complexities of real-life interactions. They recognised that osteoarthritis-management initiatives woud need to give specific attention to theory selection, as there are theories which are poorly suited to vulnerable groups. Bos-Touwen et al. (2016) argued that one of the most crucial conditions for an effective osteoarthritis-management initiative, is an in-depth understanding of the determinants of patient engagement, which Touwen et al. (2016) referred to as, "activation for osteoarthritis-management") (p. 1).

Understanding the determinants it was argued, was essential for enabling and influencing "activation for osteoarthritis-management". Touwen et al. (2016)

recognised the role that healthcare practitioners played in providing osteoarthritis-management support, yet patients' initial osteoarthritis-management capabilities were often not determined, frequently resulting in a "one size fit all approach" (Bos-Touwen et al., 2016, p. 1). Despite Bos-Towen's (2016) argument for bridging the disconnection between theory and practice, Donovan and Jones' (2004) survey of Australian health promotion practitioners, found that less than half reported the use of theory.

As Donovan and Jones' (2004) anticipated, healthcare practitioner association newsletters were more commonly read, than academic journals (only one in ten had used an academic journal to inform their healthare practice). Donovan and Jones' (2004) concluded that healthcare practitioners' in failing to utilise published theory and findings in their clinical practice, were failing to employ the most efficacious osteoarthritis-management techniques. As the literature review of the present thesis (following chapter) will demonstrate, the disconnection between theory and practice of osteoarthritis-management is not dissimilar to what has been occurring in New Zealand.

Similarly, of the five major structured strategies being used to promote Māori health, wellbeing and/or chronic condition management, only one literature source was explicit about the use of Durie's (1994b) 'Te Whare Tapa Whā' model of health in their theoretical framework. As a result, it was impossible to ascertain an appropriate theoretical framework within a cultural context, raising a noticeable gap in the osteoarthritis-management literature about creating initiatives and resources with Māori. On the contrary, Nuovo's (2010) textbook on chronic disease management outlined the significance of the 'cultural framing' of osteoarthritis-management resources.

Nuovo's (2010) textbook noted the significance of promoting healthcare practitioners and patients (stakeholders) to focus on elements of the clinical process and outcomes, that specific cultural beliefs directly impact. Nuovo (2010) depicted cultural issues that may be important to a patient's participation in the development of a, "genuinely shared treatment plan". Particularly when critical cultural beliefs are acknowledged, stakeholders are then able to work together to develop strategies that are implementable (p. 128).

Making real progress

Similar to Nuovo's (2010) views and others (Bodenheimer et al., 2002; Harris et al., 2006a, 2006b), the literature on ethnicity and inequalities suggested a need for osteoarthritis-management resources that take account of the social contexts that make a real impact on ethnic inequalities in health. As identified in an Institute of Medicine's (2002) report, there are major reasons why the unique shared values, beliefs and practices or culture and ethnicity are significant when connecting theory to osteoarthritis-management. Although dated, the report was important for defining disparities in healthcare as ethnic differences in the quality of healthcare, that was not due to access-related factors (such as needs, preferences, and appropriateness of osteoarthritis-management initiatives) (Institute of Medicine, 2002).

Since the publication of the Institute of Medicine's (2002) report, Egede (2006) noted that there had been a renewed interest in understanding sources of disparities. Such as identifying contributing factors or designing and evaluating effective initiatives, to reduce or eliminate ethnic disparities in healthcare. Irgit and Nelson (2011) emphasised health inequities in their commentary on the lower utilisation of total joint replacement (arthroplasty) by ethnic minorities.

According to Irgit and Nelson's (2011) review, there are several possible explanations for the lower utilisation rates of surgical treatment by ethnic minority groups (African Americans, Hispanic groups). While they include income, geographic location and education, causal factors were acknowledged such as health literacy, trust, and preferences as well as healthcare biases or beliefs. Irgit and Nelson (2011) recognised individual, social environmental and physical environmental barriers, that work against successful osteoarthritis-management initiatives.

Irgit and Nelson (2011) also noted that eating behaviour, dietary choices and lack of physical activity often converge with close social connections. Therefore, shared cultural expectations and environmental cues needed to be considered (Irgit & Nelson, 2011), than adopting a biomedical perspective alone (Halligan & Wade, 2004). By understanding environmental cues and social influences, may be important for identifying and managing patients at risk of developing osteoarthritis (Bierma-Zeinstra, De Vos, & Runhaar, 2014; Blagojevic-Bucknall et al., 2015). For example, considering known risk factors within social and cultural norms, in which they are understood, experienced and valued by older-people with osteoarthritis (Blagojevic-Bucknall et al., 2015)[13].

In addition to understanding the risk factors for osteoarthritis, within the context of cultural norms in which they are experienced and understood, are other important influences. Lack of access to affordable, healthy foods, inviting outdoor spaces and places to exercise in that are safe, family support, also influence cultural norms and perspectives. These aspects and others, "establish rules for living that extend to the

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[13] Obesity, previous joint injury and diabetes are known risk factors for the progression of osteoarthritis (for instance of the knee) (Lefevre-Colau, Nguyen, Palazzo, Poiraudeau, & Rannou, 2016).

cultural meaning of disease and its management" (Cockrell, Jack, Liburd, & Tucker, 2014, p. 1).

Additionally, Keynejad (2011) noted that there are additional barriers, which people from ethnic minority groups face, to seeking and gaining help that are of minor significance for mainstream community members. These can become important barriers for ethnic minority groups, with the greatest burden of negative health disparities. Keynejad (2011) suggested better training for healthcare practitioners, such as delivering a session of cultural competence training to ethnically diverse service users, to gain their feedback and make appropriate adjustments to cultural competence training.

Keynejad (2011) argued the concept of key success factors of osteoarthritis-management resources, will depend on culturally-responsive design. Namely design that gives close attention to historical, cultural and societal attitudes facing those living with a disability or osteoarthritis impairment, as well as societal and cultural norms. Culture was a recognised key element in unlocking barriers and opportunities to seeking help, potentially influencing the way that a person delineates and makes sense of their heath symptoms and coping actions (Keynejad, 2011). That cultural beliefs and values can powerfully influence the lifestyle factors of an ethnic group, is an important consideration in effective management of osteoarthritis.

In describing that there are important cultural nuances which need to be addressed to better prepare some groups toward effective osteoarthritis-management, as Cha et al. (2012) noted, initiatives may not be culturally suitable for some minority groups. Cha et al. (2012) gave the example of natural energy flow through balancing yin and yang as being important to Asian cultures, for optimising and maintaining health. Adherence to osteoarthritis-management was found to be affected by behaviours and beliefs. Emphasising for instance that to be effective, osteoarthritis-management initiatives will need to consider cultural context, which means understanding the cultural values and beliefs of the target group.

Johnson and McGee's (2014) commentary on developing cultural competence in palliative care, cautioned the importance of not treating culture commensurate with ethnicity (Johnson & McGee, 2014). Relevant to osteoarthritis-management initiatives, there are significant differences that may be socioeconomic and educational, both within and across different ethnic groups, which need to be considered. Similarly, Dominic O'Sullivan (2001) argued that minority indigenous groups do not fit easily into an assumed whole of homogeneity.

Besides, Durie (2003) argued that in the future, older-Māori would not form a culturally homogenous group, although their numbers would substantially increase.

Even if older-Māori may lack cultural and social skills required to undertake kaumātua roles effectively, yet they will also not wish to be acculturated into mainstream society. Positive Māori solutions to Māori problems were predicted by Durie (2003), noting that health was as much about culture and community empowerment as it was about realisation of cultural identity and the sharing of power.

Realisation of culture

Durie (2003) noted that emphasising cultural identity was justified on the basis that a, "negative or confused cultural identity", was in itself a chronic (mental health) condition (p. 51). Airhihenbuwa (2007) agreed that there are barriers which ethnic groups can face, such as cultural, social and economic (Airhihenbuwa, 2007) (emphasising the significance of cultural identity, relative to osteoarthritis-management). Airhihenbuwa (2007) gives the example that in the context of West African culture, identity was tied to an individual's family after participants discussed stressors affecting self-management, with their family being the most dominant theme.

Airhihenbuwa, Ford, and Iwelunmor (2014) noted that health theories about self-management, commonly framed problems within individual, "actions or inactions" (p. 78). The inference being that poor health occurred, because individuals were unable or unwilling to follow preventative methods and recommended action plans. (Airhihenbuwa et al., 2014) argued that changing negative health actions was as much about identifying and promoting positive health actions within the cultural logic of its contexts, as was using a culturally established approach.

Durie (2003) noted that the use of Māori-centred (Māori-specific) tools were promising for Māori identity. For example, Barber et al. (2012) employed the use of Hua Oranga (tool) to assess outcomes after 172 participants (94 = Māori) found that the tool had much to offer in Māori health outcomes research, for its simplicity, minimal cost and holistic Māori conceptions of wellbeing (Barber et al., 2012). Another Māori specific tool, Te Ngāhuru using a global measure of Māori wellbeing and an outcomes schema, indicated that a critical role for whānau in respect to children and kaumātua was the capacity to care (manākitanga) (Durie, 2006).

Further, the best outcome noted was when whānau members had a strong sense of identity and felt well cared for, yet remain concerned about the wellbeing of other family members. A secure identity resulted from ability to access te ao Māori (Māori society) and participate in activities and initiatives that formed the foundations of Māori society. For example, participating in Māori interest groups, such as kaumātua advisory rōpū (groups), using a Māori health service, or involvement in Māori networks and knowledge of whakapapa (Durie, 1999a, 2006).

Ahluwalia, Baranowski, Braithwaite, and Resnicow (1999) proposed that sensitivity to cultural identity was defined by two dimensions (surface and deep structures). Surface structure for example might comprise matching osteoarthritis-management resources to observable characteristics of a population group, such as language, reflected by the way that initiatives were well-suited to the culture of the target group. Ahluwalia et al. (1999) found that the use of contrasting deep structures, enabled consideration of the historical complexities of cultural, social and environmental factors, influencing the health activities of a group and their understanding of those activities.

Ahluwalia et al. (1999) as a result contended that surface structure will usually increase feasibility and acceptance of the initiative, versus deep structure that conveys salience and impact (Ahluwalia et al., 1999). More recently Sidhu's (2012) doctoral thesis argued the premise of, 'health beliefs in relation to chronic disease and self-management …". Sidhu (2012) developed a taxonomy of cultural adapttion, through a systematic review of lay-led, group-based osteoarthritis-management initiatives, with a socio-economically disadvantaged multi-ethnic group.

Sidhu (2012) critiqued cultural adaptations of self-management initiatives. Predominantly discovering that community and cultural identity membership, influenced self-management. Sidhu (2012) identified the following taxonomy of strategies, that will be accounted for in successful initiatives of self-management (Table 1):

Table 1. Taxonomy of cultural adaption (Adapted from Sidhu (2012, p. 102)

Cultural adaptation
• Delivery in the language of the community; • Cultural adaptation of education material; • Visual aids and demonstrations; • Understandable terminology; • Emotional wellbeing; • Culturally sensitive approach to delivery; • Recruitment of lay personnel; • Delivery in community locations; • Cultural and/or religious acknowledgment; • Provision of rewards; • Provision of healthy cultural foods; • Cultural branding; • Inviting family and friends

The use of language is an example of a peripheral strategy, that Sidhu (2012) used to describe the surface structure of self-management, such as clear communication with peers. Ensuring the content covered common beliefs, values and practices of the community was detailed, as was the use of visual aids and demonstrations with take home initiatives. For instance, the use of lay presentations using their bodies of knowledge about health was ideally pitched to the level of understanding by the community, using understandable terminology and culturally relevant terms, that carried socially defined meanings, and identifying social issues that caused stress and helped to reduce stress and anxiety were noted by Sidhu (2012).

Evidential strategies that attempted to raise the importance of a health issue was also mentioned by Sidhu (2012), such as cultural sensitivity towards osteoarthritis-management delivery, which was about communicating in a manner that incorporated community values. Further, recruitment of lay personnel with advanced understanding of the social issues facing the community was noted as beneficial, when they were also a part of that community. Also, noted in the delivery of osteoarthritis-management initiatives was the use of community locations that were easily accessible to participants with limited access to transport or locations that may carry some important cultural or religious significance.

Strategies of cultural adaptation outlined by Sidhu (2012), also incorporated sociocultural strategies, which reflected ‘deep structure’ characteristics that put the emphasis on cultural identity. For instance, the provision of encouragement, care and praise, and the inclusion of foods that were healthy and easily available. Cultural branding such as incorporating the name of the osteoarthritis-management initiative so that it reflected community beliefs and values were noted, for potentially helping participants to feel less apprehensive, as was inviting family for moral support and encouragement.

As will be presented in Chapter 2, some of these strategies have been utilised in previous self-management initiatives, that targeted Māori with chronic conditions. In the following section, the significance of the present research is outlined, critically reviewing these initiatives and making the argument that there are clear disconnections in the literature, and need for an osteoarthritis-management resource. That is to say a resource, that employs Māori input to assist in the methods of shaping, planning and decision-making.

Significance of the research

The focus of the present thesis is to explore the everyday experiences of kaumātua with osteoarthritis, and integrate these culturally specific factors into an osteoarthritis-management resource. In effect a resource that will assist kaumātua with osteoarthritis, to accomplish action orientated guidance (osteoarthritis-management).

By outlining and describing the process of working with an indigenous group within my own community, insight of the local group will be provided. Notably, about local social issues and the processes required in developing an osteoarthritis-management resource that is reflective of Māori cultural values, practices and beliefs.

Research objective

The focus of the present thesis will be on ascertaining how kaumātua with osteoarthritis are managing their condition. Further, to ascertain how a Māori-centred approach drawing on kaupapa Māori theory, could be employed to create a culturally appropriate resource for Hawke's Bay kaumātua living with secondary osteoarthritis. The process of working with kaumātua, to develop an osteoarthritis-management toolkit (resource), that reflects Māori beliefs and cultural practices is described.

Research questions

What are the everyday experiences of osteoarthritis-management for kaumātua? How could a Māori-centred approach drawing on kaupapa Māori theory be best employed, to create a culturally relevant toolkit for kaumātua with (or at risk of) secondary osteoarthritis (osteoarthritis that has a known cause)?

Organisation

The present thesis is divided into two pathways, the first forging Chapters 1 – 4, that acknowledge and weave together past and present literature. In particular, the 'take' or reason for exploring kaumātua experiences of osteoarthritis and a culturally appropriate resource and 'kaupapa[14]' or general principles. With that kaupapa in mind, Chapters 1 - 4 lay down the theoretical and methodological foundations of the thesis. The second pathway builds on Chapters 5 – 7 forging the stories and voices of kaumātua, alongside themes and, 'Osteoarthritis-management indicators, and an osteoarthritis-management resource.

Chapter 2, 'Laying down the 'take' (Literature review)' provides a critical review of osteoarthritis-management literature for the purpose of demonstrating, why there is a need for a locally-based osteoarthritis-management toolkit in Hawke's Bay. Notably, when creating chronic condition management resources for kaumātua, I give an overview of the limitations of initiatives that have focussed on the distribution and determinants of osteoarthritis-management. Potential lessons learnt from the literature, that might inform more fitting osteoarthritis-management initiatives with kaumātua is the

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[14] Kaupapa is derived from two base words, 'kau' means, "to appear for the first time, to come into view, to disclose". 'Papa' means, "ground or foundations. Accordingly, kaupapa means ground rules, first principles, general principles" (Marsden, 1992, p. 14).

focus.

Chapter 3, ‘Real world experience (Māori knowledge building)’, presents the methodology. An argument is provided, that fundamental to the research for providing ontological and epistemological foundation, are Māori beliefs, customs, and values systems, as a pathway for conceptualising the current study. Explanation is provided of a Māori-centred approach and justification for such an approach, alongside alignment with Kaupapa Māori[15] theory, Māori wisdom and knowledge (customary knowledge) and qualitative methods is outlined. Additional explanation is given to the appropriateness of qualitative research within the field of osteoarthritis-management, as well as specific reference to the objectives of the present thesis.

Chapter 4, ‘Mahi tahi (Research design and methods)’, details the data gathering and analysis techniques from the pathway, that were employed. Precisely to collect, interpret and review information, as well as the various processes used to ensure overall quality and rigour in the process of conducting a series of qualitative interviews with kaumātua, face-to-face focus group hui, and reflexive journalling. The data from these research activities, used to theorise contemporary practice and shape an osteoarthritis-management resource, articulated by kaumātua are presented.

Chapter 5, ‘Data gathering and analysis (Preliminary findings)’, weaves a pathway to understanding the voices and knowledge of kaumātua, presenting the interrelated themes that emerged from the data. Explanation regarding the prioritisation of the themes is provided, comparing and contrasting with the current literature. The main themes are presented in relation to what the everyday experiences of Māori living with osteoarthritis are, with a specific focus on the knowledge, attitudes and practices of kaumātua with osteoarthritis living in Hawke’s Bay.

Chapter 6, ‘Osteoarthritis-management resource (theorising outcome indicators)’, will explain how the major findings from interviews and focus group hui, informed the resource (toolkit). I outline how kaumātua feedback, helped to refine constructing a toolkit. Examples are given, as the argument is made that utilising Māori theory, enabled me to address a disconnection in the literature about how to utilise culturally appropriate research methods, when shaping self-management resources for Māori audiences.

Chapter 7, ‘Pathway appraisal (Interpretation and assessment)’ explains the pathway through, how a Māori-centred research was evaluated. I argue why a Māori centred research approach was an essential part of the research. I start by offering an

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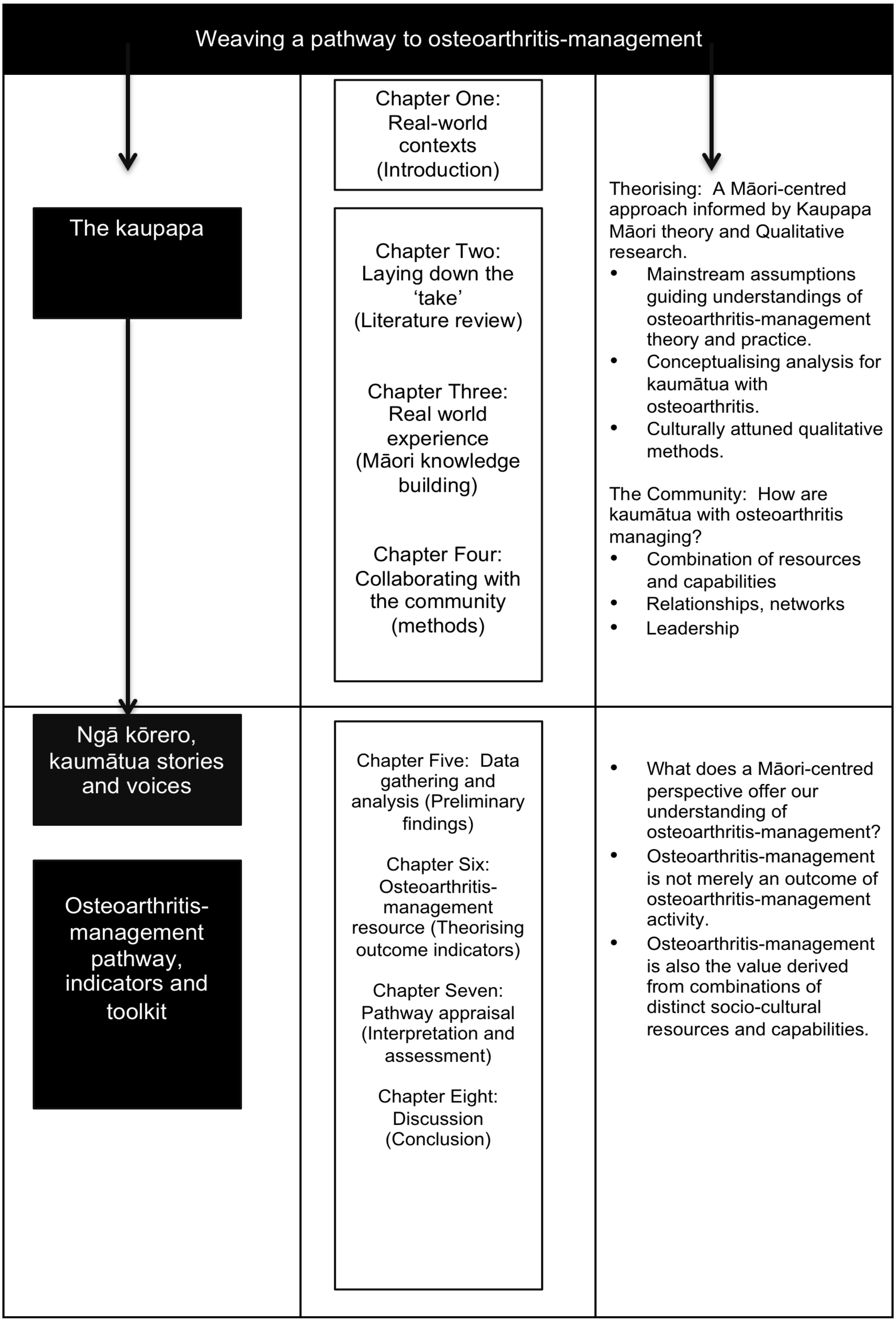
[15] According to M. Ungar (2008), ‘kaupapa’ translates to laying down a philosophy, therefore Kaupapa Māori establishes Māori epistemology and culture as that foundation (Campbell, Curran, & Grimshaw, 2011).

overview of the main purposes of the research, and some of the identified research disconnections that I hoped to address. Explanation and discussion of a range of principles, and how my research collaborated with the community to produce a culturally appropriate osteoarthritis-management toolkit is presented.

Chapter 8, ‘Discussion and conclusion’ draws the journey of the thesis to a close by discussing lessons learnt and strengths of the research, as a solid foundation for osteoarthritis-management. The stakes are just as high in confronting the issue of osteoarthritis-management, as there will be for future research, so pathways of recommendation that might prove useful for other healthcare practitioners, planners, promotors, educators and researchers contemplating Māori-centred research with kaumātua, are given attention for the continued journey. The thesis concludes by synthesising some practical policy recommendations that are informed by my research findings, Figure 1 summarising the overall structure of the thesis follows:

Figure 1. Summarising overall structure of the thesis



Weaving a pathway to osteoarthritis-management		
The kaupapa	Chapter One: Real-world contexts (Introduction) Chapter Two: Laying down the 'take' (Literature review) Chapter Three: Real world experience (Māori knowledge building) Chapter Four: Collaborating with the community (methods)	Theorising: A Māori-centred approach informed by Kaupapa Māori theory and Qualitative research. • Mainstream assumptions guiding understandings of osteoarthritis-management theory and practice. • Conceptualising analysis for kaumātua with osteoarthritis. • Culturally attuned qualitative methods. The Community: How are kaumātua with osteoarthritis managing? • Combination of resources and capabilities • Relationships, networks • Leadership
Ngā kōrero, kaumātua stories and voices Osteoarthritis-management pathway, indicators and toolkit	Chapter Five: Data gathering and analysis (Preliminary findings) Chapter Six: Osteoarthritis-management resource (Theorising outcome indicators) Chapter Seven: Pathway appraisal (Interpretation and assessment) Chapter Eight: Discussion (Conclusion)	• What does a Māori-centred perspective offer our understanding of osteoarthritis-management? • Osteoarthritis-management is not merely an outcome of osteoarthritis-management activity. • Osteoarthritis-management is also the value derived from combinations of distinct socio-cultural resources and capabilities.

Chapter 2: Laying down the 'take' (Literature review)

Introduction

The purpose of the present chapter, is to acknowledge and weave together a critical review of chronic condition self-management and health literacy literature. Having already identified the context of a distinctive osteoarthritis-management journey, the current chapter is concerned with laying down the 'take' or 'kaupapa' (the reason) for the many steps that follow. The purpose is to forge a pathway to osteoarthritis-management, and demonstrate why there is a need for Māori input, monitoring and strengths-based outcomes, when creating an osteoarthritis-management resource with kaumātua.

The chapter is organised into three main sections. The first section, provides an overview of the limitations in research, that have focussed on the distribution and determinants of chronic condition self-management, and data concerning the distribution and determinants of health and disease. A review of self-management support in New Zealand, having targeted a Māori audience is detailed. Further attention is made of the lessons that may inform better self-management support with kaumātua.

Following lessons that can be learnt from the chronic-condition management literature, Ko Awatea & Counties Manukau Health's (2016) 'Kia Kaha: Manage better, feel stronger' collaborative project (Kia kaha) is discussed. Kia kaha was a locally-based initiatiative in Counties Manukau, designed to tackle the increase in people living with long-term conditions (Ko Awatea Institute for Healthcare Improvement, 2017). Strengths of the community approach will be identified and limitations, which make drawing conclusive lessons or understand specific processes difficult, when designing a culturally appropriate resource to support kaumātua with osteoarthritis.

The second part of the chapter will focus on health literacy and the use of self-management, as a medium of support that is applicable to kaumātua with chronic-conditions and healthcare practitioners. A review of the limited literature on the efficacy of supportive tools will be included. The existing literature on osteoarthritis prevention for Māori with chronic-conditions is critiqued, offering the argument of there being an obvious need for osteoarthritis-management resources that are culturally appropriate.

The last section of the chapter is dedicated to investigating the literature on kaumātua living with long-term conditions. After discussing international and domestic examples of self-management resources, attention to relevant yet limited studies, that have expressly employed Māori input is illuminated. The chapter concludes by showing that there are clear disconnections in the literature, and need for a resource, that employs Māori input to assist in the shaping of culturally relevant osteoarthritis-management.

Part 1: Looking for real-life studies

In epidemiology, studies are carried out to identify exposures that may affect the risk of developing chronic-conditions in a particular population (O'Reilly & Yarnell, 2013). Research studies examining the disparities between kaumātua and their non-Māori peers with osteoarthritis for instance, are crucial for understanding effective management of the condition (C. Jones, Reid, & Robson, 2002; P. Reid & Robson, 2007). The development and evaluation of chronic-condition management initiatives, has a direct association with policy makers and researchers, health service providers and indigenous communities, with valuable data to improve health outcomes related to chronic-condition management.

Similarly, Fernandez-Orgega et al. (2016) reviewed chronic condition literature (from 2000 to 2013) of randomised controlled trials, addressing self-management support initiatives. In chronically ill patients with low socio-economic status, essential characteristics and components of effective self-management support initiatives for these patients were not explicit. Reporting of patient-related outcomes of self-management support and methodology of initiatives were limited, leading Fernandez-Orgega et al. (2016) to conclude that rigourous reporting on development and underlying theories in self-management initiatives was required.

Not only that, a 2015 study that evaluated the quantity and methodological quality of community health intervention research in indigenous populations (including New Zealand), found that only twenty percent of the studies published between 1990 and 2015 met the criteria for methodological quality (Calabria, Shakeshaft, Snijder, Stephens, & Wagemakers, 2015). Fernandez-Orgega et al. (2016) suggested that ethical and methodological issues may have contributed to the lack of high quality intervention research. They noted issues for instance with poorly described methods, and variable community participation throughout stages of the research (Fernandez-Orgega et al., 2016), which can be problematic, as many indigenous communities oppose research that does not incorporate partnerships between researcher expertise and community members' skills and knowledge (Calabria et al., 2015; Durie, 2011; Health Research Council of New Zealand, 2016; Waitangi Tribunal, 2014).

The importance of partnership in the project about life in advanced age (LiLAC Study NZ), involving indigenous people was also identified in Kepa's (2015) review noting challenges of the, “partnership, production and exchange of knowledges” between Māori and non-Māori (2015, p. 6). Kepa (2015) detailed involving a range of participants and kaumātua, using Māori values in the Bay of Plenty as a basis for informing principles of conduct to explore the experiences of kaumātua. Drawing on Māori lived experience to acknowledge shared ancestry and socio-cultural contexts of kaumātua, Kepa (2015) argued that Māori sharing their lived experience of ageing well, is culturally appropriate and an ethical necessity, which can otherwise compromise relationships and Māori tīkanga (cultural principles).

Location-based systems

As exploring the everyday experiences of kaumātua with osteoarthritis, and integrating these culturally specific factors into a self-management toolkit is the desired outcome for the present research. Notably, that the socio-cultural context in which osteoarthritis is experienced primarily, needs to be understood. Broad et al. (2016) argued that describing the causes of health outcomes and conditions in populations was useful, for characterising the health of a community. Similarly T. Walker (2017) found that learning about individual experiences and perspectives of chronic-conditions, provided a broader picture of the experiences, historical and current conditions of a community.

Nevertheless, studies exploring the distribution and determinants of chronic-conditions, are only able to go so far to explain how kaumātua understand and make sense of living with a chronic-condition (Russell (Pere) et al., 2013). These studies and other clinical data are unable to understand the impact that mainstream systems, persistance of colonial ideologies and practices have had on the disparity between kaumātua and non-Māori people (Crengle et al., 2014; P. Reid & Robson, 2007; S. Reid & White, 2017). Profound health and social inequities persist as a consequence of long-lasting historical, political and economic conditions (Marriott & Sim, 2014; P. Reid & Robson, 2007; Russell (Pere) et al., 2013).

Cormack, Harris, Ricci, and Stanley (2013) cautioned that focusing solely on studies investigating the distribution and determinants of chronic-conditions and use of statistical data to foreground heath inequities, can perpetuate a view of Māori communities as sick, disorganised and dependent (Cormack et al., 2013). Cormack, Harris, Ricci, and Stanley's (2013) commentary is significant to the present study, because previous research suggests that kaumātua and non-Māori healthcare practitioners can have very different ways of talking about health (Bacal, Buetow, & Jansen, 2011; Cormack, Crowe, & Reid, 2016; Howard et al., 2017). Most concerning, through the use of listening to doctors' stories, Ellison-Loschmann and Pearce (2006) discovered healthcare practitioners' lack of acknowledgment in conventional biomedical science, of elements such as the contemporary effects of colonial legacies of racism and internalised racism, as part of the picture concerning health disparities.

In addition there is evidence that recent health disparity research, has been shifting towards focusing on the links between the impact of social or cultural factors on health status, than the frequency, pattern, causes and risk factors of chronic-conditions using clinical data alone (A. Anderson, Exeter, & Fu, 2015; Dimer et al., 2017; Finau, Metcalf, Scragg, Tipene-Leach, & Willoughby, 2000; Fox, Thayer, & Wadhwa, 2017). For example, Finau et al. (2000) investigated ethnic differences in perceptions of body size in middle-aged people in New Zealand. They noted that for Māori, conceptions of the idealised figure, cultural and social factors played an important role, than physical health alone, strengthening the argument that strategies need to be contextualised to the local indigenous population.

Further, exploring the links between the impact of social and cultural factors, Dyall, Hayman, Keeling, and Kerse (2011) criticised previous research involving Māori living to advanced age, for neglecting to incorporate the concept of spiritual wellbeing ('Te Wairua'). Dyall, Hayman, et al. (2011) argued that omitting spirituality on wellbeing among kaumātua has failed to recognise the impact of culture and ethnicity, such as Māori language and cultural principles (Te Reo Māori, tīkanga Māori, extended family (tribal and whānau) links, cultural values, religion, whānau engagement, recreational activities, healthy eating and discrimination). They argued that leaving out insights concerning spirituality and wellbeing in later life prevented fully recognising, appreciating and celebrating the 'advanced' older age of kaumātua.

Cormack et al. (2013) cautioned that in a multi-cultural society, the way that people's ethnicities are viewed by others, appears to have tangible health risk or advantage and is consistent with an understanding of racism as a health determinant. Cormack et al. (2013) advocated for racism structures to be dismantled, before New Zealand society can be considered fair, in order to facilitate equitable outcomes in health (Cormack et al., 2013). These structures that shape public understanding of Māori peoples and communities can represent a need for self-management support resources, that enable self-determination of priorities and solutions for Māori with chronic-conditions (Beaton et al., 2017; Ko Awatea Institute for Healthcare Improvement, 2017).

As outlined in the introductory chapter ('Chapter 1: Real-world contexts'), there is a need for self-management resources that recognise how personal, cultural, social, historical and environmental contexts, impact on ethnic inequalities in heath. There was also an identified requirement for culturally appropriate resources that engage people living with chronic conditions, to improve potentially low levels of chronic-condition management knowledge, awareness and attitude in the community. The findings suggest that although osteoarthritis is present within the community, the condition is not being clearly translated through into appropriate self-management initiatives and resources of support.

Real life initiatives

In order to garner how chronic-condition management is being supported in Māori communities, a limited range of initiatives are presented in the sections that follow, to obtain key lessons. The lessons concern how to support kaumātua, from a review of self-management initiatives, utilising multiple intervention strategies. Accordingly, apart from locality of the study, it has not been possible to prioritise one strategy, initiative or resource over another.

Ngāti Kahungunu Iwi dashboard: Structured strategies

A dashboard for monitoring Ngāti Kahungunu health and wellbeing (dashboard), aimed to achieve excellence in all areas, "for the peoples of the iwi" (Cram, 2014b, p. 1). Similar to the 'Equity of healthcare for Māori' (framework follows), the dashboard targeted multiple levels of the health sector and Ngāti Kahungunu community. The stated aims of the dashboard, was an emphasis on measuring the wellbeing of whānau, and the responsiveness of organisations to whānau, and to show a summary of progress.

The dashboard was a locally-based tool with a geographic focus: Ngāti Kahungunu ki Wairoa (concerning the area from the traditional northern boundary the Wharerata Ranges south of Poverty Bay) and Ngāti Kahungunu ki Heretaunga (traditional eastern boundary Hawke's Bay). The emphasis of the dashboard was on Ngāti Kahungunu peoples, "to be Kahungunu, by participating as a contributing nation in the world", being healthy and enjoying a higher standard of living. An initial framework was developed, along with a proposal for the next steps of development and testing of the framework (p. 1) (Cram, 2014b), with many of the results feeding into recent Māori health plans throughout the region (Hawke's Bay District Health Board, 2016b, 2017).

Important lessons about how the dashboard was informed through structured strategies to promote the aspirations of the Iwi, may also be learnt. All marae in Kahungunu were visited, so that members of Ngāti Kahungunu Iwi Incorporated Board (Iwi Board), were able to kōrero with whānau about the future aspirations of the iwi. These insights informed the construction of the dashboard, providing a means for monitoring the goal of promoting the aspirations of iwi (Ngāti Kahungunu Iwi, 2007).

The resulting dashboard for example, received positive cut-through with its intended audience, and has ensured ability to measure iwi access to quality health services (Cram, 2014b). Further, although Ngāti Kahungunu Iwi (2007) noted that the measurement of housing opportunities was enabled, and responsiveness of education, employment and cultural development initiatives, it has been impossible to ascertain the underpinning theory used. Nevertheless, Ngāti Kahungunu Iwi (2007) claim that the desired outcome had resulted in development, encouraging a seamless service environment for whānau to gather knowledge for wellbeing and develop initiatives and strategies to progress and enhance whānau, hapū and iwi wellbeing (Ngāti Kahungunu Iwi, 2007).

He Pikinga Waiora Implementation Framework 'of levels'

Different to the unique and local vision of Ngāti Kahungunu's dashboard, 'He Pikinga Waiora Implementation Framework' ('He Pikinga') was a planning tool to help guide chronic-condition management development and implementation for Māori (Beaton et al., 2017). Funders that worked with researchers and policy makers to develop 'He Pikinga', recognised the importance of strengthening four key elements: cultural-centredness, community engagement, systems thinking and integrated knowledge translation (Beaton et al., 2016). For example, 'Cultural-centredness' involved community voice to define the problem and develop solutions, and; 'Community engagement' recognised the imperative of a conceptual suitability, with partnerships occuring between community and organisations, guided by principles of action, social justice and power-sharing.

Another element of 'He Pikinga', 'Systems thinking' was an intervention that considered multiple perspectives (levels). These levels concerned worldviews and values, multiple causes and broad focus with numerous solutions that were supported by system relationships and feedback loops, targetting change at systems levels (macro, meso and micro). For instance healthcare policy (macro level) that failed to address the need for practitioner upskilling, starts to take shape in an unprepared healthcare practitioner that requires upskilling (meso level), can be considered a problem (micro level), as it affects patients.

The final design level element of 'He Pikinga', 'Integrated knowledge translation' concerned translating activities within the context of the community, where the knowledge was to be applied. A process of bi-directional learning was established enabling tailoring information to knowledge-users' needs (Beaton et al., 2016). Again, the present thesis that seeks to explore the everyday experiences of kaumātua with osteoarthritis, can learn valuable lessons from how 'He Pikinga' research was informed. Notably by insights, following Māori aspirations and linking into indigenous knowledge creation, such as the use of stories, local experiences and whakataukī (customary proverb), for theorising positive implementation outcomes.

These insights about Māori aspirations informed 'He Pikinga' framework, that has since been applied to over 13 studies of chronic condition prevention with indigenous communities throughout New Zealand, Australia, Canada and the United States. In addition, the Healthier Lives Challenge implemented by the New Zealand Government's National Science Challenge, has implemented 'He Pikinga' in part. Although I have been unable to obtain any further information as to how 'He Pikinga' has been applied or whether its goals and outcomes have been evaluated and met, Beaton et al. (2017) noted their intention to obtain further evidence of the impact of 'He Pikinga' on health and equity over the next decade (Beaton et al., 2017)[16].

Equity of healthcare for Māori

The 'Equity of healthcare for Māori': A framework ('equity framework') aimed to reduce the health burden related to chronic-conditions (Ministry of Health, 2014b). The underpinning equity principle sought to implement measures for the, "absence of avoidable or remediable differences among groups of people", regardless of how these groups are defined (for instance, socially, economically, demographically or geographically) (Ministry of Health, 2016c, p. 4). Accordingly, the 'equity framework' was designed to guide practitioners, organisations and the healthcare system, to achieve equitable healthcare for Māori.

The 'equity framework' was part of a broader research initiative, 'the Access project'. The Access project which included three literature reviews, in-depth interviews and focus groups, was led by Māori interviewers. The interviewers conducted 47 key informant interviews with healthcare practitioners working within Māori health and chronic-condition management, as well as funding and planning workers and researchers (Ministry of Health, 2014b). Valuable lessons concerning how the research was used to inform development initiatives can be learnt, to improve access to chronic-condition management in healthcare.

In-depth interviews led by Māori interviewers provided valuable insight into challenges, barriers and facilitators for action, to improve access to healthcare services for Māori. Using real life stories for insights that informed the structure of the framework, at the patient level, tailoring information to support self-management in the home with tools and holistic initiatives was emphasised. Insights obtained at a

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[16] See healthierlives.co.nz.

practitioner level that informed the ‘equity framework’, supported the provision of clinical decision-making guidelines and tools for healthcare practitioners, to support delivery of accessible and equitable healthcare (Ministry of Health, 2014b).

Further, the establishment of Māori advisory groups and their commitment to engage with health equity tools was noted as a way, that local community networks were able to improve their success, when engaging with Māori. Embedding organisational cultural responsiveness in equity tools, was noted for being valuable at the decision-making and resource allocation level, and to support healthcare practitioners, in their evidence-based decisions about patient care (Ministry of Health, 2016c). After contacting the researchers of the ‘equity framework’ (Fiona Cram of Katoa Ltd (2017)), they confirmed that there was no available information regarding surveys conducted using the framework, to ascertain the target community’s understanding of equitable healthcare of Māori[17].

The latter point as noted by Ahluwalia et al. (1999) is significant, because gaining insight into a health issue that the project intends to address, is a key component that contributes to the success of any self-management support initiative. For example, when surface characteristics such as communication styles or music are used, testing these with the local population to ensure the appropriate dialect is employed, as preferences may reflect inner cultural values which are classified as deep structure (Ahluwalia et al., 1999). Nevertheless, the theoretical distinction is useful for examining the specific elements that may help to identify relevant self-management theories and related determinants, that are specific to the needs of those populations, and could make an intervention effective[18].

Let’s get talking resource: Role of whānau

In comparison to the ‘equity framework’, that aimed to reduce the health burden related to chronic-conditions (Ministry of Health, 2014b), the ‘Let’s get talking resource’ (‘talking resource’) supported planning and delivery of care (Te Pou o te Whakaaro Nui, 2016). The ‘talking resource’ is relevant to self-management for promoting the acquisition of skills in chronic-condition management, using a suite of tools that were launched in 2015. The tools were aimed at supporting primary and secondary health services’ delivery, using a stepped care approach developed by Te Pou o te Whakaaro

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[17] According to my personal communication with Fiona Cram (2018), who advised that the Ministry of health had previously funded workshops on self-management tools (tools), and that they found these to be quite successful in getting people to know about and use the tools. However, in so far as their research the Ministry of Health had a restructure during that period of the tool’s production and the Māori team were scattered, consequently no further workshops were funded, there being scant information concerning surveys or feedback from the community.

[18] See health.govt.nz/.../equity-of-health-care-for-maori-a-framework-jun14.pdf.

Nui ('Te Pou'), a national centre of evidence based workforce development for the mental health, addiction and disability sectors in New Zealand.

'Te Pou' work with a range of organisations and people including service providers, such as District Health Boards' and non-governmental organisations, researchers, training and education providers. A key feature of the 'talking resource' was identifying strengths and areas for development, by using a skills survey assessment, that enabled matching resources to people's needs. Te Pou o te Whakaaro Nui (2016) identified that additional competencies were required of healthcare practitioners that required changes within the training curriculum, precisely that self-management initiatives should be theory-driven, with supervision and practice support.

The 'talking resource' has been judged successful by users, for several relevant reasons (Te Pou o te Whakaaro Nui, 2016). First, the theoretical framework was culturally appropriate for utilising of Durie's (1994b) 'Te Whare Tapa Whā' health model (Durie, 1994b). The 'talking resource' focussed on, 'Te Whānau' (extended family) element of the model, which as the creators of the campaign explained, incorporated the element that is characterised by extended family playing a dualistic role (Te Pou o te Whakaaro Nui, 2016).

The dualistic role of the 'talking resource' arises first by establishing a, "seamless, integrated response", where people have the ability to obtain and access holistic packages of care across sectors and silos (Ministry of Health, 2012c, p. 53). Second, the 'talking resource' conveyed a reciprocal obligation on the part of the individual with a chronic-condition, to adopt changes in order to support their whānau members with well-matched initiatives (Te Pou o te Whakaaro Nui, 2015).

A number of assessment measures were provided, such as Kingi's (2002) 'Hua Oranga'[19] model, that determined health outcomes from a Māori perspective using 'Te Whare Tapa Whā' model[20] as a basic structure, taking four minutes to complete by the patient, their family and whānau. Completing 'Hua Oranga' required patients to choose and answer one of five key statements that best reflected their social situation (for example, rating one's situation as one of: very bad; bad; just ok; good; very good), and tied into the requirement for intervention. The 'talking resource' was a useful tool for

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[19] Hua Oranga is a Māori measure of mental health outcomes, led by Te Kani Kingi and Mason Durie. Features of Hua Oranga are consideration for outcomes according to wairua, hinengaro, tinana, whānau and mental health outcomes Institute for Healthcare Improvement (2017b).

[20] Durie's (Kingi, 2002) 'Te Whare Tapa Whā' model helps with understanding Māori health, using the concept of four cornerstones of a wharenui (house), with strong foundations and four equal sides, the four dimensions of Māori wellbeing are symbolised. See hauora.co.nz where (1994b) talk about using 'Te Whare Tapa Whā' to, "tease out the cultural, social, psychosocial and physical determinants of health", to promote the health of Māori Rochford and Signal (2009).

promoting discussion between those seeking wellness, whānau and practitioners about planning treatment[21].

Quality Standards Resource: Tailoring resources

In contrast to Te Pou o te Whakaaro Nui's (2016) 'Let's get talking resource' (the resource) that sought to reduce the health burden by promoting skill acquisition, is the Ministry of Health's (2014d) 'Quality Standards Resource' ('tailoring resource'), for chronic-condition management. The resource was created with the purpose of spreading improvements in diabetes care, using material derived from quality statements of the National Institute for Health and Care Excellence (2009). In effect high quality and structured self-management education, tailored to individual and cultural needs of families and whānau.

The 'tailoring resource' aimed to increase participation by Māori through the Healthy Families initiative, to help people with diabetes live well closer to their home, using a staged implementation approach. The 'tailoring resource' was just one element of a broader initiative, that included requiring primary and secondary healthcare practitioners who were trained and competent, to deliver the principles and content of the initiative. The initiative also included a team approach involving non-governmental and community organisations, families, whānau and people with diabetes working more closely together (Ministry of Health, 2015c).

Integral to the 'tailoring resource' were key practice points regarding resources. For instance, that group initiatives were culturally appropriate and people with chronic-conditions should have access to self-management support, that was relevant to the ethnicity they identified with. The 'tailoring resource', necessitated the use of focus groups to listen to stakeholders' concerns, experiences and stories (in contrast with survey data) alongside preliminary testing of resources with the target audience.

The 'tailoring resource' suggested that a staged approach precisely targeting culturally and linguistically diverse audiences such as Māori and Pacific communities was appropriate, when initiatives were tailored to their experiences, values and needs (Ministry of Health, 2015c)[22]. These key practice points about targeted tailoring of self-management are supported by the academic literature, discussed in the introductory chapter (Chapter 1: Real-world contexts) of the present thesis. To be more specific, that culturally appropriate self-management support needs to be appropriate for the person with the chronic-condition, their family and whānau. Similarly, Bingham et al. (2013) explained that low levels of Māori knowledge about their chronic-condition was

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[21] See tepou.co.nz/initiatives/lets-get-talking-toolkit.

[22] See health.govt.nz/.../quality-standards-for-diabetes-care-toolkit-2014-nov14-v2.pdf.

attributed to a failure to provide information reflective of cultural practices, in ways that were appropriate for use in local Māori communities throughout New Zealand.

Also, literature on self-management support, emphasised the need to spotlight the unique characteristics of ethnic groups, in order to address persistent ethnic health inequalities (Institute for Healthcare Improvement, 2017a; Stairmand, 2014). As described in Bingham et al.'s (2013) observation study of 107 participants with type 2 diabetes (between 18-80 years of age), such focus led to increases in participant confidence to self-manage their condition. Finally, Ministry of Health (2014d) standards for high quality structured self-management that was tailored to individual needs, made a number of recommendations.

The first recommendation discussed by the Ministry of Health (2014d), was that self-management initiatives draw on the community as a resource, requiring special consideration for consultation with Māori (Ministry of Health, 2014d). What is more, recommendations included that future self-management initiatives should use Māori input and capacity-building, as these approaches enriched the environment for effective learning. Also, that initiatives focus more towards being culturally tailor-made and convergent on 'tino rangitiratanga' (self-determination), for example, patient, family and whānau participation in monitoring health parameters and actively participating in activities and scheduled follow-ups.

Summarising self-management with Māori

To summarise, the self-management resources, strategies and initiatives that have been presented so far, provide lessons for the present study. Each of the initiatives have confirmed that the foundation for self-management with Māori, requires an appropriate theoretical framework within a cultural context. What is more, early ongoing stakeholder engagement was crucial, with initiatives showing responsiveness to local concerns that ensured greater buy-in when they were driven by the community.

Also important were, culturally appropriate processes such as in-depth qualitative interviewing, for identifying wider health determinants, such as social and economic support. In addition, culturally tailoring self-management resources and initiatives relative to community knowledge, experiences, needs and values. In so far as the initiatives discussed so far, all were reasonably resourced, with expertise and funding to draw from. Developmental timeframes were also fairly lengthy, with budgetary processes to ensure resources had regional or national reach.

Rise of grassroots voices

Obviously the budgetary resources of the initiatives presented so far, are less likely to be available to most community groups or health organisations (stakeholders). Such as those looking to affect positive change in an effort to deal more effectively with chronic-conditions. Even so, more frequently stakeholders are looking for ways to give power to people, to manage their own health and healthcare, by providing them with effective self-management support (Health Navigator New Zealand & Auckland District Health Board, 2014). For that reason, the following discussion will argue for the need of grassroots, home-grown initiatives, such as 'The self-management support resource' (Health Navigator New Zealand & Auckland District Health Board, 2011), offering lessons on creating an appropriate resource for Māori with chronic-conditions.

The self-management support resource

The 'self-management support resource' was initiated by Health Navigator New Zealand & Auckland District Health Board (2011, 2014) ('Health Navigator resource'). The resource was a 13-page document that signposted tools, resources, initiative information and examples, to help healthcare practitioners and teams. That is, to apply evidence and knowledge-based approaches to self-management support, for people with chronic-conditions.

In contrast to the Ministry of Health's (2014d) 'Quality Standards Resource' that sought to tailor resources to individual and cultural needs, the 'Health Navigator resource' takes a broader approach. Although it had not yet been localised for different regions such as Hawke's Bay, the plan was that the resource would be revised and refined into an essential guide to self-management support for healthcare teams throughout New Zealand. After contacting Health Navigator Charitable Trust, I acquired additional information about the 'Health Navigator Resource' ('resource'), confirming there was no available information to ascertain the target community's understanding of the 'resource'[23].

Although the 'Health Navigator Resource' is currently undergoing development, it appears to be well geared towards mainstream self-management needs. Barber et al's. (2011) study of mainstream health service approaches for major long-term

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[23] According to my personal communication with Janine Bycroft (2017a), although the effectiveness of the Health Navigator Resource had never been evaluated, it had since 2014 undergone significant restructure. Rather than being located within a single downloadable document, key topics are arranged online separately for clinicians and patients. Resources now include a range of topics, such as: enhancing self-management support within primary care, how to make a plan, build your team, work differently, using training resources such as webinars and health literacy presentations.

conditions in New Zealand, found strikingly wide variability in perception of provision and processes between District Health Boards. Relevant to the present study concerning kaumātua with chronic conditions such as osteoarthritis, Barber et al's. (2011) study noted current mainstream healthcare orientations (primary and secondary care) remained weighted towards acute care, which were unsuitable for current and future population needs.

Similarly, literature on self-management support, has emphasised the need for healthcare services to shift from secondary care, that was often reactive than pro-active (where care that ensures preventive action is taken to intervene well before the onset of symptoms than illness alone) (Barber, Carswell, et al., 2011). That is a shift towards longer-term managed care (in a social, cultural and economic context), the emphasis being on prevention (early intervention, self-management and integration within primary healthcare), consistent with a strategic context. These concern the New Zealand Health Strategy which provide the building blocks for the Healthy Ageing Strategy, that is informed by the New Zealand Disability Strategy, Positive Ageing Strategy, Treaty of Waitangi and He Korowai Oranga (King, 2001; Ministry of Health, 2001a, 2002; Ministry of Social Development, 2016; Ministry of Social Policy, 2001; Office for Senior Citizens, 2014; Treaty of Waitangi Research Unit, 1989)[24].

Kia Kaha: Manage better, feel stronger

Similar to the 'Health Navigator resource' the, Ko Awatea & Counties Manukau Health's (2016) Kia Kaha: Manage Better, Feel Stronger collaborative project ('Kia kaha'), identified the need for healthcare services to shift from being reactive to pro-active and predictive. 'Kia kaha' was launched in 2013 by Counties Manukau Health, as part of the 'Beyond 20,000 Days campaign' (campaign) (Ko Awatea & Counties Manukau Health, 2016). The campaign led to a number of projects, with the overall aim of promoting healthy communities (Ko Awatea Institute for Healthcare Improvement, 2017).

'Kia kaha' incorporated a variety of outcome indicators, such as achieving a 25 percent reduction in hospital and general practice use, for patients with two or more long-term conditions who were enrolled in the project. A change package emerging from 'Kia kaha', was developed and tested against three key drivers. That is, patient 'engagement' (homebased peer support assessment); patient 'activation' (individualised peer support) and patient 'connection' (collaborative approach), that were developed and tested.

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[24] See healthnavigator.org.nz/health-a-z/o/osteoarthritis/.

Some key lessons about how to engage Māori communities can be gathered from the three key drivers, the first being the 'Kia kaha' patient 'engagement' driver. The 'engagement' driver arose after healthcare practitioners' expressed frustration of working in a model of care that was condition focussed (reactive) (Ko Awatea & Counties Manukau Health, 2016). What is more, services were unable to support patient engagement with pro-active care solutions, or take things a step further by intervening much earlier upstream (predictive), such as pointing out lifestyle activities to avoid and actions to take, before risk factors arose.

Related aims of the 'Kia kaha' patient 'engagement driver', were to work towards giving patients more choices, hearing their voices, and giving power to patient-centred approaches across all services and settings. Activating patient engagement, referred to promoting connected, collaborative relationships between healthcare practitioners and patients. The patient 'engagement' driver was aimed towards shifting current rates of identifying patients into services from 50 to 90 percent, by using a flexible professional to peer assessment process that was called, "patient choice, patient voice" (p. 6).

Another key lesson about giving power to people can be obtained from the second driver, that sought to connect the patient up with a service (patient 'activation' driver) that arose after healthcare practitioner concerns about the complexity of multiple long-term conditions. Patients with chronic-conditions were presenting to healthcare services 'overwhelmed' with the task of managing their health, resulting in little confidence understanding their condition with knock-on effects, such as feeling unable to problem-solve or think about wellbeing. Such effects often resulted in increased emergency care presentations and admissions to hospital, creating strain on healthcare services and budgets (Ko Awatea & Counties Manukau Health, 2016).

The result of increased demands on healthcare practitioners was less time and fewer options for each patient. That unempowered position changed with weekly individualised peer support of self-management education, through the 'Manage better course' and was based upon several types of support. These incorporated peer-led self-management support, all of which had demonstrated value for people with long-term conditions.

An example of Ko Awatea & Counties Manukau Health's (2016) peer-led self-management support is depicted below (Figure 2) in their, 'wheel of self-management support' ('wheel'). The 'wheel' has been used within the Careplan of the Arthritis Foundation's National Office (2017), to support discussions and lifestyle support that guides the 'Manage Better Together: Kia Kaha self-management support course' (Kia Kaha) (Ko Awatea Institute for Healthcare Improvement, 2017). The 'Kia kaha' intervention was designed with main components that are depicted in the wheel of self-management support.

Figure 2. Wheel of self-management support (Ko Awatea & Counties Manukau Health, 2016, p. 11)

In terms of lessons that can inform better self-management support with kaumātua, one of the noted strengths of the wheel, is the use of 'Careplan groups' (peer support) (see Figure 2, above). In particular that these give patients a forum where they are able to obtain peer support in the process of building their knowledge with healthcare practitioners, about how to monitor symptoms and initiate an action plan. Using the concept of 'Careplan groups', a report on the 'Kia kaha' intervention described steps that were taken to ensure that the 'Stanford self-management project'[25] was adapted in order to be consistent with Māori values and aspirations (Ko Awatea Institute for Healthcare Improvement, 2017).

Some examples of adapting the 'Stanford self-management project' incorporated, involvement of Māori leadership in the project who were conversant in 'Te Reo Māori', also Māori elements such as karakia, mihi, pepeha, waiata, and kōrero (prayers, greetings, introductions, songs, conversations) were included. Incorporating Māori elements into self-management projects, was noted as requiring time to enable developing trust between the participating members engaging in self-management education, healthcare practitioners and community members (Ko Awatea Institute for

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[25] The Stanford chronic condition self-management project was developed at the Patient Education Center at Stanford University. The course is designed to be peer-led, over six weeks, with an interactive session each weekly. Group sizes that are 12-16 participants per course, are presented in several languages and culture-specific according to the ethnic culture of the particpants (p. I).

Healthcare Improvement, 2017). Similarly Houkamau and Sibley (2013) pointed out that initiatives will have a better chance of participant retention, when particular aspects are incorporated, for instance, when Māori leadership, marae-based hui, Te Reo Māori and tīkanga Māori are integrated, as ways of orientating participants and supporting higher participation in the Māori community.

The latter point leads to a potential limitation that makes drawing a conclusive lesson difficult. That is to say when designing a culturally appropriate resource to support kaumātua with osteoarthritis, concerning understanding the process of consulting with the Māori community. None of the published research documents arising from Ko Awatea Institute for Healthcare Improvement (2017) appear to have made explicit, the process used to promote pathways of collaboration and partnership across the community.

Micro reality

Key lessons can also be made of 'Kia kaha's' self-management initiative, concerning patient 'connection' (connection being the driver that was concerned with sustainability of self-management at a micro, macro level) (Ko Awatea & Counties Manukau Health, 2016). On a micro level, 'connection' referred to a patient's sense of connection within themselves, personal goals, their whānau and family, as well as the support received that was self-management focussed (Ko Awatea & Counties Manukau Health, 2016). For example, inclusion of family and whānau in the 'Kia kaha' project, appeared to boost patient confidence to manage better, when information and tools were provided, families and whānau started to manage better together (Houkamau & Sibley, 2013).

It is well known that self-management works well, when it is complemented by patient and family involvement and enthusiastic services (Afzal et al., 2014; Britt, Gregory, Huriwai, & Tohiariki, 2014). Patient and family involvement and 'warm, welcoming' services can impact on health outcomes. For example people with long-term conditions and poor family involvement are known to experience greater social isolation and depression (Cornwell & Waite, 2009; Wylie, 2011) affecting attrition rates from engagement with self-management projects (Alloo et al., 2017).

A limitation that makes drawing a conclusive lesson when designing a culturally appropriate resource to support kaumātua with osteoarthritis, concerns the completion and attrition rates of 'Kia kaha'. The attrition rates for Māori enrolled in 'Kia kaha' was 30 percent non-completion (Ko Awatea & Counties Manukau Health, 2016), which according to Chen et al. (2015) is common for ethnic minority populations, who often benefit from orientation sessions when self-management projects are being facilitated.

What is not made explicit in Ko Awatea & Counties Manukau Health's (2016) follow-up literature on the 'Kia kaha' project is the reason for the attrition rates and how these compared to other enrolled groups, even though I have attempted to contact a representative, a phone call and follow-up emails requesting additional information have not yet been responded to.

Liesinger, Litchy, Naessens, and Rohrer (2010) noted the difficulty of comparing the outcomes of self-management initiatives, as being hampered by there not being a common metric to monitor and measure effectiveness of outcomes. A recent review of research identified over 60 different potential variables used to evaluate nursing care in diabetes self-management (Al-Smadi, Boyle, & Gharaibeh, 2017). The diversity of indicators targeting purported outcomes is indicative of the conceptual complexity of self-management.

Relative to the present study is uncertainty. Expressly, about which outcomes of self-management support are valued, and by whom and in what context, representing a critical limitation in the design and evaluation of self-management initiatives. There appears to be little evidence in the chronic condition self-management of osteoarthritis and health literacy literature, about which outcomes were most valued by patients, families and whānau or healthcare practitioners and policy makers or funders (stakeholders). Often it is clinical indicators or health and lifestyle changes that are assumed, as being the outcomes of most value.

It may well be that health and livestyle changes could account for issues with attrition rates from self-management support initiatives, which may also contribute to less cost-effectiveness. What is required is a better understanding of the outcomes desired by kaumātua with osteoarthritis and stakeholders, otherwise there is a risk that self-management support may not adequately reflect the priorities of everyone. Stakeholders that are responsible for providing self-management support, have a key role in shifting the culture and values of healthcare systems towards supporting self-management (Ministry of Health, 2016c).

Priorities about cultural values of healthcare systems, have not always been clearly articulated in the literature. The aforesaid represents a crucial limitation in current understandings. Precisely, that tie back to patient 'connection' being the driver that was concerned with sustainability of self-management at a micro, macro level (Ko Awatea & Counties Manukau Health, 2016).

Macro reality

Again, in comparision to the micro level of self-management concerning 'connection' at the patient level, valuable lessons can be learnt from Ko Awatea &

Counties Manukau Health's (2016) 'Manage better courses' (see Figure 2, above) detailed the importance of several (macro level) points of focus that inform development. The point of focus of the 'Manage better courses' was 'coordinated care', as that occurring between services available to the patient, their healthcare setting and larger community, such as those that addressed physical and mental health needs in the same setting. The second point of focus of the 'Manage better courses' focussed on building social support (see 'Peer-led') Figure 2, above), so that patients did not feel alone, by using processes that aimed to reduce social anxiety in a group setting.

In addition, Ko Awatea & Counties Manukau Health's (2016) 'Manage better courses', enabled new skills to be adopted by patients through self-management. The presence of support people with discussions about patient symptoms were aimed at promoting a greater level of understanding, awareness and acceptance. At the same time prioritising self-efficacy, to build confidence, positivity and hope (Ko Awatea & Counties Manukau Health, 2016).

Another point of focus of Ko Awatea & Counties Manukau Health's (2016) 'Manage better courses' underscored 'Health coaching' (see Figure 2, above), that sought to build patients' confidence to gain the knowledge, skills and tools that they needed to reach self-identified goals. Health coaching was found to assist in the provision of emotional support and practical assistance, which in my personal practitioner experience is often needed by patients with chronic-conditions. The role of 'Health coaching' was performed by peers, healthcare practitioners or laypeople with appropriate training and support, and incorporated motivational interviewing, coordinating patient care and entering the progress of self-management support onto the patient file.

A further point of focus of Ko Awatea & Counties Manukau Health's (2016) 'Manage better courses' emphasised 'Be-friending' (peer support) (see Figure 2, above). Peer support actually led to improved engagement, decreased depression and reduced the use of emergency departments and hospital visits by working as a way of offering help and support. In addition, valuing exchanges about personal experiences of recovery, enabled patients to identify with peer supports and share common experiences, helping to forge a bond of understanding and mutual help (Ko Awatea & Counties Manukau Health, 2016).

Another point of focus of Ko Awatea & Counties Manukau Health's (2016) 'Manage better courses' concerned 'Manage better supporting groups' (ongoing support) (see Figure 2, above), spotlighting patients to create their own support groups at the end of each of its 'Manage Better Courses' for self-management education. These groups were created by participants, as and how they would like to continue to meet and organise themselves. Healthcare practitioners offered initial support, although most groups did not require assistance, with hui occurring on a monthly basis where course graduates were invited to train as volunteers themselves (Ko Awatea & Counties Manukau Health, 2016).

An additional point of focus of the 'Manage better courses' concerned 'Options to self-tailor care' (see Figure 2, above), that promoted the use of a health passport to help patients create a personalised summary of their condition. Finally, another point of focus of the 'Manage better courses' concerned 'online support' and use of a self-management assessment tool, to explore the knowledge of patients regarding their health condition, medications, action plan, physical activity and lifestyle. The information arising from the self-management assessment tool was scored against knowledge of, and engagement with self-management, which in turn enabled initiatives to be tailored to the needs of each individual patient (Ko Awatea & Counties Manukau Health, 2016).

Envisioning an effective 'wrap-around' referral system

One of the noted strengths of Ko Awatea & Counties Manukau Health's (2016) 'Manage better courses' was that they were (cost) free to participants and everyone, including the surrounding community were given access to attend, using referrals originating from a healthcare practitioner. Similarly, it was noted that increased referrals enabled more ability to 'wrap' services around participants, encouraging them to consistently access, improve and increase their skills and attitudes towards managing their health condition. Accordingly, medical outcomes improved, producing higher success rates, than giving patients printed self-help materials alone (without face-to-face orientation and group support)[26].

These findings of wanting to increase referrals to enable more 'wrap-around' services was also noted in the Hawke's Bay District Health Board's (2011) strategy. Hawke's Bay service providers, advocates and service users' argued that there was a lack of service coordination referrals, both across different providers and various teams. A lack of coordinated referrals has seen kaumātua, "falling between the gaps", with disconnections occurring between: (i) public sector referrals; (ii) low public awareness about the referral system, and greater need for (iii) self-referral into healthcare.

These findings signal a need for an osteoarthritis-management resource that leverages stakeholder theory to promote referral communication between kaumātua,

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[26] See koawatea.co.nz/wp-content/uploads/2016/.../kiakaha_guide_V8-lowres-FINAL-1.pdf.

and consideration of potential obstacles (i to iii, above). Stakeholder theory suggests that sharing information leverages spread throughout networks, influencing larger groups of people (Freeman, 1983). For example, stakeholder theory would propose inter-referrals between patients and word-of-mouth sharing and networking ('whakawhānaungatanga'), as a possible way to distribute specific healthcare recommendations.

Orr, Warren, and Yulong (2014) discussed that effective referral systems were needed in New Zealand, to ensure a closer relationship between all levels of the healthcare system (Orr et al., 2014). In so far as the presence of effective referral systems can mean for kaumātua, they are more likely to receive the best possible care closest to home. That is to say a good referral system will ensure that optimal care is received at the appropriate level, primary healthcare services are well used, and reputation of the healthcare practitioner enhanced.

Referral does not only reference forward referrals from primary care practitioners, but multi-directional, such as practitioner to patient and family or whānau and specialists, as well as peer to peer. The focus of referrals in the Hawke's Bay commmunity and via the Kia kaha: Manage better, feel stronger' courses, has been on lessons that can inform better self-management support with kaumātua. Accordingly, a summary of the present section follows ('Making health literacy real').

Summarising real lessons

Jones, Mishra, and Xu's (2017) review of 53 multi-morbidity and self-management initiatives, included meta-analysis and qualitative research synthesis. Due to the heterogeneity in methodology and inconsistent findings among included reviews, Jones, Mishra, and Xu's (2017) were unable to draw many solid conclusions (M. Jones et al., 2017). Similarly in the present review of New Zealand self-management support literature that have targeted a Māori audience, it has been difficult to draw many solid conclusions for kaumātua with osteoarthritis.

Nevertheless, the literature has confirmed that the foundation for successful self-management initiatives with Māori, depends on the implementation of a theoretical framework that is culturally appropriate with clearly identified outcomes. The Ngāti Kahungunu Iwi dashboard added to the discussion, by accenting the importance of community participation in decision-making, to ensure practical relevance and acceptance. Besides, 'He Pikinga' planning tool that was informed by Māori aspirations, emphasised community engagement, social justice, power-sharing and systems thinking.

The ‘equity framework’ that sought to achieve better healthcare for Māori, provided valuable lessons and insight into barriers and facilitators for action, to improve access to healthcare services using real life stories. However, it has not been possible to obtain more in-depth information about the target community’s understanding of equitable healthcare. Even so, the review was useful for drawing out the importance of identifying self-management theories, specific to the needs of the population affected.

In so far as the lessons learnt from the ‘Let’s get talking resource’, the dualistic role of whānau and importance of holistic packages of care across sectors and silos was noted. As were reciprocal obligations on the part of the individual with a chronic-condition to adopt changes and support whānau members, with well-matched initiatives. Finally the ‘Quality resource’ that was created to spread improvements with tailored self-management education, necessitated the use of focus groups over survey data, and that the community should be viewed as a resource.

Critical to successful self-management intervention design, is an understanding of the cultural determinants which influence self-management activities, in order to influence these (Bycroft, 2017b). Yet across the self-management initiatives reviewed, it has been difficult to ascertain the level of community input that was sought, for the on-going relevance and acceptance and crafting of, self-management initiatives. In addition, it is unclear from the published research the specific processes used to obtain and incorporate Māori community input, there being no process evaluations of complex initiatives published.

For these reasons, it is not possible from the literature presented, to make many meaningful determinations. From my own practitioner perspective, these concern the ways in which Māori with chronic conditions were spoken to, the type of questions asked of the participants, or how the information was analysed. Despite several attempts to obtain these, it was assumed that in most cases, the determinants of health for Māori were used, rather than the specific knowledge of the community members with chronic-conditions.

As a result lessons extrapolated from the review so far, it is argued that what is required from self-management in New Zealand is the acquisition of values, needs and experiences of the target audience. That being the case in order to understand self-management and encourage appropriate support (K. Braun, Compton, Tanoue, & Tomioka, 2012; W. Goodman, Lemondea, Paymana, & Weavera, 2014). Having synthesised the literature in the current section to understand key lessons about how to engage Māori communities, the existing literature is critiqued. Over and above that, I continue my argument of there being an identifiable need for a culturally acceptable osteoarthritis-management resource.

Part 2: Making health literacy real

Hess and Whelan (2009) discussed in their article that, 'Making health literacy real' meant more than just being able to read health literature or initiate an appointment with a healthcare practitioner successfully. The United States Institute of Medicine noted that health literacy becomes apparent from a convergence of, "expectations, preferences, and skills" of individuals seeking health information and those providing the information and services (Kindig, Nielsen-Bohlman, & Panzer, 2004, p. 4). It would seem that health dialogue and discussion has replaced, "explanatory monologue" (Stenvall & Virtanen, 2017, p. 79).

The Health literacy initiative of the World Health Organisation (2017c), identified the role of culture. In effect that the ability to understand and use social and cultural identity to interpret and act on information (cultural literacy) is what is needed by healthcare stakeholders, if the focus is on improving healthcare and health outcomes. Braun, Carter-Pokras, Coleman, and Lie's (2012) sentiment mirrored the same, in their review of patient health literacy and practitioner' cultural competence, that if unaddressed, cultural differences have been shown to contribute to poorer health outcomes through misunderstanding, "value conflicts and disparate concepts of health and illness" (p. 1).

In so far as indicators that a patient has low-literacy, Baker et al.'s (1995) study although dated, is still useful because they identified that patients (one-third of the sample of 2,659 patients) rarely thought of themselves as struggling with literacy issues. As a consequence they tended not to ask for assistance to understand health materials offered, confirming reports from earlier studies that indicated patients are less likely to identify themselves as such (D. Baker, Nurss, Parikh, Parker, & Williams, 1996). Osteoarthritis-related disabilities combined with low literacy are likely to pose a compounding threat to health (J. Barlow, Ilbery, & Turner, 2002), particularly if self-management initiatives are relying heavily on printed materials (Ko Awatea & Counties Manukau Health, 2016).

As the World Health Organisation (2017c) have argued, patients' knowledge regarding their treatment and health literacy, are known to affect treatment outcomes. Although, "knowledge alone does not always lead to changes in self-management", the real prerequisite is having people consider fully where the disconnections are in their, "knowledge, and optimising outcomes to address these factors" (p. 1). In terms of knowledge about their own health, New Zealanders on average are known to have low levels of health literacy, including Māori men (80 percent) and women (75 percent), putting them at risk of adverse outcomes (Bereznicki, Chalmers, Obamiro, & Rolls, 2017).

Poor health literacy may translate into difficulty understanding appointment letters to see a healthcare practitioner, filling in forms, understanding educational resources, and following medical instructions (Ministry of Health, 2010). Moreover, there is a disconnection for Māori, with health literacy skill issues compared to non-Māori regardless of their level of age, education, employment status or rural/urban location (Ministry of Health, 2010). That there has been very little reporting of patient-related outcomes of self-management initiatives focussed in the area of health literacy, illuminates the gaps in research and possibilities for theory development (Fernandez-Orgega et al., 2016; New Zealand Health Quality & Safety Commission, 2013).

Notably for kaumātua, there has been little reporting of osteoarthritis-management initiatives, even though Ministry of Health reports support self-management as an effective tool (Ministry of Health, 2010, 2015b). With the low levels of Māori health literacy, it is noted that most available surveys and frameworks (Ministry of Health, 2010, 2015b), have not made explicit in the research process, about the employment of theory. That is, local theories in the design of incorporating kaumātua with chronic conditions' input, into self-management initiatives.

Nor is there vast evidence of locally sourced input being sought to assist in the process of laying a strong foundation of self-management concerning kaumātua or the realities that they may face. For these reasons, it has been difficult to work out the level that initiatives are explicitly accountable to kaumātua. In addition, whether accountability is being privileged over other answerabilities which Shuker, Merry, and Walsh (2015) argued was often the case for, non-Māori funders.

Moreover, in the present literature review the, 'Kia Kaha: Manage Better, Feel Stronger project' was the only initiative that focussed explicitly on the use of self-help support group (focus group) initiatives and primary care referrals, to convey health information. Russell (Pere) et al. (2013) noted that focus groups and interactions face-to-face were helpful for enabling members with the same issues. That is to say, to come together and share coping strategies, and a sense of community, which Frings-Dresen, Hoving, Leensen, Vooijs, and Wind (2017) discussed offers several possible advantages over printed materials[27].

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[27] Face-to-face interactions for example, allow desirable self-management activities to be demonstrated. For instance, demonstrating posture and stretching techniques for improved spinal function as well as sleep practice management or the range of techniques that can encourage osteoarthritis sufferers to get more restful sleep. For example, sleeping on a regular schedule, avoiding caffeine and alcohol in the hours before bed, sleeping in a cool, dark room, turning off the TV and computer or phones an hour before bed, not lying in bed awake for more than 20 mins instead getting out of bed and doing a calm activity until ready to sleep .

In addition to showing desirable self-management activities, these strategies can be presented as relevant to everyday (real-life) circumstances (Bull, Gaglio, & Glasgow, 2012). Real-life circumstances may give the community an opportunity to show their approval and support, rather than presenting community members with these strategies in an abstract form. Similarly, few studies have shown that culturally sensitive chronic-condition management has been effective at influencing positive change (Cup et al., 2016).

Linn et al. (2016), however, obtained positive responses after screening a locally made DVD resource, that was developed within local cultural and oral understandings of Kwaio people in the Solomon Islands. Five short videos that used music and chanting (ai'imae) to convey health initiatives, resulted in an increase of knowledge (64 percent), although the number of peoples believing their condition was caused by sorcery remained the same (about 30 percent). The project evaluation indicated that health-seeking treatment may be more due to socio-cultural and health service factors, than awareness of the condition, resulting in culturally sensitive self-management resources remaining important.

Real support

It would seem that ‘making health literacy real’ is as important as receiving ‘real support’, as Geboers, Reijneveld, Spoorenberg, Winter, and Wynia (2016) noted the association between health literacy and self-management abilities in older-people (over 75 years). Especially, as an important predictor of better health outcomes and wellbeing (Geboers et al., 2016). Even so, ascertaining positive avenues of self-management of the initiatives presented so far has been difficult, due to disconnections in the existing self-management literature.

In so far as reviews of self-management support initiatives, Asugeni et al.'s (2015) analysed 6,074 chronic-condition management studies, all randomised controlled clinical trials. Even though the study is three years old, it is helpful, because Asugeni et al. (2015) notably assessed the effect of widely used self-management support initiatives against usual care[28], although none of the studies precisely targeted an ethnic or indigenous group for public health policy.

Franek’s (2013) review detected chronic-condition management (using the Stanford chronic-condition management program) led to short-term improvements in pain, disability, fatigue, depression, health distress, self-rated health, and health-related quality of life (2013). Similarly, Dahlberg, Dahlberg, and Nero (2017) found a clinically

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[28] Usual care refers to primary care doctor visits, emergency department care, hospital care (Stanford Patient Education Research Center, 2017).

relevant decrease in pain and increase in physical function and health-related quality of life[29], among a cross section of 350 men and women patients with osteoarthritis aged over 62 years (Dahlberg et al., 2017).

The only other comprehensive review of the evidence regarding the capability of strategies to support self-management in osteoarthritis, was published in 2012. Nevertheless, Brady (2012) argued that few studies have evaluated the effectiveness of supportive healthcare practitioner interactions regarding osteoarthritis, due to the difficulty of isolating effects. Further, some of the factors that researchers must embrace concern the interactive nature of self-management initiatives, such as who is delivering the intervention, where and how it takes place, and the makeup of the audience receiving the message.

In addition, there are multiple formats for delivering osteoarthritis-management initiatives in terms of the definitive strengths of each, that makes it hard to separate out the outcome effects (Marks, 2014). Brady (2012) cited four meta-analyses of arthritis and A. Morgan, Richardson, and Smith-Turchyn (2015) concerning diabetes, both discussed the benefits of self-management education that incorporated educational formats, imparting information face-to-face within small-group sessions. Most of these meta-analyses that examined pain and disability, found small but statistically significant improvements.

Other aspects of self-management that helped to make health literacy real for participants was noted in Ball and Thornley's (2015) review of self-management of long-term health conditions with Māori and Pacific populations. That is to say, initiatives that were most effective featured credible and likeable people delivering the message, requiring a shift in thinking from, delivering self-management initiatives in deprived areas, to listening to the wisdom and expertise of the local community. For example, relationships built with church and community organisations, with full support of church and community leadership was noted, as the most fundamental prerequisite for success.

The Department of Internal Affairs (2015) searched case studies and qualitative research, to identify the effectiveness of community-level initiatives and self-management of long-term health conditions. Projects incorporating features of community development such as community leadership, enabled identifying the issue or issues that they wanted to address, the outcomes they wanted to achieve, and the process for getting there. The community was seen as an agent of change, and

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[29] Health-related quality of life refers to many domains relevant to physical, emotional, mental, social function, going beyond direct measures on a population's health, causes of death, life expectancy to the impact that health status is likely to have on quality of life (Franek, 2013).

there was an emphasis on giving power, Māori input and capacity-building outcomes (Department of Internal Affairs, 2011).

In the community-development literature there is a strong focus on Māori input and capacity-building outcomes (outcomes), which are sometimes difficult to measure but are fundamental to what success looks like at the community level. Outcomes incorporate a greater sense of self-determination at a community level, and better cooperation with local organisations and connectedness socially between community members. Also, outcomes that incorporated the development of local organisations and networks, led to an increased ability to solve local issues together, and the development of a greater sense of community and community pride (Department of Internal Affairs, 2011).

The Department of Internal Affairs (2013) cited studies that had developed evaluation frameworks or indicators for assessing the quality and success of community-level initiatives. They gave the example of Māori evaluation, framing effectiveness within a Māori worldview, acknowledging that Māori communities have their own unique interests and priorities. Māori appraisal meant framing evaluations within a Māori worldview and importantly for my (the present) study, The Department of Internal Affairs (2013) noted that self-management of long-term health conditions can be further strengthened when initiatives are established in relevant cultural concepts.

As discussed earlier in the introductory chapter, a major disconnection in the literature is that few self-management initiatives identify the use of theory-informed design of implementation interventions. The importance of theory-informed design was discussed in Bally and Thornley's (2015) selective review for the Social Policy and Evaluation Unit New Zealand of community-level initiatives, which Hancock (2012) had suggested for Māori, needed to be underpinned by appropriate theory and evidence. Hancock (2012) suggested that initiatives that were focussed on Māori input and capacity-building, obtaining a multi-faceted picture of what had gone on from multiple theoretical viewpoints, was more likely to allow for consideration of a continuum of causal relationships, prevention and management (Hancock, 2012).

Summarising real-support

In the present section of the current chapter, I have concentrated on health literacy and the use of self-management, as a medium of support that was applicable to kaumātua with chronic-conditions and healthcare practice, showing that there is limited literature on the efficacy of chronic-condition management tools. The existing literature on osteoarthritis prevention for Māori with chronic-conditions was critiqued, as

I argued that there remained an identifiable need for a culturally acceptable osteoarthritis-management resource.

In the following final section of the current chapter, I critique the literature on kaumātua living with long-term conditions. In particular, international and domestic examples of self-management resources. At the same time drawing attention to relevant, yet limited studies, that have precisely employed Māori input.

In the right environment and with the right methods, osteoarthritis-management has the potential to lead the way forward for the development of culturally sensitive support with kaumātua (Rauawaawa Kaumātua Charitable Trust Research Project Team, 2013). Similarly, Yin (1992) wrote that storytelling is a regional resource and still a medium of instruction that is culturally preferred by kaumātua. Also, Mahuika (2012) noted of Māori society (pre-1840 European contact), that an oral culture was comprised of specific methods (methods) (Mahuika, 2012).

These methods refer to passing on the multiplicity of knowledge that any culture will have gathered and constructed about themselves, story being one of the common ways of imparting values, knowledge and new skills (Bishop, 1996). Similarly, the present chapter has been tasked with gathering knowledge by exploring local health literature with a comprehensive review, to identify past and current research involving the real needs of kaumātua. As well, local literature in the field of osteoarthritis-management was recognised for failing to identify a single resource, with an evaluation component with published research for kaumātua.

Although the current review identified initiatives that might work well for kaumātua with osteoarthritis was identified precisely, 'He Pikinga Waiora Implementation Framework' ('He Pikinga Waiora'). The chronic-condition management framework, 'He Pikinga Waiora' was a tool for chronic-condition intervention effectiveness in Māori communities. It was produced in 2017, with a focus on primary prevention and treatment among kaumātua. It is likely then that up until that time, the majority of chronic-condition management tools produced in New Zealand have been mainstream focussed.

Mainstream adaptations of reality – Stanford initiative

One mainstream focussed tool that has been adapted for Māori is, 'The Arthritis Self-Management Initiative' ('Stanford initiative'), developed at the Stanford Arthritis Center in California (Beaton et al., 2017). The 'Stanford Initiative' incorporated five major strategies: contingency contracting, feedback, modelling, reinterpreting symptoms and persuasion (Lorig, 1982; Stanford Medicine, 2017). These principles were incorporated to instruct course members about managing the unique presentation of their condition, in the process of developing an individualised exercise program (C. Ferguson & Ferguson, 1976; J. Ferguson, 1975, 1976; Long, 2013)[30].

Educational principles incorporated into the 'Stanford Initiative' included 'contingency contracting', where group members (participants living with osteoarthritis or other chronic-conditions) 'make a deal with themselves' on an everyday basis with practice specifying goals and rewards (Lorig, 1982; Stanford Medicine, 2017). Another principle, 'feedback' enabled participants to assess the progress of new skills learnt, to assist correcting errors, identify problems, chart progress and compare the intention of learning the new skill through the reception of it by others.

Additionally, 'modelling' followed the research of Bandura's (1977, 1991) social learning theory of self-regulation[31], which the Ministry of Education (2010) noted was at the heart of successful education involving Māori learners (Ministry of Education, 2010) and the provision of a culturally responsive environment (Kāhui Tautoko Consulting Ltd, 2012b). For kaumātua, 'modelling' means providing culturally appropriate and relevant learning environments. There is a strong understanding across the literature that Māori will be more likely to engage, when they feel that they are a central part of the learning environment, and that they belong.

Māori engagement is particularly important for those who have experienced, "being on the margins educationally and socially, they will engage if the environment of learning is culturally relevant to them" (Kāhui Tautoko Consulting Ltd, 2012b, p. 19). Intrinsic to a sense of belonging in the self-management learning environment, is the construct of whānaungatanga (sense of family connection) (Kāhui Tautoko Consulting Ltd, 2012a, 2012b; Tahau-Hodges, 2010). Developing positive relationships, connections, engaging as part of a collective with inclusive learning in a whānau-like atmosphere, can instil a sense of belonging.

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[30] Some of the 'Stanford initiative's' topics covered with group members living with osteoarthritis outlined on Stanford Medicine's (Ashing-Giwa, Kagawa-Singer, & Padilla, 2010) website (see med.stanford.edu) include: "techniques to deal with problems such as pain, fatigue, frustration and isolation; appropriate exercise for maintaining and improving strength, flexibility and endurance; appropriate use of medications; communicating effectively with family, friends and health professionals; healthy eating; making informed treatment decisions; condition-related problem solving; getting a good night's sleep" (Stanford Medicine, 2017).

[31] Acquiring a sense of self-belief or self-efficacy, is a key aspect of Bandura's (1977, 1991) social learning (or social cognitive) theory of psychological functioning. Bandura described self-belief or self-efficacy as an individual's perceived capabilities for learning and performing actions. A sense of self-belief about learning has much in common with the self-determination theory. Both of these theories have been used to explain the human agency, such as pro-active engagement in the focus of activities. It has been difficult to find research on the role of self-efficacy for people with chronic conditions who have experienced the cycle of disengagement and re-engagement. Attanasio and Kozhimannil (2017) investigated healthcare engagement and follow-up after perceived discrimination in disadvantaged ethnic patients in the United States, recognised the benefits of follow-up care. They underscored the need to reduce discrimination and improve healthcare experiences, but did not focus on resilient indicators displayed in the process of disengaging and re-engaging with healthcare services.

Fundamental, is the need for those providing self-management support, to understand each group member's current and changing needs and aspirations, so that they may be appropriately guided and supported on an ongoing basis (Durie, 1997). In the process of forging a pathway to osteoarthritis-management, the final section of the chapter is concerned with laying down the 'take' (the purpose) and kaupapa (foundation) of the present thesis. Also, I critique the literature on Māori input and capacity-building initiatives for kaumātua living with long-term conditions, the section that follows, explores capacity building in the workplace.

After discussing international and domestic examples of self-management resources, attention will be drawn to relevant, yet limited studies. Precisely, that have employed Māori input and capacity-building research in the creation of health support tools.

Capacity building for real – workplace environments

Heathrose Research Ltd's (2011) investigation into strategic responsiveness, explored ways of increasing the participation of Māori and other peoples working in the electricity supply industry. Their findings revealed that workplace training environments with above average completion or retention rates, had a strong sense of family and whānau culture and Māori leadership present (Heathrose Research Ltd, 2011). Across the literature a number of inter-related structural elements representative of a commitment to a Māori worldview, are identified as contributing to effective learning environments that are supportive, welcoming and culturally relevant for kaumātua (Kāhui Tautoko Consulting Ltd, 2012a, 2012b; Mitchell & Phillips, 2010).

Part 3: Local reality

In terms of local examples, Te Taiwhenua o Heretaunga (2017) and Te Kupenga Hauora Ahuriri (2017), are both Māori health organisations in Hawke's Bay that have been supporting a strong and vibrant Māori community in Ahuriri (Napier). Particularly kaumātua groups (Kaumātua rōpū) that meet, often on a monthly basis, as a platform where they can learn with peers about kaumātua ora (living with good health and wellbeing) in an environment with appropriate cultural protocols. The atmosphere of Kaumātua rōpū is supported by inter-related elements, that are representative of a Māori worldview.

Some examples of a Māori worldview were written from the perspective of kaumātua during 2011. At that time, six focus groups were facilitated by Māori and Pacific health workers, liaison members, and expertise from policy, planning and funding (Wairarapa DHB) and Population Health Intelligence (Hawke's Bay DHB)

(Pihema & Taurua, 2012). A number of disconnections emerged relevant to the present thesis (that seeks to understand the core-values relevant to kaumātua with osteoarthritis and effective self-management environments).

Pihema and Taurua (2012) discussed that the process of focus groups, sought to understand the context of whānau in supporting kaumātua. For example, how kaumātua wished to be supported in the community. As well, what areas of support were required to assist better access to self-management support.

Real disconnections

Pihema and Taurua's (2012) study, revealed a number of theoretical disconnections in mainstream research and literature. The first disconnection concerned Māori definitions of success for kaumātua with chronic-conditions, and what constituted successful health and social outcomes, as the majority of mainstream initiatives were not explicit in their aim of enhancing kaumātua experiences of self-management outcomes. An important theme concerned, what was missing was the development of key indicators from the perspective of kaumātua, that went beyond their physical health, to include community and cultural factors as well.

Additionally, the study of Pihema and Taurua (2012) revealed kaumātua perspectives, knowledge and experience was acknowledged. Particularly, when activities promoted effective interactions, underpinned by values demonstrating that kaumātua are cared for, valued and believed in. Kaumātua experiences and knowledge are valued and incorporated into self-management support, with collaborative peer relationships and collective group learning facilitation (Pihema & Taurua, 2012).

Collaboration and collective learning, ties in with the findings of the present literature review. In effect, of there being a lack of explicit direction on how kaumātua, their family and whānau are being engaged early on in any initiative involving self-management support. Otherwise, how a welcoming atmosphere and encouraging active involvement and support for kaumātua learning was being undertaken explicitly (see 'Micro level', above).

Secondly, another disconnection in mainstream healthcare approaches to self-management leads on from the latter conversation concerning outcomes that require expanding, to incorporate social relationships of support (Pihema & Taurua, 2012). Community and cultural factors can be compounded when living in highly deprived areas, including Hawke's Bay (Brown et al., 2017). Moreover, positive relationships and social connectedness can contribute positively to community and cultural factors, by providing increased access to kaumātua rōpū and cultural experts, which may lessen the possible effects of loneliness (Pihema & Taurua, 2012).

Tīkanga-ā-iwi as a framework

The final disconnection in mainstream healthcare approaches to self-management has been a lack of integrated Māori models of care (models) (Pihema & Taurua, 2012). Notably, models aligned to development that are explicit in defining the ways tīkanga and Māori values are embedded in self-management design (Pihema & Taurua, 2012). For example, that the outcomes of self-management initiatives are related to kaumātua' gaining an enhanced sense of cultural identity and deeper conceptual knowledge with inherent alignment to the development of a, "commitment to social justice and equity" (Aitken & Sinnema, 2008, p. 37).

Aitken and Sinnema (2008) discuss the importance of cultural identity and local protocols (tīkanga-ā-iwi). Especially as a powerful framework for the discussion, planning, and implemention of effective supportive environments of learning. Particularly by way of four mechanisms, 'Connection', 'Alignment', 'Community', and 'Interest' (Aitken & Sinnema, 2008), noteworthy to the present study, that seeks to gain an understanding of the everyday experiences of kaumātua with osteoarthritis.

Of Aitken & Sinnema's (2008) four mechanisms, 'Connection' can represent uniting self-management activities to kaumātua' lives outside of the home with peers in the community, by incorporating their prior knowledge and making links to home and culture. 'Alignment' can represent providing integrating links between self-management experiences and prior knowedge, moving kaumātua toward important outcomes, so that deeper learning about osteoarthritis-management becomes well-established. 'Community' would be about forming relationships and belonging, having 'chats' and collaborating, to support one another within a self-management learning community by maximising participant 'Interest' in self-management, through experiences that are stimulating and memorable for kaumātua.

Extending Aitken and Sinnema's (2008) synthesis iteration of tīkanga-à-Iwi, Hall's (2011) study, focussed on how a non-Māori model embedded Māori content into their teaching and learning, providing examples of the active modelling of tīkanga Māori on an everyday basis in the classroom[32]. Examples, include mihimihi (introductions) at the start of the course, manākitanga (the sharing of kai), and the consistent and regular

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[32] Mentoring from Māori peers was identified as a means to enabling non-Māori staff to build strong and appropriate practices, with professional development and training in Māori language and cultural practices, and learning on the marae (Aitken & Sinnema, 2008).

use of Māori historical events, and relevant current issues, Māori language terms and concepts, Māori statistical data and information, Māori perspectives and practices.

Hall's (2011) examples resonate with the present project and self-management initiatives of support, by accenting the need for iwi and Māori community involvement. These various forms of tīkanga, are suggestive of group members engaging in self-management support, that has sought to develop their cultural knowledge and identity. Contrary to Hall's (2011) findings, Aitken and Sinnema (2008); Ko Awatea & Counties Manukau Health (2016) both noted disconnections in self-management support and language barriers, which can be alleviated by the application of Māori knowledge (for example, community member support and expertise in te reo Māori).

Where is the management in osteoarthritis?

In addition to the above examples resonating with the present project, was a key finding in Chapter 2 'Laying down the 'take' (Literature review)'. Remarkably that the majority of chronic-condition management initiatives, frameworks and tools discussed so far, have not focussed solely on osteoarthritis. Nor have they been explicit about the ways in which they have followed principles of effective self-management support in their design for kaumātua, or how they have embedded cultural identity and local protocols and values (tīkanga-ā-iwi) into self-management support.

Remarkably, osteoarthritis-management tools for kaumātua (tools) have been modified from basic American based content (see adaptation of the 'Stanford Initiative' above). As a result, tools have not been 'home-grown' from original content, with the consensus of a kaumātua audience. At the same time, He Korowai Oranga: Māori Health Strategy requires the health and disability sector to deliver culturally appropriate services with Māori, towards improving health outcomes and reducing inequalities (Pihema & Taurua, 2012).

Also supporting the argument for utilising tīkanga-ā-iwi as a framework for osteoarthiritis-management, a review of health education resources on gout medication, considered culturally appropriate resources to be those that, "meet the needs of specific audiences" (Ministry of Health, 2002, p. 25). For example, precisely created resources with kaumātua. Ideally creating resources with kaumātua being more a case of utilising tribal knowledge, than adapting materials from existing resources that are designed and intended for non-kaumātua audiences.

Prioritising real perspectives

Prioritising community perspectives than relying too heavily on professionally-led solutions was spoken about by the Ministry of Health (2002). Especially about the centrality of community engagement initiatives for marginalised groups. The Ministry of Health (2002) asserted that developing sustainable community support structures via community engagement was a way of enabling, "discrete" opportunities for healthcare practitioner initiatives, alongside continuous support that was centred in the community (p. 25).

Paul and Sallnow (2015) cautioned that community engagement needed to "encourage members to take responsibility for protecting their health" (p. 233). Specifically that responsibilty for health may be the only way to ensure sustainability of healthcare systems. Similarly, Askham, Coulter, and Parsons (2008) suggested that among service users of healthcare, ethnicity implies diversity of concepts and attitudes towards health that need to be considered, for instance when deciding on culturally appropriate treatment options (Askham et al., 2008).

Although some of the content of self-management support will be similar among ethnic groups, there will also be important differences. These being both in perception of effective messaging and presentation of resource content. Askham et al. (2008) concluded that different ethnic groups perceive support and resources differently, and that these differences needed to be acknowledged and addressed, when creating self-management support.

Whānau and real life stories

In Te Puni Kōkiri's (2015) analysis of whānau ora research and monitoring results (stage one), noted past tendencies of mainstream healthcare practitioners and social service providers[33]. That is to say, following the absence of real life stories and insights into the daily lives of whānau, Te Puni Kōkiri (2015) detailed there being a disconnection between theory and practice. Gaps in theoretical grounding had not translated into tangible strategies for change but rather resulted in approaches that had not made a positive impact on kaumātua, family and whānau (Te Puni Kōkiri, 2015).

The past tendencies of mainstream approaches to healthcare and social services discussed by Te Puni Kōkiri (2015) ignores contrary advice, that the most

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[33] Whānau ora research refers to an inclusive approach to the provision of services for families and whānau across New Zealand, with a focus of giving power to families as a whole, rather than focusing on individual members' problems separately from other family members. Whānau ora initiatives were first announced by the Hon. Tariana Turia during 2011, and have since been building across government departments and work initiatives. The emphasis is on placing families and whānau at the centre of services delivery (Hall, 2011).

effective forms of support for Māori are based within a theory. Expressly, of whānau-centred practice with whānaungatanga (sense of family connection) being a resource for whānau. What is more, underpinning theory with stories and experiences that are whānau focussed, with the presence of role models and kaumātua enabling translation of theory into practice (Te Puni Kōkiri, 2015).

Te Puni Kōkiri (2015) supported their critique of the implementation and impacts of whānau-centred approaches, by analysing responses from over 260 research and monitoring reports, that led to whānau gains. They argued that building whānau capability is anchored in the Māori world, with practices that are shaped by relationship and kinship, being tools in and of themselves. Particularly, for linking up and building on whānau strengths.

The effectiveness of self-management support argued by Te Puni Kōkiri (2015), is measured by the extent to which initiatives promote whānau autonomy, leadership and independence. The provision of building whānau capability in Te Puni Kōkiri's (2015) analysis of whānau ora research is relevant to the present study, from the point of collaborating with kaumātua. What is more, such an approach is noted for not only building whānau capability, but improving the ability to move patients along the dependent – independent care continuum.

Te Puni Kōkiri (2015) give the example, of establishing whānaungatanga (sense of family connection). Precisely, by making connections and communicating effectively with dignity to all, throughout the delivery of self-management. Te Puni Kōkiri (2015) discuss that "whānaungatanga (relationship, kinship) as a tool for connecting and building whānau strengths", can be valuable for potentiating understanding among all stakeholders, particularly when there a sense of collective ownership is sought, concerning decisions and responsibilities (p. 10).

In so far as developing an understanding of osteoarthritis-management, Green, Kingsley, Pizzari, Semciw, and Zacharias's (2014) systematic review with meta-analysis, recognised that further work was needed to address the dearth of literature evaluating available initiatives. Similarly the present review of the literature has found that there is a need for more focus on osteoarthritis-management tools for kaumātua. Not only is there not enough resources available, but mainstream models have not been explicit about effective health communication principles with kaumātua, nor have they focussed on Hawke's Bay kaumātua and therefore do not reflect the kawa (cultural practices) and tīkanga (cultural principles) of the region.

My reality

From my perspective as a registered allied healthcare practitioner, there is a gap in the literature and a need for the creation of a kaumātua focussed osteoarthritis-management resource. Specifically a resource that is based on Māori cultural values, kawa (cultural practices) and tīkanga (cultural principles) and a focus on positive initiatives, with whānau at the centre. Based on these findings, it is recommended that research be conducted on kaumātua experiences of osteoarthritis, and focus groups be held with the target audience, as well as pre-testing and conducting a process evaluation of any arising resource.

From the present review of existing chronic-condition management tools and resources with kaumātua, it is clear that there is an identifiable need for a culturally acceptable osteoarthritis resource. That is to say, a resource that is modelled on effective health communication principles, utilising Māori input, capacity-building, and which reflects the kawa (cultural practices) and tīkanga (cultural principles) of kaumātua with osteoarthritis in Hawke's Bay, by engaging their expertise in developing an osteoarthritis-management resource. In the final section of the present chapter, attention is placed on self-management examples of resources from the international literature, bringing attention to relevant, yet limited studies focussing on lay perceptions and understandings of osteoarthritis within Māori communities and the socio-cultural meanings ascribed to the condition.

International real-world settings

Internationally, self-management studies with indigenous populations show promise. That is to say, in terms of addressing real-world settings as the public health burden, or in the homes of those seeking relief of their symptoms and minimising the progression of disability (Bailie et al., 2017; Christian et al., 2017; Keawe'aimoku Kaholokula et al., 2013). The three initiatives that follow have documented the benefits of community input and local theory, acting as models that take into account self-management resource design and evaluation, with indigenous populations.

OPREVENT initiative

The 'Obesity Prevention Research and Evaluation of Effectiveness in Native North Americans' ('OPREVENT') was a multi-level, locally-based adult obesity intervention pilot-study (2012-2015), funded by the United States Department of Agriculture. The intervention targeted American Indian populations (the population) living in six reservations in New Mexico and Wisconsin (Bleich et al., 2017), with the primary focus being to prevent obesity and long-term goal of promoting healthy eating and physical activity in the adult population. Bleich et al. (2017) argued that the population was impacted by national or regional legislation and policy approaches, that were not tailored to the resource constraints, cultural values or tribal authority of the community.

As Bleich et al. (2017) explained, Native American communities valued collaborative partnerships. The reasons being that these partnerships were conducive to creating local knowledge, at the same time encouraging participation in decisions for actions, based on the research results. For these reasons, the 'OPREVENT' partnered with tribal stakeholders, multiple levels of the physical activity environment (local community) and social environment (family, social media), to create systems-level change.

The 'OPREVENT' employed elders whenever possible to deliver initiatives about the intervention, using the population's local language in local places, organisations and spaces. One of the strengths of 'OPREVENT' was that it promoted ongoing activities and social support to help reshape everyday activities, such as healthy food knowledge or intentions about community resources. A locally-based action committee (community committee) was created to advise on intervention and evaluation objectives, activities and culture, and ensured broad involvement and the empowerment of the community over decision-making.

Another major strength of the 'OPREVENT' was the involvement of elders and community committee, that provided advice on intervention and evaluation objectives, activities and cultural practice. The 'OPREVENT' approach empowered elders to become role models for healthier lifestyles, ensuring cultural relevance and promoting the goals of the project throughout community networks. Community awareness and mobilisation was created through the use of local media, radio and newsletters, the wide range of communication helping to accelerate the diffusion of self-management initiatives.

A high level of community participation and the adoption of healthier food purchasing, dietary intake and physical activity were indicated in the results of the 'OPREVENT' initiative (Redmond, 2017). Achievements of 'OPREVENT' were attributed to full and active community participation, elder experiences, perspectives and interpretations (collective wisdom), all assisting to broaden interpretations and effectively save the community from potential stigmatisation. The 'OPREVENT' study will be later used to support the development of 'OPREVENT2' initiative, incorporating materials and approaches to inform structural and policy changes at the healthcare level[34].

Knockout health challenge

Different to the ‘OPREVENT’, The Knockout health challenge (‘Challenge model’) was initiated in 2012 with Aboriginal communities across New South Wales, Australia, as a community-led healthy lifestyle and weight loss challenge for Aboriginal people (Christian et al., 2017). Participation has been growing each year, for instance in 2012 participants numbered 324 over 13 communities, and by 2015 numbered 1200 across 33 communities (Christian et al., 2017). An important lesson from the ‘Challenge model’ is that it was led by local Aboriginal communities, and participants were local Aboriginal people.

Christian et al.’s (2017) reflections concerning the achievements and longevity of the ‘Challenge model’, emphasised obtaining community endorsement. For example, the ‘Challenge model’ used shared decision-making processes (such as planning, implementation, evaluation) and sharing the results with the community, including members in key areas and positions. Community endorsement helped to ensure that the ‘Challenge model’ remained focused on a sense of community ownership, which was seen as being crucial to success (Christian et al., 2017), which is also widely acknowledged in the literature as being key to closing the gap in health outcomes between Aboriginal and non-Aboriginal people (Broe et al., 2017; Centre for Aboriginal Health Research, 2013; Charles, 2015; First Peoples Disability Network, 2013).

Another lesson of the ‘Challenge model’ was the flexibility of adapting the program to suit local contexts. The program was devised to be accessible for participants across New South Wales from regional or rural areas, increasing its potential. Precisely, adapting the program enabled broader reach to Aboriginal populations across Australia, while maintaining flexibility to address health issues that were local priorities[35].

Partners in care

The final example was a self-management intervention among members of an indigenous community with the Native Hawaiians and Pacific People: ‘Partners in Care’ (Keawe‘aimoku Kaholokula et al., 2013) (‘Partners in Care’). A culturally-adapted intervention, ‘Partners in Care’ was aimed at developing a better understanding of Native Hawaiian and Pacific peoples’ beliefs about diabetes, to reduce morbidity and

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[34] See wrdc.usu.edu/files-ou/publications/pub__9107196.pdf.

[35] See preventivehealth.net.au/knockout-health-challenge.html.

mortality among these populations. Additional aims included developing culturally sensitive approaches to self-management and prevention.

Keawe‘aimoku Kaholokula et al. (2013) described the ‘Partners in Care’ process employed, and use of a community steering committee. Expressly, to inform the cultural adaptation of the intervention as a tool for giving power to Aboriginal community members. Intervention activities developed a set of variables.

Variables noted by Keawe‘aimoku Kaholokula et al. (2013) were delivered at twelve one-hour group meetings, by trained peers with conversational materials. A survey using a 5-point likert-scale to represent people’s attitudes to a topic, incorporated options ranging from ‘0’ (= not a problem) to ‘5’ (= serious problem) with self-management. The process then incorporated community members’ discussing their ability to maintain a medication regime and weight, by eating healthy and exercising.

Keawe’aimoku Kaholokula et al.’s (2013) ‘Partners in Care’ intervention, demonstrated that a locally-based program which used little technology and few healthcare resources can have positive effects. Particularly when working principles are established with improved understanding about the beliefs and values of indigenous peoples. The ‘Partners in Care’ intervention was successful for increasing the understanding and performance of self-management, by building on local knowledge systems and community strengths.

International real-world lessons

There are some important lessons learned from the present review of international self-management. Successful community development initiatives involved genuine partnerships and community participation in decision-making, to reflect and embrace cultural relevance. Also, shared analysis of an initiative reduced misunderstandings and strengthened results, as well as broadening interpretations. The final section that follows, presents international literature concerning the creation of self-assessment evaluation toolkits with indigenous peoples.

Self-assessment evaluation toolkits

The examples above (see ‘International real-world settings’) outlined international examples of self-management resources that were being used. Notably, to create community awareness with co-designed initiatives, that identify, build on, and mobilise local assets and resources. Otherwise studies have utilised a self-assessment evaluation toolkit, to ethically respond to legitimate needs and aspirations of a community and their ongoing participation in self-management.

The examples that follow, serve as toolkits for engagement. What is more, evaluation of engagement and consideration in the design of osteoarthritis-management initiatives with indigenous populations.

National Association's collaboration evaluation toolkit

In a report, The National Association of County and City Health Officials (2017) that represents local health departments across the United States, noted several strengths in their health centre 'collaboration evaluation toolkit':

> [Healthcare organisations that] collaborate are better able to serve their local populations and demonstrate to funders that their work deserves support (p. 11).

In addition, The National Association of County and City Health Officials (2017) suggested that their 'collaboration evaluation toolkit' consisting of three tools was an effective approach. The first tool (Tool 1), required stakeholders (patients, community members, healthcare practitioners, policy and funding) to undertake an assessment, generating information that enabled starting a conversation about specific needs, as well as gaps in knowledge and skills. The second tool (Tool 2), was for planning activities to help build and enhance a partnership between all stakeholders, prior to taking collaborative action.

The toolkit was designed to reach out to other stakeholders and assist them to learn more about one other, and look for additional collaborative opportunities. The final tool (Tool 3) was for planning joint activities to address the opportunities and health challenges, identified by the first tool (Tool 1). Each outcome (Tool) is written into a seven-page template, where actions are listed alongside resources required to carry out the activity, identifying responsible parties from each organisation, creating a timeline for completion and a column for reporting progress.

A major strength of the 'collaboration evaluation toolkit' was the use of cross-sector collaboration, planning, assessment, and evaluation through the exchange of stories and experiences from the field. These stories that facilitated support for advocacy, peer learning and collaboration were held on a database[36]. The implications of the 'collaboration evaluation toolkit' to the present study concerning exploring the everyday experiences of kaumātua with osteoarthritis, is the potential for self-management support to be culturally sensitive and appropriate, for and with kaumātua.

The 'collaboration evaluation toolkit' is relevant for emphasising the benefits of bringing self-management education into community groups. Enabling self-management education increases potential to 'seed and spread' initiatives, as the

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[36] See story database at: nacchostories.org.

people attending are hearing spontaneous stories concerning roles, responsibilities and gritty conversations as well as stories and good self-management practices (The National Association of County and City Health Officials, 2017). Reflecting on self-management stories is a notable observation to the present study, because story through the analysis of values, often remains a culturally preferred framework of instruction and learning for Māori people (Bishop, 1996).

The most effective way to engage older members of minority ethnic groups with limited health literacy, to support education and doctor-patient communication is through storytelling (De Winter, Hoeks, Jansen, Koops van ’t Jagt, & Reijneveld, 2016). As maintained by The National Association of County and City Health Officials (2017) and De Winter et al.’s (2016) evaluation of older-people’s own observations of topics, barriers and solutions is an effective approach for creating collaborative tools with diverse ethnic and cultural communities. Similarly, The National Association of County and City Health Officials (2017), argued about the strengths of collaborative self-management toolkits with communities.

Also, The National Association of County and City Health Officials (2017) maintained that a toolkit which encompassed a collaborative process was most ideal. In particular, when the process brought together healthcare practitioners and patients (stakeholders), in a coordinated approach. Furthermore, better coordination and an increased focus on wellness and prevention not only helped to make self-management work better for everyone, but encouraged **funders** to take action and support community initiatives that deserved assistance.

Simlar to The National Association of County and City Health Officials (2017) focus on collaborative approaches to self-management, De Winter et al. (2016) presented findings from several researchers of successful and effective self-management initiatives. Precisely, that gave power to older-people within a collaborative environment, towards a broader range of skills. An important feature involved incorporating opportunity for older-people to express their needs, concerns and life stories.

Brocklehurst, Goldthorpe, Mackay, and Pretty (2015) found that by incorporating patient stories, ensured these reported accounts were heard. Exchanging stories, ideas and knowledge was found to assist in countering the ‘top-down’ medical model, often dominating healthcare services. Not only was Brocklehurst, Goldthorpe, Mackay, and Pretty’s (2015) community research research an opportunity for patients to prioritise their own health issues, older people were enabled to have voice, choice and control. Similarly, Bishop (1996) noted that stories can support Māori peoples' health, resilience and positive living, by providing the means of owning, telling and re-telling one's own story.

Storytelling tree

In contrast to the self-management collaboration and evaluation toolkits that have been presented so far in the present review, Björklund and Gunnarsson (2013) described an innovative approach. The approach focussed on sustainable self-management, using the image of a tree as a tool, based on a 'storytelling tree'. Björklund and Gunnarsson (2013) detailed a method implying that patients' drawing and painting pictures of a tree, can be a useful template.

The template enables depicting various periods in the patient's life. The pictures are then used as a starting point for patients' to talk about their life story. As a result, wellbeing and management of everyday life can be enhanced, with positive significant changes in self-care performance and satisfaction occurring, over a three year period.

Chronic condition management strategies

In the final example of a toolkit for engagement and evaluation, M. Battersby, Harvey, Helps, Kowanko, and Petkov (2013) reported on chronic condition management strategies in Aboriginal communities (Aboriginal or Nunkuwarrin Yunti of South Australia, and Torres Strait Islander peoples). Over 2008-2011, M. Battersby et al. (2013), utilised a storied approach, in a project called 'Chronic condition Management Strategies' in Aboriginal Communities conducted during 2008-2011. The goal was to evaluate, and where possible develop and demonstrate effective and transferable chronic condition management strategies, and to generate research evidence about their processes, impacts and health outcomes.

M. Battersby et al. (2013) reported on integrating Aboriginal communities in South Australia directly. For instance, giving those people who are directly affected, an opportunity to affect decisions influencing the development and production of resources, as a lever. Specifically a lever that privileges local knowledge and influences personal and group agency.

Likewise, M. Battersby et al. (2013) found that a storied approach was imperative with indigenous populations. Especially when it was customary to receive information in 'bits and pieces', such as listening and watching rather than reading (Hunter et al., 2009). M. Battersby et al. (2013) presented the main outcomes of a survey with service providers and semi-structured interviews, indicating preferences for stories, rather than instructional materials.

However, details of Battersby et al.'s (2013) research design were not outlined. Rather, survey data was reported, making it difficult validating or ascertaining whether there was a change in baseline knowledge concerning healthy lifestyle behaviours. Although, the argument that involving the community, increased personal and group agency was supported in excerpts from the semi-structured interviews conducted.

M. Battersby et al. (2013) concluded their report on chronic condition management strategies in Aboriginal communities. Namely, by identifying a number of major themes that emerged from the literature, resonating with the present study. Precisely for developing self-management tools with indigenous communities, that enable healthcare practitioners' to put into practice, certain elements. These elements have potential for enhancing the development and implementation of chronic condition management tools (Table 2):

Table 2. Key elements for self-management support (adapted from M. Battersby et al. (2013))

Key elements
• Bring people together in a manner that is empowering;
• Employ real life stories;
• Support and encourage;
• Recognising real life (social) contexts;
• Create a critical and transformative environment.

Key elements for self management support incorporated bringing together and linking up healthcare practitioners, patients, their family and support networks (group members) in a manner that gives power. Further, utilising community stories of living with chronic conditions as support for others, was noted for being more effective when engaging with communities. In addition, utilising encouragement, where group members talked about positive impacts on wellbeing in a manner reflective of participant preferences, whilst evaluating throughout the initiative continuously.

Additionally, Battersby et al. (2013) recognised the importance of real life (social) contexts. For example, enablers of self-management support of group members that met regularly were documented and included elements such as transport assistance, interesting guest speakers, input by group members into what they would like and need to take control of, in so far as their own health, with shared resources. Finally, creating a critical and transformative environment for group members was identified by Battersby et al. (2013), such as adopting a coordinated and holistic ‘no wrong door’ care approach.

In essence, the present section has critiqued international examples of self-management resources, engaging older-people living with long-term conditions. Limited yet relevant studies utilising indigenous community input have been noted. These have revealed a need to break down silos of care and disconnections. Notably, between the community resources, where a person lives and the healthcare system in which they seek support, and community input, that can help to form a clearer picture of the target community and the best ways to reach them.

Summarising the literature review

By referencing relevant literature, the present chapter has outlined an argument for an osteoarthritis-management resource, that employs Māori input. Particularly employing an approach, that creates a community-based self-management resource for kaumātua living with long-term conditions and osteoarthritis. A review of self-management initiatives targeting Māori, emphasised that the basis for positive change, is a culturally relevant theoretical framework and initiatives that are theory-driven, specific to local needs of the population affected.

Both osteoarthritis-management and Māori health promotion literature indicated that the use of culturally relevant processes, are significant for distinguishing relevant determinants. That is to say, knowledge which is meaningful to the target community, than using the determinants of health alone. Additionally, there were indications in the international literature, that effective self-management support necessitates culturally tailored responses to community knowledge, experiences and values with active role models and dedicated, trusted people delivering the initiative.

Further, there were few self-management initiatives that were focussed on kaumātua wellbeing, in the area of self-management throughout the present literature review. The latter is surprising, considering the Ministry of Health’s (2016c) recommendation was for contextually relevant, practical and culturally tailored self-management. Nevertheless, there were indications in the international literature that culturally sensitive chronic-condition management support, was effective for influencing positive change at the community level, and that sharing stories was a suitable way of imparting knowledge.

Nonetheless, the majority of self-management resources created in New Zealand at the time of writing (2018), were deemed inconsequential. The latter being due to a lack of culturally tailored content, such as a base within cultural and belief systems of kaumātua influencing their interactions. Also a failure to achieve and use local Māori input in some capacity was noted.

Implementation of self-management support that is locally-based was underscored. That is to say, the importance of health literature and literature on community based projects previously conducted in New Zealand was reported. As concluded by the researchers involved with Ngāti Kahungunu iwi dashboard (Cram, 2014b) and He Pikinga Waiora planning tool (Beaton et al., 2017), community involvement ensured both relevance and acceptance. Even so, disconnections remain in the literature.

Bagg et al. (2017) in their 2017 literature review of community based initiatives for the prevention or delay of people living with osteoarthritis concluded, that best practice guidelines and initiatives were unable to address how to operationalise these within a local system. Bagg et al. (2017) argued that an ongoing process of conducting and publishing research and sharing details on process, results and lessons learnt is critical. Various examples of osteoarthritis-management resources with indigenous North Americans, Aboriginal communities across New South Wales, and Native Hawaiians and Pacific peoples were discussed, outlining how to determine useful initiatives for people living with long-term conditions.

In addition, there is some evidence of a collaboration evaluation toolkit being an effective approach for creating chronic-condition management resources, with different ethnic groups and cultural communities. Implementing good practices in strengthening transparency when working with a community need to be made and documented. Although a disconnection remains in the literature in so far as understanding the process of developing collaborative relationships or consulting with the Māori community, however.

Ko Awatea & Counties Manukau Health's (2016) 'Kia Kaha: Manage better, feel stronger' collaborative project (Kia kaha) was promising for giving patients' more choices, hearing their voices and giving power to patient-centred approaches across healthcare services and settings. Although the processes employed in obtaining and incorporating Māori community input, were not detailed in the published research documents. Given that partnership development and collaboration were noted as being key elements for support, there is a need for self-management initiatives to make explicit the processes of engaging community members.

In addition to that mentioned, I have also described my perspective as a registered allied healthcare practitioner. Notably, that there is a gap in the literature and a need for the creation of a kaumātua focussed osteoarthritis-management resource. For instance, a resource that is based on a Māori belief system, centering whānau within the design, the focus being on positive initiatives.

The resource should make explicit the application of theory and principles in shaping the self-management initiative. Yet, another critical element in the design of locally-based resources, was an understanding of the relevant determinants influencing self-management activities (Bycroft, 2017b). As a result, it is remarkable that none of the existing osteoarthritis initiatives generated in New Zealand, detail the application of theory as a basis for evaluation.

My research seeks to speak to a clear disconnection within the literature concerning how to best implement culturally appropriate osteoarthritis-management with kaumātua. What is more, effective initiatives are required to assist healthcare practitioners determine how to address gaps between biomedical perspectives and cultural, experience based beliefs of osteoarthritis, that influence how kaumātua experience and understand living with the condition. As Bobbish-Rondeau et al. (1997) said, only a handful of studies have sought to understand lay perceptions, such as the social and cultural meanings attributed by indigenous peoples of chronic disease.

Notably, the majority of mainstream self-management resources such as The 'Equity of healthcare for Māori': A framework (equity framework) (Ministry of Health, 2014b), relied on survey data, based on the distribution and determinants of chronic-conditions. For that reason, the present study will need to be organised in such a manner as to counter disconnections within the literature, such as communicating self-management information that reflects kaumātua cultural practices. Precisely in a manner that is useful, beneficial and appropriate for use by kaumātua.

It is proposed that a culturally relevant design approach arising from the present study, will rely on culturally responsive design. Especially, design that is mindful of centralising attention on transformative environments, values and norms of the community. Finally, in each of the 'Preface', 'Chapter 1: Real-world contexts', and the present Chapter 2: Laying down the 'take', and review of the literature, I have noted that a precept of effective self-management design, is framed in culturally appropriate ways. The latter concerns identifying, tailoring and incorporating self-management initiatives (Beaton et al., 2016); Ministry of Health (2014d).

A crucial limitation noted in the literature, was a lack of evidence. Expressly, about which outcomes of self-management are most valued by patients, families and whānau or healthcare practitioners and policy makers or funders (stakeholders). Notably the majority of chronic-condition management initiatives, frameworks and tools that were discussed in the present literature review had not focussed solely on osteoarthritis.

Nor had the majority of initiatives, frameworks and tools, been explicit about the ways in which they followed principles of effective self-management support in their design for kaumātua. In addition it was difficult to tell whether they had embedded cultural identity, local customary protocols, practices and values (tīkanga-ā-iwi) into self-management support. Also, osteoarthritis-management tools for kaumātua are being modified from basic American based content (see adaptation of, 'The Stanford Initiative' above), than 'home-grown' from original content with consensus of a kaumātua audience.

As a result, it is not possible to confirm whether self-management resources are being precisely tailored to kaumātua experiences, values and needs, either individually or as a group. Consequently, a culturally appropriate approach to developing an osteoarthritis-management resource, will be employed in the present study. The focus will be on centralising Māori concerns, building partnerships, and strengthening community ownership, by working with methods that are both theoretically oriented and socio-culturally sensitive.

In the following chapter, I will weave together the arguments presented in the current literature review. The aim being to build on the 'take' (Literature review), by describing a research model that forges a pathway, fortified by indigenous principles. That also allows for research design, applicable to increasing the likelihood of producing a culturally sensitive resource for kaumātua.

Chapter 3: Real world experience (Māori knowledge building)

Introduction

In the previous chapter, osteoarthritis was noted for being one of the most common causes of chronic disability among older-people in Aotearoa New Zealand (Southern Cross Healthcare Group, 2013). Although the chronic condition literature is vast, there is relatively little work within the area of self-management concerning kaumātua, at the time of writing. In the previous chapters, I also constructed an argument that employing a community-based approach to explore osteoarthritis-management was appropriate in the present study.

It was determined that a locally-based approach to osteoarthritis-management, designed for kaumātua in Hawke's Bay by Māori norms, rules, or values, would be more appropriate. Notably, it would more likely convey the cultural environment of the participating community. I also detailed Durie's (2003) work relating to Māori-centred tools that were promising for Māori identity, and provided examples such as 'Hua Oranga' (tool) and, 'Te Ngāhuru' framework.

Building on these arguments that have considered 'Real-world contexts' (Chapter 1), and in the previous literature review 'laying down the 'take' (Chapter 2), the present chapter is divided into two parts. (i) The first part of the chapter is concerned with describing Māori-centred research, an approach that ties into the work of Durie (2003) and others, with particular attention to Māori concepts that guide the community-based approach to research and evaluation. Indeed, discussion concerning 'Māori knowledge' and the work of Māori scholars in the present research, is utiilsed to demonstrate the inclusion of local values, kawa (cultural practices) and tīkanga (cultural principles) to support investigation into the everyday experiences of kaumātua with osteoarthritis.

In addition, I also explain widely recognised Māori values and interconnections with Māori knowledge and imperatives of power, before discussing kaupapa Māori theory. The discussion will outline why I believe the wisdom of Māori scholars and Māori-centred research drawing on kaupapa Māori theory, is an appropriate approach for the present study concerning kaumātua with osteoarthritis. (ii) In the second part of the current chapter, I outline my research design and methods, a multi-method qualitative approach.

The pathway to developing collaborative connections with my community, in-depth interviews, focus group hui and reflexive journaling will be defined. In addition, arguments are offered as to why these are suitable methods. I will conclude by clarifying the pre-testing process, guiding criteria, and overview that lead to evaluation and appraisal through to osteoarthritis-management resource completion.

Māori-centred research

A basic quality of collaborative research between community health research programmes and communities, is an emphasis on the transfer of knowledge between everyone involved, including the transfer of knowledge to the targeted group (Eng, Israel, Parker, D., & Schulz, 2010). Although, a potential issue is that by focusing on the gulf between knowledge and behaviour, such a narrow process can disconnect the individual from their social context. Particularly when social contexts are ignored of individuals, who may not have the personal agency or power to make decisions and follow through with action (K. Braun, Browne, Ka'opua, & Mokuau, 2014; Parker & Sommer, 2013; Tuhiwai-Smith, 2013).

Vulnerability of individuals or communities is determined by their social position, and ability to access services and power (Loh, 2017). Therefore the issues of health and development are linked to structures and social environments (Parker & Sommer, 2013). To address the issues of health and development and change to existing power relations, a Māori-centred research approach that draws on kaupapa Māori theory is committed to sharing power and engaging the community, as collaborators in the research process.

It is also important to recognise that Māori-centred and kaupapa-Māori theory in isolation, does not decisively affect, determine or impose research design and methodology. Rather than being a method, these elements orientate the research. In the section that follows, Māori-centred research will be presented as a model for enacting locally oriented approaches to research. It focuses on Māori people as Māori, with the methods of research and practices utilised, paying full attention to Māori concerns, customary knowledge and contemporary realities in all aspects of the research project (M. Durie, 1998a; Durie, 2005).

Locally identified needs

Since the mid to late 1990s, Māori-centred research has been conceptualised as relevant, legitimate and credible in public and mental health, that deliberately collaborates with people of the land (tangata whenua), locating their experiences at the centre of a situation (M. Baker, 2008; Forster, 2003). A Māori-centred approach to research, has also been acknowledged for providing researchers' with greater ability, to work with community. In effect, to make discoveries beyond a single dominant paradigm, for instance putting to use a mainstream scientific methodology alongside a

Māori framework, for better understanding a phenomena that is grounded in a community knowledge base, that of te ao Māori (the Māori world).

A growing number of Māori researchers and scholars who have described useful models of collaborative research to build knowledge between Māori and non-Māori, have also supported a Māori-centred approach (approach) (M. Baker (2008); Durie (2014); Forster (2003); Moyle (2014); Stairmand (2014)). Similar to myself, most of the aforementioned Māori authors, were also practitioners working in various fields, that utilised a Māori-centred approach (the approach) in their research. The approach enabled remaining true to Māori principles, which is a priority, given the focus of the present research. Expressly that is concerned with presenting the stories of kaumātua with osteoarthritis, in a manner that honours their realities and validates their experiences with methodologies and methods that are enabling.

What is more as previously contended, approaches to osteoarthritis-management research are needed. Particularly that consider Māori values and cultural practices, in a manner that is culturally proper for use with kaumātua, whānau and family. Namely, involving iwi Māori in all levels of the research from the outset, with strategies that follow community involvement in decision-making and planning (C. Cunningham, 1998). For example, involvement as early as possible with Māori community and stakeholder groups, in the planning of processes that can assist in identifying specific knowledge about local needs in a culturally appropriate manner.

Māori knowledge

Drawing on the lived experience of kaumātua with osteoarthritis, health decisions that are developed in line with community experiences, knowledge and values, has been a focal research point of the present research. As discussed in the previous chapter, published literature has not explained how kaumātua with osteoarthritis make sense of their condition within my community, from their perspective. Subsequently, in the preliminary stages of the present research, I explored ways to draw on Māori knowledge, to facilitate meaningful learning and elaborated understanding about the everyday contexts of kaumātua with osteoarthritis.

Given the context of osteoarthritis-management in my community, drawing on the knowledge of Māori scholars and experts both nationally and locally, has been an important orientation. Consequently Māori scholars, Bill Hodges (1994); Mason Durie (2005c, 2006) and Rev. Māori Marsden (2003, 1982) are recognised, within the context of a Māori view of health. For it is their ideas and worldviews, that are used to help answer questions about the everyday of experiences of kaumātua with osteoarthritis.

Māori scholarly expertise

The present thesis builds on works of three Māori scholars - Bill Hodges (1994), Maori Marsden (2003) and Mason Durie (1985). Basically, they advocated the importance of Māori values (the importance of language, land, family and extended family) and tīkanga (cultural principles), for understanding the health and wellbeing of Māori people. Māori scholarly expertise is important, because it calls attention to the importance of the local context in understanding the meaning of particular beliefs and activities of kaumātua concerning osteoarthritis-management.

The first of these scholars, Bill Hodges who was personally known to me, worked within the tribal areas of Hastings and Hawke's Bay in the rohe of Ngāti Kahungunu for over fifty years. Bill was acknowledged within the Wai 692 report (the Napier hospital and health services report) for providing evidence to the Waitangi tribunal, arguing for, and defending the use of, kawa (cultural practices) and tīkanga (cultural principles) knowledge in healthcare policy throughout the region (Waitangi Tribunal, 2001, p. 274). Following his call for health policy to be based on, "Māori values and Treaty principles" (p. 274), Bill's work emphasised the importance of attitudes and values that promote hauora and how to stay healthy.

Second, Rev. Maori Marsden (1924-1993) was a tohunga (Ngāpuhi Whare Wānanga), healer, minister, philosopher, scholar and writer of the latter part of the twentieth century[37] (New Zealand Qualifications Authority, 2012). Marsden's writings emphasised the importance that Māori place in observing kawa (cultural practices) and tīkanga (cultural principles), that had to be conducted, "carefully and meticulously" to ensure no spiritual offence was caused especially in relation to issues involving health and wellbeing (Marsden, 1992, p. 18). Marsden's work about Māori perceptions of what our world is ordered and informed by kawa (cultural practices) and tīkanga (cultural principles), emphasised the importance of customary protocols and practices that determine life style behaviours which impact on health.

Finally, the present thesis draws on the work of Mason Durie, a globally respected scholar of Māori and indigenous health developments (Massey University of New Zealand, 2012). It is Durie's (1999b) explanation of hauora Māori, Health promotion theory and Māori-centred research that are used to guide the current study. These assist characterising the experiences of kaumātua within their environment and that much wider, consistent with optimal adaptability within the fields of health development, social support, and ethnic minority ageing.

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[37] Māori Marsden wrote a substantial amount of material on the Māori quest for social justice, bringing together substantial statements on Māori philosophy, theology and the Māori worldview (Marsden, 1992, 2003; New Zealand Qualifications Authority, 2012).

These ideas of Hodges (1994), Marsden (2003, 1982) and Durie (1985), have been reinterpreted in the present thesis. Notably, to assist understanding the wellbeing and care of kaumātua living with osteoarthritis. Their ideas are depicted as theory framing the present study that inform the thesis methods, exploring 'What?', 'How?', 'Why?', 'Who?' questions, and what the everyday experiences are for kaumātua living with osteoarthritis.

Mātauranga Māori: 'What?'

In line with Royal's (2008) assertions, mātauranga Māori is often used synonymously with knowledge, comprehension, and understanding about a Māori way of being and engaging in the world. That is, of all things (visible and invisible) existing in the universe which in its simplest form utilises kawa (cultural practices) and tīkanga (cultural principles) to understand the world (Hodges, 1994; New Zealand Qualifications Authority, 2007; Sadler, 2007; Williams, 2008)[38].

The present thesis draws on mātauranga Māori (Māori knowledge). Particularly, the methodology used in the current chapter, and throughout the rest of the study, draws on the work of Durie, Hodges, and Marsden, who all have contributed in different ways to the fields of Māori health development and real-world research, within a broader paradigm.

Hodges' (1994) and Marsden's (2003, 1982) ideas have been reinterpreted in the research, to assist understanding and explanation of 'what' Māori knowledge informed tīkanga Māori (cultural principles), in the wellbeing and care of kaumātua living with osteoarthritis[39]. Where Hodges' (1994) local (Ngāti Kahungunu) perspective brings a level of iwi-specific knowledge (mātauranga-a-iwi)[40], Marsden (2003, 1982) enables understanding kaumātua knowledge application, in an ever-changing environment.

The local perspective of Hodges' (1994) was epitomised in his most recent role prior to retirement, as Hawke's Bay Māori Health Manager and advisor on local Māori health committees (Waitangi Tribunal, 2001)[41]. The values of Te Wahanga Hauora

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[38] Fundamentally, "kawa (cultural practices) and tīkanga (cultural principles)" are used to examine, analyse and understand the world (Tau, 1999, p. 15).

[39] Tīkanga Māori (cultural principles) is to be correct, referring to general behaviour guidelines for daily life and interaction in Māori culture (2013).

[40] Mātauranga-a-iwi (iwi specific knowledge) refers to mātauranga knowledge which is, properly located within an iwi environment. Historical accounts form the basis of mātauranga-a-iwi, which is knowledge that is described within its own context and is a lived reality. It is not to be confused by unknowingly drawing from other tribal knowledge (Hodges, 1994; Mead & Mead, 2003)

[41] Wiremu (Bill) Hodges was a strong advocate for Māori in health. He called for, within The Napier hospital and healthcare report - WAI 692 (the Napier hospital and health services report) philosophical foundations to underpin Māori health policy. He argued that these must be based on: Māori values and Treaty principles, especially those of (respect). These values (not the Treaty principles) were, "incorporated into Healthcare Hawke's Bay statements of intent and eventually integrated into Māori

Māori Health Services of Hawke's Bay District Health Board, were based on the work of Kaumātua Bill (Hawke's Bay District Health Board, 2011). The following Māori values were gifted by Bill to the Hawke's Bay District Health Board (DHB) in 1975 (Cram, 2010a), after travelling the breadth of the Hawke's Bay, to consult with the many marae elders: "'wairuatanga' (spirituality), 'whānaungatanga' (valuing people and working together), 'rangatiratanga' (excellence), 'kotahitanga' (unity) and 'manākitanga' (stewardship)" (Cram, 2010a, p. 4).

As a result, the values which lie at the heart of Hawke's Bay District Health Board's Māori Health Services, have been modelled. Particularly, through continual professional development of staff focussed on tīkanga (cultural principles), learning waiata and sharing of local knowledge to promote effective health communication principles of Hawke's Bay Māori (Cram, 2010a). The suggestion being that by drawing on these values in the present research, help to ensure the creation of an osteoarthritis-management focussed toolkit, that is derived from a Māori belief system, by centralising kaumātua and whānau, with a focus on positive messaging.

In addition to playing a role in establishing effective health communication principles, Hodge's (1994) wrote and published a Ngāti Kahungunu perspective of Māori ethic, drawing on a foundation of local Māori protocols and practices. Hodge's (1994) ethic, which is motivated by the stories of Ngāti Kahungunu Māori, discussed the importance of working with (than against) the Māori holistic approach. For example, emphasising the need for integrated management across sectors and agencies, garnering and sustaining community support, and making the most of resources.

In the same way that Miller and Rivera (2011) argued the tangible success of holistic community initiatives, Hodge's (1994) work argued the importance of communication with Māori, was dependent on culturally-responsive design strategies. For example, Hodge (1994) discussed historical, social and environmental barriers to Māori participation in governance and management, as well as a lack of recognition of Māori concepts of wellbeing, as barriers to Māori health development. It is for these reasons that Hodges' work allows me to pay close attention to a range of barriers, but also community norms, actions values and beliefs of kaumātua living within Ngāti Kahungunu rohe.

Similar to Hodges' (see Figure 3. Theory framing the study, below), Marsden's expertise was reinterpreted to assist understanding and explanation of 'what' community knowledge informed kawa (cultural practices) and tīkanga (cultural

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business and service plans" (New Zealand Qualifications Authority, 2012, p. 17).

principles), in the wellbeing and care of kaumātua living with osteoarthritis[42]. In the present study Marsden's perspectives about kawa (cultural practices) and tīkanga (cultural principles), can be used to reveal 'how' kaumātua, for example through their roles in the community and responsibilities, might combine their knowledge with hauora Māori (Māori wellbeing), to create a tīkanga Māori adaptability space. The multi-layering of kaumātua roles and responsibilities that is a part of the dynamic of whakapapa and whānaungatanga of tīkanga, provide an analytical tool for explaining the implications of the relationships studied.

The reciprocal relationship between Māori wellbeing, lands and waters, ensures ongoing whakapapa relationships between whānau, hapū (sub-tribe) and iwi (tribe), and intergenerational equity (Marsden, 2003). Marsden (2003) called the fundamental aspect of Māori cultural identity 'a woven universe', expressed through kaitiakitanga (a way of managing the environment), that all elements of the world are inter-related (holistic). It is upon those relationships and cultural understandings (adaptive structures) between kaumātua, family and whānau and their contexts, that survival depends.

Marsden's discussions of kaitiakitanga (guardianship and conservation) are re-interpreted as that which is directly related to stronger family and whānau bonds, a greater sense of complex, resilient systems and adaptability. Subsequently what follows is a holistic Māori worldview of kaitiakitanga, that considers appropriate resources to be directly related to stronger family and whānau bonds, and a greater sense of adaptability for kaumātua with osteoarthritis. A Māori worldview was used to inform 'what' Māori knowledge (mātauranga) might be informing tīkanga Māori (cultural principles) in the wellbeing and care of kaumātua, relevant to staying healthy at home and in the community.

Hauora Māori: 'How?'

In addition to Bill Hodges' local knowledge and Rev. Maori Marsden's expertise, Mason Durie's (1998a, 1998b; 1999b, 2001) scholarship in health and wellbeing (hauora)[43] support the present study. For instance, Durie's (2001) concept of hauora Māori theory[44] is reinterpreted to frame 'how?' hauora is being practiced through the

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[42] Tīkanga Māori means to be correct, and refers to general behaviour guidelines for daily life and interaction in Māori culture (Chase, 2005; Marsden, 2003).

[43] Mason Durie is respected globally for Māori and indigenous health developments (Hodges, 1994; Mead & Mead, 2003) for offering explanations of hauora Māori, Health promotion theory and Māori-centred research that are used to guide the present study. These explanations will assist in characterising the experiences of kaumātua within their environment and adaptability, within the field of Māori health development.

[44] Mason Durie is respected globally for Māori and indigenous health developments (Massey University of New Zealand, 2012). For Durie's hauora Māori theory see 'Te Whare Tapa Whā' model (Massey

use of kawa (cultural practices) and tīkanga (cultural principles) by kaumātua with osteoarthritis. Further, the concept of hauora Māori theory is used to inform the processes, attitudes and knowledge inherited by kaumātua, that is creating a system of knowledge within the context of their everyday environments.

Osteoarthritis-management: ‘Why?’

Additionally, Durie’s concepts[45] are reinterpreted to frame 'Why?' the use of Māori conceptualisations of health might be considered in the construction of an osteoarthritis-management resource. The focus of attention being on meaningful Māori indicators and understanding of what is occurring for kaumātua with osteoarthritis in an ever changing environment. That is to say Durie’s explanation of hauora Māori, would assist to characterise kaumātua experiences of osteoarthritis-management within their environment and wider support systems.

Community members: ‘Who?’

Finally in the present research, a Māori-centred approach that draws on ‘kaupapa Māori theory (in-depth explanation of which follows). The research is framed by, ‘Who?’ kaumātua view in their communities as valuing their voice and perspectives, including their diversity. Durie’s concepts would allow me to pay closer attention to strategies that bring a value-based perspective to osteoarthritis-management. Especially, where communities (whānau, hapū, iwi) are able to participate in decision-making processes, that recognise a Māori worldview and way of being.

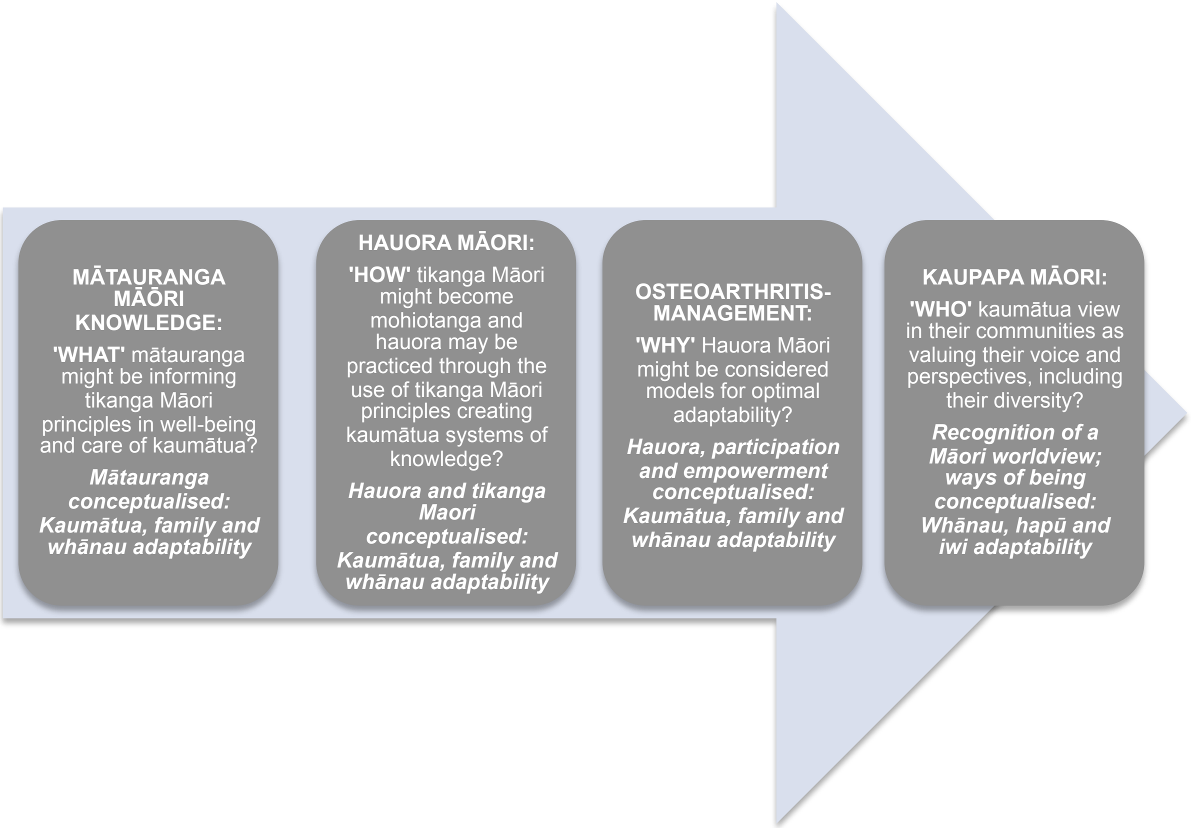
With the application of a Māori-centred lens, it is more likely that the indicators and outcomes of the present research are located within the appropriate context. It is then more likely to resonate with (and play some part in) the acknowledgement of Māori priorities and ambitions, and for health development, whānau, hapū and iwi adaptability. There are after all, many pathways to understanding, as will be discussed in the sections that follow shortly, pertaining to social scientific research.

Figure 3 below is a summary of what has been discussed in the present section, concerning Māori scholarly expertise. The flow diagram is useful for emphasising the kaupapa of the research is more than a philosophical position. The emphasis is about attempting to constructively engage with Māori, by engaging processes that maintain and enhance hauora.

University of New Zealand, 2012).

[45] Mason Durie is respected globally for Māori and indigenous health developments (M. Durie, 1998b). For Durie’s hauora Māori theory see ‘Te Whare Tapa Whā model’ (Massey University of New Zealand, 2012).

Figure 3. Theory framing the study: 'What', 'How', 'Why', 'Who'?



MĀTAURANGA MĀORI KNOWLEDGE:
'WHAT' mātauranga might be informing tikanga Māori principles in well-being and care of kaumātua?
Mātauranga conceptualised: Kaumātua, family and whānau adaptability

HAUORA MĀORI:
'HOW' tikanga Māori might become mohiotanga and hauora may be practiced through the use of tikanga Māori principles creating kaumātua systems of knowledge?
Hauora and tikanga Maori conceptualised: Kaumātua, family and whānau adaptability

OSTEOARTHRITIS-MANAGEMENT:
'WHY' Hauora Māori might be considered models for optimal adaptability?
Hauora, participation and empowerment conceptualised: Kaumātua, family and whānau adaptability

KAUPAPA MĀORI:
'WHO' kaumātua view in their communities as valuing their voice and perspectives, including their diversity?
Recognition of a Māori worldview; ways of being conceptualised: Whānau, hapū and iwi adaptability

Māori norms and local contexts

Given the centrality of people and communities to Māori approaches of research, in the previous section I wanted to acknowledge mana whenua values, local knowledge and and tīkanga (cultural principles). Furthermore, I detailed the works of Hodges (1994), Maori Marsden (2003) and Mason Durie (1985) who each advocated the importance of Māori values and concepts ('Māori scholarly expertise', above). Ahuriri-Driscoll, Hudson, Bishara, Milne, and Stewart (2012), argued that mana whenua values, local knowledge and tīkanga (cultural principles) are the 'glue' that holds a community together, "giving a common frame" (p. 20).

A cultural inclusion framework, that draws on Māori knowledge and local contexts incorporates a range of healing practices. The frame is useful for underpinning health development, for determining a pathway forward. Each aligns with cultural protocols and philosophical theories of knowledge (epistemologies):

> [Customary] Māori healing encompasses a wide range of modalities, including but not limited to: ritenga and karakia: rituals and incantations; rongoā rākau: physical remedies derived from plant materials; mirimiri or romiromi: physical touch or manipulation including massage; wai/hauwai: use of water or steam; and matakite: second sight or prophecy (Ahuriri-Driscoll, 2014, p. 34).

There is a wide scope of healing activities occurring within the Māori community. These are indicative of connections operating between kaumātua, whānau, hapū and iwi, whakapapa, whānaungatanga (extended whānau, sense of family connection), socio-ecological perspectives, and customary practices associated with hauora (Māori view of health) (Ahuriri-Driscoll, 2014). The insurmountable challenge of adequately defining Māori knowledge concerning hauora, touches on the profoundly deep breadth of Māori knowledge and understanding as conveyed by Kaumātua Bill Hodges (1994) and experts such as Marsden (2003) and Durie (1998a, 1998b; 1999b, 2001).

The collective works of Hodges, Marsden and Durie, brings a perspective and basis, enabling me to broaden my interpretations of osteoarthritis-management, both as a healthcare practitioner and researcher within my community. Hodges' (1994) local values-based perspective, enables building a basis for my work, by placing primacy on appropriate communication within the community. For example, exploring the use of open dialogue by kaumātua and the fostering of collaborative decision-making, creativity and resourcefulness, to better identify relevant areas of service delivery and self-management improvement.

In addition to Hodge's local values-based perspective, the present thesis follows Marsden's (2003) works regarding culture. Specifically, culture was defined as, "that complex whole of beliefs, attitudes, values … [of society] as guiding principles" (Marsden, 2003, p. 34), and the way tīkanga (cultural principles) influence the adaptability strategies utilised by kaumātua, family and whānau, are an integral component of the present thesis. I am interested in utilising kaumāta knowledge to build a basis for my work, that considers cultural rituals, values and social practices, which the target community are utilising to maintain wellbeing, that contribute to adaptability and resilience.

After Marsden's works regarding culture, Durie's (2001) concepts about hauora which are inherent to Māori, are unable to be sufficiently assessed within a Western medical model. In effect, that treats the individual's mental and physical as though they are completely separate. In the present study I utilise kaumātua knowledge to build a basis for osteoarthritis-management that explicitly seeks towards developing holistic integration (of wairua (spiritual), hinengaro (cognitive), whānau (family), and tīnana (physical) domains). All of these elements that emphasise building on culture and local knowledge of the community, acknowledged different ways of knowing, and expressions of both cultural and scientific knowledge regarding osteoarthritis-management.

Incorporating these perspectives would I believe, increase the effectiveness of the present study, help to reduce risk or harm from potential stigmatisation, and improve credibility of the results in my community. What is more, outcomes of the research may later be developed to help produce clinical guidelines for healthcare practitioners concerning osteoarthritis-management initiatives. Above all, that can help by influencing public policy.

These initiatives are more likely to be couched within, a Māori-centred approach when Māori-centred values characterise self-determined development. In the following section, key values pertaining to such an approach are offered. As will be discussed, these principles that are based on Māori-centred philosophy, values and practices work together, to guide the research.

Māori-centred values

Māori centred-research methods and practices place Māori at the centre of the research activity, which according to Durie, (1996) and Bishop (1996) involves three principles. The first Māori principle, 'Whakapiki tangata' (enablement) advances collaborative connections throughout stages of the research, upholding the dignity of individuals and the collective in the process (Durie, 1996; Forster, 2003). 'Whakapiki tangata' recognises community as a unit of identity, expressly by building on strengths and resources within the community (Durie, 1996; Forster, 2003). Similarly, in the present research the concept prioritises kaumātua with osteoarthritis the means, to take more control of their health by seeking to better their condition and overall health status.

The second Māori principle, 'Whakatuia' (integration) addresses health from a holistic Māori perspective. By taking an holistic approach to the research, notions are incorporated of relationships, and connections between physical health, culture, economics, social standing, historical events and environmental domains (Durie, 1996; Forster, 2003). Similarly in the present research, utilising a holistic model of health, enables reframing osteoarthritis-management away from positioning kaumātua as a problem, towards the need for integrated osteoarthritis-management that highlights community strengths and adaptability.

Finally, 'Mana Māori' (Māori control) is a concept that seeks to increase the degree of autonomy and self-determination of people and communities. The purpose of the principle, 'Mana Māori' is about enabling kaumātua to represent their interests in relevant ways that are for instance, about acting on their own authority. For these reasons Mana Māori holds capacity for authority over one's own life, and claiming one's own rights (Durie, 1996; Forster, 2003), such as controlling key impact areas of osteoarthritis-management according to a Māori perspective.

Some examples of Mana Māori in healthcare practice for instance, can be related to obtaining additional knowledge and actions about a health condition. For example, research by Māori that involves Māori as participants and investigates aspects of Māori society, for the benefit of all participants and stakeholders (partners), and disseminating the findings in a manner that facilitates Māori aspirations and initiatives. These actions represent upholding self-determination and autonomy within the research process, and protecting information that is generated. Mana Māori is the mechanism by which Māori gain control and proficiency over their lives and for those kaumātua with osteoarthritis, is concerned with growing control over their health.

Following Māori-centred principles, opportunities to create a culturally appropriate osteoarthritis-management resource should increase, particularly as these concepts reside within a Māori worldview (Durie, 1996; Forster, 2003). Gaining a deeper understanding within a Māori worldview, Māori knowledge and Māori methods introduce different ways of 'knowing' (epistemology), ways of 'being' (ontology) and ways of 'doing' (axiology and methodology)[46] to osteoarthritis-management in New Zealand. All of which can incorporate consideration of how power operates, by valuing experiential knowledge within the realms of osteoarthritis-management experiences and impacts.

When turning to the international literature on indigenous research approaches, Schroeder (2014) argued that each approach emanated from a particular ontological view of reality, introducing an epistemology, ontology and methodology. What is more, that indigenous research approaches relied on ways of knowing, that were based on shared experience and observation. Some of the interconnections of a Māori worldview that follow, inherently lead towards placing imperatives on addressing issues of power, and involvement of members of the studied community in the research process.

Connections to value and belief

Māori beliefs, custom, and values are derived from a mixture of cosmogony, cosmology, religion, and anthropology (Best, 1952, 1986; Hodges, 1994; Marsden,

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[46] M. Durie (1998b) described the following four assumptions of the research process as a whole: (i) Epistemology (how researchers know what they know) concerns ways of knowing how we know certain things (epistemology asks: what is the relationship between the inquirer-known? ('how questions')); (ii) Ontology (nature of reality) is our way of reality/ways of being ('what questions'), i.e., 'What is the nature of reality'?); (iii) Axiology (role of values) concerns the role of ethics (axiology asks: how will I be as a moral person in the world? (value questions)); (iv) Methodology (the plan of action) concerns ways of gaining knowledge (methodology asks: how can we systematically solve the research problem? (how should we study the world?)).

2003), referred to within the present thesis as Māori knowledge (mātauranga). An integral part of Māori society and belief system, are the stories about the origins of the universe and of Māori people. Māori values are both complex and evolutionary with sources of knowledge, that continue to shape the concepts and relationship that Māori have with the environment today (M. Henare, 2001; Marsden, 1989).

For example, the following extract (see below, ‘Sequences’ Table 3) from a version of the Māory story of creation, incorporated ‘genealogical’ charts, listing organic processes of cause and effect regarding growth of various kinds. The following two (of many) sequences, were recorded by Reverend Maori Marsden. One tells of the growth of knowledge and the other information and sequence concerning the rising of space and time, that existed before Ranginui (the sky) and Papatūānuku (the earth) (Royal, 2003, p. 3):

Table 3. Sequences

Growth of knowledge	Sequence of the rising space and time
Te Mahara (primordial memory) Te Hinengaro (sub-conscious knowledge) Te Whakaaro (seed word) Te Whē (consciousness) Te Wānanga (achieved knowledge)	Te Hauora (breath of life) Te Ātāmai (shape) Te Āhua (form) Wā (time) Ātea (space)

Rather than describing the central act of creation, these sequences attempt to understand processes of life itself, using a framework based on whakapapa (genealogical descent of living things), bringing together congruent forms of life. The sequencing of events suggests that Māori ways of understanding and acting, connect with a particular ontology and epistemology, concerning relational ways of knowing (Royal, 2003). Marsden’s sequencing suggests a process of selecting the details of experience, reflecting on them, giving them order, and thereby making sense of them in a way that tells a story, of which McWilliams (2010, p. 1) described (story) as a, “meaning-making experience” (p.1).

Meaning-making

From a Māori perspective, tīkanga (cultural principles) and Māori customary values (these values), are key elements of health and wellbeing. Derived from a belief system, that is based on mātauranga (Māori knowledge) (C. Barlow, 1994; T. Henare & Marsden, 1992; Mead & Mead, 2003), these values that form the basis for the Māori worldview can act as instruments, by which Māori meaning-making or making sense of experience and interpreting the environment occurs to varying degrees in everyday life (Marsden, 1988). In the present research, these values can therefore be interpreted into, and provide a basis for what is treasured, for instance what is significant, whlie at the same time prioritising shared values among kaumātua with osteoarthritis.

In contrast, European values locate essential activities of meaning-making as that which is developed through shared life experiences concerning human matters (than divine or supernatural or humanistic formulations and approaches) (Allport, 1961; Maslow, 1968; Rogers, 1962). By the same token, Martin Heidegger[47] believed that it was not possible to reduce essential activities of meaning-making by bracketing particular beliefs about the world into classifications. Rather, reflection enabled becoming aware of one's own assumptions[48]. Relatedly, Heidegger's (1986) central concerns were essentially humanistic, locating the individual in context of their life-world, social and historical contexts of existence

Avoiding a pathologising stance, Heidegger (1986) emphasised the broader influences at hand, such as grief, loss and human finitude[49]. Such as stance has implications for the present research concerning kaumātua, by offering a non-pathologising context. Such as focusing on developmental contexts, and reframing the grief and loss that can be associated with chronic conditions.

Heidegger's (1986) analysis was concerned with the question of being. Similarly my study is concerned with 'being older-Māori with osteoarthritis'. Rather more than concern for chronic health pathology or normative coping strategies, I am curious about the meanings that kaumātua ascribe to an unfolding process of living with and managing osteoarthritis within the context of 'being Māori'.

As a study of lived experience, operationalising the concept of osteoarthritis-management in terms of medical prognosis, stage of illness or disability is not the priority. The focus and intent was about understanding and including participants' self-definitions. Rather 'being older-Māori and managing osteoarthritis' is conceptualised

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[47] Martin Heidegger was a German philosopher whose work is often most readily associated with phenomenology (study of experience and how we experience) and existentialism (the study of the individual, as a living, breathing, thinking human being (Laverty, 2003). Heidegger identified the idea of ontological realities and worldviews in his seminal 1927, 'Being and time to time and being', which is a journey through metaphysics. For instance, the presence of different worldviews are embedded in distinctive cultural philosophical signification. His philosophy conveyed the idea that, "the human experience is shaped by the forces of time, the past, the present, and a speculative future" Heidegger (1986).

[48] Besides, bracketing experience would require shedding that experience and losing our capacity to understand through shared experience and meaning. The concept was understood as Heidegger's ontological difference, and formed the basis of his hermeneutic turn (McNeill, 2009, p. 97).

[49] Human finitude is a state that is without limits or bounds, and principle that because of our finitude, we cannot have any knowledge until we are given something outside of us (Frie, 2013) and which Heidegger (1986) maintained emerges from one's lived experience.

as an ontological question of being, which from a Māori perspective is an emphasis on mana tangata, that relates to capacity and capability and building the competence of people to achieve self-reliance (people power) (Lawson-Te Aho, 2010). That is for instance, uplifting the dignity and wellbeing of kaumātua with osteoarthritis by emphasising the whole person, than just their illness or a disease.

Real meaning

Alternately, had the present project not been underpinned by a Māori perspective, I could have operationalised osteoarthritis-management as a measurable variable based on physical mobility, gait or stage of the condition (such as disability). Clinical research of osteoarthritis has used various measures, such as range of joint movement and gait concerning condition status (Fadzli et al., 2017), yet Alves and Bassitt (2013) contrasts osteoarthritis more subjectively, as when a person believes that they have a reasonable chance of recovery to a decent quality of life. As mine is a study of lived experience, and following Alves and Bassitt's more inclusive definition, I am interested in Māori self-definitions and perceptions (real meaning).

As a study of lived experience, I am not interested in seeking to operationalise the concept of osteoarthritis-management, but use the definitions that kaumātua assign. In so far as epistemology, I assume that the philosophical study of the nature, origin, and limits of human knowledge is an inductive, theory generating approach, than deductive theory driven approach. Accordingly, the perceptions of kaumātua would assist to generate theory, alongside processes that draw on literature and theorising of Māori scholars.

In so far as drawing on the literature, in the previous chapters and after reviewing the self-management literature, disconnections were discovered. A crucial disconnection noted in the previous chapter, was a lack of evidence about which outcomes of osteoarthritis-management were most valued by kaumātua, families and whānau. I intend to develop an understanding about the substantive phenomena of osteoarthritis-management, not so much in terms of illness, as to expand the common theoretical agenda for kaumātua needs. It is suggested that, what is needed is a Māori perspective, for the success of osteoarthritis-management outcomes in kaumātua.

The process of developing an understanding about the lived experience in context specific settings (or phenomenology) (Moustakas, 1994), such as osteoarthritis-management within a Māori-centred framework, has certain methodological implications for the present study. For instance, firstly there is the issue of osteoarthritis-management, that often resorts to pragmatism as well as metaphysical, in that it calls into questions the possibilities of both being physically mobile and non-being or immobile (Focht, Garver, & Taylor, 2015). Issues about independence and the nature of being, call for both description and ontological reflection on the nature of being (Heidegger, 2000).

Also, subjectivity (or intersubjectivity as termed by the interpretive phenomenological stance of Heidegger (2000))[50], assumes a collaborative mutual research relationship between the researcher and kaumātua. Heidegger's (2000) viewpoint reduces the object-subject disconnection within the research relationship, by acknowledging inter-subjective experience of both parties as a significant source of knowledge (Heidegger, 2000). Being older-Māori with osteoarthritis in the world, could then be understood within the context of a Māori view of health and the intersubjectivity of interconnectedness (holistic life experiences), sociocultural experiences, and interdependence of human relationships (relational) (elements).

Carrying these elements over into a research methodology, of 'being in the world' and within the community of Hawke's Bay, encourages research exploration of holistic life experiences by participants and the researcher (people). Understanding the personal experiences of kaumātua with osteoarthritis, designated phenomenology to me as a philosophy and a method. Phenomenology is the research methodology that focuses directly on lived experience (Annells, 1996), that was identified by Peden-McAlpine and Struthers' (2005) phenomenological studies among indigenous peoples in the United States and Canada, for allowing a seamless link with indigenous oral knowledge transmission.

Oral knowledge transmission is synonymous with a more holistic overview that encompasses cultural values, real social contexts and phenomenology. Because I am seeking to answer specific questions from the phenomenon of osteoarthritis-management under study, to broader questions about the way kaumātua with osteoarthritis experience the world, I am immediately orienting myself to a phenomenological approach. As a research method phenomenology is enabling for Māori, because the product of kaumātua storytelling is the capacity to reflect on change, towards enhancing their health in a holistic and culturally acceptable manner.

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[50] The stance of Heidegger, incorporated the assertion that human existance is a more fundamental idea than human knowledge or consciousness alone. His philosophy makes it clear that human understanding of the everyday world, is derived from one's interpretation of it (or hermeneutic). Interpretive phenomenology is used when the research question asks for the meaning of the phenomenon (believing that setting one's preconceived opinions aside or bracketing was not warranted because hermeneutics presumed prior understanding and engagement with the question under study (Drew, 1998).

Sharing stories

In addition to seeking towards enhancing the health of kaumātua, the present thesis advances the use of participant stories. That is to say stories for exposing, interpreting and examining the role of kaumātua and their lived experience, managing osteoarthritis around the home and community settings (J. Clandinin, 2016; Flyvbjerg, 2001). A central dynamic of Māori-centred research is the strong cultural preference for sharing stories and metaphor, from a sense-making context and the oral communication of knowledge (Bishop, 1996, 2011; Pere, 2006).

Hodges' (1994) Ngāti Kahungunu perspective, argued Māori oral communication as constituting the collective memory and heritage of the people, as that which is, "handed down to generations still to come" (p. 20). Such knowledge in its many forms (for instance genealogies, sayings, stories and prose, tribal speeches, song, dance and chants) have been likened to archives, preserving important historical and cultural knowledge (Benton et al., 2004; Haami, 2004). As in the present study, these forms of knowledge from the past continue to underpin Māori processes of engagement such as ritual of welcome (pōwhiri) and Māori gatherings (hui) and the teaching of tribal genealogies and histories[51].

Sharing stories, offers potential in the present research, for allowing the experiences of people to flow naturally and holistically, to enhance understanding and explaining specific social phenomena (D. Clandinin & Huber, 2010; D. Clandinin & Murphy, 2009; Flyvbjerg, 2001; Lee, 2009; Polkinghorne, 1988). Russell Bishop (1999a) argued Māori knowledge is based on sharing comparable to, "collaborative storying" (Bishop, 1999a, p. 6). The researcher is positioned as a participant as researcher-researched become engaged in a collaborative process, the relationship builds and deepens as stories are shared.

The conversational method is not unique to indigenous methodologies, however. It is viewed as a useful tool, with which to explore and develop forms of understanding about the meaning of disability osteoarthritis-management experience, mediated as it is by the socio-cultural context (Canam, Henderson, Paterson, & Raoul, 2007; Grant, 1997; Marshall, 2009). As D. Clandinin and Connelly (1987, 1990, 2000) noted, human lives are woven together by stories and storying as the way by which individuals construct their identities.

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[51] As argued by (Anney, 2014, p. 1) one cultural construct concerning tangata whenua (indigenous people of the land), host or guests relates to pōwhiri, prioritisation and formalisation of the host-guest relationship. The aim of pōwhiri is to recognise the tapu (power potentiality) and mana of the attendees. Similarly in the present research, issues of power which have been problematic for Māori in the past are prioritised.

Clandinin and Connelly's (1987, 1990, 2000) form of sharing research stories requires the researcher to maintain a sense of the history of the research field during the process of entering and moving through, such involvement often being for over an extended period (D. Clandinin & Connelly, 1987, 1990, 2000). D. Clandinin and Connelly (1987, 1990, 2000) encouraged the use of reflective journalling, field notes, taped conversations and interviews. Analysis, interpretation and coding related to people (characters), places, actions, tensions (voice disconnections and silences), continuity and changes.

Due to the focus on representing the voice of the participants, member checking of transcripts and how they have been characterised is a priority in the research. Stories of experience have an important place in health research. Increasingly, the conversational method is becoming increasingly recognised, within the discourse of chronic condition literature (Canam et al., 2007; Denzin & Lincoln, 2003; Grant, 1997; Marshall, 2009). Key works relevant to health used to conceptualise the present study, include Brembo et al. (2016), for highlighting the emotional needs of patients living with hip osteoarthritis; Brorsson, Kristensson, Midlōv, Modig, and Troein (2016) emphasised frail elderly patients' experiences of information on medication.

Cormack et al. (2016) pointed out the significance of relational continuity of care for Māori patient engagement, with predominantly non-Māori doctors. Throughout much of the current literature, the lived experiences of people coping with chronic illness, their carers and significant others, have been enabled through qualitative research study in specific contexts.

Real social contexts and phenomenology

As discussed in the previous section, there is a disconnection in the health literature, concerned with assigning meaning within the context of osteoarthritis-management. That is to say, concerning the lived experiences of kaumātua, and what in their eyes would constitute a culturally appropriate approach to osteoarthritis-management. In the current section, I discuss the importance of the research methodology for enabling a process of 'talking back' and allowing space for the legitimate exchange of views that enable the marginal and silenced voice of kaumātua to be heard.

My approach is motivated by a desire to advance osteoarthritis-management, influence service provision and practice research, in a manner consistent with privileging Māori ways of knowing. In consequence of which, such an approach that attempts to unite philosophy, science and everyday experience is aligned with phenomenology. That people make sense of their world from within their lived experience of people, situations and environments (Cooney, Dowling, Murphy, Sixsmith, & Tuohy, 2013; Greenhalgh et al., 2013).

Obtaining a broader picture of a community

In so far as the origins of that tradition (qualitative), the present section discusses its roots that link to a decolonising agenda, of reclaiming indigenous knowledge and ways of knowing. The roots of qualitative research are sourced within social, cultural, and political attitudes of the 1970s (Geertz, 1973; Kuhn, 1970; Ryle, 1971). Up until that time, qualitative research was not well known, other than as a sub-discipline within anthropology and sociology (E. Guba, 1990; Laverty, 2003).

The rise and relevance of qualitative research along with other disciplines, started in the 1970s and 1980s with social and community development critiques of the health and disability systems of the time (Denzin, 2010; Sewell, 1996). A new wave of protests by scholars brought into focus power and control within context concerning the role of the researcher-researched relationship and positions of knowledge ownership. Several scholars (Freier, 1970; Geertz, 1973; Illich, 1970; Kuhn, 1970; Ryle, 1971) concerned with protest (Freier, 1970; Illich, 1970), became influenced by Marxist critiques of society and a concern for the liberation of the oppressed, led to rejection of the academic positivist tradition, arguing that it most benefited traditional power elites (Monteiro, Rennie, & Watson, 2002). Some social scientists and academics such as Paulo Friere, challenged the colonising nature of research and what they perceived as being a process of domination and manipulation[52] (Gage, 1989; Giddings, 2006; Hammersley, 1992).

The argument put forward was that colonising scholarship and research did not benefit communities, and in fact legitimised subjugation and exploitation of the people that academics 'researched' (Freire, 1982). Instead Freire (1972) noted that in order to gain an understanding in research, that it was necessary to analyse connections between the culture of silence, and one that has a voice (Friere, 1972). By the 1980s and 1990s, after sharp criticism by quantitative researchers, development of qualitative research occurred (Giddings, 2006; Hammersley, 1992).

It was during these years (1980s and 1990s), that more attention begun to be placed on dealing with issues such as data analysis, reliability, and viewing

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[52] Paulo Friere questioned the positivist tradition that governed academia. Friere argued that objectivity was a matter of people's perception (a social construct) and reality was always subjective and based on political power, rather than something that was able to be segragated out as an objective truth. In addition, Friere championed that marginalised peoples would allow their awareness of developing awareness of social and political forces influencing their lives, to guide their political actions (B. Goodman, 2014).

communities as active collaborative research partners in the process. Strengthening communites through local partnerships required a commitment to research that is grounded in social justice, by embracing the idea that knowledge was also produced by, and with input from, community members (Giddings, 2006; Hammersley, 1992). All of which required researchers' to question their own role as knowledge producers in the research process.

Alasuutari (2010) places the rise of phenomenological research within these events of community and academic research development. Notably, that qualitative research can be seen as a reaction to the scientific approach of many research-based frameworks of socio-scientific studies, where social reality was reduced to measurable variables (Alasuutari, 2010). The importance of contextualisation is applicable to the health sciences and researchers' concerned with understanding chronic diesease related health behaviours and causes that drive these (Leavy, 2014).

The subjective, practical and social conditions of experience inherent in phenomenology practices, makes qualitative research suitable to developing a complex account of social interactions (Bryman, 2001). Such as those that include collective action, examination into imperatives of power, and everyday experiences of the world, in a particular cultural context of intentional activities, and osteoarthritis-management within a community. Different from quantitative research, qualitative research, would enable me to explore everyday self-management decision-making that is all-embracing of kaumātua with osteoarthritis concerning, 'why?', 'how?' and the 'who?', compared to the 'what', 'where' and 'when' of quantitative research (value-focussed) (Alasuutari, 2010; Denzin & Lincoln, 2000; Flick, 2013).

A value-focussed emphasis on decision-making is important, particularly in the delivery of chronic care. For example, Kane, Priester, and Totten (2005) discuss that the majority of management occurs by way of patient monitoring and management of the condition in the community (Kane et al 2005). The present research which seeks to create a connection with kaumātua, families, whānau and community, leads me to discuss who is the community and what constitutes engagement in Māori-centred research.

Whānau connections and collaboration

In the previous section, I discussed the importance of decision-making in the delivery of chronic care, within a community. In the present research, that seeks to maximise community connections and collaboration with kaumātua, family, and extended family (whānau), sharing expertise between researcher and community, needs to be reciprocal. Relevant to the present research, however, there does appear to be some differences in the meaning and definition of 'whānau', across policy documents and academic literature primarily drawn from advocacy, engagement, social policy studies.

Throughout the academic literature, 'whānau' definitions are debated and in policy documents, often perceived as conspicuous, yet are imperative to maintaining and building whānau resilience and strength (Lawson-Te Aho, 2010). Generally whānau is described as a collective of people that are connected through a common ancestor (whakapapa), or as the result of a common purpose (kaupapa) (Lawson-Te Aho, 2010; T. Walker, 2005). The key Māori social and cultural unit (whānau) has been researched extensively to describe its component parts, roles and relationships in customary and contemporary Māori society (Best, 1952; Buck, 1950; Durie, 1994a; Firth, 1959; Metge, 1990).

Arising from health literature are two pre-eminent models of whānau: whakapapa (kinship) (Paipa, 2010; T. Walker, 2017) and kaupapa (purpose driven) whānau (Katene, 2010; Lawson-Te Aho, 2010). Whakapapa whānau is a permanent, culturally authentic (for instance, portrays ethnic minority-group members in a positive, non-stereotypical manner) form of whānau (Lawson-Te Aho, 2010). Whakapapa and kaupapa whānau are two whānau models that seek to make a contribution, to the achievement of Māori people (whānau ora), by means of building and strengthening bonds of kinship and giving effect to the collective practices of whānaungatanga (whānau support) (Lawson-Te Aho, 2010).

Cram, Pihama, and Walker (2002) support that a necessary part of Māori survival is dependent on the, "cultural values, customs, and practices that organise around the whanau and collective responsibility" (p. 38). Grennell et al. (2004) talks about the relationships between the physical and spiritual worlds, that are brought into the contemporary lives of whakapapa whānau, via acknowledgement and valuing of kinship ties with those who have 'passed on' (deceased). In contrast to whakapapa whānau, kaupapa whānau are bound together in relationships to fulfil a common mission (kaupapa), yet may or may not share the same whakapapa (Lawson-Te Aho, 2010; T. Walker, 2005).

Kaupapa whānau is a model, that recognises both the customary and contemporary roles that whānau perform in the lives of whānau members, such as kaumātua. The collective of whānau is recognised for being vital to the individual functioning of whānau members. Although, there is also room for whānau to include those with whom individual Māori affiliate, and identify with, which does not require a need for kinship or whakapapa relations (Lawson-Te Aho, 2010; T. Walker, 2005).

G. Hinangaroa-Smith (1995) noted that Māori, who may share an association based on some common interests such as an urban marae, may be considered to be whānau. Durie (2001) describes that in order for whānau to be well (whānau ora), there has to be a balance between the spirit, mind and emotions, physical body and whānau relationships. Also the importance of whānau groups, often referred to as 'kaupapa-based whānau', where members share a common kaupapa, rather than a common heritage) such as kaumātua whānau support groups, for linking people together as these may create powerful connections educationally with family, whānau and community.

Adding power to minority voices

Cultural, social, political, health and economic issues are all external forces acting on kaumātua, family and whānau in their community, promulgating certain types of responses and behaviours that can keep a problem from changing (Barber, Boyd, et al., 2011). R. Doughty, Poppe, and Rolleston (2016) take serious issue that in New Zealand, particularly in an environment where Māori have poor health outcomes, acknowledging culture is key to engaging in research that empowers Māori participants. That being so, in an effort towards ensuring the power of self-determination for Māori is not diminished, it is the acknowledgement of cultural context that is key when researching with Māori.

Those in control of research have the power not only to define problems, but determine the way in which outcomes are presented and perceived. Certainly, within the Māori community, is a strongly held belief that the value of social science research outcomes for Māori have been, "far from evident" (Spoonley, Teariki, & Tomoana, 1992, p. 6). In the research of Teariki, Spoonley and Tomoana (1992) for instance, negative attitudes were identified to be held by Māori, towards research that has involved their community (Table 4):

Table 4: Māori attitudes towards research (Spoonley et al., 1992)

Māori experiences of research
• emphasis on negative statistics; • an exercise and tool of control; • something that only non-Māori do; • personal career gain.

Also in research involving Māori, an emphasis on deficits (what a person or community is lacking) was identified by Spoonley et al. (1992). Expressly, that the deficit view was at odds with those in the Māori community who embraced a strength-based perspective, and the belief that Māori people, their families and whānau have strengths, resources and the ability to recover from adversity. The latter being opposed to emphasising vulnerabilities, and deficits, which lead to a cycle of victim blaming followed by a reliance on experts, rather than allowing people to act as experts on resolving problems, or opportunity to participate, take control and learn and learn from these.

In addition, Spoonley et al. (1992) identified that Māori saw research as an exercise and tool of control of local and national government over themselves. For example, use of research that seeks to control and validate knowledge concerning Māori, that is dominated by Western frameworks. Precisely, the positivist paradigm that focused on descriptive, explanatory, predictive research inquiry, assumed that there was a 'single' objective reality, best identified through experimentation.

Scientific objectivity, which expresses the idea that the claims, methods and results of science cannot be influenced by breaking down the reality of perspectives into smaller sections, is at odds with a Māori holistic view. In particular, that conveys the importance of balance, and idea that if one of these key dimensions is missing or damaged then the resulting imbalance may lead to illness. The outcomes of which were seen as having been utilised to justify policies that impacted negatively on Māori welfare (Spoonley et al., 1992).

Additionally, Māori experience of research, was of an activity that only non-Māori did. Not only did non-Māori tell Māori things about their own community that Māori already knew, but similar to other indigenous peoples Māori witnessed first hand, disempowerment through research engaging dominant Western paradigms, with claims-making to universal truth. Likewise, non-Māori researchers entering Māori communities and conducting research in a manner, that ignored Māori values and processes has lead to negative attitudes, resulting in adverse outcomes or experiences for Māori participants and their communities (Spoonley et al., 1992).

Finally, Māori also saw research as something that non-Māori did for personal career gain, regarded as intellectual exploitation, appropriation and a further abuse of Māori in the interest of non-Māori. Consequently, there has been an ever increasing desire among Māori people and Māori researchers alike, to access methodologies that reflected Māori realities and a Māori worldview. That being so, kaupapa Māori theory has emerged out of a desire by Māori to 'decolonise' the research process (Tuhiwai-Smith, 2012).

Kaupapa Māori has resulted in research and evaluation being undertaken by Māori, with Māori and for Māori, and informed by tīkanga Māori (cultural principles), or Māori ways of doing things (Tuhiwai-Smith, 2012). Battiste (2013), a Potlotek (First Nations In Nova Scotia) academic summed up indigenous resistance movements and the renaissance of indigenous language facing extinction as being about, "reconciliation from the Eurocentric institutions that have marginalised indigenous knowledge systems" (p. 2). Similarly, Lee, Pihama, Tuhiwai-Smith, and Taki (2004) argued that "the marginalisation of Māori has meant the privileging of Pākehā knowledge over Māori knowledge" (p. 8).

These observations concerning self-interest were reiterated by Tuhiwai-Smith (2012) and Taboada (2011) about education models, of the need to critically examine issues of privilege, oppression, and power dynamics related to ethnicity and outcomes with research that operationalises these recommendations. When analysing the root of the problem, complexities that impact on the lack of available health research involving kaumātua, are not only likely to be complex. González-Chávez et al. (2016), Berbin et al. (2016), and Kumarasinghe, Perera, and Perera (2014) who all worked with indigenous participants living with osteoarthritis, also note a lack of culturally appropriate research models that enable reflecting on relationship and capacity building, that is meaningful to their communities.

A lack of lack of culturally appropriate assessment tools from an indigenous perspective, has not gone unnoticed. Numerous indigenous researchers have questioned the applicability, relevance and usefulness of adding external resources, if they are not underpinned by values, principles and philosophes that complement people's strengths and goals (Aspin et al., 2014; Boulton, Gifford, & Potaka-Osborne, 2009; Penehira & Pihama, 2005). Not only may research in cultural competence in healthcare and rehabilitation services generate feelings of inclusion and empowerment, but osteoarthritis-management may also improve because of the familiarity of the material.

An example of inclusion and empowerment was noted more recently. A small New Zealand study (Griffith & Warbrick, 2018) showed that sedentary Māori men's motivation was more likely towards being physically active with resources that are culturally tailored. Similarly, Bishop (1996, 2005) advocated for research methodologies that reflected Māori realities and a Māori worldview.

Of interest to the present research, Māori models of health and respect for a Māori worldview, may provide further insight into the needs of kaumātua with osteoarthritis. For instance, culturally tailored research evaluation that seeks to respond to Māori demands for self-determination, by identifying the locus of power within knowledge systems. That being so, it is more likely that information which is provided to research participants in such a way that promotes power-sharing in relationships and decision-making, will pave a pathway for enhancing and empowering participants.

Bishop and Glynn (1999) expressed that Māori research does not necessarily exclude any particular methodology. Bishop and Glynn (1999) point out there being issues of power, which are rather significant[53]. What is more, that the use of Māori approaches to research with Māori, more readily provide a basis for collaboration and power-sharing.

Who gets to exercise power?

In order to critique or address social inequalities and health disparities, Robson (2009) argued on discrimination and Māori health. Principally, that it was first important to understand the bigger picture and ask who gets to exercise power? Knowledge is one form of power, but it is created within a broader social system (Foucault, 1980; Habermas, 1968).

Foucault's (1980) ideas, argued that all knowledge was constituted and socially constructed under conditions of power. Similarly, Habermas (1968) contended that domination was an obstacle in the pursuit of true knowledge. Both Foucault and Habermas according to Anttonen (1999) criticised distorted forms of domination and power.

Comparatively, I too have been reminded about imperatives of power early on in the research design, during conversations with peers, working within the healthcare system. Notably, peer experiences of the gulf between the dominant non-Māori (mainstream) perspective of wellbeing and Māori aspirations (Journal entry 15/02/14). Mostly research uses a universalising approach to conceptualise wellbeing, in order to account for differences among groups and in the process, consideration of local Māori understandings of wellbeing are neglected (see, Russell (Pere) et al. (2013) for more detailed discussions).

Given that a goal of the present research is to produce knowledge that promotes fair distribution of resources pertaining to osteoarthritis-management, these types of considerations were valuable insight into understanding how power operates. To understand how power operates, Te Awekotuku (1991) suggested looking at theories underpinning research, for unlocking understandings about its use within a variety of applications that are ultimately about, "control, resource allocation,

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[53] The inference is that partnership and collaboration afford a degree of power-sharing, therefore researchers need to consider frameworks for working with communities (Padilla-Díaz, 2015; Skea, 2016).

information and equity … it is about power” (p. 13). Similarly, Aroskar (1998) noted that resource distribution by a ‘social construction of a condition/political economy’ view of health, can be best understood by the power and class positions held by key organisational players’ and the actions of individuals (Aroskar, 1998).

The nature and characteristics of power are central to healthcare distribution (S. Glover & Rivers, 2008). As discussed by Dew, Howden-Chapman, and Matheson (2017):

> … differences in capacity, knowledge, resources and access to political processes are some of the places where power imbalances arise between government and community (p. 8).

The effects of these differences can be seen in the extremely powerful and enduring relationship between health, social and economic inequalities (Dew & Kirkman, 2002). The main points of discussion in the section that follows, focus on understanding how power asymmetries are constructed. In effect, consideration is given of the ways in which local Māori understandings have become obscured by inter-ethnic power relations at a local level.

Sharing power and control

Māori researchers and practitioners have, since the 1980s, been leading the way in reclaiming Māori knowledge, culture, processes and methodologies of ‘knowing’. Bishop and Glynn (1992) for example, promoted the concept of research as empowerment, of the community and its members. Such as where research is undertaken ‘with’ a community, than ‘on’ a community, requiring researchers and community stakeholders to share power and control of decision-making throughout the process

These conceptualisations of sharing power have informed my approach to the present research. Similarly in my experience at the grassroots level, is that we (healthcare practitioners) have the capacity to change the balance of power and promote patient empowerment by recognising the patient, family and whānau as experts by their own experience. Empowering resources, may in turn enhance a patients' internal locus of control, resilience, coping skills, and self-management of symptoms related to chronic disease.

In so far as resilience is concerned, Jackson, Parsons, and Sutherland (2011) commented in their background report to the Native Flora and Fauna Claim (WAI 262), concerning the challenges which Māori land rights activist Saana Murray and her people (Ngāti Kuri) endured. The subsequent resilience of Māori in the face of the Crown depriving access to their own lands, threatening their survival, and the resurgence and revitalisation of indigenous customs occurred as a result. In many ways, Murray's resistance echoed the reasons behind Māori preferences for self-determination, that continues to highlight contemporary struggles.

Similar to Murray's assertions (Jackson et al., 2011), Aspin et al. (2014) argued that 'resistance' was a more suitable term for Māori (than 'resiience'), for alluding to decolonisation and collective 'fight-back'. Notably, resistance was discussed as referring to the end of further discrimination, in the process of exposing the inequitable distribution of power resulting from colonisation. On top of that, Aspin et al. (2014) argued that resistance resonated with indigenous views and aspirations, and the subsequent struggle for equality, which in turn generated new materials, and possibilities for formulating indigenous resistance.

Also relevant to both patient healthcare management and Māori research development, are principles that can promote power and control. The first, 'Community involvement' throughout the research process, is driven by a collaborative effort involving community (Bishop, 1996), as opposed to deliberately repressing certain ideas or issues, where there is a vested interest in maintaining the status quo (A. Durie, 1998). Moreover, a 'problem-solving focus' infers that decision-making would need to be a collaborative process between community groups and researchers, for the purpose of creating new knowledge for the health of the community (Hudson, 2004).

Another focus in the literature concerning Māori research development, is 'problem-solving', that not only seeks to share decision-making but pursue new knowledge creation. Especially, that knowledge creation seeks to understand practical community issues, in order to bring about change and allowing development of new ways of thinking, behaving and practicing. A problem-solving focus contrasts the view of there being an open market of ideas (a pluralist liberal democratic view), where power is accessible to everybody and those who choose not to exercise power and participate, opt out by indifference in choice behavior (Hudson, 2004).

One more focus in Māori development literature is the key tenant of societal change and sustainability, that seeks to bring about transformation and change. Notably, that capacity of the community is enhanced through the acquisition of new skills and knowledge, related to the research (Cram & Mertens, 2016; Pihama, 2010; Tuhiwai-Smith, 2013). For example, that the outcomes of research would be ongoing in order to sustain a healthy community, with initiatives that result in positive outcomes for Māori, such as improved services, more effective use of resources; more informed policy development and increased knowledge (A. Durie, 1998).

The latter concept concerning research that seeks to support healthy community and positive social outcomes for Māori challenges the view of power, that certain ideological interests should be favoured, and in the process become so normalised that they are unquestioned (Moewaka Barnes, 2000).

Cultural humility

Conceptualisations of power also apply to my researcher role in the present study, and my background as a healthcare practitioner in the Hawke's Bay community. Both roles which require working with kaumātua, naturally relate to an attitude of hūmarie (humility, being humble or down to earth) say Roche, Ruru, and Waitoki (2017). Murray-García and Tervalon (1998) conceptualised the virtue of cultural humility, as requiring the health professions, to effectively confront conceptualisations of power and inequities in our society that result in disparate health outcomes, based on various intersecting areas of diversity, such as ethnicity, ability or disability.

These conceptualisations of power have informed my approach to the present research. For reasons including, that so often within my experience at the grassroots level as a healthcare practitioner, mainstream society has tended to emphasise individual lifestyle choices. For Māori, these framings of increasing individual, personal responsibility can act to silence their experiences, histories and worldviews, particularly when structural issues underlying stigmatisation and discrimination are downplayed or ignored (Hodgetts, Masters, & Robertson, 2004; Pihama, 2011; Tuhiwai-Smith, 2012).

From my grassroots level perspective for instance, the worldview of 'self' in the contexts of collectivism and individualism can affect relationships between healthcare practitioners and kaumātua, particularly as it is known that Māori ofen make decisions collectively, frequently as a whānau (Mead & Mead, 2003; T. Walker, 2017). Group decision-making may be complex and time-consuming, and frustrate a healthcare practitioner from the individualist perspective, to whom individual rights and autonomy are key to decision-making. For instance the healthcare practitioner that uses direct language with good intention, "you have the right to make your own decision about osteoarthritis-management ...." may find that such an approach is perceived as disrespectful with potential for shame and/or is blame oriented, effectively silencing kaumātua.

Such misunderstandings have safety implications, if kaumātua choose not to follow healthcare advice, or in perceiving judgment, opt to withhold information that is critical to care. The opportunity for trust to develop may be lost, with possibly longer-term consequences on the wider whānau, resulting in avoidance of healthcare with poor outcomes for kaumātua. By acknowledging that as a healthcare practitioner one may not have all the answers is a start to cultural humility, an approach to health care based on humble acknowledgement of oneself as a learner when it comes to understanding a patient's health and health care experience (Murray-García & Tervalon, 1998).

Frameworks for decision-making

Mason Durie (1996) recognised the importance of patient-centred care and research with kaumātua, that operated by Māori-centred frameworks. Hardison (2011) also advocated the use of frameworks which helped to change the balance of power through decision-making, that supported and enabled, yet did not over-ride community-level processes and structures. Bishop (1996) proposed the use of collaborative research and approaches that were centred on community, and Hardison (2011) drew attention to, "mutually-negotiated research agreements that served to strengthen community goals" (p. 34).

Fundamental to a Māori-centred approach to research, collaborative power-sharing processes, derives primarily from Māori epistemologies of local wisdom that incorporate 'whakawhānaungatanga':

> … the process of establishing family (whānau) relationships, literally by means of identifying, through culturally appropriate means, your bodily linkage, your engagement, your connectedness, and therefore, an unspoken but implicit commitment to other people (Bishop, 1998, p. 203).

In addition to discussing these power-sharing processes, Bishop and Glynn (2003) make a point of emphasising that relationships are not simply about making friends. They argue that researchers must be self-aware of their position within the relationship and mindful of their need for engagement in power-sharing processes. Sharing power to achieve collaboration can make a contribution to the ongoing task of reducing inequalities, such as in the manner of support that healthcare practitioners are able to provide (Ministry of Health, 2016c).

Hardison (2011) recognised the importance of research frameworks (frameworks) that enabled collaborating with indigenous communities. Similarly, many Māori authors have discussed the importance of establishing a relationship of trust and accountability when working with and particularly when researching with Māori communities. A long legacy of "researching on" Māori (Tuhiwai Smith, 1991, p. 8), resulted in Tuhiwai-Smith (2005) describing the troubled significance of a deep lack of confidence, mistrust, and suspicion of researchers by Māori communities.

Despite mistrust posing a barrier to conducting research with Māori communities, it also provides a distinct opportunity to examine factors related to trust development. Tuhiwai-Smith (2013) for instance, described conceptual research frameworks (precisely qualitative research) as being located within an, “age and time of … uncertainty” or risk. In other words, a failure to understand the intricacies of power imbalance, trust and research with historically subjugated populations was a failure to account for power dynamics that may perpetuate, “uncertainty”, or risk and oppression (p. 102).

As a healthcare practitioner working at the grass roots of my community, I have sought out research that is applicable to my practice. Yet, I find myself standing on, “tricky ground” (Tuhiwai-Smith, 2005, p. 85), knowing and appreciating Māori-centred methodology and its associated worldview and literature surrounding osteoarthritis-management amongst indigenous peoples, that has tended to originate out of America. Given the paucity of research evidence pertaining to the experiences of kaumātua with osteoarthritis, guidance on the conduct of such a study was equally limited.

Much of the unfolding process of creating through painstaking effort, of my own methodological space, has been developed away from the ‘colonial gaze’, that has marked out much of the field of self-management support literature. As an emerging researcher in the disability field of health, I can only describe creating methodological space as an uncertain practice, that is marked by a plethora of contradictory and competing discourses. I liken retrieving methodological space for my research to Tuhiwai Smith’s (2005) analogy of standing on ‘tricky ground’. As a methodological space where opportunities can flourish, offsetting potential liabilities that may lead to change, by identifying what is positive, and working to make it happen.

Standing on ‘tricky ground’ is pertinent for focussing on the complexity, uncertainty and shifting nature of, not only the ground upon which I work as a researcher and healthcare practitioner. It also refers to my community, the epistemologies and understandings of kaumātua concerning their condition, the everyday practices they engage in, and the effect that the present research may have on the participants as they tell their stories. In that sense, the knowledge that I pursue also exists within a transitional space, the space between kaumātua living with osteoarthritis and the world, and the part of our world that lies beyond language, and the effects of impairment at an everyday level.

With a contextually, conceptualised framework that is grounded in Māori-centred theory, the present research seeks to validate the everyday experiences of kaumātua living with a chronic condition, as a kind of response. By employing a Māori-centred approach to research, enables me to share my experiences as a healthcare practitioner and researcher in my community, of working on ‘tricky ground’. By openly reflecting on the complexities impacting my research, and through sharing my intersubjectivities and personal observations, is a commitment to exploring kaumātua understandings of osteoarthritis and how they negotiate the experience of disability in their everyday lives.

Kaupapa Māori theory

In the previous section, implicit was challenging mainstream ideas about what constituted knowledge, concerning Māori ways of knowing and being, that are related to everyday living contexts, of the real-world (Tuhiwai-Smith, 2005). In the present section, an example of Māori knowledge building theory and principles, that seek to connect research up with the everyday living contexts of the real-world is offered. Consequently, the present research draws on two approaches - Māori-centred research, which emerged from the field of mental health and wider health fields (Durie, 1996)[54] In addition kaupapa Māori theory is the second approach, which grew out of the experience of Māori within the education sector, particularly within the kōhanga reo and kura kaupapa Māori school movements[55] (Hinangaroa-Smith, 1997c; Tuhiwai-Smith, 1999) that is utilised within the present research concerning the everyday experiences of kaumātua with osteoarthritis.

Similar to a Māori-centred approach, according to kaupapa Māori theory, research should be accountable to the people being researched and the Māori community in general (Bevan-Brown, 1998; M. Durie, 1998b; Tuhiwai-Smith, 2013). Māori people and Māori communities are prioritised in the research. Notably by way of strategies and techniques, ensuring benefits accrue to the communities concerned, directly (Hinangaroa-Smith, 1997b). Kaupapa Māori is therefore a, "philosophy and practice of being Māori" (Hinangaroa-Smith, 1992, p. 1).

Tuhiwai-Smith (1999) also pointed out that kaupapa Māori research was clustered around issues of identity concerning 'being Māori', and identifying as Māori. Such a position was noted as, "anti-positivist[56]", grounded in Māori worldviews (p. 186) and essentially political:

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[54] "Māori-centred" was coined as a term at the Hui Whakapiripiri (Hui) in 1996. The Hui (gathering) was primarily focussed on strategic directions for Māori health research. At that gathering, Mason Durie described Māori-centred research as an approach which stood out from mainstream medical approaches to research for Māori. The approach prioritised the health of Māori people, their culture, knowledge contemporary realities. Leading up to the gathering, there were several instrumental developments which propelled Māori health development, being world-wide shifts by indigenous peoples, towards self-determination and greater autonomy, and changes to legislation and policy within Government Ministries recognising the Treaty of Waitangi (Māori worldviews and understandings of knowledge were recognised as unique and distinct) (Creswell, 2013; Durie, 1996; M. Durie, 1998b; Tuhiwai-Smith, 2012).

[55] The kōhanga reo (pre-school language nests) movement and kura kaupapa (Māori school state schools) have been driven by Māori, with an emphasis on a total Māori-language immersion setting and involvement by whānau, after Māori leaders began to recognise the dangers of the loss of the language.

[56] Anti-positivism assumes the position of being against mainly quantitative and aligned to experimental methods of research, which emphasise a deductive approach (that there is one objective reality). For instance, researcher testing of an existing theory or hypothesis (J. Clandinin, 2016).

> [Kaupapa Māori] creates the political space to enable the legitimate study and continuance of Māori language, knowledge and culture (it is not a study of mātauranga Maori). Kaupapa Māori theory makes space for Māori to legitimately conduct their own studies of mātauranga Māori [a Māori way of being] in their own terms and own ways. In this sense kaupapa Māori is not a synonym for mātauranga Māori (Tuhiwai-Smith, 1999, p. 11).

As a political strategy kaupapa Māori theory sanctions 'space' within a theoretical work that is concerned with a Māori way of being. Similar to Tuhiwai-Smith's (1999) explanation, mātauranga Māori was described by Kia Eke Panuku (2016) as, "a Māori way of being and engaging in the world" (p. 1)[57]. In so far as assumptions, propositions and accepted facts (theory) are concerned (Swanson, 2013), the present research draws on Te Ahukaramu Charles Royal's (2008) assertion that Māori knowledge (mātauranga) supports, explaining the different aspects of the world around us (Royal, 2008)[58].

Broader than a paradigm

Tuhiwai-Smith (2013) argued that kaupapa Māori research is, "both less than and more than a paradigm". Kaupapa Māori theory frames the way of seeing the world, and organising ourselves within it, as represented by the questions that we ask and solutions sought. Not only may kaupapa Māori theory be viewed as a movement of resistance that challenges norms and assumptions, it is also about possibility and desirability of change for revitalisation (p. 190).

Eketone (2008) noted that kaupapa Māori theory, was much about 'being', as it was about 'acting' as Māori, questioning the right of narrow Eurocentric interpretations of theory, to dominate or exclude Māori (Eketone, 2008). Where identities, languages, and cultures of all Māori were accepted in their own right (Hinangaroa-Smith, 1992). Eketone, Gibbs, and Walker (2006) also supported that kaupapa Māori was a broad, pro-active movement of Māori political discourse, at the same time questioning mainstream notions of knowledge, culture and research.

Similar to Eketone's criticisms concerning the concept of knowledge, Ranginui Walker (1980) noted that many Māori communities have become increasingly reluctant to engage in research, because of the damage that had been done. Māori

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[57] Mātauranga Māori is related to, "a Māori way of being and engaging in the world" (Pihama, 1993, p. 23)[57]. In so far as assumptions, propositions and accepted facts (theory) are concerned (Kia Eke Panuku, 2016, p. 1), Te Ahukaramu Charles Royal (Swanson, 2013) asserted mātauranga Māori helps to explain the different aspects of the world around us (2008)[57]. For that reason, mātauranga Māori is often used synonymously with wisdom, knowledge, comprehension, and understanding of all things (visible and invisible) existing in the universe (Royal, 2008)[57].

[58] In that process, a person obtains knowing about and understanding, some of the different purposes, meanings, and ways of learning about our world which can be transferred from one person to another (Hodges, 1994; New Zealand Qualifications Authority, 2007; Sadler, 2007; Williams, 2008).

communities were dissatisfied with the lack of control over the research process or being subjected to the, “happy hunting ground of academic” researchers, ‘dropping in’ to take what they require from the community and decamping. Often Māori are not in a position to challenge the findings of published research and there is no accountability on part of the researcher (p. 231).

Given the historical context of research concerning Māori peoples, negotiating entrance into the community could become a difficult and arduous process, with Māori arguing that research must be a process of respect, dignity and inspiration or empowerment. Particularly for those groups who have been marginalised and disempowered by research (R. Walker, 1980). Durie (1996) argued that a Māori-centred approach was an important research direction for building on local knowledge, strengths and resources. It also often emphasises the value of bulding close community networks and collaborating with community.

Bishop (1999b) also maintained that much of the recent development of kaupapa Māori theory, had been sourced in processes, that had misrepresented Māori experiences, and sought to deny Māori their own voice and authenticity. Bishop (1999b) asserted that the New Zealand research tradition had consistently maintained colonial values, which had undervalued Māori knowledge (Bishop, 1999b). That impetus had been about promoting and enhancing the learning practices of colonisers, through economic, political and cultural (neo-colonial) paradigms.

Bishop (1999b) gave the example of research approaches with an ideology of cultural superiority. A preoccupation by contemporary non-Māori researchers with value neutrality and objectivity, has effectively distanced Māori people from participating in the construction, validation and legitimation of knowledge. As a result, Māori people have become increasingly concerned with products of research implying that Māori culture is unable to cope with, “human problems … in human terms” (Bishop, 1999b, p. 1).

These approaches to research, have prevented not only, “the development of power-sharing processes”, but also the recognition of, “diverse cultural epistemologies”. On that account, kaupapa Māori theory has emerged as a Māori, “response to the neo-colonial dominance of research” (Bishop, 2011, p. ix), furthermore a philosophy, a theory and practice concerned with ‘being’ (Hinangaroa-Smith, 1992). In other words, kaupapa Māori theory validates a Māori worldview by asserting that to be Māori is taken for granted knowledge, which is not only Māori owned, but also Māori controlled (Nepe, 1991).

Similary, Eketone (2008) maintained that kaupapa Māori theory was more than a, “philosophy and practice of being” that aligned with critical theory, it was a theory of of social change (p. 2). Eketone (2008) referenced the work of Graham Hinangaora-Smith, Linda Tuhiwai-Smith and Russell Bishop for being incorporated within the, "Marxist/socialist grand theoretical tradition seeking to challenge and transform oppressive structures" (p. 1). Eketone (2008) noted that Graham Smith aligned significant components of kaupapa Māori theory, toward critiquing and changing society as a whole (critical theory).

Eketone (2008) detailed these significant components of kaupapa Māori theory and critical theory as dominant, Western hegemonic forces that marginalise Māori knowledge ("conscientisation"). These include pro-active responses to oppressive structures with social change ('resistance'), and; applying the lessons learned ('reflective' change) (Eketone, 2008, p. 2). Eketone (2008) offered an alternate positioning: a 'constructivist' understanding and knowledge of the world, that valued multiple ways of constructing society and reality, than defining itself in opposition to Western knowledge systems.

A constructivist approach to knowledge

My interpretation and understanding of constructivism aligns with that of Bishop's (1994) stance. Expressly, that initiating empowering research with Māori is a, "culturally specific discursive practice" (p. 184), and individual construction of meaning about one's position. Constructionism is bound within the current values and assumptions of society and the discipline being practised (MacKenzie, Topaz, & Troutman-Jordan, 2014; Munafo, 2016; Olusegun, 2015), as well as by the culturally bounded values and experiences that I bring with me.

For case in point, the present research sought to explore the everyday experiences of kaumātua with osteoarthritis. That the research participants' identify pertinent issues, such as adversities and challenges which they had faced, and resources for osteoarthritis-management from their own personal experiences, was therefore a necessary requirement . The relevancy of a constructivist framework to the present study engaging kaumātua with osteoarthritis, was thought appropriate for a number of reasons.

What is more, constructivism is based on the tenet that the reality which humans perceive, is created by them (Driscoll, 2000). Constructivism implies that meaning is ascribed to experiences and situations by those living them, rather than meaning being ascribed by outside others. The use of the constructivist approach in the present research, allows the voices of kaumātua (their) to be heard, in the process of me (the researcher) setting aside my own biases and perceptions, in order to enter their interpretive worlds.

Additionally, the constructivist approach focuses on meaning, that particular events hold for an individual. The significance of events in people's lives may be determined by looking at the 'what' and 'how' of meaning. Context is critical to meaning, and the situation in which events occur has a formative effect, on the meanings that kaumātua ascribe to them. Following Driscoll (2000), an understanding of culture informs the prsent thesis, with culture being viewed as a distinct and stable set of shared meanings, making kaumātua participants of the present study what they are, formulating their identities and lives in their own terms.

Another benefit of using a constructivist approach in the present research, follows Driscoll's (2000) recognition of individuality and diversity in life experiences. For example, experience of ageing or of being Māori and managing osteoarthritis. A constructivist approach puts the focus on the choices kaumātua make in constructing their realities about osteoarthritis-management. As a result, constructivism incorporates there being multiple truths in the lives of those being studied, uniting a deeper, richer understanding of life experience, provided through the qualitative research methods used in the present study.

Finally, constructivism complements the theoretical base of the present research. A Māori worldview of wellbeing incorporating physical, spiritual, mental, and family health, taking into account social contexts, historical effects and the individual stories of kaumātua, as related to the process of managing a chronic-condition. Over and above inter- and intra-individual differences in osteoarthritis-management, can a contribution to heterogeneity in the experience of being older, Māori and living with a chronic condition be made (Driscoll, 2000).

The adaptation of each participant, would be affected by internal and external resources, that are available at a particular point in time. These resources comprise a reserve capacity that facilitates adaptation, when one is faced with challenge or adversity. An adaptation lens ensures the focus affirms reparative potential and strategies for Māori communities, drawing on kaupapa Māori theory, inducing sensitivity to the Māori worldview.

Kaupapa Māori principles

In previous sections, I have argued that healthcare literature concerning chronic disease and ethnicity, has prioritised a medical and epidemiological perspective. In the process, an indigenous perspective is often denied. Determinations of resistance and denial within academic discourse leaves indigenous knowledge invisible and also limits any further theoretical or practical evolvement of theories to guide osteoarthritis-management with kaumātua.

These conversations have lead to me pursuing kaupapa Māori theory as a methodology strategy. Hinangaroa-Smith (1997a) argued kaupapa Māori, was a successful “intervention” for Māori (p. 100). Hinangaroa-Smith (1997a) made specific reference to kaupapa Māori as an ‘intervention’ in the sense of there being a need, to bring about specific positive transformation in the experiences and positioning of Maori. In my research approach, as defined by various Māori academics, educationalists and advocates, I am going to apply a number of kaupapa Māori principles (principles).

These principles have potential for not only decolonising the research process, and centering Māori knowledge across and within various sectors, including healthcare and all aspects of society (Table 5, below). Throughout the research process, these principles were activated, as I sought to transform interactions and position kaumātua, Māori customs and aspirations centrally:

Table 5. Kaupapa Māori principles (Hinangaroa-Smith, 1997a, p. 100)

Kaupapa Māori principles	
Taonga tuku iho	Cultural aspiration
Tino rangatiratanga	Self-determination
Ako Māori	Culturally preferred practice
Kia piki ake I ngā raruraru o te kainga	Socio-economic mediation
Whānau	Extended family structures
Kaupapa	Collective philosophy
Te Tiriti o Waitangi	Treaty of Waitangi
Āta	Growing respectful relationships

Table 5 above, provides a simple framework, with a description of principles and concepts and their application to the study. These principles were applied in a considered and deliberate manner, to guide the study throughout. To that end, some principles were more relevant to certain aspects of the research than others. However, each principle was threaded throughout the study, and contributed to the overall rigour and integrity of the research.

The first kaupapa Māori principle, ‘Taonga tuku iho’ (cultural aspiration) referred to legitimising the validity and relevance of Māori culture (Hinangaroa-Smith, 1997a; Pihama, 2001). A focus on meeting the needs and aspirations of Māori, provided an overall cultural framework, utilising tīkanga (cultural principles), use of te reo Māori where possible, and other cultural processes that enhanced the transmission and sharing of knowledge. For example, kānohi-ki-te-kānohi (meeting face to face), reaffirming cultural links, the gifting of koha for the participants' time and effort, and a strong involvement of whānau for support.

As well, 'Tino rangatiratanga' (self-determination) is the kaupapa Māori principle that reinforced the goal of fulfilling the desire for Māori to control their own culture, aspirations and destiny. A self-determination focus incorporated the idea that Māori research outcomes were better achieved when research is conducted by Māori (Hinangaroa-Smith, 1997a; Pihama, 2001; Tuhiwai-Smith, 2013; S. Walker, 1996). The application of Māori autonomy in the present research it was hoped, would provide an advancement in 'Tino rangatiratanga' with the construction of an osteoarthritis-management resource, representative of kaumātua responses.

That being said, the present thesis seeks to add to the established and substantial body of evidence and discourse surrounding osteoarthritis-management for kaumātua, family and whānau, appropriate to making a contribution to Māori development. What is more, 'Ako Māori' (culturally preferred practice) is the kaupapa Māori principle that acknowledged learning practices, inherent and unique to Māori, as well as those that are often preferred by Māori. A focus on culturally preferred practice, incorporated cultural communication and socialisation throughout the research process (Hinangaroa-Smith, 1997a). For example, te reo Māori was used with kaumātua where appropriate while interacting during 'kānohi ki te kānohi' (such as throughout interviews in each participant's tūrangawaewae (home)), and focus group (in a Māori space and place), framed by tīkanga Māori (cultural principles).

Also, socio-economic mediation ('Kia piki ake I ngā raruraru o te kainga') is the kaupapa Māori principle that asserted a need for kaupapa Māori research to be of positive benefit to Māori communities. Cultural knowledge and customs were incorporated, alongside social support and involvement of the community in the process of conducting the research (Hinangaroa-Smith, 1997a). Applying the principle of socio-economic mediation to the present research, supports potential of Māori derived initiatives concerning osteoarthritis-management, for making an impact on socio-economic issues.

As well, 'whānau' (extended family structures) is the kaupapa Māori principle which acknowledged that whānaungatanga (kinship, sense of family connection), was an integral component of Māori culture and identity. Relationships through kin and non-kin can be beneficial to the research process (Hinangaroa-Smith, 1997a; Irwin, 1994; Pihama, 2001; Tuhiwai-Smith, 2013; S. Walker, 1996). For instance within the present research, processes incorporating whānau guidance and kaumātua expertise, and as a result of the kinship structures akin to a Māori worldview. All of which enable seeking the advice and help from a number of Māori scholars and academics, pertinent to the research process and content.

What is more, ‘Kaupapa’ (collective philosophy) referred to the Māori principle recognising visions, aspirations and purpose of Māori communities. A collective philosophy required that the research aims of the present study, were aligned to collective desires and aspirations of the community (Hinangaroa-Smith, 1997a; Pihama, 2001). The present study for example, was initiated from a collective vision and input from myself, kaumātua, family and whānau, colleagues and academics, to explore the idea of adapting and managing osteoarthritis. To improve osteoarthritis-management of kaumātua, culture and whānau dynamics were acknowledged, as well as a collective view of political, social, economic, and cultural factors for improving health, equity and wellbeing of kaumātua.

Another kaupapa Māori principle, ‘Te Tiriti o Waitangi’ (Treaty of Waitangi) (1840) was applied in the present research, referencing the crucial document that continues to define the relationship between Māori and the Crown in New Zealand (Bishop, 1996; Pihama, 2001; S. Walker, 1996), by affirming both the tangata whenua status of whānau, hapū and iwi in New Zealand and their rights of citizenship. Consistent with three principles derived from the underlying tenets of the Treaty of Waitangi, the research was carried out in the following manner. First, the ‘Participation’ principle required that the present research would aim to promote pathways of access across the healthcare sector); also, ‘Partnership’, ensured that the research would be built on collaboration) and; ‘Protection’, called for a duty of the research to recognise and respond to Māori cultural beliefs, values and practices, all of these principles (‘Participation’, ‘Partnership’, and ‘Protection’) seeking to alleviate growing health inequalities.

Finally, the ‘Āta’ (growing respectful relationships) kaupapa Māori principle concerned negotiating boundaries, and working with the community in the creation of a safe research space, with corresponding actions (Pohatu, 2004). That is to say in the present research, I saw myself as an enabler or facilitator in my researcher role and not an ‘expert’, as is so often the case in my healthcare practice. For example, I attended kaumātua hui on a number of occasions, listening actively (āta whakarongo) as I sought the expert opinion and positions of kaumātua (their) concerning osteoarthritis-management as well as pairing with a kaumātua facilitator during focus groups, incorporating their knowledge into the data analysis and feedback into the construction of an osteoarthritis-rmanagement resource.

In addition, I drew upon the work of Pohatu (2004) throughout the entire research process, again as guiding principles. For example, ‘āta kōrero’ (communicating with clarity), āta mahi (working appropriately and diligently), āta noho (unprejudiced listening), āta tuhi (reflective writing for quality enhancement), āta whakaaro (reflective thinking and openness to possibilities). To some extent, these research behaviours closely align to Māori customs, such as aroha (respect) and manākitanga (kind support). Adopting these measures was invaluable to researching from a kaupapa Māori theoretical perspective.

Placing these elements at the centre of the research, aimed to demonstrate my learning and progress through adopting a Māori-centred research approach, by drawing on kaupapa Māori theory. Research with Māori is a valuable site, as more mainstream healthcare practitioners (practitioners/we) are attempting to work with kaumātua with chronic conditions. Broadly, these elements contribute to knowledge about how we may change when working with diverse needs of kaumātua, and what potential challenges and benefits might transpire from these encounters.

I have selected these elements, for especially reflecting the responsibilities of researcher' relationships, and how they should work with Māori communities. Also, adopting these elements during the process of working directly with my community, should increase the likelihood of generating a culturally appropriate osteoarthritis-management resource. As previously discussed in the literature review, M. Battersby et al. (2013) argued the benefit of working directly with an affected community.

M. Battersby et al. (2013) maintained that it was possible to develop and produce healthcare resources, that establish and drive or provide motivation to, privileging local knowledge and influencing personal and group agency (M. Battersby et al., 2013). On top of that, arguing that it was possible to develop and produce healthcare resources, giving power to privileging local knowledge, with important effect on personal and group agency (M. Battersby et al., 2013). For example, kaumātua who may often not be invited to engage in research, will be more likely to felt 'heard' when the principle 'kaua e māhaki' (do not flaunt your knowledge) is employed, as it asks the researcher to be consciously aware of the, "dynamics of power and the impact that this has on research, without grandstanding" (p. 33).

Of the theoretical principles that have been presented so far, each sought to rediscover osteoarthritis-management, through kaumātua sharing stories and conversations as well as relationships. The present research follows the work of Ko Awatea & Counties Manukau Health (2016), that argued the strength of their 'Manage better courses' was in providing, "a kaupapa (Māori culture) version" of self-management for Māori with chronic conditions. Similarly, the methodology of the present study sought to engage kaumātua with osteoarthritis in ways that honoured their realities and validated their experiences of managing a chronic condition.

Embracing real-world research

As noted, there are similarities between the foundations of Māori-centred research and kaupapa Māori theory, both developing out of experiences of exploitation and a desire to have self-determination. In that respect, the research methodology of the present study has similarities with real-world research developments internationally, from groups wishing to reclaim control over their research experiences (R. Armstrong, Crewe, & Gelsthorpe, 2013; Bodley, 2011; Gray, 2013). Similarly I engaged in the present research as a means of understanding how I might be able to help to chart a pathway of engagement in the care of kaumātua with osteoarthritis, that they could both endorse and apply.

Similar to the participants of the present research, I am of Māori heritage, born, raised and serving as a healthcare practitioner within my community. Correspondingly, in the process of conducting research, I was familiar with the community that I was working with. After some reflection, I realised the importance for my research design and methodology, the implications of which I proposed to address.

One issue for instance, was my known position as a healthcare practitioner in the community of the present research over the past decade. My positioning as a healthcare practitioner required me to endorse my role as the researcher, than a healthcare practitioner in the research. As well, at the grassroots level and from my own healthcare practitioner-perspective the present research needed to produce tangible outcomes, resulting from the experiences of kaumātua with osteoarthritis.

Identifying shared goals and outcomes in the form of a local resource, was intentional for strategic reasons. Namely that local realities could determine the types of responses to be pursued effectively by healthcare practitioners engaging in health promotion, such as myself. Understanding local realities was a response to the dearth of literature within my community, and lack of developed infrastructure for addressing issues of osteoarthritis-management.

Placing primacy on values, processes, and relationships (C. Barlow, 1994; Mead & Mead, 2003) enables recognising that osteoarthritis-management needed to send positive stories out from the community engaged in the present research. Utilising a holistic model of health would capacitate reframing osteoarthritis-management within the contexts of community strength and adaptability. All of which required time to develop relationships, until the trust, mutual respect and shared understanding, enabled proper acknowledgment and credit to the kaumātua participants.

In addition to these considerations my research approach acknowledges that Māori health status cannot be understood, away from the role of colonisation and history on sociocultural and socioeconomic development (Jackson, 1999; Tuhiwai-Smith, 1999). Recently, Glover and Muriwai (2016) argued the importance of decolonising healthcare promotion. What is more, that strengths-based representations of Māori (than deficit-style representations) such as in media illustrations needed to be adopted.

Positioning Māori health as a problem, with deficit explanations for the status of Māori wellbeing, without acknowledging historical and colonised context or structural explanations are examples. In contrast, these are so often recognised in research across Māori health. It makes sense then, that a mainstream medical model will be incapable of conveying a broader understanding of Māori health, especially if an individual's mental and physical needs are treated as separate entities.

R. Armstrong et al. (2013) talked about, "real-world research" being akin to endeavours that can be full of ambiguities and ethical compromise. Similarly, the present research would require me to harness ethical procedures and make clear, the boundaries of my role as researcher. For instance, that the research would not be about providing treatment or advice in the capacity of health professional[59], but directed by a clear research objective.

The intention of the present research is about privileging the voices of kaumātua with osteoarthritis about their Māori cultural understanding and experiences of managing osteoarthritis. At the same time the research is about helping to inform healthcare services engaging in osteoarthritis-management activities. The appeal of obtaining practical knowledge from kaumātua is that the research process draws from scientific and technical arenas, in a relational, intuitive, common-sensical context, and is particularly relevant in the field of chronic condition management.

Summarising Māori knowledge building

The present study employs qualitative research methodology based on the interpretivist paradigm, investigating the views, understandings, beliefs and experiences of kaumātua with osteoarthritis. Māori centred research that draws on the mātauranga of Māori scholars, experts, and kaupapa Māori theory have significantly influenced the approach to the current study. The approach allowed for research

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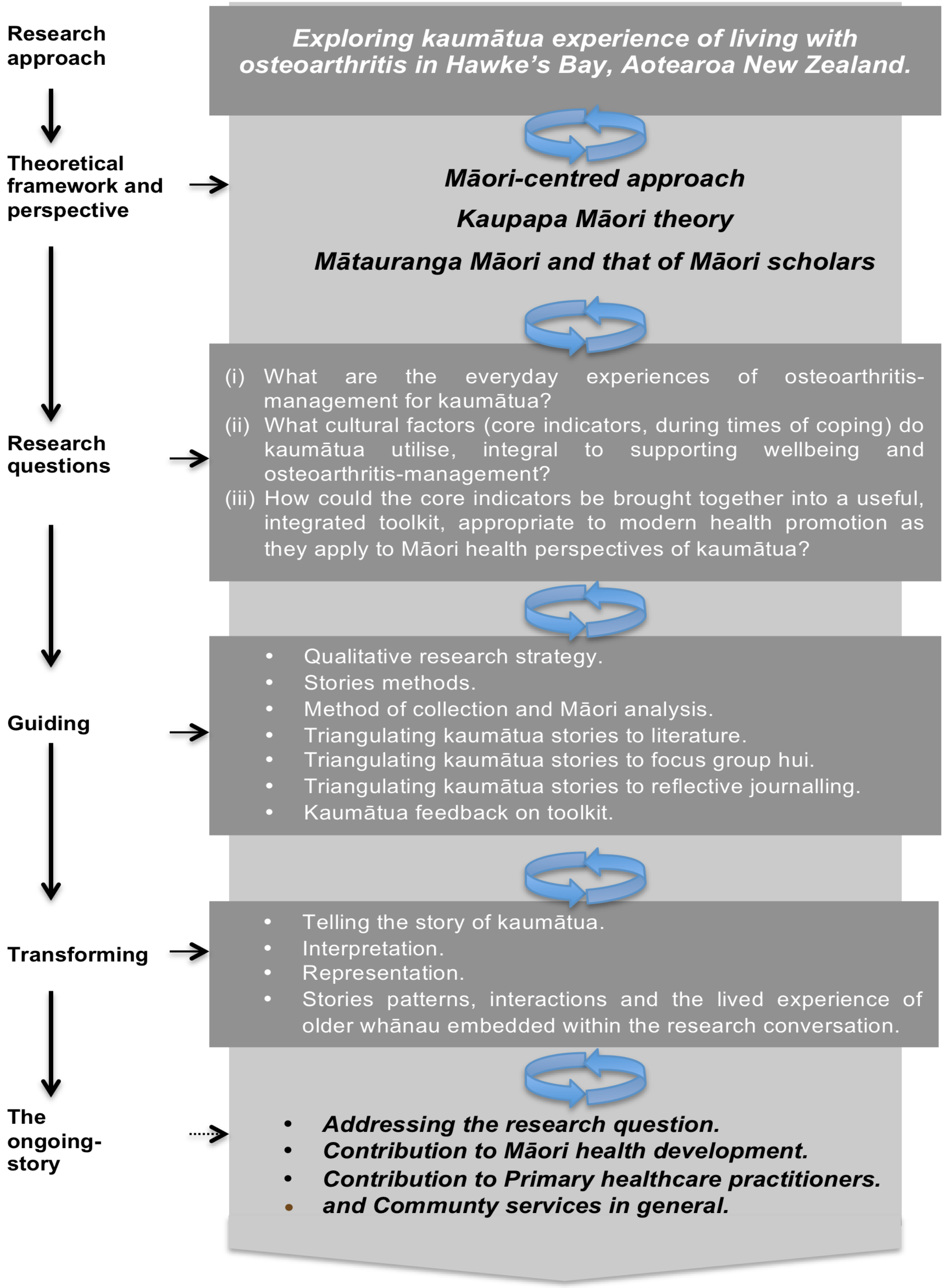
[59] To ensure that happened, I decided that I would be explicit about my professional background with the community at the outset and in all my engagements, in addition to obtaining adequate supervision throughout the process. To that end, I decided that I would talk about my professional background with each participant (that I am a health professional) and the present research would not intend to be therapeutic or to be an adjunct to my health professional role as a carer.

processes to focus primarily on Māori culture, knowledge and values, as it is intended that findings will contribute to Māori knowledge.

The dynamic interface between a Māori worldview and the interpretivist paradigm has also been discussed in the current chapter. The multi-layering of whakapapa, whānau, whānaungatanga, tīkanga, holistic health and wellbeing provides an analytical tool, for explaining the implications of the relationships studied. Moreover, central to the present research is the Māori ethic of Ngāti Kahungunu kaumātua, Wiremu Hodges. The following chapter presents the research design and methods for the study covering areas such as growing respectful relationships in the process of participant recruitment, data collection and analysis, ethical considerations and the rigour of the present research.

To summarise the dynamic nature of the research process, I have represented the framework of the research schematically (Figure 4, below). As depicted in Figure 4, I have purposefully attempted to emphasise the repeating cycle-like process of research as that which reflects the continuity of Bishop's (1995), "process of continually revisiting the kaupapa of the research" (p. 97). Accordingly, the conduct of the present research involves a continuous cycle of data gathering, analysis, and interpretation:

Figure 4. The research process (adapted from Denzin and Lincoln (2003)



Exploring kaumātua experience of living with osteoarthritis in Hawke's Bay, Aotearoa New Zealand.

Māori-centred approach

Kaupapa Māori theory

Mātauranga Māori and that of Māori scholars

(i) What are the everyday experiences of osteoarthritis-management for kaumātua?
(ii) What cultural factors (core indicators, during times of coping) do kaumātua utilise, integral to supporting wellbeing and osteoarthritis-management?
(iii) How could the core indicators be brought together into a useful, integrated toolkit, appropriate to modern health promotion as they apply to Māori health perspectives of kaumātua?

- Qualitative research strategy.
- Stories methods.
- Method of collection and Māori analysis.
- Triangulating kaumātua stories to literature.
- Triangulating kaumātua stories to focus group hui.
- Triangulating kaumātua stories to reflective journalling.
- Kaumātua feedback on toolkit.

- Telling the story of kaumātua.
- Interpretation.
- Representation.
- Stories patterns, interactions and the lived experience of older whānau embedded within the research conversation.

- ***Addressing the research question.***
- ***Contribution to Māori health development.***
- ***Contribution to Primary healthcare practitioners.***
- ***and Communty services in general.***

Chapter 4: Mahi tahi (Research design and Methods)

Introduction

Mahi tahi (collaborating) is a metaphor that speaks of working as one throughout the course of conducting the present study. The research design and specific methods used to collect and analyse the data are introduced in the current chapter, which begins by noting that within the research framework, a Māori-centred, qualitative research approach is adopted. In addition, the importance of spending time in and gaining the trust of the community are detailed, using Berryman's (2014) three strategies for collaborating with the community and Pohatu's (2004) principle of, 'growing respectful relationships'.

After introducing strategies for collaborating and growing respectful relationships that were utilised in the research, specific examples of the undertaking are presented. The remainder of the chapter is devoted to a discussion concerning my role as the researcher, and in my concluding comments I discuss the importance of ongoing self-reflection as a critical part of conducting research in my community. The chapter concludes by noting the dynamic interplay of collaborating with the community and contributing positively to Māori development not only underpinned the study, but were key principles in the success of the project.

A Māori-centred, Qualitative research approach

As Denzin and Lincoln (2000) point out, qualitative research focuses on the social world of subjective realities, where understandings of reality are negotiable to interpretation. It also employs interviews and focus groups, enabling readers to appraise the significance of the meanings (Cardno, McDonald, & Rosales-Anderson, 2017; Denzin & Lincoln, 2000), the methods of which 'talk back' with creation of space, to ensure voices of the marginalised are heard (Denzin et al., 2008b; Schroeder, 2014).

Therefore, qualitative research aligns well with the retrieval of space, which the emancipatory purposes of kaupapa Māori theory seeks (Denzin et al., 2008b; Pihama, 2010; Tuhiwai-Smith, 2012), and Māori-centred research (C. Cunningham & Durie, 1988; Durie, 1996), equally. A Māori-centred research approach guides the present project and provides an interpretive framework for the results. All the same, relative to the positioning of the present research, objective, detached researchers and methods (although credible by the dominant research culture), are often underscored for not necessarily portraying Māori peoples in a positive light (Amoamo, 2008; McCreanor, 2009; Smith & Wobst, 2004; Tuhiwai-Smith, 2012).

In so far as the present study involving kaumātua is concerned, a positivist approach to osteoarthritis-management activities might tend towards the positionality of being too clinical, and within the realm of absolute certainty. Utilisation of a positivist framework to investigate a complex health problem as osteoarthritis-management (such as pain management outcomes for example), could involve analysing the visible presentation (such as the swollen knee). There is a risk that these manifestations might take priority, rather than the underlying causal mechanisms (that are invisible to us, such as health and disability policies, or access to health resources).

In contrast, qualitative methods allow the researcher to gather detailed information and yet still acknowledge context and meaning (Denzin & Lincoln, 2000). Ritchie (2003) argued that situations are richly affected by contextual descriptions (describing the form of what exists). In terms of the the present study, qualitative research is 'contextual' for the ability of being able to describe the inherent nature of osteoarthritis-management activities[60]. Besides, explaining, arguing and describing the links between osteoarthritis-related disability, could signify the resultant effect on whānau and the kinds of coping strategies used to manage osteoarthritis[61].

In addition to enabling contextual description[62] and explanatory arguments for associations as well as appraisal are considered, for potentially generating the development of theory. Qualitative research methods can assist in describing associations occurring between specific stressors and adaptability (Michael Ungar, 2005). Such as osteoarthritis-related adaptability (disability adaptability), alongside the resultant effect on kaumātua, and the coping strategies utilised to overcome related stressors.

While it is thought that the interviews themselves would not concentrate on the specific reasons as to why adaptability occurred, they would rather focus on the response. Extrapolation from in-depth interviews can provide views into why and how adaptability has occurred. In an 'interpretive (evaluative)' capacity, qualitative research allows formation of relevant categories according to participant responses, into a conceptual framework (or matrix) (Denzin & Lincoln, 2000).

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[60] The inherent nature of osteoarthritis-management activities concern describing, interpreting and contextualising the factors associated with the impact of osteoarthritis-related pain and disability, and whānau responses to these. In addition, qualitative research enables 'explanation' of the reasons (and associations to be made between) what exists.

[61] For example, in the process of utilising regional hui (the methods of which follow below) specific reasons as to how the osteoarthritis-related disability occurred, is not being sought. Instead, the focus on such a response is obtained from key informant interviews, enabling sight of why and how osteoarthritis-management occurred.

[62] Context for example enables description and interpretation of the factors associated with adaptability and the inherent nature of Māori responses, within the context of hauora and self-management support.

For the present research, the framework is located within two worlds, that of the Māori world as well as wider society, and contained within it are kaupapa Māori theory, and the qualitative approach. Primarily qualitative methods were employed, derived from Western research practices. Expressly, practices that are supported and supplemented by Māori methods of engagement, collaboration, practice, analysis and dissemination, pertaining to a Māori-centred research approach.

A feature of the Māori-centred research approach is that both Māori methods and contemporary mainstream methods and tools, may be utilised to produce and analyse the data (C. Cunningham, 1998). Such as an interpretivist paradigm using qualitative methods and Māori principles, aligned to a tīkanga base. In the present research, the work of Māori scholars, Hodges, Marsden and Durie provide the interpretive framework for the results, with the research drawing on the strength of qualitative research, reality being represented through the eyes of the research participants.

Also, a crucial objective of the research was understanding the lived experience of kaumātua with osteoarthritis, to ascertain how they were coping in my community. As was bringing the core indicators into a useful, integrated toolkit. In exploring the everyday experiences of kaumātua, qualitative methods were also deemed the most appropriate for the present study, when little is known about a study topic (Bogdan, DeVault, & Taylor, 2015).

The specific methods used and the interaction between Western and Māori research methods, are described more fully in the sections that follow. In the immediate section, I describe the local rohe pertaining to the tangata whenua research community. Particular focus is made of the integral role of certain kaumātua in the present research for bridging intercultural boundaries within the community, particularly when there is a need to improve relations between people from different cultures.

In outline, my research design is a multi-method approach that incorporates a collection of reflective journaling (for instance written journal entries of interview notes), semi-structured interviews and a follow-up focus group hui with key informants. A Māori-centred research approach, Māori analysis and subsequent synthesis was undertaken. More specifically, to develop an osteoarthritis-management resource, that reflected the values, beliefs and cultural practices of the tangata whenua community, the details of which follow.

Tangata whenua community

In 2013, Hastings District Council's 'Safer Community Action Plan' identified there being nearly 17,000 Māori residents (approximately 14 percent of the total population of around 80,000) (Infometrics, 2017), remaining the same since 2006. Hastings District Council (2016) describe the tangata whenua of Ngāti Kahungunu ki Heretaunga as the most numerous iwi affiliation among Hastings Māori (mana whenua) with recognised authority, customary practices and management of the land and its people. Ngāti Kahungunu ki Heretaunga incorporates around 3,700 people of Māori descent identifying with that iwi as well as over 2,500 identifying as Ngāti Kahungunu (region unspecified).

Ngāti Porou is the only other iwi to have more than 2,500 people affiliating with the region. In comparison Ngāti Kahungunu has the third largest iwi population, with around 60,000 people (12 percent of the Māori population belonging to Ngāti Kahungunu). Although the Māori population has remained stable since 2006, it has risen by around 8,400 (since 2001 Census) with a large percentage of Kahungunu people also residing outside customary iwi boundaries and many others, who are not included in the census count, residing overseas (Hastings District Council, 2016).

Growing respectful relationships

Geographically, Ngāti Kahungunu has the second largest tribal rohe in the country, from the Wharerata ranges in the Wairoa District, extending to Cape Palliser in South Wairarapa, the coastal boundaries are Paritu in the North to Turakirae in the South (Hastings District Council, 2016). With regards to collaborating with tangata whenua, in the following sections (commencing with ‘Build trust relationally’), I describe a multi-method approach that incorporates a collection of reflective journaling (for instance written journal entries of interview notes), semi-structured interviews and a follow-up focus group hui with key informants.

In the following sections, commencing with the principle that is about building trust with the Māori community, I describe the strategies that were used for the purposes of, “growing respectful relationships” (Pohatu, 2004, p. 2), which I believe resulted in the present research being well received by my community. A Māori-centred research approach, Māori analysis and subsequent synthesis was undertaken. Expressly, to develop an osteoarthritis-management resource, that reflected the values, beliefs and cultural practices of kaumātua.

‘Build trust relationally’

Pohatu’s (2004) assertions are that in the context of community, there is a particular way that researchers need to conduct themselves. Particularly when interacting with people, who may have been marginalised and dis-empowered in a range of relationships. Pohatu (2004) also argued the significance of entering the

Māori community, and building good relationships with whānau and the community with, “elements of trust” deepening the dialogue (Pohatu, 2004, p. 6).

Similarly in the present study, building the trust, support and participation of community members was an important initial step, which Tuhiwai-Smith (2013) identified, for often being more important than the outcome. Although creating a relational space to engage in research, is known to require time, it is more likely to result in relationships that are respectful and research that benefits community members (Christopher, McCormick, Young, & Watts, 2008). Christopher et al. (2008) argued that developing meaningful research requires listening to the community that the researcher works with. Similarly, Tuhiwai-Smith (2013) maintained that understanding the broader history of a community, and acknowledging personal and group histories, can contribute to the process of decolonising research.

‘Listen to the community and respond accordingly’

Similar to Pohatu’s (2004) suggestions concerning ‘growing respectful relationships’ and building trust relationally, I came to understand the importance of listening, “with reflective deliberation” at what was being shared. Aside from having worked in the community, I have a history and track record of working with kaumātua with chronic conditions, requiring rehabilitation and pain management. Yet somewhat different from my healthcare practitioner role, listening (more than I talked) throughout the course of conceptualising the research required patience and tolerance, as did acknowledging the personal and collective histories of the community, and the importance of close relationships between people (Pohatu, 2004, p. 5).

Having built close relationships with the community over time, it seemed natural to communicate in person (face-to-face), and word-of mouth via whānau (extended family) over the course of conceptualising the research. Establishing, building and maintaining these relationships led to rapid growth of my networks, with kaumātua giving their support and guidance to my study through whānau.

Guidance from kaumātua

My first contact with the community, was initiated by my cousin (Ngāti Porou kaumātua (my kaumātua)). Similar to my own personal observations as a healthcare practitioner working with local kaumātua, my kaumātua felt compelled to make a difference to those struggling with their chronic health conditions. My kaumātua is proficient in Te Reo Māori, having been a teacher in kura kaupapa Māori for over two decades.

My kaumātua was very obliging and therefore gave her full support of the present research project, assisting me in the process of gaining access to the community. My kaumātua also gave her full support by accompanying me during attendance to hui. Mentorship from my kaumātua early in the process was critical. Not only did my kaumātua help to make sure that cultural safety was a central focus of the research, her mana, prestige and reputation in the wider Māori PakiPaki community, was a buffer at hui and meetings to a few people, whom I was unknown to.

Drawing on the support of my kaumātua led to me spending Sundays sitting at her table, discussing waiata, whakapapa and stories about Ngāti Kahungunu Iwi tribal history, such as crown injustices to Māori, relationshps and politics between different sub-tribes (hapū). Rameka's (2016) commentary on a Māori whakataukī (proverb) that speaks to Māori perspectives of time, encouraged me to recognise the importance of understanding: "where the past, the present and the future are viewed as intertwined" (p. 387). The significance of time shared with my kaumātua were reiterated during the course of the research, as interviewees discussed their experiences of forced redundancy after Whakatu meat processing plant was shut down in 1984 and ongoing effects on their wellbeing.

On a practical level in a process of 'opening doors' for me in the community, my kaumātua encouraged me to be prepared. For example, I was always to have a waiata at the ready, and I was encouraged not to rush things, but to take my time introducing myself through mihimihi. Attending kaumātua rōpū occurred, prior to asking individuals and organisations for support.

Seeking support from the community prior to the research commencing, included a range of positive interactions such as attending community hui and being welcomed on to local marae. As a consequence of attending a range of hui, interviews only commenced after two years into the research, by which time I had cultivated positive relationships with key leaders in the Māori community.

With the construction of such channels of communication, I was able to develop a history with the community and seek their approval, prior to the research commencing. I was also guided in so far as 'responding accordingly', and I followed Pohatu's (p. 387) advice of being honest ("Ma te pono") and clear about my intentions ("Ma te tika"). The principle of being honest proved invaluable for reasserting the importance of not 'overpromising', more than I was able deliver.

I also consulted with academic supervisors, prior to the research commencing in a process of reflection, as to the most ideal way to proceed, that is to say whether I should adopt a 'top-down' (healthcare-management down) and/or 'community-up' (grassroots-up) implementation approach. It was decided that in addition to mobilising participation of the local community at a grassroots-up level, that I would hui with leaders and community groups, to enable better ‘reach’ into the community. For example, accessing ‘hard-to reach’ kaumātua that had some involvement with outreach clinics, resulting in referral into my project.

In addition, I determined that because Ngāti Kahungunu Iwi Inc., Hastings has been instrumental in respect to health services provision, that early support from leadership was critical prior to commencing the research. Also, I obtained ethical approval for the study from the Massey University Human Ethics Committee (MUHEC) prior to the research commencing, by demonstrating evidence of consultation with Māori health and disability organisations, alongside relevance and responsiveness to Māori health outcomes. Upon being granted approval, I continued building and maintaining trust with Māori, through guidance from kaumātua, the details of which follow.

‘Identify yourself’

Berryman (2014) argued that it was not as much important as ‘what’ you are, when it comes to engaging with Māori communities, as much as ‘who’ you are and ‘where’ you are from. That is why in the present research when presenting in front of community members, rituals of engagement such as pōwhiri and hui gave me an opportunity for the community to ‘see who I am’, assisting me in establishing relationships and orienting the research. As will be demonstrated in the sections that follow, when it was appropriate by offering my story, had the effect of reinforcing ‘togetherness’ through my Māori whakapapa (identity), and allowed me to convey how my personal, ethnic and professional history related to the academic and research enterprise.

Similarly, Bishop (1998) recommended a research approach should be based on the concept of whānaungatanga (togetherness) or sense of family connection. As Bishop explained that within Māori culture, togetherness is of fundamental importance, being both a value and a social process, guiding ‘how to research’ within the context of establishing and maintaining relationships. The following sections will describe how from a researcher perspective, building trust relationally through to understanding my role and involvement at an ethical, moral and spiritual level, commenced with support from community partners.

Support from community partners

In Hawke’s Bay, ‘Kaumātua Ora’ hui are regularly organised and held by health provider organisations, for kaumātua and their whānau (Te Taiwhenua o Heretaunga, 2017; Whānau Ora Directory, 2017). The purpose of kaumātua hui primarily include: health education, fitness and mobility, and the opportunity to explore and participate in te ao Māori. Alongside primary healthcare organisations, kaumātua hui activities are developed by and for kaumātua, with member involvement in supporting healthcare services with their perspectives contributing to tīkanga best practice guidelines for working with Māori (Te Taiwhenua o Heretaunga, 2017; Whānau Ora Directory, 2017).

Having presented at 'Kaumātua ora' hui in the past, I met with representatives that organised 'Kaumātua ora' hui, and secured an invitation to introduce my research, that would be attended by healthcare practitioners, health promotion speakers, kaumātua, family and whānau. Even though I was familiar with kaumātua hui, I have witnessed attendees become quite vocal, when presenters are unprepared, or when a researchers' proposal did not sit well for them. As a precaution, I gave a mock presentation to my kaumātua obtaining feedback that it was satisfactory, prior to taking to the presentation lecturn.

Over the course of time and my attendance to kaumātua hui in my community, I was most fortunate to come across two local Ngāti Kahungunu kaumātua, who contributed to the research focus. In their own way, each became a great guide to me, enabling me to confide in them when I sought affirmation, confidence and faith in my intended approach, and to understand the links between people and the environment. Each kaumātua had an interest in osteoarthritis, with very close networks and strong community contacts across the grassroots interface.

It was through the lens of community partnership that the importance of practical knowledge, was brought to the fore. Precisely a pragmatist epistemology of knowledge provided by kaumātua, helped me to reinforce my impression concerning a logical perspective that is based on experience (Cone & Ruwhiu, 2010). A number of pragmatic decisions unfolded over the research and during the course of obtaining support with community partners.

During the course of my presentation at kaumātua ora hui, I sought feedback on the research focus and regularly offered study updates as well as eventual outcomes. The research focus was met favourably by those kaumātua interested in obtaining helpful strategies. I believe that conveying my intentions for mutual exchange of knowledge was instrumental in my research being well received.

Once everything had been fully discussed, the hui concluded with 'mihi whakamutunga' (closing session)[63], followed by karakia, waiata and kai. After the hui,

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[63] The mihi whakamutunga summarises the hui (where we have been, are going, who is going with us) and usually includes karakia (Bishop, 1999a).

those kaumātua that I did manage to speak with, expressed a strong desire for an osteoarthritis-management resource that met their needs, rather than educational leaflets on osteoarthritis health education. Also, the need for an osteoarthritis-management resource was reinforced during the stage of 'Conducting in-depth interviews' (below). Following my attendance to hui, I engaged in a process of reflection, noting down the undertakings that I had made (see 'Research journal', below).

Both Ngāti Kahungunu kaumatua and my own kaumātua, helped to facilitate support with community partners (a Senior population health advisor and a General Manager Business Growth and Design of a Māori Health provider). Obtaining community support entailed presenting the research approach and obtaining support both verbal and written, in order to pursue the research. Both community partners offered recommendations of other community groups and members to contact (below). Community endorsement was crucial for constituting support, which lead to initiating contact with Hastings-wide kaumātua Māori health promotion and community advisory groups.

Support from local healthcare organisations

One of the reasons that I was able to gain support from local healthcare organisations, was due to my kaumātua's ability to initiate contact with two key healthcare workers (kaimahi). They brought experience within the healthcare sector, and a long history of involvement in community grassroots community engagement. I was able to outline my research focus, after we met informally over coffee. Both kaimahi had family histories where osteoarthritis was prevalent.

Of the kaimahi, one had recently experienced an injurious fall re-aggravating their symptoms of osteoarthritis, which they explained had lead to personal frustration at the lack of information in circulation for kaumātua about osteoarthritis-management. Both kaimahi expressed their support of the research focus. As it eventuated, the support of kaimahi lead to my introduction to two kaumātua groups, of which kaimahi were members.

The groups which kaimahi introduced me to were, 'Te rōpū Mihiroa' and, 'Te rōpū Taiwhenua'. The primary function of these rōpū being to promote kaumātua Māori health and wellbeing, and to also draw on the expertise of each kaumātua rōpū, as community advisors. Consequently, I was brought into each rōpū, to formally present the focus of my study, which lead to me once again, securing initial support to proceed.

As will be discussed in the section that follows, most of the members participated either themselves or identified referrals into my study. Also, one of the Māori health community services staff became a key mentor (mentor), assisting me by confirming the need for my research and that an osteoarthritis-management resource was necessary, to get more kaumātua talking about their needs. Moreover, my mentor later provided instrumental support to the research, as a leader of the follow-up focus group (hui).

More support

In a process of seeking to secure broad support and be reflective of the community, it was also important to approach kaumātua who were not affiliated to Ngāti Kahungunu through iwi and waka. My cousin organised for me to speak with various Ngāti Porou whānau in Paki Paki, who had initially moved to Hawke's Bay in the 1960s in pursuit of employment at Heinz Watties. All of the older members of families that I spoke to, discussed sustaining injuries during their employment and their personal experience with osteoarthritis.

Osteoarthritis-management was an issue close to some kaumātua and they were keen to obtain more in-depth information, meanings, and reasons about a condition that was being scarcely discussed throughout the community. Once again, I received support for the focus of the present study and osteoarthritis-management resource, with some going on to participate in the research as an interviewee and in the follow-up focus group hui. In the following section, I describe testing a guide for the interviews with kaumātua.

Piloting the interview guide

According to Patton (2002), a semi-structured interview guide (interview guide) provides topics that the interviewer can freely explore, probe, and ask related questions. An interview guide is able to allow previously unthought-of connections and themes to emerge, resulting in a richer dataset. Based on the literature review of the present study, an interview guide was constructed, that consisted of a range of open-ended questions.

I utilised an interview guide, in so far as having pre-specified questions and probes. Once devised, the interview guide was piloted with cultural advisors in the community, to provide clarity and ease of understanding for interviewees. Piloting the guide also enabled me to gain experience in drawing out responses and resulted in minor amendments being developed so that the guide was administered more easily at the interview. A general interview guide approach is known to assist the interview, and when time keeping is a requirement, as is building rapport (Berg, 1995; Fontana & Frey, 1994).

The final guide comprised five main questions used to ‘guide the interview’, enabling questions to be dropped and new ones added at my own discretion, according to the expertise and knowledge of the interviewee. The use of a base interview guide also encouraged a certain degree of consistency across interviews, however. Throughout the process of constructing the interview guide, are indications of reflective practice in action during the repeating cycle-like process of reflecting, alongside the continuity of Bishop’s (1995), “process of continually revisiting the kaupapa of the research” (p. 97), which is as N. Denzin, Y. Lincoln, and Tuhiwai-Smith (2008a) argued, useful to the researcher, for increasing an understanding of the range of local belief systems and cultures.

Research journal

Over the duration of time taken in developing the research focus and learning from my kaumātua, proved to be immensely valuable to me. Particularly on a personal character development level and in the present research, it also resulted in me ‘tapping’ into Māori leadership from within my community. I reiterated the importance of managing and leading the research from a Māori perspective in my research journal, after becoming influenced by the advice of Henare (1988a):

> In social terms, tapu can be interpreted as potentiality for full realisation; to have influence, to evolve, to control, that is to be more Māori, more human. Ko tona mea nui, he tapu (Tapu is his/her greatest possession) (p. 5).

To me, Henare’s (1988a) quote (above) signified my experience of mana-enhancing behaviour, experienced in my relationship with my kaumātua. Notably that care must be taken to not trample another person’s mana in relationships. The meaning of mana or dignity was evident in the development of my relationship with my kaumātua, mana being central to the integrity of us both. I also developed my ability to listen with humility and curiosity, to the ideas and opinions of another and the process was enhanced through my use of reflective journalling.

Ortlipp (2008) argued that keeping a reflective journal created, “transparency” in the research process and explored the impact of critical self-reflection regarding research design. In the present research, keeping a research journal was also to provide a research, “trail” of the changing methodology and analysis (Ortlipp, 2008, p. 696), and I kept these as a means of tracking decisions made throughout the process of developing the methods, ethics process and field work stages of the research. I also took the time reflecting on and refining the research process.

Refining the research process

During the early stages of the research, I spent time considering whether my focus needed refining, based on the literature review. The literature review undertaken at the outset of the research, revealed that very little is known about kaumātua with osteoarthritis. In effect how kaumātua understand or experience their condition, or indeed whether culturally tailored responses should be included in osteoarthritis-management at all. That cultural imperatives may have a place in osteoarthritis-management for kaumātua, is an issue rarely raised in the literature.

The use of 'cultural indicators' of osteoarthritis-management in the health literature, appeared to be almost absent from the literature reviewed locally, similar to my experience as a healthcare practitioner working in the field. Overseas, there was some evidence in the literature related to chronic-condition management, that culturally sensitive support was effective at influencing positive change at the community level. Additionally, that sharing stories was suitable as a way of imparting knowledge. In addition, there was some evidence that a collaborative, evaluative toolkit was an effective approach, for creating chronic-condition management resources with diverse ethnic and cultural communities.

On reviewing the literature, I made an argument that there remained a disconnection concerning understanding the process of building strong relationships with kaumātua, family and whānau when investigating osteoarthritis. The first stage of the fieldwork therefore involved questioning kaumātua with osteoarthritis about their lived experience. My intention was to develop pathways that will achieve lasting and meaningful relationships in the process of understanding about osteoarthritis-management for kaumātua.

Alongside reviewing the literature during the early stages of the research, I spent time considering whether my focus needed refining, based on my experiences of seeking community support. I sought information about the relevance of Māori cultural factors (core indicators) during times of coping, that are integral to supporting wellbeing and osteoarthritis-management. I also wanted to know about the relevance or otherwise of bringing the core indicators together, into an integrated toolkit, useful and appropriate to modern health promotion.

Besides, whether an integrated toolkit might be able to promote kaumātua assessment of their needs and priorities of support, as they apply to Māori health perspectives of kaumātua was also of interest. As was whether an osteoarthritis-management resource would be able to get more kaumātua talking about their needs. The information that was being sought therefore determined the range of key informants selected.

Sampling

Having worked within Heretaunga iwi as a healthcare practitioner since 2002, my work has included focusing on osteoarthritis-management with kaumātua within community-based clinical environments, including Kahungunu Māori health provider services. I am familiar with the iwi, hapū, and whānau structures, and with Māori networks and organisations within these areas, and kaumātua from my community had expressed a desire to contribute to the present research. Consequently key informants were initially identified through my own whānaungatanga (networks and relationships), and snowball sampling.

The snowball sampling method involved asking initial respondents to suggest others. Precisely, who they knew in the target group, and who to contact and invite to take part in the research. In the present research, an initial group of key informants were identified and those respondents were asked if there were other kaumātua in the community with osteoarthritis, whom they thought would be valuable to interview.

Sampling occurred after I initially visited two kaumātua roopu groups that met monthly, to discuss health promotion and provide community advisory functions. The groups that I met were, te rōpū Mihiroa and te rōpū Taiwhenua, and hui were located at two Māori health providers. In all, a total of 150 attendees were present, enabling me to announce the undertaking of the present research and provide the community with information pertaining to the study.

Once appraised of the direction of my research, many kaumātua asked me to participate in the study. Crucial to the present research, a self-selection process was the 'whakawhānaungatanga' (making of culturally meaningful connections with others) that I observed between kaumātua. Initially I had thought that kaumātua would require more time to consider their participation with family and whānau consensus, prior to confirming their engagement. Consequently, the number of kaumātua volunteering to participate in the study was far easier than initially anticipated, from kaumātua attending these hui.

In addition to establishing, building and maintaining relationships, potential interviewees were identified through purpose sampling. For in-depth interviews, I employed purpose sampling (Patton, 2014) as a means to targetting a specific group with common characteristics that can enable an in-depth understanding (Creswell, 2007). Another strategy utilised snowballing (Patton, 2014), where kaumātua known for their involvement in healthcare promotion, volunteered to inform prospective interviewees about the research and handed out information sheets to those who were interested in the study.

Following Creswell (2007), further sampling was complete, once additional interview participants were not yielding new insights. Some kaumātua who were engaged in healthcare promotion in the community also volunteered to inform their peers about the research. They handed out information sheets to those who were interested in the study. Throughout the recruitment process, I also employed the purposeful sampling strategy that incorporated kaumātua who identified as being of Māori ancestry and ethnicity, based in Hawke's Bay, having received a diagnosis (gout, osteoarthritis, or chronic musculo-skeletal disorder) during their adulthood (see Appendix 6, Participant information sheet and Appendix 3: Interview guide).

The participant information sheet set out the purpose of the study, which was to find out what kaumātua, family and whānau thought about osteoarthritis-management. Additionally, that the study was intended to focus on meaningful experiences in the hope that information provided, would help to promote wellbeing in kaumātua with osteoarthritis. Expressly that information provided by kaumātua, family and whānau could help promote health information that is being provided by healthcare practitioners to be appropriate and easily accessible to kaumātua (see Appendix 6: Participant information sheet).

As a result, the majority of kaumātua participants to be recruited into the study, came by means of word-of-mouth (or snowballing) (Patton, 2014). Notably, those kaumātua who had been involved in healthcare promotion were invited to recommend appropriate interviewees, which usually resulted in a few key names being identified repeatedly. Once contact was established with potential participants, I offered to further explain the study to kaumātua, family and whānau.

Explaining the study to kaumātua, family and whānau, involved addressing any issues or concerns that prospective kaumātua participants may have had with the present research. As a result, the process for gaining informed consent from participants, occurred via some kaumātua confirming their participation by way of a phone call. Otherwise the majority entailed meeting face to face in person at their home, to explain the study.

Key informants

In all, a total of 20 participants took part in the present study, which consisted primarily of in-depth interviews with kaumātua living with osteoarthritis, family and whānau in Hawke's Bay. Kaumātua with osteoarthritis were the key informants, and they came from various backgrounds and disciplines. They were comprised of Māori health workers (n=4), District Health Board (DHB) workers responsible for Māori health (n=5), traithlete (n=1), academics (n=2), teachers of Te Reo Māori (n=2), carers of mokopuna (n=6).

All of the kaumātua participants had all been diagnosed with osteoarthritis, and living at that time within ngā rohe o Ngāti Kahungunu me Heretaunga. In the present research kaumātua were further defined for being known within the whānau for the knowledge and skills that they possessed. Correspondingly, the position of kaumātua was determined by age (over 55-yrs) and the perception of their whānau or the Māori community for their involvement in, hapū, and iwi, over a number of years.

Conducting in-depth interviews

Pohatu (2004) argued that in research, a major kaupapa Māori principle concerned, recognising and respecting the issues and priorities identified by participants (Pohatu, 2004). An emphasis is placed on the need to engage participants with a sense of respectful behaviour, that is closely related to Māori customs such as aroha and manākitanga. For example, the principle of 'āta' (growing respectful relationships) is an intervention that assists negotiating boundaries, by utilising behaviour that aligns with creating a safe research space.

The principle of 'growing respectful relationships' (āta) brings into focus, care and respect on the part of the researcher to display patience ('āta haere'), of the participants' context and environment (Pohatu, 2004). In the same way, 'āta whakarongo', ensured that I displayed patience, and that all my senses were engaged during our conversations. In doing so helped to impart a sense of trust of what was being shared, consequently enabling clarity of communication (āta kōrero).

As a matter of course, I interviewed kaumātua with a previous diagnosis of osteoarthritis (chronic musculo-skeletal disorder, including gout). Interviewees were invited for their ability to provide a wealth of data, about their lived experiences and their interactions with services in their community. That is to say, kaumātua were invited to share their experiences of living with a chronic condition. The lived experience of kaumātua incorporated their beliefs about quality of life, risk factors, barriers and enablers to osteoarthritis-management at home and in the community.

In terms of the approach adopted to interviewing, conversations ranged from informal, through to adopting an interview guide (see Interview Guide, Appendix 3), and standardised open-ended questions. The aforementioned interview approach was adopted following that often an informal conversational approach, is used in the systematic study of how people live their lives (such as ethnographic fieldwork), without pre-determined questions, allowing for flexibility and spontaneity (Creswell, 2007). Following the approach adopted to interviewing kaumātua, for my own psychological health and spiritual wellbeing, my supervisors were available for debriefing and I had access to additional debriefing from my kaumatua, an expert in working with hauora/total wellbeing in kura kaupapa Māori schools.

Focus group hui

As soon as analysis and interpretation of the in-depth interviews had been undertaken, the questions for focus group hui were determined in collaboration with kaumātua within a community health environment. Healthcare organisations that regularly held monthly health promotion hui for kaumātua in the community, was the forum used to examinine and broaden the themes participants' identified during the interviews. In accordance with research and Māori values, the direction and focus of the hui emerged from the in-depth interviews.

As follows, a focus group hui guide was constructed, using questions that had been refined by those kaumātua who had indicated during the interview their desire to attend a follow-up focus group hui. A common research instrument used for gathering information and local knowledge about healthcare services, enabling indigenous evaluation of initiatives and resources, is the focus group method (Burgess et al., 2014). Following Kreuger & Morgan's (1993) suggestion, focus groups are ideally suited to researchers', that are intent on acquiring in-depth understanding about the social attitudes, values and beliefs of individuals (Kreuger & Morgan, 1993).

The focus group environment enables information that is more in-depth for understanding collective social action, and accessing group beliefs (Desai & Potter, 2006). Focus groups also permit confirmation of the validity of data (triangulation), from different sources (Saulnier, 2000). At the stage of conducting a focus group hui in the present research, the goal was to reflect community concerns and needs by involving kaumātua in constructing ideas for the future direction of an osteoarthritis-management resource,.

Also, the aim was to generate Māori-centred analysis of the community perspective on osteoarthritis-management. That is to say, Māori-centred analysis which consisted of ongoing supervision from my academic university supervisors, assisted me in examining my data analysis by ensuring that I had considered other possible interpretations. In due course, I met with key people on a regular basis, such as kaumātua within the community, a cultural advisor, and participants (community members'), to inform them of the initial findings. Also, the process of seeking feedback from community members', made the study more public. Focus group discussions (hui) enabled connecting the research to the wider-community and healthcare stakeholders, by valuing, listening and adapting to community members' opinions and concerns (Bogart & Uyeda, 2009). In the following section, a description follows, as to how hui helped to construct the osteoarthritis-management resource.

Osteoarthritis-management resource

As soon as the results from the focus group hui were analysed and interpreted (see Chapter 5), the data collected was utilised to inform the construction of a culturally relevant osteoarthritis-management resource (resource). The process utilised the application of kaupapa Māori principles (Māori values) (see Table 5) and values when working with kaumātua, the aim being to prioritise Māori knowledge within the present Māori-centred research project. Earlier in the current chapter I put forward an argument that adopting Māori values, should increase the possibility of generating a culturally appropriate osteoarthritis-management resource.

Prominently, I have argued support for an osteoarthritis-management resource, that reflected the values, beliefs and cultural practices of Hawke's Bay based kaumātua living with and those at risk of secondary osteoarthritis[64] (these values). After collecting all of the required data, a process evaluation (presented below) enabled determining the application of these values (see 'Chapter 7: 'Pathway appraisal (Interpretation and assessment')). In the following sections a description is offered, as to how conducting a process evaluation helped me from a researcher, a positionality, a status and a subjectivity perspective.

Positionality, status and subjectivity

Throughout the present research, field notes were taken to capture my thinking, assumptions, experiences and knowledge in the field, as data was being collected. I recorded the field notes during or immediately after each interview and follow-up focus group hui, and these were in addition to the transcribed recordings. The following example is provided as kaumātua shared information about a negative experience with healthcare services:

> Don't forget to code for negative experiences for whānau engaging with healthcare services. Not being spoken to directly, being spoken over the top of when interacting with medical specialists. The specialist speaks to the whānau instead of addressing kaumātua directly (Field note 12/02/15).

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[64] Secondary osteoarthritis refers to osteoarthritis of a known cause, and includes obesity, repeated trauma or surgery to the joint structures or gout.

Accordingly, the use of field notes and a reflective journal, was an integral part of the research. The reflective journal for example, helped to facilitate critical reflection, concerning my positionality and subjectivity. The first key area, concerned my researcher insider/outsider status.

Notably I wrote about becoming an insider researcher after embarking on the present study with the Māori community, of which I am a member. According to Taylor (2011), insider positioning forgoes conceptions of authority and attempts to undertake research, according to the methods and practices of the community and participants under study. Although, having prior knowledge as a healthcare practitioner in my community, posed a potential conflict, as indicated in the following example of a journal entry:

> In the course of researching my community, it is necessary to consider what are the impacts that my relationship could have on kaumātua (participants)? Particularly those who are patients within my own clinic, relative to the data obtained from the interviews and focus groups. I need to avoid allowing my own knowledge about kaumātua and cultural views to 'cloud' my judgement when interpreting the data. I will need to work closely with my supervisors and cultural advisors, and use journalling as a means to avoid misinterpreting the data, if I am to be inclusive of all significant aspects. I suppose I am also an outsider researcher, becoming aware of such status after being asked pointedly by kaumātua whether I belonged to their group (living with osteoarthritis) (Journal entry 12/12/15).

Similar to Mauthner & Doucet (2003), I used journalling to be reflexive, visible and situated throughout the various contexts in which the research was conducted. As evidenced in the journal entry of 12/12/15, my role as the reseacher, the research method, and the data are interdependent and interconnected. Another key area that journalling played a role, is in stimulating reflexivity and self-triangulation, and in particular concerned my location on the continuum of observer to participant.

Following Banks (1998) typology that differentiated insiders and outsiders, on the one hand I journalled my insider status, for holding similar values, beliefs and knowledge of my Māori/cultural community that is under study as an "indigenous-insider". On the other hand I am also an "external-outsider", having been socialised in the allied healthcare community, which has only a partial understanding appreciation for the cultural values of the Māori community (p. 7). Therefore I am a visitor, interested in learning more about the group of which 'I am/am not a part', also I view these positions are not fixed or static but, “ever-shifting and permeable social locations”, with neither having a monopoly (Naples, 1996, p. 140).

Another key area that provided the foundation throughout the present research concerned my subjectivity in the research process. Similar to Van Heugten 2004, I used the journalling process as a tool to avoid potential bias and it allowed me to write about my experience in order to create distance, and deconstruct the familiar community and world of which I am part. The aim being to maintain subjectivity and be, “open to intensive scrutiny and challenge on an ongoing basis” (p.208), from the beginning of the research and beyond the construction of an osteoarthritis-management resource.

Rigour in the research process

Throughout the literature, are people’s experiences of coping with illness, and studies about such phenomena. Precisely studies that have enabled rich, thick descriptions, strengthening trustworthiness and credibility in the process (Denzin & Lincoln, 2003; E. Guba & Lincoln, 1989) of exploring people’s lived experience of a chronic condition. As with all research, a major issue concerns credibility of the data, that is collected and presented (Bussigel & Filling, 1985).

Reliability and validity are commonly used tools in establishing the rigour of data (Mays & Pope, 1995). According to Golafshani (2003), both are tools of an essentially positivist epistemology. On the other hand Patton (2002) stated that in quantitative studies, reliability was concerned with the consistency of results over a period of time (Patton, 2002). Reliability being dependent on the replicability or repeatability of the results, by way of a similar methodology that leads to the same results, under the same conditions (Grossoehme, 2014).

Heshusius and Smith (1986) noted that the rigour of qualitative research was often debated by positivists, for not addressing their concepts of validity and reliability in a similar manner. Merriam and Tisdell (2015) stated that qualitative research was generally different, in so much as recognising assumptions about the world, the approach and paradigm. Likewise, that a qualitative research paradigm required specific criteria that addressed rigour (Merriam & Tisdell, 2015), leading Guba and Lincoln (1985) to utilise the term, ‘trustworthiness’ in place of reliability or credibility. In the following section, methods used to establish rigour in the research are discussed, commencing with triangulation.

Triangulation

In the field of qualitative research, triangulation has been widely noted for being a credible method for testing trustworthiness of qualitative data (Denzin & Lincoln, 2003). In the present research, methodological triangulation, that uses different research methods to gather data was employed (Patton, 2002). Triangulation was an ideal tool to test trustworthiness, due to having gathered my data from a variety of sources including my field notes, interviews and focus group hui.

As well, observational notes taken down over the course of conducting interviews also brought more depth regarding participant environments and behaviour (Belk & Wallendorf, 1989). As a process triangulation ensured the credibility of qualitative data, and to test the validity of the information gathered. On top of that, triangulation provided a basis for convergence on the truth, enabling true information to be set aside from error information (Bernauer & O'Dwyer, 2013).

Using multiple methods also enabled capturing individual and group experiences, by regulating individual limitations by counterbalancing these, within each method. Usually, trustworthiness is established when findings from different sets of data are able to converge (Patton, 2002), what is more details pertaining to a tool to enhance trustworthiness, ‘respondent validation’ follows.

Respondent validation

The trustworthiness of results is also achieved through respondent validation, a technique for exploring the credibility of results (Doyle, 2007). For example, data or results are returned to participants, to check for accuracy and resonance with their experience. Respondent validation, which is a popular method for establishing rigour in qualitative research, provided the means for obtaining feedback after presenting the initial findings to kaumātua for oral feedback.

Also, participants were informed of the findings of the interviews, through my regular attendance to monthly community hui. My attendance to community hui occurred, as it was my intention to engage in the research process with participants as much as possible, and community hui enabled me to share the early findings and gain feedback. Feedback from kaumātua participants concerning the early findings from the interviews, indicated that a range of lived experiences had been captured.

The research also engaged in a follow-up focus group hui with kaumātua, to guage their responses to preliminary findings from the interviews. The follow-up focus group hui was well received, and the group setting enabled kaumātua to validate the interview data and share their understandings of osteoarthritis. The findings arising from focus group hui were sent to all attendees to read and make comments, with those who read the preliminary findings contacting me by text or touching base at community hui, to confirm that they were pleased with the early results, indicating that it reflected their experiences.

As soon as feedback from kaumātua concerning the findings arising from focus group hui were completed, I proceeded to obtain validation from kaimahi and kaumātua. The preliminary findings informed the osteoarthritis-management toolkit. Later, after the write-up of the analysis, another hui was held with kaimahi and my kaumātua. Conducting hui with kaimahi was crucial in terms of obtaining further feedback on developing the toolkit, as was obtaining ethics approval, which follows.

Ethics

Approval

The present research was approved by the Northern Regional Ethics Committee Application 13/049 (see Appendix 5). As noted in participant information sheets, the consent forms, data, interview and focus group hui transcripts and field notes were held in safe-keeping by the researcher or supervisor (where the project was conducted). Also, arrangements were undertaken, for the disposal of the data/Consent forms when the minimum ten years (for the present health-related research) has ended, precisely that these would be destroyed using a commercial-grade strip cut paper shredder and disposed in a waste paper container.

Furthermore, that the audio recordings would be erased after the study was completed, in accordance with the Human Ethics Application with Massey University Human Ethics Committee (Northern) (2013); and code of ethical conduct for research involving human participants as stipulated by Massey University (2015). Accordingly, I discussed safekeeping with my primary supervisor, and it was agreed that all data would be stored in a locked cabinet in the researcher's clinic. Disposal of data was the researcher's responsibility and would be carried out by Document Destruction Services in the manner discussed (above).

Storage was accessible only to the researcher and supervisor. Over the course of the research, I also attempted to uphold all ethical standards set out by the Health and Disability Ethics Committee and the Health Research Council's (2010) guidelines on conducting research with Māori. A further ethical obligation that was at the forefront throughout the course of undertaking the research, was concerned with making a positive contribution to Māori aspirations for their own development.

Keeping true to Māori expectations and aspirations required considerable commitment. The result was richness of the data and relationships being established, that cannot be underestimated. Having discussed obtaining ethics approval, informed consent is discussed as follows.

Informed consent

Participant consent is paramount to ethical health research (Baines, Taylor, & Vanclay, 2013; Hay & Israel, 2006), and there were a number of ethical implications that needed to be addressed. An important issue was the freedom to consent or withhold consent (Baines et al., 2013; Hay & Israel, 2006). In the present study, kaumātua were fully informed that participation in the research was completely voluntary, and that they could freely choose to not participate at any time.

Additionally, all participants were informed that they could withdraw from the present research if they chose to. Both oral and written consent was obtained and protective mechanisms such as kanohi ki te kanohi (face to face) hui with participants were undertaken. The contact with all participants enabled explaining the study, and answering any questions about the present research prior to signing consent, the details concerning anonymity follow.

Anonymity and confidentiality

Following Kaiser's (2009) recommendations, kaumātua participants were informed that their identity would not be disclosed and that any identifiable private information would be held in confidence. All raw data transcribed, had identifying features removed (participant names, organisation and place names). In the case of interviews and focus group hui, after transcription of recorded interviews, a pseudonym was allocated for each participant.

Although participants signed consent forms, agreeing not to disclose any information discussed at interviews and focus groups, they also agreed verbally not to disclosure the identity of individual members in their group to anyone else. On top of that, pseudonyms were used to replace each participant's name after they returned their transcripts to me. All research data and consent forms will be disposed of in accordance with Massey University Human Ethics Committee (2015) code of conduct for ethical research. Details concerning managing potential risk of harm follows.

Managing potential risk or harm

As with every study, research inevitably carries different risks and therefore, a complete guarantee of safety to participants is not possible (Barrett & Shaw, 2006).

The nature of risk requires offering reasonable protection to participants, with appropriate mechanisms to mitigate potential risks or harm that may arise from within a study. For example, physical, psychological, social which may result in discomfort (physical, social, legal and emotional), or any adverse experience as a result of participation.

In the present study, there was no potential harm envisaged, as the data obtained from participants centred on views, beliefs and experiences of living with osteoarthritis. Although, individual experiences could be somewhat discomforting emotionally for some, if voicing negative experiences. Kaumātua may have experienced frustrations associated with osteoarthritis, treatment or services.

Additionally focus group participants could also experience discomfort, if there were to be a breach of confidentiality from the focus group participants. For instance, participants sharing information outside the focus group, may lead to some participants feeling that their privacy has been invaded. Considering all these factors, participants were reminded that they did not have to answer any questions that they felt uncomfortable with.

Additionally, participants were assured that not answering questions, would not affect their participation or contribution to the study in any way. If issues concerning unmet clinical needs arose during interviews or focus group hui, participants were to be advised as to who to contact, in order to address these issues appropriately. Otherwise, participants were informed that they would be able to have a person of their choice or a whānau member present to support them.

Also, participants were asked about their comfort in so far as locations where interviews and a focus group were held. As it eventuated all participants were comfortable with the locations, even though an option was provided to choose a different venue, if they felt that they were not comfortable. Other issues to consider concerned the focus group hui environment.

During the focus group hui, it was recognised that there was the potential for participants to experience discomfort. Particularly if there were to be a breach of confidentiality from the focus group participants. For instance, participants sharing information outside the focus group, might lead to some kaumātua feeling that their privacy had been invaded, which would require inviting them to take a break from the interview or focus group, or stop either altogether.

In the case that a participant did find that the interview or focus group raised issues of a personal nature, and they decided that they would like some counselling, the contact details of a free counselling service on the Information sheet was available. Special care in conducting the focus group sessions was undertaken, to reinforce that anything shared in the focus group, particularly personal information was confidential and must not be discussed outside of the focus group.

When opening the focus group, at the time of welcoming the participants, they were reminded about the purpose of the group. Also a set of ground rules was established. During focus group hui, the approach that was adopted was to ensure each participant in the group was given sufficient time to answer questions, which prevented any one attendee domineering the discussions.

In addition, focus group attendees were offered individual interviews, if they wished to share their experiences with me away from the group setting. During the course of all interviews and focus group, none of these risks occurred. Another aspect of safe research involves cultural safety, which is discussed in the following section.

Culturally safe research

Researchers have a responsibility not only to protect participants from the risks of harm associated with participating in their research. Ramsden's (1993) concept that was developed by New Zealand nurses working with Māori during the late 1980s, has particular relevance to my study. Within the context of the present research, cultural safety is an acknowledgement of the beliefs and practices of kaumātua participants, who differ from the researcher in age, occupation, sex, sexuality, religious belief, disability, or any other different lived experiences.

As researchers, we need to acknowledge that our own culture may be different from those of the people we work with in order to guard against imposing our beliefs. Following the ideas of Ramsden (1993), I acknowledged my own culture as different from those of kaumatua, to ensure that I do not impose my beliefs (Ramsden, 1997). Also, cultural safety centres on the experience of Māori (Wepa, 2005), versus, cultural competence. The former of which (cultural safety), focuses on the capacity of the researcher or healthcare practitioner, to contribute to whānau ora (an approach that emphasises te Ao Māori resources, language and culture (ngā kaupapa tuku iho)), by the integration of cultural and clinical elements within their practice (Durie, 2001).

As Hudson, Milne, Reynolds, Russell, and Smith (2010) noted, the safe participation of a community in research requires the researcher to acknowledge the importance of cultural identity first, than consideration of political, historical, or economic influences alone. In other words, Hudson et al. (2010) acknowledged that researchers have a cultural and social responsibility, and need to understand our own cultural realities, and their impact on those of a different culture when conducting research. Hudson et al. (2010) also noted the Treaty of Waitangi principles (Treaty principles) of partnership, participation and protection, for enabling respectful relations with Māori and mana whenua in all research projects.

Within Māori-centred research, 'Partnership' according to Hudson et al. (2010) is about developing relationships, with the community being researched and establishing their needs. In the present research for example, partnership involved establishing community needs, through Māori methods of engagement. These relationships which were on-going throughout the progress of thet study, offered opportunities to develop personal and institutional relationships of long-term value.

Also, 'Participation' is recognised by Hudson et al. (2010), for encouraging researchers to move beyond consultation and look to substantial and positive engagement with Māori communities. Participation in the present research has involved in the planning stages of the study, the inclusion of vulnerable populations with osteoarthritis, a condition that is exacerbated by unnecessarily inadequate healthcare. For example, the research was identified by the local community being researched as a priority, with advice and guidance from iwi and cultural advisory support from kaumātua in the community being researched throughout the research project.

Additionally 'Protection' refers to the contribution that the research makes towards providing useful and relevant outcomes, and addressing inequalities (Hudson et al., 2010). In the present research for example, developing a Māori-centred approach has recognised the knowledge and epistemologies of vulnerable populations. What is more, Māori have been the significant participants, where methods used developing an osteoarthritis resource have incorporated Māori analysis towards broader objectives for Māori development.

Finally, Hudson et al. (2010) acknowledge 'Mana', which in a Māori context refers to 'power' and authority, requiring researchers to be willing to share power and control of outcomes and dissemination. Hudson et al. (2010) also proposed that sharing power requires having an understanding of locally specific practices or tīkanga (cultural principles), that aim to enhance relationships and, "ensure the preservation of mana (justice and equity, reflected through power and authority)" (p. 2). Conducting culturally safe research has been demonstrated in the present study, through actively engaging, developing and sustaining relationships and ongoing participation with kaumātua from the researched community.

Dissemination of information

Importantly, culturally safe research is primarily determined by the researched community, and begins from the inception of the research idea, through to the disemination of the findings (Jahnke & Taiapa, 2003). A key feature of the present research was the need to keep participants informed of how the research was progressing, and to feedback the research results as soon as possible. Dissemination of information is an area that Tuhiwai-Smith (2013) recommends is is as much about demonstrating a commitment to reciprocity, as it is about remaining accountable to the wider Māori community.

In the present research, feedback was obtained in oral and in written form, as encouraged by C. Cunningham (2000). In terms of accountability towards the community, the research participants received regular informal updates face-to-face and written, as to how the research was progressing, and the opportunity to feedback on their own transcripts. Informal feedback sessions on a monthly basis over six months enabled giving updates on the progress of the study after presentation of the final results at the Māori Health Unit and Whare Mihiroa, Hastings.

In addition to reporting the research findings to all those who participated in the study, the results of the research will also be disseminated as widely as possible to iwi, hapū, whānau and Māori. Dissemination through different avenues are in keeping with the ideals of remaining accountable to the wider Māori community (Cram, Parsons, Phillips, Taupo, & Tipene-Matua, 2012). The results of the research will be targeted towards specific community groups such as Māori academics and health researchers, through networks incorporating the use of e-mail, seminars, journal article publications and kanohi ki te kanohi (face to face) conferences and presentations.

It is intended that the results of the present research will inform public policy. As a result, the outcomes of the research are to be made available to Policy and Planning of Hawke's Bay DHB. Dissemination to Age Concern, Arthritis New Zealand and the Hastings District Council, will involve informing local Māori health organisations such as Māori service providers based in Hastings Te Tai Whenua o Heretaunga and Choices Hastings, to the research findings. In addition, copies will be offered to interested parties.

Information regarding the research findings will also be disseminated to the wider Māori community, through pānui ki te iwi (an email network). The email network is managed by Ngāti Kahungunu Iwi. Also, utilising pānui via Radio Kahungunu and Ngāti Kahungunu Iwi's quarterly newsletter that is issued to each registered member household, as a means to disseminating the results of the research.

Summarising Research design and Methods

The current chapter has outlined the research approach and methods to the present study. I have identified the rationale for making explicit the intentions and procedural principles during the conduct of the present research, raising crucial factors for undertaking research with kaumātua. The purpose of identifying the research rationale in such an obvious manner has been to assist the audience in reading the study, and ability to reproduce the study in terms of both construction and the understanding that underpins these (Bourdieu & Wacquant, 1992).

By utilising the stories of kaumātua experience within the research, guided by a Māori-centred approach, the issues of meaning, interpretation and representation of osteoarthritis are addressed in a socio-cultural context. In addition, obtaining buy-in from the research community was critical in terms of gaining approval and support. Utilising Māori practices of engagement, were all noteworthy aspects of the research process, for allowing me to establish rapport and trust with participants.

In the following chapter the findings are discussed from 20 key informant interviews and focus group hui. Community understandings about common misconceptions, barriers and enablers of osteoarthritis-management alongside the vital role of a Māori-centred approach, will be underscored. The discussion will seek to explore osteoarthritis-management beyond statistical data, by presenting key findings, illustrated by supporting stories.

Chapter 5: A little smile never costs a thing (Preliminary findings)

Introduction

Miller and Rivera (2011) argued the tangible success of community initiatives will depend on culturally relevant design. Similarly, Durie (2001) argued prioritising health promotion knowledge and practice, needed to be specific to a New Zealand context, and the use of local models, frameworks and tools (Durie, 2001). Consequently it is argued that the purpose of the interviews and focus group hui that follow, prioritises developing an understanding about Māori beliefs regarding osteoarthritis, as a means to growing the basis of a culturally appropriate osteoarthritis-management resource.

The present chapter offers preliminary findings from the data collection. An overview of the research process is provided, and how I conducted an analysis of the data. Also, the important role my kaumātua played and Māori leadership from within and outside the community, in analysing the findings is discussed. The overview is presented alongside early implications that the results had, for shaping an osteoarthritis-management resource.

The chapter concludes, by describing the reasons (how and why) the interviewees assisted in giving shape and direction to the questions for the subsequent stage of the study. Precisely, a focus group hui. The findings arising from interviews and focus group hui are located in the present chapter, illustrating the key themes with supporting quotes.

Conducting interviews

Throughout 2015, key informant interviews (interviews) were conducted. Interviews were important for understanding the culture and diversity of the community, conducive to constructing an osteoarthritis resource. Interviews involved asking kaumātua about their Māori cultural understanding and experiences of managing osteoarthritis. Furthermore, interviews explored the physical activity beliefs of kaumatua, including barriers and enablers to osteoarthritis-management.

Kaumātua who participated in the interviews had a wide range of experience, from working within mental healthcare, the education sector, community advocacy, and clinical (nursing). Kaumātua participants were recruited from te rōpū Mihiroa, te rōpū Taiwhenua ('kaumātua ora' groups and Māori health promotion and community advisory groups), via primary care practitioners such as nursing, orthopaedic referral services and Māori health providers. Identifying kaumātua with osteoarthritis as potential interview participants occurred via purposeful sampling (Patton, 2014) and by way of distributing a notice to enlist participants at key Māori health provider locations (see Appendix 7) .

My osteopathic peers helped to identify nurses, referral services (orthopaedic) and community healthcare workers, with experience in Māori health promotion that could refer kaumātua into the project. Members of my whānau and my kaumātua (whānau member), referred a high number of people that ended up participating, and each interview participant was aso invited to recommend potential kaumātua with osteoarthritis to be interviewed. As anticipated, the same few kaumātua with osteoarthritis were repeatedly identified, leading to twenty interviews in total being undertaken.

To begin with, potential interview participants were provided with an information sheet, explaining the purpose, goals and objectives of the study, as well as the criteria for accepting participants to take part in the interviews (Appendix 6). Potential risks and benefits to participating in the research as well as confidentiality and anonymity were provided. Furthermore, the ways in which the data would be used to inform the next stage of the research was detailed, jointly with an invitation to engage in a focus group (hui).

Kaumātua that were in agreeance to participating in an interview were invited to sign a consent form, acknowledging their understanding of the information provided (Appendix 8). All of the face-to-face interviews were conducted at the participant's home or homes of whānau. Audiotaping and transcription verbatim of interviews was undertaken. Each research participant was given an opportunity to review, edit and clarify their transcripts for accuracy.

Data analysis of interviews

After the member checks were completed, I discussed my overall impression of the data with my academic supervisors. That is to say there were three differently voiced positions of kaumātua, that I felt could enable a 'big picture perspective' of osteoarthritis-management in our community. It was decided that even though these three stories could stand alone on their own as they support, connect and fit together, that they may also be corroborated by remaining interviewee data and focus group hui data (see below, 'Three stories').

After selecting three kaumātua stories, each was separated out and identifiers removed from each transcript. After which data analysis occurred in a series of stages, allowing themes to emerge from the data of each story (Attride-Stirling, 2001; V. Braun

& V. Clarke, 2013). Each story was assigned a pseudonym (Mrs Smith', Mr Jones', and Mr Davies'[65]).

Thematic analysis is a qualitative method of data analysis, which allows identifying, analysing and describing patterns or themes across a data set (Attride-Stirling, 2001; Braun & Clarke, 2006). The method was initially discussed by Boyatzis (1998) and identified by Braun & Clarke (2013) (these authors) as a method in its own right, outlining a six-stage framework. Data analysis in the present study is largely based on the method demarcated by these authors for enabling me to make 'sense' of the everyday experiences of osteoarthritis management for kaumātua.

What is more, thematic analysis allowed me to meet the objective of producing an appropriate Māori-centred osteoarthritis-management resource. Braun & Clarke (2013) described thematic analysis as a rigorous way of organising and summarising data in a meaningful and systematic way from the "bottom-up"[66] (V. Braun & V. Clarke, 2013, p. 10). As a result, inductive thematic analysis was performed on the data, to explore meanings and patterns in the data set.

Engagement with self-management and Māori health literature coincided during and after data analysis. I utilised the data analysis software package 'Dedoose', a computer based application[67], offering the facility of a drag and drop code tree that enables coding and tagging interchangeably, documenting where and how patterns are occurring.

Three stories

Mrs Smith

Following Braun & Clarke's (2013) six-stage method of thematic analysis, and after familiarising myself with the data (stage-one), I set about coding for basic elements of meaning, resulting in 44 initial/basic codes (stage-two) and searching for

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[65] The convention of using formal titles (Mr and Mrs) in the current chapter will be primarily upheld as a means of protecting the identity and privacy of kaumātua. Also, I asked each kaumātua interviewee if that would be acceptable and they all agreed that they preferred Mr and Mrs over other options such as Ana, Wiremu or Pita, as these may be confused with other known kaumātua in the community. None of the interviewees knew kaumātua by Mrs Smith, Mr Jones, and Mr Davies and admitted they preferred these names. As an aside, the use of Mr and Mrs is often used within my own healthcare profession, during examination of osteopathic case presentations. It is a sign of respect that their names be written as Mr and Mrs and the patient is discussed amongst practitioners accordingly. I have also experienced that some senior people in the community have insisted that those younger than them, call them by Mr or Mrs.

[66] 'Bottom up' refers to the process of collapsing down whole parts of narrative data into sections, and dividing the sections into bits of meaning in and of themselves.

[67] Dedoose is an online software tool available for qualitative approaches (Tongco, 2007). It is an encrypted password cross-platform application which provides no local copy of the Project, allowing the data to be exported wherever it is needed. It was used in the present study to assist with the process of coding the data and generation of major categorial themes.

themes (stage-three) (Table 6, below). The initial/basic codes that emerged from the first story (Mrs Smith's kōrero), are outlined:

Table 6: Mrs Smith 44 initial/basic codes

Mrs Smith
44 initial/basic codes

1. Impact of comorbidities
2. Many things cause falls
3. Capacity for adaptability
4. Need for equitable access
5. Impact of family transitions
6. Living on a limited income
7. Fair share of home help
8. Assess the needs of kaumātua
9. Koha has no boundaries
10. It's about manākitanga, self-knowledge and identity
11. Importance of nutrition
12. Proper food instead of rongoa
13. Affordability barriers to a healthy diet
14. Sharing ideas with peers
15. Real activities
16. Skills and heritage are not being passed down
17. Improving rural access is complex
18. Access to resources
19. Sitting at home takes a while to 'warm-up'
20. Rangatiratanga role vs stagnation
21. Manākitanga in action
22. Support networks
23. Decision-making for health
24. Importance of a doctor
25. Differences vs self-autonomy
26. Exercise
27. Low-cost activities
28. Transportation
29. Community safety
30. Community access
31. Culturally tailored services
32. Whakapapa, iwi, hapū
33. Aroha
34. Manāki
35. Wairua
36. It's about weaving compassionate care around kaumātua
37. Learning = wellbeing
38. Rich everyday experience is a good life
39. Sharing real stories
40. Prayer is normal
41. Cultural and spiritual care is lacking in public health
42. Benefits of kaumātua rōpū
43. Interesting activities
44. We are role models

These initial/basic codes were then reviewed and arranged into a further fifteen higher level (provisional/organising) themes (stage-four). The provisional/organising themes follow (Table 7):

Table 7: Mrs Smith 15 provisional/organising themes

Mrs Smith **15 provisional/organising themes**	
1. Osteoarthritis, falls and lost my sight Impact of comorbidities; Many things cause falls; Capacity for adaptability; Need for equitable access **2. But my husband decided to go a bit early** Impact of family transitions; Living on a limited income; Fair share of home help; Assess the needs of kaumātua **3. You don't go empty handed** Koha has no boundaries; It's about manākitanga, self-knowledge and identity **4. Eating well makes life easier** Importance of nutrition **5. A healthy lifestyle should be natural** Proper food instead of rongoa; Affordability barriers to a healthy diet; Sharing ideas with peers **6. I work through it really** Real activities **7. Enhancing life skills** Skills and heritage are not being passed down **8. They didn't use the doctor much** Improving rural access is complex; Access to resources	**9. Those were the days** Sitting at home takes a while to 'warm-up'; Rangatiratanga role vs stagnation; Manākitanga in action; Support networks; Decision-making for health **10. Attitudes concerning services** Importance of a doctor; Differences vs self-autonomy **11. That was a natural part of life** Exercise; Low-cost activities; Transportation Community safety; Community access; Culturally tailored services **12. Wairua tipuna** Whakapapa, iwi, hapū; Aroha; Manāki Wairua; It's about weaving compassionate care around kaumātua **13. You educate yourself** Learning = wellbeing; Rich everyday experience is a good life; Sharing real stories **14. Karakia is natural** Prayer is normal; Cultural and spiritual care is lacking in public health **15. Arthritis and ageing in a community** Benefits of kaumātua rōpū; Interesting activities; We are role models

Mrs Smith's story

Mrs Smith (90 years) had been diagnosed with primary osteoarthritis in both knees and ankles, at the age of 55 years[68]. Until she retired, Mrs Smith' had been a teacher in a wharekura and a passionate advocate for education, which is why she prioritises education and learning in the community, as part of her story.

Osteoarthritis, falls and lost my sight

When asked, how she was managing her osteoarthritis around home and in the community, Mrs Smith' talked about the impact of living with more than one chronic-condition:

> I've had falls and lost my sight and things like that. I've just got to be looked after in the proper manner I mean, I've always done that until I've had falls and

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[68] Mrs Smith had been diagnosed with primary osteoarthritis in her knees and ankles. As is often the case, Mrs Smith was not aware of the trigger (specific cause) and was unable to put the condition down to having sustained an injury, characteristically in primary osteoarthritis there is often no known cause which will be identified (S. Bullock & Hales, 2012). Mrs Smith lived with pain, swelling and stiffness and had visible joint deformity (knock-knees), her level of pain often reached 10/10 on a daily basis.

> lost my sight and things like that, worn out joints, broken legs and hip replacements and things like that, I've had a lot of falls ... losing a kidney, diabetes, thyroid and things along the way … but that's all been some time ago.

As Mrs Smith' discusses, many things could cause a fall. All the same encoded within, is real experience of living with co-morbidities and resolute focus on capacity for adaptability. Mrs Smith's story should help to inform activities, about the need for equitable access of kaumātua with failing eyesight to healthcare services promoting prevention of falls in the community.

But my husband decided to go a bit early

When Mrs Smith' did talk about managing her condition, she quite often spoke about the involvement of whānau. On asking, "what's really important to you" an opportunity opened as Mrs Smith' explored life's losses:

> We were here [staying in the house] just for a little while and my husband died. At the moment we're still getting over the passing of my husband, got a few things to do, have to change to a different routine … My husband's passing ... He just went … ahem … turned over and he was dead, fell on the floor, but he was getting that way. His eye color was fading, you know how when people are not well, there's something different about their face? We've all done that [worked hard]. A lot of my Aunties and Uncles lived to 104 [years of age] and very healthy, very capable, musical, hard working farmers, whatever, no trouble. I come from a family like that. But my husband decided to go a bit early.

The kōrero speaks of the way family transitions impact on kaumātua living with osteoarthritis. Sometimes kaumātua need help, although when they do need referrals into home help, kaumātua consumers have not always been offered their fair share (Hawke's Bay District Health Board, 2011). Recognised in the kōrero is the need to be able to assess the needs of kaumātua.

You don't go empty handed

As Mrs Smith' talked about how she was managing her osteoarthritis around home and in the community, she referenced the source of her identity:

> These ones [pointing to family members in the next room] have had to come from Whakatane to look after, be in the house with me. That's my brother-in-law and sister-in-law and they've come for a fortnight. My husband's brother. They've brought a lot of stuff, even though every meal's been tucked away, they still came and brought some stuff. You don't go empty handed to other people's houses like that! So, they've just got some business to do and they're coming back to get me, because I've got some business to do, then we'll be ready to have a nice quiet evening. They live in Whakatane. As long as they're [family, are] happy, I never analyse … you give the best of your 'kind' … what you can, that's what I … and I don't worry about it … it's how you behave and how they behave and how they receive and you receive … without a fuss … just carry on with life.

Since the passing of her husband, Mrs Smith's family had travelled several hundred kilometers to support her. It was obvious that 'koha' (contribution) had no boundaries, evident in the care being provided as brother and sister-in-law. The attendance of family to assist, was to show real 'manākitanga' (kindness) and 'aroha' (compassion), all facets of tīkanga Māori (cultural principles), of self-knowledge and identity.

Eating well makes life easier

Mrs Smith' was asked about what living with osteoarthritis meant to her, in today's society. She chose to talk about the everyday experiences of living:

> No I don't have any preferences for certain foods, I just eat well. Everything's done well, properly. I don't eat madly or anything like that, I have a proper breakfast things like that. I have prunes and something or rather and wheet bix or a little bit of porridge and some fruit, a hard boiled egg and a wee bit of toast. Lunch might be a salad, a sandwich or something and a piece of fruit and tea of course, whatever is decided, but it's still rounded off, if you know what I mean. Well you try everything as you grow up. It's cooking and making meals and that is different from when I was growing up. They have different ways of doing things [now], they have wizzes [food processors] and that sort of thing. It makes life easier and there's always fruit to eat. That's always been our life. We don't have a whole lot of one thing, we always try to balance the food and it doesn't have to be big but the mere fact you've got that, gives you the sort of thing [nutrition] you need. That's the way it is!

As practitioners we know the kōrero to be correct, that in order to stay healthy as you get older, it is important to eat really well. Nutrition helps to promote health and functionality and affects quality of life (Baggett et al., 2015).

A healthy lifestyle should be natural

When asked about management strategies, Mrs Smith' shared customary uses of native plants for medicinal purposes (rongoa):

> Well I don't use that [rongoa], I use proper food. I don't go specialising in that [rongoa], I'm not sick. I'm not ill. All that [healthy lifestyle] should be natural. It is. If you're a natural person, you shouldn't even be talking about it. Because it just happens. No I never bother to … no, no, I don't talk about things like that. It's not on.

Using 'proper' food instead of rongoa (medicine) was a real (logical, reasonable, instinctive) way of maintaining wellbeing for Mrs Smith', even so in less well-off communities there are affordability barriers. These barriers might prevent kaumātua from taking up the option of a diversified, balanced and healthy diet.

I work through it really

When Mrs Smith' was asked about her quality of life and management of osteoarthritis around the home and community, her interests turned to talking about everyday challenges:

> I can't see your face. I just recently lost the … I've only got peripheral sight … I had to throw away the glasses. I can see, I'm not making eyes, I'm just looking out of the part of my eyes. It's quite good not to be having glasses any more. My vision can't change or do anything, I've just got peripheral sight and that's it. I don't care about that, I know what to do about it. We organised the help ourselves [not by our doctor]. I can't think of anything [I would like to change, which would make my life easier] because I work through it really, how to do things, how I can do the, but I can't do that. We organised it [home care assistance] through, had a meeting with the blind people and had a meeting with the one …. and when I'd had falls and things, they offered to come in. So I have people just about in, well at the moment, morning and night because they come to test, do my sugar and all that sort of thing because [my whānau] are away. They do come in and do things for me as well that I require being done. I don't know [how it is funded], probably through my doctor.

Mrs Smith' spoke about the real benefits of working through problems in life, as they arose. Some studies have acknowledged the benefits of working through problems as they arise, with peers in a group environment. In particular, what problem soiving means in terms of living with chronic disease in today's society.

Enhancing life skills

In terms of whether anything could be done to enhance the experience of living with osteoarthritis, Mrs Smith' drew down on what being older, and Māori meant, in today's society:

> In those days, everybody didn't have a phone you didn't know who was going to get off the train to come to visit. If people came and perhaps if your cupboard was empty, you could just go over the paddocks and pick up some paua or pipis or crayfish or flounder. But today they can't wait to get to the supermarket and pick up tea and go home and watch TV and something. Life is different today. We came up with just ordinary family and you knew what to do! It's certainly changed hasn't it? It has changed! Completely different life.

There were difficulties that came about, when skills and heritage were no longer being passed down the generations, and it was a decline of intergenerational responsibility that Mrs Smith' felt was adversely impacting on society.

They didn't use the doctor much

When asked about other people's experience of osteoarthritis, Mrs Smith' reflected on her upbringing:

> No they [my parents] didn't [use the doctor much themselves]! We lived in the country and people knew how to look after themselves, to eat properly and to deal with themselves. They had their own ways of looking after chillblains and whatever.

Improving accessibility of rural kaumātua to services is complex (Ellison-Loschmann & Pearce, 2006; Health, 2010; Ministry of Health, 2012a). From a practitioner perspective, having access to resources that promote better communication, understanding and agreement with kaumātua patients and community, is advantageous.

Those were the days

In a different example, Mrs Smith' spoke about osteoarthritis-management and her memories of a community:

> … Those were the days when … everybody looked after their own business and if they made jams, they dropped a jar over the paddock to so and so … They shared things! That's the way it was back then, not so much now … I can get stale, just sitting at home.

Mrs Smith' shared that if she was sitting at home and not actively being held as a kaumātua, then it took a while for her to 'warm-up'. The kōrero foregrounds the importance of valuing the role of a kaumātua and putting her in that 'rangatiratanga' (leadership) role, otherwise she might stagnate. The kōrero indicates what is needed is a bit more 'manākitanga' in action, through collaboration and sharing resources with wider support networks, that are valued by the community, and that capture the right of kaumātua, to participate in making decisions about their health.

Attitudes concerning services

When asked about her experience of osteoarthritis in the community, and what was really important, Mrs Smith' spoke of the significance of a doctor:

> Yeah but I don't think in that way [to question my doctor's decisions], he's there as my doctor and that's that. I never think of criticising or saying what he's good at or anything. That's not my part in life at all. Because you're thankful that you've got a person who is good at their work. All that should be natural. It is. If you're a natural person, you shouldn't even be talking about it. Because it just happens. No I never bother to … no, no, I don't talk about things like that. It's not on. You're thankful you're being looked after the person who's qualified and who's a nice person and that's it, who doesn't need to be analysed. Well that's wrong! I think when you've got a good doctor, in my family [they have their] doctor and I don't go sitting beside [them] and neither for me! You've got to build your own relationship with your doctor, without other people poking a little remark in! You're a better person because it comes from you, it's more natural. I've always had good doctors and I've always gone to the doctor by myself, my husband has and that's the way life has … never thought of doing it any other way.

From a Māori perspective, although there will be differences in how kaumātua want to be involved in considering and selecting treatments, 'tino rangatiratanga' (Māori self-determination or autonomy[69]) stays the same. Ascertaining patient values and confirming the meanings of these, will better enable working together.

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[69] 'Tino 'rangatiratanga' represents self-determination, ownership and control.

That was a natural part of life

When asked about how she was managing her interests and general health, Mrs Smith' spoke about regularly attending exercise classes:

> At the last meeting at [Elder Day Programe exercises classes] that I go to, I was the fastest runner, a place about as big as the [room], timed you going round. Well I was a sports girl, I'm going 90 [years of age] so I'm not a sports girl anymore. I played hockey and netball and played squash and used to go on lifesaving things, and that was a natural part of life … we work [exercise] like hell hahaha, there's a phys-ed person, a man at the exercise class. I said, "please write your programme out it would be really good when it comes to next week" … every week is different, every week has never been done before. Of course it is [good]. It makes you look forward to what you are going to do. You might be bouncing balloons, you might be walking or you might be sitting and pulling or you might be doing all sorts of things. You also get weighed, your height and all that sort of thing, talk about healthy foods. It's been quite well known. We just give $10 and that's really for the meal and you get picked up.

In a different example, low-cost community activities that considered transport, were making a regular difference to Mrs Smith's outlook on managing health and fitness. Kaumātua talked about transportation, access to healthy foods, community safety, and community access (see 'Living costs and osteoarthritis', which follows[70]) were real issues. Consequently it is likely that focussed activities which are targeted and culturally tailored, rather than one-size-fits all, will be really encouraging ('kaumātua friendly', or even 'kaumātua appropriate').

Wairua tipuna

On completion of the interview, Mrs Smith' made a brief but purposeful stop at an arrangement of family pictures in the hall of her home:

> These framed photographs, the one was carved with a pocket knife about 80 years or 100 years ago. My wairua tipuna (relatives) ... Anyway you and I have got the same waka …

Listening to Mrs Smith' as she recounted the meaning of each photographic portrait, enabled her to illustrate the 'whakapapa' of her iwi and hapū. The experience reiterated to me, the importance of values such as those naturally associated within a family setting, embodying the virtue of 'aroha', 'manāki' and 'wairua' (love, sharing and empathy, spirituality). When these meanings are combined, the image of Māori and non-Māori healthcare practitioners, weaving compassionate care around kaumātua is most powerful.

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[70] Community access refers to kaumātua access to pathways, including easy cycle paths, public parks/green spaces (if recommending increased exercise through walking).

You educate yourself

In the previous story, Mrs Smith' spoke about her preferences for services. In particular, low-cost community activities and focussed undertakings (than one-size fits all). In the following kōrero, Mrs Smith' talks about the importance of education, and her eagerness to learn about osteoarthritis-management:

> You educate yourself a bit more, and I suppose you shouldn't stop learning, you should be still going on to help yourself again.

Mrs Smith's interest in education may well have played an important role over her 90 years, particularly as there is a recognised association between learning and wellbeing (Carling-Jenkins, 2016; Pritscher & Ricci, 2015). A good life for Mrs Smith' is ordinarily rich in everyday experience. Sharing real stories between kaumātua who have imagined, planned for, and achieved a meaningful life will inspire others to try and imagine better for themselves, their whānau, and wider support networks.

Karakia is natural

When asked about being Māori and 'quality of life' and what is really important to her life, Mrs Smith' turned discussions onto the basis of living:

> Karakia (prayer), that's a personal thing. We all know that, we don't need to be told that. It's natural! In the morning at breakfast, the kitchen, what we do with others and all that.

Mrs Smith' believed that the use of prayer was normal, best delivered in a language that made sense. Relatedly, Barton's (2008) Māori-centred case study into consumer experiences of the public health system, found that cultural and spiritual care was lacking. Healthcare practitioners, uncertain about addressing the spiritual and cultural needs of patients, may find that it is helpful to build confidence via continual professional development.

Arthritis and ageing in a community

When it came to routine activities, Mrs Smith' talked about the benefits of attending hui and engaging in health-promotion activities with peers:

> Going to Māori health provider, where they have exercises. Go to the Māori kaumātua meeting, sharing ideas, learning, planning, so yes, we have a little action there too. Yes, speakers, it's interesting …

Similar to interviewee stories[71], Mrs Smith' is saying that kaumātua rōpū activities are interesting, informative and supportive. There is a lot of real experience residing within focus group hui participants, that serve as role models, in ways that are different from healthcare practitioners.

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[71] See 'Almost totally blind'; 'do-able goals'; 'I want you to worry about you!'; 'On Māori TV'.

Summarising Mrs Smiths’ kōrero

In so far as preference for services, Mrs Smith’ indicated that taking into consideration the resources available to kaumātua, was a ‘manākitanga’ indicator. In other words, focussed activities (than one-size fits all) is more likely to be kaumātua friendly or even kaumātua appropriate. When it came to living with osteoarthritis and ageing in a community Mrs Smith’ favoured learning in a kaumātua rōpū environment.

Mr Jones

The initial/basic codes that emerged from the second story (Mr Jones’ kōrero), are outlined below (Table 8):

Table 8. Mr Jones 55 initial/basic codes

Mr Jones
55 initial/basic codes

1. Impact of negative attitudes on our community
2. Negative stereotypes
3. Societal racism
4. Self-fulfilling prophecy and community ‘buy-in’
5. Positive activities are happening
6. That is what makes a community proud
7. Resist negative stereotypes
8. Relationships
9. Shared experiences
10. Community action
11. Rise and fall of a local newspaper
12. Humourous stories about whānau
13. Counterbalance marketing heft
14. Careful attention to the messag and methods you use
15. Generate real stories
16. Understand the community first
17. Community is a living ‘whakapapa’ (whānau, hapū, iwi)
18. Stories about real activities, involving tamariki, kaumātua engaging in healthy choices
19. Get positive messages about osteoarthritis-management out
20. Real stories demonstrate Māori values in action
21. Whānaungatanga (valuing everone) by representing whole family stories
22. Manākitanga is enjoyable, entertaining read for the community
23. Awhi means kids adding in their stories
24. Aroha is about breaking headlines
25. The right way to convey messages, requires a broader approach
26. Availability of healthy foods
27. Adequate physical activities
28. Supportive rōpū
29. Humour is the glue that holds human connections together
30. Humour is pivotal to conveying real messages
31. A positive attitude
32. Hone in on strengths of whānau and community
33. The community is central to wellbeing
34. The mood needs to be positive
35. Good health flourishes from positive
36. Key window of opportunity
37. Attitudinal shifts from all of society
38. Money is spent on richer suburbs not ours
39. We need better improvements around our local shopping centres
40. Fairer communication between rich and poor parts of our community is needed
41. Kaumātua have a real perspective of the needs of a community
42. It’s about disrupting the status quo
43. Collective autonomy on issues concerning kaumātua
44. An alternative approach for city councellors, council and healthcare teams is needed
45. Focus on the potentials of a community
46. Real strengths are in our stories of capacity
47. Pride in our community marae
48. The torn out bits and pieces and negative stuff sheds a negative light which is not our reality!
49. Maraenui is a vibrant community
50. Strong Māori identity can support success
51. Being able to resist negative stereotypes for Mr Jones is about being Māori.
52. Being Māori is about trying to work against something
53. If you are Māori you are working with your whole culture, your ancestors supporting you
54. You cannot take away Māori leadership, our rangatiratanga
55. It’s about activating our agency

These initial/basic codes were then reviewed and arranged into a further six higher level (provisional/organising) themes (stage-four). The provisional/organising themes follow from Mr Jones interview (Table 9):

Table 9. Mr Jones six provisional/organising themes

Mr Jones **Six provisional/organising themes**	
1. It should be shouted out, yeah! Impact of negative attitudes on our community; Negative stereotypes; Societal racism; Self-fulfilling prophecy and community 'buy-in'; Positive activities are happening; That is what makes a community proud; Resist negative stereotypes **2. Community newspaper** Relationships; Shared experiences; Community action; Rise and fall of a local newspaper; Humourous stories about whānau; Counterbalance marketing heft; Careful attention to the message and methods you use; Generate real stories; Understand the community first; Community is a living 'whakapapa' (whānau, hapū, iwi); Stories about real activities, involving tamariki, kaumātua engaging in healthy choices; Get positive messages about osteoarthritis-management out; Real stories demonstrate Māori values in action; Whānaungatanga (valuing everyone) by representing whole family stories; Manākitanga is enjoyable, entertaining read for the community; Awhi means kids adding in their stories; Aroha is about breaking headlines; The right way to convey messages, requires a broader approach; Availability of healthy foods; Adequate physical activities; Supportive rōpū; Humour is the glue that holds human connections together; Humour is pivotal to conveying real messages	**3. Negative all around us** A positive attitude; Hone in on strengths of whānau and community; The community is central to wellbeing; The mood needs to be positive; Good health flourishes from positive **4. What did they do with it?** Key window of opportunity; Attitudinal shifts from all of society; Money is spent on richer suburbs not ours; We need better improvements around our local shopping centres; Fairer communication between rich and poor parts of our community is needed; Kaumātua have a real perspective of the needs of a community; It's about disrupting the status quo; Collective autonomy on issues concerning kaumātua **5. It's a living suburb** An alternative approach for city councellors, council and healthcare teams is needed; Focus on the potentials of a community; Real strengths are in our stories of capacity **6. At the marae** Pride in our community marae; The torn out bits and pieces and negative stuff sheds a negative light which is not our reality!; Maraenui is a vibrant community; Strong Māori identity can support success; Being able to resist negative stereotypes for Mr Jones is about being Māori; Being Māori is about trying to work against something; If you are Māori you are working with your whole culture, your ancestors supporting you; You cannot take away Māori leadership, our rangatiratanga; It's about activating our agency

Mr Jones story

The second story encountered is Mr Jones (68 years). Mr Jones had been diagnosed with primary osteoarthritis in his lower back[72]. He had come from a long line of farmers, making a conscious decision to move to the more urban area of Hawke's Bay region in his adulthood. Mr Jones' had served his community the past 40 years. He had received regional awards for community work. Mr Jones' commitment to community is why he prioritises whānau, wider support networks and community as part of his story.

It should be shouted out, yeah!

When asked about his experiences of osteoarthritis and whether anything may be done to improve these, Mr Jones' spoke about the impact of negative attitudes on his own community of Maraenui:

> Maraenui, ahhh, the people they come back and say, "There's no jobs". That's a fair call … there aren't a lot of jobs in Napier and the ones that are available are there for skilled or what I call part-time, four hours here, four hours there McDonaldy type … you know! In and out, nothing you could say, "That's my career". What they haven't done is try to encourage people to be occupied. So they've said, "There's no work, you're unemployed, here's the benefit now go away and don't bother me". Sooner or later people take to what they deem to be seen as easy and to a greater or lesser degree they are actually encouraged by their peers. A whole lot of 18 year olds will get together with $10 each and buy four boxes or three and a half, you know what I mean. They'll pool their money, they're sitting the back yard of somebody's house and just you know spend just 8 hours drinking … and if they run out they'll just try and scrounge money off somebody else or bully somebody else or go and pinch off their grandmother or whatever … So, Maraenui, yeah, it's dark, it's obvious, I think it's always been like that. Well I think instead of chastising Maraenui, there aren't enough people making positive comments or stories around Maraenui. Alright. So we're not really, if the negativeness is given out often enough, we all are affected by it. That positive stuff .. it should be shouted out, yeah!

Mr Jones' was very aware of the negative stereotypes expressed through societal racism, that were being held by members of wider society in regard to Māori. Mr Jones' believed that perpetuating negative stereotypes by wider society acted as a self-fulfilling prophecy which continued to hamper Māori development, particularly when there was community 'buy-in'. The kōrero foregrounds that instead of focussing on negativity, that wider society acknowledges positive activities that are happening,

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[72] Mr Jones' had been diagnosed with lower back or lumbar spine osteoarthritis. Lumbar spine osteoarthritis is a common condition in the lower back. Mr Jones' shared experiencing on a daily basis, pain and stifffness alongside muscle spasms. His x-rays (radiograph imaging) showed boney spurs along the spine which had been irritating and compressing nearby nerves in the spine. He lived with pain, swelling and stiffness and had a visible painful gait, his level of pain was often 8/10 on a daily basis. Primary osteoarthritis usually refers to osteoarthritis which is without a trigger, such as an injury that first began to damage the joint. It therefore has no known cause and so is referred to as primary osteoarthritis (S. Bullock & Hales, 2012).

because that is what makes a community proud. For Mr Jones', it was important to actively resist and overcome these negative stereotypes.

Community newspaper

Community has a meaning that can be partly expressed by the concept of relationships, through shared experiences (Cram & Pitama, 1998). On the topic of community, the importance of sharing experiences makes sense when listening to the kōrero of Mr Jones', as he spoke about osteoarthritis-management, turning conversation back onto community action:

> … And I try to say to them [staff at the newspaper], "Look, I'm not really interested in looking at your daily rag [newspaper]", … the community started that years ago and it was to be a full sectional sort of a newspaper rag, that had stories around Maraenui – people of, places of da di da di da and that in turn was divided up into community, family, kids.… Well they've lost all that now. All that's gone into telling us how to get our immunisation. It's [community newspaper] a bloody marketing tool now that's all, piss me off. It's not an informative or an entertaining or enjoyable read, 'cos you go, "Shit, there's my Uncle, awesome … he just won the snail race of the decade or something", you know! Yeah, and the way it was written when the newspaper first started – the paper was also written in a language that wasn't academic, it wasn't social etiquette, 'cos we asked kids to write a story, you know, their story. Well it's not that way now …

Mr Jones' talked about the rise and fall of a local newspaper. The newspaper had strengthened his community, after capturing the imagination of locals with humourous stories about whānau. Overall, the kōrero raises the importance of counterbalancing marketing heft, with careful attention to the message and methods that you are going to be using.

From Mr Jones' perspective, if you want to generate real stories about a community, then you need to understand the community in the first place. Similar to Metge's (1990) harakeke metaphor[73], Mr Jones' uses the analogy of his community as a living 'whakapapa', representing whānau, hapū and iwi. So having stories about real activities, involving tamariki and kaumātua engaging in healthy choices, will help to get positive messages about osteoarthritis-management out, across a community.

Real stories in and around the community, will demonstrate Māori values in action and community environments, that are supportive of kaumātua. The stories of 'whānaungatanga' (sense of family connection) appear alongside 'manākitanga', by the manner in which the newspaper strived to produce an enjoyable, entertaining read for the community. What is more, there is 'awhi' (assistance) represented in the kōrero, as Mr Jones' talks about asking the kids to add in their stories. Importantly, 'aroha'

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[73] Similar to the harakeke metaphor, the community is a living whakapapa and represents a whānau, hapū and iwi. The rito (centre blade) can represent tamariki, surrounded by its parents all the way through to kaumūtua (Metge, 1990).

(reciprocating support) value is seen there in the kōrero, in the making of breaking headlines.

These elements ('whānaungatanga', 'awhi', 'aroha') are an exemplar for the right way to convey messages about osteoarthritis-management, which requires a broader approach. Some examples of priorities brought to light across the cohort so far, include availability of healthy foods, adequate physical activity facilities, supportive rōpū and positive messages about a community. Essential to these activities will be tīkanga Māori (cultural principles) and inherently, leveraging the distinctiveness of Māori humour. Humour is after all, according to Mr Jones', the glue that holds human connections together, and will be pivotal to conveying real messages of wellbeing in a community.

Negativity all around us

When asked about osteoarthritis-management, Mr Jones' shared perceptions about his community:

> Alright. So we're not really [pause] … if the negativeness is given out often enough, we all are affected by it. So, if some positive stuff … So, yeah, our community it's dark, it's obvious, I think it's always been like that. Well I think instead of chastising Maraenui, there aren't enough people making positive comments or stories around Maraenui. That's what you are talking about managing your health, well how can we do that when we got this negativity all around us.

When asked about osteoarthritis-management, Mr Jones' spoke of the benefits of a positive attitude for community health and wellbeing. It was important that the strengths of whānau and community be honed in on. The community was central to wellbeing and unless the mood was positive, it was difficult for good health to flourish from that.

What did they do with it?

Mr Jones' talked about a key window of opportunity, that required attitudinal shift from sectors of society:

> Yes, you look at Taradale, they did a refurbishing of Taradale … marketing … they went all out – they would have spent hundreds of thousands in its shopping centre. Now Maraenui had a shopping centre, still has what you might call a shopping centre – what did they spend? I think about $19 thousand. What did they do with it? They put some cobbles along the footpath, street front, they've made five planter boxes and they've chucked in some shitty scrub! Yeah. I mean, if you do that and you look at that and you say if it were suburban renewal, revitalisation – what does that look like? Does it need to be and could that be equally distributed? I mean Pirimai is just the same. Pirimai is getting to be ghetto Maraenui and it's a shame because to me it needn't happen. It's wasted on Taradale too because there's empty shops - where as Maraenui there's hoardes of kids outside the dairy everyday and it's a real busy metropolis. Yeah, well that's nothing truer than that. Like I've always said, you

> know it's a living suburb! I mean you know, and the problem is that those who are on the street are the ones that know about street – you know, but others tend to ignore that resource.

Mr Jones' talked about more money being spent on suburbs that he associated as having a higher socio-economic status. Those suburbs with lower deprivation, had received better improvements around the local shopping centres, to greater monetary value. Mr Jones' is saying that things would be much fairer if communication between groups living within the community was behind these changes, than imposed.

Mr Jones' kōrero casts considerable expertise on development issues within a community. Kaumātua have a real perspective of the needs of a community that naturally seek to disrupt the status quo. By including kaumātua views and 'mana whenua' in decision-making processes, satisfactory outcomes may be achieved that directly inform health issues for whānau.

It's a living suburb

As the conversation progressed with Mr Jones', the idea of negativity developed into suggesting an alternate approach:

> I mean every city, size over 50 odd 55 thousand will always have its quazi getto type suburb and it's not always a whole suburb, it could be half a suburb but yeah. Yeah, and you know my response to those critics is simply to say, "Aren't you lucky you don't live there? Or do you think if you lived there it would be better? What will you do to help?" Exactly! But I can't get to the buggers all the time, there's some snarkey, snarley things. Then on the other hand if you're in power and making decisions on what [health or council] resources get allocated to what suburbs, the last one you want to support is the one that's already under resourced, it's already the ghetto.

The kōrero represents a window of opportunity available to city councellors, their council and healthcare teams, to focus on the potentials of a community. Real strengths are represented in the stories and capacities of community members, appropriate resources that promote better communication, will help to unlock these stories.

At the marae

In so far as other people in the community and their experiences with osteoarthritis, Mr Jones' spoke with pride about a community marae, which had been established in 2007:

> … I mean at the marae [Pukemokimoki], they're actually using the marae to do catering courses and operating it, it's being run by the EIT [Eastern Institute of Technology] … but nobody knows about it! Everybody just drives past thinking, "Oh that's the marae". Well the people of Napier should be told that the marae that was originally bloody built, blah, blah, blah, it is taking in and holding

> catering classes or cheffing [cookery] classes or whatever, as well as other things that are going on there or whatever. Now only those who go there, know that. What I'm trying to say is you need to tell the whole of Napier man. On marae is where we are speaking the reo, kawa being carried out, singing our waiata, kaikōrero and kaikaranga. It's a living, bustling, busy place and it's right here. Yeah because it's some of that positive stuff, it should be reported, it should be shouted out, yeah! Otherwise you get the same story which talks about the garbage, refuse and torn out bits and pieces, you know all that negative stuff, yeah.

The, 'torn out bits and pieces' and 'negative stuff', were conveying his community in a negative light, which was not a reality for Mr Jones'. As far as Mr Jones' was concerned, Maraenui was a vibrant community. The kōrero articulated that strong Māori identity was something that could support success, rather than being something which is perceived by wider society that contributes to a lack of success.

Being able to resist the negative stereotypes for Mr Jones', was about being Māori. He spoke about the implications, when a lot of people think that being Māori is about 'trying to work against something'. According to Mr Jones' if you are Māori, you are 'working with your whole culture', you also have your ancestors, your family all 'behind you supporting you', which is not something that you have to 'fight against'.

In sum, the kōrero provided by Mr Jones' refuses to accept that the dream of Māori attaining leadership ('rangatiratanga'), may be taken away. A real response to the negative stereotypes and role of osteoarthritis-management resources, will be about kaumātua, their peers, whānau and wider community, activating their own agency.

Summarising Mr Jones kōrero

Right across the kōrero of Mr Jones', strength-based kōrero, Māori leadership was prioritised. The stories of Mr Jones' community recognised 'whānaungatanga' (valuing everyone, sense of family connection), 'awhi' (assistance) and, 'aroha' (reciprocating support) as an exemplar for conveying messages about osteoarthritis-management[74]. Useful resources incorporating an evaluation lens, drawing on culture to set the baseline could help to avoid misunderstandings and establish a set of expectations. An equity lens within resources will be crucial to identifying mutual incentives for practitioners and kaumātua to join and sustain a partnership.

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[74] Whānaungatanga refers to valuing people, 'awhi' refers to assistance and 'aroha', compassionate, reciprocating (balanced relationships) within the process of osteoarthritis-management.

Mr Davies

The initial/basic codes that emerged from the third story, Mr Davies’ kōrero, are outlined below (Table 10):

Table 10. Mr Davies 46 initial/basic codes

Mr Davies
46 initial/basic codes

1. Family of shearing contractors
2. Youth in sheds, scrub cutting
3. Social services trust
4. Truck driving
5. Employment is my story
6. Equipment did not meet safety standards strained his joints
7. Osteoarthritic joints under stress
8. Poor posture
9. Jobs can place stress on joints, repetitive motions, heavy lifting
10. Employers responsibility
11. Need to drive down the record of safety standard breaches, accidents, death of Māori
12. Tikanga of respect, generosity, care for others
13. Manākitanga elevates the status of all
14. Health equity (Oritetanga)
15. Shearing sheep and joint injury
16. Prevent serious injury and illness in the first place
17. Children without a parent
18. Our Dad, killed in an accident
19. A widowed spouse
20. Family without their principal wage earner
21. Grieving parents, friends, workmates is a reality.
22. Human grief and suffering was immeasurable
23. Safety steps that save lives
24. Put fences at the top of the cliff
25. Awhi one another to get there
26. Wealth creation is not seen as an end in itself
27. Balancing financial viability with social and cultural priorities
28. Protecting Māori mana and people, responsibility, accountability in business management
29. Healthcare services are profit-oriented, kaumātua are not
30. Professional and community visions (kotahitanga) is a baseline to avoid misunderstandings = shared expectations
31. Mutual accountability
32. Reciprocity
33. Working life and mokopuna
34. Produce quality work consistently
35. Pass the values of work ethic down to grandchildren
36. Relational epistemology that is culturally and socially constructed
37. People and the environment are in a relationship
38. Whānau involvement is a vital ingredient to make activities sustainable
39. Working hard is instilled from a young age
40. Work tirelessly
41. Employer willing to break the law not paying for sick leave – stressful
42. Survivor identity, highly adaptable and high in adaptability
43. Building strong relationships can help you get through
44. Values and track record help you to overcome challenges
45. Oritetanga (equity)
46. Kaumātua need allies in the community and healthcare professions

These initial/basic codes were then reviewed and arranged into a further fifteen higher level (provisional/organising) themes (stage-four). Six provisional/organising themes follow from Mr Davies interview (Table 11):

Table 11. Mr Davies six provisional/organising themes

Mr Davies **6 provisional/organising themes**	
1. Osteoarthritis and my employers Family of shearing contractors; Youth in sheds, scrub cutting; Social services trust; Truck driving; Employment is my story; Equipment did not meet safety standards strained his joints; Osteoarthritic joints under stress; Poor posture; Jobs can place stress on joints, repetitive motions, heavy lifting; Employers responsibility; Need to drive down the record of safety standard breaches, accidents, death of Māori; Tikanga of respect, generosity, care for others; Manākitanga elevates the status of all; Health equity (oritetanga)	**4. You had to have accountability** Wealth creation is not seen as an end in itself; Balancing financial viability with social and cultural priorities; Protecting Māori mana and people, responsibility, accountability in business management; Healthcare services are profit-oriented, kaumātua are not; Professional and community visions (kotahitanga) is a baseline to avoid misunderstandings = shared expectation; Mutual accountability; Reciprocity
2. Dad was a hard worker Shearing sheep and joint injury; Prevent serious injury and illness in the first place	**5. Lost on our moko** Working life and mokopuna; Produce quality work consistently; Pass the values of work ethic down to grandchildren; Relational epistemology that is culturally and socially constructed; People and the environment are in a relationship; Whānau involvement is a vital ingredient to make activities sustainable
3. Killed in an accident Children without a parent; Our Dad, killed in an accident; A widowed spouse; Family without their principal wage earner; Grieving parents, friends, workmates is a reality; Human grief and suffering was immeasurable; Safety steps that save lives; Put fences at the top of the cliff; Awhi one another to get there	**6. It's all about building relationships** Working hard is instilled from a young age; Work tirelessly; Employer willing to break the law not paying for sick leave – stressful; Survivor identity, highly adaptable and high in adaptability; Building strong relationships can help you get through; Values and track record help you to overcome challenge; Oritetanga (equity); Kaumātua need allies in the community and healthcare professions

Mr Davies story

The third story encountered is Mr Davies (59 years). Mr Davies had been diagnosed with secondary osteoarthritis in his lower back, both hips and knees at the age of 45 years[75]. He was from a family of shearing contractors. Mr Davies' had spent most of his youth in the sheds or scrub cutting. He ran a social services trust in his adulthood. More recently, he had been truck driving full-time the past nine years, which is why he prioritises his employment as part of his story.

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[75] Mr Davies had been diagnosed with secondary osteoarthritis in both hips and knees. His condition had worsened over time and was something which his doctor had put down to his lifelong history of manual labouring jobs. Mr Davies case was different from Mrs Smith and Mr Jones', because he was living with secondary osteoarthritis which does have a known cause. Alongside truck driving, Mr Davies had a history of the ongoing challenge of weight control (obesity), repetitive trauma from getting in and out of a logging truck. He also had a history of gout. He lived with pain, swelling and stiffness and had a visible limp, his level of pain was often 8/10 on a daily basis.

Osteoarthritis and my employers

The types of jobs over the course of Mr Davies' life, had involved hard physical labour:

> Well, my arthritis, I think driving the truck has been the cause of all my problems … My employers know about problems with the seat in my truck, but they haven't done anything to replace my seat in the truck. My seat is not up to the safety standard and they will not do anything to fix it.

Years of using equipment on the job, which did not meet the safety standards, had put Mr Davies' osteoarthritic joints under stress. Otherwise poor posture, such as sitting in a truck seat which lacked the ability to be adjusted for maximum comfort and safety, had strained his joints. Employers taking responsibility for the care of their employees, will be appalled by Mr Davies' story.

Efforts will only go so far without cultural change in our workplaces. We do need to drive down the record of safety standard breaches, accidents and death of Māori (Davie, Derrett, Maclennan, Wilson, & Wyeth, 2014; Turia, 2007). In contrast, from a Māori values perspective, the tīkanga of respect, generosity and care for others, will underpin safer culture in the working environment. Demonstrating 'manākitanga' (kindness) for example, will be exhibited in behaviour that elevates the status of all. People caring about people, within the context of health and safety, will make achieving health equity ('oritetanga') more likely.

Dad was a hard worker

When asked, how he was managing osteoarthritis around home and in the community, Mr Davies' talked about the impacts:

> My Dad was a hard worker, used to be a sharing contractor. He probably suffered from arthritis, like I am now. We spent our youth out in the sheds, scrub cutting, yeah. But times have changed, we're far better off having a 40 hour a week job, it's all about security now. Oh we used to start at five in the morning and finish at five in the evening. Well a lot of the time, we would carry on till we finish the shed. No it was just part of our upbringing. The employer were usually around the shed when the sheep go out so … they can tell when their sheep aren't being treated or being shorn completely.

Handling sheep as Mr Davies' had done, has been associated by the Department of Labour (2008), with the development of joint injury. Shearing sheep for example, while they are damp or wet has been noted for increasing the risk of workers developing arthritis arising from related injury (Department of Labour, 2008). Reducing work-related health and safety risks, involves identifying and understanding these, to prevent serious injury or illness in the first place (National Center for Farmer Health, 2011, p. 1).

Killed in an accident

In another example, Mr Davies' talked about safety in the workplace and the loss of his Dad, in a forestry accident:

> … Our Dad, sadly he was killed in an accident in the bush in 1979. Mum coping once Dad passed away, yeah … I worked truck driving since, which I enjoy just doing the 9-5 [hours].

Children without a parent, a widowed spouse, the family without their principal wage earner, grieving parents, friends and workmates is a reality. The findings are substantiated by media reports, that suggest the Forestry industry remains the most dangerous sector in which to work (Papatsoumas, 2014)[76]. Logging since the early 1900s has been substantiated by H. Armstrong (2017) for being extremely dangerous for Māori.

Accidents and deaths for Māori and Pacific peoples remain higher than non-Māori (Statistics New Zealand, 2014). From a practitioner perspective, sometimes safety comes down to simple steps that save lives. For instance, a seat belt put to use in a bulldozer, safety equipment worn or installed. In other words easy, 'cheap' and 'simple' ways may prevent workplace death and serious injury, a brief conversation could be life changing.

In a similar way to handling sheep (see above, "Dad was hard worker"), if hazards are known and managed, employers and employees when aware, will be able to follow safer practices. Relevant to osteoarthritis-management, waiting for workplace injury or fatality to gain publicity, is similar to 'ambulance at the bottom of the cliff' scenario. Focussing on 'putting fences at the top of the cliff' will affect everyone, it is important not only for industry, employers and employees to not only take notice but responsibility to 'awhi' (assist) one another to get there.

You had to have accountability

When asked about what being older, and Māori, living with osteoarthritis meant in today's society, Mr Davies' talked about his whānau:

> I got involved at one point managing Māori social service provider as a trustee. I went on as a trustee, they were going nowhere fast, they needed help and I put my hand up. A lot of our people were, when you had funding you had to have accountability … I wasn't afraid to take it on, if I didn't it was going to go down the tubes anyway. They were set up to help people, especially the young kids, wayward. The placement into homes. It's still going cos when I finished they were in credit. The office job I was there for just under two years. Well it [the job] did take it's toll on me. My [family member] used to be in the

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[76] Māori aged 25-64, particularly men, are more likely to be injured at work, diseased, ill or even killed because of the work which they do, than non-Māori. The types of occupations in which Māori men are over-represented are reflected in their employment, within high-risk labour industries.

> administration there … so between us we managed to turn it around. I mean they had a policy procedure manual, but a lot of it they didn't understand it. The manual is [good, you got it all there as a back up to run the thing].

Work experience in shearing and more recently truck driving had been interspersed working for two years, running a Māori social service provider. Wealth creation was not seen as an end in itself, evident in the way that Mr Davies' talked about the challenges of balancing financial viability with social and cultural priorities. The kōrero identifies elements, engaging kaitiakitanga (guardianship) in protecting Māori 'mana' and people, responsibility and accountability in business management, and to the communities Mr Davies' was engaging.

From a healthcare practitioner perspective, the kōrero brings home to one that healthcare practitioners and services (services) are profit-oriented, keeping in mind that kaumātua are not. It is important to keep the distinction of profit-oriented healthcare in mind, and to develop a strategy that is aligned with the interests of kaumātua. One way to address differing priorities is by collaborating with kaumātua and respective healthcare services, to facilitate frequent and candid conversations about capturing community vision ('kotahitanga'),.

Setting a baseline ('kotahitanga') may help avoid misunderstandings, and establish a set of shared expectations. Research suggests that it is crucial to identify mutual incentives for both healthcare practitioners, patients and their communities to join and sustain a partnership. 'Kotahitanga' is a value that requires frequent and candid conversations regarding practitioner and community visions of osteoarthritis-management.

Within the kōrero of the participants engaged in the present study, is a sense of mutual accountability and responsibility. As Mr Davies' discusses his work in social services, reciprocity and responsibility intersect with many areas of his life. It involves maintaining a healthy and balanced life and leadership, through modelling healthy behaviour and wellness in the workplace.

Lost on our moko

When asked about what was really important to him in his life, Mr Davies' spoke about working life and mokopuna (grandchildren):

> No I think it's got a lot to do with, how you do your job. I believe that you should do your job as though you own the business. Well, that's, I've always worked like that. I think it has been lost on our moko, yes. My moko were quite naughty when they were younger. Now they know it was all sensible what we taught them. Then they get their own kids. In terms of them having an easier life than me, I think we had a pretty good life. We spent most of it in the countryside so … too many distractions in town.

Mr Davies' parents had worked hard to survive, and these values were passed on to him. Certain principles guided Mr Davies' work behaviour and had enabled him to produce quality work consistently, than being prodded by management to stay on track. He talks about the importance of passing the values of work ethic down to grandchildren.

The kōrero acknowledges a relational epistemology, which is culturally and socially constructed. There is a fundamental belief that people and the environment are in a relationship with one another. Whānau involvement is a vital ingredient in osteoarthritis-management, and involving the extended family and community of kaumātua must be acknowledged to make activities sustainable.

It's all about building relationships

Mr Davies' spoke about his experience of working and living with osteoarthritis in today's society:

> Well the middle management guy at work wanted me put off work 'cos of the length of time I've been off work for my arthritis – he wanted to lay me off, but my foremans and my managers stuck up for me … so ... I been there nine years. I think my work acumen paid off 'cos I get on well with the other managers in the other departments as well, it's all about building relationships. But times have changed … life is a bit tougher now I think. No matter what you do now it costs money, more pressures yeah. Less jobs …

Mr Davies' ethic of 'working hard', had been instilled in him from a young age. It was his belief that hard work and diligence have a moral benefit, which had led to him working tirelessly, demonstrating that he could succeed, in spite of his experience of osteoarthritis-related disability. Although Mr Davies' shared that an employer was willing to break the law by not wanting to pay for sick leave, or otherwise terminate his employment. The experience of feeling that he might be laid off for taking sick leave was stressful, but Mr Davies' was a survivor identity, highly adaptable and high in adaptability.

Building strong, positive relationships at work and 'giving it his all' everyday, was part of a strong work ethic which Mr Davies' worked by. Represented in the kōrero, Mr Davies' approach, values and track record, had helped overcome the challenges of possible termination of unemployment. The kōrero emphasises the 'oritetanga' (equity) value, accenting a need for allies in the workplace, who do not stay silent in the moments when discrimination occurs, that avocate for equity.

In osteoarthritis-management, kaumātua need allies in the community and in the healthcare professions. Engaging these segments of the community with multi-lateral learning, could target the oppressed and the oppressors. Accordingly, everyone will benefit from the transfer of knowledge in the process of advocating for equity. At the organisation level, acknowledging that there is a problem that needs to be changed, in particular resources, implementation and follow-through, monitoring and evaluation to enable real change.

Summarising Mr Davies' kōrero

When it came to talking about osteoarthritis relative to today's society, 'kaitiakitanga' (active guardianship, responsibility and accountability) was emphasised by Mr Davies'. Collaboration and commitment or unity ('kotahitanga') with workplace support and worksafe networks and responsibility by everyone was noted. Having conversations about a community vision of osteoarthritis-management, and the importance of an equity lens will gauge whether understanding, trust, assurance and confidence is being established in activities.

Summarising three stories

Osteoarthritis-management for Mrs Smith' was all about education and learning in the community. Osteoarthritis-management for Mr Jones' was all about his community. Osteoarthritis-management for Mr Davies' was all about work ethic. The voiced concerns of Mrs Smith', Mr Jones', and Mr Davies' were privileged, to show how these connected to the lived experience of osteoarthritis.

Remaining key-kaumātua interviews

In the current section, I aim to describe the remaining kaumātua voices, to explore their understanding of their own world. Participants reported osteoarthritis symptoms at various sites. Of the participants who had received joint surgery, these included hip (n=2) and knee (n=3) joint replacement surgery.

All of the participants (n=20) reported pain as part of their experience of living with osteoarthritis-related disability (mobility limitations). These symptoms were reported in their fingers (n=3), hips (n=7), knees (n=8), shoulder (n=3) and neck (n=3), the nature of symptoms for one particular kaumātua, are discussed in the first story.

Views, priorities and perspectives

Your life just narrows down

When asked about living with osteoarthritis, kaumātua talked about managing the effects of the condition on weight bearing joints, such as the knees:

> … the pain [of osteoarthritis] is constant, you can't sleep you can't settle, the pain is just intense and just goes on, and on, and on the whole time. Nothing you can do. Some of the pills the doctor gave me, one lot god I got awful, I used to have heinous nightmares, like they were just awful so I woudn't take those, those were scarey, I wouldn't take those. Your life just narrows down when you can't do things and you lose your balance, like because I was falling

> over and tripping. Because in my head I was lifting my feet, but they weren't actually lifting as much as I thought, I wasn't lifting them at all. When the joints just disintegrate it's really quite difficult. When you are independent and your used to doing things yourself, because I like pottering around, I cut the grass (Kaumātua 3).

The reality of living with osteoarthritis for kaumātua, is prioritising the role of medications. Although we know through the literature, that management could be much wider[77].

I'm not alone

Most kaumātua interviewees, expressed the belief that osteoarthritis was a common condition which was being under-diagnosed. They felt that there were many older-Māori with undiagnosed osteoarthritis:

> … I'm not alone, I think there are many kaumātua out there that I have met that sound like it is osteoarthritis, but they've not had it checked out (Kaumātua 15).

Across Aotearoa New Zealand, Māori are suffering more from arthritis at a younger age, but are delaying presentation to tertiary orthopaedic services[78]. Threats against kaumātua and public health, breaches 'manākitanga' (kindness[79]) and recognises the need for greater respect, generosity and care in making sure a diagnosis is not missed or delayed.

It's normal for getting old

A reoccurring theme from kaumātua interviewees concerned a desire to learn more about managing their symptoms. Many participants, struggled to know how the condition may potentially be managed. One kaumātua for example spoke about trying to obtain information about their condition:

> Oh well the doctor just checks … pushes here … I feel all the tingles and the pricks and everything like that … says it's normal for getting old, but I've had it for years and years, don't know what [osteoarthritis] it is [means] (Kaumātua 11).

Many kaumātua interviewees, wanted to know what they could be doing to help themselves. Most expressed the controversial belief provided by their doctor that osteoarthritis was due to older-age[80]. The same expression has been noted in

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[77] The nature of osteoarthritis-management activities can encompass a wide-ranging spectrum of activities and supports. For example, specific exercise regime, managing one's diet and personal care such as dressing oneself, the use of mobility aids and involvement of social supports and networks.

[78] Recognised in the findings of Buddicom, Poutawera, Singleton, and Vane (2013) are that delayed presentation may relate to "negative attitues towards surgery, poor doctor-patient communication in the primary or tertiary care setting, or socio-economic constraints" (p. 1).

[79] 'Manākitanga' represents in the present study, kindness (caring for other people's wellbeing).

[80] That osteoarthritis is due to older-age is controversial for being held as an ageist misconception. Osteoarthritis is most closely related to risk factors, such as joint injury, obesity, genetics, or anatomical factors which are affecting joint mechanics. Age-reated changes in the body increase the propensity to

gerontology literature for being a common ageist misconception, (DeBrew, 2015; Hooker & Phibbs, 2017; Lagacé, Laplante, Lavallée, Robichaud, & Tanguay, 2012; Regan, 2009).

What I can do to help myself

One interviewee raised the idea that being informed, helped to make the right choice in the face of difficult decisions:

> Osteoarthritis, it's about falls and prevention and things we need to be doing, I would like to know more about what I can do to help myself. Well I like to be kept informed (Kaumātua 17).

Kaumātua admitted to having limited knowledge of osteoarthritis-management strategies.

What I should be doing

These findings of wanting peers to obtain the help required, to make informed changes, were echoed across the cohort, as one kaumātua commented:

> On Sunday I woke up and I could hardly move my, bend my knees. Could be the arthritis … and um … and so it was too cold yesterday so hahaha. The cold, yes … and pain in my back. My knees are coming right, I thought I'd better get some advice, what I should be doing. My doctor says it's obviously old age playing up on me … ahhh … there are a lot of us out there that don't know what it is, haven't got help for it, I want to know more about what it is, about what I should be getting or taking to be able to cope with it … just get a bit creaky, worries me so! Sore, yes. Most of the time I can manage it, you know do less (Kaumātua 10).

Similar to the previous example ('I am not alone'), what these results show is that osteoarthritis is common among kaumātua, with many living in the community that do not know what their joint pain is.

What is causing it

In the following kōrero, kaumātua expressed a sense of powerlessness and a desire to know more about their diagnosed condition:

> I would like to talk to someone about my joint pain: What is causing it? I would also like to talk to someone, especially about my diet. I wonder if I should be taking anything special for my knee, it's so frustrating I've spent a fortune visiting the doctor and still don't bloody know what the arthritis [osteoarthritis] actually is (Kaumātua 14).

The kaumātua interviewee explained that they did not understand why they experienced joint pain, even after attending consultation with their doctor. The kōrero

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osteoarthritis but provides an incomplete picture, conversations relative to risk factors being more on point (S. Anderson & Loeser, 2011).

tells us as healthcare practitioners, that a lot more could be done to raise awareness of the condition and management strategies.

In summary the current section ('Kaumātua talk about osteoarthritis') confirms that osteoarthritis is a known problem for the kaumātua community. Potentially the condition is going under-diagnosed, with gaps occurring in management strategies. As well, breaches of 'manākitanga' such as dismissing osteoarthritis as a feature of old age, implicating the type and amount of informed osteoarthritis-management treatment being offered, requested and received.

Osteoarthritis-management and whānau

When kaumātua did talk about managing their condition, they quite often spoke about involvement of whānau members. The question, 'what's really important to you in your life' was a catalyst for in-depth conversations bringing the essence of whānau, into the present.

I don't want to worry them

Whānau played an important role in the wellbeing of kaumātua and in the management of osteoarthritis:

> It's harder for me as the whānau all are working, doing their own jobs … that's good … so I don't like to ask them or bother them about my stupid old knees. But I find my mobility is deteriorating and I don't want to worry them with my ailments, I got to work it out (Kaumātua 5).

The priorities of kaumātua, suggested that living with osteoarthritis was as much about whānau, as it was an individual concern. Most kaumātua shared their observations about whānau practices that were occurring at home and in the community, as a significant motivation factor. Kaumātua generally supported the notion that the basis of managing a chronic condition is about the wellbeing of individuals and whānau operating as a whole to achieve health and wellbeing.

It's raining

In a different example, kaumātua spoke of worrying about peers not being dressed well enough for the weather conditions:

> Yeah, apart from that, this is numb. This is I don't know. Yeah it is the cold. I wear gloves to keep them warm, yeah. I've got mittens, I've got gloves. When you go to tangis, you keep yourself warm. Not a lot of people over there. You know I used to say, "you got to think of the living now". We get some stupid koroua, you know they like to think you can go on and on, talking on and on and it's raining and you're standing out there. While you're over there, I said to one of them, "hey what with, where's the umbrella's? Are they too proud to stand with an umbrella over them?" One of our kuia's told him off. You know, yeah, now they go out there and hold a brolley. They got to learn to look after themselves. They trying to be the – a lot of men they stand out there in the

> rain, humble I suppose. In the wet. Our kuia's are the same, see my mum, when she got a bit older. It's a long day, you sit out there from 8 in the morning till 8 at night. Sometimes you don't even have a cup of tea, you don't' even have lunch. You know if it's a big crowd coming in all the time. They don't even know how to say, arrange – OK we'll have two go and have a cup of tea and the kāranga, you know just have your cup of tea. But some forget and they go on and on and on- you go back and relieve the other one - go have a cup of tea, that's how it should be (Kaumātua 5).

The kōrero indicates that kaumātua are a great support of one another and through these networks, changes may happen for betterment and wellbeing.

He [son] depends on me

As kaumātua shared how they were managing their osteoarthritis around home and in the communtity, the observation was made that their children depended on them and that was a reason for seeking control over their condition:

> My son, this really pains him, he's like, he [son] depends on me. So I can't let him down with my health issues. Don't want to end up like my Mum, she had a terrible back, unable to walk (Kaumātua 6).

In most instances kaumātua felt that osteoarthritis was a burden, which hindered their ability to assist younger family members. The burden appears to arise from past observations of close family members' experience of osteoarthritis-related disabilities. Even so, direct family experiences with osteoarthritis were not discussed as translating into an understanding of causes, symptoms, or modern-day ways to prevent, detect, or manage the condition.

Putting on a brave face

One interviewee spoke about their perception that osteoarthritis could be incredibly limiting and frustrating for kaumātua:

> They (kaumātua) might say they aren't in pain but don't worry [nodding head as if to say, no that often is not the case – they are in pain but putting on a brave face (Kaumātua 3).

Kaumātua considered that osteoarthritis-related pain will lead to the experience of whakamā (frustration, powerlessness). Pōtiki-Bryant (2016) maintained that often Māori living with disability, unable to fulfil desired roles in their whānau as they would like to, feeds back into the whakamā cycle (Pōtiki-Bryant, 2016).

In addition to the experience of whakamā, kaumātua talked about men being humble ('Māhakitanga'), a trait that is often referred to in 'te ao Māori' as the mark of a rangātira (leader) (see, "It's raining"). The kōrero indicated that kaumātua are a great support of one another and through these networks, positive changes are happening to mitigate these.

Kaumātua knowledge about osteoarthritis

When kaumātua were asked about their knowledge and awareness of osteoarthritis, a range of conversation transpired. Observations across the cohort, revealed a range of challenges faced by kaumātua interviewees.

Stick falls over everywhere!

Kaumātua were asked to talk about their experiences with osteoarthritis and whether anything might be done to improve these. Similar to a previous kōrero (see 'Putting on a brave face'), the experienced emotion of feeling whakamā, was mirrored by kaumātua:

> The [walking] stick falls over everywhere! … the National Services [Club], and I've been trying to go in without my stick. I had my stick because I've had a number of falls … but I've been trying to go into the Club without the stick … you know, so I'm just very, very careful when I walk. So I've gone two Fridays now without me stick … cos we park, you know I have a disability sticker and it's not far to walk in so, then you go and sit down anyway (Kaumātua 11).

Aside from the nuisance of a walking stick falling over, making a noise and attracting attention, using a mobility aid could make the person look abnormal or unusual. The kaumātua interviewee expresses whakamā over using a walking stick.

Men … to do with pride

Gender differences were evident as kaumātua responded to being asked to talk a little bit about themselves:

> Men .. probably a lot to do with pride. Men, I think in the sense of getting help when we're in pain, I think they try and work it off. It doesn't work that way with aches and pains. It's a major old thing I guess. Pride I suppose, probably a lot to do with pride. Once they know what to do it's easier. Well one would hope so that they'd learn how to look after themselves at a young age (Kaumātua 3).

Kaumātua observed that men were typically anxious of diagnosis impacting on pride, after potential loss of their ability to work and get around without assistance.

Use it or lose it

Kaumātua shared key areas relative to obtaining diagnosis:

> Yes I have had an x-ray – osteoarthritis I was told. I think so, yeah, use it or lose it, got to keep moving down there [pointing to knees] … (Kaumātua 14).

Kaumātua pointedly spoke that the best way to off-set problems that come with ageing, was to keep the joints moving. Although there is some discordance that the philosophy of 'use it or lose it' prevails, since during a flare-up episode of osteoarthritis, it is recommended to rest the joint[81] (Arden et al., 2016; Cooke, Cooper, Lee, & Shield, 2017).

No hinu (oil) left

Likewise, another interviewee made sense of their diagnosis and the cause of their joint disease:

> That's the thing with arthritis … no hinu (oil) left around the joints … which is why they rub, bone-on-bone, pain and stiffness. So it makes sense to find a way to include those sorts of foods in your diet that have that in it (Kaumātua 15).

The kōrero shows the thought-cause of osteoarthritis, and interest for incorporating more fats and oils into the diet. Although there is some discordance, that more fats and oils in the diet can assist osteoarthritis symptoms, the general recommendation takes a broader view of a balanced healthy diet and lifestyle (Rayman, 2015)[82].

The weather's turning

Another observation provided by kaumātua, was that osteoarthritis was caused by meteorological elements of the weather:

> I was looking at my knuckles. The weather's turning. It will get damp and cause my fingers to start aching, oh I better warm up the room (Kaumātua 6).

Kaumātua shared the belief, that there is a connection between osteoarthritis and the weather. Even so, the current osteoarthritis-management literature suggests that changes in weather factors, do not appear to cause or exacerbate osteoarthritis (Bennell et al., 2016). Particularly in an individual who is otherwise healthy.

Diet

When asked about how they were managing their osteoarthritis, kaumātua talked about non-traditional remedies, such as dietary management:

> Diet [I cook very little]. I don't know about nice and trim, I am overweight. I eat what I feel like, let's put it that way, um cooked things sometimes, yeah. Easy meals let's put it that way. I am overweight and I wonder if that is making my knees worse. Exercising might make it worse? (Kaumātua 14).

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[81] When an osteoarthritic joint is hot and swollen and more painful than usual, the standard recommendation is to rest the joint and immobilisation. For instance, in the case of a knee or hip, not putting weight on the affected side. Instead the use of crutches for walking during the painful period is usually recommended (Arden, Bijlsma, Dalbeth, Doherty, & Hunter, 2016).

[82] The common recommendations based on best practice is to focus on adopting dietary cholesterol-lowering strategies by dietary means (cholesterol lowering strategies refers to the consumption of sterol spreads or drinks). Additional recommendations include losing weight (if overweight) with combined exercise; adopting safe levels of sun exposure (or taking vitamin-D which is thought to affect joint articular structures); eating green leafy vegetables (or taking vitamin-K, thought to affect cartilage metabolism of the knee for example); finally, as the kaumātua interviewee recommended eating oily fish twice a week (Rayman, 2015).

Kaumātua believed that being overweight can worsen osteoarthritis of the knees, which was recently been substantiated by Apaydin et al. (2017)[83]. An additional interviewee belief, concerning exercise is in contrast from what we know. Namely, that during non-acute stages of osteoarthritis, exercise helps to maintain healthy weight (versus too much rest[84]), which can cause osteoarthritic joints to become stiffer and lose their range of motion (J. Allen et al., 2017).

I wasn't telling anyone

In a different example, kaumātua shift from querying the cause of joint pain, to talking about their reasons for delay in seeking diagnosis and treatment:

> I wasn't telling anyone anything, I didn't want them [family and friends] to worry. How do we do that, delay diagnosis and speak about our health concerns]? Why six years? Well we self-diagnose sometimes, can leave going to see the doctor for too long, it's just old age (Kaumātua 15).

Kaumātua talked about struggling to cope with obtaining a diagnosis, resonating with other participants that kaumātua did not think anything could be done to help age-related osteoarthritis[85]. In summary, the current section ('Kaumātua knowledge about osteoarthritis') confirmed the challenges, that permeated the beliefs and understanding of kaumātua. Their limited knowledge of osteoarthritis-management requires improvements.

Living costs and osteoarthritis

Kaumātua were asked about how they were managing their osteoarthritis in the home and community. In terms of home ownership status, most of the participant homeowners privately owned, or their family trust owned, their homes (n=18) and the remainder were renting (n=2). A few were either borrowing funds and using the home as security or receiving help with housing and living costs by Work and Income New Zealand (WINZ) (n=4). Most participants were dependent on government pensions for day-to-day living expenses (n=14) and/or savings.

The remainder of participants were working full-time (n=6), part-time (n=3) or disability benefit (n=1). A few spoke of obtaining governmental assistance, borrowing money to help cover some unexpected costs such as dentail bills and eye prescriptive glasses, which they were paying back. Many shared issues of affordability in different areas of their lives, including the cost of food (n=5), heating (n=18), rent (n=1), petrol

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[83] Apaydin et al. (2017) recently advocated that weight loss has beneficial long-term effects on pain in osteoarthritis sufferers.

[84] Rest will also de-condition the muscles, which will result in less absorption of force around the joints so that when they are weak, the boney surfaces incur more of the load and less stability (J. Allen et al., 2017).

[85] See 'Remaining key-kaumātua interviews' ('It's normal for getting old').

(n=5) and car or public transport (n=14), the experience for particular kaumātua is told in the story that follows.

It all adds up

Kaumātua often talked about the financial cost of services and medications. They talked about what could be done to improve access to services[86]. One kaumātua cited concerns about the cost of care as reasons for delaying treatment:

> But now … I know they're [District Health Board] trying not to have so many people going to hospital for x-rays. He's [doctor] been sending me to the Hastings Doctors for x-rays quite a bit, and I said, "I have to pay to go there!" You know, it's the cost of the medications too. Yeah … it all adds up. I try not to go. He said, "I know, I know [it costs], the way you get treated straight away. You can go to the hospital, but I can be sitting there on my walker [walking frame] for hours, which is true, you have to wait your turn … (Kaumātua 4).

Co-payments or fees-for-services[87] and time spent sitting on a walker for hours waiting their turn, kaumātua focus on what accessing medical imaging radiology (x-rays) really means. Recognised in the kōrero shared by kaumātua, are financial barriers coupled with functional obstacles, associated with having to sit for long periods of time, waiting to be seen on a walking frame. Consequently, issues cited by kaumātua are not only about cost, but physically exhausting challenges, associated with waiting and negotiating.

Heck it gets really cold

When kaumātua were asked about how they were managing osteoarthritis around the home, they spoke about financial constraints during the winter months:

> We all just stay in there, put the heater on. The little one (grandchild) sleeps with me, the boy and the girl on there … Better than going in the rooms. It's cold, I put heaters on in there. Even with insulation, it's expensive, yeah … Heck it gets really cold, jeeze. Have to decide is it heating or groceries (Kaumātua 6).

There is a sense of kaumātua needing to juggle whether to pay for power or buy food.

Struggle to meet my expenses

In a different example, kaumātua talked about the meaning of being on a low income. That is the challenges posed to their wellbeing. Some had to juggle whether to pay for everyday existence or medical care:

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[86] Access to services refers to the level that people are inhibited in their ability to gain entry and obtain care from the healthcare system.

[87] Structural barriers include the fee-for-service system used by doctors, with small medical practices increasing user charges. The fee-for-service method of payment encourages economic incentives so that doctors see many patients as quick as possible (high turnover medicine). Longer appointments are not encouraged, which is often what is needed to enable a thorough check-up or for the management of chronic-conditions, which need engagement in primary preventive healthcare.

> Sometimes I struggle to meet my expenses, you know rent, power and that can leave little for food. Cheap food is not always good food but it comes down to cost (Kaumātua 15).

The kōrero evidences the struggle associated with access to healthy food, for many living on a limited income.

Quality of food

When raising the topic of food affordability, the issue of quality was scrutinised by kaumātua:

> Quality of food, oh they were beautiful cooks at preserving saving food, all had gardens, where I lived anyway, everybody had a garden because so and so had better carrots than yours so they'd come over and drop some on the doorstep or a hello and a cup of tea and we exchanged food, that was natural. You never went to a house empty handed, you took a cake, preserves, jam, whatever. Never went empty handed, ever! So our life has really changed. Only the ones who sort of know we do that, also the polluted waterways and land well that's a big change, less people are caring for these and it is important for our mokopuna – what will they be left with (Kaumātua 1)?

Observations about how kaumātua were taught to gather and preserve food were considered all part of growing up. Kaumātua shared their concern for the impact of food quality on mokopuna, such as living out of the supermarkets, than off the land. In summary, 'Kaumātua talk about access' presented reasons for delaying seeking treatment emphasised by the financial cost of services, transport, medications and functional logistics of sitting, waiting for a medical appointment for hours at a time.

Barriers to osteoarthritis-management

As well as talking about issues relating to access, kaumātua interviewees spoke of confounding factors related to osteoarthritis. A range of matters were spoken of, that were important to kaumātua managing osteoarthritis.

I fractured my arm

When asked about how kaumātua were managing osteoarthritis in and around the community, one participant shared an experience:

> You know I fractured my arm, the Council [Napier City Council], it's not doing its job on the pavements to keep them safe. I should have used my own thing and just rung the ambulance, take me to hospital when it happened. It happened on a Monday morning and we were walking, there was a hollow and a bent steel bar, steel rod sticking up out of the pavement. The steel rod sort of flicked up and went in my leg and I fell onto my side, my arm. When I went in, my doctor wasn't there so I saw an emergency doctor, who referred me to the fracture clinic who gave me an x-ray and asked me, "how long you been like that for?" He said look at it you got a fracture! I had already had an x-ray up there but they didn't pick it up at the emergency doctor. I didn't want to see him the next time I went there. Forty bucks for that through ACC. I just couldn't afford it.

> So, yeah well that's me anyway, going to be more cautious out there (Kaumātua 5).

The kōrero foregrounds the need for respect ('manākitanga') towards all older people, by ensuring a safer outdoor environment for them, where everyone feels valued ('whānaungatanga', or sense of family connection). Weaving the insight and experience of kaumātua and the whānau into matters of safety outdoors, 'rangatiratanga' of kaumātua will be expressed through their leadership. In addition, kaumātua leadership on making neighbourhoods more walkable and safe, will set standards and provide sustenance of future generations.

Gyms are so expensive

When asked about what kaumātua were doing to manage osteoarthritis around the home, being realistic about exercise was a priority that emerged from the interviews:

> So many of my friends complain that gyms are so expensive. You start out encouraged but soon enough lose interest and waste all that money. You know what I do, I exercise at no cost. So that's what I, you know that's how I, I like to keep fit. Bed mobility. I exercise, especially in bed, in winter-time you know, come on get out of bed. So I jump out of bed, move around, once I get moving, then I get ready. I vacuume, wash floors all that it's part of it (Kaumātua 5).

Although barriers to exercise were often discussed, such as lack of time, money and motivation, there was a realisation of the importance of exercise in different shapes and forms. Kaumātua identified that they performed exercise in ways which were not expensive, but a part of everyday activity. So exercising in bed during the winter-time, gardening, the washing etc., are all ways kaumātua were personalising osteoarthritis-management, to fit in with their daily schedule.

Green prescription exercise

When asked about how they were managing osteoarthritis in the community, kaumātua talked about exercise:

> Auntie and I jumped onto green prescription, we got $2 discount with our swimming. Yep, yep, she's awesome the one that runs the green prescription programme for physical activity, I mean you can go to the gym. She runs it from Sports Hawke's Bay in conjunction with the doctors, nurses. That's what green prescription is, I think public pay $4.50. If you're on green prescription you pay $2, you've got the spa pool. Oh hey a disability of some sort [is what you need to access Green Prescription]. A lot of them [older-people] are there because they have disabilities and they needed to, or they may have heart problems or depression. Just something, so get them to tag into their own doctors, tell them to ask their doctors to put them on to – put them on to Green prescription, or the gym, at your level. You have a trainer there that will say OK then, let's stick with this goal. So, you know, always beneficial. Once you get into the exercise regime it will be motivating, even though I've been in the

> position before where I wouldn't do the exercise – I couldn't see the change, I lost my confidence, self-esteem, and motivation (Kaumātua 9).

The kōrero indicates that Green prescription[88] is getting results for kaumātua, with healthy advice, support and motivation to increase their physical activity levels. Kaumātua talked through their preference for realistic goal setting and, self-selected exercise options with peers.

Mobility scooters

Of the interviewees, one kaumātua shared that they were borrowing a mobility scooter (n=1), otherwise they were uncertain about the affordability and sedentary nature of mobility scooters (n=19). The data confirms that there are some gaps around affordablity, availability and/or information about mobility scooters. A few discussed not wanting a scooter because it might make them 'lazy' and they wanted to preserve their mobility.

I couldn't walk

The following kōrero speaks of the untold benefits of mobility scooters:

> In the past I would have said that if I couldn't walk somewhere without a [walking] stick then I wouldn't bother to go anywhere … but with the scooter … actually it's [mobility scooter is] really good, once you get the hang of it. No it's great, I was a bit nervous … No it's a great way to get around and walk your dog, if you can't walk. I've met so many people along there, yeah. Just by stopping and talking to them with the dogs. They're [dogs] are my social lifeline. I've been for coffee with three of them [walkers]. I met another new person the other day (Kaumātua 19).

For one kaumātua interviewee, who was borrowing a mobility scooter, powered scooter-related activities[89] were enabling them to get out into the community, physically and socially.

You can have my scooter

In the previous kōrero, kaumātua talked about mobility scooters helping their participation in more activities, than they normally would. In a different example, kaumātua detailed a few useful features of mobility scooters:

> It's quite a long stream where I walk the dogs. The wheels are not that big but they are very stable. I think the one [I am borrowing] is a four-wheel scooter, which makes it bigger and it needs a bigger area to turn around. If I was to get one, I'd get one with slightly bigger wheels I think. There's heavy duty ones and light ones, whatever … yes [you'll see] flags and tinsel [scooters with safety

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[88] Green prescription is a health professional referral that supports and encourages people to improve physical activity and healthy nutrition levels. It is funded to support physical activity to enhance holistic (physical, mental, social) wellbeing. In Hawke's Bay, Sport Hawke's Bay manage the activities and can be contacted on 0800 ACTIVE (228 483) or by email: grx@sporthb.net.nz.

[89] Mobility scooters are devices which have three or four wheels (Kim & Mortenson, 2016). They are used by people who have difficulty walking and are different from wheelchairs as they provide driving controls, seating, a particular method to get on and off and programmability (Kim & Mortenson, 2016).

> flags]. You recharge them [mobility scooters], just plug it in. Sure saves the hassle of filling up on petrol, plus with the prices of petrol these days. I wish I could afford to buy one. They're [mobility scooters cost] $4 to 5 thousand [dollars to purchase]. I don't think the District Health Board funds them, I've heard the Lottery Grant [provides funding] ... People apply for funding from them ... with disabilities. You can get them [mobility scooters] everywhere, they're all over the net [internet]. Some days my arthritis makes it hard to stand up for long periods. People when they see me on the scooter and say, "Some people on mobility scooters are dangerous". I tell them, "you can have my scooter and I'll have your legs" (Kaumātua 19).

These features of a mobility scooter, are what stood out as important to kaumātua. Given that only one of the interviewees had mobility scooter usage experience, more steps will need to be made in order to ensure kaumātua have access to knowledge about the benefits and risks of a mobility scooter.

In summary, barriers to osteoarthritis-management discussed by kaumātua, were illustrated by their stories about gyms, green prescription and mobility scooters. Reasons for barriers to engaging in some management strategies emphasised equity. In a Māori context, unaffordable healthcare breaches a range of values, especially 'aroha' (support for one's fellow man).

Kaumātua talk about access

When asked about osteoarthritis experiences in the community, kaumātua often talked about perceptions of negative attitudes held by services' staff.

You're not gonna be batting for me

When asked about the meaning of being Māori, older, and living with osteoarthritis, a common experience across the cohort spoke of being unfairly overlooked:

> Oh the other thing, this will get you. Something came up about eyesight and I said to the doctor, well I have got two cataracts, which I am hoping to be able to get rectified in the next year or so and they said, "Well good luck with that!" that's what they said! "Well good luck with that". I thought OK, I don't think you're for me! There's lots of hidden meaning behind that. Well I think they was saying, we've got such a long waiting list, you're old, you'll probably be at the bottom of the list. That's how I read it! Yeah I thought, "well you're not gonna be batting for me, I'm sorry I'm walking"! Not all people think like that, absolutely. Oh look some of them [doctors] are wonderful they really are (Kaumātua 12).

The kōrero provides a disturbing exemplar of explicit ageism[90], of being 'talked over' as though they do not exist.

Heart to their paperwork

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[90] Ageism refers explicit (overt) or implicit (subtle) ways, in which older-people are unfairly assessed and treated by healthcare practitioners (Boock, 2012).

When asked about the experience of living with osteoarthritis, kaumātua provided examples, of what they thought might assist services to be more welcoming for kaumātua:

> People need to connect their heart to their paperwork. If they're not able to integrate those values – simple stuff about engaging – talk about things like āta[91] – so it is about having that ability, that engagement, rather than the hello thing – which is part of the mahi. Giving it more time – can't get that, then the rest of that journey, the experience for the whānau it's not going to happen – they (healthcare practitioners) won't get that (Kaumātua 8).

Connecting their heart to their paperwork, use of whānau values, and giving kaumātua more time during consultation, are all noted factors for building respectful relationships.

But the piling pills onto you

In a different example, kaumātua talked about their quality of life. Here, one particular kaumātua shares their experience of medication taking, and the potentiality for mis-prescribing/overprescribing:

> … and my experiences of overmedication, of being treated by the cardiologist and treated by my doctor you know, I just feel like there is a place for medication of course, but the piling pills onto you all the time, it might cure some things but it breaks down something else. You know, that's how I found it over the years. So that, like I let my doctor know, you know. Cos I never had a doctor and then when I needed to have one, I used to go and, you know I just couldn't blend with them? … I know I have to have them [medications] but the chopping and changing and, you know, and all that, I just can't take it. But the over medication thing, my girls [daughters] were ready to go down and have a go at him [doctor] … (Kaumātua 4).

The kōrero is useful for understanding the reality of living with mulitiple chronic-conditions, and conflicting advice from doctors.

Talking past each other

After experiencing verbal and non-verbal communication between Māori and Mainstream, 'talking past each other' was a phrase coined by Joan Metge (Kinloch & Metge, 1978). It appears to have relevancy among educationalists of the time, as it has today with kaumātua living with osteoarthritis and their interaction with services:

> He [doctor] did make a comment to me he goes, "you so fit, you cycle you swim, so how come you so [moving his hands as if to say, you are too big']. I said, "come sit over here", I want to talk to you. He sat down, "yes". I said, now where are you from? "I'm from the Phillipines" [says the doctor]. So Phillipines their stature is [hands moving as if to say small]? Aren't you – you're a good advert – small bone structure, fine featured face". He goes, "yes". I goes … but I happen to have this shape, but I'm fit, I'm reasonably healthy and I'm me, I'm not you." He sat there and said, yes! I mean, I said to him that I come back

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[91] Āta refers to deliberate, intentional, open, deliberate thoroughness in carrying out and activity.

> down to 88 [kg's] 'cos before I was up to 94 [kg's] agggh. I think it comes down to portion sizes and 'manākitanga', that's how we host, we care for one another (Kaumātua 9).

Kaumātua suggested they felt the need to educate their doctor about their cultural view of size and weight control, and the connection between food based hospitality (manākitanga). There is a cultural aspect with hospitality, that you always want people to feel welcomed, than to leave your home, and say that they were not cared for (fed enough). The kōrero emphasises the point that practitioners will need to work with kaumātua about cultural conceptions, that could affect over-consumption.

They didn't want to listen to us

When asked about what might be done to improve their experience of osteoarthritis in the community, one kaumātua interviewee talked about the importance of being heard:

> Just those little things that can make all the difference. Just like um, when Nan and them used to make rongoa – there were special vessels, kept out, that were kept outside that were used, just for rongoa. Food never, ever, eating food never went anywhere near those pots or those containers. Rongoa was kept separate. Just like your wash things are kept separate? In the hospital eh, so they didn't want to listen to us but it's taken them a while to, "oh, oh, oh, well that infection, it's not right to go from the face right down to the bum and back this way with a flannel, disgusting. Infection control, that's what we teach our own whānau – tapu and noa - and that's all part of it, it's all part of it. So it's taken them a long time but hey, they're doing better in the hospitals and things now but they still got a long way to go. I can see some progress. Maybe not as much as we'd like (Kaumātua 9).

Guided by whānau values and tīkanga Māori (cultural principles) concepts that have been practiced from generation to generation, kaumātua told a story about how to give a bath in a hospital bed. In everyday practice, tapu and noa relationships were the gold standard, in best practice care.

Using plain language

In a different example, kaumātua spoke of there being a noticeable gap in communication with services:

> What else, what else, what else, yeah, anything like that I've just got from my niece, she's given me some flax root. I went, OK. So, what am I having this for dear? That's for your general wellbeing. She says, "if there's anything stuck in your pipes, it'll clear that out". Hey a lot of them, it was done naturally, you weren't taught – this was done as a matter of course, we're not taught on a blackboard, we weren't taught on a blackboard – we live it? So when we get told about your osteoarthritis, what is that? In a Pākēhā world how do you – what sort of things you classify when you talk about what does 'whānaungatanga' embrace, what does 'manākitanga' mean? What do all those things mean in the wider sense, so Tauiwi (Mainstream) can understand a bit more about how we roll really (Kaumātua 9).

Rather than 'blinding' them with science, kaumātua demonstrate, through the use of metaphor, that plain language could be a promising strategy for communicating clearly. Clearing out 'stuck pipes' and 'setting free' were metaphors, emphasising benefits of plain language.

Writing for Māori

In another example, kaumātua talk about what is important for them, using the analogy of racism as something simmering under the surface:

> There's a lot of racism in social services as well. I think government does it – policy doesn't go far enough, Māori are over-represented in every statistic, it's not working is it? When you write policy from a western perspective it's never going to work. It should be Māori writing for Māori. There are 'white Māori' too entrenched in Western ways. I would like more Māori ways to be – more white people had to follow Māori ways we would be happier. The whānau ora integrated model is absolutely holistic. I don't like the medicalised model. That whole extended family – the spiritual aspect is what is missing in most people's lives, there is institutionalised racism, it's there it's simmering under the surface all the time (Kaumātua 3).

This kaumātua is talking about how mainstream privilege in the health sector is still being promoted. Kaumātua shared that osteoarthritis-management framed within Māori-centred activities such as the 'whānau ora' integrated model is holistic, so it will have the capacity to enable and empower Māori, hapū and iwi. In summary, the stories ('Barriers to osteoarthritis-management') confirmed the experience of kaumātua engagement with services, regarding effective chronic-condition management.

Kaumātua preferences for services

In the previous stories, barriers of inequity were outlined, for impacting negatively on kaumātua access to services. In comparison, the following stories reflect kaumātua preferences for services.

Just a little smile, something like that never costs a thing

Kaumātua expressed a clear preference for services delivery to be welcoming:

> The part-Māori lady [at Welfare and Income New Zealand], well she's lovely. Even the way she talks to you. It does make a difference! Yes so do put that in your paper! Yes it does make a difference to how people, how an older person feels when they are sort of having an interview or whatever, it does make a difference if they – well I don't know that it's respect – just treat you like a person. Yeah, I like to be treated like a person, a little smile never costs a thing, individual, you are an individual – just be nice – show a little love hahahaha! No it doesn't cost anything, just a little smile, something like that never costs a thing hahahahahaha (Kaumātua 11).

Kaumātua, reiterated a strong preference for services that valued older-people. The message was clear that kaumātua preferred those services that were being delivered by Māori (n=12).

Holistic, it should be normalised

Kaumātua felt that it was extremely important that healthcare practitioners, considered all the dimensions of an individual before them. For example:

> Services are based on Western philosophies and in that way they can be very oppressed to the people who receive them – even to white people. I'm not surprised we don't get better – they are not holistic. Holistic, it should be normalised. We are made up of many different things (Kaumātua 3).

Kaumātua, emphasised a perception that services are starting from the condition (disease-focus) than accumulated knowledge of the whole person (kaumātua-focussed), so questioned the point of the service.

I believe in natural

When asked about what is really important to kaumātua, they talked about tipuna (ancestral history) and components of an indigenous Māori healing system[92]:

> Well my mother used to get up … go out on the maunga, do her karakia. I suppose so [that's where I got it from]. Using rongoa - natural, I believe in natural. I was using the 'Rongoa' … kawakawa, cabbage, cabbage leaves, you just put the leaves around the arthritic joint, helps draws out all the paru, toxins … you got to believe in those things, heat, cold, massage, plus I say a prayer every morning. Yeah, well … three o'clock if I wake up I say my karakia. I just use, you know just normal [karakia]. Any, you know, I just say anything prayers to … and I use the affirmations. You believe in affirmations? Yeah, I'm into those. Even when you take your rongoa, you bless that, "whakapaia enei rongoa, hei painga mo te tinana. Hei oranga mo taku tinana". I believe in those … (Kaumātua 5).

The kaumātua interviewee talks about how they are preventing future illness and managing osteoarthritis self-care autonomously. Overall the kōrero is an exemplar of kaumātua health preferences, across a range of dimensions (physical, mental, emotional, spiritual, cultural, environmental).

Four taha – referral systems

In addition to spiritual alignment, most kaumātua described the importance of a more comprehensive, holistic approach to patient care. For instance using 'Te Whare Tapa Whā' (the four cornerstones of health)[93] model to promote health and wellbeing:

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[92] Components of the healing system concern, 'wairua' (spiritual healing), 'rongoa' (herbal medicine), 'mirimiri' (body work), 'mana' (authority), 'tīkanga' (procedure), 'reo' (language), and 'mātauranga' (knowledge) (Ministry of Health, 2001) Māori.

[93] 'Te Whare Tapa Whā; refers to a four sided house. The concept represents four basic tenets of life, essential for wellbeing: 'te taha wairua' (spiritual wellbeing), mental wellbeing or 'te taha hinengaro', physical wellbeing or'te taha tinana' and family wellbeing or 'te taha whānau'. Altogether, all four need to be in balance for best health (Durie, 1985).

> So coming from the four taha [four aspects of 'Te Whare Tapa Whā' model] – it's recently been about educating the clinicians, the doctors, the psychologists. The Psychiatrists are more challenging. I mean how do you measure wairua [spiritual side of wellbeing]? How do you measure a hongi at the car door when you discharge kaumātua? You can't! but that's the information that they require. So all I'm interested in is that we take the recommendations from our kaumātua and we sit down and figure out – how can we break that down into the clinical.
>
> That's what I'm interested in, don't have you [healthcare practitioner] worrying me, that you don't understand it! So that's an issue and so is getting them referred into services, they [services] still need to be better at talking to one another. So we don't wait for them [services to make a referral], we take kaumātua ourselves, for example getting their medications reviewed so they aren't over-medicated that leads to falls, we fill that … but some fall through the cracks (Kaumātua 8).

Kaumātua preference is that contemporary healthcare services widen their approach by incorporating broader concepts, than focussing on physical or psychological domains, as a measure of treatment progress.

The whole house collapses down

In a different illustration of 'Te Whare Tapa Whā', kaumātua spoke of the wide reaching significance, of a holistic emphasis on osteoarthitis-management:

> You know with my joints, osteoarthritis, the wairua, the mental, physical – the wairua and the 'whānaungatanga', social. They all go together. If one doesn't work, the whole house collapses down and it is so true, you know. You got to have the four corners, otherwise your family doesn't … (Kaumātua 5).

Using the analogy of Durie's (1998b) 'Te Whare Tapa Whā' (house), kaumātua articulated that osteoarthritis-management and services need to widen their approach to understand and support wellbeing of the whole person. In summary the stories ('Kaumātua preference for services') confirm that holistic approaches to osteoarthritis-management should be normalised, with a kaumātua-focussed approach.

Osteoarthritis-management sources

In the previous stories, kaumātua talked about their preferences for services. In the stories that follow, the main sources of knowledge regarding osteoarthritis-management for kaumātua is presented.

Pou-Rewarewa – like the tree eh?

In the following kōrero, kaumātua shared preferred approaches to acquiring knowledge:

> Well we've got a new name for ourselves (kaumātua rōpū), … Pou-Rewarewa like the tree, instead of being called kaumātua, we are a collective that is all about learning for our health and listening to great speakers, so that's the name

> we going under now, us, kaumātua. Pou-Rewarewa – like the tree eh? And they know kaumātua and kahungunu, at least they know that, Pou-Rewarewa – what that means (Kaumātua 7).

An expression of an holistic frame of thinking, may be seen in the naming of kaumātua rōpū. 'Pou-Rewarewa', uses the Ngāti Kahungunu native species (Pou-Rewarewa, the tree)[94] as a metaphor to refer to kaumātua standing as tall, proud elders and leaders of the whānau. The kōrero shows that one of the main sources of knowledge regarding wellbeing for kaumātua, comes from peers, whānau, health educators and other healthcare practitioners engaging with the group. The finding shows that strong friendships with peers, is promoting knowledge amongst kaumātua and that kaumātua rōpū, are therefore likely to be a rich and captive audience for future osteoarthritis-management activities.

Almost totally blind

Across the community, osteoarthritis-management promotion could be found to be occurring within peer-group forums (kaumātua hui), where listening to real stories about other kaumātua was a help and a motivator:

> Yesterday a kaumātua gave us a wonderful presentation … 90 years old … almost totally blind … talking about how to relate to blind people, and how to be helpful to them, without being smothering or taking away their dignity. Gosh she was great. I learned more from her, than ... I went up to her afterwards and I said, "Oh I just wanted to thank you so much of making us more aware of how we can help". I said, "I think I have learned more from you today that ever", but there's a lot more to it than that and she was just so … oh it was just so informative, it really was. Yes the kaumātua hui. They have some wonderful speakers (Kaumātua 12).

The kōrero indicates that kaumātua learn more from their peers, because peers knew what it feels like to live with osteoarthritis.

Go and listen at the Pa

It was obvious right across the cohort of kaumātua, that they enjoyed attending and listening to speakers on marae:

> … we could hear everything that was going on down at the pa. We used to stand out there and that's the, go and stand out there and go and listen at the Pa [marae] and I was interested to learn … reading not much 'cos of my vision (Kaumātua 7).

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[94] Kaumātua shared that as a collective they had come to a general consensus of naming their rōpū after the metaphor, 'Pou-rewarewa'. The name follows the 'Rewarewa' tree which is found all around the valley forests of Hawke's Bay. It is a tall upright tree with a paritcularly majestic look and long and the word 'Pou' is used alongside to reference kaumātua standing tall, like a pou which refers to being upright, a symbol of support.

Right across the cohort, kaumātua showed a strong preference for real stories, story telling, recounting stories of tipuna and listening to new ways of how to keep one's health in check.

Korowai and real stories

In a different example, another kaumātua interviewee, reminded the importance of real stories:

> I'm doing the korowai … on Anzac day … on your tipuna in the Māori Batallion and the wonderous things he did? They told wonderful stories and what happened when he come home … just wonderful! (Kaumātua 10).

The kōrero recognises the power of telling real stories. Stories will be used to express whānau values and worldviews, and is consistent with Māori oratory custom. The telling of real stories will inform and educate, particularly when stories draw on cultural connections.

Do-able goals

When asked about their experiences with osteoarthritis and, 'can anything be done to improve these in the community', one particular kaumātua, incorporated the idea of being realistic:

> I got an addictive nature so, yeah … I found that anything, I'm easily persuaded to do things when I have do-able goals. I don't trust myself basically, that's what it is. I would have a drink, I mean I'm not happy till I can't drink anymore. Umm I'm liable to just keep going and going and going, just for the hell of it. That's where I got myself in trouble to begin with … Just like any other addiction eh. I'm already there – addicted to IronMaori. It's a training thing, it's about being realistic – It just makes me feel good in a positive sort of a way. It's like a big whānau out there now, it's really good. It's an investment, an investment in my health is how I look at it. Instead of wasting my money on throwing it against the wall, better definitely relationships, with my family (Kaumātua 19).

When asked about their experience of osteoarthritis, kaumātua drew down on past experience, of setting 'do-able goals'. Goal setting was spoken of as an enabling motivating approach to self-care, as kaumātua talked about the importance of setting realistic, incremental steps toward achievement. Aligning practitioner support then, will be about introducing sources of osteoarthritis-management incrementally, that make sense to kaumātua and their whānau, one step at a time.

I want you to worry about you!

Another way kaumātua expressed being realistic, was discussed in terms of taking control of one's food choices:

> A lot of older ones it's about coca cola, no good for them. See that's why I won't go to visit Auntie, she's a lovely 'kind'-hearted person but she's defeating the purpose. Well she'd come out and shower us with chocolate, biscuits, fizzy drinks and um, she defeats. You know what, she was paying this woman, lady,

> sixty something bucks to massage her leg, because she was drinking all the wrong, she'd have all these cokes and boxes, she wanted us to drink – hell no, I'm not going to drink that! She'll eat biscuits and all these fast foods – "you can have some friend". I don't want to be around someone like that – you're not trying to help yourself, I worry about my weight – I don't want you to worry about me, I want you to worry about you! (Kaumātua 5).

A powerful negative peer influence was motivating kaumātua to maintain realistic expectations of self, others and the world.

Cooking on our marae

In a different example, kaumātua were obtaining realistic self-care knowledge on marae:

> On our marae, we been starting to cook healthy meals, which is good. Yeah, so um, mmm that's where I'm at. We go down and help out in the kitchen. Usually meet down there and we get the menu and go from there … (Kaumātua 5).

These observations of realistic strategies occurring at the marae level for kaumātua are substantiated by Eastern Institute of Technology (2017). Pokemokimoki Marae in Maraenui, Hawke's Bay for example, is where chefs are being trained to plan and cook 'marae style', setting examples of healthy kai.

He's [Kaumāua's] an inspiration

Across the cohort of interviewees were community-focussed kaumātua role models for whānau:

> And he's [kaumātua's] an inspiration for the other younger IronMāori [triathletes] – the guys look at him, they come along and say look at that old fella, if he can do it, I can do it (Kaumātua 17).

The kōrero speaks about kaumātua incorporating regular fitness, as part of Māori grassroots efforts, that is having an enabling and supportive effect on whānau. Kaumātua engagement in IronMāori are serving as role models in the community.

On Māori TV

In a related example, kaumātua shared that it is real people who are the positive role models:

> I read, I can watch TV. I like watching things that kaumātua are talking about on Māori TV, they have to have something I can learn from, how to help yourself (health). Not only about the subject but, something that makes you feel that you could do as well, say like weight loss, if it's got a bit of funny in it and it makes me laugh then it is even better. But you know it has got to be something behind it. Like, yeah, we got to make sure we're doing it right, it's got to pertain to something that, like I mean we are in Hawke's Bay here, it's got to be, I guess. Everybody, fits in with the whānau, everybody (Kaumātua 5).

Kaumātua 5 is talking about enjoying informative self-care messaging on television programmes (programmes), particularly when real people from the community are referenced. Programmes showing how real people are staying well, may be informative. Even better if there is some humour in the message.

In summary, the stories ('Osteoarthritis-management sources') confirm that kaumātua learn more from their peers and interdependent focus group hui participants, because peers knew what it feels like to live with osteoarthritis. Further, there was a strong preference for listening to real stories about do-able goals. Reclaiming 'tino rangatiratanga' (self-determination[95]), and goal setting strategies were supported.

Coding the interviews

Similar to the procedure adopted analysing the data of three stories ('Three stories', above), with the remaining interview data, I set about coding for basic elements of meaning, resulting in 49 initial/basic codes (stage-two) and searching for themes (stage-three) (Table 12):

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[95] 'Tino rangatiratanga' represents self-determination in the present study and concerns opportunities for kaumātua leadership, engagement, and participation in relation to osteoarthritis-management activities. 'Tino rangatiratanga' is a domain which is provided for under Te Tiriti o Waitangi's Article 2, which Māori health priorities for osteoarthritis-management can be established. Osteoarthritis-management have an obligation to honour the beliefs, values and aspirations of kaumātua and whānau as patients, practitioners and healthcare community.

Table 12. Interviews 49 initial/basic codes

Interviews
49 Initial/basic codes

1. Osteoarthritis limits activities
2. Safety first
3. I’m not alone
4. It’s normal for getting old
5. What I can do to help myself
6. What I should be doing
7. What is causing it
8. I don’t want to worry them
9. It’s raining
10. He [son] depends on me
11. Putting on a brave face
12. Stick falls over everywhere!
13. Men … to do with pride
14. Use it or lose it
15. No hinu (oil) left
16. The weather’s turning
17. Diet
18. I wasn’t teling anyone
19. It all adds up
20. Heck it gets really cold
21. Struggle to meet my expenses
22. Quality of food
23. I fractured my arm
24. Gyms are so expensive
25. Green prescription exercise
26. Mobility scooters
27. I couldn’t walk
28. You can have my scooter
29. You’re not gonna be batting for me
30. Heart to their paperwork
31. But the piling pills onto you
32. Talking past each other
33. They didn’t want to listen to us
34. Using plain language
35. Māori writing for Māori
36. Just a little smile, something like that never costs a thing
37. Holistic, it should be normalised
38. I believe in natural
39. Four taha
40. The whole house collapses down
41. Pou-rewarewa – like the tree eh?
42. Almost totally blind
43. Go and listen at the Pa
44. Korowai and real stories
45. Do-able goals
46. I want you to worry about you!
47. Cooking on our marae
48. He’s [Kaumātua’s] an inspiration
49. On Māori TV

These initial/basic codes were then reviewed and arranged into a further eight higher level (provisional/organising) themes (stage-four). Eight provisional/organising themes follow from the interviews (Table 13):

Table 13. Interviews eight provisional/organising themes

Eight provisional/organising themes		
1. Realities of osteoarthritis Your life just narrows down; I'm not alone; It's normal for getting old; What I can do to help myself; What I should be doing; What is causing it	**4. Costs of living with osteoarthritis** It all adds up; Heck it gets really cold; Struggle to meet my expenses; Quality of food	**7. Service preferences** Just a little smile, something like that never costs a thing; Holistic, it should be normalised; I believe in natural; Four taha; The whole house collapses down
2. Whānau realities I don't want to worry them It's raining; He [son] depends on me; Putting on a brave face	**5. Barriers to activity** I fractured my arm; Gyms are so expensive; Green prescription exercise ; Mobility scooters; I couldn't walk; You can have my scooter	**8. Sources of support** Pou-rewarewa – like the tree eh?; Almost totally blind; Go and listen at the Pa; Korowai and real stories; Do-able goals; I want you to worry about you!; Cooking on our mare; He's [Kaumātua's] an inspiration; On Māori TV
3. Osteoarthritis awareness Stick falls over everywhere!; Men … to do with pride; Use it or lose it; No hinu (oil) left; The weather's turning; Diet; I wasn't telling anyone	**6. The struggle for access** You're not gonna be batting for me; Heart to their paperwork; But the piling pills onto you; Talking past each other; They didn't want to listen; Using plain language Māori writing for Māori	

After reviewing and arranging the initial/basic codes into a further eight higher level (provisional/organising) themes (stage-four), analysis of the data continued. In the process of refining themes, was I able to consider each on their own and in relation to others, focussing on kaumātua and whānau wellbeing. Consequently, themes were defined, named and organised (stage-five).

The process ensured that all themes were supported, by weaving multiple extracts arising in the data together into a story (stage-six), reflecting the merits and validity of the analysis. Hui were then conducted with advisors (advisory hui), to talk about the research findings and representing the story of kaumātua. Following Kaupapa Māori principles, advisory hui were consistent with an exchange of mutually respectful ideas, theories and understanding.

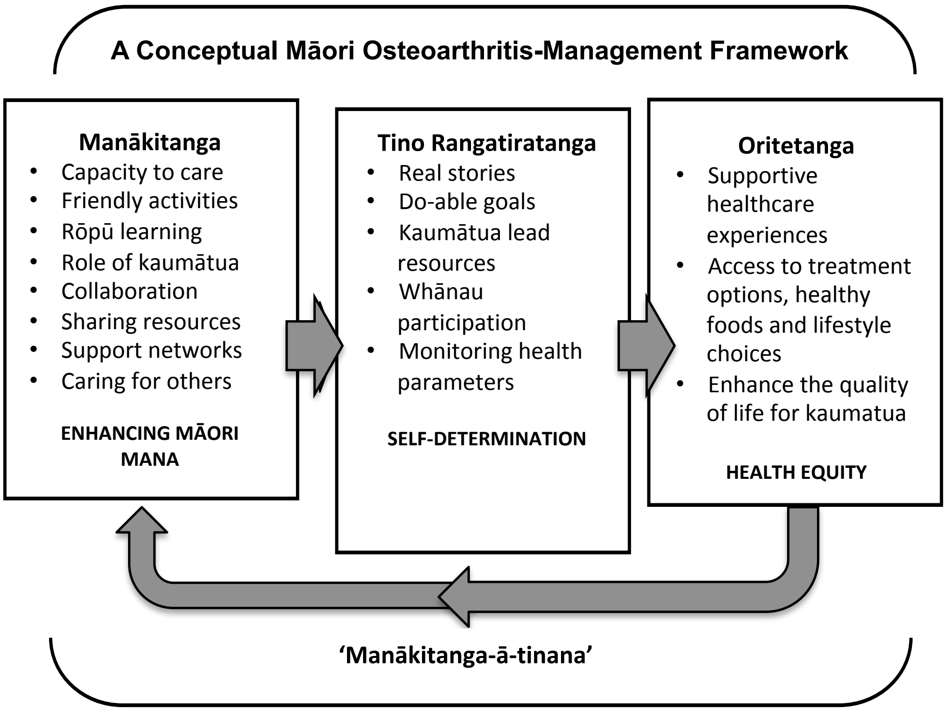
In preparation of my advisory hui, I put together a summary report (4-sided leaflet) in non-academic language, grouping themes alongside interviewee responses (Appendix 2) and a Conceptual Māori Osteoarthritis-Management Framework (conceptual framework) (Figure 5, below), to aid in the overall discussion with my advisors concerning the analysis of themes.

The conceptual framework enabled me to map the data to key Māori concepts, by collapsing themes to form a coherent pattern. I then defined and refined the themes, in order to identify the essence of what they were about, and determining which aspects of the data each theme captured. In the process of refining themes, was I able to consider each on their own and in relation to others, focussing on kaumātua and whānau wellbeing.

In the process of refining the emerging concepts, several themes were defined, named and organised (stage-five). The process ensured that all themes were supported, by weaving multiple extracts arising in the data together into a story (stage-six), reflecting the merits and validity of the analysis. A follow-up hui conducted with advisors, enabled presentation of the results in a summary report, and confirmation concerning accuracy of the interpretation.

Several organising themes follow from the interviews (Figure 5). The diagram which leads and discussion that follows, aims to provide exposition of the analysis and justification of the derived themes.

Figure 5. Conceptual Framework



'Manākitanga' (Kind support)

The conceptual framework (framework) (Figure 5) is representative of the lived expressions and realities of kaumātua with osteoarthritis. Many of whom spoke of often trying to engage effectively with health professionals and other environments within the Hawke's Bay community. Over the course of the present research, kaumātua discussed that the nature of face-to-face interviews and focus group hui was a highly appreciated factor, as well as the extended contact time over the duration of the research.

Interwoven into kaumātua relationships was the principle concerning reciprocal care or, ‘Manākitanga’ as depicted in the framework (Figure 5, Column 1). The ‘manākitanga’ main/global theme aligned with a critical review of health promotion and osteoarthritis-management literature (Chapter 2) literature), indicating that how one lives with a chronic condition interfaces with the Māori worldview (Te Ao Māori). For instance within Te Ao Māori, the caring (manāki) concept is not just about how you care about someone, but involves caring for others (Marsden, 2003; Te Pou o te Whakaaro Nui, 2015).

Within the framework (Figure 5, Column 1) ‘Capacity to care’ (‘Manākitanga’) is a substantial theme to emerge from the data, illustrating the various responsibilities that kaumātua living with a chronic condition and whānau may face. Within Te Ao Māori, kaumātua must care and give emotional and all other kinds of support to others, and no one counts the quantities or costs. Manāki means that even though you may be chronically ill with osteoarthritis related joint pain, you always have a responsibility to whānau and community (Ahuriri-Driscoll, 2014; Cram, 2010b; Durie, 1999a; Kāhui Tautoko Consulting Ltd, 2012a, 2012b; Tahau-Hodges, 2010; Te Puni Kōkiri, 2015).

Another key area that kaumātua indicated was imperative to their everyday experiences of osteoarthritis-management, concerned acknowledging an holistic perspective of wellness. Kaumātua pointed out the importance of osteoarthritis-management approaches that are geared toward the totality of a person, who they are, the context of their family, whakapapa and life long lived. The determinations of kaumātua concerning an holistic perspective of wellness were consistent with, ‘Friendly activities’ (‘Manākitanga’) (Figure 5, Column 1).

These findings support the literature which indicated that within Te Ao Māori. Specifically, literature framing health-management related activities by means of a cultural lens is key. In practical terms, that utilising a cultural lens can encourage understanding and engagement with services, than adopting a ‘one-size fits all’ approach (Bishop, 2005; Griffith & Warbrick, 2018; Ko Awatea & Counties Manukau Health, 2016; Ministry of Health, 2014b; Rauawaawa Kaumātua Charitable Trust Research Project Team, 2013).

Additionally, kaumātua emphasised the benefits of engaging in a peer ‘Rōpū learning’ (‘Manākitanga) (Figure 5, Column 1) environment, with active modelling of tīkanga Māori. ‘Rōpū learning’ relates directly to the previous organising theme, ‘Friendly activities’, and imperative that osteoarthritis-management is framed within a cultural lens. Accordingly, the findings support the literature which indicated the significance of respecting tapu, the importance of karakia and inclusion of cultural protocols and values for health-promotion activities involving Māori (Durie, 1999a, 2006).

As well as the previously noted organising theme 'Rōpū learning', when enquiry explored the 'Role of kaumātua' ('Manākitanga) (Figure 5, Column 1), many of the participants had been ascribed leadership roles within community kaumātua rōpū hui, whānau, hapū and iwi. Valuing the role of a kaumātua and putting them in that leadership position was important at an individual level, and also for future generations that depend upon their elders to pass on mātauranga Māori, te reo Māori, and tikanga. As a result of such values, the findings support the literature which indicated that within Te Ao Māori, kaumātua have specific aspirations and goals, with the bigger picture being to build platforms contributing towards a better world for Māori health and wellbeing, and bringing people together in unity (Aspin et al., 2014; Durie, 1997; Hinangaroa-Smith, 1997a; Ko Awatea Institute for Healthcare Improvement, 2017; Ngāti Kahungunu Iwi, 2007; Pihama, 2001).

Similar to the 'role of kaumātua', action through 'Collaboration' ('Manākitanga) (Figure 5, Column 1) accented the importance of creating spaces and places of osteoarthritis-management learning and activities where kaumātua 'feel good'. 'Collaboration' also stressed the importance of cultivating the expertise of whānau by focussing on the collective purpose of bringing kaumātua together to share their everyday experiences of osteoarthritis-management. These findings support the literature, which indicated that services are viewed more positively when approaches are founded on establishing inclusive practice in which everyone feels a sense of belonging and knows that their knowledge and opinions are respected and valued.

Another theme that flowed from the former ('Collaboration' organising theme) concerned, 'Sharing resources' ('Manākitanga) (Figure 5, Column 1) with wider support networks. Similar to the literature, sharing coping strategies and a sense of mutual understanding and validation with peers within a supportive rōpū environment is a resource in and of itself (Auckland District Health Board & Waitemata District Health Board, 2015; Mauri Ora Associates, 2010; Rauawaawa Kaumātua Charitable Trust Research Project Team, 2013; Russell (Pere) et al., 2013). Sharing experiences of osteoarthritis provides a potentially useful mechanism for mobilising community support in a learning context, where the identity and culture of kaumātua and whānau is affirmed.

In the same way, also surfacing from patterns within the data, 'Support networks' ('Manākitanga) (Figure 5, Column 1) was a further main/global theme that emphasised manākitanga as integral to the culture of kaumātua. On occasion, kaumātua participants shared that their ongoing challenges of living with osteoarthritis related disability at home and in the community, alongside family conflicts (oftentimes resulting in anxiety and depression) were mediated by networks of support. Similar to the literature, knowledge from these relationships ('Support networks') can assist mainstream services (services) to meet the needs of each kaumātua, and enable understanding as to who else may need to be involved in their health and wellbeing (Ahuriri-Driscoll et al., 2012; Bishop, 1998; Durie, 1999b; Tuhiwai-Smith, 2013).

Overlapping 'Support networks' was an organising theme, 'Caring for others' ('Manākitanga) (Figure 5, Column 1) as culturally located individuals. Specified by the range of experiences expressed by kaumātua concerning the capacity of services towards becoming more culturally sensitive and inclusive, developing culturally appropriate services is challenging. Similar to the literature, proressing strategies which capitalise on kaumātua knowledge by valuing their contributions, could translate evidence into policy by addressing the local community context.

Expressions of manākitanga that were evident in kaumātua stories, incorporated aroha (love), hospitality, generosity, and mutual respect, acknowledging others' mana as having equal or greater importance than one's own. In doing so, everyone (all parties) could be elevated and their 'mana' or status enhanced, building unity through humility and giving. Ultimately, all eight of these values (see 'Manākitanga) (Figure 5, Column 1) lock together, providing a culturally centred structure for strengths-based conversations to address kaumātua health need ('Enhancing Māori mana') as Māori.

'Tino Rangatiratanga' ('Self-determination')

Ultimately the first main/global theme, 'Manākitanga' (kind support for kaumātua as culturally located individuals), interweaves the framework to inform priorities for Māori leadership and participation with greater regard for osteoarthritis-management. The second principle, which flows from the first is, 'Self-determination' ('Tino Rangatiratanga') (Figure 5, Column 2). A recurring main/global theme throughout kaumātua experiences of living with osteoarthritis, 'Tino rangatiratanga' is relevant as kaumatua expressed a desire for Māori to control their own culture, aspirations and destiny.

'Tino Rangatiratanga' refers to reclaiming self-determination, by the manner in which opportunities are being provided for kaumātua leadership, engagement, and participation with osteoarthritis-management activities. This is a domain which is provided for under Te Tiriti o Waitangi's Article 2, where Māori health priorities for osteoarthritis-management can be established. It is within this context that the obligation emerges for osteoarthritis-management activities to honour the beliefs, values and aspirations of kaumātua and whānau actively, as patients and as a healthcare community.

Within the framework (Figure 5, Column 2), 'Real stories' ('Tino Rangatiratanga') was a consistent organising theme to emerge from the data, illustrating the power of sharing stories, beliefs and actions that link to the values of kaumātua. The findings support the literature indicating that Māori is an oral society (Mahuika, 2012). Further, that sharing stories is an appropriate method for allowing kaumātua to bring people together through their experiences with others, whilst empowering whānau to think long-term about their goals and draw from their strengths in planning to achieve them.

In addition to 'Real stories', 'Do-able Goals' ('Tino Rangatiratanga') concerning osteoarthritis-management, was an enduring theme to emerge from the data and the framework (Figure 5, Column 2), extending the focus on support and caring, towards the realisation of potential. During interviews and focus group hui, kaumātua spoke about how helpful it was to be given an opportunity to share their health experiences, significant life challenges and the processes which they had traversed to making positive lifestyle changes. Participants' goals indicated that attaining best outcomes with kaumātua, will require involving the whānau in systematic approaches to longer-term planning, so that objectives can be set and realistic plans of action developed (Durie, 1999a).

Moreover, 'Kaumātua led resources' ('Tino Rangatiratanga') was another constant theme to emerge from the data within the framework (Figure 5, Column 2). The findings support the literature indicating that the Māori community can be viewed as a resource and kaumātua as role models for osteoarthritis-management, by setting examples (leading by example). Further that there is a need for more Māori-specific resources and focus on osteoarthritis-management tools that are lead by kaumātua and these could be capacity building, when they reflect the kawa (cultural practices) and tīkanga (cultural principles) of the region.

What is more, within the framework (Figure 5, Column 2), 'Whānau participation' ('Tino Rangatiratanga') was another theme to emerge from the data. Similar to local literature (Te Kupenga Hauora Ahuriri, 2017; Te Taiwhenua o Heretaunga, 2017), kaumātua participants of the present study suggested that when hauora or Māori wellbeing underpins osteoarthritis-management, the aspirations, needs and realities of whānau become part of the solution. For example, engaging kaumātua, family and whānau participation in monitoring their own health parameters and actively participating in activities such as scheduled follow-ups.

Additionally, ‘Monitoring health parameters’ (‘Tino Rangatiratanga’) was a firm theme to emerge from the data within the framework (Figure 5, Column 2). Kaumātua spoke about reclaiming self-determination, by the manner in which opportunities are being provided for Māori leadership, engagement, and participation with osteoarthritis-management activities. This is a domain which is provided for under Te Tiriti o Waitangi Article Two, by which Māori health priorities for osteoarthritis-management can be established.

Tino Rangatiratanga challenges the status quo of present health management systems, with mechanisms that enable kaumātua to contribute to decision making, or participating in the delivery of osteoarthritis-management. The findings support literature indicating that more accurate data about how kaumātua are managing their condition is needed. The ‘Tino Rangatiratanga’ value represented in the present study, as self-determination to improve health outcomes for Māori, by focussing on systems that are conducive to the desire for kaumātua to control their own priorities, aspirations and destiny in a manner which takes account of Māori needs and perspectives.

Oritetanga (Equity and assessment)

The previous two main/global themes, ‘Manākitanga’ and ‘Tino Rangatiratanga’ bind together with a third main/global theme, ‘Equity’ (‘Oritetanga’) (Figure 5, Column 1), which is the core of Te Tiriti o Waitangi Article Three, achieving health equity. ‘Oritetanga’ exposes the negative realities of many kaumātua living with osteoarthritis and the manner in which whānau access and utilise osteoarthritis-management support from services. Ultimately, The ‘Orietanga’ main/global theme emphasises uncertainty of kaumātua about what osteoarthritis-management means and available services.

Emerging from data, presented within the framework (Figure 5, Column 3), ‘Supportive healthcare experiences’ (‘Oritetanga’) is a persistent main/global theme. The findings confirm the literature of the overriding importance of whānau, whakapapa, manāki (support), reciprocity, friendship and quality time for kaumātua developed through shared interests and through consistency of care, such as building a relationship by membership to a community rōpū, or seeing the same health professional. The ‘Orietanga’ main/global theme aligned with literature concerning the urgent need for measures that guage progress towards reducing systematic inequalities in the determinants of health, health outcomes and health service utilisation. For example, kaumātua discussed the benefits of utilising the Maori model of health, ‘Te Whare Tapa Wha’ as a possible framework for generating solutions related to effective osteoarthritis-management resources, and considering progress towards achieving equity in health outcomes within the community.

Also to emerge from data, presented within the framework (Figure 5, Column 3), ‘Access to treatment options, healthy foods and lifestyle choices’ (‘Oritetanga’) is another enduring organising theme. The findings confirm the literature concerning the overriding importance of promoting osteoarthritis-management for kaumātua is an imperative of increasing effective access to health information, support and services. An appraisal of the research findings demonstrated manākitanga via kind support (particularly that which enhances Māori mana) underpins perceptions and acceptability of osteoarthritis-management practices, but is not exclusive to osteoarthritis-management activities.

Finally, to emerge from data, presented within the framework (Figure 5, Column 3), ‘Enhance the quality of life for kaumātua’ (‘Oritetanga’) theme emerges. The findings confirm the literature of the overriding importance of a range of connections to kaumātua, such as place, space, people, experience between peers, family members and healthcare practitioners. Quality time spent with mokopuna (grandchild[ren]) was an important factor for kaumātua through a range of topics concerning their health, medications and wellbeing seamlessly to meet immediate need and that of future generations.

Potential indicators taking shape

The research question of the present study asked what the everyday experiences of kaumātua were, with regards to living with a chronic condition, and in particular osteoarthritis. It was evident from the stories shared by kaumātua interviewed, that their level of knowledge reflected lived experience and perceptions of living with and managing, osteoarthritis. In so far as reinforcing data from health-management research (Ahu et al., 2014; Ministry of Health, 2014c; Workbase Education Trust, 2014), key-kaumātua interviews, suggested there being low-levels of knowledge and awareness about chronic conditions occurring in the Māori community.

Key-kaumātua who participated in the interviews, represented community members living with osteoarthritis. All of whom were both knowledgeable and vocal in discussing issues, regarding the obstruction of social justice faced by Māori. Experiences in connection with the presence of osteoarthritis in the community, accompanied by knowing little about the condition in the Māori community, has implications for an osteoarthritis-management resource (resource). As a result, potential indicators and approaches to the resource also begin to take shape at the analysis stage.

In the literature review, I made an argument that what is needed is effective osteoarthritis-management resources and initiatives. Especially if the disconnection between biomedical knowledge of osteoarthritis and the cultural and experience based beliefs that influence the decisions of kaumātua to manage their condition are to be addressed. As an example, it was clear throughout the interviews with kaumātua that a biomedical model of osteoarthritis does not always fit well with many Māori living with degenerative joint disease. Interviewees shared that speaking in 'plain language' was a promising strategy for communicating osteoarthritis-management clearly, for better information transmission.

Interviewees also talked about there being a more holistic approach to osteoarthritis-management, namely incorporating elements of 'Te Whare Tapa Whā'. In comparison to a mainstream model of care, kaumātua described preferences for services, where exploring the past and whānaungatanga (sense of family connection) was centralised to osteoarthritis-management. One of the interviewees reiterated that their joint condition for instance meant that the wairua, the mental, the physical and the social, were all working together to emphasise a sense of wellbeing.

Osteoarthritis-management related activities such as lifestyle and dietary choices or physical activity, required consideration according to Māori cultural contexts and established cultural norms. Such as those concerning the manner in which osteoarthritis is experienced and understood by kaumātua, than from a biomedical perspective alone. The latter points were supported throughout key-kaumātua interviews and data analysis.

Also, there was a clear disconnection throughout key-kaumātua interviews between what is known about osteoarthritis, and kaumātua priorities about managing the condition. Mostly these were situated within a framework of social, economic, political barriers, which were impeding ability to manage osteoarthritis. The contrast between the biomedical model, and Durie's (2001) concept of hauora Māori theory was a suitable illustration of concerns for kaumātua as they seek osteoarthritis-management and wellbeing.

Provisional findings from interviews

There were eight provisional (organising) themes (Table 13) and three main/global (overarching) themes (Figure 5), which it was decided would need to be followed up in a focus group hui. Priorities concerned broadening osteoarthritis-management resources. Also, the burden of osteoarthritis and role of whānau was significant. What is more, the interviewees raised matters pertaining to autonomy and independence, which led me to question further, what kaumātua view as promoting their ability to participate in whānau and community events.

Additional priorities flagged for exploration through a focus group hui concerned kaumātua health values and preferences, pertinent to accessing services. What is more, a number of barriers were evident, alongside ingenious ideas about osteoarthritis-management, which could be shared amongst kaumātua rōpū. On top of that, the idea of kaumātua tailoring osteoarthritis-management activities to their own circumstances, would need to be further explored through a focus group.

Another priority that was carried through to a kaumātua focus group hui was about their preference for services, testing the idea of constructing an osteoarthritis-management resource. A further priority concerned ascertaining sources of support, there being a need to recognise the links between kaumātua their health, their social contexts, and related actions taken, to improve health and reduce health inequalities (Bodenheimer et al., 2002; Harris et al., 2006a, 2006b; Nuovo, 2010). Finally, a focus group it as thought could potentially give prominence to experiential knowledge, with kaumātua and their peers coming together to talk about possible strategies (the outcomes pertaining to these priorities follow).

Focus group hui: Discussion guide

Following key-kaumātua interviews, a subsequent stage of the research concerned conducting a focus group hui. That is to say, the hui focussed on exploring the experiences of kaumātua with osteoarthritis, such as their beliefs and attitudes concerning their condition. Exploring their experiences is critical in the research, with an approach that prioritises tīkanga (cultural principles) while engaging in research, such as karakia tīmatanga and karakia whakamutunga (opening and closing blessing for focus group hui).

Moreover, as Ko Awatea & Counties Manukau Health (2016) argued, the tangible success of community initiatives will depend on culturally relevant design. Particularly there is a need to pay careful attention to historical, social and environmental barriers, as well as community attitudes, beliefs and norms. Even so, there is little in the way of published literature on Māori knowledge or beliefs with respect to osteoarthritis, or more in-depth knowledge concerning the ways in which Māori with chronic conditions were spoken to in research initiatives, or what they were asked, and how the information was analysed.

The literature review of the present thesis, demonstrated that despite several attempts to obtain more in-depth knowledge from initiatives engaging in self-management, these were not fruitful. It was assumed that in most cases, the determinants of health for Māori were used, rather than the specific knowledge of community members living with, and managing osteoarthritis. For these reasons, it is important that any interview or focus group guide, needs to make sense to kaumātua, and be useful for stakeholders and community partners.

In order to fulfill the requirement of grounding the research within each participant's own sense-making, interviewees were invited to offer any advice on the focus group (hui) questions, concerning structure and wording. Not only that, their opinion was sought as to the most ideal approach to obtaining appropriate information, or whether there were any particular ways that hui should be conducted. At the end of each key informant interview, a draft focus group hui discussion guide (guide) was provided, explained, and feedback sought on the structure and wording, resulting in minor changes.

The guide was then adapted to enable the exploration and extension of emerging themes from the arising interviews (see Appendix 4: Focus group hui guide). Questions explored understanding of osteoarthritis, barriers and enablers to hauora. In the following sections, the results from focus group (hui) are presented, and how data analysis reinforced the key interview findings. In-depth data was generated from the hui, concerning the everyday experiences of kaumātua with osteoarthritis. After providing relevant illustrations, a discussion pursued significant implications arising from the research data to guide the viability of an osteoarthritis-management resource.

Once again following Braun & Clarke's (2013) method of thematic analysis, coding for basic elements of meaning were applied first to the data. Following the previous analysis of key-kaumātua interview data, a similar process was adopted, which involved assigning initial/basic codes, searching for themes. Similarly, I created tables providing a summary of the analysis to utilise during talks with my advisors.

Focus group hui: Analysis

I utilised a procedure similar to that adopted in the analysis of data pertaining to three stories and key-kaumātua interviews, with the focus group hui data. Precisely, I set about coding for basic elements of meaning. As before, I followed Braun & Clarke's (2013) six-stage method of thematic analysis.

Data analysis of focus group hui

After completing an inductive thematic analysis on the data pertaining to the focus group hui, 49 initial/basic codes emerged from participants' stories. These basic elements are presented (Table 14):

Table 14. Focus group hui 49 initial/basic codes

49 Initial/basic codes

1. Wairuatanga is reality
2. Taking action relieves fear
3. We want to take charge of it
4. Osteoarthritis is a reality
5. Family and whānau live with it
6. What is causing it?
7. It’s inevitable
8. Diagnosis can be a big shock
9. Manual labour has taken its toll
10. It’s part of getting older
11. Learning in a hui is a relief
12. Preventative measures are not well known among kaumātua
13. Listening to others helps me understand my own condition better
14. Getting on a positive momentum
15. The diagnosis label is frustrating
16. Being shown how to navigate resources is great!
17. We want to find out more about helping ourselves.
18. We want to stay independent!
19. Prevention impacts whānau
20. Reality is constantly living in fear of loss
21. Staying healthy for mokopuna
22. The big picture of osteoarthritis
23. Being healthy is spiritual
24. Healthy means making changes that includes whānau
25. Time spent with whānau means having something to look forward to.
26. Participation is healthy
27. Incorporating exercise into everyday routines is essential.
28. Unintentional exercise makes you feel more energetic and ‘free’
29. Exercising with whānau is a proud feeling
30. Some whānau find change difficult
31. Home-grown initiatives keep us healthy
32. Roles in the community are important to us
33. We enjoy developing and supporting Māori
34. Our knowledge is in and of itself a form of positive role modelling for others who fear growing older.
35. Leading by example
36. Supporting everyone
37. Promotes planning and delivery
38. Reflect realities (Māori values)
39. Osteoarthritis keeping it real toolkit
40. Simple to administer
41. Encompass complexities
42. Can be coordinated by kaumātua facilitator within a hui forum
43. Can be coordinated between practitioner-patient and wider
44. Implemented within a few minutes
45. KISS acronym: Keep It Simple and Smart, i.e., culturally relevant
46. It’s about transforming our circumstances
47. Support learning in culturally safe environments
48. It’s about sharing the lived experience of osteoarthritis with real people (kaumātua).
49. It’s about dealing with the realities of the condition

These initial/basic codes were then reviewed and arranged into a further eight higher level (provisional/organising) themes (stage-four). The provisional/organising themes follow from the interviews (Table 15):

Table 15. Focus group hui eight provisional/organising themes

Eight provisional/organising themes	
1. It's about time Wairuatanga, it's reality; Taking action relieves fear; We want to take charge of it	**5. Fun, laughter and manākitanga** Participation is healthy; Incorporating exercise into everyday routines is essential; Unintentional exercise makes you feel more energetic and 'free'; Exercising with whānau is a proud feeling; Some whānau find change difficult
2. It's reality in our community Osteoarthritis is a reality; Family and whānau live with it; What is causing it?; It's inevitable	**6. Favourite supports** Home-grown initiatives keep us healthy
3. The truth about osteoarthritis Diagnosis can be a big shock; Manual labour has taken its toll; It's part of getting older; Learning in a hui is a relief; Preventative measures are not well known among kaumātua; Listening to others helps me understand my own condition better; Getting on a positive momentum; The diagnosis label is frustrating; Being shown how to navigate resources is great!; We want to find out more about helping ourselves; We want to stay independent!	**7. Valued roles** Roles in the community are important to us; We enjoy developing and supporting Māori; Our knowledge is in and of itself a form of positive role modelling for others who fear growing older.
4. Prevention is about whānau Prevention impacts whānau; Reality is constantly living in fear of loss; Staying healthy for mokopuna;The big picture of osteoarthritis; Being healthy is spiritual; Healthy means making changes that includes whānau; Time spent with whānau means having something to look forward to.	**8. Resource toolkit** Leading by example; Supporting everyone; Promotes planning and delivery; Reflect realities (Māori values); Osteoarthritis keeping it real toolkit; Simple to administer; Encompass complexities; Can be coordinated by kaumātua facilitator within a hui forum; Can be coordinated between practitioner-patient and wider; Implemented within a few minutes; KISS acronym: Keep It Simple and Smart, i.e., culturally relevant; It's about transforming our circumstances; Support learning in culturally safe environments; It's about sharing the lived experience of osteoarthritis with real people (kaumātua); It's about dealing with the realities of the condition.

Once again, the results (Table 15 above) were organised into a brief format that my cultural advisor and academic supervisors (advisors) clarified was easily understandable. In addition, the findings were generated in non-academic language and incorporated into a leaflet to share with my advisors, where themes were grouped alongside some of the interviewee's responses. In addition, for the purposes of generating discussion and analysis, a range of initial observations were made.

Eventually eight provisional/organising themes arising from the focus group were defined, named and organised. These themes supported the three overarching, main/global themes from the interviews (1. Manākitanga (kind support); 2. Tino rangatiratanga (self-determination); 3. Oritetanga (equity and assessment). The results were presented to my advisors. As before, a hui was held in which the research was discussed and later shared with people in the community who had shown an interest.

As intrigue in the present project was building, copies were provided to kaumātua working within Māori health, who had attended the focus group, to share with peers and healthcare providers. As with the stage of the research involving key-kaumātua, interview analysis and higher level provisional/organising themes were confirmed. Themes were named and organised. In the process three overarching, main/global themes arising from the key-kaumātua analysis were identified, for further development and presentation to advisors to confirm accuracy (presented in the following section). The following section details an 'ice-breaker', that was utilised in focus group discussions.

Focus group discussions

As an 'ice-breaker', the focus group participants (hui participants/Mihiroa rōpū) were asked to share their experience of the everyday effects of their condition. As hui participants shared their limitations in activities around the home and in the community, they said that it was about time attention was put on osteoarthritis-management. One kaumātua participant said that humour and singing had helped them through the emotional pain of standing for long periods during tangihanga with 'swollen, crooked' ankles and knees. Threaded through living with osteoarthritis-related pain and changes to physical appearance, kaumātua expressions of wairua (spirit) and wairuatanga (spirituality) was that, it's [wairuatanga] a reality, which held potential for enhancing one's physical state.

In addition to experiencing swollen joints that had a tendency to buckle and 'give way', kaumātua hui participants felt that they preferred options for seating that were supportive with arms that enabled them to rise easily to a standing position. Plastic chairs were most feared, after one kaumātua participant had a plastic chair collapse from under them at a marae, resulting in them becoming increasingly selective and cautious about seating arrangements in new environments. Taking action to reduce risks in new environments could make alleviating your fears and anxiety a reality.

All of the kaumātua hui participants spoke about the uncertainty of being able to be physically active with osteoarthritis-related limitations relative to their everyday activities. The most difficult limitations included doing heavy household duties or leisurely activities such as cycling, with participants confirming that they wanted suggestions about coping and taking charge of their condition. These findings substantiate previous academic research that leisurely and household physical activity is extremely important for kaumātua (Dyall, Kerse, Teh, & Wham, 2011)[96], as hui participants signalled a need for strategies to help them maintain independence and quality of life.

It's reality in our community

During the focus group hui, and after sharing their experience of osteoarthritis, Mihiroa rōpū were asked about their perception in our community of osteoarthritis. For instance, whether negative effects of osteoarthritis out in the community is a reality. All of the hui participants had previously observed during their participation in key-kaumātua interviews, that within their own community, 'it's (the incidence of osteoarthritis) reality'.

The hui discussion substantiated observations concerning prevalence as all hui participants spoke of knowing family or whānau members that were living with osteoarthritis. Most hui participants spoke of multiple family members that were living with the condition, with one sharing that the condition had been present in her family as long as she could remember. For instance, her parents and grandparents, siblings, and particularly the eldest two.

Despite the fact that osteoarthritis was prevalent in families, there was no correlation to an understanding concerning self-management. Even in families where the condition was prevalent, an understanding concerning the cause of osteoarthritis was not being carried over to other family members. Kaumātua participants spoke of having no understanding of their condition when they were first diagnosed, they were keen to know what was causing 'it' (osteoarthritis).

For some kaumātua focus group attendees, osteoarthritis was to be expected (the condition was inevitable). Especially, given their family history, and perception of 'joint wear and tear' being a hereditary condition (inevitable attitude) which commonly led to pain and disability. The implications being that an 'inevitable attitude', could contribute to the belief that there are few benefits derived from osteoarthritis management. Kaumātua reflected on growing up knowing about osteoarthritis, but not being informed about the causes, range of symptoms, or whether it was possible to prevent the condition. There was an expectation that they (kaumātua (participants))

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[96] Dyall, Kerse, et al. (2011) measured Māori and non-Māori, aged between 78 and 90 years. Precisely their current levels of leisure, occupational and household physical activity. The findings revealed median physical activity scores were signicantly higher for for Māori (than non-Māori aged 85 years, particularly for leisure-time activities (such as walking, swimming, equipment-based exercise, bowls, fishing, golf, dance, pilates, cycling) and household-related (for instance, vacuuming, gardening) activities.

would also be diagnosed with osteoarthritis, enabling some participants to rationalise the cause of their diagnosis.

The truth about osteoarthritis

As demonstrated in the the previous section, kaumātua shared their direct experience of family members living with osteoarthritis. The direct experiences of kaumātua did not always equate towards a better understanding of the condition. Interviewees continued to talk about their perception of osteoarthritis as they shared that prior to their condition first 'flaring up', that they were unaware of how to deal with osteoarthritis. Some kaumātua hui participants conferred that the truth about osteoarthritis is that when you are diagnosed it is a 'big shock', particularly when you think that you are living a relatively healthy life, and did not 'drink' (alcohol) or 'smoke' (cigarettes).

Hui participants did, however, discuss that their work over the years had taken its toll on their joints. Some misconceptions about the cause of osteoarthritis revealed uncertainty about specific activities that could benefit osteoarthritis, the weather and sitting on cold surfaces and dressing inappropriately. A history of manual work, or the lack of hinu (oils) in the diet, were also considered by kaumātua as a possible cause of osteoarthritis.

One hui participant said that in the course of their employment history, having to immerse their hands in ice-cold water for long-periods of time, canning at Heinz Watties[97] and working many long hours at Whakatū freezing works had resulted in osteoarthritis. These findings substantiate Vera Keefe-Ormsby's (2008) research in Hawke's Bay, documenting the consequences of working in manual labour that were evident in older workers:

> You can tell a freezing worker. You only have to look at his hands. It's hard work alright. You don't really notice it until you get a bit older. When you're younger you're running up those stairs. To the latter years we had a lift and even the younger ones used to take the lift. Some of the old fellas, they'd only walk a couple of steps and then they'd stop and you wondered how they coped on the job, but that was their life' (Men's Focus Group) (p. 40).

Vera Keefe-Ormsby's (2008) research was validated in the present research, by the Mihiroa rōpū. Particularly, as each participant was invited to share their awareness of the causes or symptoms of osteoarthritis, the men confirming that prior to receiving their diagnosis, that they did not know about the condition. Despite having conversations with their doctors, they considered their condition was caused by getting

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[97] Canning at Heinz Watties refers to a labour intensive process where the hands are required to cut, lift, pull and push in the processing of preserving fruit and vegetables into cans for sale in supermarkets.

older. Many spoke of noticing themselves slowing down to some degree (such as difficulty walking up stairs), and admitted that it was a relief to know that they were not the only one that felt that way.

One hui participant spoke about the importance of exercise, eating less, culturally relevant food preparation and exercise, as helping osteoarthritis. Out of the whole group, only one individual made specific reference to exercise and diet being preventative measures for osteoarthritis. During the hui, a male participant shared that listening to peers had reminded him of how much his knee had improved (possibly slowed the deterioration even), since taking up biking around Hawke's Bay's cycle trails.

These links were being made as the hui unfolded between osteoarthritis prevention and exercise. Another kaumātua admitted that in addition to starting up an exercise routine that they would like to change their dietary habits, and get on top of their weight (change their eating habits). They shared that changing their eating habits was all about keeping the momentum going, getting on that momentum and then, positive events for wellbeing were more likely to eventuate.

These comments from kaumatua suggested that some participants who were engaging in exercise, were motivating peers to make lifestyle adjustments. One kaumātua for instance, talked about discovering that they had been diagnosed with osteoarthritis, after attending a fitness check at a marae. They expressed their frustration at receiving their diagnosis initially and tried to forget that they had been given the 'label' of osteoarthritis as such.

Overall, the group appeared to be in agreeance of how enjoyable it was to be able to share their experiences and support one another, particularly as some members of Mihiroa rōpū had experienced injurious falls. The kaimahi shared that by listening to others, that he was also learning from the discussions. At the same time, I distributed Southern Cross and ACC literature around the participants[98].

My experience of outlining the information contained within the literature, and how to navigate the same resource online was useful. I sought to identify, evaluate and change misconceptions, as an appropriate and ethical response. Identifying and dealing with misconceptions was met by great (positive) feedback from hui participants.

All of the participants agreed that their priority was to find out more about helping themselves. A focus group hui was the forum that kaumātua enjoyed learning about ways to prioritise self-care. The kaumātua hui participants were keen to learn more about how they could improve their strength and balance. The reason discussed,

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[98] See, "Osteoarthritis-symptoms, diagnosis, treatment" - southerncross.co.nz and "Staying safe from trips and falls – acc.co.nz).

was that primarily everybody wanted to stay independent into their retirement for as long as possible.

Prevention is about whānau

The kaumātua hui participants were asked to share their experience of osteoarthritis, and how much these impacts had affected their being a part of the whānau, since obtaining a diagnosis. They shared that over the course of their working lives they had experienced pain, but the nurse at Heinz Watties would tape-up (splint) their wrists and tell them to get on with the job. They wished that they had known the damage that they were doing to themselves and ultimately their family over time, resoundedly conveying that the motivation for osteoarthritis-management and prevention is about whānau.

One of the women spoke about worrying about her osteoarthritis worsening and impacting on whānau, as she did not want her condition to affect her energy levels and her duties to 'being there for mokopuna' (grandchildren). She looked forward to having mokopuna to stay, dropping them to Kōhanga Reo (Māori language pre-school) was an important part of her day. Nevertheless, she was nervous about what might happen if her joint pain became worse, osteoarthritis represented a reality of constantly living in fear of loss.

A Māori understanding of health was expressed of the following question, there being a resounding response from all participants as they were asked, 'What does being healthy mean to you?' The response given was that kaumātua participants wanted to stay healthy, for the sake of the mokopuna. Participants spoke that it is their role in whānau that gives them strength to focus on maintaining health and wellbeing.

In many instances, kaumātua participants' thinking concerning 'being healthy', is best described from a Māori understanding. Participants reinforced observations from key-kaumātua interviews, of the preference for a holistic approach to osteoarthritis care. For instance, one participant spoke that understanding the 'big picture of osteoarthritis' would be better done less by dividing osteoarthritis-management into smaller and smaller parts, because Māori do not think on an individual basis alone, but on a collective level.

One participant shared that being healthy is not only about medical care but for kaumātua, there is a spiritual dimension, and having whānau supporting you was a big part. Being healthy was making changes that included whānau. Examples were exercising with mokopuna, eating healthy kai with whānau and making preparations for the future together, along with always having something to look forward to.

Fun, laughter and manākitanga

Being healthy was also about participating in whānau and community events. Some of the kaumātua participants shared the fullness of their diaries that included land meetings, community development committee hui, matariki celebrations, whakamana wānanga, kapa haka competitions, koroneihana, IronMāori kaumātua visits, pa sports days. Participants discussed that community events which brought fun, entertainment and laughter, were mana enhancing, and ultimately about manākitanga.

Kaumātua participants spoke about spending time as children attending events with their elders. Those days were much simpler without much of the technology that is seen nowadays, and kaumātua held hope that the younger generations would become more active. Participants reflected as young people, that they were always outside, crossing rivers and streams roaming freely, so things were quite different for the younger generations of today where most of the activities are supervised, and the car is used more. Whānau have to focus more on incorporating exercise into their everyday routines.

One kaumātua participant shared her approach to 'unintentional' exercise, such as 'bucketing water' around the plants in the garden, weeding and planting. Another participant admitted to storing things on higher shelves so that they would have to stretch, chopping wood and biking, rather than taking the car or mobility scooter were all ideas that were shared. Kaumātua participants also admitted that not only did these types of exercise make them feel more energetic, they diverted attention away from thinking about ones' ailments.

The cost of gymnasiums to help keep fit through exercise, was considered a barrier to exercising, alongside not having transport, time and osteoarthritis. Whānau were also an inspiration to exercise, as one participant spoke of exercising with his grandson, whom he was proud of. He enjoyed relaying how many hills his grandson was able to run up, and that he felt really proud about his running times.

On the whole, hui participants felt that most of their whānau were living healthy lives, but there were one or two community members that were peceived as struggling to manage their condition. At times, certain whānau members were noted for making hui participants feel tired, trying to encourage them to make better lifestyle choices. Following Durie (1994a), the realities of coping with a chronic illness can be explained by the socio-economic realities and dominant values of society, that emphasise individual lifestyle choices than a focus on how whānau are maintaining their Māori identity (Durie, 1994a).

Favourite supports

Maintaining Māori identity was evident in the manner by which kaumātua participants answered a question concerning, their 'favourite' supports in the community. The hui participants made clear that in the community, what is making the difference is home-grown initiatives, that are working in partnership with local iwi or mainstream healthcare services. For example, Kaumātua ora, which is based on a Māori kaupapa and whānau values that work together to encourage Māori and the whole community, to live a healthier lifestyle[99].

Valued roles

When asked whether there was anything that hui participants would like to share, that they found to be helpful for their wellbeing and therefore osteoarthritis, mostly discussion revolved around their roles in the community. All kaumātua were in some way engaged in developing and supporting healthy family and whānau, hapū (extended family) and iwi. In doing so, the presence of kaumātua frequently provided guidance on matters, reiterating that often small steps are achievable and easier to fit into the daily routine, than big (sudden) changes.

Also, hui participants spoke about adapting to the death of loved ones, poor health and trauma among their family and whānau. The burden of loss is something that Dyall, Hayman, Kēpa, Kerse, and Skiller (2013) observed. In effect, that adapting to challenges in life was in and of itself, positive role modelling by kaumātua. Especially for those members who feared growing older, that it is possible to overcome difficulties when you make small, realistic adjustments to good health, one step at a time.

Resource toolkit

At the end of the hui focus group, a brief concluding discussion eventuated, concerning the kaumātua participants needs as I asked, "what do you need to manage your osteoarthritis?" Hui participants admitted to being less interested in medical interpretations of osteoarthritis. One kaumātua participant gave a detailed argument, that osteoarthritis-management strategies should be lead by kaumātua setting examples (leading by example).

The argument that kaumātua should lead by example, was also reiterated throughout previous hui participant discussions (see, 'Valued roles'). Precisely positive

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[99] Kaumātua ora a primary healthcare programme that are run by kaumātua and Māori health workers within a culturally safe environment. Aunty's Garden at Waipatu Marae by Aunty Hanui Lawrence is where marae-based, full-time horticulture courses are being provided and produce sold locally. IronMāori is a half-iron Māori event.

role modelling for mokopuna, so that they know how to apply the same management and preventative measures. After listening to kaumātua, I was asked by Mihiroa rōpū about my perspective regarding osteoarthritis-management, as to what may assist kaumātua needs. I spoke about that coming from a healthcare practitioner perspective, having something that helped to get kaumātua, family, whānau (everyone) talking about osteoarthritis-management, would be a huge bonus to everyday healthcare practice.

Further, I spoke with hui participants from a practitioner perspective, that having a resource such as a toolkit that promoted planning and delivery of initiatives, using a culturally appropriate approach could benefit everyone. I also shared that similar to Kingi's (2002) Hua Oranga[100] framework, that a useful toolkit which took less than four minutes to administer by the patient, their family and whānau or practitioners would be advantageous in a busy clinic environment. One participant said that a resource would need to reflect the realities of osteoarthritis and Māori values, leading me to ask whether there being a need for an, 'Osteoarthritis-management toolkit' resonated with the participants.

Kaumātua hui participants came to a positive consensus, concerning the latter idea of an 'Osteoarthrtis-management toolkit'. Additionally that the toolkit would need to be simple to administer, yet able to encompass the complexities of living with osteoarthritis. Overall, kaumātua felt that having a toolkit resource would need to be amenable to being coordinated by kaumātua (kaimahi), within a hui forum.

I also spoke about the importance of 'usability' from a practitioner perspective, because I am working one-to-one with kaumātua in my clinical situation and at other times in one larger group with their family and whānau, so a useful toolkit would need to be adaptable. Finally, as clinical interactions are time-limited, that it would be important for any arising osteoarthritis-management resource, to be able to be implemented rapidly, i.e., within minutes.

Some hui participants reflected that ideally, the resource would need to follow the old adage and acronym of KISS (for Keep it Simple and Smart!). The reason for KISS was that the resource should be amenable to a range of contexts that are relevant to everyday living. For instance used within kaumātua hui, culturally appropriate healthcare practitioner premises, or even at home with whānau. The conversation followed that simplicity was the ultimate sophistication, meaning the

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[100] Hua Oranga is a Māori measure of mental health outcomes, led by Te Kani Kingi and Mason Durie. Features of Hua Oranga are consideration for outcomes according to wairua, hinengaro, tinana, whānau and mental health outcomes Institute for Healthcare Improvement (2017b).

toolkit needed to be flexible in use, so that two people, or a whānau, through to a community hui of over a hundred may benefit.

Reflecting feedback from key-kaumātua interviews and data arising from the hui participants, kaumātua spoke that the ultimate aim of an Osteoarthritis-Management Toolkit was about transforming their circumstances. Further hui participants were interested in learning and engaging with others in culturally safe environments. There was an expectation that managing osteoarthritis was inherently connected to sharing the lived experience of osteoarthritis, with real people (other kaumātua with osteoarthritis in the community) that are also dealing with the everyday realities of the condition.

Frank and open communication

The hui encouraged frank and open communication between myself and the participants. Two of the participants spoke to me subsequently to say that they enjoyed the hui, because it was a comfortable way of sharing their experiences. On reflection, key-kaumātua interviews and focus group hui, helped to forge a clearer pathway on the kaupapa of osteoarthritis-management with kaumātua.

Hui discussions revealed the prevalence of osteoarthritis in the community, with most kaumātua directly experiencing family members living with osteoarthritis (the condition). Even so, it was not evident that family experiences of the condition was being generated into knowledge concerning osteoarthritis-management. Data arising from the hui, confirmed there being a common misconception concerning osteoarthritis, the causation of the condition being due to exposure to cold.

As indicated by the interviews previously, living with osteoarthritis was conveyed as being 'normal for getting old', with numerous kaumātua participants conveying that diagnosis eventually was inevitable. Also, there was a great deal of fear, grief and suffering around the condition, that often led to pain and disability. Most importantly, a predominant motivator for kaumātua to maintain and aim towards good health and wellbeing, was about being present for the mokopuna.

There were also considerable barriers to good health that included time, cost, transport, and osteoarthritis related pain and disability. Some participants felt that some whānau members struggled to make better lifestyle choices, which could be explained by the dominant values of society, socio-economic realities, as well as emphasis on individual lifestyle choices and how whānau have maintained their identity. These findings underscored the challenges of managing osteoarthritis, and the sedentary nature of the younger generation was noted as a significant challenge to osteoarthritis-management.

Summarising Preliminary findings

By now, the present chapter has identified there being potential key indicators. Comparable to the previous stage of research, misconceptions concerning osteoarthritis were recognised. Expressly that osteoarthritis was an inevitable part of ageing that often led to pain and disability, with uncertainty regarding prevention and management that needed to be addressed.

Another key finding was that mokopuna provide encouragement to kaumātua who are striving to be healthy, also important was 'being there' for whānau. In addition to these points, my academic supervisors and cultural advisors (advisors) also agreed that barriers to accessing services would have a bearing on an osteoarthritis-management resource. In particular, there being a need for kaumātua to be able to assess their experiences of services and initiatives, via the osteoarthritis-management resource (toolkit).

It was also felt that the toolkit would need to be amenable to use within hui ideally. It would be important to enable usage of the toolkit by kaumātua, healthcare practitioners and other stakeholders. Employing the toolkit within community hui would enable drawing on the expertise of kaumātua, kaimahi, practitioners and stakeholders (encouraging collaboration) to counter the prevailing sense of inevitability (that osteoarthritis is about getting older, living in pain and disability), seemingly common throughout the community. Encouraging collaboration may shift a sense of inevitability, onto forging more of a clearer pathway concerning the kaupapa of osteoarthritis-management.

In the following chapter, how the research data was carried over into an appropriate osteoarthritis-management resource, representative of kaumātua knowledge is presented. The application of Māori-centred theory drawing on kaupapa Māori principles and the mātauranga of Māori scholars and experts is described. Talks held with my advisors about the resource will be outlined, alongside explaining the imperative of refining the osteoarthritis-management resource through an additional hui. The chapter that follows, explores application of hauora Māori theory, in the process of theorising outcome indicators of osteoarthritis-management.

Chapter 6: Osteoarthritis-management resource (Theorising Outcome Indicators)

Introduction

The present chapter aims to explain the major findings from the key informant interviews (interviews) and focus group hui. Specifically how these informed the osteoarthritis-management resource, in so far as content and indicators. The role of kaumātua in shaping the osteoarthritis-management toolkit was imperative in the research. Maintaining a commitment to the ongoing participation of kaumātua, aligned with a Māori-centred research approach and my awareness of the health literature, suggesting that theoretical indicators have been absent from self-management initiatives with Māori.

During December 2016, I contacted all of the participants, to advise them of the data analysis, and arising organising themes. A note enabling me to touch base, with all of the participants, was met by positive responses of encouragement. I also met with my academic supervisors and cultural advisors (advisors) to ascertain the approach towards, and content of, an osteoarthritis-management resource.

Together, my advisors and I reviewed the key themes arising from interviews and hui, alongside the non-technical report that went out to kaumātua summarising the data. First, immersion in the details and specifics of the data led to us asking, 'What did kaumātua want to know about osteoarthritis-management?' In other words the motivations establishing kaumātua to seek out new choices (knowledge) that promote wellbeing.

What did kaumātua want to know?

Durie (2003) stated that beyond lifestyle and personal risk, chronic diseases were associated with social disadvantage. The effects of colonisation, cultural imperialism of colonising powers and racist philosophy have all contributed to creating disadvantage. Expressly physical, social and spiritual disadvantage.

These disadvantages provide a backdrop, against other causative interactions and factors (obesity, smoking, physical inactivity) which Durie (2003) termed, "post-colonial traumatic stress disorder" (p. 189). Durie (2003) went on to discuss that against the face of causative interactions and factors implementing, "strategies for change" is the first step required and knowledge about risk factors. Similarly, throughout kaumātua stories, a recurring theme was a desire for strategies for change, to better manage osteoarthritis.

Strategies for change

The data arising from the present research suggests that community knowledge about osteoarthritis is at low levels, and it was agreed that improving health literacy at the local level required more people to be talking about the condition. Therefore the osteoarthritis-management resource is established on the premise, that although the condition is a considerable health concern for kaumātua that it may, however, be managed and is amenable to strategies of change. The ideal forum for using an osteoarthritis-management resource could be hui amongst kaumātua, with healthcare practitioners, experts, kaumātua facilitators,, to encourage people to start talking about addressing common misconceptions about osteoarthritis.

What represents a culturally appropriate resource?

In addition to answering 'what did kaumātua want to know?', the second question we (advisors and myself) asked of the data was, 'what did kaumātua (the collective) believe would represent a culturally appropriate resource?' The 'KISS' (for Keep it Simple and Smart!) acronym mentioned by kaumātua during hui, could it was thought enable the toolkit to be used in a range of contexts that required holding to Māori values, yet keeping osteoarthritis-management related activities simple which was about getting things done (achieving health equity). Weaving all these elements together promotes collaborative communication, making the toolkit ideally suited to a group enviroment, i.e., hui, culturally appropriate healthcare practitioner premises, or even at home with whānau.

The ultimate objective of a toolkit

Following answering 'what did kaumātua want to know', and 'what represented a culturally appropriate resource', a final question was offered. That is to say, 'What is the ultimate objective of the osteoarthritis-management toolkit?' The key message to emerge was that the toolkit needed to address the misconception that osteoarthritis is inevitable, giving power to positive culturally appropriate strategies for change.

Appropriate strategies were outlined in the data of the present research as kaumātua conveyed the idea that being healthy was about understanding the, 'big picture of osteoarthritis'. Being healthy for Māori is based on a holistic perspective. Other strategies that came through from the data were that making changes impacted on the family and whānau, osteoarthritis is a community responsibility. Taking small steps were also advocated for which need not be expensive, the example of 'unintentional exercise' was offered by kaumātua.

By focusing on the power of the group environment to learn about osteoarthritis-management, the toolkit will be more likely to make a long-term contribution. Not only will it provide a talking point, but bring an assessment component. Namely, allowing kaumātua to assess their needs and priorities for osteoarthritis-management and collaborate with others (peers, healthcare practitioners and other experts) about their condition, and determine appropriate strategies for change.

Kaumātua collaborating with experts

Arising from my talks with advisors, was that kaumātua were more comfortable with the idea of adapting to small steps, towards change. For instance, kaumātua could bring healthcare practitioners and other experts into their hui to share perspectives. The toolkit may potentially be used as a mechanism for collaborating, to determine what is working well and what could be working better.

An example of use of the toolkit could be during kaumātua hui, where healthcare experts are often asked to present on matters pertaining to health promotion. A physical activity expert for example may be guided through the toolkit with kaumātua to promote collaborative discussions, enabling the expert to understand kaumātua aspirations, from their value-base. Together they would be able to work together to ascertain realistic strategies that are applicable to their lived experience of osteoarthritis.

Experts collaborating with kaumātua

From a practitioner perspective, I also realise the toolkit has potential to my clinical practice, when working with kaumātua. For instance, the toolkit may be utilised as a collaborative mechanism within a culturally appropriate clinical environment. The toolkit may be able to allow me to determine what is working well for kaumātua, and what could potentially be working better, based on their value set.

An example of use of the toolkit may be that during a clinical treatment, as a healthcare practitioner, I might be able to explore areas that kaumātua aspire to see changes. In the case of physical activity for instance, we might use the toolkit to explore these aspirations from their value-base. Connecting kaumātua aspirations to expectations, could enable collaborating across an osteoarthritis-management continuum, in a way that is mutually determined.

Hui with prominent kaumātua

As part of refining the osteoarthritis-management toolkit, I met informally with two prominent kaumātua hui facilitators (kaimahi) in 2016. Specifically, the hui was conducted at Mihiroa whare. The kaimahi (male and female) were over the ages of 65 years, one of which had been diagnosed with osteoarthritis. The goal of the discussion was to share my findings of the research (Appendix 2, Non-technical summary report) and seek feedback.

Kaumātua value-base

During my hui with kaimahi, I asked whether they would be open to me testing the toolkit and that I sought to receive their feedback on my analysis and interpretation of the research findings. I started by talking about the three main/global themes, asking whether kaimahi felt that these were representative of kaumātua living with osteoarthritis. The response was that the value, 'manākitanga' (kind support) was appropriate to the experiences of kaumātua, and that in order to work well, an osteoarthritis-management resource would need to start out, right from the 'manākitanga' (kind support) value, then tino rangatiratanga (autonomy and self-determination), and; oritetanga (equity and assessment) is more likely to naturally follow.

Furthermore, once kaumātua have been able to tend to the three dimensions ('manākitanga', 'tino 'rangātiratanga', and, 'oritetanga'), kaumātua, family and whānau will be in a suitable position to move towards action. For instance, helping to mobilise the community around the issue of osteoarthritis-management. The activism, advocacy, advice and support for kaumātua health and wellbeing, lead back to the place of 'manākitanga' (kind support).

Talking point

I then discussed the concept of an osteoarthritis-management toolkit (framework), specifically that the framework could be used to focus in on an area of concern for kaumātua with osteoarthritis. It was a flexible toolkit that would need to adapt to the changing needs, reflective of the variable nature of kaumātua circumstances and their condition. I gave the example of changing the misconception that osteoarthritis was inevitable, to the possibility that the toolkit could potentially be used as a talking point about potential strategies for change.

I demonstrated how an osteoarthritis-management toolkit could be used. For instance, I used the example of improving the physical activity of kaumātua as a group with a healthcare practitioner or expert in the field who could potentially work through rating potential areas for change, according to their value base and behaviours (values). Identifying osteoarthritis-management according to their values, it was decided, could enable ascertaining where whānau felt that kaumātua were positioned on a continuum (Table 16):

Table 16. Spectrum of rating options

Rating options
1. Not satisfied at all
2. Slightly satisfied
3. Neutral
4. Very satisfied
5. Extremely satisfied

As indicated in Table 16, the initial rating that I presented to kaimahi for the toolkit consisted of 1-5. The response from the kaimahi was that the rating did not resonate well with their strength-based stance, that kaumātua would probably feel very uncomfortable, rating healthcare practitioners, experts or initiatives a, "1. Not satisfied at all, or 2. Slightly satisfied". Kaimahi gave the example that not only may having five options be confusing, but the resource needed to reverse deficit perspectives and prioritise communicating positive stories of change throughout the community.

During the process of obtaining feedback from kaimahi , I realised that as much as I felt that I operated out of strength base model in my clinical practice as a healthcare practitioner, in reality I had much to learn. Kaimahi took a pen and marked a line through both options 1. Not satisfied at all, or 2. Slightly satisfied, leaving three remaining options. Obtaining the feedback from kaimahi was a reality check, finally a consensus was arrived at (Table 17):

Table 17. Adapted spectrum of rating options

Rating options
~~1. Not satisfied at all~~
~~2. Slightly satisfied~~
3. Neutral
4. Very satisfied
5. Extremely satisfied

As discussed by kaimahi, ‘Neutral’ would be a culturally appropriate indication, that there was scope for improvement. Kaimahi admitted that they preferred to build on the strengths of initiatives, than rating in a deficit manner. Also, it was felt that by presenting three measures (Table 17, above), would go some way towards ensuring toolkit usability for kaumātua, and keep to the kaupapa of KISS (for Keep it Simple and Smart).

Another area of discussion concerned the need for the toolkit to be flexible, so that various indicators may be used. A key concern in the community mentioned by kaimahi and kaumātua with osteoarthritis during interviews and hui, involved the need to gain a deeper understanding about osteoarthritis-management and counter misconceptions. Recognising a need to counter myths and misunderstandings about osteoarthritis-management led to asking, ‘Who is where? When? Doing what? (4w’s), which it was thought would facilitate conditions for mobilising support and referrals into culturally appropriate services in the community (see Table 18).

Table 18. Indicator description

Indicator description
1. Who is Where? 2. When? 3. Doing What? (the 4w’s)

The osteoarthritis-management toolkit contents were highly influenced by kaumātua facilitator (kaimahi) suggestions, as to what would be useful to kaumātua with osteoarthritis. As recommended by kaimahi, the toolkit needed to ‘stand alone’ and be applicable to all chronic conditions, not just osteoarthritis. Following the meetings’ conversational style (between kaimahi and myself), the preference of kaimahi was that I should take notes and participate actively, instead of focussing on audio recording the conversation or my computer.

At the time of closing our our hui, I undertook a review of my notes by summarising the main points kaimahi had made. I also asked kaimahi to verbally confirm that my observations and summary was an accurate reflection. Once I had secured confirmation of kaimahi, I incorporated these points immediately proceeding the hui into my reflective journal.

Toolkit testing

The first part of hui discussions with kaimahi were based around testing the toolkit. I put the toolkit in front of kaumātua, using a detailed handout. The handout presented an outline of the toolkit to kaumātua, presented below with the adjustment incorporating feedback from kaimahi, concerning 'kaumātua rating' (Figure 6, below):

Figure 6. Osteoarthritis-management toolkit

Questions	Indicator description	Kaumātua rating
(i) Manākitanga (kind support)		
What activities are you no longer able to do, that you wish you could do?	Who is Where? When? Doing What? (4w's)	1. Neutral 2. Very satisfied 3. Extremely satisfied
(ii) Tino rangatiratanga (self-determination)		
Are there opportunities to experiment with small changes?	Who is Where? When? Doing What? (4w's)	1. Neutral 2. Very satisfied 3. Extremely satisfied
(iii) Oritetanga (equity)		
Are there opportunities to explore strategies of change in culturally safe environments?	Who is Where? When? Doing What? (4w's)	1. Neutral 2. Very satisfied 3. Extremely satisfied

Toolkit purpose

I queried with kaimahi whether they believed that the toolkit (Figure 6) may be useful for kaumātua with osteoarthritis, family and whānau, their peers, healthcare practitioners, experts and kaumātua facilitators (kaimahi) (everybody). Kaimahi said that the toolkit is an elegant and shining example of valuing and upholding the taonga and dignity of kaumātua with osteoarthritis. Further, that osteoarthritis-management is about 'Manākitanga-ā-tinana' (a supporting indicator of my research), sharing resources to ensure that everyone benefits, and no-one misses out.

Represented as a culturally relevant approach to osteoarthritis-management and relationship-based care, The Toolkit (Figure 6) is consistent with three themes emerging from the data. Right from the start, kind support for osteoarthritis-management using self-determination. Moreover, that with these two values (‘manākitanga’ and ‘tino rangatiratanga’) in place, then equity (‘oritetanga’) may emerge. Kaimahi agreed that the kaupapa of getting everybody talking about osteoarthritis, was tika (correct) for promoting deeper conversations, to go beyond the ‘sore’ osteoarthritic knee or other physical complaint.

Further, kaimahi concurred that the more the community started to talk about osteoarthritis, the greater likelihood misconceptions will be reconceptualised, these concepts will become commonplace at the grassroots level, which is a positive move for health equity development. Some of the potential purposes that have been discussed concerning the toolkit as agreed by kaimahi are outlined in Table 19:

Table 19. Toolkit feedback

Potential purposes of the toolkit
• Get the community talking about osteoarthritis and strengthen referral networks between kaumātua and healthcare practitioners, by making information available using the 4w’s: who is (i) where? (ii) when? (iii) and doing what? • Provide a ‘big picture’ community perspective of osteoarthritis-management. • Identify misconceptions about osteoarthritis and enable coordinated action. • Improve transparency and legitimacy of Māori values through documented outcome indicators to monitor and draw lessons from. • Improve possibilities for future planning and delivery of osteoarthritis-management initiatives.

In addition, to some potential purposes discussed by kaimahi (Table 20), I also bring a clinician’s voice to the relevance of the toolkit. By way of example, the toolkit could enable decisions about osteoarthritis-management to be made closer to kaumātua in the community, in a flexible manner which may better meet the needs and aspirations of whānau. As a practitioner, the toolkit (it) could also enable me to collaborate and share power with Māori, empowering kaumātua in the process, for it encourages practitioners to ask, ‘who does have control?’ Further, ‘is control in the hands of mainstream or is control shared?’ or, ‘are Māori in control?’

In addition, the toolkit emphasises Māori experiences, for instance that we do not ask or say: ‘how can I adopt this osteoarthritis-management approach to kaumatua?’ Rather, the toolkit enables commencing first by asking, ‘what is important to kaumātua?', then ascertaining the best health outcomes and practice implications to meeting the needs of Māori with chronic conditions. Osteoarthritis-management may then become kaumātua centred or kaumātua centric.

In addition to emphasising Māori experiences, the toolkit could capacitate Māori analysis. For instance, identifying directions, competencies and osteoarthritis-management outcomes, that may be of benefit to kaumātua, whilst producing knowledge that could be useful at the same time for the health development of kaumātua and Māori development. At this time, there are chronic condition workshops emering from within my community, so the toolkit could particularly be useful for influencing those, as an example looking at and reflecting upon what workshops are being purchased, and where they could go forward?

The toolkit could also be used as an assessment and monitoring tool, if kaumātua wanted to use it themselves in a community rōpū, extending this also to visiting healthcare practitioners. As a healthcare practitioner, I think the toolkit is potentially a resource that we can use to think about our osteoarthritis-management activities with kaumatua, that we have been involved in, or future possible activities which kaumātua rōpū might want to engage with.

Also, the toolkit is representative of the everyday experiences of kaumātua in regards to joint health, and in particular osteoarthritis-management. The toolkit has enabled the themes of kaumātua transcripts to be understood in relation to higher order themes. The consequences of which, provide the overarching fundamentals of an osteoarthritis-management toolkit.

Implementing the toolkit

After exploring potential purposes of the toolkit, I offered two examples to kaimahi, of how the toolkit might potentially be implemented (see 'Whānau scenario and, 'Practitioner perspective' outlined below). Firstly kaimahi and I felt that the framework (Figure 6 above) could be fit for purpose, in the format of three columns under three sections, allowing for: column one, 'Questions' (for rating); column two, 'Indicator description'; and, column column three 'Kaumātua rating'. Further we agreed that the process may be undertaken by working methodically from left (column one) to right (column two and three).

Kaimahi responded favourably to the suggestion that the toolkit should be flexible, so that kaumātua needs and priorities for strategies of change are met. Similarly, that healthcare practitioners need to be able to use the toolkit, enabling knowledge exchange, and services to become more in line with kaumātua values.

Whānau scenario

Coming at the toolkit from a whānau perspective, I presented a possible scenario, using the osteoarthritis-management toolkit, to kaumātua (kaimahi) for their feedback. Turning to the toolkit, (i) 'Manākitanga' (kind support), asks the question: 'What activities are you no longer able to do, that you wish you could do?' The question shifts kaumātua from being unaware (pre-contemplative); to considering a change (contemplative).

Kaumātua are then asked to prospect through the questions: 'Who is Where? When? Doing What?' with a rating facility (1-3). Through telling stories about potential referrals in the community, kaumātua are telling stories about themselves. According to Allen, Macguire, and McKelvey (2011), change comes about by telling different stories, and in a way the storyteller becomes a change agent, in the process of facilitating story re-telling (P. Allen et al., 2011), and by way of 'whakawhānaungatanga' (making culturally meaningful connections with others) (Bishop, 1998; Carlson, McCreanor, Moewaka Barnes, & Reid, 2016).

Connecting to storytelling is a genuine tool for understanding, through quality conversations what influences, motivates and inspires kaumātua, according to their different perspective and worldview (Durie, 1999a, 2001, 1997). By engaging in a referrals process, kaumātua may shift from considering a change (contemplative), to deciding and preparing to make a change (preparative). Therefore, referral facilitation presents an opportunity to develop short-term changes (action), or long-term changes (maintenance).

The process progresses through (ii) 'Tino rangatiratanga' (self-determination), asking about opportunities to experiment with small changes, with a rating facility (1-3). Again, the toolkit enables shifting kaumātua from a state that is pre-contemplative, through contemplative, preparative, action, to maintenance. Kaumātua are important people in our community, the toolkit facilitates these capacities as 'key informants' to one another, which could be escalated to others in the community, in the process identifying people in need and areas of community concern.

In addition, kaumātua are major sources of information and referral for numerous individuals in their social networks, potentially reaching those kaumātua who may have become isolated from family, whānau and friends. Finally, the third stage (iii) Oritetanga (equity), seeks to move kaumātua towards transformational change, as the toolkit prompts: Are there opportunities to expore strategies of change in culturally safe environments in the short-term (action)? Longer-term (maintenance)?, with a rating facility (1-3). The toolkit closes by noting the overall rating and experience of osteoarthritis-management in the community, monitoring activities over time.

Practitioner scenario

The toolkit is also applicable to practitioners, seeking to work in ways that are culturally appropriate. Once again I presented to kaimahi a practitioner scenario for their feedback. Commencing with (i) ‘Manākitanga’ (kind support), prompting the practitioner to ask: What activities are kaumātua/you no longer able to do, that you wish you could do? (allowing people to shift from being unaware (pre-contemplative); to considering a change (contemplative), with a rating facility (1-3).

Discussions over the course of utilising the toolkit could lead to practitioners offering referrals to supports in the community, shifting kaumātua towards deciding and preparing to make a change (preparative). Providing guidance could lead to short-term changes (action) or long-term changes (maintenance). The process progresses through (ii) ‘Tino rangatiratanga’ (self-determination) that seek opportunities which encourage realistic changes, with a rating facility (1-3).

Once again, the process enables shifting kaumātua from a state that is pre-contemplative to contemplative, to preparative, to action, to maintenance. Finally, the third stage (iii) ‘Oritetanga’ (equity), seeks to move from a pre-contemplative stage, to a contemplative stage, as the toolkit is able to prompt: Are there opportunities to explore strategies of change in culturally safe environments, in the short-term (action) (see, ‘Who is Where’)? Longer-term (maintenance) (‘When?’, ‘Doing What?), with a rating facility (1-3).

The toolkit includes being able to note an overall rating and experience of osteoarthritis-management in the community, over time. In so doing, the toolkit encourages kaumātua to share. Moreover, the toolkit supports kaumātua to pass on sources of information and referral from their own networks in the community (see ‘Doing What?’).

The toolkit offers application to a variety of needs. As an illustration, strategies of change concerning levels of physical exercise, healthy eating choices, risk reduction (smoking and alcohol cessation/reduction), or opportunities to ‘whakawhānaungatanga’ about osteoarthritis. From my own healthcare practitioner perspective, the toolkit facilitates the ability to obtain explanations and examples of what personalised care is all about. For me (as a healthcare practitioner), personalised care is about supporting the holistic development of the patient through ‘whakawhānaungatanga’, getting to know your patient, and then knowing your patient, family and whānau.

Potential for content

In the latter part of talks conducted with kaimahi, an overview of their feedback was sought. Kaimahi agreed that the toolkit was simple, yet able to accommodate complex ideas. It was important that the toolkit was amenable to including mokopuna in conversations, and use positive indicators that showcased kaumātua capacities. The talks incorporated the title of the toolkit, 'Osteoarthritis-management toolkit'.

Community feedback

After obtaining feedback from kaumātua facilitators (kaimahi), I took the toolkit back to kaumātua interviewees and hui participants for their feedback. Specifically, the priority was to ascertain whether or not the values were clearly understood and perceived as culturally appropriate. The group preferred the simple approach of the toolkit and could see how it could be capable of incorporating the complexities of kaumātua experiences of osteoarthritis, with clear questions and indicators.

The osteoarthritis-management resource is representative of a dynamic process, that will continue to be adapted, evolve and move kaumātua from one stage to another as part of an ongoing story. The major findings from the interviews and hui discussions presented in the current chapter, have informed content and indicators of the osteoarthritis-management resource. I also intricated formalising the knowledge and experience of kaumātua, and manner in which Māori knowledge and hauora theory was applied.

In addition to formalising the knowledge and experiences of kaumātua, the process of the present doctoral study, utilising qualitative research data, community input from kaumātua with osteoarthritis and Māori-centred theory in Hawke's Bay of New Zealand, was quite novel. Differentially creating a culturally appropriate osteoarthritis-management toolkit with Hawke's Bay kaumātua with osteoarthritis. In the following chapter the process that I used at the completion of the research is detailed.

In particular the application of Māori principles to evaluate the research is outlined. Examples are used, that are drawn from the present research to build an argument. These demonstrated in detail, evidence of successful collaboration with kaumātua, Māori leaders and community members.

The purposes of collaborating in my community, concerned showcasing, that utilising a Māori-centred research approach helped to establish the contexts of kaumātua with osteoarthritis, their cultural values and preferences. Further, that drawing on the mātauranga Māori of experts and local scholars, provided a suitable process to construct an osteoarthritis-management resource.

Summarising and theorising outcome indicators

Maintaining a commitment to the ongoing participation of kaumātua in constructing the osteoarthritis-management resource content and indicators, has been a priority of the present research. The motivations for the research concern establishing kaumātua to seek out lifestyle choices that promote wellbeing. In the process of summarising and theorising outcome indicators, a question arose asking, 'What did kaumātua want to know about osteoarthritis-management?'

Throughout kaumātua stories, the desire to have strategies of change for better managing osteoarthritis was a recurring theme. A further question then arose in so far as, 'what did kaumātua (the collective) believe would represent a culturally appropriate resource?' Kaumātua were adamant during hui that the 'KISS' (for Keep it Simple and Smart!) acronym held sway, enabling the toolkit to be used in a range of contexts that required keeping to Māori values, which are renowned for their complexity, yet keeping osteoarthritis-management simple and actually getting things done.

A key message to emerge was that the toolkit needed to address the misconception that osteoarthritis is inevitable, giving power to positive culturally appropriate strategies for change. Kaumātua were also more comfortable with the idea of adapting to small steps, such as bringing healthcare practitioners and other experts into their hui to talk about their perspective. The toolkit may then be used as a mechanism for collaborating, to determine what is working well and what could be working better.

From my perspective as a healthcare practitioner, the toolkit has interesting potential in clinical practice, when working with kaumātua, for providing a collaborative mechanism within a culturally appropriate clinical environment. Additionally, the toolkit will enable me to clarify what is working well for kaumātua, and what could be done to improve the current quality of osteoarthritis-management. All of that being based on the value set of kaumātua, in a way that is mutually determined.

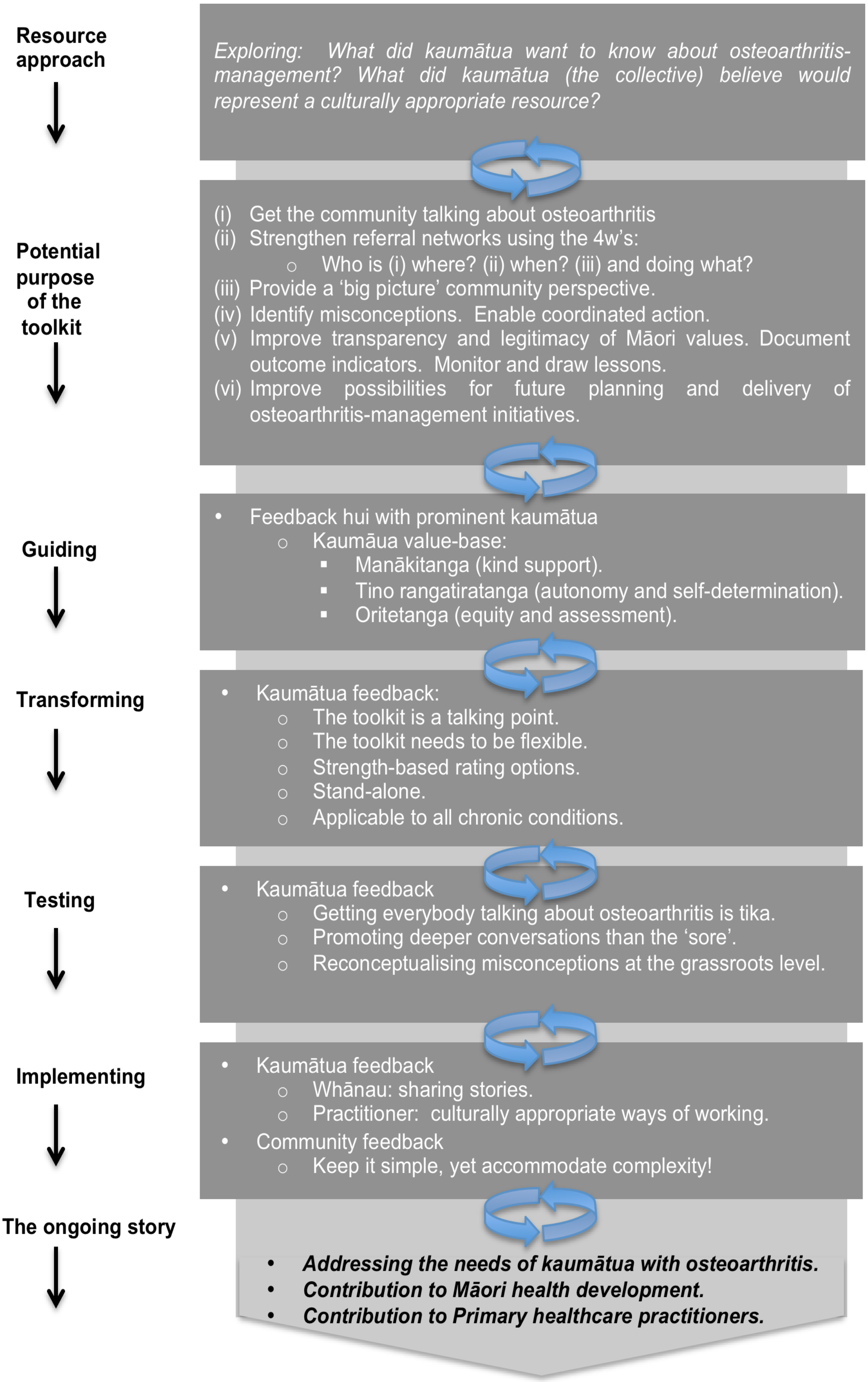
In the process of constructing the toolkit, obtaining feedback from prominent kaumātua, ensured the toolkit was aligned to a tīkanga base. Maintaining a culturally proper or appropriate value base (base) reflected the realities of kaumātua with osteoarthritis, who live in both the Māori world, and wider society. The base is encapsulated in outcome indicators and by the idea that kaumātua, family and whānau know what issues deserve their attention, and what is needed to address local problems.

The research found that osteoarthritis-management for kaumātua, may be characterised by a two dimensional concept that incorporated, a process dimension and an interpretive appraisal dimension. The process dimension is consistent with a values perspective. The appraisal dimension was described in terms of complementary Māori specific outcome indicators of osteoarthritis-management.

The Māori-specific outcome indicators for optimal osteoarthritis-management theorised were consistent with: 'Manākitanga' (kind support); 'Tino rangatiratanga' (self-determination), and; 'Oritetanga' (equity and assessment).

The framework of these indicators converges to portray journeying towards the construction of an osteoarthritis-management toolkit, schematically presented as a clearer pathway for kaumātua on the above-named kaupapa (Figure 7, below). As depicted in Figure 7, I have purposefully attempted to emphasise the kaupapa (reason) for the many stages that lead to constructing the toolkit. The journey is representative of forging a clearer pathway to osteoarthritis-management, with input from kaumātua and strengths-based outcomes. Figure 7: Pathway appraisal follows.

Figure 7. Forging a pathway to the toolkit



Resource approach

Exploring: What did kaumātua want to know about osteoarthritis-management? What did kaumātua (the collective) believe would represent a culturally appropriate resource?

Potential purpose of the toolkit

(i) Get the community talking about osteoarthritis
(ii) Strengthen referral networks using the 4w's:
  - Who is (i) where? (ii) when? (iii) and doing what?
(iii) Provide a 'big picture' community perspective.
(iv) Identify misconceptions. Enable coordinated action.
(v) Improve transparency and legitimacy of Māori values. Document outcome indicators. Monitor and draw lessons.
(vi) Improve possibilities for future planning and delivery of osteoarthritis-management initiatives.

Guiding

- Feedback hui with prominent kaumātua
  - Kaumāua value-base:
    - Manākitanga (kind support).
    - Tino rangatiratanga (autonomy and self-determination).
    - Oritetanga (equity and assessment).

Transforming

- Kaumātua feedback:
  - The toolkit is a talking point.
  - The toolkit needs to be flexible.
  - Strength-based rating options.
  - Stand-alone.
  - Applicable to all chronic conditions.

Testing

- Kaumātua feedback
  - Getting everybody talking about osteoarthritis is tika.
  - Promoting deeper conversations than the 'sore'.
  - Reconceptualising misconceptions at the grassroots level.

Implementing

- Kaumātua feedback
  - Whānau: sharing stories.
  - Practitioner: culturally appropriate ways of working.
- Community feedback
  - Keep it simple, yet accommodate complexity!

The ongoing story

- ***Addressing the needs of kaumātua with osteoarthritis.***
- ***Contribution to Māori health development.***
- ***Contribution to Primary healthcare practitioners.***

Chapter 7: Pathway appraisal (Interpretation and assessment)

Introduction

In the current chapter an argument is supported, that a Māori-centred approach drawing on kaupapa Māori principles, is useful to the interpretation and assessment of research engaging kaumātua with osteoarthritis. In each instance, the interpretation process that was used, as well as appraisal at the completion of the present research, beginning by outlining briefly the purpose of the study and why a Māori-centred approach was utilised is detailed. Disconnections that it was hoped would be addressed through the present research, followed by Māori principles, that enabled collaborating with my community, to produce a culturally appropriate osteoarthritis resource are specified.

Study purpose

Exploring the everyday experiences of kaumātua with osteoarthritis in a collaborative process, was the purpose of the present study. The focus of which was concerned with developing a culturally relevant osteoarthritis-management resource. The literature review (see Chapter 2) presented a major argument. Notably, there being a local need for approaches to chronic conditions such as osteoarthritis-management that are reflective of Māori cultural practices, and appropriate for use in Māori communities.

I also offered an example, that few studies have focussed on the experiences and lay understandings of osteoarthritis for older-people, or the socio-cultural meanings ascribed to the condition (Darmawan et al., 2004; García-Ferrer et al., 2012). Building on the evidence, it was argued that effective osteoarthritis-management initiatives were needed. Most of all, addressing the disconnect between cultural and experience based beliefs, that influence how kaumātua encounter and understand osteoarthritis and medical professionals’ biomedical perspectives of the condition.

Similarly, it was argued that there was a need for an osteoarthritis-management resource. Notably, that recognised and engaged with the social context of health inequalities (Bodenheimer et al., 2002; Harris et al., 2006a, 2006b; Nuovo, 2010), including consideration of historical and environmental barriers. Not only that, utilising a Māori-centred approach was argued for, in order to fill the void of a much needed resource for kaumātua with osteoarthritis in my community.

In addition, relevant literature referencing Māori-centred principles for being more likely to portray the context of the participating community, personally, socially and culturally (Durie, 1996; Forster, 2003) were cited. Chiefly Māori principles were adopted, as it was believed that these would improve the chances of increasing respectful engagement. Besides, the methodology chapter of the present thesis established a novel process for working in my community, and need for transparency (see 'Rigour in the research; Confirmability').

A disconnection in the literature was also noted, concerned with collaborating with the Māori community and understanding the imperative of developing relationships. Also, the literature review detailed strengths pertaining to the community approach, adopted by Ko Awatea & Counties Manukau Health's (2016) 'Kia Kaha: Manage better, feel stronger' collaborative project. Although similar to Matamua's (2010) review of social marketing campaigns, in the present research it was difficult to ascertain the process utilised in New Zealand studies concerning collaborating with the Māori community.

As advocated by the Ministry of Health (2014d), self-management initiatives should draw on the community as a resource, which would require special consideration for collaborating with Māori (Ministry of Health, 2014d). Collaborating with the community is central to Māori-centred research, that makes explicit the processes of building on strengths and resources from within the community. For these reasons, appraising the pathway on the kaupapa of creating an osteoarthritis-management resource, was considered important.

The appraisal process, seeks to assess the present research according to cultural appropriateness, and application of Māori concepts in the process of collaborating with the community. What is more, the methodology chapter (see Chapter 3) noted there being a continued debate concerning 'valid', 'reliable' appraisal and interpretation in healthcare research. In the process of wanting to appraise the success of my study, the rationale for three criteria that enabled appraisal (see below, and in the Methodology chapter, specifically 'Rigour in the research') were identified.

Appraisal

Criteria that have been used to determine methodological rigour are introduced, and approach to evaluating the completed research follows. In detail trustworthiness/credibility, transferability and confirmability (Denzin & Lincoln, 2003; E. Guba & Lincoln, 1989). Strategies for demonstrating that findings emerged from the data is followed by Māori principles, which it is suggested are most appropriate because they relate to the purpose of, "growing respectful relationships" (Pohatu, 2004, p. 2) with Māori communities.

To begin, determining methodological rigour, trustworthiness/credibility, transferability, dependability and confirmability were the criteria used (Denzin & Lincoln, 2003; E. Guba & Lincoln, 1989). The level of collaborative effort involving the community (incorporating principles of authenticity criteria) is utlised to determine the level of their involvement. Moreover, 'problem-solving' asks whether knowledge creation has understood the root cause of a community issue and whether the process of finding a solution has been achieved, in order to bring about change.

There is another focus on societal change and sustainability, that provides a framework to evaluate whether the capacity of the community has been enhanced (Hills & Mullett, 2000). Such as through the acquisition of new skills and knowledge related to the research. Not to mention, whether the osteoarthritis-management resource is useful to the community.

Methodological rigour

To establish critical appraisal of methodological rigour, one can look towards strategies for establishing trustworthiness/credibility, transferability, dependability and confirmability (Denzin & Lincoln, 2003; E. Guba & Lincoln, 1989). The overall methodological rigour, indicates the extent that causal conclusions can be drawn. In the current section, the field application of these criteria and adaptations to the local setting, (Ngāti Kahungunu ki Heretaunga rohe (Hastings, Hawkes Bay region)) will be discussed.

Trustworthiness/credibility

A major criteria of trustworthiness, is credibility in the eyes of the target community (E. Guba & Lincoln, 1985). There were a range of processes that paralleled with perceived trustworthiness of the data, by kaumātua participants of the present study. Following E. Guba and Lincoln (1985), transparency and perceived trustworthiness in the present research concerned increasing credibility through establishing relationships with kaumātua for over two years prior to testing the toolkit, and this resulted in prolonged engagement and building trust.

Having such a long period of engagement, enabled me to ascertain community approval and buy-in, and enabled ensuring that social and cultural principles (tīkanga) had been adhered to. In addition to prolonged engagement and immersion in the community, feedback and validation was solicited from kaumātua participants, through member checking with interviewees and hui focus group participants, to ensure accuracy.

In conjunction to offering all kaumātua participants, an opportunity to revise, amend and authorise their transcripts, a debriefing process was utiised. Debriefing occurred during and after each stage of the research. I was also invited to attend kaumātua hui intermittently over the duration of the study. These processes of research and engagement provided me with the means to conduct an evaluation, establish a foundation, and facilitate my own support processes in a systematic yet flexible fashion, with academic supervisors and cultural advisors.

I also talked aobut the findings with my advisors and peers (doctoral researchers engaging in Māori health), to obtain their insight at a grassroots level. Moreover, non-technical reports were written for kaumātua groups in conversational (non-academic, informal) language, as a means to obtaining broad-ranging feedback. Regular presentations were also given at kaumātua hui, and conversations with academic supervisors conducted, as a means to assuring relevant rigour in the research.

Ability to transfer research findings

Transferability demands of the researcher a rich, thick description of the research setting, to enable another reader to obtain enough information enabling its application, in a different research context (E. Guba & Lincoln, 1985). Although, the present research was concerned with generating local knowledge and sought to produce change socially, at a local community level. In terms of transferability, rather than the applicability of the findings to other situations and other people, it is the described research process that can be applied.

Moreover, in my methodology chapter, the steps taken, in the process of detailing the findings of interviews and focus group hui have been discussed. That being the case, steps taken to ensure community collaboration and greater involvement have also been detailed. For example, 'whakawhānaungatanga' (making of culturally meaningful connections with others) between myself and kaumātua, family and whānau, as well as between kaumātua and wider Māori networks at a grassroots level.

Additionally, articulating qualitative research design as well as presenting the interviews and hui have been imparted. Further, identifying the ways in which the content, overall strategy and pathway to the osteoarthritis-management resource have been implemented. That being the case, alongside articulations of hauora Māori theory.

Dependability and confirmability

Murphy and Yielder (2010) recommended during data collection and analysis, documenting the key steps taken and decisions made. In addition, Murphy and Yielder (2010) encouraged transparency of research reporting. Characteristically through regularly sharing questions about the research process and/or interpretations with others. In the present study, I imported and coded all of the data using descriptor fields, with Dedoose software.

I also journalled my observations and early interpretations of the data, linking the corresponding transcript. Additionally, some initial observations that were utilised in generating discussion and analysis were journalled. In the process of completing each stage of the research and data analysis, hui enabling conversations concerning the findings were conducted with academic supervisors and cultural advisors. At the initial meeting we talked about thematic analysis, the stages of thematic coding, and feedback obtained. Non-technical reports with the community were also shared, as broad-ranging feedback was sought.

Application of Māori principles

As detailed in the methodology chapter ('Developing connections'), Mere Berryman's (2014) strategies were followed. In detail, three strategies for collaborating with the Māori community: 'identify yourself', 'build trust relationally', 'listen to the community and respond accordingly'. Within these strategies, the use of kaupapa Māori principles working, that are essential when seeking to connect with kaumātua, family and whānau, hapū and iwi.

'Identify yourself'

As previously reported in the 'Preliminary findings' (see Chapter 5), the concept of 'whānaungatanga' (togetherness or sense of family connection) was used to prioritise local knowledge and protocols. 'Whānaungatanga' forms a necessary base or core of central importance within Māori culture, and in the present research provided guidance on establishing and maintaining positive research relationships. Characteristically, 'whānaungatanga' orientated me towards understanding the importance of ethical, moral and spiritual involvement, throughout the research process (Bishop, 1996).

An example of 'whānaungatanga' in the present research follows Bishop's (1996) recommendations. Specifically, interviews and hui focus group (hui) commenced and closed with a karakia, and sharing of kai with decisions being made as a group throughout, as approved by kaimahi (a kaumatua facilitator). These processes that occurred throughout the interviews and hui were central to cultural protocols, representations of manākitanga (kindness, hospitality), are the bedrock of customary practice within my community.

In addition, the 'culturally preferred practice' of incorporating cultural communication and socialisation, was represented throughout the research process (Hinangaroa-Smith, 1997a). Precisely, prioritising research methods 'kānohi ki te kānohi'. Interviews occurred in the homes of kaumātua (tūrangawaewae)), and focus groups, in Māori spaces and places, framed by local tīkanga Māori helping me to build trust relationally.

'Build trust relationally'

During the early stages of developing connections in my community, I recognised that building trust takes time, and requires being transparent, open and honest about my motives. At times, I needed to put aside what I knew as a healthcare practitioner, and be willing to learn about osteoarthritis from kaumātua. Building trust relationally, required being careful about making assumptions regarding others' intentions, many of whom were living with osteoarthritis-related pain and disability.

I also learned that not everyone was always as passionate about osteoarthritis-management research, resulting in my subsequent perceptions of 'reservation' from kaumātua. My attendance to Kaupapa Rangahau Workshops and conversations with fellow doctoral researchers, validated a concern often found in Māori communities. As an instance, Māori people being subjugated to research that has often failed to include Māori views, or provide Māori with genuine benefits from the research process (Tuhiwai-Smith, 2013), or opportunity to participate in shared decision-making (T. Morgan, 2006; Stairmand, 2014).

A consequence amidst the Māori community of which being that research is often held commensurate with the history of colonisation, by a profound connection to questions about the concept of power (Bishop, 1994; Tuhiwai-Smith, 2013). A history of colonisation in New Zealand, lead me to take the time to journal Foucault's (1980) arguments concerning power, especially as I reflected on my early expectations, where I had envisioned leading focus group hui myself. I realised that by being led by a kaumātua facilitator (kaimahi) was an important shift in power dynamics, and ensured that cultural protocols were honoured.

The benefits of collaborating with and obtaining feedback from kaumātua also, enabled interpretations to be built on community strengths, that are relevant and acceptable to the community. A focus group hui, conducted under the guidance of kaimahi, was a culturally sensitive method, indicative to kaumātua and Māori culture, that recognises and values a collective entity. Additionally, Montell (1999) argued that wider group dynamics may be both, “consciousness-raising and empowering” of participants and the researcher, by promoting two-way communication, and exchange of information and ideas, in a sense shifting the balance of power (Montell, 1999, p. 44).

During focus group hui, comparable to the interview method, kaumātua were asked to freely express in their own words and language, divergent views on their everyday experiences of living with osteoarthritis. With kaumātua as facilitators of hui (kaimahi), the worldviews and perceptions of kaumātua participants (with a similar demographic profile), were most important. Moreover, participants possibly spoke more freely than they would have done, had I lead discussions, fortifying the notion of richer data.

Also, key to how I approached the osteoarthritis-management resource, was the relevance and connection of kaumātua experiences of osteoarthritis, to real-world issues, problems and context. Accordingly, well-known and respected kaimahi made recommendations applicable to personal and life relevance. The utilisation of a hui-focus group is also a good example of, “tactical authenticity”, allowing kaumātua to tell their stories, share perspectives and offer strategies, established within the everyday experiences or realities of everyday living (E. Guba & Lincoln, 1989, pp. 245-246).

Also inherent, “catalytic authenticity” was evident in specific actions, stimulated by the process of engaging kaumātua in focus group hui (E. Guba & Lincoln, 1989, pp. 245-246). Participants took encouragement from one another, such as considering utilising lifestyle changes, which in the process, stimulated and facilitated behaviour, with everyone working together. All of which ensured cultural relevance in a realistic and comfortable setting, and a sensible plan, which kaumātua may be more likely to attempt.

‘Listen to the community’

Reflecting on the influence of my own power on the research relationship, related to the way in which I worked. Specifically, with members of my academic supervisors and cultural advisors (advisors), kaumātua facilitators (kaimahi), kaumātua participants and focus hui participants, and other members of my community. In considering ontological authenticity, I considered the way in which my own perceptions and worldviews evolved throughout the course of the research. All of that requiring a degree of cultural humility on the part of my researcher role.

As detailed in my methodology chapter, reflecting on ‘handling’ power is an overarching goal of my researcher role and is also relevant to my capacity, as a healthcare practitioner. These roles require self-reflective practice and with that an attitude of, “cultural humility”. Predominantly that by utilising the virtue of cultural humility, sought to invoke and redress potential power imbalances between myself (the researcher) and the target community, is also relevant in the clinical encounter between practitioner and patient (Murray-García & Tervalon, 1998, p. 1).

Throughout the research process, I journalled processes that had helped me to share power. Such as reflecting on having built expectations for certain kaumātua, whether they are able-bodied or with disabilities for instance. Considering my own perceptions as an ablebodied person around the issues of disabled people, enabled me to recognise the value and guidance from my kaumātua (whānau elder) and kaumātua facilitators (kaimahi) from the community.

Kaumatua support, guided me through cultural protocols and provided a level of protection during some initial hui. It helped to ensure that those kaumātua participants at hui who had reservations about me and my research, were encouraged to be open to listening to what I had to say. Likewise, kaumātua support assisted my efforts to collaborate with and develop a sense of sharing with my community and kaumātua support was invaluable (see Chapter 4: Growing respectful relationships; ‘Guidance from kaumātua’) during hui, but also for providing feedback on the osteoarthritis-management toolkit.

In addition to kaumātua guidance, the concept of manākitanga was inherent to the research process. As important as sharing food together, was sharing the results, in non-academic reports. The feedback from kaumātua was that they preferred results that were both understandable and useful. In response, I displayed the data in a format that could be easily understood, writing using non-technical language to share with the community.

Embracing the value of manākitanga allows knowledge to flow both ways (Cram et al., 2012), so instead of the research being about simply gathering data, I was the learner. Manākitanga being a powerful expression of the way kaumātua share and care for one another, just as Māori community hospitality implies kind responsibility for visitors. Through manākitanga a common ground may be sought, upon which a sense of sharing and responding accordingly may begin.

’Respond accordingly’

As Pohatu (2004) has argued, ‘growing respectful relationships’ brings an inclusive focus, where Māori epistemologies, cultural protocols, knowledge and healing practices are prioritised. The focus is on fairness and negotiated boundaries. To the extent, that the worldviews of the community are requested and respected, and the creation of a safe research space with corresponding actions.

In the methodology chapter of the present research, a Māori-centred approach was adopted, drawing on Kaupapa Māori principles, enabling critique of the dominant cultural worldview of Western society. Even though it is argued that the present study values Māori tīkanga, knowledge, justified belief and epistemologies. Also important, are the significant differences that Māori-centred research to Kaupapa Māori, concerning Māori involvement (C. Cunningham & Durie, 1988).

It is also suggested, that incorporating common key elements of Māori knowledge, described by various Māori scholars and experts, is applicable. Especially for allowing me to draw on particular elements, that share features of a kaupapa Māori framework. In the methodology chapter, it was argued that these principles had potential for not only decolonising the research process, but centering Māori knowledge across and within various sectors, including healthcare and all aspects of society (Table 5, 'Kaupapa Māori principles, Chapter 3, 'Māori knowledge building').

Throughout the research process, Kaupapa Māori principles have been actively incorporated, as I sought to transform the position of kaumātua participants, through interactions consistent with the application of tīkanga (cultural principles), te reo Māori and other cultural processes that enhanced the research process. The purpose of incorporating Kaupapa Māori principles was to validate local knowledge and expertise and bring about positive change in the research community.

In the process of validating local knowledge, 'Tino rangatiratanga' (self-determination) reinforces the goal of fulfilling the desire for Māori to control their own culture, aspirations and destiny. Adopting a local focus incorporated the idea that kaumātua determine what is a valid osteoarthritis-management resource. Comparably, my approach to the research recognised the historical use of deficit explanations for the status of Māori health and wellbeing and impact of colonisation on socioeconomic and sociocultural development (impacts) (Jackson, 1999; Tuhiwai-Smith, 2013).

On account of those impacts, is an understanding that within the context of 'hauora' (Māori wellbeing), all dimensions of an individual's health are acknowledged. For that reason, Māori health cannot be established within a Western medical model, that emphasises an individual's physical and mental health as separate entities. Consequently in the present research, questions were incorporated at each stage of the qualitative research, encouraging discussion of osteoarthritis within the context of hauora theory (M. Durie, 1998b).

Dialogue that encompassed taking care of emotional and spiritual health was supported. Conversing about areas that made kaumātua 'feel good', allowed for a wider understanding and application of 'hauora', relative to kaumātua with osteoarthritis. In the process, identifying significant service barriers by both interviewees and focus group hui participants was enabled.

Also informing the direction and content of the osteoarthritis-management resource, was the knowledge of Māori scholars and experts (mātauranga). As an illustration, the primary findings of the research unearthed the chief focus of kaumātua. In particular, kaumātua making health changes for the sake of the whānau, reflecting a family health ('Taha whānau') dimension of wellbeing. Additional dimensions revealed whānau resources, 'Taha tinana' (physical health), 'Taha hinengaro' (mental health), 'Taha wairua' (spiritual health), and 'Taha whānau' (social) dimensions of health, which were incorporated into the indicators. In the section that follows, challenges and limitations to the present research are discussed.

Challenges/limitations

Conducting community-based research is a challenge. Difficulties which I faced for instance, were not dissimilar to that of Moyle's (2014) research, all of which utilised interpretative phenomenological analysis and application of Māori-centred theory. Also, the small number of research participants meant that the present doctoral research (the research) was not exhaustive or representative of all kaumātua. Although the sample in the research was kept small, Durie, Fitzgerald, Kingi, McKinley, and Stevenson (2002) acknowledged Māori-centred research for assuming that knowledge is diverse, than research seeking universal understanding (Durie et al., 2002).

Similar to Bishop's (1995) doctoral work, gaining the trust of community members was an important challenge to overcome. In the present research, obtaining confidence from kaumātua took time. Trust can enable researchers access to under-represented communities, intensify community engagement and shape genuine partnerships (Bishop, 1995). The way in which relationships in the Māori community are developed at the initial contact, is often of larger importance than the outcome (Tuhiwai-Smith, 2013).

Initially I perceived that my track record of having worked with kaumātua in the community as a healthcare practitioner, was the reason why my research proposal had been positively received. I was also committed to obtaining feedback on the research design. Additionally, it was possible that my efforts were perceived in terms of offering to assist the present research, and the community acquiring an osteoarthritis-management toolkit in return. Moreover, spending time in the community enabled me to get to know people more, in the process of building a relationship with the community.

In the present research, similar to Pohatu's (2004) work within Māori communities, I did not commence interviews until two years into the research process. Pohatu (2004) also noted that it takes time, effort and encouragement to grow respectful relationships. As Pohatu (2004) astutely observed, there is a special way that researchers need to conduct themselves.

Nevertheless, the fullness of time required to obtain trust may also be challenging. Pohatu (2004) argued that the principle of, 'āta' centers on boundaries in relationships that are conducive to safeguarding people with a safe environment and aligned behaviours (Pohatu, 2004). Although so often for all involved throughout the research, time is the one thing that may be in short supply. Similarly, throughout the years of proposing the research through to constructing the toolkit, some frustration from kaumātua concerning the length of time the research was taking was encountered.

In the evaluation, I spoke of having to learn to adjust expectations that I had placed on myself around time and space, 'āta'. I came to accept that my concept of time, which was often structured around academic deadlines, was not always shared by the participants of my research. Above all, the tension between academic and community expectations, was a limitation on the research.

A further limitation concerned balancing academic needs and community interests, leading me to question the source of the values that were driving the research. The evaluation criteria demonstrated a Māori-centred approach, integrating into the research design and toolkit construction, Māori principles. Resultantly, the research indicates how to apply a Māori-centred approach, to create culturally relevant indicators of osteoarthritis-management and a toolkit resource for kaumātua with osteoarthritis.

Indicators of osteoarthritis-management

Aspin et al. (2014) offered that with adaptability or, "endurance" acknowledging community strengths are more likely to lead to positive outcomes for Māori (p. 102). In a New Zealand context, "resistance to colonisation and ongoing dominant population systems", are discussed as being unable to detract from Māori status, as tangata whenua. Pro-active strategies, such as cultural and socio-economic survival (strength-based strategies) suggest that, "resilience may be as much a part of our identity as our [Māori customary] knowledge and ways of being" (p. 98).

In a New Zealand context, as Aspin et al. (2014) have argued, Māori have over generations drawn inherently, from values and customary practice that respects the capacities and resilience of Māori communities. Indeed, when working with Māori, using strength-based approaches with a tīkanga base is a significant principle, which has been found to increase the chances of transformational change (A. Anderson et al., 2017). Similarly kaumātua facilitators (kaimahi) in the present research, argued that the osteoarthritis-management resource needed to communicate positive stories from the community (Chapter 6, Table 17: 'Spectrum of rating options').

That is to say, communicating positive stories about the community was a tenet of the present research, underpinned by Māori-centred values. These values were evidenced in kaumātua stories that spoke of preferring a holistic model of health, for reframing osteoarthritis-management. Specifically moving the focus from positioning kaumātua away from limiting labels and diagnosis, to noting their osteoarthritis-management abilities and adaptability. The strength and adaptability of kaumātua with osteoarthritis was reinforced at every stage of the present research.

As detailed in, 'Chapter 5: Preliminary findings', through key-kaumātua interviewees and focus group hui, were positive, realistic indicators of osteoarthritis-management able to emerge. During the process of discussing their preference for services, kaumātua participants clarified that there were many basic tenets of life, essential for wellbeing. Within a holistic framework, the 'manākitanga' value was described as being a foundation principle for 'real physical support', represented as kindness, caring for other people's wellbeing, sharing support and leading with moral purpose.

Kaumātua with osteoarthritis were also motivated by initiatives that were flexible and capable of incorporating whānau (and mokopuna) in their design. Kaumātua, family and whānau know what issues deserve their attention, and what is needed to address local problems. Osteoarthritis-management that is motivated and driven by kaumātua with osteoarthritis whom are being directly affected, could support 'Tino-rangatiratanga' (self-determination) and wellbeing.

Finally, 'Oritetanga' (equity and assessment) represented importance of validating local wisdom and expertise. The aim being about bringing positive change for the betterment of my community. A key point of difference is that kaumātua facilitating, assessing, and leading initiatives will be better received when these are generated by, with, and for kaumātua with osteoarthritis, as well as indicatively developing out of their cultural norms and values.

Kaumātua facilitators (kaimahi) also confirmed, drawing on a tīkanga Māori values-base was appropriate to the experience of kaumātua. Also, that in order to work well an osteoarthritis-management resource would need to start out, right from the 'manākitanga' (kind support) value, then 'tino rangatiratanga' (autonomy and self-determination), and; ‘oritetanga’ (equity and assessment), was more likely to naturally follow.

Evident within the stories of kaumātua was an interest in osteoarthritis-management resources and related initiatives (initiatives). Pointedly, that these be built on positive indicators that promote kind support, self-determination, equity and assessment. As outlined in the introduction of the current thesis (see, Chapter 1: Introduction; ‘Personal-agency model’), Bandura (1989) noted that the ability to be self-determining in one’s self-care, is also concerned with the motivation behind the choices that are made, without external influence or interference (Bandura, 1989).

Again, Bandura argued that collective efficacy was a mechanism of human agency, collective agency and shared beliefs. To a greater extent, the way people motivate themselves and behave, depends on their confidence in their ability to embark on a successful course of action (Bandura, 2000). Similarly, the present research centred on the premise that collective efficacy was influenced by a collaborative assessment process.

That being so, the arising toolkit contained an assessment function, enabling kaumātua to rate, where they see themselves on a continuum of osteoarthritis-management. The setting of realistic strategies in a collective space with peers, or in a way that is mutually determined with others (healthcare practitioners for instance), in a culturally appropriate space. The process promoted positive action by encouraging people to start talking about osteoarthritis, generally that the condition is controllable and manageable, than inevitable was the goal.

Like other Māori-centred studies that draw on Māori values and principles, my research recognises the importance of developing theory, that considers barriers to health equality. Respectively, theory that is inclusive of historical, social, ethnicity, and environmental barriers. Correspondingly, that seeks to make a contribution to the ongoing task of reducing inequalities via the support that healthcare practitioners provide (Ministry of Health, 2016c).

Since the present Māori-centred research project has been concerned with making a contribution to achieving health equity for Māori and social change, the arising osteoarthritis-management-hui toolkit is apt. Distinctively, quality health care that meets the health care needs and aspirations of Māori.communities, that have more often than not felt barred from partaking in the decision-making process (Ministry for the Environment, 2010; Stairmand, 2014). Prior (2007) maintained that by acknowledging individual and collective histories which the researcher works with, alongside understanding the broader history of the community, can contribute to the process of decolonising research.

In the same way, Bury et al. (2006) noted that we were in the age of self-management. Bury et al. (2006) argued that self-management models, toolkits and strategies have grown in interest, particularly for policy-makers' focussed on encouraging lay-led self-management approaches (Bury et al., 2006). Further, that it is important to emphasise primacy on the characteristics of given communities. Bury et al. (2006) argued that self-management initiatives needed to be acceptable at the interface of user and healthcare practitioner.

More recently, The National Association of County and City Health Officials (2017) argued about the strengths of collaborative self-management toolkits with communities. Especially The National Association of County and City Health Officials (2017) maintained that a health promotion toolkit was most ideal, when it brought together patients, families and community in an integrated and coordinated approach. By following these recommendations and utilising Māori principles, an osteoarthritis-management toolkit (toolkit) has been approved in the present research, by way of testing and subsequent acceptance by the target community.

Contributing to healthcare system debates, the toolkit is concerned with improving health outcomes, by addressing how to best work with the Māori community. Correspondingly, some contributions that the osteoarthritis-management resource seeks to make are outlined further, throughout the final chapter of my thesis that follows. Also, a summary is provided of the research findings, alongside explanation of how the research makes a contribution to current understandings, concerning creating a culturally appropriate osteoarthritis-management toolkit with kaumātua.

Additionally, recommendations are included within the discussion. Indicatively that by engaging in osteoarthritis-management resource design with kaumātua, researchers should utilise a Māori-centred research approach, and draw on local Māori, scholars and experts, and Māori principles. Special attention will be given to making future research suggestions, the thesis concluding with policy recommendations, that have a practical focus are guided by the results of my research.

Summarising interpretation and assessment

To summarise, appraising the pathway on the kaupapa of creating an osteoarthritis-management resource, was an essential part of the present research. Exploring the everyday experiences of kaumātua with osteoarthritis, in a collaborative process required special consideration. Appraising the pathway on the kaupapa of creating an osteoarthritis-management resource, sought to assess the present research according to cultural appropriateness, and application of Māori concepts in the process of collaborating with the community.

Māori principles were noted most appropriate, for growing respectful relationships with Māori communities. Through interactions consistent with the application of tīkanga (cultural principles), te reo Māori and other cultural processes enhanced the research process, by validating local knowledge and expertise. The focus being about bringing positive change in the research community, by communicating positive stories about Māori people. Drawing the journey of the current thesis to a close, the following chapter (‘Discussion and conclusion’) that follows, reflects on the lessons learnt and strengths of the research, as a solid foundation for osteoarthritis-management.

Chapter 8: Discussion and conclusion

Introduction

There were two research questions in the present study. The first asked, what the everyday experiences of kaumātua were in regards to joint health, and in particular osteoarthritis-management. Second, the present qualitative study also asked how a Māori-centred approach, drawing on kaupapa Māori theory could be best employed. Notably to explore kaumātua experiences of living with secondary osteoarthritis (osteoarthritis) and the creation of a toolkit, appropriate to modern health promotion and Māori health perspectives in Hawke's Bay.

The current chapter considers the research questions in relation to the results, alongside theoretical underpinnings of the study and the literature. The chapter concludes by outlining the contribution and implications of the research. In addition, learning outcomes for healthcare practitioners, healthcare planners, health promoters, educators, and researchers are provided.

Exploring the everyday experiences of kaumātua

In the present study, kaumātua indicated that within the context of their everyday experiences of living with osteoarthritis, that their condition was sometimes informed by medical advice. All the same, managing their condition was predominantly influenced by lifestyle, whānau interactions, social and cultural commitments. Kaumātua engaged in the study referred to such an approach as 'whānau ora' or achievement of Māori people, and frequently mentioned the importance of 'hauora' (Māori wellbeing).

The term 'whānau ora' was proposed by kaumātua, as being closest to the concept of osteoarthritis-management. Moreover, these words were often used to refer to an overarching strategy, and aspiration that kaumātua and whānau are supported to achieve the fullness of health and wellbeing within te ao Māori or Māori society and New Zealand Society. In the preceding context, kaumātua emphasised the need to shift from an exclusive focus on individual illness, to a broader holistic and cultural perspective of health as captured by the following quote: "You know with my joints, osteoarthritis, the wairua, the mental, physical – the wairua and the 'whānaungatanga' [togetherness, sense of family connection], social. They all go together. If one doesn't work, the whole house collapses down and it is so true, you know. You got to have the four corners".

To be effective for kaumātua, osteoarthritis-management would need to adopt a wider approach, such as educating whānau about the impacts of lifestyle choices, and addressing long standing issues around social development and justice. Also, 'hauora', as expressed by kaumātua in the present study was distinctive with at least three key characteristics: (i) a culturally relevant approach to relationship-based care based on 'manākitanga' (kind support); (ii) self-management as a form of 'tino rangatiratanga' (self-determination); and, (iii) a desire to be active and valued members of society in accordance with 'oritetanga' (equity).

A culturally relevant approach to relationship-based care is underpinned by 'manākitanga', and is focused on enhancing kaumātua and whānau wellbeing. In the whānau context, 'manākitanga' is closely linked to 'aroha' (compassion), and the 'kaupapa' (expression) of the group operating as a whole, to encourage health and wellbeing for its members. In many instances the personal stories shared during the present research, frequently described whānau caring for and providing safe and nurturing environments for mokopuna and kaumātua, which in turn contributed to their inclusion and participation within Māori society.

The concept of 'manākitanga' is applicable to the basis of strong communities and strengthening of Māori identities, for contributing to cultural recovery and survival. In the whānau context, 'hauora' is closely linked to a strong cultural dimension, for informing Māori identity. In the whānau context, kaumātua aspired towards hauora, which was closely linked to preferences for te reo Māori, kawa (cultural practices) and tīkanga (cultural principles), as well as cultural preferences for food, recreation and socialisation.

The second characteristic of hauora was centred around, 'tino rangatiratanga' (self-determination). Notwithstanding that from time to time, outside assistance is needed by kaumātua and family. All the same, the foundation of hauora is a whānau environment where all feel valued, respected and care for each other. In that context, a strong sense of pride in osteoarthritis-management and self-determination is fostered. The aim is to enable kaumātua, family and whānau, to assume responsibility for their own concerns.

Long-term dependency on outside assistance from healthcare practitioners and services is not consistent with hauora. Instead, kaumātua considered positive and empowering interactions between generations, to be at the heart of hauora. Notably, interactions aligning with intergenerational transference of knowledge between kaumātua and mokopuna about osteoarthritis, healthy lifestyles, cultural values and mobility technologies.

Also, 'tino rangatiratanga' in the context of hauora, is secured by the ways in which kaumātua with osteoarthritis interact with wider society. For example, access to institutions such as healthcare practitioners, healthcare clinics and social services is integral to osteoarthritis-management. However, the characteristics of entry into care and the relationships that kaumātua build with health professionals, is critical for achieving results that are consistent with community aspirations.

Furthermore, in relation to osteoarthritis management kaumātua aspire towards positive health partnerships where they are able to freely negotiate with healthcare practitoners and organisations (services). Enabling health partnerships is closely linked to the idea of 'oritetanga' (equity). Accordingly, there were innumerable institutions within the community that kaumātua held a high relevance for, such as recreational, cultural and health agencies.

Also, interaction with community institutions incorporated relationships within Māori society, namely hui held for marae and Māori community groups. The expectation is that whānau, hapū and iwi could add value to services. Moreover that they (whānau) would be able to make contributions concerning aspects of hauora, interconnecting with cultural affirmation and participation in tribal endeavours, tīkanga-ā-iwi approaches to hauora and heritage preservation.

To summarise, kaumātua with osteoarthritis in the present study identified three key characteristics for aspiring towards 'hauora', in particular 'manākitanga', 'tino rangatiratanga' and 'oritetanga'. 'Hauora' or Māori wellbeing in osteoarthritis-management is distinctive for requiring the recognition of collective enterprise, and endorsing kaumātua aspirations for self-determination and equity. For a 'hauora' approach to be effective, intergenerational relationships and the observation of cultural codes of conduct or kawa (cultural practices) and tīkanga (cultural principles), are integral to whānau enablement.

Hauora as a model of osteoarthritis-management

Another area that kaumātua emphasised with regards to their everyday experiences of osteoarthritis-management, concerned conceptualisations of hauora (Māori wellbeing). Hauora for whānau enablement is not a new concept, evidenced by the manner in which kaumātua intuitively embraced hauora into their everyday experiences of dealing, coping and living with osteoarthritis. Mainstream health and social services have been well aware of the collective needs of whānau for many years, but efforts to meet them have often been constrained.

Kaumātua with osteoarthritis discussed disconnections within the context of mainstream health and social services (services). For instance, difficulty obtaining osteoarthritis-management support from services. Furthermore, services are not always respecting the ability of whānau to take ownership of their realities and identifying the solutions that they need to achieve wellbeing. When hauora or Māori wellbeing underpins osteoarthritis-management, the aspirations, needs and realities of Māori society become part of the solution. For example, working with kaumātua and family to identify wellbeing goals, and developing pathways to achieve these or inviting their (whānau) input, advice and feedback on policy and service initiatives. By building whānau knowledge with holistic interventions that are Māori-centred, could increase the ability of kaumātua to take control of their own wellbeing.

A hauora or Māori wellbeing approach to osteoarthritis, recognises that the circumstances pertaining to the symptoms experienced by kaumātua with osteoarthritis, will inevitably impact on other people in the group and vice versa. Accordingly, effective healthcare services may require healthcare practitioners to deal with the whānau, rather than individual kaumātua living with the condition. Inevitably, communication becomes a critical part of a Māori wellbeing approach.

In contrast kaumātua reported that more often than not, communication with healthcare practitioners and social services could seemingly disregard their views. Namely, expertise and needs of kaumātua and/or the wider circumstances of the whānau. In such cases, an opportunity to achieve real and sustainable change in osteoarthritis-management was lost.

Implementing hauora or Māori wellbeing may, however, be difficult. Kaumātua expressed that aside from mainstream services focussing on individuals, and the presence of narrow understandings of wellbeing, that there were additional reasons why the holistic approach was fraught with difficulty. A significant issue being the lack of suitable tools to measure indicators of kaumātua wellbeing.

Even so, the increased acceptance of hauora or Māori wellbeing as a determinant of effective healthcare was evident. All the same, services have often retained conventional approaches of measuring and reporting on the gains achieved by kaumātua as individuals. The focus on individuals, rather than indicators of hauora for kaumātua and whānau for instance, means that the wider dimensions of wellbeing which whānau deem appropriate, are not considered. Alternatively, medical and epidemiological outcomes are prioritised, which in part is due a paucity of indicators that are able to be deployed.

To reiterate, the research questions of the present thesis asked, ‘What are the everyday experiences of osteoarthritis-managment for kaumātua?’ The findings suggest that osteoarthritis-management could sometimes be informed by medical advice, and influenced by a whānau ora approach. In the section that follows, the second research question is answered, as to how a Māori-centred approach drawing on kaupapa Māori theory could be best employed.

Application of a Māori-centred approach

In the current section, the second research question is articulated, relevant to how a Māori-centred approach drawing on kaupapa Māori theory could be best employed. The purposes of this being to create a culturally relevant toolkit. Specifically a toolkit for kaumātua with (or at risk of) secondary osteoarthritis, appropriate to modern health promotion and Māori health perspectives in Hawke's Bay.

Throughout the literature review and methodology chapters, a Māori centred, kaupapa Māori informed methodology was recognised for enabling me to give the participants (kaumātua) a level of autonomy. Specifically, that I would be able to keep kaumātua at the centre of my project. Consequently, all the way through, kaumatua were sitting right beside me in the research process.

Another feature with a Māori-centred approach was that it let me recognise Māori tikanga associated with research, recognising that as a culture we have specific practices in the research context. Further, Māori centred research allowed me to bring in other analytical tools. By way of example, a literature review lead me to being able to make certain claims.

In my literature review, I argued there being a need for a locally-based approach for kaumātua, illuminating a disconnection in the literature concerning the use of 'cultural indicators', in collaboration and partnership with kaumātua locally. In addition, how to best implement culturally appropriate osteoarthritis-management with kaumātua and the need for appropriate tools. There was some overseas evidence supporting culturally sensitive support.

Relatedly, the value of sharing stories and that a collaborative, evaluative toolkit was an effective approach, with diverse ethnic and cultural communities. In particular, a collarative, evaluative toolkit was useful for creating an osteoarthritis-management resource. Also, for me on a practitioner level the toolkit strongly recognises our Treaty obligation, and it is a comfortable feeling to know that this is how things can be done at the practitioner leve.

It also makes sense, that practitioners could have affected outcomes. Particularly when working with kaumātua, whose health I am often seeking to improve by further enabling increased control over osteoarthritis. Māori-centred elements have orientated the research, using common standard procedure commencing traditionally with a literature review.

In the process of how exploring how kaumātua are managing their condition, have I been able to delve into osteoarthritis-management material and kaumātua health. Exploring positive health management as viewed through Māori eyes has been enabled by way of Māori-centred research. The research has specifically,been designed to collect information concerning the lived experience of kaumātua in the Maori world, and wider society.

Māori-centred values were evidenced in kaumātua stories, that spoke of preferring a holistic model of health, for reframing osteoarthritis-management, positioning kaumātua away from limiting labels and diagnosis. Within an holistic framework, kaumātua confirmed that in order to work well, an osteoarthritis-management resource would need to start out right from the 'manākitanga' value, then 'tino rangatiratanga' (autonomy and self-determination), and; 'oritetanga' (equity and assessment) was more likely to naturally follow.

Values-based osteoarthritis-management toolkit

Arising from the methodology of the present research, a values-based osteoarthritis-management toolkit (toolkit) emerged, that could take account of kaumātua and whānau experiences and aspirations. To facilitate adoption of osteoarthritis self-management decision-making in relation to toolkit outcomes, is a shared process. Shared decision-making shifts osteoarthritis-management away from healthcare practitioners being the expert, who typically identifies what is required and then seeks to prescribe an intervention.

The toolkit enables kaumātua to work with others to identify preferred outcomes, and then jointly mapping a pathway forward to achieve these. The pathway could adopt a whānau inclusive process that fosters independence, otherwise referring to the capacity of kaumātua to care for themselves, self-determination, opportunities and kaumātua leadership, as an integral part of the collaborative process. A collaborative approach is premised on the idea that kaumātua with osteoarthritis, have a better understanding of their condition, within the context of the local environment and lived reality, and are better equipped to determine how holistic health values and diversity might be recognised.

Another key component of the toolkit approach, draws on the idea that peer support could shape lifestyles, by establishing codes of conduct that endorse healthy behaviours. There are numerous community hui forums, that regularly provide opportunity for kaumātua to support each other and share resources. These types of collaborations are more likely to reflect culturally appropriate practices for addressing the needs of whānau.

Contribution to osteoarthritis-management

To reiterate, the objectives of my study were about ascertaining how kaumātua are managing their condition. My research contribution emphasises the importance of the lived experiences of kaumātua living with a chronic condition. The importance of cultural values and beliefs and relationships are reiterated and the signficiance of collaborating with kaumatua.

Consistent with existing statistical data concerning knowledge and awareness about osteoarthritis, my research findings have shown there to be considerable scope for improvement within the Māori community (Bingham et al., 2013; Ministry of Health, 2010, 2015b). Contributing to these understandings, the present qualitative study provides an explanation as to why there is room to improve osteoarthritis-management strategies within the Māori community. In the process, the study makes a contribution to a limited collection of international research existing on managing chronic disease. Specifically understanding lay perceptions of osteoarthritis amongst Aboriginal peoples and the spiritual, cultural, emotional and social wellbeing ascribed to the condition (Broe et al., 2017; Centre for Aboriginal Health Research, 2013; Charles, 2015; First Peoples Disability Network, 2013).

Because lived experience is a key consideration and one that remains under-developed (Brunn et al., 2013; Faltermaier, 1997; Isaacs, 2014), the important contribution of the present research is realised. Particularly when it comes to planning and implementing resources targeting osteoarthritis. By utilising key-kaumātua interviews and focus group hui in the research design of the study, gathering rich data exploring historical, social and environmental barriers for kaumātua with osteoarthritis, additionally community norms, values, and beliefs are enabled. As an instance, there were often intricate reasons given by kaumātua concerning their chronic condition and perceived osteoarthritis rates amongst whānau, hapū, iwi.

Also in the present study, were examples emphasising that culture must be taken into account, when explanation and understanding osteoarthritis and designing appropriate resources is the objective. By illustration, one kaumātua had noted there being a cultural connection to food-based hospitality or 'manākitanga': "I think it comes down to portion sizes and 'manākitanga', that's how we host, we care for one another". The kōrero emphasised how cultural values and beliefs, have a powerful influence over everyday living.

In relation to the latter example concerning food-based hospitality, is the implication that healthcare practitioners working with kaumātua, will need to understand and work with cultural conceptualisations. Namely those concerning weight control, to avoid miscommunication. For instance, a collaborative approach to weight management, may support an inclusive conceptualisation of culture-based knowledge, and make a real difference to the wellbeing of kaumātua. In this context being contradistinction to an approach based on obesity or biomedical conceptualisations of health, that does not take into account social acceptance of larger body sizes or the effects of colonisation on health.

Implications of the research

A strength of the osteoarthritis-management toolkit developed as part of the present study, is that it seeks to make a connection between academic research and culturally appropriate healthcare practice. That is to say by way of translating, transforming and disseminating academic scholarship into a usable resource. Arguably, a strength of generating an osteoarthritis-management toolkit using a Māori-centred approach, is reframing mainstream ways of knowing Māori, by incorporating alternative worldviews and ways of knowing.

Within the context of my continual professional development as a healthcare practitioner and doctoral researcher, I intend to pursue the use of Māori-centred theory. To be more specific, incorporating theory into practice, and how to bring new knowledge to bear on the everyday realities of healthcare practice. I also hope to design as part of a post-doctoral study, an assessment framework that facilitates gauging positive change in kaumātua users, of the osteoarthritis-management toolkit.

I am keen to ask, ‘what is the scope for changes in knowledge and attitude?’ An ongoing challenge for chronic-condition management research, concerns the lack of studies that are explicit in documenting the process. Following discussions in the literature review of the present thesis also, are a range of reasons concerning, including that there are so few studies evaluating the effectiveness of supportive healthcare practitioner interactions regarding osteoarthritis, because isolating effects is difficult.

However, there is evidence that engaging in face-to-face self-management initiatives within small-groups, leads to small but statistically significant improvements in pain and disability. Further, that listening to insights and expertise of the local community, is a fundamental prerequisite for success (D. Battersby et al., 2009). Although for some people, a shift towards whānau self-determination and osteoarthritis-management, will introduce new challenges.

What the research challenges

The present research challenges healthcare practitioners, to consider how they perceive holistic healthcare for kaumātua within their communities. A hauora or Māori wellbeing approach, requires re-examining our key values in healthcare practice that determine the manner in which we may advocate, empower and provide care for kaumātua. Even so, patient-centred care has long been a well-established philosophy in relation to holistic approaches to care.

Hauora or Māori wellbeing, is somewhat different to patient-centred care, however. Remarkably utilising a hauora lens, challenges healthcare practitioners to reconsider the way in which we engage with kaumātua and whānau, by shifting our outlook from that of working with an individual, to working with whānau as a collective. It also challenges healthcare practitioners and workers to acknowledge the wider environment, and the determinants that impact on health and wellbeing. Consequently, these challenges affect the way in which osteoarthritis-management activities and resources are developed for healthcare practitioners.

Learning outcomes for healthcare practitioners

The present research provides a more nuanced understanding of kaumātua experiences with osteoarthritis. I challenge healthcare practitioners to develop a greater understanding of kaumātua knowledge of osteoarthritis, and to reflect on their own communication styles, as a way to enhance health outcomes for Māori patients. Towards that end the following observations are worth noting.

- A common experience for kaumātua is having witnessed a whānau member with osteoarthritis-related disabilities. Osteoarthritis is perceived by some kaumātua as a condition that is inevitable rather than one which, with the proper care could be managed or controlled. As a result, healthcare practitioners need to anticipate that ‘denial’ may be a common reaction to diagnosis, and plan accordingly. Attaining best outcomes will require healthcare practitioners to support and encourage whānau involvement.
- Hauora theory and Māori health models are highly valued by kaumātua. Accordingly, incorporating these into discussions about health, will help to recognise and support the needs both spiritual and/or emotional of Māori patients. At the same time, recognising the importance of acknowledging and understanding historical events, relevant current issues, Māori language terms and concepts are important for engaging kaumātua. At a practical level, these might include the healthcare practitioner exploring the concept of

'whakawhānaungatanga' (making of culturally meaningful connections with others).

- Exploring 'whakawhānaungatanga' may require healthcare practitioners (practitioners) to establish connections, and build a relationship with kaumātua and peers. Otherwise practitioners could enquire more broadly about family life, prior to embarking on the medical history (exploring 'whakawhānaungatanga'). For instance, describing one's own (the practitioners') genealogical background, family composition, academic experience, clinical and academic affiliations and interests.
- Easier information and services access is critical, if self-management of osteoarthritis is to be effective. Heathcare practitioners have a responsbibility to facilitate access, that enhances health literacy and empowers kaumātua to make informed decisions.
- Maintaining a positive Māori identity and an active role in the community is important for kaumātua wellbeing. Perspectives towards Māori identity may have implications for how health practitioners communicate and engage with kaumātua. For example it is important to recognise how to ask questions in a way that is mana enhancing, and promotes active hosting, warmth and support ('manākitanga').
- Kaumātua strongly encouraged the idea of healthcare practitioner collaboration. Collaboration in healthcare enables a level of independence and self-determination, so that osteoarthritis-management may be achieved and is mana enhancing. Kaumātua indicated that healthcare practitioners would be able to contribute to such an objective, by ensuring they actively listened to kaumātua and worked on explaining the condition in a language that kaumātua might be able to understand. For example, taking the time to understand how the condition will impact on kaumātua lived realities, and providing more information about choices. Then kaumātua may be able to exercise greater control over decisions and actions affecting their health.
- Active consideration will need to be given to the importance of customary practice for good health and wellbeing. If, for instance an identified problem is linked to osteoarthritis-mis-management. Healthcare practitioners will need to be skilled at working with whānau and individuals in the community. For example, considering whether kaumātua have a mobility problem that is increasingly making it difficult for them to participate in the community. Further, ascertaining

whether services might be able to create an environment for osteoarthritis-management, that is relevant to kaumātua and a whānau point of view.

- More often than not, all of the latter explanations will have a degree of relevance and the task will be for the healthcare practitioner to decide where to place the main emphasis. It may be that the primary focus will need to be placed on the whānau, but there may be other options that may be explored in tandem. For instance, dietary advice might consider ceremonial eating, as a demonstration of hospitality ('manākitanga') and mana (prestige).

In sum, the toolkit takes into account these observations and offers the potential for practitioners to work with kaumātua, to set 'do-able' goals, and gain a greater sense of control for oneself and ultimately for one's whānau. For that matter, progress may be made towards reducing systematic inequalities of health. These encompass addressing issues with access to healthcare services, and enhanced health status. It is also an appropriate health promotion tool for encouraging kaumātua to talk about their condition, as the toolkit is built on Māori cultural beliefs and practices. For that reason, the toolkit is suitable for use during hui, enabling people to share their own experiences, perspectives and stories about health.

Learning outcomes for healthcare planners

The present thesis has provided more nuanced understandings of osteoarthritis-management for healthcare practitioners and planners. Par example, a Māori-centred approach to qualitative study documented low levels of osteoarthritis knowledge and awareness in the Māori community, substantiating previous quantitative studies. As a consequence, my research data has learning outcomes that may be of interest to healthcare planners, to inform and possibly improve healthcare services for kaumātua, family and whānau.

- The present research documents there being a number of persistent barriers in service delivery that continue to prevent kaumātua from successfully engaging with healthcare services. In Hawke's Bay for kaumātua with osteoarthritis, engagement with healthcare services was characterised by a number of barriers. That is to say, poor communication, distrust, negativity and institutional racism. It will be important for mainstream healthcare services to ensure blame is not apportioned to patients, in which a positive response is expected, when critical examination of services themselves should be undertaken.

- The present study supports there being a long history of culturally insensitive healthcare services for Māori. Part of overcoming health inequity requires improving healthcare services, which is about increasing the number of Māori in healthcare practitioner roles. The reason being that a healthcare workforce with knowledge of Māori cultural values and rights, is more likely to improve the experiences of kaumātua, family and whānau accessing these.
- In addition to the importance of building the Māori workforce, the present research emphasises Māori and mainstream engagement in practice. It provides opportunity for policy and decision-makers involved in healthcare service delivery, to re-think the use or adaptation of international trends, systems and models of collaborative care towards osteoarthritis-management. It is critical to re-examine local evidence-based research, which is driven by the very communities that public health policy affects.
- Tīkanga-based models of collaborative service delivery, particularly for kaumātua are notable for promoting accessibility of relevant services for Māori. Tīkanga-based models of service delivery, serve in ways that may be able to meet the needs of Māori in terms of culturally-based service delivery, and also for mainstream stakeholders and funders in relation to expressing Treaty principles and obligations in the provision of services. The toolkit, arising from the present research is an example of how osteoarthritis-management may be achieved in the community, when pathways accommodate Māori values and tīkanga, as well as mainstream Treaty principles.
- Building on the idea of pathways accommodating Māori values, in the present research kaumātua talked about a preference for tīkanga within healthcare environments that is delivered by Māori practitioners. Working to address the demographic mis-match between Māori practitioners percentage-wise and Māori patients, will be key. Increasing the Māori healthcare workforce, needs to continue being the main priority, toward ensuring more culturally sensitive healthcare services in Hawke's Bay.
- Similarly, the findings of the present study suggest that healthcare planners could be considering workforce initiatives[101]. These training programmes are important for encouraging practitioners to explore their healthcare modalities from a hauora Māori perspective, such as 'Te Whare Tapa Whā' model. Corresponding actions are likely to actively encourage hauora or Māori wellbeing into use, within mainstream and allied health services. On a practical level, it may well be that

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[101] Workforce initiatives include Mauri Ora Associates (2018) online training. See mauriora.co.nz.

engaging more effectively with kaumātua, will require sensitive re-scheduling of appointments, as money was an issue for some.

- Another point in hand concerns scheduling appointments appropriately, for enabling healthcare practitioners' adequate time to establish 'whakapapa', 'whakawhānaungatanga', and on a practical level ensure the ability to be able to offer extra seating for whānau support. When planning future research, oversight and education activities conducted by healthcare professionals to help patients with **chronic** diseases that incorporates osteoarthritis-management, could be better prioritised. For example, research that focusses on the experiences of living with a chronic condition from a lay-perspective, and meanings ascribed to osteoarthritis both socially and culturally.
- Also, using a Māori-centred approach may help when working with kaumātua and conducting research that concerns them. That is, to ensure that healthcare initiatives are able to be responsive to community needs. Utilising a Māori-centred approach is more likely to increase the chances of community support, particularly when initiatives are defined according to community needs.

Learning outcomes in health promotion

In addition to healthcare practitioners and planners, arising from the research data, are implications for educators, engaging in health promotion. The findings may help to shape the future design of educational resources in various ways.

- Utilising alternative approaches to identifying modifiable determinants of osteoarthritis-management with kaumātua, requires a sensemaking perspective. In effect, a perspective that is based on a culturally appropriate theoretical framework, incorporating early and ongoing engagement with key stakeholders.
- Community driven osteoarthritis-management initiatives are more likely to be locally responsive, and ensure greater osteoarthritis-management commitment or buy-in. As an illustration, qualitative interviewing with key informants and focus group hui, that are established within a tīkanga base, are imperative to recognising wider determinants of health. Also, indicators need to be cuturally tailored, so that they align to community knowledge, values and experience, upon which ideas about possibilities and actions are based.
- Qualitative research that seeks insight into exploring and solving issues by collaborating with the community, is a major component of any successful osteoarthritis-management initiative. Activities may potentially be better placed, when they are based on experiences, values and needs of the target community, as a means to understanding their unique requirements and promoting

transformation. Māori-centred research may be considered by healthcare practitioners engaging in health promotion, and osteoarthritis-management with kaumātua, as being an appropriate model at every stage of the research involving Māori and in so doing, is amenable, accessible and receptive to community needs.

- Understanding kaumātua experiences and needs, will help to influence osteoarthritis-management. Understanding the role of culture in self-management is more likely to occur, when health promoters and educators utilise qualitative, key informant interviews that are led by Māori, and focus group hui with the guidance of kaumātua facilitators, to obtain a more nuanced understanding, concerning barriers and enablers for change. By moving planning beyond statistical analysis, could lead to deeper understanding of Māori experiences of 'where they are positioned', so that realistic health outcomes may be set.
- In the present research kaumātua spoke of 'where they were' in terms of health aspirations, and required being realistic about exercise (see, 'Gyms are so expensive'). For some interviewees, exercising in the process of doing housework, or in bed over the winter was realistic. The findings indicate that educators will need to tailor their guidelines on physical activity for older-people, rather than following Ministry of Health directives, as these would be out of reach of some of the kaumātua participants of the present study[102].
- Considering the low health literacy of kaumātua, future osteoarthritis-management initiatives with a Māori focus, need to consider incorporating culturally sensitive tools. For example, kaumātua in the present research showed a strong preference for real stories, story telling, recounting stories and listening to new ways of how to keep one's health in check. Accordingly providing ample opportunity for informal conversations, have potential for Māori, with a strong oral storytelling culture.
- The osteoarthritis-management toolkit of the present study that has grown out of kaumātua stories, is an appropriate health promotion tool as it encourages kaumātua to talk about their condition. It also works well within a hui environment, because it is built on Māori cultural beliefs, practices, and shares their own experiences, perspectives and stories about health. What is more, the present research emphasises the importance that health promoters utlilise Māori theory and principles, in the design of osteoarthritis-management resources.

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[102] Ministry of Health recommendations are that exercise needs to occur for half an hour on five day of the week. The level is moderate-intensity physical activity, i.e.: cycling, fast dancing, golf, hill walking, housework, kapa haka, kaumātua line dancing, stair climbing, strenuous gardening, swimming, walking, waka ama, water aerobics/aqua jogging (Ministry of Health, 2013). For more info, see: health.govt.nz/system/files/documents/publications/guidelines-on-physical-activity-older-people-jan13-v3.pdf.

- Theories in healthcare are significant, because they may help to explain the, ‘why’ (reasons behind people’s actions), and encourage identifying points for change. Consequently, selecting suitable theoretical ideas with the help of Māori collectives, that have a practical and useful focus is sensible. Keeping in mind also, that collective efficacy is a mechanism that enables kaumātua to work out issues, and improve their lives.
- An important distinction in the present research concerning osteoarthritis-management that may be useful to health promoters, is the importance of collective community-based activities. Kaumātua are a collectivistic people, living within a largely individualistic mainstream society. For that reason, the importance of observational learning may need to be ascertained in future research, through the means of attaining knowledge via others, by utilising local Māori role models.

Learning outcomes for researchers

As I have already made clear in the current chapter, the research was concerned with generating local knowledge. The purpose being to produce change socially at a local community level, according to regional needs and characteristics. The following outcomes, should influence how initiatives are developed and implemented by community needs, which inevitably means compromising generalisability and universalisation.

- Although universal perspectives could be applied to Māori, the present research has shown Māori specific measures to be well attuned to Māori realities and Māori worldviews. Although I am not suggesting that my research findings are generalisable, the Māori-centred research approach offers researchers contemplating culturally sensitive approaches to research design. Additionally, in the present study, I have argued that a Māori-centred research, drawing on kaupapa Māori theory, provides a culturally appropriate approach. In effect that is able to enact local transformational-oriented approaches.
- The present thesis has sought to reflect the cultural preferences of the participating community. The reasoning behind supporting Māori cultural preferences being that positive outcomes will be more likely. Particularly when initiatives are designed following Kaupapa Māori theory.
- My Māori-centred study, reflective of cultural values, offers several examples pertaining to tīkanga Māori customs. Utilising for instance, the concept of ‘whānaungatanga’ (togetherness, sense of family connection) (the concept), by prioritising local knowledge and protocol. Specifically, the concept orientated me

towards understanding the importance of ethical, moral and spiritual involvement, throughout the research process.

- I also sought to build trust relationally, by being transparent, open and honest about my motives. Rather than assuming the role of expert, I sought to garner community support and guidance. Further, the researcher is more likely to be assisted, when kaumātua are approached for support and guidance at the outset of the research. So too will utilising a Māori-centred approach to the research.
- Utilising a Māori-centred approach to the research, legitimised the validity and relevance of Māori preferences, community context and culture. Māori-centred research resulted in a resource that was constructed with kaumātua to ensure greater relevance for the promotion of hauora or Māori wellbeing. Qualitative research design, should be considered by researchers intent on exploring Māori experiences, knowledge and perceptions of a chronic health condition.
- Qualitative data, key informant interviews and focus group hui helped to ascertain what Māori knowledge informs wellbeing, and how a Māori perspective was being practiced. On top of that, a Māori-centred approach may help to frame 'why' Māori conceptualisations of health are applicable, in the construction of a healthcare resource. Similarly, 'who' kaumātua view in their communities as valuing their voice, perspectives and diversity.
- In the present study, kaumātua with osteoarthritis described often complex historical (i.e. loss of language) and structural (service barriers) that prevented engagement processes. There were also economic (cost of healthy food and exercise) and social elements, that affected osteoarthritis-management in the Māori community. Qualitative, community-based research using Māori analysis is able to support researcher identification of factors related to wellbeing, which may influence health actions, such as support from family and in the community.
- Kaumātua participants that engaged in my research, identified mokopuna as being the catalyst for change, as well as opportunities that required leading whānau. For example, providing leadership or having responsibilities for whānau wellbeing. Understanding kaumātua preferences is a prerequisite, essential for constructing culturally, meaningful resources. It is essential that in order to understand and encourage potential change in the target audience, researchers need to consider their historical context experiences, values and needs.
- A qualitative approach might also prove useful when researchers are working alongside other groups with chronic conditions in New Zealand. The qualitative methods of the present research, such as key informant interviews and focus

groups enable opportunity for gathing rich data concerning community norms, values and beliefs, alongside historical, social and environmental barriers. Even so, my study has noted a disconnection occurring between a dominant mainstream, biomedical understanding, and a more holistic understanding of osteoarthritis.

- A Māori-centred approach is particularly relevant for researchers, seeking to incorporate more holistic models into academic research. Reframing osteoarthritis-management towards highlighting community strengths and resilience by using a holistic model of health, will be more conducive than positioning Māori people as a problem. What is more, 'Te whare tapa whā' model enables understanding the physical, alongside whānau and social, spiritual and mental elements.
- In addition, incorporating multiple ways of seeing the world was potentiated through Māori-centred research, drawing on kaupapa Māori epistemology, rather than there being a single objective reality. What is more, Māori-centred research is an important tool, that could be used to explain socio-cultural realities of diverse Māori communities. Not only does a Māori-centred approach appportion equal weight to scientific and cultural expressions of knowledge, but it acknowledges there being different ways of knowing.

Conclusion

To conclude, culturally appropriate osteoarthritis-management needs to be prioritised. Otherwise, osteoarthritis-related costs have the potential to overburden the New Zealand healthcare system, if left unchecked. A whole of health sector approach is required, if we are to better support culturally appropriate chronic condition management. It is imperative that researchers employ Māori-centred approaches and that the rationale for utilising health theory be reported. In order to engage the community, the research process and strategies implemented, need to be made clear.

As has been demonstrated, Māori-centred research provides a strong approach which future research needs to apply, engaging kaumātua with osteoarthritis, with the goal of achieving 'orietanga' or equity. These components, when implemented within a sound policy framework, have the ability to unlock the latent potential in relationships between kaumātua, healthcare practitioners, whānau and iwi, to accelerate Māori development. Then the resulting relationships will more closely reflect the spirit and intent of the Treaty partnership, and may indeed serve as a model of success not only for kaumātua and whānau, but also for many older non-Māori New Zealanders and families.

Haere rā, farewell!

Glossary of terms

Abbreviations used

ACC	Accident Compensation Corporation
DHB	District Health Board
GP	General Practitioner
MOH	Ministry of Health
MUHEC	Massey University Human Ethics Committee
WHO	World Health Organisation

Māori/English Glossary of terms

Māori/English terms provided in the glossary are explanations for use in the context of the present thesis only. As many words may be used in different ways (providing different meaning in different contexts and dialects) these terms, are not definitions.

Aotearoa	New Zealand
aroha	feel concern for, feel compassion, empathise, to reciprocate
awa	river
awhi	assist, aid
European/Pākēhā	not-Maori, New Zealander's, usually of European descent. Those of a different breath. Those that changed the essence of what they touched "Pā" meants to touch or affect; kē is an indication of reversal and, hā refers to essence or breath.
haka	ceremonial vigorous dances with actions and rhythmically shouted words
hapū	sub-tribe
hauora	health and wellbeing
Hawke's Bay	rohe or region of New Zealand on the east coast of the North Island
he mihi	initial greeting, speech of greeting, acknowledgement, tribute
hinengaro	emotional and mental health
hui	gathering, bring together, ceremonial, ritualised meeting
iwi	tribe
Kahungunu	Tribal leader, name of an iwi located on the eastern coast of the North Island of New Zealand.
kai	Exercise, eat, consume, partake
kaikaranga	caller - the woman (or women) who has the role of making the ceremonial call to visitors onto a marae, or equivalent venue, at the start of a pōwhiri
kaikōrero	speaker, narrator
kanohi ki te kanohi	face to face
kapahaka	the practice and performance of Māori songs and dances
karakia	to recite ritual chants, say grace, pray, recite a prayer, chant, invocation used in traditiona Māori religion
kaumātua	elderly man or woman of status within the whānau
kaupapa Māori	Māori focussed, values or basic idea, foundation
kawa	Māori customs or protocol
kawakawa	Kawakawa, pepper tree, Macropiper excelsum - a small, densely-branched tree with heart-shaped leaves. Found throughout the North Island and as far south as Banks Peninsula. Used for ceremonies, including removing tapu

	for medicinal purposes, and as a symbol of death
kia ora!	hello! cheers! good luck! best wishes!
koha	a small gif or a donation, given as a way of covering hospitality expenses and as a mark of appreciation for manākitanga. Koha used to be given in the form of Exercise – kumara, pigs, etc. but in a cash economy these traditions have been replaced by the donation of money. In the present study koha was a $20 supermarket voucher and Exercise (biscuits; soup)
Kōhanga Reo	Māori language preschool
kōkiri	Diving
kōrero mai	speak to me (I am listening, you have my attention)
koro	elder man
kotahitanga	Collaboration, the process of working with others to produce something special
kuia	elder woman, grandmother, female elder
mana	prestige, authority, control, power, influence, status, spiritual power, charisma - mana is a supernatural force in a person, place or object, tangible and intangible expressions of power
mana Māori	Māori authority, control, power; Māori control recognises the rights of Māori under Te Tiriti o Waitangi to both ‘Rangātiratanga’ and protection
manāki	support, protect, look out for, show respect, generosity and care for others
manākitanga	respect, hospitality, caring, reciprocity, support, generosity for others
Māori	normal, indigenous to New Zealand, of Māori descent/blood/whakapapa
marae	Māori meeting ground
mātauranga	Māori beliefs, custom, and values that are derived from a mixture of cosmogony, cosmology, religion, and anthropology, also referred to within the present thesis as Māori knowledge.
maunga	Mountain
mihimihi	a mihimihi is a basic introduction to let people know a little bit about yourself. It tells people where you are from and who you are, linking you to the land (and mountain), river, sea, tribe, sub-tribe, whakapapa (genealogy) and marae (sacred meeting place)
mokopuna, Moko	grandchild - child or grandchild of a son, daughter, nephew, niece, etc.
Ngāti Kahungunu	Ngāti Kahungunu are New Zealand's third largest tribal group. Stretching down the North Island from the Māhia Peninsula to Cape Palliser, the territory is divided into three districts: Wairoa, Heretaunga and Wairarapa
noa	free from restrictions
oritetanga	equity, health equity
papatūānuku	the earth, earth-mother
pēpeha	proverb
Pou-Rewarewa	the name of the Rewarewa tree, grows in Hawke’s Bay. Pou refers to ‘upright support’. In the present research Pou-Rewarewa refer to the Rewarewa tree standing tall and is referred to by kaumātua in the study as an analogy for kaumātua, as standing tall and proud
rangahau	research
rangātira	chief (male or female)
rangātiratanga	leadership, enablement, authority, self-management, developing ownership of learning and responsibility for

	self, others and the environment.
ranginui	sky father
rohe	region
rongoa	traditional medicine made from plants, etc. To treat, apply medicines
rōpū	group, party of people, company, gang, association, entourage, committee, organisation
taha	side margin, edge
Tai Whenua [Te Taiwhenua O Heretaunga - nga marae o Heretaunga-	Mandated hauora provider in Heretaunga
tangata	man, people
tangata whenua	people of the land
tangihanga	funeral
taonga	treasure
tapu	prohibition, restriction, protection. protected, special, sacred.
te ao Māori	the Māori world, including Te Reo (the language and dialects), Tīkanga (the processes and practices), Marae (the community focal point), Waahi Tapu (sites of importance) and access to whānau, hapū and iwi
te reo Māori	the language of Māori
te taha hinengaro	thoughts and feelings
te taha tinana	physical, self, person reality
te taha wairua / wairua	spiritual. Spirit, soul - spirit of a person which exists beyond death. It is the non-physical spirit, distinct from the body and the mauri
te taha whānau	whānau and community
te tiriti	treaty (Treaty of Waitangi). Treaty signed between Māori and English in 1840
Te Whare Tapa Whā	Model of house that is based on four walls of a house
tika	correct
tīkanga	Māori customary health knowledge and practices
tīkanga o Kahungunu	correct procedures relative to the Kahungunu tribal group of the southern North Island east of the ranges from the area of Nūhaka and Wairoa to southern Wairarapa
tino rangātiratanga	self-determination, Māori leadership, participation and control over their own wellbeing, sovereignty, autonomy, self-government
tipuna	ancestors, grandparents - eastern dialect variation of tūpuna
tohunga	skilled person, chosen expert, priest, healer - a person chosen by the agent of an atua and the tribe as a leader in a particular field because of signs indicating talent for a particular vocation
toolkit	a set of tools that are used for a particular purpose
tūrangawaewae	the place where a person lives or affiliates to or domicile, standing, place where one has the right to stand - place where one has rights of residence and belonging through kinship and whakapapa.
waiata	Māori song, chant, psalm
wairua	attitude, quintessence, feel, mood, feeling, nature, essence. Spiritual wellbeing
wairua tipuna	ancestors, grandparents
wānanga	Māori learning process for holistic wisdom, seminar, conference, forum, educational seminar.
whakamā	feeling inferior and inadequate
whakangā	Meditation
whakangāwari	calming prayer and meditation

whakanoa	to be free from tapu
whakapapa	genealogical connections over many generations, cultural identity
whakapiki tangata	enablement refers to optimising the benefits of the research for Māori-people and minimising the chance of exploitation of those participating in any way
whakarongo	listen
whakataukī	proverb, significant saying, formulaic saying, cryptic saying, aphorism. Like whakatauākī and pēpeha they are essential ingredients in whaikōrero
whānau	whānau
whānau ora	healthy families
whānaungatanga	valuing people, connectedness, kinship, relationship, strengthening relationships, sense of family connection
whare	house, home, communal living
whenua	country, land, nation, state, territory, domain, placenta

Appendices

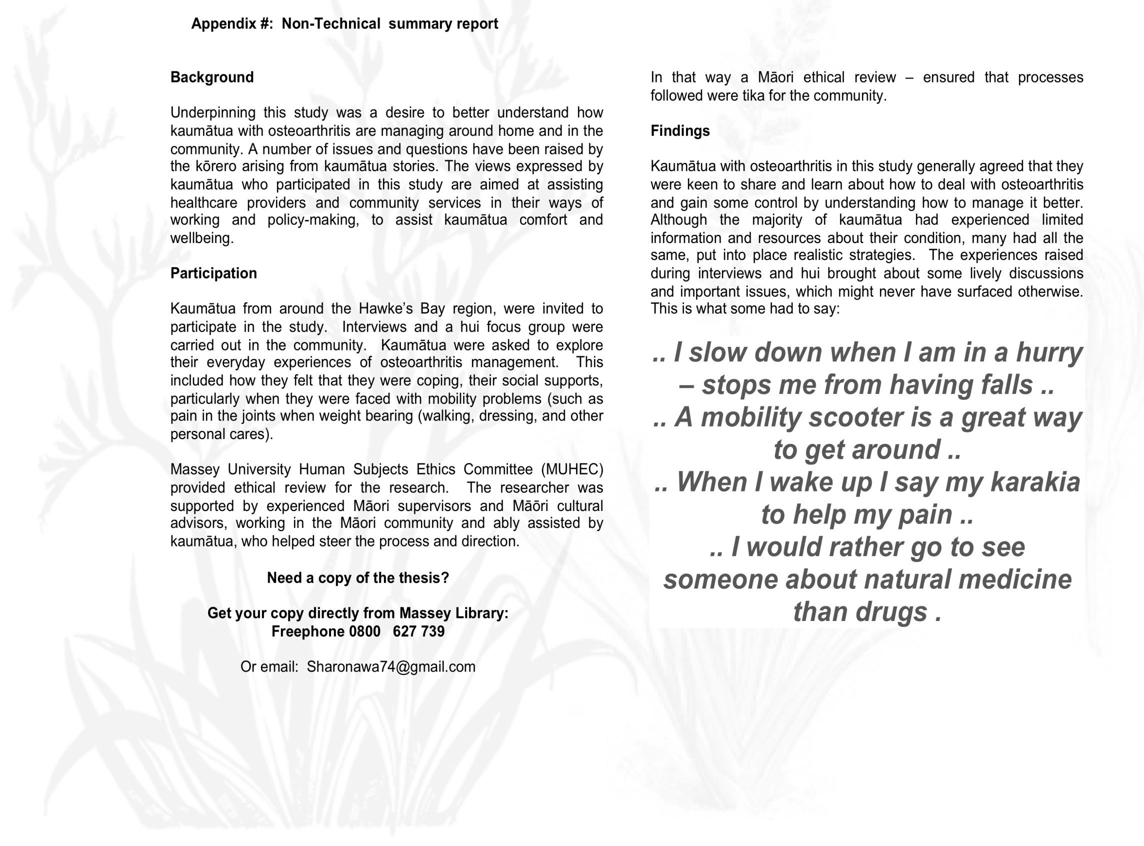
Appendix 1: Stages of the research

Stages	Activity	Timeline	Comment
Planning the research	Preparation and submission of application for ethical approval	MUHEC Northern Regional Ethics Committee (Application 13/049) Nov 2013. Study end date Aug 2016.	Muhec approval allowed the research to progress.
	Funding HRC grant approval	Dec 2013	
	Established ongoing feedback protocol with cultural advisors and stakeholders to ensure that Māori views were centralised throughout the study	Feb 2014	
	Conducted a systematic literature review to build up a sound and informed repertoire of knowledge (utilised in decision-making/guidance etc.).	March 2014	
	Developing methodology and data analysis, incorporating journal and field notes.	April 2014	
	Developing questionnaire	April 2014	
	Conducted feedback hui. Confirmed geographical location.	May 2014	Attended two locations. Kaumātua approval obtained.
	Attendance Kaupapa Rangahau Workshop	June 2014; July 2014; Aug 2014.	
	Touching base with kaumātua.	May 2014, July 2014, August 2014, October 2014, February 2015.	Attended two locations kaumātua rōpū
Kaumātua interviews	Developing and piloting questionnaire	Jan 2015	Pilot feedback was used to adapt the questionnaire. Great positive response from kaumātua
	Developing methodology and data analysis, incorporating journal and field notes.	April 2015	
	Interviewed 20 kaumātua. Applying questionnaire. Invited them to attend face-to-face focus group hui to support and share	May 2015 – Nov 2015	Ventured around the homes of kaumātua throughout Heretaunga.

Stages	Activity	Timeline	Comment
	knowledge.		
	Initial analysis of data incorporating journal and field notes.	May 2015	Analysis within 48 hours of each interview, returning transcripts, receiving and incorporating feedback
	In-depth analysis incorporating journal and field notes.	Aug 2015	Computer assisted analysis Dedoose.
	Feedback to kaumātua	Sept 2015	Attendance kaumātua hui to update on progress
	Validation of kaumātua data	Sept 2015	Note taking. Identifying themes. Obtaining feedback from kaumātua.
	Decision to proceed to stage 2 focus group hui. Piloting the focus group hui guide. Conducting the focus group hui.	Sept – Oct 2015	Based on kaumātua feedback and analysis of data.
	Feedback to kaumātua	Oct 2015	Attendance kaumātua hui to update on progress
Focus group hui	Approached all of the interview participants to attend focus group hui.	Oct 2015	17 attended focus group. Timing was an issue. I utilised regular rōpū hui to avoid disruption of kaumātua scheduling.
	Informed participants at completion of hui of stage 1 and 2 results	Feb 2016	
	Feedback to kaumātua	March 2016	Attendance kaumātua hui to update on progress
Data analysis and feedback	Initial analysis incorporating journal and field notes.	March 2016	
	Comprehensive data analysis. Attendance to kaumātua hui to field any questions, queries and feedback.	March 2016	Incorporating journal and field notes.
	Shared my approach and criteria to guide selection and analysis of the literature. Comprehensive data analysis.	April 2016	Attendance kaumātua hui to update on progress
	Shared my initial analysis, seeking feedback.	May 2016	Attendance kaumātua hui to update on progress
	Discussed aspects concerning evaluation for feedback.	June 2016	Attendance kaumātua hui to update on progress
	Talked about the benefits of interviewing vs. focus group hui.	July 2016	Attendance kaumātua hui to update on progress
	Shared the research protocols of the research.	August 2016	Attendance kaumātua hui to update on progress
	Toolkit development support from key	August 2016	Note taking Computer assisted

Stages	Activity	Timeline	Comment
	kaumātua to extend the values. Feedback obtained on usability of the Toolkit at the Māori Health Unit and Whare Mihiroa, Hastings.		Memos Identifying themes Attendance 'testing the toolkit' hui with kaumātua facilitators (kaimahi).
Reporting, feedback and disseminating the data	Feedback to kaumātua of the results of the research and disseminated more widely to the Māori and research communities.	December 2016 (xmas)	Attendance kaumātua hui to update on progress of toolkit, feedback sought. Posted a non-technical summary report.
	Feedback to kaumātua	Feb 2017	Delivery non-technical summary report to all participants, kaumātua rōpū and their whānau.

Appendix 2: Non-technical summary report



Appendix #: Non-Technical summary report

Background

Underpinning this study was a desire to better understand how kaumātua with osteoarthritis are managing around home and in the community. A number of issues and questions have been raised by the kōrero arising from kaumātua stories. The views expressed by kaumātua who participated in this study are aimed at assisting healthcare providers and community services in their ways of working and policy-making, to assist kaumātua comfort and wellbeing.

Participation

Kaumātua from around the Hawke's Bay region, were invited to participate in the study. Interviews and a hui focus group were carried out in the community. Kaumātua were asked to explore their everyday experiences of osteoarthritis management. This included how they felt that they were coping, their social supports, particularly when they were faced with mobility problems (such as pain in the joints when weight bearing (walking, dressing, and other personal cares).

Massey University Human Subjects Ethics Committee (MUHEC) provided ethical review for the research. The researcher was supported by experienced Māori supervisors and Māori cultural advisors, working in the Māori community and ably assisted by kaumātua, who helped steer the process and direction.

Need a copy of the thesis?

Get your copy directly from Massey Library:
Freephone 0800 627 739

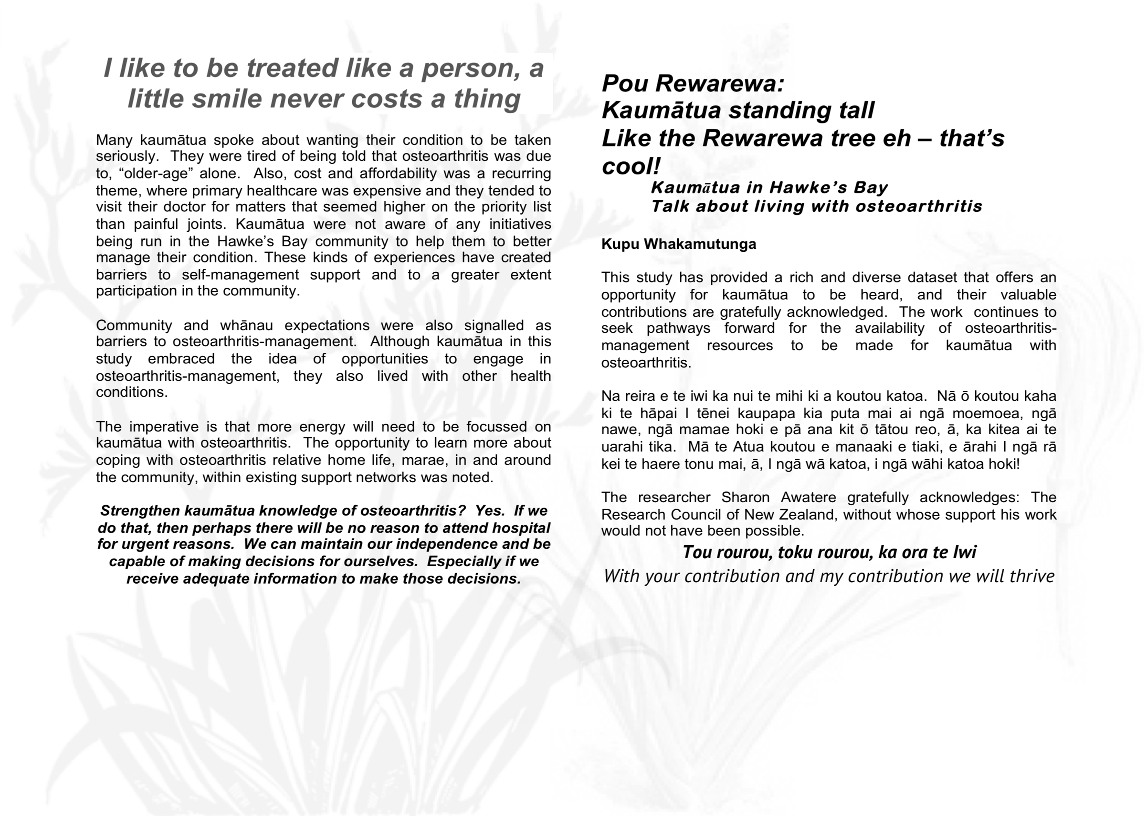
Or email: Sharonawa74@gmail.com

In that way a Māori ethical review – ensured that processes followed were tika for the community.

Findings

Kaumātua with osteoarthritis in this study generally agreed that they were keen to share and learn about how to deal with osteoarthritis and gain some control by understanding how to manage it better. Although the majority of kaumātua had experienced limited information and resources about their condition, many had all the same, put into place realistic strategies. The experiences raised during interviews and hui brought about some lively discussions and important issues, which might never have surfaced otherwise. This is what some had to say:

.. I slow down when I am in a hurry – stops me from having falls ..
.. A mobility scooter is a great way to get around ..
.. When I wake up I say my karakia to help my pain ..
.. I would rather go to see someone about natural medicine than drugs .



I like to be treated like a person, a little smile never costs a thing

Many kaumātua spoke about wanting their condition to be taken seriously. They were tired of being told that osteoarthritis was due to, "older-age" alone. Also, cost and affordability was a recurring theme, where primary healthcare was expensive and they tended to visit their doctor for matters that seemed higher on the priority list than painful joints. Kaumātua were not aware of any initiatives being run in the Hawke's Bay community to help them to better manage their condition. These kinds of experiences have created barriers to self-management support and to a greater extent participation in the community.

Community and whānau expectations were also signalled as barriers to osteoarthritis-management. Although kaumātua in this study embraced the idea of opportunities to engage in osteoarthritis-management, they also lived with other health conditions.

The imperative is that more energy will need to be focussed on kaumātua with osteoarthritis. The opportunity to learn more about coping with osteoarthritis relative home life, marae, in and around the community, within existing support networks was noted.

Strengthen kaumātua knowledge of osteoarthritis? Yes. If we do that, then perhaps there will be no reason to attend hospital for urgent reasons. We can maintain our independence and be capable of making decisions for ourselves. Especially if we receive adequate information to make those decisions.

Pou Rewarewa:
Kaumātua standing tall
Like the Rewarewa tree eh – that's cool!
Kaumātua in Hawke's Bay
Talk about living with osteoarthritis

Kupu Whakamutunga

This study has provided a rich and diverse dataset that offers an opportunity for kaumātua to be heard, and their valuable contributions are gratefully acknowledged. The work continues to seek pathways forward for the availability of osteoarthritis-management resources to be made for kaumātua with osteoarthritis.

Na reira e te iwi ka nui te mihi ki a koutou katoa. Nā ō koutou kaha ki te hāpai I tēnei kaupapa kia puta mai ai ngā moemoea, ngā nawe, ngā mamae hoki e pā ana kit ō tātou reo, ā, ka kitea ai te uarahi tika. Mā te Atua koutou e manaaki e tiaki, e ārahi I ngā rā kei te haere tonu mai, ā, I ngā wā katoa, i ngā wāhi katoa hoki!

The researcher Sharon Awatere gratefully acknowledges: The Research Council of New Zealand, without whose support his work would not have been possible.

Tou rourou, toku rourou, ka ora te Iwi
With your contribution and my contribution we will thrive

Appendix 3: Interview guide

INTERVIEW GUIDE

Exploring the everyday experiences of kaumātua with osteoarthritis

Purpose: Semi-structured interviews with kaumātua. Interview question guidelines (topics to be covered and some probe questions).

Criteria (checklist)

Male ☐ Female ☐
Age 55 (aged 55+ years) ☐
Māori ethnicity ☐ Māori ancestry ☐ Based in Hawkes Bay ☐

Previous diagnosis:
Gout ☐ Osteoarthritis ☐ Chronic musculo-skeletal joint disorder ☐
Living independently ☐ Living in residential care ☐

Background

Can you tell me a little bit about yourself, how are you managing (coping) with your osteoarthritis around home and in the community (for example, pain in the joints when weight bearing, walking, dressing, personal cares)? When you think of osteoarthritis, what do you think about? What would you like to know (management-strategies)?

Experience of Osteoarthritis

- We hear people talking about kaumātua and quality of life. I guess this means what's really important to you in your life? What would you say is important in your life? What are the most important supports for you and your whānau in managing osteoarthritis at home or in the community?
- Tell me about a time when you and your whānau responded to a challenge in a way that made you feel on top of things?
- How would you describe the supports and resources that are available to you? What about other people in your community, what are their experiences with osteoarthritis? Can anything be done to improve these? What additional resources would be useful?
- What does being older, and Māori, living with osteoarthritis mean to you, in today's society? Do we need an osteoarthritis-management toolkit? If so, what would it look like? What would it role be? What criteria should be used when assessing osteoarthritis-management for kaumātua?
- After this research is complete, I will be coming back to share the results. What do you think is the best way to do that?" Do you have any preferences to be referred to as older Māori, kaumātua or anything else as a collective and/or a made up name (pseudonym), when relating your personal interview in the final study?

Appendix 4: Focus group hui guide

Exploring the everyday experiences of kaumātua with osteoarthritis

Focus Group hui guide

1. Karakia tīmatanga and karakia whakamutunga (opening and closing blessing)
2. Kaupapa of the study (see ‘Participant information sheet’)
3. Purpose of the study
4. Risks and benefits to participating in the focus group hui
5. Confidentiality (not to disclosure the identity of individual members in the group to anyone else)
6. How the data would be used to inform the content of an osteoarthritis-management resource
7. Consent forms signed

Discussion guide:

a) Ice breaker: Could we go around and introduce ourselves, and if you want to, please feel free to share your experience of osteoarthritis?
b) Out in our community what’s your perception of osteoarthritis?
  - Prevalence, diagnosis, causes, symptoms, management?

c) Are your osteoarthritis limitations impacting on you being a part of the whānau?
  - What does being healthy mean to you?

d) What do you view as promoting your ability to participate in whānau and community events?
e) Do you have any favourite supports that you access in the community, that you most enjoy?
f) Is there anything you would like to share that you have found is helpful that assists your management of osteoarthritis?
g) What do you need to manage your osteoarthritis?
h) What would be helpful?
  - Would it help you to have osteoarthritis-management activities tailored to your own circumstances? What would these look like?

i) Do we need an osteoarthritis-management resource?
  - What would it look like for kaumātua?
  - What would it need to do?
  - Should this be broadened to include other chronic conditions (not just osteoarthritis)?

Appendix 5: Ethical Approval

MASSEY UNIVERSITY
ALBANY

25 November 2013

Sharon Awatere
c/- Dr F Te Momo
Te Putāhi-a-Toi
School of Health & Social Services
Massey University
Albany

Dear Sharon

HUMAN ETHICS APPROVAL APPLICATION – MUHECN 13/049
Exploring the everyday experiences of older Māori living with Arthritis

Thank you for your application. It has been fully considered, and approved by the Massey University Human Ethic
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

Associate-Professor Mark Henrickson
Acting Chair
Human Ethics Committee: Northern

cc Dr F Te Momo
Te Putāhi-a-Toi
School of Health & Social Services

Te Kunenga ki Pūrehuroa
Research Ethics Office
Private Bag 102 904, Auckland, 0745, New Zealand Telephone +64 9 414 0800 ex 43279 humanethicsnorth@massey.ac.nz

Appendix 6: Participant information sheet

INFORMATION SHEET:

18th November, 2013

Exploring the everyday experiences of kaumātua living with Arthritis

Tena koe

Ko Ngāti Porou raua ko Ngāti Kahungunu ōku iwi. Ko Sharon Awatere tōku ingoa. Tena koe e awhi nei i tenei kaupapa. He mahi tenei hei whakatutuki i taku tohu, ara, he PhD. I would like to invite you to participate in this study that will look at issues to do with your knowledge, attitudes and behaviours in relation to the management of Arthritis within the home. At the completion of this study I will be submitting the final report for consideration for my Doctoral thesis to complete my studies toward a PhD at Massey University. This study is funded by a grant from Health Research Council New Zealand.

Your participation is entirely voluntary and you may opt-out or withdraw yourself and any information that you have provided for this study by 1st February, 2015, without being disadvantaged in any way. There will be no need to offer an explanation. There will be no pressure to remain in the study if you wish to withdraw.

Who can take part?

- You are over the age of 55 years;
- Are of Māori ancestry and ethnicity ;
- based in Hawke's Bay;
- have been diagnosed with gout, osteoarthritis, or chronic musculo-skeletal joint disorder at some point in adulthood (not childhood);
-

What is the purpose of the study?

Recent research tells us that older Māori have really high rates of Arthritis like gout, wear and tear (osteoarthritis) and post-traumatic (after an injury) Arthritis. However, not much is known about the knowledge, everyday experiences and opinions of older Māori living in Hawke's Bay in relation to their home environment.. This research study aims to find out what older Māori think about Arthritis management, which is meaningful to you, your whānau, and the older Māori community. It is hoped that this information will help to promote wellness in older Māori Arthritis sufferers like yourself to see that health clinics and the health information provided by health professionals is appropriate and easily accessible for people like you.

How have I been chosen for this invitation?

I have talked with a wide range of people, kaumātua roopu, Māori liaison staff, health professionals, and other contacts in the local Māori community about this study. Together, we believe that you can provide important information to help others cope with pain. Also you will be given the opportunity to help by sharing your experiences with other Arthritis sufferers. Posters providing information about the study will be placed in the Medical Centre and kaumātua Whare - Te Taiwhenua O Heretaunga.

What will happen in this research?

Interview: If you are interested in taking part, I will arrange an interview that will take about an hour. We will sit down and discuss your views, what you think, and your opinions on issues related to your arthritis. There are no right or wrong answers; I'm interested in your honest opinions. ☺ The interview will be recorded so that I can listen to it again later and type it out. The findings from your interview will be used to inform a focus group. Only my supervisors and I will have access to the data

Focus group: You will also be invited to participate in a face-to-face hui focus group for up to 3 hours. You will be in a group with 6 to 9 other older Māori living with Arthritis. The purpose of the focus group will be to explore your ideas and opinions regarding living with Arthritis. There are no right or wrong answers to the focus group questions. That's why we will establish focus group "ground rules" before we commence our session. We want to hear many different viewpoints and would like to hear from everyone. We hope you can be honest even when your responses may not be in agreement with the rest of the group. In respect for each other, I ask that only one individual speak at a time in the group and that responses made by all participants be kept confidential.

You can choose whether or not to participate in the focus group and stop at any time. Although the focus group will be tape recorded, your responses will remain anonymous and no names will be mentioned in the report. If you understand this information and agree to participate fully under the conditions stated above, you will need to sign and complete a consent form. I'll bring this for you to sign at the time of the interview.

The date and time of the focus group will be advised at the time of your interview. These will be conducted at Te Awa Marae located on the grounds of Te Wahanga Hauora Māori Health, Hawke's Bay District Health Board and also Te Taiwhenua O Heretaunga. Please look for signs once you arrive directing you to the room where the focus group will be held.

What are the discomforts and risks?

As we chat, some of the information that you may share with me may be personal and of a sensitive nature. There is the possibility that you may become upset, or feel sad during the interview because of this. Remember - anything you tell me will remain totally confidential.

How will these discomforts and risks be alleviated?

If you feel sad or upset during the interview or focus group, you are welcome to take a break from the interview, or stop the interview altogether. If you find the interview raises issues of a personal nature and you decide that you would like some counselling, you can contact: Maree Leatherby at the Eastern Institute of Technology Health Counselling Clinic at Ph. 974 8922. Hours of opening are Monday – Friday 8am – 5pm. The clinic is located L B on Level 2, Gloucester St, Taradale. Counselling sessions are free.

If you find that your participation in the interview or focus group raises discomfort relating to your condition and/or the healthcare services you have received, you are welcome to take a break from the interview or focus group, or stop your participation altogether. If you decide that you would like to receive independent advocacy services, which can help people to ensure that their rights are respected, you can contact: Louise Grant or Judy Hylton at the Advocacy Network Services Trust. Phone 0800 555 050 or 06 835 1640 for the Hawke's Bay office. Hours of opening are Monday – Friday 8.30 - 5pm. The Trust is located at 1 Milton Road Napier 4110. Advocacy services are free.

What are the possible benefits of taking part?

Some possible benefits you might get from taking part in this research study include receiving information relating to arthritis and available resources. Additionally information from this study may benefit other people in society now or in the future.

How will my privacy be protected?

All information that may personally identify you, like your name, address, phone number etc., will remain confidential and private at all times. Only my Study Supervisors and I will have access to identifying data. Identifying data will not be included in any research reports or presentations, and you will not be named. No one else will know you have participated in the study, unless you choose to tell them. Your personal information will only be used for the purposes of this study.

How much time will I have to give to participating in this research?

The interview may range from between 45 minutes to 1 hour. You will be invited to participate in a hui focus group, this will take at least 3 hours.

What opportunity do I have to consider this invitation?

If you are interested in participating, then please contact me and I can tell you more about the study and you can ask me any questions you may have. If you agree, we will schedule a time for an interview for sometime that week, or the following week. You are welcome to change your mind and withdraw from the study at any time without penalty – just contact me (phone, email or text) to let me know.

How do I agree to participate in this research?

You can let me know – Sharon Awatere - that you would like to participate in the study by phone, text, or email (see below for details). You will also need to sign and complete a consent form. I'll bring this for you to sign at the time of the interview.

Will I receive feedback on the results of this research?

On the consent form you can tick if you would like a copy of the report. If you tick 'yes', then I will send you a copy of the report at the end of the study, probably September 2016. I will also ask you at the time of the interview if you would like to offer you a brief summary report and whether you prefer this to be by telephone, text, email or hard copy.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this study should be notified in the first instance to the Study Supervisors, Dr. Fiona Te Momo, F.TeMomo@massey.ac.nz, 09 414 0800 extn 43347, or Dr. Margaret Forster m.e.forster@massey.ac.nz, 06 3569099 extn 7091, or Dr. Bronwyn Campbell, b.campbell@massey.ac.nz, 06 3569099 extn 2954, or Dr. Mere Kēpa, m.kepa@auckland.ac.nz, 09 923 6574.

Whom do I contact for further information about this research?

Contact Details for student: Sharon Awatere, sharonawa74@gmail.com, 06 844 6678 or Mob 0211 836 894

Contact Details for Supervisors: Dr. Fiona Te Momo, Development, Research & Oral History Office, Te Pūtahi-a-Toi, Massey University, Auckland. Telephone: 09 414 0800 ext 43347 or F.TeMomo@massey.ac.nz

Committee Approval Statement

This study has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application __/__ (insert application number). If you have any concerns about the conduct of this research, please contact Associate-Professor Mark Henrickson, Acting Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43350, email humanethicsnorth@massey.ac.nz.

Appendix 7: Notice to enlist participants

Are you …
Māori
living with Arthritis
aged 55+ years?

Have you ever been diagnosed with Gout, Osteoarthritis, or joint problems after an accident?

Are you keen to volunteer to be interviewed for
an Arthritis osteoarthritis-management research study?
Then please read the following information,
then phone, email or text me …
and I will ring you back with more info.

Or pick up an info sheet from:
Te Wahanga Hauora Māori Health Services,
Te Tai Whenua o Heretaunga's Kaumātua Whare or Hauora Heretaunga

Contact: Sharon Awatere
sharonawa74@gmail.com
Mobile 0211 836 894 / 844 6678

Your time and contribution is valuable
and if you participate in an interview you will be given a koha.

Appendix 8: Consent Form

CONSENT FORM: Exploring the everyday experiences of kaumātua with osteoarthritis

	Please tick box
I have read and understand the information provided about this research in the Information Sheet.	☐
I have had an opportunity to ask questions and to have them answered.	☐
I consent to participating in an interview, which may take from 45 minutes to 1 hours or so. I understand that the interview will be audio-taped and transcribed.	☐
I consent to participating in a face-to-face hui focus group, which will take up to 3 hours. I will be in a group with other kaumātua living with Arthritis. The purpose of the focus group will be to explore ideas and opinions of kaumātua living with Arthritis. Focus group "ground rules" will be established before we commence our session to enhance communication and so that responses made by all participants are kept confidential. I agree that the identity of individual members in the group must not be disclosed to anyone else. Although I understand that the focus group will be tape recorded, my responses will remain anonymous.	☐
I understand that I may opt-out or withdraw myself and any information that I have provided for this study by 1st February, 2016, without being disadvantaged in any way. There will be no need to offer an explanation. There will be no pressure to remain in the study if I wish to withdraw.	☐
I understand that all relevant information including tapes and transcripts, or parts thereof, will be stored securely at Massey University for five years following publication of results, and will then be destroyed.	☐
I agree to take part in this research.	☐

I wish to receive a copy of a summary report arising from this study (please tick one):
No ☐ Yes ☐
Participant's Contact Details (if you would like a copy of the report – by email or hard copy):
Email, Postal Address: Participant's signature: Participant's name (please print): Date

Appendix 9: Letter requesting access to an institution/s

19th November, 2013

Aroha Karaitiana
Kaumātua Coordinator
Te Taiwhenua O Heretaunga
PO Box 718
Hastings 4156

Tena koe Aroha

Permission to Conduct Research Study

My name is Sharon Awatere, and I am a student at Massey University completing a doctoral research study on “Exploring the everday experiences of kaumātua with osteoarthritis”. A priority of this research will be to identify how kaumātua are managing their at home and around the community.

This research seeks to contribute to broader professional debates within the older Māori community and research communities (concerned with the healthcare of older people). Key informant interviews with kaumātua will be conducted at their home. Therefore, I am seeking your permission to attend your kaumātua roopu hui, to let them know about my study and ask them for their feedback.

I am also writing to your colleagues, Patrick LeGeyt and Nathan Harrington, in case they are able to make any referrals. Please find attached a copy of this thesis proposal, which includes copies of the Information Sheet and Consent forms to be used in the research process, a copy of the approval letter from the Massey University Human Ethics Committee is also attached.

This study is being supervised by Drs Fiona Te Momo, Margaret Forster and Bronwyn Campbell, Te Pūtahi-a-Toi, Massey University, Palmerston North and Dr Mere Kepa from Auckland University. Upon completion of the study, I undertake to provide Te Taiwhenua O Heretaunga with a bound copy of the research results and regular updates throughout the study. If you require any further information, please do not hesitate to contact me on Ph 844 6678 or Sharonawa74@gmail.com. Thank you for your time and consideration in this matter.

Yours sincerely,

Sharon Awatere

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