

# **Te Ao Māori: Māori nurses’ perspectives on Assisted Dying and the Te Ao Māori cultural considerations required to guide nursing practice**

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## Abstract

The ultimate purpose of this thesis and its research is to contribute to and participate in the end-of-life care discussion in Aotearoa New Zealand and to validate Māori nursing as an authentic research community with its own unique voice, which deserves to be heard. In 2020, end-of-life care in Aotearoa New Zealand took on an added dimension with a majority of New Zealanders voting 'yes' to support the End-of-life Choices Act 2019 coming into force in 2021. For Māori nurses working in end-of-life with Māori patients and their whānau (family group), the legalisation of assisted dying under certain circumstances adds a further layer of complication to what is already a complex environment. This thesis explores, through kaupapa Māori (Māori ideology) research principles, the underlying, fundamental concepts that guided ten Māori nurses working in end-of-life care settings. These concepts of whanaungatanga (establishing connections), manaakitanga (generosity and care for others), and kaitiakitanga (guardianship) are lived and breathed by these Māori nurses along with the guiding ethical principles of tika (the right way), pono (honesty) and aroha (generosity of spirit). Taken together, these concepts and guiding principles shaped how these Māori nurses cared for their Māori patients and whānau, and for themselves in the face of long-standing systemic and institutional barriers to equitable Māori health care. These barriers are perpetuated by inequity, poverty and a lack of access to culturally appropriate services for Māori patients and their whānau when at the end-of-life. For Māori nurses working in end-of-life care settings, endemic discrimination, racism and marginalisation also meant their unique contributions and connections with their community have been devalued and ignored for too long by the Western medical model they work within. The qualitative research demonstrates the resilience and practicality with which these Māori nurses navigate the system they work within, and the primacy of caring for and advocating for their Māori patients and whānau. Crucially, the research also makes the case across the whole health sector, as well as in end-of-life care, for comprehensive work to address racism and bias, and the marginalisation of Māori nurses' voices and experiences. Better education and knowledge about the Māori worldview on death and dying for healthcare professionals can only lead to better care for Māori patients and whānau. Similarly, better funding of and access to appropriate services for Māori patients and whānau, and better support for Māori nurses working in end-of-life care will ensure that value, resourcing and space will exist in the health system for Māori, both carers and patients and their whānau.

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I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed: 

Date: 2/2/21

## Glossary

Au	me, or I
Ahi-ka-roa	to keep the fires burning, establishes continued occupation of land
Aroha	generosity of spirit, show sincerity and mutual respect
Aroha ki te tāngata	a respect for people
Awa	river
Hapū	kinship group
Heke	to descend
Hine-ahu-one	the first woman
Hine-nui-te-pō	goddess of death and guardian of the underworld
Hine-tītama	the dawn maiden, who became Hine-nui-te-pō
Huawhenua	vegetables
Iwi	extended kinship group
Kai	food
Kaimoana	food from the sea
Kaitiakitanga	guardianship
Kaiwhakahaere	leader of Te Rūnanga o Aotearoa
Kanohi-ki-te-kanohi	face to face
Karakia	prayer
Karanga	call
Kaumātua	elders (plural), not gender specific
Kaupapa	subject, theme, philosophy
Kaupapa Māori	Māori ideology
Kaupapa whakahirahira	important issue or topic
Kawa	ceremonial rituals, protocol
Kia tūpato	to be cautious
Kina	sea urchin
Koe	you
Koha	offering or gift
Koha putea	gift of money
Kōrero	story, discussion
Mahi	work



Mahi whakahirahira	important work
Mana	prestige
Mana tāngata	status of the person
Mana wāhine	prestige of Māori women
Manaaki/Manaakitanga	generosity and care for others
Māori	indigenous people of Aotearoa New Zealand
Marae	Māori gathering place
Maramataka	traditional Māori lunar calendar
Maunga	mountain
Mauri	a life-force and a spirit
Mihi	greeting
Mokopuna	grandchild, descendant
Ngā mihi ki a koutou katoa	greetings to everyone
Ōritetanga	equity
Papatūānuku	earth mother
Pono	honesty
Puha	sour thistle
Rangatira	chief (male or female), leader
Rangatiratanga	sovereignty
Rangimarie	peace
Raruraru	troubles or disagreements
Rohe	district
Tāngata whenua	local indigenous people of Aotearoa
Tapu	sacred, prohibited, restriction
Tapuhi kaitiaki	Māori nurse
Tapuhi kaitiaki o Āpōpō	future Māori nurse leaders
Tautoko	support
Te ao hurihuri	the changing world
Te ao Māori	Māori worldview
Te ao wairua	Māori spiritual word
Te Ika a Māui	North Island
Te Poari o Te Rūnanga	Māori governance board representatives of Te Rūnanga o Aotearoa

Te Rūnanga o Aotearoa	Māori health professional members of the New Zealand Nurses Organisation
Te Taihū	Northern South Island and the name for the group of tribes living there.
Te Tiriti o Waitangi	foundation treaty document for Aotearoa New Zealand
Te Waipounamu	South Island
Te whare tapa whā	the four-sided house Māori model of health
Tika	the right way
Tikanga	custom or practices, or protocol
Tino Rangatiratanga	self determination
Tohu	a sign or symbol
Tumu whakarae	deputy leader of Te Rūnanga o Aotearoa
Tūpuna	ancestor
Tūpuna wāhine	female ancestors
Wāhine	women
Wāhine toa	women of strength and bravery
Waiata	song
Wairua	spirituality defined by Māori worldview
Whaea	women of mother's age
Whaea tapuhi kaitiaki	Māori nursing leaders
Whakaaro	idea, thought
Whakapapa	genealogical ties
Whakatauaakī	traditional proverbial saying
Whakawhanaungatanga	process of establishing relationships
Whakawhiti kōrero	discussion
Whānau whanui	extended family
Whānau	family group
Whanaungatanga	establishing connections
Whenua	land, country, earth, placenta, afterbirth

## Preface

Tūtawa mai i runga

Tūtawa mai i raro

Tūtawa mai i roto

Tūtawa mai i waho

Kia tau ai

Te Mauri tū, te Mauri ora ki te katoa

Hāumi e, hui e, tāiki e!

*Ehara taku toa i te toa takitahi, engari he toa takitini*

My strength is not mine alone, but that of the many (Mead & Grove, 2003)

### **Ko wai au?**

*Ko Ranginui kei runga*

*Ko Papatūānuku kei raro*

*Ko ngā tāngata kei Wanganui*

*Tihei mauri ora!*

Ko Parapara tōku maunga

Ko Pariwhakaoho tōku awa

Ko Waikoropupū tōku puna waiora

Ko ngā uri o Ngāti Tama ki te Tau Ihu rāua Ko Te Ātiawa

He tapuhi kaitiaki āhau

The concepts of whanaungatanga, manaakitanga, kaitiakitanga are central to Māori nurses' identity, and are embedded in kaupapa Māori principles. These principles have driven my worldview along with the ethical principles of tika, pono, and aroha. Growing up in a bicultural household (Māori and European mother, New Zealand-born Scottish and English father), and in the Nelson region that was acknowledged as one of the first to be colonised by the New Zealand Company's Edward Gibbon Wakefield in 1841 (Te Papa Tongarewa National Museum of New Zealand, 2020). Self-identifying as Māori but educated in a Western worldview in the 1980s, in an area with a low population of Māori. It was not until I lost my beloved mother too early to Hine-nui-te-pō (goddess of death and guardian of the underworld) that I started my tertiary learning in te ao Māori

(Māori worldview), hoping in part to recreate that which I had lost. In turn, this journey opened my eyes to other possibilities to learn skills and a love of research, analysing and writing.

The whakataauakī (traditional proverbial saying) below has always guided my life and has a deeper meaning for me as it was my mother's favourite whakataauakī, and was a testimony to the way she lived her life and her expectations of her whānau, her friends and others.

*Whaia te iti kahurangi, me tuoho koe he maunga teitei,*

Pursue, that which you cherish the most, if you need to bow your head let it be to a lofty mountain (Mead & Groves, 2003).

The whakataauakī meaning also reflects determination and persistence and not letting obstacles stop you from reaching your goals, and what is required to undertake, pursue and complete he kaupapa whakahirahira, he kaupapa nunui tera! (Moeke-Maxwell et al., 2019b).

As a policy advisor Māori, my role in this research is as the primary researcher to ensure that the participants' experiences and meanings are captured and documented. Achieving this also goes hand-in-hand with ensuring that tikanga (custom or protocol) practices are adhered to and that my actions reflect my whakaaro (thought) Māori underpinned by Māori values and beliefs.

As a Māori researcher, it was extremely important to use a Kaupapa Māori research methodology. Thereby, honouring the wāhine toa (women of strength and bravery) who contributed to this research and also acknowledging the whaea tapuhi kaitiaki (Māori nursing leaders), who have gone before us, and who have endured many years of structural barriers to have led the way in Māori nursing — ngā mihi ki a koutou katoa (greetings to everyone). Their role has contributed to my research and will ensure that their resilience and mana (prestige) as Māori wāhine (Māori women), and Māori nurses, are upheld and celebrated.

From a Māori perspective, the researcher and participants share whakapapa (genealogical ties), as wāhine Māori (Māori women) and as members of a community of Māori nurses, with a joint understanding, knowledge and tikanga of Māori nurses, a nursing worldview and the wider health system. Māori nurses have had to face underlying issues of discrimination, racism and marginalisation, including years of being undervalued for their unique work demonstrating being both culturally and clinically competent to work with the community they serve (Parahi, 2018).

## Inspiration

I draw inspiration from Pihama's (2001) inspirational description of mana wāhine below that validates why I am writing this thesis. This validation strengthens my argument and my research question. My thesis creates space to challenge and change Western health system processes, and actively acknowledge and engage Māori nurses' worldview and resilience.

"It is important that Māori women take control of spaces where our stories can be told. This includes theoretical space. Our voices have been silenced for too long. The silencing of Māori women's voices has meant the silencing of our theories, worldviews. It has meant that Māori women's stories are able to then be defined as 'myths', and therefore some figment of the cultural imagination. The marginalisation of mana wāhine has meant that Māori women are constantly having to try and 'find' ourselves in the images created by the colonisers. It is also necessary in the process to look to the work that our tūpuna wāhine [female ancestors] have already undertaken in laying a foundation for ensuring Māori women are active in all areas that pertain to our wellbeing" (Pihama, 2001, p.240).

Pihama's kōrero encapsulates the silence of Māori women's voices and sends a silent karanga (call) to my wairua (spirituality defined by Māori worldview):

*Maranga mai, whakaoho ki te kaupapa whakahirahira o ngā tapuhi kaitiaki wairua, whakarongo mai ki te kotahitanga ko te mauri, ko te kaha o ia mana wāhine, o ia mana wāhine. Whakatau ki te rangimarie, Tihei mauri ora!*

Awaken your spirit to the importance of Māori nurses' kōrero, listen to the collective strength of their kōrero, come together in peace in the essence and spirit of Māori women.

My reason for starting this research was to ensure that Māori nurses have their voices and their perspectives heard. I felt I was in a privileged position, trusted and able to write from the worldview of a Māori, tapuhi (nurse). Secondly, it does not matter whether you are for or against assisted dying, or undecided, that is not the kaupapa of this research. Rangimarie (peace) and goodwill together with whakawhanaungatanga (process of establishing relationships) drove the sharing of kōrero (stories). My principle action was to nurture the voices of Māori nurses to be heard on a topic, because all too often they get left out and all too often their voices are not considered. My aim is also to ensure Māori views on cultural guidelines are documented to promote practice changes in end-of-life cares.

# Acknowledgements

## Mihi to participants

As a Māori nurse I feel privileged, committed to this research, and with an understanding of the community involved. I wish to firstly mihi (greet) and thank all the participants for sharing your heartfelt stories, your whakaaro and your manaaki (generosity and care of others) with me. Thank you for the valuable kōrero about Māori death, stages of death, and Māori worldview that I have gathered and present to you all to consider.

Often researchers do not have the luxury of engaging or having access in a culturally appropriate and respectful way to have whakawhiti kōrero (discussion) with fantastic Māori nurses about health topics. It was therefore such a positive experience for me to have the opportunity to have access to Māori nurses who wanted to engage in and talk about assisted dying.

It is often difficult to describe our work with death and dying, and the stages of grief and processes of our patients' and their whānau journey to te ao wairua (Māori spiritual world). For most, it's a foreign language talking about the signs of death, the different stages and yet there is comfort in supporting patients and whānau through this process ensuring that there is nothing to be fearful of and that this is all part of living.

## Mihi te whaea tapuhi kaitiaki

I wanted to start this section by reflecting on the *words of* an inspirational leader, kaitiaki, carer, scholar, and legendary wāhine toa, Te Puea Herangi:

*Te ohonga ake i ōku moemoeā, ko te puawaitanga o te whakaaro*

I awake from my dreams; and they blossom, into ideas, they are realised (Mead & Grove, 2003).

I pay homage to my tūpuna whaea, ngā tapuhi kaitiaki o Aotearoa, me ngā tapuhi kaitiaki o āpōpō (future Māori nursing leaders) hoki. Ngā mihi aroha ki te Kaiwhakahaere (leader of Te Rūnanga o Aotearoa, NZNO), Kerri Nuku, Tumu whakarae (deputy leader of Te Rūnanga o Aotearoa), Titihuia Pakeho, Te Poari o Te Rūnanga o Aotearoa (Te Poari), me ngā kaumātua (elders) hoki. Whether you are kei te tika, kei te kaore ranei ki tēnei kaupapa whakahirahira (important issue), for or against the kaupapa of assisted dying, the most important thing to me is validating your voices and your perspectives as part of this journey and thesis. We all agree that we need Māori-led solutions informed by Māori knowledge to guide our future health and wellbeing. Achieving this is the challenge that collectively we share.

## **Mihi to ngā tapuhi kaitiaki o āpōpō**

Ka aroha ki a koutou, ngā tapuhi kaitiaki o āpōpō claim the space, it is your heritage and your right, don't let anyone tell you that Māori nurses do not have a voice or a perspective to share. Be brave and courageous, mana wāhine challenge the narrative and the patriarchy, question, be curious and ask questions and demand answers.

Special acknowledgement to my supervisor, Professor Denise Wilson. Thank you for your manaakitanga, your guiding and patient kaitiakitanga over more than my thesis, mihi aroha ki a koe e rangatira (leader).

## **Whānau whanui**

To my whānau, both in this world and those who live on the other side of the veil of te ao wairua, I draw inspiration from you, and think of you all every day in my mahi (work), mihi mai mihi atu. The whakatauaikī *Ko te mauri, he mea huna ki te moana, the life force is hidden in the sea, powerful aspects of life are hidden in plain sight*, reminds me of your courage and bravery to heke (to descend) to Te Taihū (Northern South Island), and the sacrifices, achievements to remain ahi-ka-roa (to keep the fires burning) in Te Taihū. Whakatau ki te rangimarie! To dear dad and granddad who we lost during the writing of this thesis, I acknowledge your interest in the kaupapa (subject), and your support and encouragement.

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*He aroha whakatō, he aroha puta mai,*

if kindness is sown then kindness you shall receive (Massey University, 2010).

## **Wāhanga Tuatahi – Chapter One: Introduction**

The overall aim of this research is to contribute to the end-of-life care discussion and contribute to validating Māori nursing as an authentic research community with its own unique voice to be heard. This research asks the questions: What are te ao Māori Māori nurses' views on assisted dying? And what are the te ao Māori cultural considerations required to guide nursing practice? The aim of this study was to explore the perspectives of Māori nurses on assisted dying, using a collaborative Kaupapa Māori research methodology (Bishop, 1999; Pere & Barnes, 2009) and communicate the study findings.

Understanding Māori nursing's unique viewpoint will strengthen the health sector's response to end-of-life issues and influence patients' and their whānau care provision that will have far reaching benefits that extend beyond clinical nursing practice. There is an absence of current literature about Māori nurses' perspectives. This is not limited to contemporary health issues like assisted dying, but other health, wellbeing, cultural and social issues. Considering the lack of prior research that includes an understanding of cultural awareness of death and dying, an enquiry into Māori nurses' perspectives of assisted dying use kaupapa Māori values would provide a unique and valuable contribution to the literature.

### **Background**

A capable and competent Māori health workforce is widely recognised as being central to improving health outcomes for Māori (Baker & Levy, 2013). Wilson (2003) argued that nurses can build on the existing strengths of Indigenous health models to improve the people's health outcomes. The Māori population is 16.7% of the national population (Statistics New Zealand, 2020). Currently, there are 54,456 practising nurses (January 2020) in New Zealand, with only 7.5% (4,206) identified ethnically as New Zealand Māori (Nursing Council New Zealand, 2020). Māori health professionals continually acknowledge and understand why it is necessary to be proactive in addressing health inequity (Russell et al., 2013). Despite structural barriers (Human Rights Commission, 2012), such as being an underrepresented health workforce, Māori nurses continue to advocate for better quality, culturally responsive health care systems that deliver equitable access across the spectrum from birth to death. Barton and Wilson (2008) indicated that Māori often confront nursing practices and services at odds with their holistic and spiritually based worldview.

Contemporary and contentious health issues, like the 'right to assisted dying' are not new issues for nurses. It has long been debated and articles on assisted dying have



existed as early as 1912 in the Australian Nurses Journal (Johnstone, 2016). Globally, many professional nursing associations are being confronted with taking a definitive stance on either supporting or opposing legislation for euthanasia and adopting a formal position statement verifying their respective stance (Johnstone, 2016). As health professionals and advocates, nurses are being asked to formulate their own thinking and viewpoints on the subject and to be able to contribute to a broader professional discussion on the whole issue of the right to die (Johnstone, 2016).

Nurses play a considerable role in end-of-life cares for patients and their whānau. This responsibility extends to clinical nursing shifts covering a 24-hour period, 7 days a week. No other health professional groups provide such continuous clinical care, like nurses who provide trusted holistic nursing care to patients and their whānau. With any potential formation of assisted dying legislation, Māori nurses play a unique role in guiding or influencing changes to nursing practice. However, the current views, roles or responsibilities of Māori nurses are generally unknown. Barton and Wilson (2008) argued that nurses needed to be committed to improving health outcomes for Māori clients, who continue to face challenges in the delivery of culturally appropriate and acceptable health services. Assisted dying will challenge nurses' practice and future research is essential to ensure that Māori nurses' views are captured in health policy.

Recent New Zealand research on physicians' aid-in dying (where a physician administers a lethal dose of medication to a competent patient at their explicit request) was silent on Māori perspectives about proposed changes to assisted dying petitions and proposed end-of-life choice legislation (Malpas et al., 2017a). Malpas et al. (2017a) concluded that Māori voices must be heard in any future assisted dying legislation as the implications will have significant impacts for Māori and for health professionals providing end-of-life care. Malpas et al.'s (2017b) study specifically looked at gaining an insight into the attitudes towards physicians' aid-in dying of 20 kaumātua living in the Auckland region. The results identified interrelated themes such as influences of power, and the significance of kawa (ceremonial ritual), whānau relationships and wairua. This study reaffirmed the importance of Māori concepts of tikanga and kawa and the inclusion of kaumātua which have been identified as important processes and concepts to understand death and dying. It also affirmed the central role of whānau in the processes involved in dying (Malpas et al., 2017b). The research was, however, limited by the number of kaumātua involved as participants and the criterion that they needed to live in the Auckland region. Further research that looked at regional differences in kaumātua knowledge and attitudes would be beneficial.

During the writing of this thesis, assisted dying became legalised in New Zealand. The public endorsed the End-of-Life Choices Act by a public referendum during

the national election in October 2020 (Young & Geddis, 2020). Implementation has a lead-in time of one year, making the option of assisted dying publicly available from 6 November 2021. In recent years, assisted dying has been debated in highly publicised court appeals (Gillett, 2015); an inquiry into public attitudes towards assisted dying petitions, (Street, 2014); Select Committee inquiries (Health Select Committee, 2017); and in Parliamentary Bills (Seymour, 2017); the End-of-life Choices Act 2019. Not surprisingly, assisted dying continues to draw strong debate and divides the public - including communities, the health sector and various health professions. Drawn as a member's bill (that is the End-of-life Choices Bill), the End-of-life Choices Act gave people with a terminal illness the option of requesting assisted dying.

In the context of Aotearoa New Zealand, the interaction between death, grief and culture has been relatively unexplored despite international attention (Nikora & Te Awakotuku, 2013). Struggles for tino rangatiratanga (self-determination) as Māori women continue 23 years after Hoskin's (1997) article on the interest of Māori women's discourse of reclamation. Validating Māori nurses' voices is also required. Historical views of Māori women were distorted by the colonial gaze; racist, gendered and sexist ideologies; and simultaneously being viewed as 'savages' and 'sexual objects'. This has been well documented by Linda Smith (cited in Pihama and Johnson (1994), and Irwin (1992) who have written about the construction of Māori women.

Barriers to health care in Aotearoa New Zealand are both systemic and institutional. Challenging these barriers opens new and future landscapes to end-of-life care in Aotearoa New Zealand. The purpose of this research project is to explore Māori nurses' perspectives of assisted dying in Aotearoa New Zealand. Despite the universality of death, it does not necessarily provoke the same responses and accompanying expressions across both individuals and cultures (Stroebe, Gergen et al., 1992; Hayslip and Peveto, 2005 in Edge, 2013).

It is anticipated that this research will be of interest to a range of stakeholders both nationally and internationally. These include all nurses and student nurses practising in the Aotearoa New Zealand health sector, but particularly Māori nurses and Māori student nurses. This research will engage other indigenous nurses and health practitioners both nationally and internationally and will influence other nurses, health practitioners, government officials, health agencies, whānau, hapū (kinship group), iwi (extended kinship group) and communities within Aotearoa New Zealand.

## **Thesis Outline**

The structure of this thesis is presented in a way that takes the reader on a journey through the research. It is important to describe how this research was initiated, using a kaupapa Māori framework to identify, and critically review the literature that had been previously carried out. The thesis identified Māori nurses' views and perspectives that could guide future cultural considerations for influencing nursing practice guidelines for assisted dying in Aotearoa New Zealand.

The Wāhanga Tuatahi – Chapter One: Introduction, I have outlined the overall study and provided the context for this kaupapa Māori research.

In Wāhanga Tuarua – Chapter Two: Literature Review, I will outline existing research surrounding the kaupapa of assisted dying and what this means for Māori nurses. The literature review critically explores existing research and mahi that has been done on assisted dying.

Wāhanga Tuatoru – Chapter Three: Methodology covers the research design and methodology, and outlines the theoretical framework underpinning the research design, including kaupapa Māori methodology using thematic analysis. This chapter also outlines indicative questions, and participants' information.

Wāhanga Tuawhā – Chapter Four: Findings presents the research findings from the semi-structured interviews with Māori nurses from the study. The themes and sub-themes that emerged from the participants' interviews are presented.

Wāhanga Tuarima – Chapter Five: Discussion provides a discussion of the research findings. The findings are discussed and situated amongst the existing body of literature. The research strengths and weaknesses are examined.

Wahanga Tuaono – Chapter Six: Conclusion is the concluding chapter which weaves together and summarises the findings of the research. Included in this chapter are recommendations for future study, and best practice guidelines that promote cultural considerations for assisted dying in Aotearoa New Zealand.

## **Conclusion**

In conclusion, public support of enacting the End-of-life Choice Act and its implementation will enable the administration of a lethal dose of medication to those competent adults suffering from a terminal illness likely to end their life within six months should they voluntarily request it and who meet the criteria (Young & Geddis, 2020). The following chapters will outline a broad discussion of assisted dying legislation in Aotearoa New Zealand, including the current end-of-life choices referendum, which provides the

context for undertaking this research. Further, I provide discussion to validate Māori nurses' role as trusted health professionals in end-of-life care; the importance of the patient-nurse-whānau relationship; and the need for Māori nurses to guide and influence changes to nursing practice. This will also ensure that cultural considerations are included in any future assisted dying or end-of-life cares kōrero and inform the development of guidelines.

## Wāhanga Tuarua – Chapter Two: Literature Review

*Me whati te tikanga kia ora ai te tikanga*

There are times when tikanga needs to be broken for tikanga to survive (Karakā-Clarke, 2020).

This chapter outlines the purpose of the literature review and provides a critique of the current body of literature on health professionals' perspectives about their role in assisted dying. Based on the literature, the rationale for undertaking this research is presented. Further, the literature review outlines the context for and justifies why it is important that knowledgeable indigenous communities, such as Māori nurses, should be included in health research about assisted dying. Key concepts used in the research, such as assisted dying, will be defined.

It is clear that Māori nurses will have to decide the position they wish to take on assisted dying drawing strength from past and present Māori nursing leaders to advocate for future changes and decision-making related to nursing practice and patient care. There is little empirical research that has focused on the nursing role or nurses' experiences in the context of assisted death, because most global assisted dying evidence largely focuses on physicians (Pesut et al., 2019b; Young & Geddis, 2020; Tsai & Menkes, 2020). In particular, the focus has been on the Western medical model, its curative practice and upholding the motto of "*first, do no harm*". Physicians pride themselves on doing no harm, using this motto to justify their position for or against assisted dying (Tsai & Menkes, 2020). Furthermore, there is relatively little known about the impacts of asking health professionals to participate in the process of euthanasia or the moral distress that may arise when clinicians believe they are unable to act in patients' best interests (Tsai & Menkes, 2020).

Understanding what Māori nurses' perspectives of assisted dying is essential for the inclusion of cultural considerations in any nursing guidelines in Aotearoa New Zealand. International research reviewed included nurses' roles in assisted dying and end-of-life settings. However, there was a scarcity of literature about Māori nurses' perspectives on assisted dying in New Zealand. Further, this chapter discusses health disparities in Māori health and broadly explores the latest report from the Waitangi Tribunal kaupapa Māori health inquiry (Waitangi Tribunal, 2019). This discussion provides context for why tikanga cultural practices in health care associated with death and dying are important for Māori wellbeing. The collective similarities of indigenous people's experiences of death and dying are included along with a section on the

historical and continual impacts of colonisation. These global effects include the consequences of racism, bias and marginalisation of indigenous customs or holding alternative values and beliefs to the Western worldview.

## **Search strategy**

A systematic approach was used to access literature review using the inclusion criteria from 2010 to 2020 using PubMed, EBSCOhost, and CINAHL databases including articles sourced from ResearchGate as well as the internet. I searched networks and journals that published Māori and Indigenous writings, research and literature, which included AlterNative, MAI Journal, the Journal of indigenous Wellbeing: Te Mauri – Pimatisiwin and Te Arai research group's palliative care and end-of-life research newsletter (<https://tearaireresearchgroup.org>). Key words used to access literature included assisted dying, end-of-life care, palliative care, Māori, indigenous, aboriginal, native American, nurses, nursing, and health professionals. Information was available on assisted dying, end-of-life care and indigenous perspectives of death and dying and Māori experiences of palliative care and end-of-life conditions. The inclusion criteria for selecting articles for the literature review included:

- International and national literature that explored Māori, indigenous, aboriginal, native American, views of assisted dying, death, dying, palliative and end-of-life conditions;
- National literature that explored Māori and/or health professionals' professional context of assisted dying, death, dying, palliative and end-of-life conditions; and
- International and national literature that explored health professionals' context of assisted dying, nurses' experience of assisted dying, death, dying, palliative and end-of-life conditions from an indigenous or Māori perspective.

## **Locating indigenous health globally**

International literature documented indigenous people, Aboriginal, Native Hawaiian, Native American and Alaskan Natives' experiences of palliative care (Anngela-Cole et al., 2010; Colclough & Brown, 2018; Thompson et al., 2019). For many Indigenous communities around the world, death and dying are part of spiritual teachings and are deeply embedded in traditional cultural knowledge. There has, however, been little written about indigenous people's views or experiences of assisted dying. Available literature indicated that there are differences between indigenous people's holistic perspectives of death and dying and the Western medical model. End-of-life indigenous experiences are not dissimilar to those of Māori. In death, indigenous people clearly want a different approach to end-of-life care including decision making that is not individual

but collective. A growing body of evidence has also indicated that indigenous people faced systemic structural barriers when accessing care (Te Ohu Rata Aotearoa, 2018).

There were similarities in the literature about different indigenous people's experiences with systemic barriers to health care at the end-of-life and in palliative care (Anngela-Cole et al., 2010; Colclough & Brown, 2018; Thompson et al., 2019). Shared indigenous experiences of barriers included health care professionals not understanding cultural beliefs (Colclough & Brown, 2018). Further, Anngela-Cole et al. (2010) confirmed similarities between a lack of cultural sensitivity; or missed communication opportunities between health professionals and the needs of the sick or dying patient and their families; or unintentional disrespect for the patient needs, and lack of family and community support.

Diversity of indigenous people's perspectives on death and dying ranged from death being a part of life and the continuation of a spirit afterlife to a hesitancy or reluctance to talk about death for the fear of 'jinxing' oneself or one's loved ones, or invading the Creator's realm of decision and control on a time of passing, or that it could bring increased fear and anxiety towards preempting talking about different ways to die (Colclough & Brown, 2018; Thompson et al., 2019; Stewart & Mashford-Pringle, 2018). Australian researchers discussed the importance of finding or creating a safe space to discuss dying and end-of-life wishes within the community setting and that this was viewed as significant by many participants (Thompson et al., 2019). Further, Thompson et al. (2019) confirmed the importance and vital need for culturally appropriate end-of-life services for Aboriginal people as many people remained reserved about sharing their death and dying wishes even with those most closest to them.

Indigenous individuals often have difficulty in discussing spiritual and pragmatic matters of dying with bio-medically focused or Western health professionals, as the latter are often non-Indigenous, and hold Western values and beliefs about death and dying (Stewart, & Mashford-Pringle, 2018). A lack of access to palliative and end-of-life cares including hospice was faced by indigenous people (Isaacson, 2018). Further, Isaacson (2018) confirmed that this was due to a range of issues; remote geographical location; or social isolation; limited cultural content in institutions' programmes; and a lack of cultural sensitivity from health professionals. The American Indian Health Service's (IHS) mission and goal are to improve the health of tribal communities through the provision of culturally relevant care, although Native Americans are still unable to access culturally relevant palliative and end-of-life care (Isaacson & Lynch, 2018). Native American talking circle members expressed the need for mandatory cultural awareness training for all new health services staff (Isaacson, 2018). This training included attending cultural awareness education to get to know the language and cultural stories. Other barriers to

accessing care for some Native Hawaiians included being ineligible for insurance to pay for health care (Colclough & Brown, 2018).

## **Aotearoa New Zealand context**

Most New Zealand literature refers to end-of-life cares, death or dying. However, the literature does not clearly separate the setting or approach to care. Palliative care articles featured a lot in the context of Aotearoa New Zealand. This may be due to assisted dying only recently becoming legal in New Zealand, so that there has not been a great deal of Aotearoa New Zealand-specific literature yet. Published research in relation to Māori nurses has been difficult to find. Only a small amount of literature reviewed nurses' experiences at all, let alone specifically Māori or indigenous nurses' experiences.

Literature indicates that there are similarities between inequitable treatment for Māori in both end-of-life care and hospice settings. Māori have historically been underrepresented as patients and providers of hospice care despite being entitled to equitable treatment, resources, and support for all stages of the cancer care journey (Slater et al., 2015). This inequitable end-of-life and palliative care treatment for Māori can be seen in the wider context of colonisation. Further, Selak et al. (2020) confirmed "Colonisation was, and continues to be, a traumatic experience for Māori" (p.9). This process resulted in moving Māori, as *tāngata whenua* (local indigenous people of Aotearoa), from being normal to being seen by Pākehā as different and classified as outsiders (Selak et al., 2020). The disproportional impacts of both the historic and ongoing colonisation processes have signified that not all Māori individuals or *whānau* have been able to hold fast to their traditional care customs (Mason et al., 2018). Mason et al. (2018) confirmed that despite the collective strengths of Māori *whānau* to provide end-of-life care, it often left the *whānau* socially and economically disadvantaged.

It is well documented that Māori do not receive the same standard of health services as non-Māori (Slater et al., 2015). This has led Māori to be blamed for their own 'inferior' health outcomes compared with Pākehā without acknowledgment of the structural bias inherent in our health system because it is designed to advantage Pākehā over Māori (Selak, et al., 2020). Further, Māori have not been able to influence changes to the current health system that should acknowledge that Māori are diverse, and that a holistic approach to caring for Māori who are dying and their *whānau* is required (Te Ohu Rata Aotearoa, 2018).

Identified areas of need include further resourcing of the Māori health workforce in hospice and palliative care settings and introducing cultural safety training amongst



health professionals (Slater, et al., 2015; Mason et al., 2018). Within the context of Māori end-of-life journeys, the palliative care discourse is relatively new. However, the philosophy of palliative care does not allow the option of assisted dying. Similarities in barriers to care that impede whānau from providing end-of-life care are shared with palliative care (Te Ohu Rata Aotearoa, 2018; Mason, et al., 2018). These include being burdened by financial costs associated with end-of-life care such as transportation, parking, clothing, linen, general practitioner visits, medication, alternative therapies, and access to appropriate housing and food. Further, financial constraints were experienced when whānau members gave up paid work to provide care (Mason et al., 2018).

The New Zealand literature is focused on barriers to care that Māori who were living and dying with cardiovascular disease and receiving community based palliative care faced (Mason et al., 2018; Cottle et al., 2013). Key findings highlighted that Māori whānau provide the bulk of care at the end-of-life. Further, the findings examined how best to use concepts of manaakitanga and whakawhanaungatanga to engage, assist, nurture and guide whānau needs as they navigated the journey through end-of-life cares (Mason et al., 2018; Cottle et al., 2013). Cherrington (2011) explored the challenges of being a Māori nurse in a far north rural community. This included exploring the professional and personal boundaries of paid and volunteer work to support whānau care, such as medication management, and supporting and educating whānau in what to expect. Cherrington's (2011) experiences highlighted the importance of Te Tiriti o Waitangi (foundation treaty document for Aotearoa New Zealand) and Māori models of care such as Te Whare Tapa Whā in her day to day nursing practice. It was important for Cherrington to embrace and incorporate holistic Māori health care dimensions into nursing assessments of patients and their whānau. This holistic assessment includes a focus on the physical, psychological, social, whānau and environmental aspects to provide comprehensive care.

The role and inclusion of whānau in the decision-making process was also critically explored by Cherrington (2011) which she found was crucial to care. Slater et al. (2015) confirmed whānau were pivotal in both contributing to decisions around treatment options as well as the provision of patient care, especially at the end-of-life. This included collective decision-making that involved discussion and input from multiple family members. The collective whānau involvement is as important as individual choice when considering health care options and ensuring the planning of and implementation of treatment and care options, and importantly, that referrals were made to appropriate services (Slater et al., 2015). The absence of Māori perspectives and understanding in relevant assisted dying literature is evident, reinforcing the need for Māori nurses to advocate for change and ensure their voices are heard on this issue. Writings or stories

about nurses adapting their nursing practice to respond to challenging and contemporary health issues remain untold. Capturing these stories going forward will be important for whānau who choose assisted dying as an option.

## **Nurses' role in end-of-life care**

The role of nurses is recognised as crucial in assisted dying. However, this varies between countries. In the Netherlands (2001) euthanasia and physician-assisted suicide (client administered death) are authorised, while in Belgium (2002), only euthanasia is legalised (Pesut et al., 2019b). However, Belgium law does specify that any request for euthanasia must be discussed with the patient's regular nursing team. In 2016, Canada became the first country in the world to allow nurse practitioners to carry out assessments and provide Medical Assistance in Dying (MAiD). Pesut et al. (2019a) aimed to capture and accurately reflect nurses' experiences with assisted death. However, difficulties in data collection existed due to many Canadian employers limiting nurse practitioners' involvement, resulting in less than 5% of the MAiD procedures in 2017 being performed by nurse practitioners (Pesut et al., 2019b). The only regulatory requirements around death in Aotearoa New Zealand are that a medical doctor signs a death certificate, that sudden deaths are investigated and that the mortal remains of a person are disposed of in designated places such as a cemetery or a crematorium (Nikora et al., 2012). Additionally, this process now allows for a nurse practitioner to complete both a death and cremation certificate, providing they have cared for the person in the last months of life and have developed a relationship with their family.

## **Te Tiriti o Waitangi**

The status and rights of Māori as tāngata whenua to determine their individual and collective identities are affirmed by Te Tiriti o Waitangi (Selak, et al., 2020). The newly arrived first governor of New Zealand, William Hobson, said, "He iwi tahi tatou," (we are one people now) at the conclusion of the treaty signing ceremony between the British Crown and some Māori chiefs at Waitangi in 1840. This set in motion the debate about cultural differences and national identity that has dominated the country's politics throughout its short post-settlement history (Smits, 2019). Hutchings (2002) raised an important point that the role, status and rights of Māori women under Te Tiriti o Waitangi have never been truly explored. Further, while a lot of research has focused on Te Tiriti o Waitangi signing in 1840 and its process, little has been done to progress and actively protect the rights of Māori women (Hutchings, 2002).

Despite general acknowledgment of the need for Māori solutions in health, there are still significant blocks in place that inhibit the widespread use of kaupapa Māori

approaches to health care (Came, 2012). The recent release of the Waitangi Tribunal (2019) report on stage one of the *Hauora - Health Services and Outcomes Kaupapa Inquiry: Wai 2575 Kaupapa Māori health inquiry* had a significant disruption on the health space (Rolleston et al., 2020). The outcomes of Kaupapa Māori interventions are interwoven with the holistic and collective nature of the Māori health worldview which often cannot be measured by a Western standard (Rolleston et al., 2020).

## **Nurses' experiences with assisted dying**

The terminology associated with assisted dying is varied, with many definitions, terms (assisted suicide, euthanasia, aid-in dying) and descriptions used and misused. The definition I have chosen describes assisted dying is:

“a regulated intervention by an authorised health practitioner, either providing the person with the means to end their life or (if the person is unable to do so) ending the person’s life with the primarily intent of relieving pain and/or suffering at the person’s voluntary, repeated, and fully informed request” (Australian Nursing & Midwifery Federation, 2019, p.1).

Currently, many professional nursing associations are being confronted as to whether they should take a definitive stance in either supporting or opposing assisted dying or euthanasia legislation and whether to adopt a formal position statement verifying their respective positions (Johnstone, 2016). Wilson (2003) argued nurses can expand on the strengths of indigenous health models to improve health outcomes for all population groups. Although the health system presents many challenges, Māori nurses must continue to advocate for better quality, culturally appropriate health care systems that deliver equitable access to health care across the continuum from birth to death. Barton and Wilson (2008) reiterated that “Māori are often confronted with nursing practices and services that are at odds with their holistic and spiritually based worldview” (p.6).

As a profession, Rook (2018) drew attention to the lack of nurses’ voice in New Zealand. This resulted to nurses’ feeling frustrated at not being valued, not respected and not financially rewarded equally as others in the public sector. The End-of-Life Choices Bill had its first reading with limited input from the nursing profession. Further, we (nurses) need to ask ourselves why is it that as a profession that we have been unable to harness our voice and energy to engage in a critical debate about hard-hitting issues like assisted suicide. Pesut et al. (2019a) confirmed that the lack of attention to nurses’ roles, experiences and processes with assisted death is due to the act being performed widely by physicians. Further, Pesut et al., argued that:

“Any nurses who care for those nearing end-of-life will find themselves communicating with a patient requesting a wish to die and will therefore need to do the necessary moral reflection about an increasing array of end-of-life options that have arisen as a result of the wider social context of changing ideas about a good death” (Pesut et al., 2019b, p.229).

A key finding across the Canadian nurses’ experience studies was that nurses sought to provide professional holistic care without judgment, irrespective of their private moral stance towards assisted death (Beuthin, Bruce & Scaia, 2018). Further, the majority of the participants were experienced nurses who had observed patient and family suffering and were unable to help their patients have a peaceful death. Many felt that the narrow focus of assisted dying and the task of administering medications overshadowed the central role of the nurse (Pesut et al., 2019b).

Nurses have a central role in negotiating enquiries about assisted death; in providing wraparound care; communication; and support for patients, families, and other health care providers. Additionally, nurses are also involved in the preparing of equipment; fostered rituals; and in monitoring the situation to ensure that everything was going according to plan and that everyone felt supported (Pesut et al., 2019a).

Finally, the importance of nurses’ communication with patients in the context of assisted death cannot be over-emphasised. The reviewed data showed that nurses played a central role in the communication process, particularly in determining the nature and intent of the initial request. Beuthin, Bruce and Scaia (2018) indicated that further research was required to fully understand nurses’ moral distress and the importance of communicating openly and nonjudgmentally with patients, families, and the health-care team.

## **Conclusion**

In conclusion, it is clear from reviewing the literature that there is little empirical research that has focused on the nursing role or nurses’ experiences in the context of assisted death. Globally the focus of assisted dying evidence has largely focused on medical physicians’ views. Despite being one of the most trusted professional groups in the world, nurses’ views and perspectives are currently underrepresented in the end-of-life or in assisted dying literature. Literature is metaphorically silent on indigenous perspectives and extends to silence about Māori nurses’ perspectives or views. This similarly may be in part to the space being claimed by physicians who in many countries are responsible for administration of medication to assist dying. This of course does not include the role and responsibility of nurses in building a trusting relationship and caring and communicating with patients and their families during this time. The role of indigenous Māori nurses caring for patients and their whānau is also absent. The lack of

voice of Māori nursing communities reinforces the need for their views and perspectives on contemporary and contentious issues like assisted dying to be researched.

Collective similarities and values of indigenous people's experiences of death and dying provide a rich understanding of the shared spiritual customs of life and death. The review highlighted the unique differences between indigenous holistic perspectives of death and dying and Western medical models. This included acknowledgement of the extensive trauma that colonisation has left impressed on generations of indigenous people including Māori people. The extent of this trauma for Māori is still being reviewed and relived in whānau and iwi evidence at the Waitangi Tribunal hearings (Waitangi Tribunal, 2019). It was apparent that little has been written about indigenous people's views or experience of assisted dying. There is room for more research on indigenous perspectives and views of living and dying issues.

Understanding gaps in knowledgeable indigenous communities, such as Māori nurses, should be a focus for further health research and will provide a foundation for shaping my methodology chapter. It is intended that this research will provide a unique and valuable piece of research to inform nursing practice. Additionally, it is anticipated that this study will further identify additional cultural considerations required to guide nursing practice.

## **Wāhanga Tuatoru – Chapter Three: Methodology**

*Mā te tauihu o tōu waka, e ū te waiora  
Kia mahue atu, ngā mea whakahirahira i roto i te koriparipo*

May the prow of your canoe cleave the waters of life  
and leave in its wake, mighty deeds (*Massey University, 2010*).

Māori nurses are frequently resilient and draw on strength from the past and present to advocate and plan for future changes and decision-making for the betterment of hapū, whānau and iwi. The overall aim of this research project was to ensure that Māori nurses' perspectives on assisted dying are available and able to assist with cultural considerations required to guide nursing practice.

In this chapter I will describe the approach and methods that have informed this study and the rationale for using a kaupapa Māori method. The research will explore the perspectives of Māori nurses on assisted dying, using a collaborative kaupapa Māori methodology (Bishop, 1999; Pere & Barnes, 2009) to design, facilitate, record, collate and communicate the study and its findings. The underlying methodology is centred in a te ao Māori worldview using the ethical values of tika, pono and aroha to frame cultural knowledge, tikanga and the values of whanaungatanga, manaakitanga, and kaitiakitanga, which guide and support the chosen method. The approach used for data collection and analysis will also be discussed, including the identification and recruitment of participants.

### **Research aims and question**

The overall aim of this research was to contribute to the end-of-life care discussion, and contribute to validating Māori nursing as an authentic research community with its own unique voice to be heard.

Using a kaupapa Māori research framework and the place of kaupapa Māori values, this qualitative research study addressed the following question: Te Ao Māori: what are Māori nurses' views on assisted dying and cultural considerations that guide nursing practice?

### **Kaupapa Māori Methodology**

A qualitative research approach using kaupapa Māori research methodology was utilised to gain an understanding of Māori nurses' views on assisted dying and cultural considerations that guide nursing practice. This methodology was chosen to ensure

Māori cultural values and knowledge were upheld throughout the entire research process from beginning to the end.

Pihama (2001, p.113) “describes kaupapa Māori research as evolving, multiple and organic”. The strength of kaupapa Māori research is that it creates space for Māori voices to be *‘heard’* (Cram, 2006). Further, at its heart, it is about power; not so much the power to undertake research but the power to have the knowledge generated by research considered legitimate. Smith (1997) summarised the contemporary expression of kaupapa Māori theory in the following way. A kaupapa Māori base is a local, theoretical position where the validity and legitimacy of Māori is taken for granted. That is,

- “the survival and revival of Māori language and culture is imperative;
- the struggle for autonomy over our own culture wellbeing; and
- over our own lives is vital to Māori survival” (p.256).

It is essential that wāhine Māori nurses’ perspectives are captured as a legitimate viewpoint and Māori nurses are a credible research group.

### **Concepts of whanaungatanga, manaakitanga, kaitiakitanga**

Underpinning the overall research methodology is a kaupapa Māori approach, which highlights that the key concepts of whanaungatanga, manaakitanga and kaitiakitanga are central to understanding te ao Māori worldview, along with guiding ethical principles of tika, pono and aroha. Traditional Māori spiritual practices, and cultural concepts, have been marginalised across Western academic mediums and worldview (Kennedy et al., 2015). Concepts of tika, aroha and pono guide the decision-making process to ensure a dignified death occurs (Mane, 2009).

Mane (2009) describes the Māori concepts of tika, pono and aroha as follows:

“Tika is about doing things right, for the right reasons, for the long-term benefit of the collective whānau. Pono upholds the principles of being truthful and acting with integrity, while supporting spiritual faith and maintaining the connection to the spiritual realm, acknowledging a greater being; and those who came before us. Pono is also about having faith in ourselves and our actions. Aroha is specific to the notions of compassion, care and empathy for others and also for the self. Aroha is also expressed as love for who and what we are, our language and culture, our people and our environment” (p. 3).

Cultural values of sharing and reciprocity are also expressed in the formal rituals surrounding sickness, grieving, dying, and death, and serve to bind the kin community together (Ngata 2005). Further, Mane (2009) argued that:

“Core values of tika, pono and aroha were integral to how Māori lived and were central to their cultural values, ensuring decisions were made primarily for the benefit of the collective wellbeing of the whānau, and extended family” (p.3).

## Methods

### Participants and recruitment

Ten to fifteen Māori nurses who worked in end-of-life care setting were sought to take part. The inclusion criteria for participants were they:

- were a nurse (registered nurses, enrolled nurses or Nurse Practitioners) who had whakapapa Māori; and
- worked in health services that provided end-of-life care throughout Aotearoa New Zealand.

An inclusive recruitment based on whanaunga; shared whakapapa; an understanding or knowledge of te ao Māori was used to invite any Māori nurse (registered nurses, enrolled nurses or Nurse Practitioners) who worked in end-of-life care setting to participate, rather than be limited by Western nursing hierarchical scopes of practice.

Informal Māori nursing networks were used to recruit participants via Te Rūnanga o Aotearoa NZNO (Te Rūnanga). That is, Māori nurses who were members of Te Rūnanga representing their regions and who were members of Te Poari, a Māori health professional leadership governance board. They also included members of Tōpūtanga Tapuhi Kaitiaki o Aotearoa, New Zealand Nurses Organisation (NZNO) which acts as their professional association and union.

The Te Rūnanga regional representatives were keen to invite members to be involved in this research. Emails were sent to all regional members, rather than an isolated or targeted approach for those deemed as meeting the criteria.

The information sheets were sent using regional representatives inviting Māori nurses to take part in the research project, which aimed to look at their perspectives as Māori nurses on assisted dying. Timing issues meant that the distribution of information sheets coincided with the Christmas holidays, alongside finding a limited pool of Māori nurses in the two designated District Health Board (DHB) areas. A further application to AUTEK was made to widen the scope to include Māori nurses working in end-of-life care in any area of Aotearoa New Zealand and to include the use of Zoom to interview participants from any area in Aotearoa New Zealand. Kerri Nuku, Kaiwhakahaere sent regional representatives a pānui (information sheets (Appendix B), flyer (Appendix F) and support letter (Appendix E) for distribution to their regional members.

Each regional area represents members, cutting across the geographical area, DHBs, schools of nursing and iwi boundaries. Despite this, the regional representatives are well known and extremely well connected with Te Rūnanga members across the



large regions that they represent. I was contacted via email by 10 Māori nurses who wanted to speak to me about their perspectives of assisted dying. All the Māori nurses were recruited via informal Māori nurses' networks, via the Te Poari regional representatives. While the focus of the research is on Māori nurses who live and work in end-of-life care in Aotearoa New Zealand, it did not focus on particular iwi or hapū; rather, that Māori nurses identified as having whakapapa Māori.

### **Data collection**

Ten semi-structured interviews took place mainly at the NZNO national office or via the use of Zoom with participants from across Aotearoa New Zealand. The sites were chosen as being independent from nurses' workplace settings and for those nurses who were also members of the NZNO it enhanced the experience as this setting was both familiar and comfortable. The duration of each interview was more than an hour, which included karakia (prayer) and whakawhanaungatanga.

I started by offering the participants the opportunity to begin with karakia and whakawhanaungatanga. Starting with whakawhanaungatanga determined a relaxed environment for interviewing and allowed time to acknowledge and share whakapapa connections, nursing knowledge and expertise, and nursing networks. This allowed me to establish a trusting relationship with participants. It also allowed time to centre myself and karakia to focus in on the intent and kaupapa of research. From a Māori perspective, the researcher and participants share whakapapa, as wāhine Māori and as members of Te Rūnanga, as a community of Māori nurses based on a shared understanding, knowledge and tikanga of Māori nurses, a nursing worldview and the wider health system.

Before each interview began, I tested the digital recording equipment to ensure that the participants' kōrero could be heard. I ensured that all participants were aware that kaumātua support was available if anyone required tautoko. The process I then used was to go through the information sheet, answering any questions and then the consent form outlining the process, including note taking and digitally recording and transcribing of tapes. I also reinforced that the purpose of the interview and research was to answer the question: What are Māori nurses' views on assisted dying and cultural considerations that guide nursing practice? The purpose was to complete the requirement for my thesis. The challenges of any health issues such as assisted dying can impact on Māori nurses' practice and their te ao Māori cultural approaches to health care. The indicative interview questions in Table 1 aimed to assist the interview process.

**Table 1: Indicative Interview questions**

1. What does assisted dying mean to you?
2. Is your nursing view different from your personal view?
3. Where does assisted dying fit with your cultural worldview?
4. How has your views on assisted dying influenced your nursing practice?
5. What would you see as essential cultural considerations to guide assisted dying practice?
6. How do you implement Tika, Pono and Aroha in to your nursing practice?
7. Do you have support from your employer / colleagues to practice nursing based on your cultural beliefs – if Yes / No can you explain further?
8. What support is available to you in working with patients who are viewed as terminal and considering assisted dying?

Using the indicative questions as a guide, I learned to adapt to the timing and flow of the questions to each participant, and my ability as an interviewer developed overtime as I became more comfortable with my interview style. At the conclusion of the interviews, I asked participants if they had any further questions. Further, due to the nature of the research, I reminded the participants that kaumātua support would be available if they required tautoko. A mihi and karakia concluded the kōrero. A koha (offering or gift) was given in the form of a gift voucher for their time, knowledge, stories, whakaaro and contribution towards the research.

A skilled transcriber was recommended by my supervisor to assist with transcribing the interviews from a digital recorder. Further, my supervisor and I wanted to ensure that the data were transcribed in an accurate, reliable and trustworthy manner. Once interviews were transcribed, they were checked for accuracy by reviewing the written transcriptions while listening to the recordings. I assigned pseudonyms to each participant, and all identifying information was removed (such as names, place names and organisations). A confidential agreement form was signed by the transcriber that detailed the process for transcribing information, confidentiality and that no copies were to be kept or third party allowed access to them. Further, the agreement limited the contents of the recordings to be discussed only with the researcher.

### **Data Analysis**

I chose thematic analysis to analyse the data as it provided a clear framework to analyse the participants' data and assist with recurring themes (Braun & Clarke, 2006). Once the transcribing process had been completed, I analysed the data using the Braun and Clarke steps to analyse process. This included an inductive approach to guarantee the themes emerged directly from the data, rather than having predetermined themes.

The framework identifies six phases/processes to identify themes to address research and includes (Table 2):

- familiarisation with the data and identifying items of potential interest;
- generating initial codes;
- searching for themes;
- reviewing potential themes;
- defining and naming themes; and
- producing the report.

**Table 2: Process of Thematic Analysis**

	<b>Steps to familiarisation of data</b>	<b>Process outlined</b>
1.	Reading the data and making notes with some initial ideas	Once transcribing was completed I coded each participant's transcripts and wrote down ideas and highlighted quotes and themes in the margins of the transcripts.
2.	Coding the whole dataset	I populated a table with themes for each participant and used pseudonyms for each participant.
3.	Searching for themes within the data	I collated a table of lists looking for reoccurring themes in each transcript. I familiarised myself with each participant's data and patterns within the data.
4.	Reviewing themes and creating a "thematic map" of the analysis	Using tables of themes, and assigning symbols to help group the data into themes and sub theme headings
5.	Define and label the themes, sub themes	Review the themes that emerged and refine/reduce the number to key and sub themes.
6.	Write up an analysis of the themes	Further discussion and reflection on themes with my supervisor enabled the compilation and writing up of the findings, including balancing the decision making and ensuring that evidence contributed to the findings.

The benefits of thematic analysis is its robust explanation of the process. This creates a trustworthiness and flexibility in analysing the data and its ability to be used within different frameworks without requiring detailed theoretical and technological knowledge of other qualitative approaches (Braun & Clarke, 2006). Braun and Clarke, (2013) also indicated that coding and analysis always takes longer than you ever anticipate so advised not to rush the process because it will not help in pattern identification.

First, I familiarised myself with the data by reading each participant’s transcript. Then when re-reading the transcripts I highlighted initial codes, underlined potential quotes, and made notes in the margins. I then sorted each transcript’s themes into a table. I searched for common codes between transcripts, assigning symbols to guide these being grouped into key themes into tables using common headings. These themes were then reviewed again for patterns. This ensured that participant’s voices drove the findings and reflected their voices and with their quotes. Braun and Clarke (2013) maintained developing themes from coded data is an active process: the researcher examines the codes and coded data and starts to create potential patterns; they do not ‘discover’ them.

During the analysis of the data, 12 initial themes emerged, which after further analysis and reflection were refined into four themes with eight sub themes. Table 3 sets out the 12 initial themes, and their distillation into the final themes and sub themes.

**Table 3: Initial Themes’ Distillation into Final Themes and Sub Themes**

<b>Initial themes</b>	<b>Grouped reviewed themes</b>	<b>Final themes and sub-themes</b>
Role of whānau	<ul style="list-style-type: none"> <li>Assisted dying</li> <li>Role of whānau</li> <li>Patients’ choice</li> </ul>	<b>Patients’ choice</b> <ul style="list-style-type: none"> <li>Assisted dying</li> <li>Role of whānau</li> </ul>
Assisted dying		
Patients’ choice		
Barriers to care	<ul style="list-style-type: none"> <li>Exacerbation of inequities and gaps in care</li> <li>Barriers to care</li> </ul>	<b>Barriers to care</b> <ul style="list-style-type: none"> <li>Exacerbation of inequities and gaps in care</li> </ul>
Exacerbation of inequities and gaps in care		
Tapuhi kaitiaki	<ul style="list-style-type: none"> <li>Patients’ safety</li> <li>Tapuhi kaitiaki</li> <li>Whakawhanaungatanga</li> <li>Work environment</li> </ul>	<b>Tapuhi kaitiaki</b> <ul style="list-style-type: none"> <li>Patients’ safety</li> <li>Whakawhanaungatanga</li> <li>Work environment</li> </ul>
Work environment		
Patients’ safety		
Whakawhanaungatanga		
Cultural safety of patients and whānau	<ul style="list-style-type: none"> <li>Needing wrap around services</li> <li>Cultural safety of patients and whānau</li> <li>Silencing of cultural views</li> </ul>	<b>Cultural safety of patients and whānau</b> <ul style="list-style-type: none"> <li>Needing wrap around services</li> <li>Silencing of cultural views</li> </ul>
Silencing of cultural views		
Needing wrap around services		

## **Ethical considerations**

Ethical approval for this thesis research was awarded by AUTECH, reference number 18/290 on 4 December 2018. Copies of the ethical approval (Appendix A), participants' information sheet (Appendix B), consent forms (Appendix C), confidentiality agreement (Appendix D), Te Rūnanga letter of support (Appendix E) and recruitment flyer (Appendix F) are included in the named appendices.

## **Informed consent**

I provided participants with an information sheet that explained the purpose of the research, their role and responsibilities including potential risks of their involvement. As the Māori nursing community in the research areas is relatively small, there may be a remote chance of identification. However, all steps were taken to remove all identifiable information to minimise this occurring. Participation was voluntary and potential participants were informed they could withdraw at any time up until the data collection was completed. If participants opted to withdraw from the study, then they were offered the choice between having any identifiable data belonging to them removed or allowing it to continue to be used. However, participants were informed that once the findings had been produced, removal of their data would no longer be possible.

## **Confidentiality**

Confidentiality was managed by first assigning participants pseudonyms and the removing all identifying information such as institutional, geographical and other place names.

## **Data storage**

The data will be kept securely in a password protected external hard-drive at the research's completion in the Taupua Waiora Māori Research Centre archive on the AUT's South Campus. The consent forms will be held separately from the data in a locked cabinet by Professor Denise Wilson for six years before being destroyed in a secure manner. Participants will be sent a summary of the findings before any publication, if they indicated they wished to receive a copy at time of consent to participate.

## **Illegal Activities**

Because of the nature of this research, participants were made aware that if they talked about any involvement in an illegal activity or activities while they were engaged

in this research, this may need to be disclosed to the Police. However, no action was required during the course of the research.

### **Minimisation of risk**

Participants were informed that assisted dying is a controversial and challenging professional issue. Therefore, it was essential that participants' identity remain confidential. Further, participants were advised that discussing death and dying, feelings of sadness, being uncomfortable, or emotionally upset may be expressed. If any participants in the study experienced any of these feelings, they were told the interview would be stopped until they felt ready to continue. If participants did not want to continue the interview, they had the opportunity to withdraw from the study or make another interview time. However, no participant chose to withdraw from the study or reschedule their interview.

### **Reflexivity**

Jootun, McGhee, and Marland (2009) discussed reflexivity as one of the pillars of critical qualitative research that relates to the degree of influence the researcher exerts, either intentionally or unintentionally, on the findings. I did not want to influence the findings but to uphold *aroha ki te tāngata* (a respect for people) and allowing participants their own space and meet on their own terms (Cram, 2009).

It was also important to uphold kaupapa Māori research methodology as an authentic framework to answer the research question. As a Māori nurse, my own bias that Māori nurses do not have a voice meant that I am keen to tell their stories through research. Therefore, my role as the primary researcher was to ensure that tikanga practices were adhered to and that my actions reflected my whakaaro Māori and were underpinned by Māori values and beliefs. These actions underpinned my capturing and documenting that the Māori nurses' experiences and meanings. It was extremely important to me to use this kaupapa Māori research methodology to ensure that tikanga were used to maintain both the researcher's and participants' cultural safety (Cram, 2009). This methodology included using ethical principles of *tika*, *pono*, and *aroha* before, during and after the research project. Further, I wanted to value and respect *kanohi-ki-te-kanohi* (face-to-face) relationships between the researchers and the research community (before, during, and after the research project), so that the researcher is someone who is known to, and seen around, the community (Cram, 2009).

Pihama (2001) argued the importance of Māori women taking control of spaces where our stories can be told. I also agreed with Johnstone's (1999) statement that "researchers who are brave enough to write about their own emotions risk being ridiculed, dismissed and marginalised" (p26). Courage and bravery was required to

ensure that Māori nurses' voices were heard in te ao hurihuri (the changing world), challenging a patriarchal health system. Māori nurses' leadership has contributed to my research and will ensure that their resilience and mana as Māori wāhine, and Māori nurses, is upheld and celebrated. Accordingly, Pihama (2001:p. 110) argued:

“Kaupapa Māori research must be about challenging injustice, revealing inequities and seeking transformation”.

This research honours the wāhine toa who contributed to this research and acknowledges the Whaea tūpuna, who have gone before us, they have endured many years of structural barriers and have led the way in Māori nursing.

## **Establishing Research Rigor**

Cram's (2009) framework for organising Māori researcher roles and responsibilities within a relationship ethic used a “community up” approach to defining researchers' conduct. I established research rigour using two aspects of this framework: kia tūpato (to be cautious) and aroha ki te tāngata, and interweaving kaupapa Māori research ethical principles of tika, pono and aroha.

## **Tika**

Cram (2006) argued that the first element in any process is whakawhanaungatanga (making connections or links) whereby connections between the researcher(s) and the participant(s) are established. This is regardless of the methods we choose; the process for engaging with research participants is often the same. At the start of each interview, time was provided to ensure that participants could make an informed decision, this included going over the information sheet and answering any questions the participants had, prior to them signing a consent form.

Further, Cram (2006) reinforced that as researchers we take our role seriously and the responsibility of presenting the realities of our participants to wider audiences. Our aim with kaupapa Māori research is to create a legitimate space for Māori voices and realities to be heard and considered 'valid'. At the same time, we want to be able to say something, as researchers and analysts, about the society that positions our Māori participants with certain subjectivities. I listened repeatedly to the participants' kōrero and remained vigilant to be kia tūpato of my position within the research study. Further, I reflected on the findings in a cautious manner this included the themes and subthemes identified (Cram, 2009).

## Pono

Smith (2007) argued getting the story right and telling the story well are tasks that indigenous activists and researchers must perform. This is reinforced by ensuring the participants' kōrero is heard and the researchers' unbiased approach to uphold the integrity and credibility of this research. Due to the study's qualitative methodology, it was essential to establish its rigour or trustworthiness with participants, and to ensure I had an appropriate supervisor. Audio recorded transcripts were checked for accuracy and personal data and other identifying data had been removed and replaced with pseudonyms to ensure participants' identity was kept anonymous. Cram (2006) confirmed that analysis is often done using a database of interviews transcripts and any interview notes written by the researcher. A process of reading and re-reading this database, listening to the audiotapes, and discussions among the researchers (if there is a research team) to reveal common themes, as well as points of contradiction, disagreement, and agreement both within and between participants.

Maguire and Delahunt (2017) claimed the themes themselves should be coherent and distinct from each other. They indicated things to consider or questions to ask to ensure a rigorous process when reviewing themes (Table 3):

**Table 4: Checking Themes for Rigour**

<b>Questions</b>	<b>Answers</b>
Do the themes make sense?	Yes, the data reflects Māori nurses' stories
Do the data support the themes?	Yes, have used data to support the themes and sub-themes presented
Am I trying to fit too much into a theme?	Possibly, after reviewing the data I think one of the key themes is patient choice, of which assisted dying is a sub theme.
If themes overlap, are they really separate themes?	Having time to reflect allowed me to check against each other and back to the original dataset
Are there themes within themes (sub themes)?	Yes, some of the sub themes could be separate subthemes under the broader key themes
Are there other themes within the data?	No

Allowing time to reflect was an extremely important part of the coding process. The time allowed me to check the themes and to realise that the sub theme of assisted dying was missing. Furthermore, reviewing the eight sub themes, it became clear that cultural safety of patients and whānau, a key theme, required its sub themes to be separated into 'silencing of cultural views' and 'wrap around services needed'.



## **Aroha**

Cram (2006) confirmed that “research is about the people, about being accountable in the production of knowledge that is for the good of the community and informs how we live our lives” (p.41). Further, that “one of our roles as researchers is to listen to and document Māori experiences and meanings” (Cram, 2006, p.39). Smith (2007) also confirmed the importance of connecting with trust and respect with indigenous people, as a way of thinking, knowing and being, can be sustained for generations.

Aroha ki te tāngata honours the principle of respect and the need to share participants’ thinking, knowing and being for the benefit of Māori nurses and the whānau, hapū and iwi. At the completion of this research, a research thesis will be produced, and the intent is to draft an article for publication. Participants will be provided with a copy of the research findings, before presenting at an Indigenous conference.

## **Conclusion**

This chapter has provided insight into the use of a kaupapa Māori research methodology using a qualitative research design. This methodology ensured adhering to tikanga practice, upholding kanohi-ki-te-kanohi engagement of whakawhanaungatanga. Participants’ criteria were outlined and the informed consent process. Data were analysed using a thematic analysis method allowing key themes and subthemes to be directly derived from the data gained from participants interviews.

Accordingly, Māori concepts of kia tūpato and aroha ki te tāngata ensured that participants determined the themes and subthemes and removed the potential for pre-determined themes held by the researcher. Further tika, pono and aroha ensured participants’ cultural safety and ethical research was upheld from beginning to end and after the report. These principles and values also ensured the research remained robust, trustworthy, and reflective.

## Wāhanga Tuawhā – Chapter Four: Findings

And when we speak, we are afraid our words will not be heard, nor welcomed but when we are silent, we are still afraid. So, it is better to speak remembering we were never meant to survive  
(Audre Lorde, 1978, p. 201).

From this research, four key themes were identified: *Patient Choice*, *Tapuhi Kaitiaki* (Māori nurses), *Barriers to Care*, and *Cultural safety of patients and whānau*. These themes and their eight sub-themes (see Table 5) are presented and illustrated with selected quotes from Māori nurses that reflect their voices. The interconnection between the themes and sub-themes, has similarities to whakapapa lines in te ao Māori linking whānau, hapū and iwi.

**Table 5: Themes and Sub-Themes**

	Themes	Descriptors	Sub themes
1.	Patient Choice	Ways in which contemporary health issue like assisted dying influences patient choice	<ul style="list-style-type: none"> <li>• Assisted dying</li> <li>• Role of whānau</li> </ul>
2.	Tapuhi Kaitiaki	Ways in which Māori nurses draw on and use their skills in end-of-life care	<ul style="list-style-type: none"> <li>• Whakawhanaungatanga</li> <li>• Patient safety</li> <li>• Work environments – what needs changing</li> </ul>
3.	Barriers to Care	Broad range of systemic issues that prevent best care	<ul style="list-style-type: none"> <li>• Exacerbation of inequities and gaps in care</li> </ul>
4.	Cultural safety of patients and whānau	Ways in which te ao Māori influences patient and whānau care	<ul style="list-style-type: none"> <li>• Silencing of cultural views</li> <li>• Needing wrap around services</li> </ul>

In this chapter, I present the findings from interviews undertaken with 10 Māori nurses between May and August 2019. The participants prioritised and spoke at length about how assisted dying influenced patient choice and ways in which Māori nurses used their skills in end-of-life care and address systemic issues that prevented best care. These nurses influenced patient and whānau care from a te ao Māori worldview. The nurses included two nurse practitioners (NP), and registered nurses (RN) working in a range of end of life cares (primary care, hospices and DHB settings across the North Island). The participants nursing work experience ranged from two to over thirty years of clinical practice (see Table 6).

**Table 6: Participants' nursing work experience**

	<b>Participant (pseudonym names)</b>	<b>Title</b>	<b>Years of nursing experience</b>
1.	Roimata	NP	15
2.	Waimana	RN	6
3.	Ani	RN	15
4.	Maia	RN	3
5.	Hinekaha	NP	15
6.	Manawa	RN	13
7.	Koa	RN	2
8.	Rona	RN	7
9.	Mihi	RN	9
10.	Rata	RN	30+

All nurses had whakapapa links to Te Ika a Māui (North Island) iwi except one who had connections to Te Waipounamu (South Island). The nurses were committed to having their voices heard on the kaupapa, and improving health outcomes for whānau, hapū and iwi. Pseudonym names have been used.

### **Theme 1: Patient Choice**

Patients having choice about their treatment decisions was part of their journey, and the role of nurses was to support them and their whānau. The outcome Māori nurses desired was that patients died with dignity in accordance with their choices. *Patient Choice* has three key dimensions that involve nurses' actions, their views and their trustworthiness. Nurses talked about making a transition from their personal role to their professional role. This transition involved both physical dimensions, such as putting on their uniform, and separating their personal views from those associated with professional nursing. Maia explained how she moved into her professional role:

*Putting on the uniform, I am now a registered nurse and my patients really become my sole priority, no longer my personal views. (Maia)*

Nurses understood their need to demonstrate they were trustworthy. They did this by connecting with the patient and whānau in authentic and credible ways. This process of connecting was seen to be vital for building the relationships they had with patients and their whānau. Roimata talked about the importance of honouring a patients' choices:

*It means that you are on the same journey. That you are assisting someone who's dying, and you are taking that final step with them to support them in whatever means to make their dying comfortable in whatever shape or form that means. It is not an easy journey. But you know more. The better we can make it for them means we would be making sure that they don't have to worry about, or they don't have to sweat, the small stuff. (Roimata)*

How nurses viewed the patient's role in their end-of-life journey involved prioritising their right to choice — that included the choice to assisted dying. The right of choice also involved the inclusion of whānau through this time. Waimana explained the consequences of not connecting with patient and whānau:

*If I don't connect on some level, then there's no trust and there's no dignity for the patient towards their whānau. Because if I'm not genuine and authentic, then I'm doing a disservice to their whānau member and a disservice to my own values. (Waimana)*

*Patient Choice* has two sub-themes, *Assisted dying* and the *Role of whānau*.

## **Assisted dying**

Māori nurses discussed their views on *assisted dying*. *Assisted dying* has three broad dimensions that involved the nurses' personal interpretation of *assisted dying*, understanding the burdens associated with assisted dying, and the patient's journey to te ao wairua or the spiritual world.

Assisted dying included asking someone to help or assist in a process to end their life, receiving medication or an injection from a health professional, and dying on a particular date. Maintaining a patient's dignity and right to informed choice were essential to nurses' own definition of *assisted dying*. Hinekaha explained that:

*My assisted dying definition is that I'm just helping them in their process until they pass away. It obviously means, you know, going in and having an injection given by a health professional and you're going to die on this date. (Hinekaha)*

Accompanying the *assisted dying* process was a sense of burden that Māori nurses held associated with upholding and promoting dignity and mana of the patient and their whānau. Waimana expressed her own personal struggle to maintain mana and dignity at the end-of-life:

*I don't want to leave people behind [if I chose assisted dying]. If it was me, I wouldn't want them to carry the burden of trying to maintain my mana and dignity. I wouldn't want them to feel that they were actually releasing me to something more wonderful than what is here on earth. I believe that anything [death with dignity] can be settled with, good karakia and with aroha and pono and tika. (Waimana)*

Patients' journeys when they died included leaving the physical world to ascend to te ao wairua or the spiritual world. Nurses explained te ao wairua or the spiritual world journey including wairua leaving one's physical being or physical realm behind. In doing so, they believed a person's wairua or spirit carried on to the next life or the next journey. Manawa expressed her understanding of this spiritual journey:

*I think it's interesting to know what they did back in those days you know how on the spiritual side of things because we know in te ao wairua moving from this plane to the next plane is just another journey. Sometimes you're only dying*

*physically but your wairua carries on like, it's a light beam. The Tohunga knew this, that the wairua was just carrying onto its next journey from here, it's just the physical body that they're leaving. (Manawa)*

## **The role of the whānau**

The second sub-theme is *the role of the whānau*. It has two dimensions: first, acknowledging the role of the whānau as part of a loved one's care. The role of the whānau was an inclusive part of a loved one's care was essential to the assisted dying process. Nurses demonstrated this by including and acknowledging the whānau. This involved nurses accepting whānau as part of their patient's' death journey and enabling the whānau opportunities to express their needs alongside their loved one. Manawa clearly expressed this:

*Assisted dying is not just about the actual medication, helping that person to go, it's about assisting the whānau as well to get through that process. (Manawa)*

The second dimension involved nurses facilitating or creating space to educate and empower the whānau to be involved in the loved one's care. Nurses demonstrated this by facilitating teaching whānau about the signs and symptoms of impending death, encouraging their questions, and calming them regarding the fears they may hold about their loved one's death journey. Nurses also talked about facilitating whānau to be actively involved in nursing tasks, such as providing mouth comfort cares, assisting to position pillows, so that whānau could spend time with their loved one. Ani expressed this by teaching whānau about the signs of death, encouraging them to reveal their fears and involving them in cares:

*I facilitated and showed the whānau what the tohu (the signs) are and then this helps to calm the whānau. It's how to empower the whānau to be involved. What it means for staff to step back and encourage and allow the whānau to be involved in patient cares. Teaching them - here's a cup of water, here are the mouth salts, you guys, you know every time you think mum's got dry lips you grab this and show the whānau how to do it and taking a step back. Facilitating the whānau to know where pillows go to position the feet or facilitating the whānau reading the signs of breathing. This involves the whānau because they want to be involved – it's their manaaki, that's their aroha. So few people in the medical profession will take a step back. Will empower the whānau by showing them little things that they can do. (Ani)*

## **Theme 2: Tapuhi kaitiaki**

The term tapuhi kaitiaki describes the breadth of Māori nursing, which includes practice informed by te ao Māori (Māori worldview or perspective) alongside the clinical components and skills of nursing. This includes demonstrating the use of whakawhanaungatanga, tika, pono and aroha in patient and whānau care and in ensuring their own cultural safety.

Tika, pono, and aroha, cultural and clinical skills and cultural safety were central to having Māori nurses' practice validated by whānau or acknowledging a nurse's trustworthiness, expertise, and culturally safe or appropriate nursing practice in patients' end-of-life journeys. *Tapuhi kaitiaki* theme has four dimensions including the use of tika, pono and aroha in nursing practice, validation of nurses' practice, culturally safety, and being clinically and culturally competent.

Māori nurses demonstrated the use tika, pono and aroha in their end-of-life clinical practice through their interaction with patients and their whānau during nursing assessments during patient home visits. Hinekaha demonstrated whakawhanaungatanga with whānau during home visits and using tika, pono and aroha as part of patient health assessments:

*Tika, pono and aroha is pretty much entwined into the kōrero and the way you present that kōrero. It's your physical wellbeing, how you sit with someone, how your facial expressions entwine all of that, you're always active, actively listening for the patient. This happens during the physical examination, education session and when discussing plans. You are always looking for an understanding or any misconceptions that they hear your kōrero and the correct information they need to maintain their wellness. (Hinekaha)*

Nurses also felt validated by patients' whānau for their nursing practice by their acknowledgment of the nurse's trustworthiness, expertise, and cultural safe or appropriate nursing practice. Whānau validation of nurses' practice involved whānau returning for further care, telling nurses they did a good job, and recommending a nurse's practice to other whānau members. Mihi expressed that she knew she was providing a high quality service and culturally appropriate care when whānau were recommending her to other whānau members:

*It can cause a big burden on me because you know when you do a really good job you have whānau coming back asking for you. I know that's kind of like my job satisfaction, you know that satisfies me. They'll be able to see you cared for their whānau and come back and say, "Oh, you know you did a really good job." You need to look after me too, that kind of thing. (Mihi)*

Participants spoke about reflecting on their own cultural safety by questioning how they were tika, aroha and pono, demonstrated; cultural knowledge; maintained their own cultural safety in their practice. Koa explained how she used tika and pono in her nursing practice to protect her own wairua:

*Sometimes it's about my tika and pono for my practice – protecting my wairua (water outside of a room to keep me safe). I give it back to the person I suppose, go with them, follow my own guidance to keep me safe but allow them to be their own and provide them care. (Koa)*

Being both clinically and culturally competent included using tika, pono and aroha in their nursing assessments or practice with patients and their whānau. Hinekaha explained how she used tika, pono and aroha as part of her patient nursing assessments:

*Tika, pono, and aroha pretty much follows you around (in your nursing practice). You really can't walk into a home and not use it. It's just part of your cloak, during your health assessment, you provide your first initial assessment with the patient, you're using whanaungatanga during the health assessment stage. (Hinekaha)*

Tapuhi kaitiaki has three sub themes: *whakawhanaungatanga*, patient safety and workplace environment — what is needed.

## **Whakawhanaungatanga**

Establishing kanohi-ki-te-kanohi relations through sharing whakapapa, building trustworthiness, having the right attitude and heart, and aroha or generosity of spirit is essential to *whakawhanaungatanga*. Nurses demonstrated this in their practice of *whakawhanaungatanga* in the care of patients and whānau. *Whakawhanaungatanga* has three dimensions; establishing kanohi-ki-te-kanohi relations, having the right attitude and heart and demonstrating aroha or generosity of spirit.

Establishing kanohi-ki-te-kanohi relations is a respectful way to cement a trusted patient, whānau and nurse relationship. Nurses believed introducing, sharing or connecting whakapapa with patients and their whānau was their number one priority. This included practising *whakawhanaungatanga* at the start of their shift. Maia demonstrated *whakawhanaungatanga* at the start of every shift:

*Respect for patients and whānau is very high and having kanohi-ki-te-kanohi is very important to me as well. I would not go a day or a shift without introducing myself first to my patients before I get into anything else. Because I like them to know who I am, you know, and I like to know who they are and how was their night or how are they going or if they need anything. (Maia)*

It is essential to have the right heart and attitude when engaging with patients and whānau. Nurses believed the right heart and attitude were essential to *whakawhanaungatanga* and engaging with patients and their whānau at the end-of-life. Rona expressed the importance of having the right heart and the right attitude, and treating every whānau situation with flexibility to adapt to their needs:

*This is what I love to do. If you don't go in with the right heart and the right attitude. It's never the same as the last one (patient). You can never walk into a home thinking, "Oh, this is easy, I did this the last time." It's all different and everyone is different with what end-of-life looks like and feels like for them. If you can't fit into what that is, then, you shouldn't be there. And that's what tika, pono and aroha is for me. I don't go in there with a preconception about what I should do. The only knowledge I go in there with is that they haven't got long to live. How can I make what they do have left quality and what can I offer them and the family at the time. And for me I don't put any limitations on what it might look like. (Rona)*

Essential for establishing connections was demonstrating Māori values of kindness, compassion and generosity of spirit occurred by sharing resources with those struggling or living in poverty. Nurses demonstrated aroha, kindness, and generosity of

spirit by taking koha of huawhenua (vegetables) from their own gardens when they visited patients and whānau who they knew were struggling, living and dying in poverty. Roimata expressed her aroha ki te tāngata by taking huawhenua from her garden to share with whānau:

*You know to give aroha, manaakitanga, whanaungatanga, it just comes naturally and what we have you and what you do it's always to humble ourselves and to provide the service. Often it just comes out of you. I know a lot of nurses will do whatever it takes, even if we have to pick veges from our garden. We will do it for the whānau because it is that connection with Māori that they are part of us, and we are part of them. Whānau are living in poverty and will probably die in poverty as well. Some patients have nothing. Even to make sure that the whānau are aware that you will support them right to the end after the tangihanga. (Roimata)*

## **Patient safety**

Ensuring patients were supported to make their decision based on an informed view, understanding their prognosis, and having whānau support is important for both *patient safety* and end-of-life cares. *Patient safety* has two dimensions: awareness of patient rights and the role of supporting patients in their decision.

Making sure patients were informed, aware of their rights, and supported to make their decisions was important. Nurses demonstrated their awareness of patients' right to choose, and their role in ensuring patients were safe to make informed decisions. Maia demonstrated her awareness of ensuring patients were informed, understood their rights and their decisions:

*Patient safety is ensuring that my patient is aware of that pathway or that decision they are choosing. I make sure that the patient's comfortable with their decision and make sure that whānau are aware of the decision being made and I am there to tautoko the whānau as well as the patient. (Maia)*

Nurses believed that assisting patients to make their informed decision did not include imparting their own personal views but supporting patients in their decision-making and decisions. This included a duty of care as a nurse to ensure that patients had all the information to make an informed decision, making sure the patient and their whānau understood their choices, and that as a whānau they felt comfortable deciding about their care. Patient decisions did not include or require nurses imparting their own personal views. Koa explained the importance of always supporting the patient's choice, which did not include her own views:

*My views and everything like that is not important. It is always about [the] person's choice. We don't always understand the choices people make but it's still their choice. You know, still always their choice. (Koa)*

## **Work environment**



Ensuring staff feel culturally safe in the *work environment* improves the health and wellbeing of all staff. Work environments did not always reflect Māori nurses' cultural needs, personally or professionally. This included other staff having an awareness or understanding of staff cultural needs and an understanding of tika, pono and aroha in nurses' practice, and their need for cultural professional supervision and facilitated debriefing sessions after patients' deaths. *Work environment* has two dimensions: staff cultural requirements and the need for debriefing sessions after patients' deaths.

Nurses identified that having other staff to work and talk with, who shared their cultural worldview, was extremely important. This required an awareness and understanding of cultural requirements, essential in any work environment. Koa explained that in her workplace there are only a couple of Māori staff, who do not necessarily work on her shift. This limited Koa's interactions and her ability to have her needs and cultural requirements met:

*I've got a few colleagues at work that I feel I can go to and talk about things, but not from a cultural understanding. I need other Māori staff member[s] to talk to from a Māori point of view. It's not that it's not understood, it's just not the same talking to someone that doesn't understand it, you know. And I find myself not giving as much information as I would with someone that understood that. (Koa)*

Having closure, allowing staff and whānau to acknowledge a patient's passing and ensuring staff have an opportunity to have a debrief or engage in a poroporoaki session were all important in end-of-life care. Nurses demonstrated that this process was important for the wellbeing of staff and whānau and included activities such as attending the patient's tangi, having time to grieve and paying their respects with the whānau. Hinekaha expressed how much she valued debriefing with other staff and whānau after a patient's death:

*It would be really nice to have someone to debrief with afterwards. So often the focus is on looking after these patients and then towards the end I will attend their tangi as well. Ensuring I go through the whole grieving process, I usually go and see the main carer, and those whānau that I would see with the patient. Just to see or check that they're doing ok. I have a debriefing session or poroporoaki with them because you can get quite close as you've looked after them for three years. (Hinekaha)*

### **Theme 3: Barriers to care**

*Barriers to Care* in end-of-life are well-known and evident in Aotearoa New Zealand. For Māori nurses this extended to having an awareness, understanding, knowledge, frustration, and distress in response to the impacts of structural and systemic barriers affecting patients and their whānau receiving end-of-life services. Examples of barriers to care encountered, included funding inequities; whānau living in poverty,

inconsistencies in hospital and community processes, co-ordination of services, discharge planning, communication with whānau and respecting tikanga or cultural practices. Nurses felt strongly that the system needed to change to provide better support for those dying and who had the greatest needs regardless of where they lived. *Barriers to care* had two key dimensions that impact on end-of-life nursing care: *funding inequities* and *living in poverty*. Nurses' resilience, in spite of the impacts of these barriers, was aided by whanaungatanga, generosity of spirit and manaaki as part of their daily nursing care with the aim to provide high quality and culturally responsive patients' and whānau care.

Existing *funding inequities* were evident and did not assist those with the greatest need. Nurses indicated funding decisions were not always fair or based on patients' needs; rather, the funding only extended to those patients who had specific conditions or diseases, such as dementia, Parkinson's disease, and specific types of cancer. In spite of their distress, nurses were resilient about ways that they could provide care on limited resources. Roimata expressed her distress that funding was not available to those with the greatest needs, while other patients were able to receive specific funding for simply having a diagnosis of cancer:

*We had one lady who had cervical cancer and funding was available for cervical pads. Someone had written to the Prime Minister and the CEO of the hospital to get funding. It's difficult when someone dying [that isn't due to a specific disease] doesn't get funding. What happens to that whānau who are desperate for help? There needs to be a pool of money available to access. Just for the little things, like making their houses warm or getting them to their appointments that they shouldn't be worrying about when they are dying. (Roimata)*

Distressed about patients and their whānau struggling to make a living to support their loved one who was dying in poverty meant nurses used a variety of ways to support patients and their whānau. This included providing blankets, vegetables, curtains or sometimes giving koha putea (a gift of money) to pay for chemist bills or put petrol in the car. Roimata supported and managed patients and their whānau in her community who were struggling by taking items from her own home (vegetables, blankets, and curtains) or by paying patients' bills at the chemist so that they could access medicines:

*Our whānau are dying in poverty. I know I might take a blanket, some vegetables, or curtains, or it might be some putea, some money for their car to get to the garage, or pay [a] bill at the chemist. If you got 6 months to live you don't really get much because you are not entitled. So, where's your extra money coming from. If you do have caregivers, then Work and Income New Zealand will make it really hard for that person to look after the whānau member if they are behind sometimes. (Roimata)*

*Barriers to care* has one sub theme: *exacerbation of inequities and gaps in care*.

## Exacerbation of inequities and gaps in care

Current inequities and gaps in care are exacerbated by inconsistencies in nursing care, poor communication between service providers, and staff not following their own tikanga and cultural protocols. This exacerbated the inequities and gaps in care that patients and whānau endured, and impacted Māori nurses care delivery.

As a result Māori nurses encountered distressed whānau about the lack of co-ordination they believed they would receive when their love one was discharged. As a result many felt abandoned. Examples of this abandonment included service providers not turning up at scheduled times, equipment not being delivered, no education on how to use equipment at that was delivered, and no consideration for space in whānau whare. As a consequence, Māori nurses bore the brunt of whānau anger which added to their workloads. Manawa was visibly upset at how a distressed whānau who had been abandoned, despite referrals being sent to hospice services, were not getting the help they needed or deserved:

*I turned up to do a whānau assessment but ended up staying way after my shift. The whānau were very angry. The hospice services had not turned up, despite referrals being sent before they left the hospital. I see this happening all the time. The ambulance staff had taken them home, chucked their dad on the bed and left them with all the equipment and did not show them or communicate how anything worked. No one had told the family what the pain medication pump was for, or how to use it. The family freaked out. No one had communicated with them at all. So when I got there they were ropeable. They were so scared and anxious about their papa being in pain. They asked me what happens if he passes away what [do] we do. I had to support them and to explain what was happening. I said to them to just be with papa, allow him to go and let him know it's okay to go, help him pass from this world into te ao wairua. (Manawa)*

Constantly checking and rechecking aspects of a patient's discharge care planning is an additional administration task which is time consuming. Mihi spoke of having to make doubly sure that referrals to services were sent and checked to see if they were received, and that services were available to deliver the services on a specific day before whānau left the hospital:

*Pre-empting a lot of whānau needs means organising services before that whānau needs them. If this is a hospice, we as nurses and doctors need to get our referral processes right because, from experience, I've heard stories of whānau going home to die and referral processes haven't been done. Or other stories of whānau that get discharged on a Friday and service doesn't kick in on until Monday. (Mihi)*

Communication is the key or essential link between patient, their whānau and the health professional in end-of-life care, including ensuring that everyone feels well informed, respected and safe. Manawa spoke about communication being the key for whānau to understand and feel safe:

*Communication is key for whānau to understand these things. So they're at a time of mourning, you know, and being left alone like that was really unsafe, not knowing what to do. If I had not been at that home at that particular time, this whānau was at risk of being unsafe. They were panicked not knowing what to do. By the time I left the house, people were hugging each other and they were getting the beds ready and you know we had karakia and waiata (song). (Manawa)*

Inconsistencies in organisational tikanga or cultural protocols meant that nurses did not always feel culturally safe in their workplace. Blessing patients' rooms after someone died was repeatedly mentioned as an area of concern if staff or chaplains were unavailable or if the person died after hours. Waimana often advocated for trained staff to come and perform karakia, more often when they were not available, Waimana carried out this duty herself:

*Often the ward doesn't wait for our rooms to be blessed, which is a time management issue. We're so under the pump and we don't have enough beds and we just have sick people, coming all the time. As soon as one's gone the next one's got to come in. I will actually stick my neck out now and say no the room hasn't been blessed. And if we are so pushed for it [the room], we are supposed to have our managers come in and do it right, hospital managers or the chaplains and if they can't get in and do it, oh I just do it myself, I just do it myself. I take it upon myself to bless the room and bless the people that have been in there and bless the person who is leaving and then bless us to clear it for our next person that we're going to look after. (Waimana)*

#### **Theme 4: Cultural safety of patients and whānau**

Awareness or knowledge about the differences between indigenous and Western cultural views remains undervalued, and overlooked in clinical environments. Cultural safety of patients and their whānau and understanding the importance of whānau visits was crucial in upholding the mana of patients and their whānau. This included paying respect, acknowledging tribal status and whakapapa of the person dying and their whānau, which is often in violation of hospital policies that aim to restrict and limit whānau contact.

Manawa expressed cultural differences between indigenous and western views, focused on a whānau approach rather than a single or individual approach:

*Cultural differences exist between indigenous and [a] Western view. It's that we are used to thinking as a whole, not as an individual or a single thing. Instead of just being focussed on the person dying I would focus on the whānau around that person. Indigenous nurses, we're really good at that stuff, that's the point of difference. We go the extra mile. (Manawa)*

Ani also spoke about the difficulties she faced trying to uphold tikanga for the patient and whānau, while working in health facilities that did not value or see the importance of whānau visits:

*I would like to see facilities be a little bit more sensitive to whānau. Every whānau that comes through [the facility] has their own dynamics or raruraru (problem or troubles). We had whānau member [the second or the third wife and husband's children] coming to visit and they're upset and swearing at the present wife who has the EPOA [Enduring Power of Attorney]. It's that kind of dynamic which brings raruraru into the ward that needs a discussion about tikanga. Our facility managers often shut the facilities down and put restrictions on whānau or try and to not allow full whānau to come through and visit. In my opinion this makes it difficult to manage whānau cultural considerations and nursing practice. Whānau will want to stay and as a nurse, I will want the whānau to stay with their loved one. But, other nurses will often see it [whānau staying] as a health and safety issue because they can't get in to the room, they can't access, they can't deliver care, they can't get to the pump, all these things, and technical difficulties around working with a patient in a cramped room when you've got lots of whānau there. (Ani)*

The extent and importance of manaakitanga was not always understood by nursing colleagues including the benefits of kai (food) as a tonic for the person; meaningfulness to the whānau; restoring 'ora' or life for the unwell person; and demonstrates aroha for the person's status or mana. This included bringing delicacies (many of which have strong odours) for the dying person who may be craving kaimoana (seafood), kina (sea urchins) boil up (pork bones and watercress or puha (sour thistle), fish, eels, rotten corn, mussels and certain cheeses. Maia spoke about her experience of whānau bring kai for sick and dying patients, and her colleagues not understanding or valuing this koha or gesture:

*I've actually seen whānau being told not to bring certain foods in because of the smells and effect on other people. The kai was about whanaungatanga and manaakitanga for the whānau. They were just coming in [from a position] of aroha and love and, and then you have someone comes along from a total different cultural background, with no understanding of what that means [cultural importance] to have that it's almost like your kind of poroporoaki (farewell or final goodbye) without it being that. The whānau probably broke their backs to get that you know. They wouldn't just go to the supermarket [these kai are not available in the supermarket and whānau would spend a lot of time gathering and preparing these cultural important kai]. (Maia)*

## **Silencing of cultural views**

Cultural perspectives on nursing care and end-of-life care were often silenced. Nurses gave examples of instances where their voice, opinion or cultural perspective was treated in a tokenistic manner by other staff or their input was not presented or included in the final report or decision. In these instances, nurses were distressed that often the decision were being made on a cultural issue by non-Māori staff. Rata spoke of the difficulty to get her perspective heard on the cultural needs of whānau when her colleagues had no understanding of the cultural perspective:

*I am here for a purpose, so I have strong feelings in my mahi and I know I'm guided by the needs of the people. It's not so much as left out [their opinions or perspectives] they do have a voice but it doesn't seem to be heard. It seems*

*tokenistic. It's often like we have Māori input, there is a lot of talking but not much action in decisions. One of the problems here for Māori, is non-Māori calling the shots or making the decisions. (Rata)*

Some nurses wanted support to engage in learning about their cultural knowledge and to be guided by tikanga Māori using tika, pono and aroha as part of their clinical practice.

*Māori nurses are not going back to their whānau, hapū, iwi they're not going to wānanga held by their own, in their rohe (district). They're not engaging. We have our own hui maramataka, (traditional Māori lunar calendar) the moon phases and understanding the impacts of our indigenous knowledge. We need more Māori nurses who actively engage in te ao Māori. We need to empower nurses, so that they can be culturally empowered and engaged with te ao Māori outside of nursing. (Ani)*

### **Needing Wrap around services**

Needing wrap around services was essential to improve nursing services. The wrap around services required included increasing the number of Māori health units; wrapping around services for whānau; and providing better whānau spaces for patients and their whānau to have privacy to grieve. Nurses believed that Māori health units helped to nurture cultural knowledge, understanding and support for whānau and staff. Waimana spoke about the 'added value' of tikanga Māori guidance and knowledge that Māori health units provided for Māori and non-Māori staff about te ao Māori perspective:

*They [Māori health units] nurture whānau that I am looking after, as well as guide us [Māori nurses]. I think they're [Māori health units] there to guide our non-Māori colleagues, than to guide me. Because we work together and side by side whereas others, you know, don't. It's great for me I love the team. (Waimana)*

Having access to support provided by Māori health unit staff was valuable and helped Māori nurses better respond to patients' and whānau requests to access tikanga Māori and cultural support. Nurses said that having other Māori staff to provide guidance supported their own wairua and cultural learning. Maia expressed how much she valued the Māori health unit tautoko that supported her nursing practice:

*I am always referring people to them, I just love dialling the Māori unit. I should have them on speed dial in my cell phone. A lot of people don't even ring them as they don't ever think about using that resource. I don't know if it's a lack of understanding or that they believe it's only for Māori to access. I ring them all the time for anybody that needs something. (Maia)*

Nurses were desperate for practical help and wrap around services for whānau including; services to support whānau with shopping; putting food in whānau cupboards; heating cold houses; and transport to health appointments. Rona strongly advocated for wrap around services to support whānau:

*It's about how can I assist the whānau family in my role, sometimes even after the patient has died. So I'll support them you know as much as I'm able to do. So often it's about getting them kai. I can get them food grants straight away they don't need to come in, I just get them to put the money on the card and I take the card to them. Often the houses are cold. I am lucky I have a direct relationship with Well Homes and I'll ring the manager and say I need this and this and this please and I will go and pick the stuff up and get it to them on the day. (Rona)*

Nurses wanted to urgently address access to whānau rooms including; having access to a range of different sized whānau rooms; to accommodate whānau needs; to reduce unnecessary stress on whānau who want to stay with their dying loved one but being restricted by the size of whānau rooms. Ani spoke about the need for larger whānau rooms to accommodate whānau, with access to kitchen facilities:

*If I could ask for one thing it would be for larger whānau rooms. At the last facility I worked at, the whānau room used to be the hairdresser's room, so it was small and it didn't really accommodate a small [one or two people] whānau, let alone a Māori whānau who need a bigger room for whānau to be in. It would be great to have tea and coffee amenities provided for the whānau. (Ani)*

Nurses expressed their concern with hospital restrictions that impacted on whānau in critical settings that did not support manaakitanga including; access to a place to rest; food and drinks; and the number of whānau able to stay. Waimana expressed her concerns at the loss of her unit's whānau room and how hospital restrictions impacted on whānau who travelled to visit their dying relative who did not have access facilities to have a rest, a kai and a drink:

*We have got signs all over our whānau room, saying patients have rights and need whānau space. Then our small whānau room was changed into an interview room, which is locked and only used for family meetings. It's because staff don't want whānau being in there taking over or occupying space when there are palliative people in critical care beds. There's no access to food or drinks. The whole not eating and drinking for whānau who have travelled from far and wide to see people or that aren't allowed to replenish and recharge and self-care in times of tragedy. That really annoys me. (Waimana)*

## **Conclusion**

In summary, the chapter showed rich and diverse views, which were grouped into four main themes and sub themes identified from findings. Discussion in this chapter included understanding Māori nurses' perspectives of assisted dying on their nursing practice and discussed assisted dying as part of the options of end-of-life care. The themes reflect the need for Māori patients and whānau having choice about their treatment decisions was part of their te ao wairua journey, and the role of nurses to support them and their whānau and how important whānau, whakapapa and whanaungatanga and kinship identity are to being Māori and in aiding patient wellbeing. Further, how tika, pono and aroha helped to guide participants in their nursing practice

both from clinical and cultural dimensions. This chapter also highlighted nurses' desire that patients died with dignity. Disparities in health and barriers to end-of-life care were also discussed. The need is evident to have Māori nurses' voices represented within studies, helping to guide future areas of research that may affect them.



## Wāhanga Tuarima – Chapter Five: Discussion

### Privilege me

*How do you tell your own stories through others' lips?*

*How do you tell your truths through other's eyes?*

*How do you nurture your wairua, carry your tūpuna on your shoulders and stand tall in their lies?*

*Privilege me*

*The brown tapuhi views*

*Privilege me*

*Bicultural waka blonde*

*Privilege me*

*Manawāhine e tūturu nei*

*Whakarongo mai, we have a lot to say*

*Stop silencing me with your white lies,*

*Your arrogant pink mainstream*

*Overemphasised defiance*

*Polluting my hinengaro and choking my wairua*

*With your over talked, over opinionated voice drowning out and standing on my silence.*

*Ka oho mai, maranga mai ngā tapuhi, wake up, rise up!*

*E hī ake ana te atākura, Tihei Mauri ora!*

*Its your turn to shine, a new day is dawning. (Manson, 2020).*

Currently, there is no single or clear approach to assisted dying, just as there is no single view or approach to Māori death and dying. This thesis offers valuable insights into Māori nurses' perspectives about what is important in end-of-life care, which can provide cultural considerations to inform nurses' practice. This chapter includes an interpretation of the findings, research question and aims. Woven throughout are values of tika, pono and aroha to uphold the mana and integrity of the participants, who are Māori nurses working in end-of-life care settings.

In the wider context of health, Māori nurses are structurally disadvantaged within a non-Māori nursing-dominated culture. Additional sections in this chapter are aimed at providing critical debate and general discussion about Māori nurses in the wider Aotearoa colonial, historical and social contexts. This includes an interpretation of the wider systemic barriers that impact on Māori nurses' practice in the New Zealand health system. Accordingly, the influences of colonisation, marginalisation, racism, bullying, bias and dominant white nurse culture have contributed to the invisibility and silencing of Māori nurses' voices. I have examined these influences as barriers that impact Māori nurses working with whānau, hapū and iwi in end-of-life care settings.

Understanding the connection between life and death and validating communities' different perspectives is important, particularly for those health professionals who work closely in life and death situations. Critically, the lived realities of Māori nurses and their voices or perspectives are currently lacking in the end-of-life care research in Aotearoa New Zealand. Any improvements to health equity must ensure Māori nurses and their whānau are involved in shaping future health and nursing practice.

A Māori worldview sees life and death as equals on a continuum of ora, the living or health and wellbeing of the individual, whānau, hapū and iwi. A delicate balance is maintained through laws of tapu (sacred), and systems of customary practice and ritual, whereby a person lives in harmony with the natural, physical, and spiritual world (Ngata, 2005). This interconnectedness through whakapapa extends beyond a person living within whānau, hapū and iwi but also with their ancestors, land (whenua) and environment (Mead, 2003). Fleming (2018) confirmed that "as Māori, we are born from the earth and we return to the earth when we die as is whenua (the placenta or land) that is returned to the earth upon the birth of a child" (p.27). This section also explains the connections through whanaungatanga, the interwoven whakapapa between Māori myths, the living and the dead, and the central roles of Māori women, land and whānau. There are also similarities between the role of Māori nurses and women in Māori myths as the nurturer, protector or guardian of people both in life and death. Participants spoke about assisted dying being more than the task of administering the medications. This included guiding and protecting and nurturing the patient and their whānau through the assisted dying process and journey both in life and death.

Oetzel et al. (2014) confirmed that currently Māori underutilise palliative care services even though more culturally relevant services are now available. The need to connect with whānau, hapū and iwi and be at home during the end-of-life journey is one reason that Māori avoid palliative care services unless they can be offered in their home. Bellamy and Gott (2013) confirmed that Māori are more inclined to be 'hands-on' when

caring for loved ones faced with the end-of-life journey in order to ensure balance, unity, and harmony. This study confirms participants believe that assisted dying was an accepted option. However, barriers continued to remain in end-of-life care delivery. Barriers to accessing information, resources, and funding for patients and whānau were articulated by participants. In this chapter, I also intend to discuss the key implications of the findings for Māori nurses and their practice despite participants working in a Western medical system that does not value a Māori worldview.

A significant finding in this thesis was that whakawhanaungatanga is an extension of the patient, whānau and nurse trust relationship interwoven with a Māori worldview and the patient's and whānau te ao wairua journey. Participants believed cultural considerations like whakawhanaungatanga were often overlooked, not acknowledged, valued, or understood as part of nurses' practice. This included understanding and being guided by tikanga Māori using tika, pono and aroha as part of their clinical practice. Participants were aware that they needed to demonstrate they were trustworthy. They did this by connecting with the patients and whānau in authentic and credible ways using whakawhanaungatanga, whakapapa and manaakitanga. This link between the past, present and future and connections through whakapapa links to tūpuna and future mokopuna (grandchild) can be found in King's (1992) whakataukī:

*Te Ao Hurihuri ai ki tona Tauranga te ao rapu ko te huripoki e hurinei i  
runga i te taumata o te kaha*

Te Ao Hurihuri is a world revolving, a world that moves forward to the place it came from, a wheel that turns on an axle of strength (p. 191).

This whakataukī suggests that a Māori world continues to evolve forward without ever forgetting the link to the past, present or future, which is the right platform to discuss and debate contentious issues.

## **Importance of Whakawhanaungatanga**

The literal meaning of the word whānau is often translated as 'family' (Walker, 2017). However, it has a more complex meaning that is based on whakapapa and includes physical, emotional, and spiritual dimensions (Walker, 2017). The importance and benefits of whakawhanaungatanga are often underestimated or undermined in clinical practice settings. The simple Māori phrase, Ko wai koe? or who are you? invites sharing wider whakapapa connections to people, places, mountains (maunga) land, rivers (awa). The whakapapa relationship between the land and health are interdependent (Fleming, 2018). This includes the spiritual dimensions of tūpuna

(ancestors), the environment and the holistic balance and health and wellbeing of the land and the people, which are all intertwined.

In general, participants believed that whakawhanaungatanga was an extremely useful way of connecting, sharing whakapapa and important in introducing and establishing a relationship. The findings confirmed that participants choosing to engage in whakawhanaungatanga is just as valued and important to patient wellbeing as are their clinical nursing skills. This was evident in the value that participants placed on whakawhanaungatanga and its use in clinical practice for connecting with whānau using whakapapa and wairua. Lyford and Cook (2005) confirmed that in a clinical environment, whakawhanaungatanga is the central dimension for participants and was practised in their nursing clinical roles with whānau throughout Aotearoa New Zealand. Further, Parry Jones et al. (2014) described whakawhanaungatanga as having a purposeful cultural focus aimed at health professionals establishing a connection with the patient and their whānau instead of rather than identifying it as a greeting.

Participants prioritised whanaungatanga at the start of their shift, making it the first thing that they did. Quality time spent with patients was an important factor in developing a connection and a positive relationship (Carlson et al., 2016). Furthermore, prioritising or valuing whakawhanaungatanga is a key concept that is broader than just kin connectedness or as a task, but focuses on a group rather than the individual (Bishop, 1995). Participants prioritised kanohi-ki-te-kanohi engagement processes differently compared to their colleagues who focused on their duties based on nursing tasks. This commitment to whanaungatanga highlighted the importance of establishing relationships and building trust, something not to be rushed, ensuring the prioritisation of patient and whānau care needs. This face-to-face communication is a key principle of being and practising as Māori as it allows one to not only see who or what one is communicating with, but also to hear, feel, and smell the relationship (Ngata, 2017). It gives mana to one's kōrero (O'Carroll, 2013). This extended to a greater dimension than just the physical presence and relates to mana tāngata (status of the person) and a person's credibility in words, actions, and intentions with the sense of honesty and truth (O'Carroll, 2013).

Participants described the connection between whakawhanaungatanga and whānau wellbeing as an effective process to reduce stress, restore calm and find solutions to address inequities in service provision and find better outcomes for whānau members. This connection provided comfort also for the participants who felt a whakapapa link to the people, the land and their hapū and iwi. Whakawhanaungatanga has been described by Parry et al. (2014) as a critical concept that benefits engagement with Māori patients and their whānau both from cultural and clinical aspects.

Furthermore, whakawhanaungatanga is based on key cultural principles that acknowledge the interwoven and interrelationship between an individual, members of the whānau, immediate and extended family, community and wider society (Parry et al., 2014).

The concept of patient connectedness has some similarities to whakawhanaungatanga as it is instrumental in demonstrating a respectful relationship between patient, whānau and the nurse, which assists in gaining the patient and whānau trust. Mitchell (2007) described patient connectedness as the bond that develops between a nurse and a patient. This bond reinforces how trust and integrity are vital for quality and effective patient care and for better health outcomes. The term patient connectedness is used to describe “a relationship that begins at the moment of initial contact between nurse and client with recognition that the relationship itself is integral to the nurse's ability to model the client's world” (Erickson et al., 2006, as cited in Mitchell, 2007, p.79).

The overall aim of participants establishing a strong patient-nurse relationship based on whanaungatanga was to ensure that patients died with dignity and mana at the end of their lives. This was evident in participants valuing their duty of care as nurses to ensure patients had all the information to make an informed decision, and would honour patients' choices. This meant that participants ensured that they supported their patients to make their final choice by supporting them in whatever way to make their dying comfortable. This meant ensuing patients were supported to make their decision based on an informed view, understanding their prognosis, and had whānau support. The following whakataukāi describes the importance of whakawhanaungatanga, connecting through whakapapa to establish trusted relationships:

*He kitenga kanohi, he hokinga mahara, he koanga ngakau*

A familiar face stirs one's memory and the emotions that are associated with that memory bring joy (Pihama et al., 2019).

This whakataukāi evokes a sense of positive wairua when meeting people and that we are not only connecting to them but to all the memories and ancestors they represent (Pihama et al, 2019). Bishop (1995) confirmed that whakawhanaungatanga is one of the most fundamental concepts within Māori culture, both as a value and as a social process for connectedness and engagement. The process of whakawhanaungatanga links the use of Māori metaphor creating a sense of familiarity, support, and shared concern (Bishop, 1995).

Participants indicated that whakawhanaungatanga was an effective process to connect with whānau who were distressed and angry with the health system in delivery

of care services. This relationship with health professionals often existed outside of the consultation room just as much as inside, such as whakapapa, manaaki, reciprocity, friendship, and shared interests (Carlson et al., 2016; Wepa & Wilson, 2019).

## **Whakapapa Connection to Whenua and Hapū**

The concept of whakawhanaungatanga is an integral part of te ao Māori worldview and is a way of life that extends beyond the clinical setting. It is through whānau, whenua, hapū all being interconnected that links being born and dying. These words (kupu) have deeper, multifaceted meanings in our te reo Māori that help to guide our understanding (Fleming, 2018). Fleming (2018) confirmed that within a Māori worldview, wellbeing includes dimensions of whenua; environmental; spiritual; psychological; and cultural connections between people and the land. Further, whakapapa and interpersonal connections link whānau, hapū and iwi groupings.

Participants spoke of their admiration of ancestral healers, wāhine toa, protectors and guardians in Māori mythology such as Papatūānuku (earth mother), Hine-ahu-one (the first woman), Hine-tītama (the dawn maiden), and Hine-nui-te-pō. Participants demonstrated active protection through waiata, karakia and use of rongoā to guide loved ones wairua on their te ao wairua journey to the waiting protector arms of Hine-nui-te-pō. It is through their identification with Papatūānuku that Māori women have a special role in generally supporting and nurturing life and especially in doing so for close kin and those of the extend family (Wyse, 1992). Furthermore, Mikaere (2005) stated that women played a key role in linking the past with the present and the future.

Participants talked about the importance of having the right heart and attitude when engaging with patients and whānau at the end-of-life. The findings fit with Moeke-Maxwell's (2014) belief that nurses who see the patient's whānau in terms of their cultural and spiritual fullness will be more likely to empower the patient's whānau and enrich their relationship with them. This holistic approach to wellbeing encapsulates the physical, psychological, spiritual, and social aspects as demonstrated in Durie's Te Whare Tapa Whā model, a model that most nurses in Aotearoa New Zealand are likely to be familiar with (Moeke-Maxwell, 2014). Including whānau in care was important, with nurses facilitating or creating space to educate and empower whānau to be involved in a loved one's care. Furthermore, whānau-centred nursing care models can achieve equitable health status for Māori. This is due to the genuinely holistic manner and the inclusion of wairua as a fundamental dimension of health care (Moeke-Maxwell, 2014).

Love (2004) confirmed that "whakawhanaungatanga refers to kinship and social roles and bonds, continuity of the whānau from the past, through whakapapa to the preparation and nurturing of future generations" (p.43). Participants clearly demonstrated

tika, pono and aroha in providing holistic care as part of their approach to wellbeing in their clinical practice. These concepts included showing kindness, compassion and generosity of spirit when sharing resources with those whānau struggling or living in poverty. The findings clearly demonstrated participants' commitment and expression of aroha, kindness, and generosity of spirit by taking koha of huawhenua from their own gardens when they visited patients and whānau who they knew were struggling, living and dying in poverty. Participants demonstrated manaakitanga through the actions of caring, protection and respect, as they went above and beyond in their role as health professionals to share and give kai (Carlson et al., 2016).

The findings reflect the connectedness of whanaungatanga within a whānau, and end-of-life care setting through whakapapa. This aspect of whakawhanaungatanga is confirmed by Love (2004), who noted the health and wellbeing of the individual and the whānau as being indivisible. Robinson et al. (2020) discussed the importance of whakawhanaungatanga in describing fundamental aspects of care in the Kapakapa Manawa framework, which focused on patients' needs in the end-of-life care and establishing relationships with patients and their whānau (Robinson et al., 2020).

The significance of wairua for Māori is known globally and acknowledged as a necessity of their health and wellbeing (Valentine et al., 2017). The connection between wairua and health has been well documented for many decades by Māori academics (Marsden, 1992; Mead, 2003; Durie, 2005; Moeke-Maxwell, 2014; Fleming, 2018). The circle of life is inclusive of life and death. This connection of life to death is reflected in the whakataukāi of my tūpuna matua o Te Ātiawa, Te Whiti o Rongomai;

*I te po te kaihari i te ra, ko te mate te kaihari i te oranga*

Night is the bringer of day, death is the bringer of life (Te Whiti o Rongomai).

According to Moeke-Maxwell (2014, p. 14), "Wairua is a fundamental dimension of health care, which underpins all Māori cultural beliefs and practices". Moeke-Maxwell et al. (2019) claimed living with a life-limiting illness and the process of dying are critically important times in the human lifespan for Māori. It is a sacred time when a person's wairua is prepared for its journey across the ārai during its transition to the spiritual realm. The interconnectedness between the physical world to ascend to te ao wairua can be explained through whakapapa or genealogical ties one has, not only with their living whānau, hapū and iwi, but also with their ancestors, land, and environment (Fleming, 2018).

The findings of this thesis indicated that nurses' roles in supporting the patient's and whānau wairua is a vital dimension of end-of-life care. Barton and Wilson (2008)

argued that wairuatanga is the basis of all things. All living things have mauri (a life-force and a spirit). Moeke-Maxwell (2014) confirmed that mauri is a vital energy that feeds the spiritual integrity of wairua, which can wax and wane depending on the sense of safety experienced by the patient and their whānau within the health system. Moeke-Maxwell (2014) confirms that “providing information that is accessible and care that is culturally respectful goes a long way to strengthening the mauri of the whānau at a time when they are likely to be vulnerable” (p.16). Further research is recommended given that indigenous perspectives of palliative care are not commonly known (Moeke-Maxwell et al, 2019).

The role of Hine-nui-te-pō in maintaining the tika, pono and aroha of the deceased’s journey to te ao wairua reinforces the relationship of nursing in caring for the living and the dead. The journey of te ao wairua to its final resting place can vary depending on iwi beliefs. The findings examined patients’ journeys when they died. Participants believed that they were a part of the patient’s and whānau te ao wairua or the spiritual world journey and witnessed the wairua leaving one’s physical being or physical realm behind to be carried onto the next life or the next journey. When the physical body dies, Māori believe the spirit leaves the body to return to the heavenly realm. In other words, the life of the wairua is eternal and lives beyond the physical realm once death occurs. The journey of te ao wairua commences at death when the mauri that a person is born with dies and disappears with the last breath or heartbeat.

Protecting and maintaining a loved one’s wairua and mauri often falls to their whānau. Moeke-Maxwell et al. (2019) explained that as “pou aroha” (care stalwarts), whānau carry out the majority of end-of-life care, and ensure that the patient receives the best physical, emotional, mental and spiritual care before they die, no matter what health care setting they are in. Mead (2003) described that “the wairua of departed ancestors are an essential part of our environment and our universe” (p. 57). Further, Mead (2003) confirmed that the spiritual significance to Māori of retrieving the body from the undertakers as the wairua will stay with the body for a few days before departing. During tangihanga (process of grieving/funeral) the body of the deceased will usually be taken to a marae (Māori gathering place) where grieving friends and whānau will farewell the person and their wairua is encouraged to move into the spiritual realm (Mead, 2003). A wairua link between the spiritual world can be felt by mourners, the deceased and with their ancestors (Durie, 2005).

## **Diversity in Māori perceptions of Death and Dying**

Participants highlighted that Māori perceptions of death and dying are diverse and continually adapting or changing. This approach to death and dying was described



by Reid (2005) as “being fluid by necessity, or plural, diverse, multiple, flexible, and changeable” (p.47). Malpas et al. (2017) acknowledged that Māori perceptions of death and dying are diverse and continually changing, and understandings are strongly influenced through cultural connection and post-colonial disconnection. Death and dying remains central to a Māori worldview and the connection to the living is reflected in this whakataukāi in Higgins and Moorfield (2004):

*Ka āpiti hōno tātai hōno, te hunga mate ki te hunga mate. Ka āpiti hōno tātai hōno, te hunga ora ki te hunga ora*

Let the ties that bind the dead be joined with the ties that bind the living (p.86).

In 2017, Malpas et al. provided the following example of one kaumātua who explained the processes around the hastening of death, which showed that this was not a new concept for Māori:

“I’m reminded of a fact that my own people, my elders, they had a method of ending life. They would just sit a person up and then just lean on the back of that person and then a way of cracking the neck, and as soon as the neck cracked, the life, their life was finished” (p. 548).

There are many examples of rangatira creating new pathways and pushing the boundaries of Māori traditions of death and dying. In 2002, Manchester interviewed one of Māori nursing’s great rangatira, Irihapeti Ramsden, shortly before her death, who admitted that finding the positive in such devastating life events can be very difficult:

“At times staying mentally healthy is hard and I have to make a real effort not to go under. I now have a better understanding of those who do succumb to depression in these sorts of circumstances. I’m also more aware of everyone else’s fragility, as well as my own. The experience made me think about euthanasia and the ethics involved in the decisions. We put our pets down to protect them from further suffering but what about we humans? Don’t we deserve the same consideration? I am sure euthanasia will one day be accepted in our society, but it may take another 50 years of debate” (p. 20-21).

In 2016, the well-respected rangatira Ranginui Walker chose to push the boundaries of Māori traditions in a contemporary world, by not journeying home to be buried at his ancestral Whakatōhea marae; instead, he chose to be cremated and scattered in places dear to him and his whānau and to have a live streaming at his tangi (Radio New Zealand, 2016). Just as live streaming at tangi, cremation rather than burial, and organ donation are being accepted and chosen by Māori. It is inevitable that assisted dying will challenge Māori, Māori worldviews and traditions. Reid (2005) argued that: “We must resist people trying to make us into museum exhibits of past behaviours. We are complex, changing, challenging, and developing – it is our right” (p. 46-47). Practical solutions, goodwill and manaakitanga will ensure that whānau members will have hope and support to access culturally appropriate assisted dying options.

## Barriers to end-of-life care

Participants expressed their concerns about barriers to end-of-life care. These included restricting whānau members visiting their dying relative, or limiting whānau members staying due to confines of space, or lack of suitable areas to maintain privacy and to carry out cultural practices like karakia, waiata, and for visitors to bring food delicacies. Shahid et al. (2018) confirmed that sometimes restrictive hospital policies prevent extended family members from gathering around a dying Indigenous person or practising prayers and ceremonies at the end-of-life. Furthermore, offerings of foods were thought to bring comfort to the dying person and may be more spiritually and emotionally healing than restrictive diets (Shahid et al., 2018).

The findings of this thesis confirmed that barriers to end-of-life care exist and perpetuate inequities through a lack of co-ordinated health services. It was clear from participants' kōrero that not all patients and their whānau received the same standard of end-of-life service throughout Aotearoa New Zealand. Examples of barriers to care include funding inequities, whānau living in poverty, inconsistencies in hospital and community processes, coordination of services, discharge planning, communication with whānau and respecting tikanga and cultural practices.

The findings indicated that resourcing for whānau in end-of-life care is not always a priority. The resourcing (funding, disease-specific care, communication, education, discharge planning, equipment, or involvement in their loved one's care) varied across the country and was dependent on where you lived. The concept of rangatiratanga (sovereignty) is vitally important for dying Māori; however, exercising the full meaning of rangatiratanga means that whānau must be resourced properly (Stephens, 2019). Participants realise daily the struggles to provide resources to aid patient and whānau needs. Their resilience despite the impacts of barriers to provide patients and their whānau with care is through whanaungatanga, generosity of spirit and manaaki as part of their daily nursing care. Furthermore, participants clearly indicated that providing support for whānau living rurally is a burden. Moeke-Maxwell et al. (2019) confirmed that living rurally can present a challenge for whānau as end-of-life care support is limited.

Underpinning an indigenous holistic health care system is the idea that good end-of-life care pays critical attention to the wellbeing of the energy life force and spirit that dwells within every living being (Moeke-Maxwell et al., 2019b). However, New Zealand's bio-medically-focused health system does not cater for the type and level of holistic care preferred by its indigenous population (Moeke-Maxwell et al., 2019b).

Barriers associated with providing care are discussed by participants within the context of a set of complex end-of-life circumstances. These barriers include health

inequities, racism, poor access to palliative care and statutory (government) support, inadequate information, and poor communication (Moeke-Maxwell, 2019b). To date, Māori cultural preferences have largely been subjugated beneath a Western bio-medical health care system approach (Moeke-Maxwell et al., 2019b). This can be clearly seen in end-of-life health issues. Often, the physical domain is prioritised in palliative care without including the social, cultural, and spiritual care domains, which are often seen as add-ons (Moeke-Maxwell et al., 2019b).

## **Wrap around services needed to improve nursing service**

Participants expressed the desperate need for practical help and wrap-around services for whānau. This included practical services to support whānau with shopping, putting food in whānau cupboards, heating cold houses, and transport to health appointments. Wilson (2009) argued that nurses have the potential to positively contribute to the development of whānau and individual members. Furthermore, Wilson (2009) continued to emphasise that whānau ora requires nursing and nurses to revisit the way in which they work with Māori in order to keep whānau as the central concern in their practice. It requires being aware of the holistic health needs of the whānau and their capability and resources to optimise their health and wellbeing.

I agree and support Moeke-Maxwell's (2019) argument that specifically focused Māori palliative care cultural competency training is required to help health professionals have an understanding of Aotearoa New Zealand history, and include: Māori language; local iwi knowledge; and traditional end-of-life care customs (rongoā Māori, Māori medicines); spiritual practices; and customary rituals. Further training is also needed to ensure that health professionals understand Māori worldviews and anti-racism training. This will improve the diversity and availability of culturally appropriate end-of-life services that continue to align with Māori cultural aspirations.

Education for all health professionals on te Tiriti o Waitangi articles and colonisation were also a recommendation of the findings. Moeke-Maxwell (2014) indicated that if 'nurses' had an awareness of New Zealand's indigenous people's experiences of colonial history, this can help foster a deeper understanding of the issues whānau face (cultural alienation, social deprivation, poverty and an array of health problems), as well as the most appropriate way to care for Māori. Assimilative policies, legislation and practices have weakened Māori ways of life, Māori worldviews and Māori identity (Pihama, 2001). By supporting Māori health literacy, for example, nurses can make a real difference in reducing the difficulties many Māori have accessing and using health and palliative care services. Participants had a range of views about cultural considerations and what was needed to improve nursing practice. This included

increasing the number of Māori health units, wrap around services for whānau and providing better whānau spaces for patients and their whānau to grieve.

## **Silencing, invisibility of Māori nurses in critical debates**

The participants expressed struggles working in a Western medical system that did not value a Māori worldview. Participants spoke of their distress that Māori nurses' voices were often silent or missing. Māori nurses' views are rarely valued or well-articulated in literature in the same way in Western nursing philosophies (Barton & Wilson, 2008). Participants wanted to contribute, to bolster their voices and demanded space to have their say on health.

Trying to find a space to legitimately have your voice heard has been difficult in the colonised world. This has been true of Māori nursing leaders, who have guided the direction and nurtured the next generation of Māori nurse leaders despite being disadvantaged. It has also been difficult determining aspirations and critical kaupapa to talk about their lived experiences and the tensions of having a different viewpoint to the nursing norms. Waitere and Johnston (2009) confirmed that:

“A struggle for Māori women has subsequently been the act of distancing ourselves from Pākehā women and men as a means to explore our differences, centre ourselves and [re]claim, [re]define who we are. At times Māori women must [re]mind Māori men, as much as non-Māori men and women, about who they are and from whom they descend” (p.27).

Like their forebears, mana wāhine and Māori women, Māori nurses have been silenced for too long. The existence of their forebears and their voices, roles and responsibilities were removed from history, whether by the pen taking away 'herstories' or by continually being over talked or suppressed by male or non-Māori female voices and colonial systems. These stories highlight how colonisation was used as a tool for marginalisation and silencing of indigenous voices (Moreton-Robinson, 2000; Trask, 1999; Smith, 2012; Pihama, 2001, 2005). Pihama (2005) confirmed that “the denial of our knowledge and theorising has been an integral part of the colonising agenda” (p.191). Trask (1999) also confirmed the impacts of colonialism in Hawaii replaced the Hawaiian world with the haole (white) world. Hawaiian women, including their chiefly women, lost their place just as Hawaiian men lost theirs.

Simon (2006) confirmed Māori nurses' long history of practice within the New Zealand health care system, although it is still not easy to identify what might constitute Māori nursing practice. Often Māori nurses were structurally disadvantaged within the nursing-dominated culture. This included a nursing career faced with discrimination, racism, limited promotion, bullying or marginalisation. Māori nurses could also encounter

oppression by systems and structures, and domination by patriarchal doctors and European nursing matrons who used their power as a control to ensure that procedures and protocols were strictly followed.

Participants gave examples of instances where their voice, opinion or cultural perspective was treated in a tokenistic manner by other staff or their input was not presented or included in the final decision. Currently, there are a lot of health topics that should include Māori nurses' voices that are never included. Māori nurses' views are irrelevant, absent, or simply unknown in the nursing narrative. This silence has been the driver for my research in and on assisted dying and to support Māori nurses' *kōrero* and views about topics such as this one, particularly what they choose to talk about. A lack of research currently exists, including an understanding of Māori nurses' cultural awareness around death and dying. Nurturing the voices of Māori nurses is essential to ensure they are included and heard on a topic because all too often they are omitted, and their voices are viewed as insignificant.

The most important thing about the *kōrero* is that Māori nurses have their perspectives and their voices heard about assisted dying; it doesn't matter whether you're for it, against it, or undecided, that's not *kaupapa*. Rarely is it seen that Māori nurses are valued for their cultural knowledge or excel within a Western nursing world unless they are clinically astute or accepted by the nursing hierarchy. Walker et al.'s (2016) research confirmed that while they knew many Māori nurses undertake caregiving and cultural responsibilities, the compelling detailed issues that were raised in these stories need to be escalated, advocated and addressed at all levels.

These influences (being torn between cultural responsibilities and organisational requirements within a health system that does not acknowledge their beliefs, customs, and cultural requirements) provided examples of power and control played out through gender roles. Moreton-Robinson (2000) described how whiteness as an ideology and practice conferred privilege and dominance in power relations between white feminists and indigenous women. Trask (1999) confirmed that men are bred for power, women for powerlessness except within their own sphere of the family. Smith (1992) illustrated this further as:

“Māori women belong to the group of women in the world who have been historically constructed as ‘other’ by white patriarchies and white feminists. As women we have been defined in our difference from men. As Māori, we have been defined in terms of our difference from our colonisers. As both we have been defined by our difference to Māori men, Pākehā men and Pākehā women. The socio-economic class in which most Māori women are located makes the category of ‘other’ even more problematic” (p. 33).

In terms of Māori women attempting to define their own space. Smith (1992) argued that:

White feminists have come dangerously close to smothering us (Māori women) in their metaphors (p.34).

This is often reflected in nursing. Yet Māori nurses' voices are continually overlooked and others speak on their behalf. This is usually by well-meaning white nursing leaders who interpret or assume the role of leaders speaking for all nursing rather than representing other differing views or unique perspectives. Pihama (2001) further confirmed the impact on Māori women by silencing their voices:

“Silencing of Māori women’s voices has meant the silencing of our theories, worldviews ... the marginalisation of mana wāhine has meant that Māori women are constantly having to try and ‘find’ ourselves within the texts of the dominant group. We are forever trying to see ourselves in the images created by the colonisers” (p. 234).

This silence is often over talked, the space quickly filled with other agendas. Often an individual white nursing voice will speak for the collective. Māori nurses have been undermined as nursing leaders and are often overlooked if they do not excel in the Pākehā nursing world, or if they choose to practice or express a te ao Māori worldview, which is not always understood or accepted.

Simmonds (2011) confirmed that:

“As Māori women we are constantly trying to find space where we can represent and give voice and legitimacy to our experiences. They make the point that ... it is for us, as Māori women, to decide what differences count” (Johnston & Pihama, 1995, as cited in Simmonds, 2011, p.1).

Kathy Irwin (1992) contended that “Māori women must be provided with the time, space, and resources necessary to develop the skills to undertake this work, starting with the exploration, reclamation and celebration of *herstories*, our stories as Māori women” (p. 7). Waitere and Johnston (2009) argued that Māori and women were defined through colonisation. An example of this is the invisibility of Māori women in written Māori ‘history’ and being written out of mythological stories where the lead characters are Māori men.

## **Colonisation of indigenous people**

Over a century’s worth of systemic barriers, undermining, marginalisation and racism have limited Māori nurses’ engagement in a Western health system and nursing’s hierarchy. Minority groups, and women of colour have been dominated by patriarchy, white women, and a dominant nursing hierarchy. Colonisation has written indigenous people out of history. Pihama (2005) confirmed that:

“Māori women, like indigenous women, black women and women of colour worldwide, have consistently voiced outrage at being constantly located as ‘other’ within dominant discourses, raising issues of difference and marginalisation. Dominant power replaced or denied indigenous views and privileged the colonisers” (p.68).

Hierarchical structures in the New Zealand health system have been largely dominated by bio-medical models, such as medical philosophies with a disease focus

rather than a wellness model. Hours of work are structured around doctors and patriarchal 9am to 5pm, Monday to Friday hospital hours and the role of nurses as handmaidens. Alternative views or health models have long been undermined for stemming from an oral culture, or not being grounded in scientific theory, such as rongoā Māori, which has been relegated as an alternative therapy. Anyone who held an alternative view conflicted with the patriarchal society. European nursing sisters were party to implementing this patriarchal structure, carrying out the doctors' views with precision and without question (McKillop et al., 2013).

How can we value Māori nurses' views when we do not acknowledge or address the systemic issues that impede their lives in society, and within nursing hierarchies? How can this occur when systemic issues such as marginalisation, bias, racism exist within the health system? Māori nurses, whose numbers have increased but not the proportion of the nursing population since the 1990s, and their views remain tightly controlled by the sheer size of the European nurses' numbers, increasing numbers of internationally qualified nurses and the generalised push to multiculturalism before biculturalism or recognition of the articles of te Tiriti o Waitangi.

It seems that every government's health plan or related strategy, places Māori nurses or the Māori health workforce as the solution to Māori health inequities (Russell et al., 2013). The centre of power sharing, including resourcing and control remains firmly in the hands of non-Māori. It is, however, in the interests of Aotearoa New Zealand to ensure that Māori women and Māori nurses' voices are heard and that a commitment to future health change must include their views and perspectives.

To date, colonial interpretations of Māori women's kōrero that concern areas pertaining to wairua have been and continue to be reduced to superstitious and spiritual nativist discourse (Pihama, 2001). This undermining of and attacks on the dimension of wairua also attacks Māori worldviews and indigenous voices. This clear tension that Māori women experience has been described by Waitere and Johnston (2009) argued that Māori women's presence were often absent in forums that aimed to address inequities; better living standards; good health; quality education and protection within the law. Often, even if Māori women were physically present, our voices were absent or misrepresented. Participants spoke of their experiences within their workplaces where they are often the only Māori staff.

Moeke-Maxwell et al. (2019b) expressed the impact of colonial history as a tsunami of power that continued to reverberate on contemporary Māori identity formation. This tsunami of power and colonialism also impacted nursing history in Aotearoa New Zealand, harshly affecting Māori nursing identity, history, whakapapa, cultural safety, and voices. Examples of colonial educational processes that created invisibility of Māori

women can be seen through the 'rebranding' Māori history as Māori 'mythology' and portraying Māori women as non-consequential, and in unimportant roles (Smith, 1992).

The state also played a part in assimilating Māori women by channelling them into 'suitable' occupations like nursing or teaching (Jenkins & Morris-Matthews, 1998). An example of this 'suitable' occupation was the provision of continuation scholarships to enable Māori girls to receive nursing training, which emerged from the Conference of Old Boys at Te Aute College in February 1897. Not only did the course specialise in nursing theory and practice, bandaging and changing dressings but it also had classes in cooking for invalids (Jenkins & Morris-Matthews, 1998). Feminists have fiercely debated whether it is wrong for outsiders to criticize gendered customs and practices identified with cultural minorities (Curchin, 2011). The association of the women's movement with Pākehā women means that, for Māori women, challenging gender roles entails the risk of being seen as anti-Māori or divisive (Hoskins, 2000, p. 44). Hoskins wrote: "As a Māori woman, as an 'insider', it is not easy to speak critically about aspects of your cultures, society or cultural practice without providing ammunition to a racist and fearful society, or risking personal attack or exclusion" (p. 33).

Further Moreton-Robinson (2000) confirmed the view that:

"... indigenous women as embodiments of racial difference can never know what it is like to experience the world as a white woman, just as white women can never know what it is like to experience the world as indigenous woman" (p. 184).

Curchin (2011) believed that there is a long history of gender roles and gendered practices being used to demonise non-Western cultures. Further, colonisers have reinforced the domination of men over women within a colonised people.

The relocation of Māori women's status has impacted the day-to-day lifestyle, whānau life and working life and for female-dominated workforces like nursing, which is 91% female (Nursing Council of New Zealand, 2020). Collectively, women in Aotearoa New Zealand were marginalised by this idealism, yet Māori women were further disparaged through racism (Gemmell, 2013). Assimilative policies, legislation and practices weakened Māori ways of life, Māori worldviews and Māori identity (Pihama, 2001).

### **Nursing leaders, racist, bias views**

It was clear that nursing history in Aotearoa New Zealand did not always treat Māori nurses well. Māori health was not seen as a priority, often it only became a concern when it threatened that of the non-Māori population (McKegg, 1992). Nursing leaders of the day were not supportive of Māori nurses, their skills, abilities or increasing the



numbers. Māori women were discriminated and handicapped by the attitudes of the government and hospital officials in the nursing training scheme process. Distrust of Māori women's capabilities meant that there was never the support for such a scheme needed from the hospital authorities of the day (McKegg, 1992).

Bryder (2018) said many of the historians believed that the Māori nursing scheme, which trained them to work within their own communities was a failure, owing to matrons not wanting to train Māori women and because there was simply not enough interest from Māori women to meet the demand. Examples of nursing leaders' bias and racism can be seen below. Hester Maclean, Assistant Inspector of Hospitals (1906-1923) in charge of nursing services, believed that the Māori women lacked 'application and reliability' (McKegg, 1992). Similarly, matrons of Thames, Napier and Waikato hospitals were all extremely reluctant to train Māori women:

"I don't want Māori nurses; I have quite enough trouble with the white ones. We have to do our duty and leave them to do theirs! I have got quite a number of our own women wanting to come and be trained in order to earn their bread and I don't see why I should have to put them off in order to make room for Māori girls. Let them get a Hospital of their own" (Miss Stewart, Matron at Thames Hospital, 1906).

Personally, I prefer not to have them at all but of course we have to help to train these girls to help their own people (Miss MacDonald, Matron at Napier Hospital, 1928).

We ought to have a rest for a time and give one of the other hospitals the privilege of training a few (A G Keddie, Matron at Waikato Hospital, 1928).

The failure of the Māori nursing scheme was due in part to only recruiting Māori women attending the elite secondary schools. Further, there were limited positions available for Māori women in hospitals, and limited numbers of Māori women to staff this ambitious health programme (McKegg, 1992). Few Māori nurse leaders excelled in this controlled environment, except those who were protected or accepted for their exceptional clinical skills or assimilated into the inner nursing circles.

### **Tension of being a nurse and being Māori**

The cultural safety of Māori nurses is complex. Once you describe yourself as a Māori nurse, you can be marginalised, ridiculed, or dismissed in the New Zealand nursing sector. Defining yourself based on whakapapa Māori should be a proud moment and relatively easy to do when we live in Aotearoa, especially when we are confident in our tūrangawaewae, place to stand and identity. However, defining oneself as a Māori nurse, or a Māori woman and a nurse can sometimes be confusing and, depending where you live and work, a scary place to be. For some nurses identifying as a Māori nurse, they have choices of whether they boldly step out of the shadows, as waka blondes, or as on their own cultural journey, unsure of their culture and identity.

The cultural safety journey according to Irihapeti Ramsden (2003) also included the ridicule, dismissal and marginalisation. Further Koptie (2009) argued that “cultural safety comes from challenging conventional practice and perceived experts, which avoid orientations requiring emotional or spiritual connections with “subjects” (p. 39). Having worked in clinical areas where I was the only Māori nurse can be isolating, even when confident in whakapapa, and having the protection of ancestral tūpuna. Some would say why do we need to choose, why we cannot be who we are and feel comfortable in our skin. Cultural safety sometimes highlights the racism and bias in the nursing sector, especially for the 8% of total Māori nurses who try and attempt to maintain resilience in a sector dominated by white female nursing voices.

Koptie (2009) argued that young people especially need cultural safety in learning to retell, revise and restore traditional wisdom to navigate the despair, helplessness and hopelessness they see in their communities. Bishop (1999) confirmed that colonisation removed the guarantee for Māori to protect and define their own stories and impacted on traditional Māori healing practices, rongoā Māori, and the role of the Tohunga.

Tensions have also arisen about being a nurse and being Māori. The ability to work in two worlds has been reflected in our bicultural heritage, which has long documented the tensions between Western ideologies and Māori models of health and wellbeing. Baker’s (2008) work with Māori mental health nurses resonates with the findings of this study, particularly as being a Māori nurse is met with challenges when working in two worlds. Māori nurses encounter struggles and challenges in order to fulfil their nursing roles and to practice well. Māori nurses constantly operate in te ao Māori, bringing a Māori perspective to the nursing profession. We need to define what a Māori nurse is, protect it and have the courage to not back down from our worldview. This includes building resilience necessary for challenging the status quo to change from what is presently seen as normal. Further, key issues that Māori nurses experienced included; juggling work; study; children and elders’ hospital and doctors’ appointments; community responsibilities; as well as attending to the mental and physical health needs of whānau in both the workplace and the community (Walker et al., 2016).

Māori nurses as a population group understand death and dying, but the government is not listening to them (Waitangi Tribunal, 2019). So how can we ensure that their voices are heard? So that is part of the kaupapa and the driver for ensuring that Māori nurses’ perspectives are heard. Using the collective voices of Māori nurses to work together in whakawhanaungatanga influences and drives cultural change, adds value and influences cultural guidelines for nurses if assisted dying becomes legal in Aotearoa New Zealand.

## Validating nurses' practice

Before her early death, Irihapeti Ramsden (2002) wrote that some efforts have been made to investigate increasing the Māori nursing workforce on the premise that more Māori nurses could give better service for Māori. The ability to work in both clinically and culturally safe ways is not fully understood or accepted by the nursing or health hierarchy. Wilson (2018) argued that increasing the Māori nursing workforce is crucial to the delivery of high-quality, culturally responsive health-care services, and for Māori and their whānau to feel culturally safe. Wilson (2018) indicated that:

“Demonstrating different cultural and clinical perspectives. Most Māori nurses have an innate understanding of Māori culture — they understand the integral role whānau have in the care and healing of a person, they understand Māori realities and the challenges in their daily lives that impact on their health and wellbeing” (p. 1).

Further, they also understand colonisation and its ongoing effects, historical trauma, structural discrimination and racism that many Māori and their whānau encounter in their health journey (Wilson, 2018).

Māori nurses' clinical and cultural skills are not always supported by colleagues. Wilson (2018) argued that most Māori nurses remain marginalised, isolated and with inequitable workloads brought about by addressing “Māori issues” for their non-Māori colleagues, or by working within environments where Māori nursing approaches are not recognised or valued, despite achieving positive outcomes. It gives me heart that Aotearoa New Zealand demographics predict significant changes in our diversity, indicated by the proportion of each ethnicity now under the age of 25 years: New Zealand European (32 per cent), Māori (51 per cent), Pacific (53 per cent), Asian (34 per cent), and Middle Eastern, Latin American and African (41 per cent) (Health and Disability System Review, 2020). This diversity will create change in acceptable behaviour, culture and anti-racism training and practice.

## Conclusion

Te ao hurihuri, the ever adapting, evolving, and changing Māori worldview continues forward, linking the past, present and future. The opening chapter whakataukāi, ‘ka āpiti hōno’, reminds us that death and dying remains central to a Māori worldview and connected to the living. Reaffirming that te ao hurihuri is the right platform to discuss and debate contentious issues. As whakapapa connects life and death, tūpuna, mythology and history has been woven together through whakawhanaungatanga. This thesis makes a contribution to knowledge related to Māori nurses' perspectives and assisted dying.

Central, and very significant to the findings was whakawhanaungatanga, an extension of the patient, whānau and nurse trust relationship interwoven with a Māori worldview and the patient's and whānau te ao wairua journey. This unique and special relationship between patient, whānau and nurse extends long after death to include other members of the wider whānau and their holistic health care journeys. This continuum allowed the research space and time to pause and reflect on the influences that impacted on and contributed to silencing or the invisibility of Māori nurses' voices in the wider health environment.

It is clear from the findings and nursing history that being a Māori nurse takes courage and bravery. Courage to stand tall and identify as Māori. Bravery to battle the conflicting tensions of a health system that does not acknowledge cultural responsibilities alongside organisation requirements. Working in this system, practising principles of whakawhanaungatanga, tika, pono and aroha in your nursing practice can be a difficult place to be. This can create tension and place you at odds with colleagues, your profession, and the wider health setting. This tension is caused mainly by the history of colonisation, marginalisation, racism, bullying, bias, and dominant white nurse culture. These negative influences have disrupted mana wāhine, Māori women, and Māori nurse's leadership roles and responsibilities. The findings allowed participants' perspectives of assisted dying the space and the platform to be heard while exploring past trauma that remains influential in their present and future nursing practice. This tension has harshly affected Māori nursing identity; wrestled with the conflict of cultural identity, interwoven whakapapa, cultural safety of being Māori, as a mana wāhine and as a nurse.

It is key to honour the diversity that Māori nurses' resilience brings to culturally and clinically appropriate nursing care. Incorporating whakawhanaungatanga, manaakitanga, tika, pono and aroha while maintaining clinical excellence is no small feat. Finding a way forward into the future requires an acknowledgement from the government and health system of the importance and value that holistically, culturally and clinically trained nurses provide to whānau, hapū and iwi. Further, it is about a commitment to investing, supporting, and growing more resilient culturally and clinically trained nurses to support health equity.

From a holistic perspective, the findings and other research highlighted significant barriers to care that will require a whole of government approach to find solutions. These include funding inequities, whānau living in poverty, inconsistencies in hospital and community processes, coordination of services, discharge planning, communication with whānau and respecting tikanga and cultural practices. None of these inequities are new to health professionals; however, unless these are addressed these inequities will

continue to challenge aspirations for health equity. While participants showed resilience in addressing these inequities with simple, practical, and effective solutions, it is no longer fair or just that these remain barriers to accessing appropriate health care.

Aspirations to measure and improve the health equity of the New Zealand population will first and foremost require Māori nurses' input at all levels of decision making. The future health system will require mandatory anti-racism training for all health professionals working in Aotearoa New Zealand to eliminate bias, marginalisation and racism from their practice and the health system. Investment must occur in holistic wellbeing models that value tika, pono, aroha and whanaungatanga will certainly improve health equity for whānau, hapū and iwi. These holistic models must be embedded and practiced in any new health system.

Further investigation is required on the extent to which the broader systemic barriers have impacted on Māori nurses' practice in the New Zealand health system, alongside the significant aspects of Māori nursing resilience and whanaungatanga outside of the end-of-life care setting.

## Wahanga Tuaono – Chapter Six: Conclusion

A Western medical framework continues to control and govern the health system in Aotearoa New Zealand. Historical colonisation practices such as marginalisation, racism, bullying, bias and dominant white nurse culture has left traumatic imprints that continue to impact and silence Māori nurses' voices. Examining these historical barriers in this thesis has made me reflect on my own privilege, and my own bicultural heritage. I also reconfirm and acknowledge my ongoing commitment to nurturing Māori nurses' voices and rights to be heard on assisted dying, and with legislation in place to drive a changing space for the right to choose end-of-life care options.

Further, this thesis has explored how tools of colonisation have left a crushing blow or burden on the health of Māori, roles and responsibilities of Māori women, career progression of Māori nurses, and their whakawhanaungatanga relations with whānau, hapū and iwi in end-of-life care settings. These systemic barriers have reinforced that Māori nurses' abilities, talents, skills, views, and perspectives are constantly undermined and undervalued by their colleagues and the Western health system.

In concluding this chapter, revisiting the research question and the importance of understanding Māori nurses' views towards the assisted dying process through a kaupapa Māori research method will be discussed, along with key findings within the thesis, recommendations for future research studies, and concluding comments. As with abortion or euthanasia, assisted dying is one of the most controversial bioethical issues to have captured the public and health professionals' attention in Western liberal democracies (Johnstone, 2016). Alternatively, the Māori worldview is inclusive of a profound belief in wairuatanga, the deeply flowing beliefs and cultural practices involving the spiritual realm, which permeate all aspects of life and govern all stages of living and dying (Pere, 1991). The Māori worldview provides a broad and valid platform to discuss bioethical issues such as assisted dying rather than the narrowly focused Westernised medical framework.

This chapter summarises the results of this thesis and explains how the findings of this study are important, how they influence our knowledge and understanding of Māori nurses' perspectives on assisted dying, and the impact this has had upon them and their nursing practice and care of end-of-life care patients and their whānau. The strengths and weaknesses of this research are discussed, and the limitations of the research are explored.

## Key findings

The findings recommend further investigation into Māori nurses' perspectives of end-of-life care. Further support is needed for researchers to add to the limited body of knowledge in this field and a better understanding of Māori nurses who work in end-of-life care settings and their perspectives of nursing practice. The main challenge will be to ensure Māori nurses' views are captured and reflected in cultural guidelines to promote practice changes in end-of-life cares.

The findings have been discussed under four broad themes with associated sub themes. Each theme has been identified, described, and supported by direct quotes from Māori nurse participants. The findings validate that Māori nurses are an authentic community whose perspectives are valuable to research. The strengths of this research highlighted and reflected the connectedness of whanaungatanga within end-of-life care settings with patients and their whānau, using whakapapa to form trusting relationships. Further, it highlights whakawhanaungatanga as a credible and authentic way of connecting whanaungatanga, whakapapa, manaakitanga in any nursing practice, alongside tika, pono and aroha processes.

The findings highlight the importance of whakawhanaungatanga as an engagement process for building a trust relationship between the nurse, patients and their whānau. The research emphasises the significance strength and depth of whakawhanaungatanga as an essential part of Māori nurses' practice to greet and mihi to their patients and their whānau. The research provides clear linkages between whakawhanaungatanga and patients' and whānau health and wellbeing. Positive aspects of the whakawhanaungatanga engagement I believe is the demonstration of Te Tiriti o Waitangi articles, such as active protection of wairuatanga in nurses' practice. The usage of whakapapa connections to aid oranga, or wellness, is clearly demonstrated by Māori nurses. Further, Māori nurses are acknowledging and demonstrating this in daily practice, by upholding patients' and whānau tino rangatiratanga, strengthening partnership relationships and Ōritetanga (equity) while providing options for care provision. Future generations of New Zealanders will benefit from further work on this model to capture aspects of this te Tiriti o Waitangi Māori nursing of care.

Additionally, the findings also revealed and indicated that resourcing for whānau care in end-of-life care is not prioritised or well-funded. Addressing issues or barriers such as resourcing should be a priority for any health system. Unfortunately, health care provision varies across the country and is very dependent on your postcode as to what services are available. These inconsistencies exist in health care service provision, including access to funding, specific disease, or condition resources; communication,

education, discharge planning, equipment or support for some whānau who wish to be involved in or care for their loved one in their home. Further investment, resourcing, planning, and monitoring is required to improve the health of those who have the greatest burden or the greatest need at the end-of-life, and the whanau who care for them.

The term health equity is a relatively new concept. The recent Ministry of Health definition aims to promote measurability, accountability, and consistency of health services. However, current funding models and resources are not based on equity or standards of care provision for end-of-life care. Addressing the issue of equity requires all New Zealanders to reflect on their own bias, marginalisation, and racism, which is the greatest challenge for the health and wellbeing of future generations.

### **Limitation of Research**

A restriction of this research was the amount of current literature that pertained to Māori nurses' views or perspectives on assisted dying or end of life cares. The intended focus of the research was assisted dying. However, the data was limited in the focus and nestled in within the themes. It was clear that there was more data presented on the second part of the research question than the first relating to assisted dying. The findings will benefit the current debate on the End of life choices Act, particularly to support Māori and nursing practice change. More investigation in this area could support researchers to add to the limited body of knowledge in this field so a better understanding of Māori nurses' perspectives on assisted dying is available.

Inequities remain in care provision across end-of-life settings. The research identifies underlying issues of poverty, homelessness, dying without necessities of life, racism, poor communication and lack of co-ordinated services. The limitations of the thesis and the scope of the research are more to do with addressing and resolving barriers to care. Barriers associated with providing care included health inequities, racism, poor access to palliative care and statutory (government) support, inadequate information, and poor communication. These limitations, however, are not able to be addressed in this research. Issues with consistency of care across the country did highlight that rural whānau carry the brunt or burden of care delivery. Any future funding models must take into consideration the increasing number of barriers to care.

The recruitment of participants produced a small qualitative study, which provided useful insights into Māori nurses working in end-of-life care settings. Further research to gather a larger data set may be beneficial.



## **Recommendations**

In the wider context of health, Māori nurses are structurally disadvantaged within the dominant nursing culture. However, Māori nurses remain resilient and draw on strength from the past and the present to advocate and plan for future changes and decision-making for the betterment of hapū, whānau and iwi. Changes to health care require Māori nurses' voices, skills, cultural lens, and advocacy. Courage and determination will be required to address issues of silencing or marginalising Māori nursing voices that participants' findings reported. This includes addressing tokenistic manners, racism, marginalisation, or bias.

Recommendations going forward in any nursing or health professionals' practice must include whakawhanaungatanga as an essential aspect and a comprehensive dimension of care. This also clearly demonstrates Te Tiriti o Waitangi article of active protection in any future health and cultural guidelines in end-of-life care. Further, understanding the connections between life and death and validating communities' different perspectives is important, particularly for most health professionals, who work closely with life-or-death situations regardless of their particular area of practice.

Any recommendations must include further investigations into barriers of end-of-life care. Participants recommended that education is necessary for all health professionals on te Tiriti o Waitangi articles and colonisation. Others include increasing the number of Māori health units, wrap around services for whānau and providing better whānau spaces for patients and their whānau to grieve. Practical solutions for supporting wrap-around services for whānau are what participants and their whānau are in desperate need for. Further, this requires health leaders to advocate for better wrap-around health care services for end-of-life care patients and their whānau as essential to address inconsistencies in discharge planning and inconsistencies in end-of-life care delivery. It is essential that value, resourcing, and space be given in the health system for a Māori worldview. Ensuring that Māori values and worldview are given space to flourish and thrive is essential to address the growing health and social inequities in Aotearoa New Zealand. Having legitimate space to have Māori nurses' voices to be heard is also required. This should be an essential part of any future health structure, leadership or decision-making table, governance boards or Crown entity.

## **Concluding remarks**

In conclusion, I draw inspiration from one of our greatest nursing leaders, Irihapeti Ramsden (2002) who said "... change can happen with the right ingredients in the right

amounts and at the right time. For me, those ingredients are curiosity, vision, passion, critical enquiry, energy, consistency, integrity, relevance, and excellent alliances” (p. 31). There are many health topics that should include Māori nurses’ voices but are never heard. This has been the driver for my research in and on this topic and to support the views that Māori nurses’ kōrero about assisted dying, particularly what they wish or choose to talk about.

A Māori worldview sees life and death as equals on a continuum of ora, the living or health and wellbeing. A kaupapa Māori research framework and narrative process helped to address the research question and supported me, as a Māori researcher, to uphold and adhere to Te Ao Māori worldviews throughout the research and to ensure a Māori perspective was maintained through this study. The data from this research revealed invaluable information and insights into the difficulties associated with being a Māori nurse working in a Western health system that does not recognise or value Māori nurses’ perspectives or views.

Further training is also needed to ensure that health professionals understand Māori worldviews and anti-racism training. This will improve the diversity and availability of culturally appropriate end-of-life services that continue to align with Māori cultural aspirations. Furthermore, Māori nurses’ perspectives and how they integrate their culture into their nursing practice should be shared with others.

I would like to conclude my thesis with a whakatauaakī that I believe has strong relevancy to the work ahead of us all in supporting Māori nurses to be empowered to achieve, to serve the communities, whānau, hapū and iwi and future generations of mokopuna. It is said that wisdom and wellbeing will come to those who seek it, when we ask questions with a genuine desire to understand the answers:

*Whāia te mātauranga hei oranga mō koutou*

Seek after wisdom for the sake of your wellbeing (Mead & Grove, 2001).

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# Appendices

## Appendix A: Ethics Approval



### Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology  
D-88, Private Bag 92006, Auckland 1142, NZ  
T: +64 9 921 9999 ext. 8316  
E: [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)  
[www.aut.ac.nz/researchethics](http://www.aut.ac.nz/researchethics)

4 December 2018

Denise Wilson  
Faculty of Health and Environmental Sciences

Dear Denise

Re Ethics Application: **18/290 What are Te Ao Maori: Maori nurses' views on assisted dying and cultural considerations that guide nursing practice**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 3 December 2021.

#### Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <http://www.aut.ac.nz/research/researchethics>.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <http://www.aut.ac.nz/research/researchethics>.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: <http://www.aut.ac.nz/research/researchethics>.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation, then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)

Yours sincerely,

Kate O'Connor  
Executive Manager  
Auckland University of Technology Ethics Committee

Cc: [71kahurangi@gmail.com](mailto:71kahurangi@gmail.com)

# Appendix B: Participants' information sheet



## Participant Information Sheet

March 2019

*Ko Ranginui kei runga,  
Ko Papatūānuku kei raro,  
Ko ngā tangata kei Waenganui,  
Tihei mauri ora.*

Ko Ngāti Tama rāua ko Te Atiawa ōku iwi, Nō Whakatū tōku kainga tuturu, ēngari, ko Whanganui ā Tara tōku kainga ināianeī, ko Leanne Manson āhau.

**Te Ao Māori: Māori nurses perspectives on Assisted Dying and the cultural considerations required to guide nursing practice.**

Tēnā koe

Nau mai, haere mai, whakatau mai ki te Rangimarie. You are invited to take part in a research project to look at your perspective as a Māori nurse on Assisted Dying.

### What is the purpose of the project?

It is important that Māori nurse's voices and perspectives should be heard and considered where they may impact Te Ao Māori cultural approaches to health care.

This study will be completed as part of my Master's in Public Health degree, and I will explore the perspectives of Māori nurses on assisted dying, using a collaborative Kaupapa Māori methodology (Bishop, 1999; Pere & Barnes, 2009) to design, facilitate, record, collate and communicate the study and the findings. Currently, a lack of research exists that includes an understanding of a Māori nursing cultural awareness around death and dying. Therefore, this study aims to gather Māori nurses' perspectives about assisted dying and the place of kaupapa Māori values. I am anticipating this study will further identify additional cultural considerations required to guide nursing practice. I will go over the information sheet and answer any questions that you may have, prior to you signing a consent form. At the completion of this research, I will be writing my thesis and intend to write an article for publication and present the findings at an Indigenous conference.

### What type of participant are we looking for?

I am seeking between 10-15 participants who are required to be a nurse (Registered Nurses, Enrolled Nurses and Nurse Practitioner) with whakapapa Māori and work in health services that provide end of life care in any area of Aotearoa New Zealand.

### **How do I agree to participate in this research?**

Please consider this information sheet carefully. Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you in any way. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible. You will be asked to complete and sign a form consenting to your participation in the study prior to your interview.

### **The process -what will happen in this research?**

You are invited to take part in a kanohi ki te kanohi interview (including the use of zoom for participants from any area in Aotearoa New Zealand) using Kaupapa Māori principles of whanaungatanga, manaakitanga and kaitiakitanga. Participants will be involved in interviews which will be for a limited period of time (1-2 hours) to answer some questions. The interviews will commence and close with karakia.

There will be time before the interview to answer any questions you may have about the information sheet and before signing the consent form. The interviews will be audio-recorded, and during the interviews I will be taking notes. Data from the interviews will be transcribed, checked, and an analysis of data will be undertaken across the interviews that I have undertaken.

The interview data will be analysed using Braun, and Clarke's (2006) thematic analysis framework, which identifies six phases /process and includes:

- familiarisation with the data and identifying items of potential interest;
- generating initial codes;
- searching for themes;
- reviewing potential themes; • defining and naming themes; and
- producing the report.

I will be using the findings from the interviews to write my thesis, an article for publication in a peer-reviewed journal, and present at a nursing conference. I will send all participants a summary of the findings and a link to the full thesis, once it has been examined.

### **What are the discomforts and risks?**

It is important to be aware, that when discussing death and dying, there maybe feelings of sadness, being uncomfortable, or emotionally upset. If you experience any of these feelings, the interview will be stopped until you are ready to continue. If you do not want to continue the interview, you are free to withdraw from the study or make another interview time. I also need to inform you about the following:

**Confidentiality:** There may be a risk that you could be identified through this research as the Māori nursing community in the research areas are relatively small. However, your name and the place you live or work will not be published in any reports or presentations, and the findings will be presented so individuals cannot be identified.

**Illegal Activities:** You need to be aware that if you talk about any involvement in an illegal activity or activities while you are engaged in the research, I may need to disclose this information to the Police. You are advised to think carefully about talking about any involvement you may have had in illegal activities related to end of life care.

### **How will these discomforts and risks be alleviated?**

A Kaumātua has been identified to support this research and will be available to support participants during this project.

### **What are the benefits?**

This research will explore Māori nurse's unique views to provide guidance and cultural considerations for nurses working with terminally ill patients and assisted dying in New Zealand health sector. While there are no direct benefits to you by participating in this research, there are indirect benefits that include having your voice and perspectives heard and contributing to advocacy in the area of assisted dying and end of life care. Furthermore, this is an opportunity for you to influence nursing practice and cultural responsiveness for whānau, hapū and iwi by sharing your whakaaro. I will directly benefit from this research by being able to complete a Master's thesis and a qualification, and from the kudos that can derive by sharing the research findings in different forums. It will also assist in developing my research capability. This is separate to my employed role as NZNO policy advisor Māori. The development of knowledge in the area of end of life care that is culturally relevant and meaningful will contribute to improving outcomes for whānau, hapū and iwi.

### **How will my privacy be protected?**

Each participants will be allocated a pseudonym assigned by the researcher. The notes and audio tapes generated from the interviews will have all identifying features removed, such a names, organisation names, geographical areas. The data will be kept securely in a locked safe at the researcher's residence in Wellington during the research, and at its completion it will be stored securely in the Taupua Waiora Centre for Māori Health Research archive on the AUT South Campus. You need to know that the consent forms will be held in a locked cabinet by my supervisor, Professor Denise Wilson, and will be kept separately from the data. You will be sent a summary of the findings before any publication, if you so choose.

### **What are the costs of participating in this research?**

There are no costs to the nurses for participating in the research other than giving your time. I will provide a small koha and kai to acknowledge your valuable input into my research.

### **What opportunity do I have to consider this invitation?**

Participants will have one to two months to consider the invitation to participate in the research. You are able to withdraw from the study at any time. If you chose to withdraw from the study up until the time I begin the analysis of the interviews undertaken. If you elect to withdraw before this time, you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

### **Will I receive feedback on the results of this research?**

You will be sent a summary of the findings before publication, and a link to the full thesis, if you so choose.

### **What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Professor Denise Wilson, [dlwilson@aut.ac.nz](mailto:dlwilson@aut.ac.nz) or **phone:** +64 9 921 9999 ext 7392 or +64 27 407 0022.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz) or 921 9999 ext 6038.

**Whom do I contact for further information about this research?**

Please keep this Information Sheet and a copy of the Consent Form for your future reference.

Contact the research team as follows:

***Researcher Contact Details:***

If you have any questions about this study, you can contact at any time:

Leanne Manson

Email: [71kahurangi@gmail.com](mailto:71kahurangi@gmail.com) or mobile 021 585 210.

***Project Supervisor Contact Details:***

Professor Denise Wilson

**Email:** [dlwilson@aut.ac.nz](mailto:dlwilson@aut.ac.nz) or **phone:** +64 9 921 9999 ext 7392

Approved by the Auckland University of Technology Ethics Committee on *4 December 2018*, AUTEK Reference number *18/290*.



# Appendix C: Informed consent



## Consent Form

For use when interviews are involved.

**Project title:** Te Ao Māori: Māori nurses perspectives on Assisted Dying and the cultural considerations required to guide nursing practice.

**Project Supervisor:** Professor Denise Wilson

**Researcher:** Leanne Manson

- I have read and understood the information provided about this research project in the Information Sheet dated March 2019.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews (including the use of zoom) and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.
- I wish to receive a summary of the research findings (please tick one): Yes  No

Participant's signature: .....

Participant's name: .....

Participant's Contact Details (if appropriate):

.....  
.....  
.....  
.....

Date:

**Approved by the Auckland University of Technology Ethics Committee on 4 December 2018, AUTEK Reference number 18/290.**

*Note: The Participant should retain a copy of this form.*

# Appendix D: Confidentiality Agreement



## Confidentiality Agreement

*For someone transcribing data, e.g. audio-tapes of interviews.*

**Project title:** *Te Ao Māori: Māori Nurses perspectives on Assisted Dying*

**Project Supervisor:** *Professor Denise Wilson*

**Researcher:** *Leanne Manson*

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- I understand that all the material I will be asked to transcribe is confidential.
- I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- I will not keep any copies of the transcripts nor allow third parties access to them. I will return these to the researcher.

Transcriber's signature: .....

Transcriber's name: .....

Transcriber's Contact Details (if appropriate):  
.....  
.....  
.....  
.....

Date:

Project Supervisor's Contact Details (if appropriate):  
.....  
.....  
.....  
.....

**Approved by the Auckland University of Technology Ethics Committee on 4 December 2018, AUTEK Reference number 18/290.**

*Note: The Transcriber should retain a copy of this form.*

## Appendix E: Te Rūnanga o Aotearoa, NZNO Letter of Support



13 July 2018

Tēnā koe

On behalf of Te Rūnanga o Aotearoa, Tōpūtanga Tapuhi Kaitiaki o Aotearoa, New Zealand Nurses Organisation (NZNO), I am writing to tautoko and recommend to your attention Leanne Manson's research which aims to explore *Te Ao Māori: Māori nurses' views on assisted dying and cultural considerations that guide nursing practice*.

In my position as the Kaiwhakahaere of NZNO, I represent over 52,000 members, nurses (registered, enrolled, and nurse practitioners), midwives, health care assistance, kaimahi hauora and taura. Te Rūnanga members (3,800) have participated in NZNO submissions on the *End of Life Choice Bill* and the Maryan Street petition and further inquiry into ending one's life in New Zealand. It was clear that Māori nurses' voices were not evident in any research that has been undertaken with New Zealand health professionals, hence the importance of Ms Manson's research.

Nāku noa, nā

A handwritten signature in black ink, appearing to read 'Kerri Nuku', is written over a light blue horizontal line.

Kerri Nuku  
**Kaiwhakahaere o Te Rūnanga o Aotearoa**  
**Tōpūtanga Tapuhi Kaitiaki o Aotearoa**

---

**Tōpūtanga Tapuhi Kaitiaki o Aotearoa**

New Zealand Nurses Organisation

Level 3, Crowe Horwath House, 57 Willis Street, Wellington 6011 | PO Box 2128, Wellington 6140

Phone 0800 23 38 48 [www.nzno.org.nz](http://www.nzno.org.nz)

## Appendix F: Research Study Recruitment Flyer



**Te Ao Māori: Māori nurses perspectives on Assisted Dying and the cultural considerations required to guide nursing practice.**

Tēnā koe

Nau mai, haere mai, whakatau mai ki te Rangimarie.

You are invited to take part in a research project to look at your perspective as a Māori nurse on Assisted Dying.

I am seeking between 10-15 participants who are required to be a nurse (Registered Nurses, Enrolled Nurses and Nurse Practitioner) with whakapapa Māori and work in health services that provide end of life care in Aotearoa.

You are invited to take part in a kanohi ki te kanohi interview, using Kaupapa Māori principles of whanaungatanga, manaakitanga and kaitiakitanga. The interview will take approximately an hour, in person or via zoom and will commence and close with karakia. There will be time before the interview to answer any questions you may have about the information sheet and before signing the consent form. The interviews will be audio-recorded, and during the interviews I will be taking notes. Data from the interviews will be transcribed, checked, and an analysis of data will be undertaken across the interviews that I have undertaken.

It is very important that Māori nurse's voices and perspectives should be heard and considered where they may impact Te Ao Māori cultural approaches to health care.

***Researcher Contact Details:***

If you have any questions about this study, you can contact at any time:

Leanne Manson (Ngāti Tama Ki Te Waipounamu, Te Ātiawa Ki Te Waka a Māui)

Email: [71kahurangi@gmail.com](mailto:71kahurangi@gmail.com) or mobile 021 585 210.

Approved by the Auckland University of Technology Ethics Committee on 4 December 2018, AUTEK Reference number 18/290.