# Māori lived experience of osteoarthritis: a qualitative study guided by Kaupapa Māori principles

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## **ABSTRACT**

**INTRODUCTION:** Osteoarthritis adversely affects people's quality of life; however, the effects of osteoarthritis on Māori in New Zealand remain unknown.

AIM: To explore the Māori lived experience of osteoarthritis.

**METHODS:** A qualitative study guided by Kaupapa Māori principles. Māori adults (≥30 years) with clinical knee or hip osteoarthritis took part in semi-structured interviews that were recorded and transcribed. Thematic analysis and a model of Māori health (Te Whare Tapa Whā, outlining four dimensions of wellbeing (taha tinana- *physical*; taha hinengaro- *mental*; taha wairua- *spiritual*; and taha whānau- *family*)) were used to analyse data.

**RESULTS:** Seven Māori females aged 44–71 years participated. Physical manifestations of osteoarthritis, namely pain and limited daily activities, affected mental, spiritual and family wellbeing. Participants experienced whakamā (*shame*) and frustration. Cultural duties such as attending the marae were impeded, affecting spiritual wellbeing and cultural identity. Participants described drawing on the strength of their ancestors to cope with their impairments. Western medicine was commonly used, although side-effects were prominent and few participants had received information about the condition from health professionals. Both positive and negative experiences of health-care and treatments were reported.

**DISCUSSION:** Osteoarthritis inflicts a substantial burden on the physical, mental, spiritual and family wellbeing of Māori women. Primary care practitioners must consider spiritual and family wellbeing when providing care for Māori with osteoarthritis. Culturally sensitive education for patients and their whānau is needed.

**KEYWORDS:** Osteoarthritis; New Zealand; ethnic groups; primary health care; qualitative research.

#### Introduction

Osteoarthritis is prevalent, disabling and costly. In New Zealand, osteoarthritis affects  $\sim\!\!10\%$  (370,000) of the adult population and is the  $16^{th}$  highest contributor to disability. By 2020, the prevalence of arthritis is predicted to reach 17%

of the adult population.<sup>3</sup> The total cost of arthritis, of which osteoarthritis is the most common form, in New Zealand was an estimated NZ\$12.2 billion in 2018, including \$7.9 billion in loss of wellbeing and \$993 million in health sector costs.<sup>4</sup>

Osteoarthritis affects an estimated 37,000 (7.4%) Māori adults in New Zealand. Rates of osteoarthritis are slightly higher among Māori women (7.7%) than men (7.2%).¹ Māori undergoing total joint replacements for osteoarthritis are likely to be younger, have poorer general and mental health, have greater pre-operative comorbidities and have poorer post-operative outcomes than non- Māori. <sup>5,6</sup> Optimising primary care management for Māori with osteoarthritis to prevent or delay the need for surgery is critical, particularly considering that Māori encounter greater barriers to accessing primary care.¹

Persistent pain, poor function, depression and impaired work and social activities have been reported as common sequelae of osteoarthritis.<sup>79</sup> However, no research has yet investigated the experience of Māori living with osteoarthritis. A lack of knowledge regarding the effects of osteoarthritis on Māori and how the condition and current treatments are perceived by those affected, precludes development of culturally sensitive treatments and education. Therefore, the aim of this study was to explore the lived experience of Māori adults who have osteoarthritis in order to inform the development of appropriate management strategies.

#### Methods

#### Kaupapa Māori research principles

Principles of Kaupapa Māori were used to guide this research, placing Te Ao Māori at the centre of research and analysis.<sup>10</sup> The primary researcher (N. McGruer) and associate researcher (B. T. Ruakere) both acknowledge the significance of Kaupapa Māori as well as Te Ao Māori as a whole. Kaupapa Māori research recognises Māori values, customs and protocols as a core aspect of the research process.11 Kaupapa Māori research methodologies are underpinned by three main assumptions: (1) Māori have a distinctive world view and manner by which to organise knowledge in accordance with the distinctive nature of Māori knowledge; (2) acknowledging the relationship between Kaupapa Māori and other bodies and forms of knowledge; and (3) Māori experiences are at the centre of the research activity.12 The principle of collective philosophy

## WHAT GAP THIS FILLS

What is already known: Adults with osteoarthritis experience persistent pain, impaired physical function and reduced work and social activities.

What this study adds: This study investigates the lived experience of Māori with osteoarthritis. Osteoarthritis adversely affects the spiritual and family wellbeing of Māori women in addition to their physical and mental health.

• Culturally sensitive osteoarthritis education for Māori and their whānau is needed in primary care.

describes the collective vision, aspiration and purpose of Māori communities. This research has been designed and conducted with a view to inform the wider community about the effect of osteoarthritis on Māori, such that the knowledge generated by participants sharing their stories can be adopted by healthcare providers and applied to clinical practice.

The principle of whānau, or extended family structure, lies at the heart of Māori society. Whakapapa is paramount as it epitomises all the major components of Māori knowledge. As this research was done by Māori for Māori, tikanga Māori prevailed and the foundational relationship necessary when engaging Māori was established through the process of whanaungatanga. This process was adopted for all interviews. Manaakitanga and pono, tika and aroha were also expressed during engagement with participants.

The notion of rangatiratanga, or autonomy, is relevant to research in terms of allowing Māori to shape their own research processes. The principle governs the way that critical questions regarding the research are answered; for example, What research do we want to carry out?, Who is the research for?, What difference will the research make?, Who will carry out the research?, How do we want the research to be done?, Who will own the research? and Who will benefit? For this study, the research question, study design and acquisition of funding were developed by three academic researchers (J. N. Baldwin, B. T. Ruakere and P. J. Larmer), one of whom identifies as Māori (B. T. Ruakere). The primary researcher

(N. McGruer) who also identifies as Māori, joined the research team as a student intern and carried out recruitment and data collection. A Glossary of Māori terms used in this article is provided in Appendix 1.

## Study group

Participants were invited to participate in the study if they identified as Māori, were aged > 30 years

and had been diagnosed with knee or hip osteoarthritis by a health professional or who fulfilled the American College of Rheumatology criteria for clinical knee or hip osteoarthritis: knee, hip or groin pain; stiffness for > 30 min; knee crepitus; bony tenderness and enlargement of the knee; and no unusual, palpable warmth.<sup>13</sup> Participants were excluded from the study if they had: a significant injury in the previous 3 months, a history of total joint replacement, a medical

Appendix 1. Glossary of Māori	i terms
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Āhua hēmanawa	Āhua - sort of, kind of hēmanawa flustered, stressed		
Āhuatanga Māori	All things Māori related		
Hui	A meeting or gathering		
lwi	A tribe		
Hinengaro	Refers to the mind or psychological state		
Kaikaranga	Caller – usually a female who calls guests onto a marae		
Karakia	Prayer		
Kaupapa Māori	A Māori approach, topic, agenda or ideology incorporating all things Māori		
Kawakawa	A plant commonly used as rongoa		
Manaakitanga	Hospitality or kindness, to be hospitable		
Pakiwaitara	A story or story-telling		
Pono, tika, aroha	To be truthful, to be correct, to love		
Rongoa Māori	Traditional Māori medicine, natural remedy		
Tangihanga	Māori funeral, commonly held at a marae		
Te Ao Māori	Refers to all aspects related to the Māori world. Generally used to describe th Māori world view		
Tikanga	A term to describe correct procedures or customs used since the beginning of Māoridom. Although the world has evolved over time, tikanga has always remained the same and is still continuously upheld by Māori to this day		
Tinana	The physical body		
Tūpāpaku	Corpse or the body of a person who is deceased		
Tūpuna	Ancestors from whom one has descended		
Wairua	Spirit or soul of a person that exists beyond death		
Wānanga	University or tertiary education institution		
Whakamā	To be ashamed or embarrassed		
Whānau	Family group or extended family, sometimes also used to include people who do not have kinship ties		
Whānau pani	Bereaved relatives of one who has deceased		
Whakapapa	A term to describe ones genealogy or the ancestral line from which one has descended		
Whakawhanaungatanga	Used to describe connections/relationships established between Māori through korero (discussion) and whakapapa (genealogy)		
Wharenui	Traditional meeting house		

condition significantly affecting day-to-day function (e.g. fibromyalgia) or difficulty communicating verbally in English or Te Reo Māori. Purposeful sampling was used to recruit participants. Social media and advertisement flyers were used to recruit participants from the Tauranga and Auckland regions.

#### **Data collection**

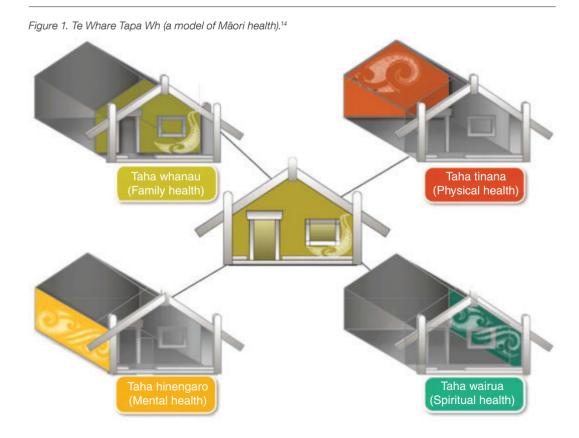
A semi-structured and open-ended question method was used to conduct interviews. Questions explored participants' personal history of osteoarthritis, their knowledge and experiences of the condition (including treatment) and the effects of the condition on their wellbeing. Interviews were conducted in Te Reo Māori, English or both, at participants' discretion.

## **Data analysis**

All interviews were recorded and transcribed by the primary researcher. Data were analysed using Te Whare Tapa Whā (a model of Māori health) as a guiding framework.14 Te Whare Tapa Whā uses the symbol of the wharenui (meeting house) as having four equal walls representing the four equal dimensions of Māori wellbeing: taha tinana or physical health; taha hinengaro or mental health; taha wairua or spiritual health; and taha whānau or family health (Fig. 1). Analysis of the transcripts was undertaken through their repeated readings, allowing the dominant themes to emerge. Themes were identified through kupu and phrases used by participants, as well as their stories. Each theme was considered in the context of Te Whare Tapa Whā and mapped to a particular dimension as applicable. Initial thematic analysis was carried out by the primary researcher. The associate researchers (JNB, BTR, PJL) reviewed the transcripts and confirmed the identified themes. Consensus was achieved by discussion.

## **Ethical approval**

This research was granted ethical approval by the Auckland University of Technology Ethics



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Committee (17/382). Written informed consent was provided by each participant.

#### Results

## Study group

There were seven participants. All were female (age range 44–71 years) and living in either the Auckland or Tauranga regions.

#### **Themes**

Nine key themes emerged from the data. These themes are described in the context of the four dimensions of Te Whare Tapa Whā and summarised in Table 1.

## Taha tinana

Two themes related to taha tinana: pain affecting daily activities and coping strategies.

Theme 1: Pain affecting daily activities

Pain was a strong and recurring theme. Participants described the unpleasantness of the pain as well as how it affected their function, imposing limitations on their daily activities.

'It's sore, it is sore. It's like 'Ohhh hell, I need to get up' and I struggle to get up.' [Participant #7] 'It is really difficult because you know I used to be really house proud. I'd be down on my [knees]

Table 1. Themes relating to the Māori lived experience of osteoarthritis linked to the four dimensions of Te Whare Tapa Whā (a model of Māori health)

Māori health dimension	Theme	Supporting quotes
Taha tinana	Pain affecting daily activities	'It's sore, it is sore. It's like 'Ohhh hell, I need to get up' and I struggle to get up.' [Participant #7]
	Coping strategies	'I might jump in the bath in the middle of the nightand then I'll be able to sleep another couple of hours' [Participant #2]
Taha hinengaro	Whakamā	'I used to walk with a stick. It's embarrassing. People are like 'You're too young to have a stick.' [Participant #2]
	Frustration	'I think that's probably one of the most frustrating things with this is that it actually, it's not reversible. You can't change it.' [Participant #1]
Taha wairua	Āhuatanga Māori	'I'm not even there [the marae]. I stopped going there because I can't even get down on the mattresses. I used to be very much part of it. I used to be the custodian and I gave it up.' [Participant #4]
	Whakapapa	'I think of my nanny all the time She's 87, she still lives with us and very rarely does she complain she must be really uncomfortable at times. So, I often think about her and kind of think that I've actually got no right to complain.' [Participant #1]
Taha whānau	Effects on whānau	'I feel really mean when I say things like that because they're trying to be helpfulyesterday the eldest one was here by herself for a while and I said to her 'nan gets grumpy sometimes ay?' and she goes 'yeah, you didn't used to get that grumpy nan.'' [Participant #3]
Additional themes	Experience of treatment	'I've got a lot of drugs to take and when I am getting close to the next lot I get anxiousI want to take them earlier than I should, but I try and hold off. I get a prickly sensation because then I know that I'm going to get pain in my joints.' [Participant #4]
	Need for education	'It would be great if there was better education around telling you how and what's going to happen to you over the next couple of years  They could've prepared me a lot better rather than 'you've got arthritis, there's nothing much that can be done about it.' [Participant #2]

scrubbing my floors - I just cannot do that now.' [Participant #2]

#### Theme 2: Coping strategies

All participants discussed various ways of coping with their physical pain. Strategies described by participants included heat and regular movement.

'... sometimes I'll go and have a shower in the middle of the night because I need the heat, it makes me feel better. Or I might jump in the bath in the middle of the night...then I'll be able to sleep another couple of hours...' [Participant #2]

#### Taha hinengaro

Two themes relating to taha hinengaro emerged from the data: whakamā (a term to describe being ashamed or embarrassed) and frustration.

#### Theme 3: Whakamā

Participants had a sense of whakamā regarding their physical limitations, in particular the younger women. Whakamā was also evident during interactions with health professionals, as some participants told their doctor they understood what was being communicated to them despite having little or no understanding.

'...When you are the whānau pani and you can't get up on your knees, it's not good. Then, if I've been sitting down in the wharenui for even an hour, I have to whisper around and ask someone to 'give me a hand up please."

[Participant #5]

#### **Theme 4: Frustration**

All participants experienced some level of frustration because of their osteoarthritis. The frustration was linked to how the condition has affected their daily lives, as well as feeling as though little can be done.

'It just felt like you were so disempowered because you couldn't do anything about it. You really just have to live with it or find things that help relieve the pain.' [Participant #2]

#### Taha wairua

The physical and mental manifestations of osteoarthritis carried over to have an effect on participants' spiritual wellbeing. Two themes relating to taha wairua were identified: āhuatanga Māori and whakapapa.

## Theme 5: Āhuatanga Māori

Āhuatanga Māori relates to aspects, characteristics or attributes and traits of Māoritanga. All participants described, some with deep emotion, a degree of effect on āhuatanga Māori. In some cases, pain precluded participants from carrying out required tasks at the marae, such as kaikaranga, custodian and kitchen duties. Some participants had stopped attending their marae as a consequence.

'... when you go to tangi you can't get down to the tūpāpaku and then when you go to wānanga and things you don't want to sleep overnight because you can't get in and out of the mattresses.' [Participant #3]

The importance of upholding tikanga, a significant and unique aspect of Te Ao Māori, was also raised as an essential element of āhuatanga Māori. For example, one participant described how she would not attend hui or tangihanga in other regions so as not to breach tikanga because her pain precluded her from getting down onto the floor (a custom for women at marae in some regions).

'I'm very careful where I go, like I won't go outside of Tauranga. As women, we can sit at the back of the men here. Whereas a lot of other places you really can't. You [women] really got to go and sit down by the coffin.' [Participant #2]

## Theme 6: Whakapapa

Whakapapa refers to the ancestral lineage from which one has descended. Having the knowledge to recite one's own whakapapa is an important aspect of Te Ao Māori. Participants described how certain characteristics of their ancestors, in particular stoicism, influenced how they managed their own pain and physical limitations.

'I come from a long line of strong women. Yeah, I think that has everything to do with it, everything to do with the way I was brought up... The women run everything in my family, not the men. We just put up with it.' [Participant #5]

#### Taha whānau

#### Theme 7: Effects on whānau

Participants discussed how osteoarthritis had an effect on their whānau (family). Participation in certain activities with other members of their whānau was limited, and relationships were affected by the physical impairments and mental sequelae of osteoarthritis. Whānau also emerged as an important source of support and strength.

'My son, he wanted to give up work to look after me. You know they all wanted to come and look after me because they just didn't want to see their mother you know, because I was crying all the time.' [Participant #4]

#### **Additional themes**

Two additional themes, the experience of treatment and need for education, emerged from the data.

#### Theme 8: Experience of treatment

Participants told of mixed experiences of treatment. Five participants talked about using Western medicine for pain relief, although often mentioning adverse effects. Some had stopped taking medication altogether because of side-effects. Three of the seven participants mentioned using rongoa Māori (traditional Māori healing practices) as treatment. In some cases, participants reported being offered limited options for treatment and were dissatisfied with their interactions with health professionals, although others spoke positively about the health professionals they had encountered.

'I've got a lot of drugs to take and when I am getting close to the next lot I get anxious, I start getting ahua hēmanawa [sort of flustered] and I want to take them earlier than I should, but I try and hold off. I get a prickly sensation because then I know that I'm going to get pain in my joints. Yeah so,

it's an awful experience, and when I started taking drugs for a year I couldn't think straight.' [Participant #4]

'I actually did go and see a specialist after those x-rays just 'cause my physio was really concerned. And he basically just told me to go away and wait until I couldn't walk at all, he said I'm too young. So, I'm like, well, there was no other option given to me, which was a little bit frustrating.' [Participant #1]

#### Theme 9: Need for education

When participants were asked about their knowledge of osteoarthritis, most participants stated they had been given only a little, if any, information about the condition, although some reported doing their own online research. Almost all participants felt that more education about the condition and available treatments was needed.

'It would be great if there was better education around telling you how and what's going to happen to you over the next couple of years. You know it's going to progressively get worse. You're going to have to learn how to manage it. They could've prepared me a lot better rather than 'you've got arthritis, there's nothing much that can be done about it'.' [Participant #2]

#### Discussion

This study investigated the lived experience of Māori women with osteoarthritis. A Kaupapa Māori philosophy was applied and tikanga was upheld throughout. Themes relating to all four dimensions of Māori wellbeing depicted in Te Whare Tapa Whā were observed, demonstrating the wide-ranging effects of osteoarthritis on Māori women.

The centrality of spiritual wellbeing within the Māori outlook on life emerged clearly in our data through the themes of āhuatanga Māori and whakapapa. These themes are unique in that they address cultural identity, a significant aspect of being Māori. Critically, women in this study described how their osteoarthritis affected their ability to participate in activities at the marae, having serious implications for their spiritual wellbeing. Provision of culturally sensitive

information about the causes and management of osteoarthritis to marae and iwi would enable Māori to implement strategies to better support their own people while also maintaining the customs and protocols of their marae.

Our findings regarding the physical and mental effects of osteoarthritis are in agreement with studies investigating non-Māori populations. High levels of pain limiting daily activities have been described, as well as the mental sequelae of shame, depression and frustration. 7,9 Whakamā has also been reported by Māori with other chronic conditions such as gout and chronic kidney disease. When faced with physical disability or pain, some Māori overcome feelings of weakness by either hiding their condition or by avoiding situations. 15,17 This experience of whakamā has been attributed to the stigma associated with these chronic conditions, given their association with lifestyle behaviours, in addition to reports that health professionals and whānau place the blame on people with chronic conditions. 16 Our results in the context of the wider literature demonstrate that support is needed for Māori living with chronic conditions such as osteoarthritis.

In this study, few participants had been provided with information regarding the causes of or management strategies for osteoarthritis. Most women in our study discussed using some form of pharmacological management. This was often the sole treatment and side-effects were common. The use of rongoa Māori highlights the role of alternative medicine, particularly when Western interventions are not available or cause harm. Few participants had experienced nonpharmacological conservative treatments such as education, exercise or weight loss. This is despite strong evidence regarding the effectiveness of these modalities,18 demonstrating the large evidence-to-practice gap that exists in New Zealand.19 Optimising osteoarthritis management for Māori would involve delivery of culturally appropriate and evidence-informed conservative interventions such as exercise and education, 18 with support from a multidisciplinary team.

Importantly, health-care professionals may need to upskill their cultural knowledge, as awareness and sensitivity to Māori values and concepts are

the prerequisites to the provision of culturally safe practice for Māori women.<sup>20</sup> Ultimately, any future development of a New Zealand osteoarthritis Model of Care, which would provide a policy framework to implement best-practice health care,<sup>21</sup> must therefore take into account provision of culturally sensitive interventions for Māori. The Māori health model, Te Pae Mahutonga, which identifies four key tasks of health promotion (mauriora – cultural identity, waiora – physical environment, toiora – healthy lifestyles and te oranga – participation in society),<sup>22</sup> is another model that could guide development of a system-wide Model of Care for osteoarthritis.

The importance of whānau in the context of health and disability was highlighted in our study. Māori have always done things collectively: 'The Māori did not think of himself or do anything for his own gain. He thought only of his people, and was absorbed in his whānau, just as the whānau was absorbed in the hapu, and the hapu in the iwi'.<sup>23</sup> When a health condition affects the wellbeing of one individual, there are flow-on effects to the whānau. Furthermore, whānau provide an essential support structure, as we also observed.<sup>15,16,24</sup> Accordingly, primary care professionals can better support Māori with osteoarthritis by involving whānau when planning and administering treatments.

## **Limitations and strengths**

One limitation of this study is its small sample size. Despite our intended use of purposive sampling to capture an equal proportion of males and females, only female participants residing in urban areas agreed to take part. Caution is therefore needed in translating the findings to the broader Māori population. A key strength of this study was that Kaupapa Māori principles were applied. The use of practices such as whanaungatanga facilitated the development of a reciprocal relationship between the primary researcher and participants. This ensured that tikanga was upheld and that individual autonomy was protected. The supportive environment that these practices created facilitated the sharing of stories by participants, resulting in generation of new knowledge that will be used to advance health outcomes for Māori.

The model we used to guide our interpretation of data, Te Whare Tapa Whā, is one of many models of Māori health. While this model captured the physical, mental, family and spiritual effects of osteoarthritis described by our participants, the themes 'Experience of treatment' and 'Need for education' did not fit. These themes could be considered in the context of Te Pae Mahutonga (a health promotion model),<sup>22</sup> particularly with the relevance of patient education to Te Mana Whakahaere (autonomy). Another Māori health model, Te Wheke, uses the symbol of an octopus to define family health, with the head as te whānau and the tentacles as eight dimensions of health.25 The themes identified in this study can also be mapped to this model, and specifically the theme 'Whakapapa' aligns strongly with the dimension 'Hā a koro ma, a kui ma' (breath of life from forebearers).

#### **Conclusions**

Osteoarthritis affects the physical, mental, spiritual and family wellbeing of Māori women. The pain and physical limitations caused by the condition generate feelings of whakamā (shame) and frustration and affect relationships with their whānau. Osteoarthritis also has effects on spiritual wellbeing and cultural identity of women with the condition. Lack of access to information about osteoarthritis and available treatments indicates a need for provision of culturally safe, evidence-informed primary care.

# **Competing interests**

Peter Larmer is currently serving as President of Arthritis New Zealand. There are no financial competing interest for any of the listed authors.

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