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

A thesis presented in partial fulfilment of the requirements for the degree of
Masters of Science
in
Health Psychology
at Massey University, Wellington, New Zealand

Zoe Caroline McGavock

2011
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.
Acknowledgements

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

To the seven participants: ngā mihi mahana ki a koutou, tēnā rāwā atu koutou (warm greetings to all of you, and many thanks). It was an honour and a privilege to talk to you all about your experiences regarding your chronic pain, and lots of other aspects of your lives. I totally appreciated the openness, genuineness, humour and honesty through which you shared your own personal journeys.

To my supervisors Helen Moewaka Barnes and Antonia Lyons: first of all, thank you both for agreeing to supervise this research, even though chronic pain is not your usual area of interest. Your support this year has been fantastic and truly appreciated. Helen thank you for sharing your knowledge of Kaupapa Māori research and your useful comments and korero about my work, and Antonia thank you for being my supervisor ‘on the ground’ in Wellington and for your eye for detail.

Thanks to the Health Research Council of New Zealand who granted me a summer studentship in Māori health, which ultimately led to the identification of this thesis topic. Thanks also to Tim McCreanor, who along with Helen, supervised the studentship and encouraged me to pursue it further in my thesis.

There were many people (including family, friends, colleagues, health professionals and strangers) who not only showed an interest in this topic, but also went to great lengths to find participants for me and connect me to useful contacts; your encouragement and help was so heartening for me throughout the year.

Thanks to my wonderful friends in health psychology and beyond, who provided me with encouragement, advice, a sounding-board for ideas, a break from my brain, and delicious baking and coffee!

I’d also like to thank my family for just being there, and acknowledge the passing of my Nana, who played such a big role in my life.

Finally, thanks to Jack, who has saved me repeatedly from the perils of Microsoft Word, mastered the art of proof reading, and continues to help me through the tougher moments of living with chronic pain.
Table of Contents

Abstract ................................................................................................................................. ii
Acknowledgements .............................................................................................................. iii
Mihimihi .............................................................................................................................. vii
Overview ............................................................................................................................ viii
Chapter 1: Chronic Pain ..................................................................................................... 1
  Definitions of pain ......................................................................................................... 1
  Epidemiology ................................................................................................................. 2
  Significance and complexity of chronic pain as a health issue ...................................... 3
  Current pain theories ...................................................................................................... 5
Chapter 2: Pain, Culture and Ethnicity .............................................................................. 8
  Defining race, ethnicity and culture ............................................................................... 8
  Ethnic/cultural differences in pain ................................................................................. 8
  Ethnicity/culture and treatment of pain ........................................................................ 11
Chapter 3: The Aotearoa/New Zealand Context – Māori and Pain ................................. 13
  Ethnic identity in Aotearoa .......................................................................................... 13
  Colonisation and Te Tiriti o Waitangi ......................................................................... 13
  Health disparities .......................................................................................................... 14
  Māori views on health and healing .............................................................................. 15
Māori and Pain .................................................................................................................... 17
  A note on publications and review methods .............................................................. 17
  Quantitative research .................................................................................................... 18
  Qualitative research ...................................................................................................... 24
  Summary and comparison to the international literature ............................................. 27
Chapter 4: Lived Experiences of Chronic Pain – The Present Research ......................... 30
  The importance of understanding the lived experience of Māori with chronic pain ...30
  Exploring the lived experience of chronic pain .......................................................... 33
Ethnic and cultural influences on the lived experience of chronic pain .............................. 36
Aim and Research Questions ........................................................................................................ 40
Chapter 5: Methodology and Research Methods .................................................................... 41
  Kaupapa Māori research ........................................................................................................... 41
  Interpretative Phenomenological Analysis ............................................................................ 46
Research Methods .................................................................................................................... 51
  Ethics ...................................................................................................................................... 51
  Participants ............................................................................................................................. 51
  Materials ............................................................................................................................... 53
  Interview processes ............................................................................................................... 54
  Transcription, review and feedback ...................................................................................... 56
  Analysis .................................................................................................................................. 57
Chapter 6: Results and Discussion .......................................................................................... 59
  Results ................................................................................................................................. 59
  IPA Results ........................................................................................................................... 59
  A Life Transformed by the Experience of Chronic Pain ....................................................... 61
    Summary .............................................................................................................................. 76
  Experiences of Chronic Pain as Māori ................................................................................ 76
    Summary .............................................................................................................................. 89
  Evaluating Treatment Experiences ....................................................................................... 90
    Summary .............................................................................................................................. 97
  Negative Perceptions, Negative Experiences ..................................................................... 97
    Summary .............................................................................................................................. 103
  The Relationship between the Four Superordinate Themes ............................................. 104
Chapter 7: Reflexivity, Implications, Research Considerations, and Conclusion .................. 107
  Reflexivity ............................................................................................................................ 107
  Implications and recommendations ...................................................................................... 109
List of Tables

Table 1: Participant Gender, Age, Type of Pain, Duration, Average Pain Rating, and Additional Health Issues ..................................................................................................................52
Table 2: The Four Superordinate Themes and their Thirteen Subthemes .............................................................................................................................60

List of Figures

Figure 1: A conceptual model of Māori experiences of chronic pain - the 'pain-full world' ..................................................................................................................104
Figure 2: Example - Delia's 'pain-full world' .................................................................................................................................105
Figure 3: Example - Jake's 'pain-full world' .................................................................................................................................106
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 ināianeī

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\(^1\)), where significant health disparities exist between Māori (the indigenous people) and non-Māori, sometimes referred to as Pākehā (New Zealanders of European descent). Furthermore, what little research there is on Māori and pain is inconsistent, perhaps due to the diverse range of methodologies used and types of pain that have been covered. What is also immediately apparent is the lack of research with a specific focus on the chronic pain experiences of Māori in Aotearoa.

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

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

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

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

\(^1\) Translates literally as ‘land of the long white cloud’; I respectfully note that not all iwi accept this as the Māori name for New Zealand. Also note that Māori words are translated within the main text on their first use, and there is a glossary of Māori words to refer to on p. 124.
in the significant health disparities that exist between Māori and non-Māori. Māori perspectives of health and healing are also discussed. I then review the extant literature on Māori and pain. Chapter 4 focuses on the importance of conducting research with Māori about their experiences of chronic pain, research on the lived experience of chronic pain in both majority and minority populations, and the aims and research questions for the current research. In Chapter 5 I describe the methodology, including the Kaupapa Māori approach (Māori agenda/philosophy/rationale), Interpretative Phenomenological Analysis (IPA), and the research methods. Chapter 6 presents the analysis and results, which consisted of four superordinate themes and thirteen subthemes. These were ‘A life transformed by the experience of chronic pain’ (four subthemes: Causes and sources of pain; Pain embodied – living through the painful body; Restrictions imposed by the painful body: Change and identity; It’s not just physical), ‘Experiences of chronic pain as Māori’ (four subthemes: Māori identity and culture: Embedded in experiences of chronic pain; Experiences of rongoā Māori (general name for traditional remedies) and complementary/alternative treatment; Racism in the medical system; Restricted access to the medical system), ‘Evaluating treatment experiences’ (three subthemes: The decision to seek treatment; The medical system: Gatekeeper to treatment; The search for relief: Medication and other substances), and ‘Negative perceptions, negative experiences’ (two subthemes: Living with chronic pain: Stigma and isolation; Stoicism: I don’t want to be a burden). The conceptual relationship between the four superordinate themes is also discussed. Finally, in Chapter 7, reflexivity, implications, and research considerations are discussed, and conclusions are drawn.