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

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## Abstract

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

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## Mihimihi

Ngā mihi mahana ki a koutou

Ko Te Ūpoko o Tahumaata te māunga

Ko Ōkana te awa

Ko Uruao rāua ko Tākitimu ōku waka

Ko Tukuwaha tōku whaea tūpuna

Ko Kai Tahu tōku iwi

Ko Kāti Makō tōku hapū

Ko Wairewa tōku marae

Ko Te Awanga rāua ko Heretaunga ōku papa kāinga

No Te Whanganui-ā-Tara tōku kāinga ināiane

Ko Zoe McGavock taku ingoa

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



## Overview

Due to its subjective nature, pain can be a complex and difficult health issue to address; pain and pain experiences need to be better understood in order for improvements to be made in how it is responded to and managed. This need becomes even more pertinent in light of extensive evidence suggesting that culture plays a role in experiences of pain, including differences in how pain is expressed, how socially acceptable it is to express pain, pain thresholds and tolerance, and of particular concern, disparities in treatment and care for individuals experiencing pain. Although there is some international research exploring cultural issues in pain (mostly from the USA), very little research of this kind has been conducted in Aotearoa (New Zealand<sup>1</sup>), where significant health disparities exist between Māori (the indigenous people) and non-Māori, sometimes referred to as Pākehā (New Zealanders of European descent). Furthermore, what little research there is on Māori and pain is inconsistent, perhaps due to the diverse range of methodologies used and types of pain that have been covered. What is also immediately apparent is the lack of research with a specific focus on the chronic pain experiences of Māori in Aotearoa.

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

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

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

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

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

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