Te Tatau o te Pō:

Perceptions and Experiences of Palliative Care and Hospice - A Māori Perspective

A thesis

presented in partial fulfillment of the requirements for a

Master of Arts

In

Psychology

at Massey University, Manawatū Campus,
New Zealand.

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2013

DEDICATION

I tāpaea tēnei tuhinga whakapae hai whakamaharatanga ki ōku tīpuna
ko **Julian ‘Arthur’ Brooking** raua ko **Hinetewhiu Brooking**,
kua wehe a raua i tēnei ao, engari kua whakapiri tonu.

I dedicate this thesis to my amazing grandparents,
Julian ‘Arthur’ Brooking and **Hinetewhiu Brooking** (nee Ngarimu),
who have left the physical world but remain close.

Kati ra e hika te takoto i raro ra
he ue ake ra ka he to manawa
ka titiro ki uta ra ki Hikurangi maunga
Ko te puke tena i whakatauki ai a Porourangi e
Ka rukuruku a Te Rangitawaea i ona rinena e

Ka mamae hoki ra te tini o te tangata
Ka mamae hoki ra ki a tama na tu
Ka takitahi koa nga kaihautu o te waka o Porourangi
Ka arearea koa, puanga i tona rua

Taku hiahia e i
Kia ora tonu koe hei karanga i o iwi
Ka tutu o rongo ki nga mana katoa
Ko tama i te mania
ko tama i te paheke
Kua ngaro koe e hika ki te po aue
Ko nga iwi katoa e aue mai ra
Ka nui taku aroha, i na![1]

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[1] I takea mai i te moteatea tahito a Ngāti Porou. Na Arnold Reedy ngā kupu i huri i te matenga o Apirana Ngata. An ancient Ngāti Porou moteatea. Words altered by Arnold Reedy upon the death of Apirana Ngata.

ACKNOWLEDGEMENTS

I te taha o tōku matua
Ko Tainui te waka
Ko Rangitoto, ko Pirongia ngā maunga
Ko Mokau, ko Waipaa ngā awa
Ko Taanehopuwai te papa kainga
Ko Motiti te marae
Ko Ngāti Apakura, ko Kinohaku ngā hapū
Ko Ngāti Maniapoto te iwi
Ko Kuini Koti raua ko Freda Borell ōku kuia
Ko Graham Koti tōku matua

I te taha o tōku māmā
Ko Whetūmatarau, ko Kokai ngā maunga
Ko Awatere, ko Hotohoto ngā awa
Ko Awatere, ko Whareponga ngā marae
Ko Te Whānau a Te Aotāihi, ko Te Aitanga a Mate ngā hapū
Ko Ngāti Porou te iwi
Ko Julian 'Arthur' Brooking raua ko Hinetewhiu Brooking ōku tīpuna
Ko Audrey Koti tōku māmā
Ko Diane Koti tāku ingoa
Tihei mauri ora.

To my baby, Hawaiki, you are and have been the best motivation I could have hoped for. You have given me purpose and drive to get through this.

To mum and dad thanks for all the support, belief, babysitting, petrol, money, money and more money. I couldn't have done it without you both.

To my fellow Amibros, Nei, and JJ, you guys made this journey bearable, not only knowing first hand the highs and lows, but also keeping it real. Having you both there was and continues to be priceless.

To all my friends and whānau, big ups for all the supportive texts, Facebook messages telling me to get off there, pep talks, belief and coffees.

To my supervisor, Tash, thank you for picking up the phone in my times of panic, for listening to my moaning and ramblings, and for your guidance.

To Massey University thank you for the academic and financial support via Te Rau Puawai and the Purehūroa awards. Many thanks to The Ministry of Health and the Health Research Council for their financial support, as well.

To the staff at Cranford hospice, I am grateful for you support, thank you very much.

To my participants, words cannot express my eternal gratitude for allowing me to undergo this experience with you and your whānau. I hope I do your stories justice.

Finally, to Brian thank you for supporting and putting up with me, being me.

ABSTRACT

Palliative care and hospice service demand in New Zealand is predicted to increase, due to New Zealand's growing and ageing population. The Māori population is youthful, and ageing at a faster rate than non-Māori. Māori currently under utilise palliative care and hospice services, compared to non-Māori, but given the growing population, they will potentially be high future users of these services. Consequently, palliative care and hospice services, facilities, and health professionals must ensure they are competent to meet the needs of Māori. This project investigates Māori experiences and perceptions of palliative care and hospice services. Three Māori palliative care patients and four whānau members, were recruited. A kaupapa Māori (Māori cultural ideologies) approach underpins this research project, and uses pūrākau (Māori narratives) to illustrate the participants' discussions. In-depth interviews were conducted, transcribed, and thematically analysed, exploring how they navigated their journey through palliative care and hospice services. Particular interest lies in their personal experiences and perceptions of whether palliative care and hospice meets their Māori cultural needs, and identifying any influential barriers or benefits. The findings were presented under five primary themes: 'Something is wrong', 'Knowledge and understanding', 'Hospice', 'Te ao hurihuri: Changing times', and 'Te tatau o te pō: The door of the night'. The interpretation of the results highlighted the diversity between the participants' expectations, perceptions, and experiences of palliative care and hospice. Through interviewing these Māori patients and their whānau, their intimate pūrākau have established a foundation for further investigation of palliative care and hospice services for Māori. This research will not only contribute to the limited literature existing on Māori and palliation, but it will also provide a voice for those interviewed.

PREFACE

Tukua te wairua kia rere ki ngā taumata
Hai ārahi i ā tātou mahi
Me tā tātou whai i ngā tikanga a rātou mā
Kia mau kia ita
Kia kore ai e ngaro
Kia pupuri
Kia whakamaua
Kia tina! tina! hui e! tāiki e!

Allow one's spirit to exercise its potential.
To guide us in our work as well as in our pursuit of our ancestral traditions.
Take hold and preserve it.
Ensure it is never lost.
Hold fast, secure it.
Draw together! Affirm![2]

I have been contemplating this research for some years. I experienced a number of events that led me to this point. I do not believe in coincidences, so I truly believe these experiences were meant to be, to guide me through this journey.

My grandmother had been unwell, and I was told by other whānau members to meet at her home. Once there, I found out she was sicker than I expected, which was not unusual, as she did not like to burden us with her troubles, no matter how severe. Over a couple of days, we watched her get progressively worse. Eventually, we were told to gather our whānau together to say our farewells, as she was close to death. Over the next couple of days, I greeted most of her children and her grandchildren, who had travelled from all over New Zealand and the world to be with her in her final days.

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[2] Karakia (prayer).

She was experiencing a lot of pain; I noticed a lot more activity around her home and discussions between my mother, my aunty, and uncles. Then I noticed an unfamiliar person. He came into her home, into her bedroom, examined my Nan, and then administered some medication. During this time, I was wondering what was happening. After this person left, I asked what was happening, and I was told that he was a nurse from the local hospice. I asked what is hospice, but cannot remember the answer given. A couple more days passed, with the hospice nurse making regular visits, and with my Nan slipping in and out of consciousness. Her last morning, in a moment of consciousness, she said she was ready. But we were still waiting on my uncle to return from overseas, and on reflection, so was she. The hospice nurse was doing his routine check, when I asked him how long he thought she had. He said something along the line of, “it's hard to tell, it could be a couple of days”. For some reason, I knew this would be her last day.

Later on that day, I received a phone call from my uncle, informing me that he had been delayed, and he wanted me to read Nan a message. So I did as he asked. She died that night.

That was my first encounter with palliative care and hospice. On reflection, I still didn't know or understand anything about either, other than a nurse visited and a short time later my Nan died. I didn't think anymore about it until two months later when I applied for an administration job at the hospice that cared for my Nan, I got the job. From this, my awareness and understanding of what palliative care and hospice are grew, and has been an area of interest ever since.

I have included the following extract about Hine-nui-te-pō for two purposes, firstly, as an example of a pūrākau, the method used in this research project to collate the data. Secondly, it illustrates the beginnings of human immortality, of death. From a te ao Māori (Māori worldview) perspective, the reality of and why death looms near for the participants of this study, originates from the following event.

HINE-NUI-TE-PŌ

He ai atu tā te tangata, he huna mai tā Hine-nui-te pō.
Man begets, but the goddess of death destroys
(Brougham, Reed, & Kāretu, 1999, p.32).

The picture and the following extract were taken from the book *Wahine toa: Women of Māori myth.* Robyn Kahukiwa painted the picture depicted above with the following extract written by Patricia Grace.

The pūrākau of Hine-nui-te-pō.
It was because of shame that I left the world of light for the dark world and promised to await my children and their descendants to welcome them here in Rarohenga (the underworld). Now the time is near.

Now, at last, this Māui comes towards me, coming in the hope that he will conquer me, and that the children of hard-won light will never know death.

When I have defeated Māui, I will thereafter welcome my descendants in death.

But I do not cause death, and did not ordain it. Human death was ordained when human life was ordained. And we - my father-husband Tāne; Taranga who gave special birth to Māui; Makea-tutara, speaker of the tohi rites; Māui-pōtiki, and I, Hine-nui-te-Pō, are merely the instruments, the practicalities, and the sequence of death. See Māui now. In the world of light he has achieved all he can achieve. He comes now to challenge me in the world of no light, seeking to achieve what cannot be achieved. To defeat death he will need to gain living entry to my womb, and living exit, but this he cannot do. Now he stands at the edge of light, exuberant, changing from one disguise to another while the little birds watch, excited and trembling. My vagina, where he must enter, is set with teeth of obsidian, and is a gateway through which only those who have already achieved death may freely pass. He will attempt to enter in life, hoping that I am asleep, but he will be cut in two, meeting his death. Only then can he be made welcome (Māui is depicted as the lizard).

Come Māui-tikitiki-a-Taranga. Your bird companions chuckle and flutter at the strange sight of you, but they are not your undoing. There is one purpose only for these obsidian teeth. In this your last journey, you will give your final gift to those of earth, the gift not of immortality, but of homecoming, following death. Come survivor of seas, lengthener of day, obtainer of fire, fisher of land, keeper of the magical jawbone of Muriranga-whenua.

Death is yours, your chosen, death is yours. Your deeds will be spoken of in the world of light, but you will never be seen there again. I will wait at this side of death for those who follow; because I am the mother who welcomes and cares for those children whose earthly life has ended (Kahukiwa & Grace, 1984).

From this encounter between Hine-nui-te-pō and Māui a saying has emerged:

Mehemea i puta a Māui i tua, kua kore te tangata e mate, kua ora tonu te Māori me te Pākehā.

If only Māui had passed through (the body of the goddess of death), then man would never have died, and Māori and Pākehā would both have live-forever (Brougham, Reed, & Kāretu, 1999, p.32).

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GLOSSARY

Ako Māori	Culturally preferred pedagogy
Aroha ki te tangata	Respect for people
Hā a koro ma, a kui ma	Breath of life from forbearers
Hapū	Kinship group, clan, sub-tribe - section of a large kinship group.
Hau-mate	Vital essence is dying or deceased
Hine-nui-te-pō	("Great woman of night") is a goddess of night and death and the ruler of the underworld.
Hui	To gather, meet, assemble.
Iwi	Extended kinship group, tribe, nation, people.
Kaitakawaenga	Māori liaison
Kanohi ki te kanohi	Face to face, in person, in the flesh.
Karakia	To recite ritual chants, say grace, pray, recite a prayer, chant.
Kaua e takahia te mana o te tangata	Uplifting the dignity of the participants
Kaumātua	Adult, elder, elderly man, elderly woman, old man.
Kaupapa	Topic, purpose
Kaupapa	Collective philosophy
Kawa	Etiquette, rules
Kia piki ake i ngā	Socioeconomic

raruraru o te kainga	mediation
Koha	Gift giving
Kōrero	Speak, talk
Kōrero tawhito	Old or ancient talk or stories
Koro/koroua	Male elder
Kuia	Female elder
Māhaki	To be humble
Makea-tutara	Makea-tutara is the father of Māui
Mana	Prestige, authority, control, power, influence, status, spiritual power, charisma.
Mana ake	Unique identity of individuals and family
Manaaki ki te tangata	Being generous and hospitable
Māori	Indigenous people of New Zealand
Māoritanga	Māori culture, practices and beliefs.
Marae	Courtyard - the open area in front of the wharenui (meeting house), where formal greetings and discussions take place. Often also used to include the complex of buildings around the marae.
Mātauranga	Education, knowledge, wisdom, understanding, skill.
Māui	Well-known Polynesian character of narratives. He performed a number of amazing feats. Also known as Māui-tikitiki-a-

	Taranga, Māui-tikitiki-o-Taranga and Māui-pōtiki.
Mauri	Life principle, special nature, a material symbol of a life principle, source of emotions.
Moko	Short for mokopuna. Grandchild or grandchildren.
Mōteatea,	Lament, traditional chant, sung poetry,
Muri-ranga-whenua	Grandmother of Māui.
Pākehā	New Zealander of European decent.
Pākeke	Adults or the elderly.
Papatūānuku	Earth mother and wife of Ranginui. All living things originate from them.
Pono	Be true, right, valid, and honest.
Pūrākau	Myth, ancient legend, story.
Rarohenga	Underworld - the place where the spirits of the dead go.
Rongoā	Remedy, medicine, drug, cure, medication, treatment, solution (to a problem), tonic
Taha hinengaro	Mind, thought, intellect, consciousness, and awareness dimension.
Taha Māori	Māori side or dimension.
Taha tinana	Physical dimension.
Taha wairua	Spirit, soul, quintessence - spirit of a person, which exists beyond death.

	Wairua dimension.
Taha whānau	Family dimension.
Tāne	Man, male.
Tangihana	Funeral.
Taonga tuku iho	Cultural aspirations
Taranga	Mother of Māui.
Tauheke	Deteriorate
Te ao hurihuri	The changing world.
Te ao Māori	The Māori world.
Te reo Māori	Māori language
Te tatau o te pō	The door of the night
Te Tiriti o Waitangi	The original Māori-language version of, the Treaty of Waitangi,
Te whare tapa wha	The four-sided house, Māori model of health by Sir Mason Durie.
Te wheke	The octopus, Māori model of health by Rose Pere.
Tīkanga	Customs and protocols
Tīkanga Māori	Māori customs
Tino rangatiratanga	Self-determination, sovereignty,
Tohi	To perform ceremonies
Tūpāpaku	Corpse, deceased
Tūrangawaewae	Domicile, place where one has rights of residence and belonging through kinship and whakapapa.
Tūroro	Patients
Ūkaipō	Origin, real home.
Urupa	Burial ground, cemetery,

	graveyard.
Wahine toa	Brave or warrior woman.
Waiata	Song.
Waiora	Total well-being of the individual and family
Whakataukī	Proverb.
Whakawhanaungatanga	Relationships, kinship
Whānau	Extended family, family group, a familiar term of address to a number of people.
Whatumanawa	The open and healthy expression of emotion
Whenua	Land.

CHAPTER ONE: INTRODUCTION

Introduction

Palliative care and hospice service demand in New Zealand is predicted to increase. This is presumed mainly due to New Zealand's growing and ageing population (Ministry of Health, 2010). Due to the Māori population being youthful, as well as increasing and ageing at a faster rate than non-Māori, Māori are expected to become high future users for New Zealand’s palliative care and hospice services (Ministry of Health, 2010). Consequently, it is pertinent palliative care, hospice services, facilities, and health professionals are competent in meeting the needs of Māori.

This section introduces the elements covered throughout this research project. Firstly, the research goals and the research question are explained. Then a chapter synopsis is provided to outline the content presented in this thesis. Furthermore, Māori words will be accompanied with an English translation in the first instance throughout this thesis, and there after only the Māori word will be used.

Research goals

The primary focus of this thesis was to explore a Māori perspective of palliation and hospice services. The research question developed to:

> ***What are the perceptions and experiences of Māori patients and their whānau of palliative care and hospice services?***

From the research question two research objectives were formulated:

1. Investigate Māori patients and their whānau experiences and perceptions of accessing and utilising palliative care and hospice services in the Hawkes Bay region; and

2. Explore barriers and enablers that influence access and utilisation of palliative care and hospice services by Māori patients and their whānau in this region.

A lot of research has been conducted about palliative care and indigenous populations (Brabyn & Skelly, 2002; Castleden, Crooks, Hanlon, & Schuurman, 2010; Evans, Stone, & Elwyn, 2003; Goodridge & Duggleby, 2010; Hotson, MacDonald, & Martin, 2004; Prince & Kelley, 2010; Kelley, 2007; Kortes-Miller, Habjan, Kelley, & Fortier, 2007; McGrath, 2010; McGrath, Patton, McGrath, Olgivie, Rayner, & Holewa, 2006; Payne, Kerr & Hawker, 2004; Phillips, Davidson, Jackson, Kristjanson, Bennet, & Daly, 2006; St. Pierre-Hansen, Kelly, Linkewich, Cromarty, & Walker, 2010), however, this research is one of a few studies that have investigated palliative care and hospice from a Māori perspective.

Review of chapters

Chapter one introduces and lays the foundation for this research project.

Chapter two examines the literature of palliative care and indigenous populations. Discussed are the international and New Zealand notions of palliative care, under five commonly found topics: access; knowledge, education and literacy; communication; isolation; and care facilities for the dying.

Chapter three illustrates the theoretical perspectives utilised for this study. A kaupapa Māori methodology underpinned the research approach, complemented with Pūrākau (Māori narrative) as the method of data collection, which was thematically analysed.

Chapter four outlines the procedures used. Aspects discussed are: the consultation process; the recruitment of the participants; how the data was collected and analysed; ethical approval; and a description of the participants.

Chapter five and six present the findings and discussions of the participants' extracts. Chapter five explores the participants' experiences and perceptions of palliative care and hospice services, from when they knew something was not right with their health up till the present day. Chapter six looks at diverse realities of Māori in an ever-changing world, and how this has influenced their perceptions and experiences of palliative care and hospice. Also, included in this chapter are their discussions about their desires, and plans they had thought about whilst receiving palliative care and utilising hospice services. These desires and plans had been realised upon being confronted with the reality that they are living with a terminal illness.

Chapter seven finishes this research project by concluding the information presented in the previous chapters. Other aspects discussed were the limitations and future research aspirations.

Conclusion

Like many other indigenous communities, divergent worldviews between Māori and Western cultures influence experiences and perceptions of palliative care and hospice services. This research looks to explore perceptions and experiences of palliative care and hospice services by Māori patients and their whānau. Thus, bringing Māori patients and their whānau to the forefront of the research process, honouring their experiences.

CHAPTER TWO: LITERATURE REVIEW

The World Health Organisation (WHO; 1990) defines palliative care as a specialised health care service for people who have been diagnosed with a terminal illness caused by cancer. In a short time period, palliative care has evolved from a philosophical care aimed at terminal cancer patients to a movement aimed at all peoples no matter the disease, but for those “whose death can be medically anticipated” (Gott, Seymour, Ingleton, Gardiner, & Bellamy, 2011, p. 233). This saw the redefinition of palliative care for adults to:

> *an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual* (WHO, 2002, par. 1).

WHO (2002) continued by describing palliative care as being accessible early, offering aid, assistance, and support from painful symptoms, whilst acknowledging and normalising the dying process by neither delaying nor speeding up death. Palliative care also considers the patients' spiritual and psychological views and practices as being important, offering supports to assist patients live an active and fulfilling life until death, and supporting the families at the same time. Palliative care expresses the significance of quality of life and the inclusion and importance of a multi-disciplined team approach to caring and managing the diverse needs of patients and their families.

Palliative care services are a health area in New Zealand that is predicted to develop and increase. This is presumed mainly due to the growing and ageing New Zealand population (Ministry of Health, 2010). Consequently, the Palliative Care Subcommittee of the New Zealand Cancer Treatment Working Party (2007) defined New Zealand palliative care as:

> *care for people of all ages with a life-limiting illness which aims: to optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs; support the individual’s family, whānau, and other caregivers where needed, through the illness and after death* (p.5).

Furthermore, palliative care should be accessible by all terminal patients due to a persons need no matter the time frame of pending death, be it days or years away. Palliative care in New Zealand should be delivered recognising the diversity of New Zealand populations, including the uniqueness of Māori, children, immigrants, refugees, and isolated peoples. Finally, generalist and specialist palliative care should be available no matter the geographical location of the patient (Palliative Care Subcommittee, New Zealand Cancer Treatment Working Party, 2007).

The New Zealand Ministry of Health (2009) defined specialist palliative care; as provision of specialised palliative care health professionals who have been specifically trained and/or accredited in palliative care or medicine. These professionals can provide palliative care from hospices and palliative care units, or specialised paediatric palliative care teams at hospitals. These teams are normally made up of proficient palliative care multidisciplinary teams (McKinlay & McBain, 2007). The Ministry of Health (2009) further stated that specialist palliative care is provided in two main areas. Firstly, by managing and supporting complex palliative care needs patients and their families, whether continuously or sporadically. Complex need is defined as “a level of need that exceeds the resources of the generalist team: this may apply in any of the domains of care – physical, psychological, spiritual or cultural" (Ministry of Health, 2009, p. iv). Secondly, specialist palliative care strives to assist and offer supportive advice and educational training for “other health professionals and volunteers to support their generalist provision of palliative care" (Ministry of Health, 2009, p. iv).

Generalist palliative care is defined as palliative care provided by a health professional that is not classified as an expert in palliative care, such as general medical teams, Māori health providers, and paediatric teams usually located in the community or local hospitals. Usually, generalist palliative care will be provided and integrated by health professionals into their standard clinical practice (Ministry of Health, 2009). However, the amount of contact by these health professionals varies, from on-going contact with families throughout treatment and care, while other health professionals will only have sporadic contact, such as hospital teams and community nurses (Ministry of Health, 2009). Generalist palliative care professionals and services are connected with specialist palliative care professionals and services for educational purposes, assistance, advice, and referral if there is a complex case (McKinlay & McBain, 2007; Ministry of Health, 2009).

When considering the two differing professional roles and the application of the WHO (2002) definition of palliative care, other factors need to be considered when used in a New Zealand context. The Palliative Care Subcommittee of the New Zealand Cancer Treatment Working Party (2007) illustrated further factors needed to be considered such as; the continuing progression, development, and advancement of palliative care; recognition of New Zealand's diverse population, cultural beliefs, and practices; an integrated approach to palliative care; continuity of care; equitable access for children and young people the distinct cooperation; the provision of equitable access, and collaboration of generalist and specialist palliative carers and services; and acknowledgement of how Te Tiriti o Waitangi shapes decisions, practice, and responsibilities because of the unique Crown and Māori constitutional relationship.

New Zealand's health inequities between Māori and non-Māori are a well known, highly documented, and a greatly researched topic. Many governmental, organisational, and systemic policies note this inequality with regular mention about ensuring equitable provision for Māori (Ministry of Health, 2010; Robson & Harris, 2007). However, even with the abundance of research, non-Māori have and continue to achieve greater gains in most governmental measures of social, political, economic, and health outcomes than Māori

(Ministry of Health, 2010; Robson, Cormack, & Cram, 2007; Robson & Harris, 2007). While these health inequalities in New Zealand are not random, the causes are complex and multifaceted, influencing the provision, access, and utilisation of palliative care and hospice services. With a governmental focus on palliative care, it is timely to conduct this research project (Health Workforce New Zealand, 2011; Ministry of Health, 2009).

My interest in investigating this area is due to the Māori population being youthful, as well as increasing at a faster rate than non-Māori, thus assuming Māori will be potential high future users of New Zealand's palliative care services (Ministry of Health, 2010). Consequently, the future need is apparent, to ensure that palliative care and hospice services, facilities, and health professionals are competent in meeting the needs of Māori. Therefore, health professionals should be educated in the unique cultural needs and considerations when working with, and caring for, Māori.

Access

Appropriate access of palliative care services makes up part of the vision for palliative care services in New Zealand. The vision statement for the delivery of palliative care services is described as "all people who are dying and their family/whānau who could benefit from palliative care services will have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way" (Ministry of Health, 2001, p. vii).

The primary aim in ensuring successful implementation of the New Zealand Palliative Care Strategy (NZPCS, 2001) vision, is to increase community and health care provider's knowledge and awareness of palliative care services, and to foster a 'palliative care culture' (Ministry of Health, 2001, p. vii).

Māori have been identified and highlighted as a population group with variable access to palliative care services. Due to this inconsistency, five problematic areas focused at improving Māori accessibility have been identified in the NZPCS (2001), these are:

1. a lack of knowledge about palliative care
2. currently no Māori palliative care providers
3. a lack of coordination between non-Māori and Māori providers
4. planning palliative care services for Māori; and
5. the provision of culturally appropriate palliative care from non-Māori health professionals and providers (Ministry of Health, 2001).

Ultimately, equal access of palliative care services and facilities such as hospital palliative beds, hospices, community in home resources, and residential aged care facilities, assumes that individuals have identical opportunities to utilise these services (Walshe, Todd, Caress, & Chew-Graham, 2009). The authors continue by mentioning that the majority of research investigates utilisation of services opposed to access to services. Many studies discuss the importance of improving access to palliative care, and give recommendations about how this may happen (e.g., Brabyn & Skelly, 2002; Ellison-Loschmann & Pearce, 2006; McGrath et al., 2006; Nichols, 2005; Oliver & Mossialos, 2004; Payne et al., 2004; Zerzan, Stearns, & Hanson, 2000), yet there is no definite definition of what and how 'access' in terms of palliative care can and should be achieved.

General health access definitions can differ depending on the speciality. For example, Andersen (1995, p. 4) described access as being a complicated "health policy measure", and defined access as comprising four components: potential access, realised access, equitable access, and inequitable access. Potential access is described as enabling resources, consequently enabling resources to provide better channels and ways for utilisation. Realised access is outlined as "the actual use of services" (p.4). Equitable access has been termed as happening when demographic and need have limited effect on utilisation. Inequitable access is when determinants such as ethnicity and socioeconomic status (SES) govern who receives health care (Andersen, 1995). These components were created with a purpose to ascertain if there were certain circumstances that influenced utilisation of health services (Andersen, 1995). SES is further discussed by Schwass (2005) as a determining factor as to whether New Zealanders' have equal access to hospice care. Schwass (2005, p. 20) stated “not all people who seek hospice care will have access to it, especially in rural areas”. Palliative care facilities such as hospices obtain a large proportion of their funding through fundraising and charitable donations (Hospice New Zealand, 2013; Ministry of Health, 2001; Schwass, 2005). Funding for the provision of community palliative care is varied and can depend on such things as geographic location. This then places financial burdens on families who have limited access to palliative care services and facilities (Schwass, 2005). The author continues by suggesting that lower income households and geographic location negatively influences access to palliative care for children, the elderly, and minority ethnic groups.

Jennings, Ryndes, D’Onofrio and Baily (2003) discussed equitable health end-of-life care in the context of social justice. Stating the provision and access to fair and equal end-of-life health care for all citizens is a moral, social obligation. However, what is ‘equitable access to health care’? It has been argued that there is yet to be a specifically defined meaning for this (Oliver & Mossialos, 2004). This literature review focused primarily on circumstances related to equitable and inequitable access using the following definitions.

For this research, equitable access has been broadly defined as the provision of treatment and services which should be available to persons with equal need, without the influence of external health factors (Burt & Raine, 2006; Jennings et al., 2003; Walshe et al., 2009). Many health care services, facilities, and government agencies discuss the importance of equitable health care access, usually within their own publications, institutional codes, and policies (Hanson and Associates, 2007; Hawke's Bay District Health Board, 2008; Hawke's Bay District Health Board, 2012; Health Workforce New Zealand, 2011; Ministry of Health, 2001; Ministry of Health, 2010; Palliative Care Subcommittee, New Zealand Cancer Treatment Working Party, 2007; Tairawhiti District Health, 2012).

Inequitable access of health care services is multidimensional and has many determinants. Some determinants that influence access to health care are; age, gender, ethnicity, SES, geographic location, and culture (Durie, 2003; Ellison-Loschmann & Pearce, 2006; Marmot, 2005; Ministry of Health, 2010). For example, New Zealand’s population of non-Māori women have a significantly lower mortality rate from cervical cancer than Māori women (Priest, Sadler, Sykes, Marshall, Peters, & Crengle, 2010; Robson & Harris, 2007; Robson et al., 2006). These ethnic trends are consistent with international research of cancer incidences and outcomes (Ahmed, Mohammed, & Williams, 2007; Andersen, 1995; Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003; Dachs, et al., 2008; Jong, Vale, & Armstrong, 2005; Valery, Coory, Stirling, & Green, 2006; Zhao & Dempsey, 2006).

One focus of the NZPCS was Māori and non-Māori health inequalities and disparities (Ministry of Health, 2001). It is well documented that non-Māori have and continue to achieve greater gains in most governmental measures of social, political and economic outcomes (Ministry of Health, 2010; Robson et al., 2007). Harris, Tobias, Jeffreys, Waldegrave, Karlsen, and Nazroo (2006) suggest personal and institutional racism influences the level of Māori participation of New Zealand’s health services, through avoidance of health services, facilities and health professionals. These ultimately lead to even less utilisation, and further health inequalities (Harris et al., 2006). Nichols (2005) suggests; Māori, Pasifika, children, migrants, and rural people have been identified as the groups less likely to have equitable access and are less likely to utilise palliative care services. So what does this say for rural Māori and their children? Are they then twice disadvantaged than non-Māori of urban centres? Should one's choice of geographic location result in inequitable access, and thus limit utilisation of palliative care and hospice services?

Like Māori, other colonised indigenous peoples are challenged with similar health inequalities and disparities. Research reveals the gap between colonised indigenous populations and their Western counterparts (Browne & Shultis, 1995; Harris et al., 2006; King, Smith, & Gracey, 2009; Reading & Wien, 2009). Four categories have been used to describe determinants of health inequalities of Aboriginal peoples of Canada (Reading & Wien, 2009). They are; social determinants, proximal determinants, intermediate determinants and distal determinants of health. From these and other studies, a number of barriers have been highlighted. Some of the most common barriers include; access to and utilisation of health services, mistrust of these services and practitioners, institutional systems, colonialism, racism, socio-political issues, limited literacy of health care services and differing cultural ideologies and practices of personal, family and community (Ahmed et al., 2007; Browne & Shultis, 1995; Durie, 1994; Firth, 2004; Harris et al., 2006; King et al., 2009; Lupton, 1992; McCreanor & Nairn, 2002; Ngata, 2005; Prince & Kelley, 2010; Reading & Wien, 2009; Tuhiwai Smith, 2012). The next section looks at, literacy, one of the common barriers identified.

Knowledge, education, and literacy

The first part of this section investigated indigenous consumers' knowledge and perceptions of palliative care. The second part of this section looked at providers' provision of palliation education and literacy initiatives. What is palliative care? How do we find out more? Who do we contact? Whose responsibility is it to be informed or to inform? The NZPCS recognised the need to inform the public of palliative care services as a requirement and responsibility of each District Health Board (Ministry of Health, 2001). A recommendation was to ensure information is available to consumers on ‘how to’ access and utilise palliative care and hospice services. This included, who provides palliative care, how and where palliative care is accessible, the public’s entitlement and rights to palliative care services, what services are offered from palliative care providers, and provision of public expectations of palliative care services (Ministry of Health, 2001).

What is palliative care? The perception and knowledge of indigenous peoples about palliative care and hospice services were varied. A study conducted in the Northern Territory of Australia, explored the knowledge of indigenous peoples’ understanding of Western palliative care and hospice. It was found that the majority of their consumer participants had no knowledge of palliative care or hospices (McGrath & Patton, 2007). The authors continued by highlighting that once education and literacy training was provided about the central notions of palliative care, awareness increased, assuming that indigenous peoples of this community may better access and utilise palliative care and hospice services in the future.

Other studies have found perceptions of palliative care and hospice by indigenous communities perceive death to be imminent upon utilisation. Further perceptions were that hospices serviced predominately white, middle class, Christian peoples, and have the physical appearance of a church (Bellamy & Gott, 2013; Ronaldson & Devery, 2001). This reputation and physical appearance can be intimidating for indigenous peoples, further hindering access and utilisation of palliative care and hospice services and facilities. Bellamy and Gott (2013) found that, in their New Zealand study after discussions with Māori groups, environment transformation initiatives were suggested as easy changes to make the hospice setting more inviting for Māori. Highlighted in their research, they encouraged the use of artwork and native floras to make the hospice's physical appearance more inviting. However, there is still limited literature of Māori patients' perceptions and experiences of palliative care and hospice services.

Awareness of palliative care and hospice has been recognised as a barrier for indigenous populations. Palliative care professionals have stated that there is an issue with the limited amount and quality of palliative care information resources that are available for patients, families, and carers, thus influencing palliative care accessibility and uptake (Bellamy & Gott, 2013; Castleden et al., 2010). Increasing the number of Māori palliative care health professionals has been recommended in New Zealand's palliative care national strategy yet, there is limited information outlining how this will be achieved or ensured (Ministry of Health, 2001). Increasing the Māori palliative care and hospice workforce would increase Māori cultural competency, and culturally appropriate provision of palliative care and hospice services. It has been noted that a lack of educational resources and poorly culturally trained palliative care and hospice staff are barriers further hindering access and utilisation of palliative care services by Māori and other indigenous populations (Beach, et al., 2006; Castleden et al., 2010; Hotson et al., 2004; Ministry of Health, 2001). Many studies, organisational guidelines, and strategies, highlight the cultural safety appropriateness of ensuring more indigenous palliative care workers are trained (Bellamy & Gott, 2013; Castleden et al., 2010; Doorenbos & Schim, 2004; Durie, 2001; Hanson and Associates, 2007; Hotson et al., 2004; McGrath, 2010; Ministry of Health, 2001). A lot of literature indicated that research has been conducted around the creation of palliative care frameworks and models, and assessing integrative partnerships between providers and indigenous communities. Yet, there is still a lack of indigenous peoples as palliative care health professionals, and palliative care researchers and educators, highlighting the gap between research, implementation and practice (Goodridge & Duggleby, 2010; Hampton, et al., 2010; Kelley, 2007; Kortes-Miller et al., 2007; McGrath, 2010; Prince & Kelley, 2010; St. Pierre-Hansen et al., 2010).

Communication

This category examines communication preferences of information exchange between palliative care patients, their families, and palliative care and hospice professionals. Currently there is limited literature exploring Māori perceptions, even non-Māori New Zealanders' perceptions of palliative care communication. However, Kelly and Minty (2007) found from their review that communication differences are apparent among Canadian medical practitioners and Canadian Aboriginal patients. Some of the differences identified were, expectations about how communication is conveyed, and who is included and privy to the information. For instance, Canadian aboriginal patients' preferred information to be relayed indirectly via family or friends, as well as family and friends, being included with all communications (Kelly & Minty, 2007). Furthermore, it was believed that discussing terminal illness or death can hasten death, and because of this it was not uncommon for family members to withhold a terminal diagnosis and the extent of the situation from the patient (Kelly & Minty, 2007).

Comparably, communication by medical clinicians preferred directness and did not value the significance of sharing information with family, friends, and community members of the patient (Kelly & Minty, 2007). Yet, for Australian aboriginal patients' communication with medical professionals involved different assumptions and expectations. McGrath, Ogilvie, Rayner, Holewa and Patton (2005) highlighted that information exchange should ensure the "right story goes to the right person" (p.306). They go on to explain that hierarchal structures can exist in traditional Australian aboriginal family systems, where select family members have seniority and access to knowledge and information that others may not. It is vital that palliative care practitioners adhere to these cultural and family practices (McGrath et al., 2005). Direct and open communication from practitioners has been identified as a preferred form of communication from some indigenous peoples, allowing for a true understanding of the situation and ensuring no sense of ‘false hope’ was experienced (Kelly et al., 2009). The breakdown of communication procedures between patients and palliative care professionals can have an everlasting negative affect, due to poor experiences having been had by both parties. For non-indigenous palliative care workers, this can cause frustration and avoidance of wanting to care for indigenous patients (Shahid, Finn, & Thompson, 2009; Willis, 1999). In general, between 50-75% of bereaved carers' stated that they received appropriate information about the patient they cared for (Ramirez, Addington-Hall, & Richards, 1998). The assumption would then be that 25-50% of bereaved carers did not receive appropriate information about the patient they cared for.

Isolation

Should geographic location influence access and utilisation of palliative care? In Canada, access to complete and appropriate palliative care proves to be challenging in both rural and urban locations (Castleden et al., 2010). For rural areas, a lack of resources has been identified as hampering palliative care delivery, and for urban areas palliative care is frequently detached from the appropriate cultural needs of the indigenous peoples (Castleden et al., 2010; Hotson et al., 2004).

Isolated communities struggle with a lack of resources for best palliative care delivery. It has been reported that Māori, Australian aboriginals, and Alaskan natives of isolated communities often have no or limited access to palliative care, respite, and hospice services (Evans et al., 2003; Kelley, 2007; McGrath, 2010; McGrath et al., 2006; Payne et al., 2004; Phillips et al., 2006). Often, many hours of travel are needed from these rural and at times extremely isolated communities to a major city, to access palliative care and hospice services (McGrath, 2006; McGrath & Patton, 2006; McGrath et al., 2006). For example in New Zealand, the Northland and Te Tairawhiti regional areas accommodate some very isolated rural communities, where hours of travel are needed to access a medical facility (Brabyn & Skelly, 2002; National Health Committee, 2010). The National Health Committee (2010) identified a number of barriers that hinder these communities' accessibility to health and disabilities services. The lack of resources, cost of accessing services, transport issues, and telecommunications influencing the acceptability of service provision, were identified (National Health Committee, 2010). Māori are more likely to live in rural areas than non- Māori, and are more likely to feature within the higher deprivation rural population too (Ministry of Health, 2012; National Health Committee, 2010). An assumption is then that Māori would be more highly affected by the lack of health and palliative care resources due to geographic location. Because of these lack of resources it frequently means indigenous palliative care and hospice patients, such as Australian aboriginals, Alaskan natives, and First Nation peoples, often relocate to different, urban cities to gain access to specialised respite and/or end of life care treatment and facilities, which then creates new problems (Kelley, 2007; Kortes-Miller et al., 2007; McGrath, 2010; Prince & Kelley, 2010; St. Pierre-Hansen, Kelly, Linkewich, Cromarty, & Walker, 2010).

Fear for rural patients is a strong emotion that has been found to influence the utilisation of palliative care. The prospect of hospitalisation in unfamiliar and often distant cities, compounded with the absence of family, contributes to the underutilisation of services (Browne & Shultis, 1995; McGrath, 2006; McGrath, 2010; McGrath & Patton, 2006; Mann, Galler, Williams, & Frost , 2001). With the prospect of relocation, fear was experienced. Fear of unfamiliar cultural differences, leaving their home, family and support structures, different languages, economic pressures, and dying away from home, are some identified fears and stresses perceived and experienced by patients (McGrath, 2006; McGrath, 2010; McGrath & Patton, 2006). For example, DeCourtney, Jones, Merriman, Heavener, and Branch (2003) illustrated Native Alaskan's fears of dying hundreds of miles away from their homes in hospitals or nursing homes. Additionally, it has been found that difficulty navigating a foreign and alien health system and facilities in an unfamiliar city can add to the fear (St. Pierre-Hansen et al., 2010).

Western Australia has been a region identified where access to specialised palliative care services is an issue (Rosenwax & McNamara, 2006). A retrospective study was conducted on people who had accessed, and who had not accessed palliative care services during the last year of their life. It concluded similar results were found to that of global literature, where rural communities struggled with accessing specialised palliative care services (Maddocks & Rayner, 2003). Disadvantaged groups such as children, the elderly, being single, divorced or widowed and ethnic minority populations had the greatest difficulties with accessibility of palliative care services (Maddocks & Rayner, 2003). So could it then be assumed that indigenous peoples', who are single, divorced or widowed and older than 85 years, are further disadvantaged than others?

Weather is another barrier for palliative care patients, practitioners and service providers of rural communities. Along with time and distance the weather can determine whether patients can leave or whether practitioners can access remote locations. For example, Maddocks and Rayner (2003) outline the difficulty a possible 6 month 'wet' season in rural Australia can have on access to rural communities. It is not uncommon for these communities to be unattainable for days, even weeks at a time, either by air or road. Also, for extremely isolated communities the 'dry', hot season can make road access impractical (Goodridge & Duggleby, 2010; Maddocks & Rayner, 2003).

Care facilities for the dying

This category looked at how palliative care and hospice facilities accommodate indigenous peoples. Hospices and hospitals are not homogenous in the provision of general health care, let alone the provision of specialists and generalist palliative care (Brabyn & Skelly, 2002). So can it also be assumed that cultural appropriateness of care, dying, and death also varies from hospice to hospice, hospice to hospital, and hospital to hospital?

Dame Cicely Saunders is referred to as the founder of the modern hospice movement of Great Britain (Bennahum, 1996; Clark, 1998; Saunders, 1996; Saunders, 2001). She explained that hospice is an ancient word describing "a long tradition of offering hospitality and care which dates, in Europe, from the 4th century of the Christian era" (Saunders, 1996, p.1). Whereby, those in need of care were welcomed and cared for with honour and respect (Saunders, 1996). The St Christopher's Hospice headed by Dame Cicely Saunders was opened in 1967, and since then many hospice facilities have opened globally (Clark, 1998; Clark, Small, Wright, Winslow, & Hughes, 2005). Many people perceive hospice as just a building, when, in fact, it is a philosophy of care (Hospice New Zealand, 2013). Hospice New Zealand (2013) defined the philosophy as:

> *Extending beyond the physical needs of a person to their emotional, social and spiritual needs and those of their family as they live with a life limiting condition...Most hospice services have inpatient facilities, however, the majority of people are cared for at home in the community. Our goal is to help people make the most of their lives; to live every moment in whatever way is important to them* (par.2).

As defined by WHO (2002), the ethos of hospice and palliative care, intends neither to hasten nor postpone death. This philosophy is the cornerstone of hospice care in New Zealand (Hospice New Zealand, 2013).

The hospice movement began in New Zealand in 1985. From that year, a series of factors arose from a workshop in Auckland that saw a national hospice body established with the support of the Cancer Society. Today that organisation is known as Hospice New Zealand (Hospice New Zealand, 2013). Hospice New

Zealand was fully operational in 1986, with the purpose of gaining "government funding, licensing, annual inspection of hospices, establishing standards and monitoring them at a national level and providing education and resources" (Hospice New Zealand, 2013). Currently, Hospice New Zealand is proactive in palliative care development, through assisting in research and education, workforce development, and supporting hospices nationwide.

People primarily wish to die at home. Nichols (2005) stated that it is acknowledged and accepted globally that people generally wish to die at home. Yet in New Zealand, 40% of deaths happened in public hospitals for the year 2005, and 60% of deaths were recorded as happening at hospitals or residential aged care facilities for 2010 (Ministry of Health, 2013). Several factors have been identified as influencing place of death. Such as, age, ethnicity, SES, and the underlying cause of death (McNamara & Rosenwax, 2007; Naylor, 2011). It was recorded that more than half of Māori with cancer die at home (Ministry of Health, 2001). The desire to die at home has been linked to patients wanting to spend the last days in the comforts of their own home surrounded by family and friends (Bellamy & Gott, 2013). However, if final days were spent elsewhere, then family were highlighted as being pivotal in the provision of ‘hands on’ personal care for their loved ones (Bellamy & Gott, 2013). For Australian aboriginal peoples, being close to their homelands ensures that cultural practices can be performed. It is important when nearing death, to be near their land, thus being reassured that the ‘animal spirit’ of a dying person can go back to their land (Mc Grath, 2007; McGrath, 2010). For Māori, this can mean laying at their own homes and/or laying at their Marae, thus allowing mourning practices to be carried out (Mead, 2003).

Appropriate palliative care and hospice facilities to cater for indigenous populations needs are important. Limited physical space has been highlighted as an issue for families and patients, as this limits the amount of family that can visit with their loved one at any one time (Kelly, et al., 2009; Lawrensen, Smyth, Kara, & Thomson, 2010; Mazanec & Tyler, 2003). For many indigenous peoples, being with their dying loved one is paramount (Doorenbos & Schim, 2004; Goodridge & Duggleby, 2010; Hampton, et al., 2010; Kelly & Minty, 2007;

Mazanec & Tyler, 2003). Yet, this may not be physically possible due to space restrictions at facilities. Ngata (2005) conceptualised the need for space as not just being physical, but to accommodate mental and spiritual needs for Māori care for their dying, ensuring cultural rituals can be practised. He illustrated the formal customs and traditions of Te ao Māori (The Māori world); practices before death; practices upon death; what happens at the funeral; how the changing world may influence these practices; and the recognition of cultural diversity. This highlighted some Māori cultural requirements of palliative care and hospice facilities necessary to ensure appropriate care is facilitated for Māori, during all stages of their care. Some practices include the ability to sing waiata (songs), recite karakia (incantations/prayer), and with the option of being present 24 hours of the day with the patient if desired (Ngata, 2005). Palliative care and hospice facilities may not provide these needs presently. Due to the limited literature available of Māori and palliation, further research is required.

CHAPTER THREE: THEORY

E tipu, e rea mō, ngā rā o tōu ao; ko tō ringa ki ngā rākau a
te Pākehā hei ora mō tō tinana, ko tō ngākau ki ngā
taonga a ō tīpuna Māori hei tikitiki mō tō mahunga,
ā ko tō wairua ki Te Atua, nāna nei ngā mea katoa.

Grow and branch forth for the days of your world; your hand to the
tools of the Pākehā for the welfare of your body, your heart to the
treasures of your ancestors as adornments for your head,
your spirit with God, who made all things (Mead & Grove, 2003, p. 48).

Introduction

This section looked at the relevant theory associated with the methodology, method, and analysis utilised for this research project. The difference between methodology and method was summarised by Cram and Lenihan (2000), as methodology being a process of enquiry that determines the methods used whilst the methods are the mediums used to collate and analyse data. With this being said, kaupapa Māori is the methodology that determined the use of pūrākau as the means to collate the data, and thematic analysis was the method used to analyse the data. The following section further illustrates these concepts.

Kaupapa Māori methodology

Historically, there have been many injustices and little to no benefit for Māori individuals, hapū, and iwi as research participants (Bishop, 1994; Cram, Phillips, Tipene-Matua, Parsons, & Taupo, 2004; Durie, 1998; Hakopa, 2011; Pihama, 1994; Tuhiwai Smith, 2012). Research in New Zealand has been dominated by the hegemonic power of Western research theory, methods, and conceptualisations of data gathered. The 1970's saw the emergence of kaupapa Māori theory as an approach to negate the bitter taste that lingered from the exploitation of Māori by Western research and researchers (Bishop, 1994; Tuhiwai Smith, 2012). From then and in recent decades, numbers have grown of those who were traditionally the researched to now being the researchers (Tuhiwai Smith, 2012). Māori scholars saw that there was a need for a more appropriate philosophical framework that honoured, supported, respected, and acknowledged our Māori worldview.

Kaupapa Māori theory as a research methodology can best be described as a philosophical framework that resists the prevailing ideologies of western research superiority (Bishop, 1994; Mahuika, 2008). Kaupapa Māori theory is a doctrine that endorses social justice, tino rangatiratanga (self-determination, sovereignty), and the Māori worldview, through the validation of whānau, mātauranga Māori, Māori culture, and Te Reo Māori (Durie, 1998; Peapell, 2012; Tuhiwai Smith, 2012; Walker, 2004; Walker, Eketone, & Gibbs, 2006). "Therefore, kaupapa Māori is an attempt to improve effectiveness for Māori by using inherently Māori processes, values and beliefs to frame and guide our behaviour" (Cram & Lenihan, 2000, p. ix). When advocating for kaupapa Māori to be the foundation when partaking in power dealings in New Zealand, Pihama (1993) provided the following definition:

> *Kaupapa Māori theory is a politicising agent that acts as a counter-hegemonic force to promote the conscientisation of Māori people, through a process of critiquing Pākehā definitions and constructs of Māori people, and asserting explicitly the validation and legitimation of te reo Māori and tīkanga (p.57).*

Since the inception of kaupapa Māori theory, academics have been disseminating philosophical frameworks that underpin the theory to "guide Māori researchers' practice", as well as those who wish to work with Māori (Peapell, 2012).

Smith (1997) suggested kaupapa Māori by emphasising six intervention principles that he considered essential: tino rangatiratanga (self-determination);

taonga tuku iho (cultural aspirations); ako Māori (culturally preferred pedagogy); kia piki ake i ngā raruraru o te kainga (socioeconomic mediation); whānau (extended family principle); and kaupapa (collective philosophy).

Tuhiwai Smith (1999) described the general legacy of western research has influenced "Māori attitudes towards theory and academic knowledge, attitudes which have led some Māori, at least, towards the direction of being anti-ALL-theory and anti-ALL-research" (p.196). This 'anti-ness' is believed to have emerged because Western research and researchers have objectified Māori, by privileging Western research approaches, procedures, and methods (Cram et al., 2004). Because of this, Western research and researchers have left a legacy of distaste, mistrust, and dissatisfaction through the exploitation of Māori as research subjects and topics, which is still felt today (Tuhiwai Smith, 2012).

This was apparent during the consultation stage for this study. Upon discussing my research intentions with my pākeke and other whānau, just with the utterance of the word 'research', I could tell by their faces that they were not sure. Scepticism was apparent, many questions were raised about this very matter, and a lengthy discussion took place. I explained that I would be using a Kaupapa Māori approach for my research. I explained the Kaupapa Māori methodology and the practices that I would uphold. The principles I guaranteed I would practice were: aroha ki te tangata (respect for people); kanohi ki te kanohi (presenting yourself face to face); manaaki ki te tangata (being generous and hospitable); kaua e takahia te mana o te tangata (uplifting the dignity of the participants); koha (gift giving); and, māhaki (to be humble) (Tuhiwai Smith, 1999). This brought about some reassurance for my pākeke and whānau. However, I think it will take time along with positive research experiences to lift this cloud of distrust and uneasiness from the word 'research' and everything it encapsulates. Therefore, a kaupapa Māori approach was adopted as an appropriate methodology for this research, thereby acknowledging, legitimising, and giving voice to Māori knowledge, practices, and realities within the realm of this research (Cram et al., 2004). Finally, a kaupapa Māori approach uses methods that enable the utilisation of tīkanga Māori, the building of relationships with Māori patients and whānau, and consequently the investigation of issues related to kaupapa Māori provision within mainstream palliative care and hospice services.

Method: Pūrākau

In the search for an appropriate approach to complement the kaupapa Māori methodology, I considered many other methodologies and complementary methods. There are numerous methodologies within methodologies, and as many suitable methods to confuse any budding postgraduate student, striving to impress and gain adequate approval from the almighty senior academics, mentors, and in some cases academic idols. I tried to find a method that I could tick enough boxes that justified and met the majority of the elements required to fit with a kaupapa Māori methodology. Feeling disheartened about the method I originally chose, I began the process of trudging through scores of literature to get a better understanding. However, it was difficult trying to match up a Western method to appropriately collate data via kaupapa Māori approaches and practices. But amongst the reading, I discovered Pūrākau.

Pūrākau feels natural. It is described as "a traditional form of Māori narrative, contains philosophical thought, epistemological constructs, cultural codes, and worldviews that are fundamental to our identity as Māori" (Lee, 2009, p.1). Developed by Jenny Lee (2008) in her doctoral thesis, pūrākau as a research method was "a culturally defined narrative to enable the diversity" of Maori teachers' to be perceived and understood within pedagogy (Lee, 2005; Lee, Pihama, & Smith, 2012, p.3). The inception of pūrākau as a contemporary approach was initially created to aid the area of pedagogy, however it is not limited or restricted to this domain solely. Like kaupapa Māori theory, pūrākau has no set definition, instead it is fluid, taking on many forms and taking on the needs and realities of the researcher, the research, and in this case, the participants and their stories (Lee, 2009; Pihama, 1994;).

Pūrākau is based on the conceptualisation of phenomena through story telling. Story telling is a traditional Māori art form, skill base of learning, teaching, and knowledge retention and recognition (Lee, 2008; Wirihana, 2012). Pūrākau are used to construct and maintain the generational transmission of Māori knowledge (Hakopa, 2011; Ka'ai, 2005; Kahukiwa and Pōtiki, 1999; Jahnke, 1997; Pere, 1982; Royal, 2002). According to Lee (2009):

> *Pūrākau provides a conceptual framework of representation that is relevant to research. The innovative methodological work of indigenous scholars as well as local Māori writers and academics provides inspiration to look beyond conventional research methods and academic styles of documentation and return to our narratives, to experiment with literacy techniques to research, and disseminate knowledge in ways that are critically relevant and accessible. Pūrākau offers a kaupapa Māori approach to qualitative narrative inquiry (p.5).*

Patterson (2008) supported the notion that experience-centred, explorative studies, which gather narratives from a small number of participants about "a particular area or phenomena", come under a qualitative methodology (p.24). This research is indeed an explorative study with a small group of individuals, about their lived experiences as Māori receiving palliative care and utilising hospice services.

Pūrākau can be drawn on to evaluate human behaviour (Cherrington, 2003; Dickson, 2010; Smith, 2000; Walker, 1978). Walker (1978) highlights how stories create a foundation of how people make sense of human behaviour, which then becomes a way of informing social behaviours that are often a reflection of the ideological, principles, and behaviours of a society. He continued by stating that:

> *Embedded in the stories are themes and myth-messages that provide precedents, models and social prescriptions for human behaviour. In some cases the myth-messages are so close to the existing reality of human behaviour that it is difficult to resolve whether myth is the prototype or the mirror image of reality* (p.32).

On the other hand, myth-messages may be an external ideological projection of human behaviours, creating the ability to measure social practice, thus enabling a form of validation (Walker, 1978). Furthermore, Reissman (2002) describes narratives as being representative of participants' choice of what was told or what was not told within the story. Whilst it is human agency that determines the meaning of the stories, no matter how fictionalised the stories may appear, deeper meanings behind participants narratives can be interpreted (Bell, 2002).

Hakopa (2011) looked at pūrākau from a geographical perspective. He discusses the traditional practice of kōrero tawhito (old or ancient talk or stories) as a bigger umbrella with pūrākau, mōteatea (lament, traditional chant, or sung poetry), and karakia as some of the oral elements that are used to portray kōrero tawhito. The purpose of these narratives is a way to construct, deliver and retain knowledge from generation to generation. He described that "embedded in these oral narratives were their notions of place which informed their concept of a cultural landscape; a landscape informed by narratives; the geography of narratives" (p.ii).

Wirihana (2012) broke down the word pūrākau, to form a framework illustrating the workings of indigenous knowledge at the interface with Western knowledge (Durie, 2004). She developed a pūrākau model as an analytical method to interpret and bring to life the stories of her participants. Pūrākau was broken down into four sections, pū-rā-ka-u, to aid in making sense of their lived experiences. *Pū,* embodies identifying the origins of their leadership; *rā*, suggests that from experience comes enlightenment; *ka*, evaluates the past, present and future, looking back so we can move forward; and *u*, reaffirms the need to hold firm to your mana. Pū-rā-ka-u was an analytical way for her to portray her participants "stories using their words in a way which would honour their voice and experience without academic interpretation" (Wirihana, 2012, p.227).

For me, pūrakau looks beyond the conventional Western hegemonic research methodologies, towards honouring and respecting the research, and most importantly, the participants from a Māori cultural worldview. As stated by Lee (2005):

> *In Māori culture, ... pūrākau (stories/story telling) are viewed as central in the connecting, nurturing, sustaining and flourishing of our people. A pūrākau approach encourages Māori researchers to research in ways that not only takes into account cultural notions but also enables us to express our stories to convey our messages, embody our experiences and keeps our cultural notions intact (p.8).*

With this being said, it seems appropriate to use pūrākau. As, pūrākau enables the exploration, and values the subjectivity, of the participants' stories. Additionally, as a method pūrākau complements a kaupapa Māori methodology, which acknowledges that within te ao Māori story telling is an accomplished skill, and form of knowledge construction.

Analysis: Thematic

The interviews were subject to latent thematic analysis; conducted within constructionist and kaupapa Māori focused paradigms (Braun & Clarke, 2006). Latent thematic analysis has been selected as the method to use due to its flexibility when analysing qualitative data. This identifies themes within the data, while enabling the interpretation of several aspects of the research topic (Braun & Clarke, 2006). This approach also recognises the historical and socio-political context of the discourse (Lupton, 1992). There may also be some overlap of discourse analysis, “where broader assumptions, structures and/or meanings are theorised as underpinning what is actually articulated in the data” (Braun & Clarke, 2006, p. 13). These forms of analyses also blend with kaupapa Māori research principles, and all parties are accountable to the participants, the wider whānau, hapū, iwi and Māoridom respectively (Walker et al., 2005).

CHAPTER FOUR: PROCEDURES

Tīkanga Māori: Māori processes, protocols, and concepts

As a kaupapa Māori approach research project, tīkanga Māori guided all processes from start to finish. The practice of tīkanga by participants could best be described as a continuum (Mead, 2003), ranging from daily adherence of tīkanga, to not at all, or somewhere in between. This differed on the continuum from individual to individual, individual to collective, and collective to collectives. No matter the level of participation of tīkanga Māori, each participant, was given the same options, acknowledging each participants right to manage, lead, and guide tīkanga customs within their own comfort levels. A whānau pākeke was prearranged to attend all interviews if required. Karakia was offered at the beginning and at the close of each interview, to respect the sacredness of the topic, information shared, and people involved. Following the karakia, whakawhanaungatanga took place. Whakawhanaungatanga enables the building of relationships, establishing rapport, and it ensured transparency on my part (Mead, 2003; Pere, 1997). Whakawhanaungatanga enables connections to be made by common experiences and through "common kinship, thereby binding Māori together, creating a sense of oneness" (Tassell, 2004, p.17). Whakawhanaungatanga is an important aspect of Māoridom, serving a variety of purposes. It establishes the purpose of the meeting, enables participants to establish rapport, and facilitates whānau connections through the sharing of whakapapa. Finally, a koha was given in the form of food or a small gift to show my appreciation of their time, stories, space, and knowledge shared.

Consultation

Initially, I discussed my desire to conduct this research with my immediate whānau. This was important to me, as we had all shared the same experience of encountering palliative care and hospice for the first time as whānau members. Our grandmother utilised the local hospice services, during the last days of her life. Palliative care and hospice were new for all of us at this time, so it seemed like the right place to start. They were all supportive of my research aspirations.

I then approached my uncle, a whānau pākeke. He is proficient in te Reo Māori me ona tīkanga (Māori language and customs). I discussed my research plans, and asked if he would support my research by accompanying me during my meetings with others, during the consultation process, and during the interviews. He was very obliging, and gave his full support.

Next, I approached the Māori cultural advisor of the parent organisation of the local hospice. I approached him to get his view on my pending research and to seek his approval, as this was very important to me because of his position, I thought it was pono (right) to consult him too. I met with him a couple of times to discuss the study.

The final consultation step was with the General Manager of the local hospice. I approached her requesting their support for participant recruitment via their patient database. After a face-to-face hui, submission of my research proposal, and providing my agreement to abide by other various ethical and institutional requirements of the hospice and its parent organisation, approval was gained.

Recruitment

The aim was to recruit six participants, who identified as being Māori, 18 years or older, either male or female, and current palliative care patients of Cranford Hospice.

The reason for selecting the non-probabilistic sample size of six was guided by literature on saturation. Guest, Bunce and Johnson (2006) operationalised saturation regarding sample sizes for interviews. They suggested the sample size typically relies on the concept of "saturation," or the point at which no new information or themes are observed in the data. Furthermore, they discussed that saturation ensures sufficient, quality data is collected to support research, but the use of saturation can vary according to particular methods. For samples with a high level of homogeneity, a sample of six interviews should be sufficient to enable development of meaningful themes and useful interpretations (Guest et al., 2006). They found that saturation occurred within the first twelve interviews, although meta-themes were present as early as six interviews. Therefore, six participants are considered an appropriate sample size for this research.

Early in the recruitment process it became apparent that not all potential participants of the original study criteria were appropriate to participate, so new recruitment parameters were added. Further recruitment parameters included focusing on the ‘middle range’ of current patients. This meant excluding the newly referred patients who had not yet had contact with the hospice, therefore unable to comment on their perceptions and experiences. It also meant excluding those patients who were not physically or emotionally capable of participating in a 30 - 60 minute interview, or were perceived to have only 4 weeks or less to live. This then left what I have called the 'middle range' of potential participants, to contact. The selection and suitability of the middle range of potential participants was decided solely at the discretion of a hospice staff member. Along with having the medical knowledge, the hospice staff member had already established relationships with these patients, and she had an intimate understanding of their physical and mental wellness.

Three potential participants responded to the recruitment request. Upon confirmation of their interview, I asked whether a whānau member would also like to be interviewed and included in this study to share their perceptions and experiences of palliative care, and hospice from a whānau members' point of view. The research objectives and aims were altered to include whānau members’ perspectives too.

To ensure confidentiality, anonymity and voluntary involvement was maintained, Cranford hospice sent out recruitment information packs to potential participants that met the new study criteria. Once the packs were sent this was the end of the recruitment involvement by Cranford hospice. The potential participants were informed to make contact with me directly from here. This ensured confidentiality and anonymity remained so the participants could speak openly and freely without fear of compromising their care and treatment. The study recruitment pack included; a researcher information sheet: with background information about the researcher and the motivation behind the research, as well as the researcher's contact details, and the aims and goals of the study; a participant consent form; next of kin information sheet and authority for the release of transcript form; and a participant information sheet providing a preferred choice of dates and times for interviews, and a choice of which language (i.e., Māori or English) they wanted the interview conducted in (see appendices). A pre paid self-addressed envelope was included for the convenience of returning the participant information form, acknowledging that they wish to partake in the study. Potential participants were also given the option of emailing their information sheet, if preferred. Upon receipt of the participant information form, respondents were contacted to confirm details of the interview.

Data collection: Ngā uiuinga - Interviews

Participants were provided with the option of having a whānau pākeke (Māori elder) present at the interviews. None requested this option, and all participants chose to speak English for their interviews. Whānau and friends of the participants were welcome to attend; all participants had at least one whānau member present during their interviews. Whakawhanaungatanga took place before all interviews. For most of the interviews, I started by sharing my personal experiences of how I came to know of palliative care and hospice, and our whānau experience with my grandmother having been a past hospice patient. The interviews took place in their own homes, and the interview times ranged from 45 minutes to 120 minutes. Topics were given to prompt discussion, but the participants were asked to tell their story by sharing their experiences and perceptions of palliative care and hospice. A timeframe was given for guidance, from when they were first informed or referred for palliative care and hospice services until the present day. All of the participants that were patients also discussed their future plans and desires. The discussions were audio recorded, with permission from the participants.

Data analysis: Thematic analysis

I transcribed the interviews. The transcriptions were then read and reread a number of times to get a thorough understanding of the data. The data was originally categorised into 29 themes. These themes were identified through commonality of the participant's extracts and common topics discussed. The themes were then coded and reassessed. Once coded, the data was re-themed into 12 primary themes and 20 sub ordinate themes. Upon rereading the data and considering the layout of the data for presentation, a final 5 main themes and 13 sub-themes were decided on. I have kept an audit trail of procedures, insights, reflections, and decision making to enhance the rigour of the study. This will also help with possible future studies.

Ethical considerations

Informed consent, anonymity, and confidentiality was explained, discussed, and assured. Participants and a next of kin were asked to sign a consent form. The inclusion of a next of kin was at the choice of the participant. However, the purpose was to ensure a whānau member was aware of the research and could be contacted due to the real possibility of a participant passing away before the completion of the research. It was also to ensure the whānau was still happy for the information to be shared. The personal details were not coded, as the participants were happy for their identities to be known. The right to withdraw from the research at any time without consequence or question was also explained, discussed and assured.

Prior to the commencement of this study, ethical approval was sought, and approval gained from the Massey University Human Ethics Committee (see appendices for a copy of the approval letter).

Participants

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

My strength is not that of a single warrior but that of many
(Mead & Grove, 2001,p.24).

This whakataukī refers to the combined and collective effort that was necessary for the success and completion of this research. The participants were identified by name, as requested. Figure 1 provides the names of each participant, and their respective relationships as patients and whānau members.

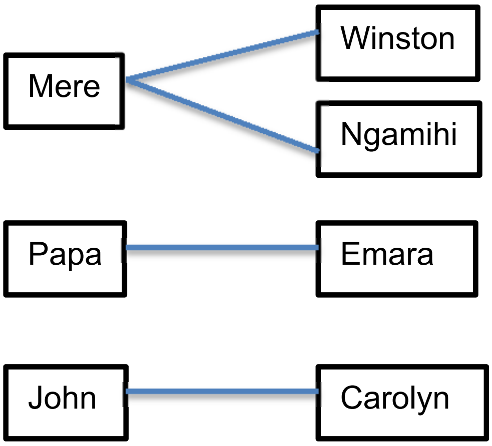

Figure 1. Participant relationships

Mere (28-06-1945 - 13-11-2013) was a retired Māori wahine (woman). She was a registered palliative care patient at Cranford hospice diagnosed with cancer. She had bone metastases, chronic renal failure, and had bilateral mastectomies. Mere passed away during the course of this research.

Winston is retired and husband to Mere. He identifies as Pākehā.

Ngamihi is a volunteer, a niece of Mere and identifies as Māori.

Ruawharo 'Papa' (14.10.1960 - 04.10.2013) was a Māori tane (male) and a teacher prior to becoming sick. He was a registered palliative care patient with Cranford hospice. He had Cancer, specifically malignant neoplasm of the oesophagus – unspecified. Papa passed away during the course of this research.

Emara is a mother and student who identifies as Māori. She is the eldest daughter of Papa.

Unfortunately, this brief introduction of the participants does not highlight the colourful, successful, and full lives lived thus far. However, the objective of this project is to exhibit the knowledge shared, with the hope that their stories can positively aid and influence current palliative care and hospice practices for Māori, now and in the future.

John Winiata is Māori, and was a mental health worker prior to being ill. He is currently a registered palliative care patient with Cranford hospice. He was diagnosed with cancer. His clinical diagnoses are malignant neoplasm of the small intestine – unspecified and metastases to the lymph nodes.

Carolyn is a Māori wahine employed at the local hospital and wife to John.

CHAPTER FIVE: RESULTS AND DISCUSSION PART ONE

Introduction

This chapter provided a glimpse into the lives of three Māori patients enrolled with Cranford hospice and currently living with a terminal illness, and four of their whānau members. The results were organised by presenting three primary themes along with eight subordinate themes, which emerged to illuminate the participants' pūrākau. The participants' pūrākau were interpreted and discussed at the end of each primary theme, incorporating significant literature. The identified themes do not justify or give full credit to the complexities of the perceptions and experiences of palliative care and hospice, underpinning the collective stories of the participants.

Palliative care, hospice, terminal illness, end of life care, and dying are all sensitive topics to discuss. Having been through this phenomenon as a whānau member, I knew the emotional and verbal difficulty of describing and discussing perceptions and experiences of palliative care and hospice. I explained that I wanted to hear their pūrākau, from when they knew something was not right with their health until the present day. The presentation of the information does not represent how the participants' told their pūrākau.

Something is wrong

The participants reflected upon their experiences of knowing something was not right with their health. Beginning their pūrākau at the point of thinking something was wrong, enabled a natural progression into the two subordinate themes, 1) from living to dying to live, and 2) accessing palliative care and hospice services. The pūrākau were presented in a way that illustrated the natural navigation of perceived illness, confirmation of having a terminal illness, and being referred to Cranford hospice.

From living, to dying to live

Tihei mauri ora ki te wheiao, ki te aomārama.

This is a Māori saying depicting the state between the world of darkness and the world of light (Barlow, 1991, p. 184).

In this context, the participants are in a liminal state, a state of transition, from once being healthy, to now living with a terminal illness. Being sick is never nice, however, for some of the participants' they knew that something was wrong. Over a period of time, Papa noticed a change in his physical wellbeing, such as weight loss:

> *I was starting to get sick, I noticed I was losing a lot of weigh, my GP said I better send you to a specialist. So it was ... the specialist that told me ... very nice man very apologetic, "but I’m sorry you've got cancer". I've got cancer of the throat and it's not recoverable (Papa).*

For John, it was a lengthy period of time knowing something was not right before medical staff uncovered the underlying cause to their ill health:

> *Mine started years ago, but I was going to the doctors but all they were giving me was simple medications ... if I knew what I know now at that time, I would have pushed for other things. Just upset tummies, then in the last, probably ... two years I started losing weight. Then towards the end of last year ... this time last year ... he [general practitioner] referred me to a specialist in Hastings hospital. When they did a scan it confirmed ... I had a tumour ... It was March this year that I went to hospital, and I came out on March 22nd, even then I wasn’t told, I didn't know for quite a while after ... I went to see ... my doctor that's when he told me ... It must have been 3 weeks after I was in hospital (John).*

These diverse experiences about their state of wellness, were shared by a sense of knowing something was wrong. Emara also shared in this sense of knowing something was not right, with her father:

> *We'd see him and he had a cold or flu, something wasn't right he never got sick. I think we were all there for dinner one night, I was going to announce I was pregnant, and he goes ... I've got something to tell you, mum ... didn't want him to tell us that night, but he did anyway ... it sort of just come out like that (Emara).*

For Carolyn, she had no choice of how or where she received the news of her husband's health prognosis:

> *I didn't realise that he [John] hadn't been told. So I never said anything after he came out of theatre. She [surgeon] said she would come to see and talk to me but she didn't do that, she told me on the phone. The surgeon told me on the phone, she used the phone ... lucky I was with the other girls having lunch, I took the phone call ... and what she said to me was that its not very good, and I said ok and that she would catch up with me, and that didn't happen (Carolyn).*

Upon receiving confirmation of having a terminal illness, the next stage navigated was 'how to' access palliative care and hospice. This is outlined in the next sub theme.

Accessing palliative care and hospice

The next stage in the journey was the referral officially requesting to be registered with Cranford hospice as a palliative patient. Mere, John, and Papa discussed their experiences of this process. Mere explained how she had little knowledge of how she became a hospice patient:

> *I don't remember how I got to that stage or if I just naturally took it for granted that these things come to you, I've probably been fortunate that it has come to me in that sense. So I think it was because of this doctor this specialist ... that enrolled me for Cranford care (Mere).*

Yet for John, his referral process to Cranford hospice was more informative:

> *I was told by my doctor ... he does a lot of work at Cranford apparently ... he's very good ... he got me straight on to Cranford so he did all that work for me (John).*

Papa was told about Cranford hospice from his general practitioner:

> *I was getting sicker by the day so ... my doctor hooked me up with the hospice, she said there's another organisation the hospice ... I said what's that? (Papa).*

The pūrākau of this primary theme and consequent sub-themes are interpreted and discussed next, including relevant literature to support the pūrākau explored.

Discussion

This section discussed the primary theme of 'something is wrong' and the two sub-themes: 1) from living, to dying to live, and 2) accessing palliative care and hospice. Through their pūrakau, John, Emara, and Papa discussed knowing something was physically wrong. Emara noticed Papa was more sickly than usual, and Papa highlighted he noticed his own weight loss. Mead (1997) explained, when a Māori person becomes very sick, the body is said to start to tauheke or deteriorate, where weight loss is seen and the person's mauri (life force) or "essence, lacks spark" (p. 219). Even though over a longer period than Papa, John knew something was not right with his health, as he was also experiencing and noticing weight loss, eventually he found out he too had a terminal illness and was dying. For Māori, dying is seen as progressive. A person is in a liminal state, neither in a form of good health and neither deceased, however, in a state of dying or "a state of hau-mate (vital essence is dying or deceased)" (Mead, 1997, p. 219).

The liminal experiences of patients have been the focus of prior research in social science and medicine. McKenchnie, Jaye and MacLod (2010) defined liminality as a social space, characterised by ritualised degrees of separation from society. The participants discussed knowing something was wrong with their health. Menkes, Davison, Costello and Jaye (2005) described and referred to this sense of knowing as the beginning of a liminal stage, identified as acute liminality, where the patient is suspicious of the diagnosis and consequent medical investigations, thus maintaining a sustained state of liminality (Menkes et al., 2005). This sustained state of liminality described where John was until his confirmed diagnosis. Furthermore, Long, Hunter and Van der Geest (2008) described care facilities, such as hospices and hospitals, as:

> *liminal spaces, where people are removed from their day to day lives, taken into a betwixt and between space of being diagnosed, treated, operated upon, medicated, cleansed etc. For many people, hospitals are places in which their previous identities as a healthy person, as a mobile person, as an immobile person, are stripped bare. New identities such as a cancer survivor, ... are forged (p73).*

In this context, having been diagnosed with a terminal illness, and accessing and utilising hospital and hospice spaces, the participants were now in a state of hau-mate, in a liminal space, a transition phase between the world of the living and the spirit world (Barlow , 1991; Mead, 2003).

For John and Carolyn, their pūrākau extracts highlighted some of their frustrations when they sought medical answers for John's ill health. Frustrations experienced included medical time delays, putting their trust in medical professionals knowledge and advice, as well as inadequate and impersonal communications.

The emotional impact of how impersonally this sensitive information had been conveyed to Carolyn was apparent. She discussed the effect this had on her. She is hospital staff, so she understands of the process of how sensitive information should be communicated between medical staff and patients or their whānau. She was not at all happy that she was told over the phone instead of in person. Generally as a preference, Māori like to communicate kanohi ki te kanohi (face to face) (Cram & Pipi, 2000; Pipi, et al., 2004; Tuhiwai Smith, 2012). Kanohi ki te kanohi is an important element in te ao Māori. It is a Māori value, practice, and concept, where the act of meeting face to face is considered respectful and necessary, when important information is to be discussed. Meeting face to face enables trust and rapport to be established (Cram & Pipi, 2000; Pipi, et al., 2004; Tuhiwai Smith, 2012). This means that written communication such as outcome letters, emails, and phone calls, may not suffice as an effective form of communication with Māori. This was seen by Carolyn's discontent with the phone call from the specialist.

This section of the discussion explores the sub theme of accessing palliative care and hospice. The patients extracts highlighted that they were either unaware that the referral was made, or had little knowledge of palliative care and hospice services at that time. Stated by Hospice New Zealand (2013), New Zealand's process of accessing palliative care and hospice services is through referral, usually by a general practitioner, hospital doctor, or a nurse. However, occasionally individuals can approach a hospice directly. There was no direct access to Cranford hospice by the participants; instead a medical professional referred them.

When referrals are made, also varies. Sometimes referrals are conducted upon diagnosis, and other times, referrals are made closer to a patients' end-of-life (Hospice New Zealand, 2013). The understanding of what was taking place and what was being actioned on behalf of the participants, was diverse. The referral process appears to be actioned at the discretion of a general practitioner or a specialist, with little or no consultation or discussion being had with the patients. These issues of accessing palliative care are highlighted as an area of needed improvement in New Zealand (Ministry of Health, 2001). This is indeed an issue of accessibility that needs to be addressed. A lack of communication and information given about the process of referral when medical health professionals are referring patients for palliative care or hospice services only creates additional barriers of accessibility for Māori.

The 2001 NZPCS highlights these very problems within the current health system. Māori access to palliative care is featured, illustrating the barriers hindering access for Māori to palliative care services (Ministry of Health, 2001). The main issues were; lack of awareness among Māori of palliative care, there are no Māori palliative care providers, better coordination is needed between Māori and mainstream providers; over half of Māori die at home, and ensuring mainstream palliative care providers are Māori culturally competent (Ministry of Health, 2001; Ministry of Health, 2009). Twelve years later, these issues are still present as seen through this research. A primary example was when participants first knew that they had been referred to Cranford hospice, was when a staff member made initial contact. The extracts shared for the sub theme accessing palliative care and hospice, illustrated that the referral process was at the sole discretion of the participants general practitioner or a specialist.

This theme explored the processes from initial un-wellness up to becoming a hospice patient. The next theme explored the perceptions and realities associated with the utilisation of palliative care and hospice services.

Knowledge and understanding

This theme looked at the participants' knowledge and understanding of palliative care and hospice services. For many Māori, palliative care and hospice are new terms and phenomena. Many Māori have not heard of, not encountered, and/or have had any need to access or utilise palliative care and hospice services.

Perception

A person’s perception is their reality. Negative experiences ultimately shape one's perceptions and reality. If this is correct, negative perceptions and experiences create barriers such as avoidance, and negative knowledge transfer, hindering access and utilisation of palliative care and hospice services. This theme looked at the initial perceptions participants had of hospice services and palliative care. The secondary themes uncovered to aid in navigating this theme are 1) a place to die, and 2) reluctance and first impressions.

Is hospice perceived as a place to die? People do die at hospices, however hospice is much more than just that. Hospices provide palliative care, psychosocial assistance, respite care, bereavement assistance, counselling, inpatient and community care, health professionals specialising in end-of-life care and quality of life, and pastoral care to name a few (Hospice New Zealand, 2013). However, Hospice New Zealand (2013) highlights, there is a misconceptualisation that hospices are places people go to die. Carolyn talked about how her perception of hospice was formed:

> *I ... heard from people; that [hospice] was the last place for people. Listening to a lot of Pākehā at work and the way they were talking, listening to them say my grandmother went in to hospice and a couple of days later ... gone (Carolyn).*

Other whānau members have encountered hospice and palliative care, when their whānau members were on their deathbed. At this time, a person's perception would be to assume that hospice is a place to die, if there had been no prior utilisation. As Emara explained:

> *When my dad’s brother died I didn’t know anything about hospice I thought it was a place to go and die. Hospice was where people go to die, I mean people do, do that but ... I didn’t know anything before that really. I think ... the kids, my partner's family, they ... thought, well I think by how they reacted, they thought hospice was where you go to die ... He [Papa] started having a couple of days in*

> *hospice and that’s when he did tell me about ...palliative care ... and that just threw me, its just like he’s going to die but I didn't know when (Emara).*

Emara highlights that not just her but her whānau, extended whānau and many of her friends, still think hospice is a place to die. This is also reiterated by Papa's statement:

> *A lot of our people think that it's a place to go and die. Not really. It's a place for preparing, if it's going to happen (Papa).*

A change in perception is needed if more Māori are to access and utilise palliative care and hospice services in the future. The next subtheme explored the participants' realities of palliative care and hospice utilisation.

Reality

The participants talked about their first impressions of hospice, and why Māori may be reluctant to use hospice. Mere's first impression was in all respects positive:

> *When you go there [hospice] they don't make you feel like a patient, they make you feel on top of the world, and I think that has been an eye opener for me, and I think it also helped my understanding towards the illness and seeing other people in the same situation (Mere).*

John’s first encounter with palliative care was when he partook in a job orientation process. He spent a couple of days at a rest home facility accommodating persons in need of palliative care. He discussed his experience, and his perceptions of the reluctance of Māori to seek and use palliative care and hospice:

> *How I learnt was through the rest homes about palliative care that people needed care and ... that's when I found out too that Māori didn't like it, they are reluctant to put their people into a rest home let alone a place like that [hospice]... I think it is a good idea [having a Kaitakawaenga (Māori liaison)] I do, because there are some ... Māori people who are a bit reluctant, and they can go see a Māori person ... I can understand a person who doesn't know nothing and all of a sudden a Pākehā comes around ... no disrespect to them but that's just how we are. When I first went there [Cranford], that day I was late, there was a Māori woman there in a wheelchair and it looked like her moko (grandchild) was pushing her around, and I looked and thought oh well they have got some Māori here, and ... I thought our people must be coming here, some of our people. I enjoyed that [day programme] but then to me that's not going to be every Māori's thing too. They'll walk in there and see all those Pākehā and walk out. They will, I can just see it. I think, because when you walk in, when I walked in there, there were all these Pākehā in there, it wasn't half way through [the day programme] and I was thinking if any other Māori saw this they would just turn around and walk back out the door ... unfortunately that's how our people work they won't go in there by themselves (John).*

Papa voiced similar concern at the lack of Māori people involved with hospice, yet expressing a sense of happiness when having seen another Māori person:

> *Ummmm I had know idea what it [hospice] was until I got there and spoke to people, and then they had Māori, two Māori officers they were good. It was good to see a brown face (Papa).*

Carolyn and John shared their perceptions of why Māori are reluctant to access and utilise palliative care and hospice services. Her point of view comes from talking about palliative care and hospice with friends, whānau, medical professionals, palliative care, and hospice staff:

> *They know a lot of Māori are very reluctant; they are getting them now apparently (Carolyn).*

John explained his thoughts:

> *Our Māori people they do not like to see their whānau put into care like that, to them, some of them its a failure on their part and they look at it like, if I cant look after them why should I give them to somebody else. That's the content we need to change, you're not a failure you can put them in there for respite, I mean the Pākehā use it for respite, but it hard to get our people to change (John).*

As a mum with young children, Emara had different perceived concerns upon her first impression of the hospice. She was apprehensive about having young children visit. She was anxious that her children would be too active and noisy for both staff and patients:

> *The first few times I was there I was paranoid because I was aware there is sick people there and they just want rest, not listen to kids (Emara).*

Children make up the nucleus whānau unit; therefore, it is important Māori whānau feel their children are welcome when utilising palliative care and hospice services.

Papa talked about how Māori are not aware of what is offered:

> *They [Māori] don't know ... My brother died of cancer too, my younger brother. If I had known what I know now when he was in palliative care I would have done what I'm doing now to help him. We didn't know anything about palliative care... I had no idea what palliative care was ... never heard of it. They explained to me what it would be then it was like, oh ok ... now I have a bit more understanding of palliative care. I've meet a lot of people that are in palliative care, I've meet a lot of doctors, I've meet a lot of people*

> *due to illness so I understand what palliative care is at this time (Papa).*

A similar response was given by Mere. However, she had heard of hospice previously, but not yet utilised palliative care:

> *A lot of people don't know ... much about what you can get [in regards to palliative care and hospice services] ... the main issue is people don't know ... I've heard about hospice because I have had breast cancer (Mere).*

Not knowing what palliative care and hospice are and not knowing what resources, care, and services are available was evident, as mentioned by Emara:

> *Never knew or didn’t even know what the words 'palliative care' were ... Now having to be with him [Papa] everyday, it's opened my eyes a lot and it's helped me understand it [palliative care] (Emara).*

Apart from not knowing what palliative care and hospice are, apprehension of the unknown creates barriers, as described by John:

> *I knew nothing about palliative care but ... I went to that rest home for that orientation [for a job] where I met a couple of people...so that's when I started to learn. I was asking some different nurses and other people what it was and they said it was palliative care and that’s how I found out about it ... I understood that they were there to support your whānau, support your wife, not only there for me, but for the family too. You can just see that they [Māori] don’t want to go into there [care facilities] because it's unknown ... for them, I think if people were to go out with our Māori people and ... spread what these places [hospices] are like ... I think you will find a lot of them [Māori] will eventually turn around... you got to go and try change some of those barriers too (John).*

Discussion

Hospice can be a scary place; a fear of the unknown, coupled with negative experiences and perceptions, only exasperates reluctance in accessing and utilising palliative and hospice care. Shown throughout the pūrākau, there was a perception that hospice was a place to die. This is a perception shared by other indigenous peoples (Bellamy & Gott, 2013; Ronaldson & Devery, 2001). As illustrated by the participants, the impact of this perception influenced the uptake and utilisation of hospice services and palliative care by Māori and their whānau members, essentially creating barriers where Māori avoid using these services. Furthermore, the perception that hospice is for Pākehā, provokes underutilisation by Māori. As highlighted by Carolyn, second-hand anecdotal information formed her perception of hospice as a facility utilised by Pākehā end-of-life consumers. Bellamy and Gott (2013) suggest non-White people perceive hospice as an unwelcoming White middle-class institution, for White middle-class end-of-life patients (Ronaldson & Devery, 2001). Cottle, Hughes and Gremillion (2013) stated they encountered this discourse numerous times during their careers in palliation. These misconceptions are primary barriers for palliative care and hospice access and utilisation by indigenous communities and Māori alike, as seen in the pūrākau (Bellamy & Gott, 2013; Castleden, Crooks, Hanlon, & Schuurman, 2010; Johnson & Slaninka, 1999). Furthermore, as mentioned by John, utilising hospice can be perceived as a failure, as traditionally Māori cared for their own whānau members (Barlow , 1991; Best, 1998; Mead, 2003).

As highlighted in the extracts, there was mostly no or minimal prior knowledge and understanding of palliative care and hospice services. Confusion, cultural differences, cultural mistrust, and a lack of community education provision, are more barriers hindering palliative care and hospice provision for Māori (Bellamy & Gott, 2013; Castleden et al., 2010; McGarth & Patton, 2007). For example, Papa discussed how his younger brother utilised hospice during his fight with cancer. However, Papa refers to not knowing about palliative care at the time his brother was using hospice services. Even though hospice provides palliative care, the connection is not made, skewing the ideology that one is not synonymous with the other. This lack of awareness and understanding are additional barriers hindering palliative care and hospice access and utilisation by Māori (Ministry of Health, 2009; Ministry of Health, 2001; Ngata, 2005; Palliative Care Subcommittee, New Zealand Cancer Treatment Working Party, 2007).

Additionally, palliative care and hospice are Western concepts. This is significant, because these concepts are new for Māori. Seeking and utilising these services are not traditional behaviours. Therefore, there is a need for knowledge generation among Māori communities, highlighting the benefits of what these services can offer. However, this will take time. Breaking down these barriers by increasing the acceptance and sense of normality for seeking palliative care and hospice assistance, will enable positive generational knowledge transference by Māori in the future (Mann et al., 2004). However, as Shahid, Finn, Bessarad and Thompson (2009) stated, palliative care and hospice services are Western initiatives. Therefore, indigenous cultural differences needs to be understood, acknowledged, and accepted, to ensure equal opportunity for access and use of palliative care and hospice services between Māori and non-Māori are realised.

Hospice

"You matter because you are you. You matter to the last moment of your life,
and we will do all we can, not only to help you die peacefully, but also to live
until you die".
Dame Cicely Saunders, founder of the Hospice movement □(1918 - 2005).

This theme explored the participants' experiences and perceptions of Cranford hospices' staff, facilities, and services. Cranford Hospice started in Hawke's Bay, New Zealand in 1982. It started with volunteers only but now manages around 400 volunteers and approximately 60 paid staff, who care for over 600 patients and their whānau every year (Cranford Hospice, 2013). The paid staff are made up of doctors, nurses, pharmacists and family support, whom are available 24 hours of the day, seven days a week. Cranford hospice states their goal "is to help people make the most of their time left on their final journey, to help them live every moment whether they are at home, in a rest home or come for a short stay with us in our eight-bed inpatient facility" (Cranford Hospice, 2013, par. 1). As well as providing palliative care, Cranford Hospice has a strong educational and learning service, offering several programmes, and opportunities for those working in primary and secondary care settings in the wider community (Cranford Hospice, 2013). Also, they highlighted that their services are free no matter one's age, cultural, ethnic or religious affiliations.

The data for this theme was analysed and presented by four sub-themes; 1) facilities and services, 2) staff, 3) Kaitakawaenga, and 4) the hospice day programme.

Facilities and Services

The participants utilised the hospice facilities in various ways. Mere currently uses the hospice for information and the hospice day programme only, choosing to use the local hospital for her medical management:

> *I use the emergency department a lot, but as for the hospice for medical side of things I haven't. Yeah got a lot of information though (Mere).*

Papa has utilised inpatient facilities at the hospice. He has had a few respite stays at the hospice, and enjoyed his stay when he was there. He discussed his appreciation for some of the hospice facilities and hospitality experienced whilst there:

> *Like the whānau room for instance ... opening up the kitchen ... you know Māori they just want to go and have feeds... if you have your own food you can come in here and cook it which is good... I think it is important for Māori, I think it is important for all people because that sort of way makes you feel like aye, a home, I felt really at home. I really didn't want to come home but I did. My couple of days [of respite] was up and I made some really nice friends there [Cranford hospice] (Papa).*

Emara enjoyed the space available for her and her children at the hospice when she visited:

> *When we visit at the hospice they are so good with the kids. I'm so paranoid, with the noise, they say your kids are well behaved, they say don't worry. There's a playroom, family room, lounge, and a game room. My son likes that there is a game, and a big huge dollhouse... For me, you know how Māori all get together, I don't expect them to bunk everyone around, just to have that place. They [hospice staff] said go down and use the family kitchen... for me that is good and accommodating because Māori are like that, we want to be with our loved ones, and some could be there or at the house and rotate and I think that made his family feel better. So when mums away I've booked him in at the hospice. I said some nights you don't have to stay home with me, you [whānau of Papa] can stay there, because I don't think he likes to be left alone. That made me feel better, that was in the back of my mind (Emara).*

Staff

All of the participants praised the interactions had with Cranford hospice staff. Papa was the only participant to stay and utilise respite care at the hospice, with everyone receiving some form of community palliative care. Respite care is planned, temporary relief care for unpaid carers (Cranford Hospice, 2013; Hospice New Zealand, 2013), who are usually whānau (Ministry of Health New Zealand, 2005, 2009). It enables patients to spend time as an inpatient at a hospice, to allow their carers to have a break (Cranford Hospice, 2013). Community palliative care is when palliative care is provided in private homes or residential rest homes. Papa utilised both respite and community palliative care:

> *They [hospice nurses] come out and see me, or I go and spend a couple of days down there ... they have been here for me when I need them, I couldn't do without them. I'm reluctant to go to*

> *hospital. I wont go. The doctor will say go to hospital and I would say no, I’m not going there, I want to go to the hospice (Papa).*

Emara too has been pleased with the provision of care for Papa, her, and their whānau, from the hospice staff:

> *They are really good, yeah, keep me up to date with everything. It’s not just about if papa needs anything, if mum or I need anything, we can just ring them. They don't just come and then go, they sit for a bit and talk, even if he's not talkative or lively ... They talk about just coming back from holiday, it's just friendly and comfortable ... They are really good, the nurse that comes everyday she is lovely, they don't just explain to Papa what they’re doing or what's going on stuff like that, because I’m there when they come they acknowledge me too which is good and just talking through the medicines... I’ve met a few nurses like the one that comes everyday to do his line thing that’s in him, I feel a great trust with her and a bond that I could just call her, and I feel that the hospice staff are so accommodating to what the family want ... I am pleased with their services. When he [Papa] has been staying there, it's just like the things that they do for the patients there... I don't like hospitals but when you go there it's not really a hospital because they got little activities that they do. It must be boring to just come in here and just sit in your room, they don't just leave you in your room. But if you're not feeling up to it they do just leave you alone they give you your space, and what not and I guess there are days when I don't want my dad to feel like he's dying (Emara).*

Carolyn and John were impressed with the availability of services by hospice staff:

> *The nursing staff are amazing... They are 24 hours on call (Carolyn).*

> *If you need anything 24 hours they are there... I find them very good, they are here to help, if there's any help we need they are there, they ask questions of how I'm feeling, that way it is good because then you know you've got someone there to support you... The day visits are good, when they come out cos the one thing they do when they do get here they focus on you, every little thing you're doing they want to know because to them they can help with anything, so they want to know how you're getting on, how's your medication going, so that is good too. ...It would be hard cos they go to a lot of places and to do that sort of work you're going to meet different people and meet some people who are pretty staunch, but for me I can get on with anybody as long as they don't push the wrong buttons, they have been good (John).*

Knowing and having the hospice staff available anytime 24 hours of the day, gave Carolyn and John peace of mind, knowing someone was contactable if the need arose.

In summary, the participants gave only positive praise for the hospice staff and care received. The following sub theme examined the Kaitakawaenga role, a Māori specific initiative within Cranford hospice.

Kaitakawaenga

Ma ngā tīkanga Māori hei tohutohu, hei arahi ngā mahi o te Kaitakawaenga.

The work of the Kaitakawaenga will be informed and guided by Māori concepts (Cranford Hospice, 2012, p.1).

The "Kaitakawaenga works to promote and improve access to palliative care services for Maori tūroro (patients) and their whānau and ensure their needs are met in a culturally appropriate way" (Cranford Hospice, 2012, p.1).

Papa refers to the Kaitakawaenga as whānau:

> *Yes, although my immediate whānau are very young. When they [Kaitakawaenga] come, they [grandchildren] see them as aunty and uncle so they use that role, which is good. The Kaitakawaenga see them [grandchildren] and say kia ora moko, which is fine. So that makes that relationship and bond a bit closer, a bit more meaningful (Papa).*

Papa went on to describe his own interactions with the Kaitakawaenga:

> *If they know I'm in the hospice they come and see me, they don't talk about my illness, and we talk about other things ... They interacted as brother, sister style role, you know how we are, they interact as Kaitakawaenga, as a Māori officer for whatever they are doing, they interact as a very professional role, yeah we talk for hours ... They are very good, very very good; it's like talking to your sister or your mother. They can be very professional, but I just think the Kaitakawaenga there is a new role its starting to branch out, I think Pākehā are starting to understand how important it is to have that Māori input not only just for Māori but for all people, there are somethings that, we have, Māori have that are very valuable to our wellbeing (Papa).*

Papa mentioned that there are 'some things' that we as Māori have that are vital for health and wellbeing. John discussed having knowledge of tīkanga and kawa as being important:

> *In some ways, it [the Kaitakawaenga role] would be good for Māori. I think you have to have knowledge of tīkanga and kawa ... When we first hear about palliative care and then I heard about Cranford, it crossed my mind about [whether there was] a Māori support person there (John).*

John continued by describing his self-awareness of his coping behaviours and how he conducts himself in new situations. He went on to discuss how he preferred to deal with events as they arose, independently. Furthermore, he discussed his understanding of the Kaitakawaenga role:

> *I think it's just myself because I can do everything myself, that’s why when I said to you I hadn’t planned out what I was going to do, just like when I go to a new situation like Cranford. I just handle it when I get there. That's how I work, I’ve always worked like that ... and I didn’t even think about those roles [Kaitakawaenga]. I don’t understand it all really; I think it is what this relation of mine is. She did come here that day to introduce herself...We didn’t talk much about that [Kaitakawaenga role], we talked about whānau, and I didn’t realise until I went to the father's day. What is she called, Kaitakawaenga? (John)*

John talked about not knowing or not really understanding the Kaitakawaenga position and what specific services it offers. However, he is familiar with who is currently in the Kaitakawaenga role. Like John, Emara described Papa as an independent person. Able and capable to navigate situations on his own, however, she mentioned that he was not the only whānau member that may need to utilise the Kaitakawaenga:

> *I did talk to her on the phone ... I would like to have met her not just because my dad's in there and there’s a Māori person, but because he would automatically say no I’m fine I don't need her. My dad's not fussed, if he was feeling like something doesn’t feel right, he would ring to organise for her to come, but what about the rest of us, it would be nice just to have that contact just in case (Emara).*

Emara and Mere are polarised in the need, desire, importance, and utilisation of Māori staff and resources. Emara is at one end of the continuum where she likes to be aware of all services and resources available for Māori patients and their whānau. However, Mere at the other end, feels content whether there are Māori specific resources and services or not. When we discussed the Kaitakawaenga role, I asked Mere if she knew what and who was currently in that role. She knew who was the Kaitakawaenga, but not the specifics of the position:

> *Not really, no, no not really, not properly to be honest no. I just thought she's part of the system, to help out. I haven't really got anything to question or to add (Mere).*

Day Programme

Cranford hospice offers a day programme called 'day hospice". The living well day hospice programme caters for Cranford hospice patients living with terminal illness (Cranford Hospice, 2013). The day programme is a great way for patients and whānau to source information about palliative care, as well as Cranford hospice services and facilities. The programme creates the opportunity to mix and mingle with other patients, their whānau members and hospice staff. For Mere and Winston this was the primary interaction they have with the hospice:

> *The only involvement we have had is the gatherings. Periodically ... gathering at Cranford once or twice a month they have a gathering for outpatients. They discuss different topics at the gatherings. Not a hang of a lot seem to attend, there might only be five, six or seven outpatients. For some it's probably not their thing (Winston).*

Not all of the day programmes are focused around education. At times, there are day programmes facilitated to celebrate annual events:

> *They have different topics, hopes, and dreams of what you want to do. They sometimes have a make up day, and mother's day or fathers day, then they will have something for the carers. They come along and have a pampering for the carers, so they get quite a lot of things. I hardly miss, if I can I will go ... First experience at a gathering, you can see that some of them [patients and whānau] are not comfortable, but the next time they come you see the change (Mere).*

The celebration of annual events held, such as fathers and mothers day, appealed, as shown by John:

> *I’ve only been over there twice. We went to a carer’s lunch sort of thing, that was very good and then I went to the father’s day one about two weeks ago. But it was a wet, cold and miserable day, a lot of them [patients and whānau] didn’t turn up, a lot of the clients because I think it was too cold and wet for them (John).*

The day programmes are a great opportunity to educate patients and whānau members about palliative care and hospice. They are beneficial in providing education, information, and building relationships. Carolyn thought:

> *They are very informative and they are very welcoming (Carolyn).*

The day programme has been a way for patients to positively interact with hospice staff, whilst learning of the services available to them and their whānau.

In summary, this theme looked at the knowledge and awareness of palliative care and hospice encountered by the participants. Four sub-themes helped to bring alive the pūrākau shared by the participants. Illustrated throughout the pūrākau was the need for strategies to increase the awareness of palliative care and hospice among Māori communities. This is discussed further in the following section.

Discussion

As illustrated by the participants' pūrākau, the provision of culturally appropriate hospice facilities for Māori needs was highlighted as important. The pūrākau illustrated the access to a communal kitchen and a whānau room or lounge area was beneficial, so whānau could share food and withdrawal for time out when needed. Other palliative care and hospice studies of indigenous communities also found similar parallels where physical space is important

(Mazanec & Tyler, 2003; Kelly, et al., 2009; Lawrence et al., 2010). Furthermore, Emara explained that the provision of a whānau room was important for her, so whānau members could stay at the hospice with Papa when needed. Reid (2005) explained that:

> *Māori whānau often want to provide care for their relations who are terminally ill or have high needs—either at home, or in a hospital or hospice. But there are many barriers still in the way of this, in the kind of state support provided, and in the services in hospitals or hospices. We have to improve the palliative care services themselves, and the flexibility of how and where the services are provided. And we have to ensure those whānau are supported in their care for family members. That's not only providing real choice—it's also meeting needs and rights (p.45).*

For Māori, similarly for other indigenous peoples, being with a dying whānau member is essential (Doorenbos & Schim, 2004; Goodridge & Duggleby, 2010; Hampton, et al., 2010; Kelly & Minty, 2007; Mazanec & Tyler, 2003). The notable absence of Māori staff and patients was discussed throughout many of the participants' pūrākau. Papa highlighted that seeing a brown face either as a staff member or a patient, was comforting. Comforting knowing that there was someone around who understood Māori cultural needs, values, and practices. So for Māori staff, does this then mean they are expected to be proficient in Māori cultural values, and practices as well as palliative care and hospice expertise? From the pūrākau shared this was the perception illustrated. In recent years, there has been a focus on increasing the Māori workforce in palliation (Hall, 2012; Ministry of Health, 2001, 2009). However, as previously mentioned, palliation and hospice is still a relatively unknown phenomenon amongst Māori communities, therefore can it also be assumed that Māori are not pursuing careers in this area for the same reason? Similar problems were found amongst other indigenous palliative care workforces (Bellamy & Gott, 2013; Castleden et al., 2010; Hanson and Associates, 2007; Hotson et al., 2004; McGrath, 2010).

For Cranford hospice, the appointment of the Kaitakawaenga has been beneficial. Through the NZPCS, the Ministry of Health (2001) recommended the implementation of care-coordinators to specifically cater for the palliative needs of Māori. From the pūrākau shared, the Kaitakawaenga role has been beneficial for Māori patients and their whānau. Beneficial, as it has increased the engagement of Māori patients and whānau members through having a designated staff member knowledgeable of te ao Māori, to call on when needed. Mentioned in some of the participants' pūrākau, there was a lack of awareness when the title Kaitakawaenga was raised. However, the participants' better understood and knew the Kaitakawaenga as the Māori liaison or a Māori staff member within the hospice. Job title did cause some confusion. Furthermore, Papa referred to the Kaitakawaenga as a whānau member, and that her level of interaction with his whānau was positive. Some of the participants were not completely sure what assistance the Kaitakawaenga role had to offer. However, the level of understanding of this role appeared to be dependent on the level of interaction the participants had with the hospice, and the Kaitakawaenga role is only in its infancy within Cranford hospice. Overall, this role can only improve positive Māori engagement by encouraging, educating, and advocating the benefits of palliative care and hospice services for Māori and their whānau.

Most of the participants have had some involvement in the hospice day programmes. For Mere and Winston, this is their primary interaction with Cranford hospice. As mentioned in their extracts, they find the day programmes to be very informative, and an opportunity to socialise with other patients and whānau members. John and Carolyn highlighted the same benefits. The positive impact of the day programmes for the participants, other than palliative care education, was whakawhanaungatanga. It enabled relationships to be formed between, patients, whānau and staff, trust to be created, and positive perceptions and experiences encountered. This encouraged further interaction and positive knowledge transfer to whānau and friends, building positive awareness of palliative care and hospice services.

Conclusion

This chapter looked at the participants' perceptions and experiences of knowing that something was not right with their health, and the accessibility process for palliative care and hospice. The primary themes were 1) something is wrong, 2) knowledge and understanding, and 3) hospice. Eight sub-themes further illustrated the primary topics. In summary, it was found there was diversity amongst participants’ perceptions and experiences of being diagnosed as terminal, and the health ailments leading to the diagnoses. Generally, there was a lack of awareness and understanding of palliative care and hospice services, but once utilising these services, the overall consensus of their experiences was positive.

CHAPTER SIX: RESULTS AND DISCUSSION PART TWO

Introduction

This chapter focuses on the diversity of Māori identity, the changing world for Māori, and how this has influenced the participants' perceptions and experiences whilst utilising palliative care and hospice services. The analysis of this chapter is presented and discussed under two primary themes: 1) te ao hurihuri: changing times, and 2) te tatau o te pō: door to the night. Six sub-themes were formed to illustrate the participants' pūrākau. Also, illustrated were their final wishes, thoughts, plans, emotions, and desires for their whānau and their funeral arrangements. It felt right to include these parts of their pūrākau, as all patients discussed that funeral planning and preparations became important once they found out they had a terminal illness. For some, funeral planning consumed a big part of their thoughts, and shaped how their time was used whilst receiving palliative care and utilising hospice services. Finally, the participants' rich stories were interpreted, discussed, and intertwined with supportive literature.

Te ao hurihuri: changing times

Te Ao hurihuri, te ao huri ai ki tona tauranga: te ao rapu;
ko te huripoki e huri nei 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 (King, 1992, p.191).

A substantial amount of research has been conducted about the importance of Māori identity to health and wellbeing (e.g., Cram, Smith, & Johnstone, 2007; Durie, 2001; Pere, 2006; Stevenson, 2004). Durie (1995) suggested there would be a greater expected preference to identify as Māori. He continued by stating that there was no way to ascertain the level of Māori ethnic selfidentification. Furthermore, it was highly likely people will choose to identify with a number of ethnic groups, as well as a number of different parts of their community (Durie, 1995). This evolution of Māori culture, identity, values, beliefs, and practices can be seen throughout the participants' pūrākau. The majority of the participants identify as Māori. However, their level of interaction, practice, and navigation of te ao Māori varies between each of them. The participants' choice of participation in palliative care and hospice service provision also varies.

Being Māori navigating palliative care and hospice services

John discussed his interactions between Māori and Pākehā systems:

> *I'm sort of in the middle, being Māori and also working with the Pākehā side (John).*

He continued by giving his interpretation of what he considered necessary steps to improve utilisation of palliative care and hospice for Māori, suggesting a reluctance to progress as a barrier. He suggested a balance was needed between the past, present, and future use and incorporation of traditional tīkanga Māori and Māori advancement.

> *I don't agree with us having our own facilities as Māori, like having a Māori Cranford or whatever. I believe it's good to mix with other people whether they are Chinese, European or whatever, because that's how, you got to advance ahead ... You can't just look back how our old people were, which, a lot of people are doing which is ok. You can hold on to all that tīkanga and that and keep it there but you also have to move with the times and that's the hardest thing to try and keep telling our people.*

Emara talked about her perception of Cranford hospice. She then discussed its Māori cultural aspects, as well as her experiences there, and her understanding of her father's level of Māori values and practices expected of Cranford hospice:

> *I think that it [hospice] hasn't been like Māori Māori, he's [Papa] not like that, some people are, they want all of that [Māori values and practices] (Emara).*

She continued by discussing more of her perceptions and expectations of the levels of Māori cultural competency, values and practices by the hospice:

> *For myself ... it’s not like Māori in your face but it’s not bubbling there [hospice] either ... I’m not saying you got to 'Māorify' the place, I don't know may be I felt awkward because I’m Māori then again I feel awkward in places that are not Māori orientated ... It doesn’t mean all things are Māori so let’s notify a Māori thingy ... but I guess to be aware of services for Māori ... because I still don't know if there are, I mean the hospice has catered well for my dad. There’s nothing wrong with the place; I just don’t know what it needs, because the place is lovely, it’s really really nice, I’m actually not sure. I’m comfortable there [now] and love being there visiting ... but my dad’s not bothered if there was or wasn't [tīkanga adherence and practice] but there maybe people that are very tīkanga orientated, it would be nice to cater for them (Emara).*
>
> *Just because I’m Māori I don't have to do things that way, but I do prefer to follow tīkanga. So I think within the hospice they could take a bit more notice, because I didn’t actually see any other Māori people in there (Emara).*

In comparison to Emara, Mere was less concerned with the level of tīkanga Māori adherence. Mere does not speak te reo Māori, her husband Winston is Pākehā, and she was not troubled by what level of tīkanga Māori, Māori cultural competency, Māori values, and practices that the hospice may or may not have or uphold:

> *I got to say now, I was not asked about the Māori side of things... I sort of felt more comfortable [not worrying about the Māori side of things], mainly because of him [Winston], because he is the one that does most of it [communication and interaction with hospice staff, acquisition of knowledge and caregiving] (Mere).*

Whānau support: caregiver, nurse, doctor, and pharmacist

Whānau is the heart of Māoritanga. Walker (2004) explained the Māori whānau unit as "an extended whānau, which included three generations" (p. 3). This included the kaumātua and kuia (elders), their children and sons and daughters in-laws, and their children. At times, the whānau unit were large. The participants discussed their views of what and how the ever-changing environment influences whānau support.

John explained the traditional support roles of his kaumātua, and how today's systems may not necessarily be appropriate or capable to extend the same support that was once more readily provided:

> *Our old people back home they lived at home ... and they were tough, they were strong people ... They were brought up on farms and did their own things, all our kai and preserves for the marae were done by the old people, our pataka (food storage houses) were full. She [Carolyn] was brought up on a marae, and so was I. We had all that support from our kuia, now when we stay at home that support is not there ... I think about that, and I think at times if it's palliative care ... the best thing you can do is put them [palliative care patients] in there [hospice] just for the support that they can do (John).*

Carolyn and John discussed their perceptions of Māori whānau size and whānau support; realising that it is not always accessible or available:

> *Maori have a lot of whānau (Carolyn).*

> *We are ok we've got heaps of whānau, but then you got some [Māori] who don’t have that support group around them (John).*

Also realised was the effect that geographical distance has when whānau live in different towns. This has changed the face of whānau caregiving, as some whānau have to choose between work or caring for loved ones:

> *One of the problems is, a lot of the whānau work now and are living away. Like there's me here I’ve got wonderful work ... they are really great, and they are always worried about me whether I’m eating properly that sort of thing, and they want to know how I’m coping, so that’s what I’ve got here cos I haven’t got ... his whānau or my whānau here (Carolyn).*

> *Even my own son I hardly have him back, because he's been away a lot, he's in Auckland he's got a wife and two kids, and he's trying to hurry up and get back (Mere).*

> *I think it's the unknown and not having the whānau support around them that they need and the care that the whānau can give them compared to somebody strange. My mother is the same, if we were to put her in there [care facility] she wouldn’t be here today, yeah, and that’s how they think. Where as I think a lot of us coming up to this sort of work we can understand a lot of it. It's taught me that I have to go into care. Somebody else to do your cares and whatever, that's a big thing to Māori, like doing the hair, the head is tapu you know like those sort of things, and I think that’s a lot to do with it and I think too it's not the way our people have been brought up. I know there’s slowly a lot of people going in there, you know it's just the change of times you know I think that some of them do understand that they don't have the support at home (John).*

> *We've done a roster, his family knows when I can't do him because I work as well, so we get organised (Emara).*

The participants have taken on various new roles since being diagnosed with a terminal illness. Some of the role changes have been challenging and difficult:

> *It's quite embarrassing that your own family is doing that, its quite embarrassing that anyone does that, but that's life and I can't do without her [Emara] and they are just the little things that she does and helps out. She does a lot of palliative care for me, but not the major stuff (Papa).*

For Papa, the transition from father to patient took some time to get used to. It was not an easy road for him, to come to the realisation that he needs assistance to conduct and achieve his daily activities. Papa knows there are professional caregivers available to assist; however, this was not an option he needed or wished to uptake:

> *[there are] caregivers out there that do the job, but they might not be suitable for me, as a Māori I prefer my own, I prefer my own family (Papa).*

Papa talked about his different expectations of each whānau member:

> *She [wife] was my partner, support partner throughout. My wife couldn't look after me; there are certain people for that role. That's not my wife. Her role is to go to work, and I'm happy with that. Some of my other family members are going to come up and look after me ... I'm getting a bit slow at dressing now, but I can do quite a lot, I'm quite independent. It's also important not to be stubborn and if you can get help, take it. We've made it very clear to all the whānau wanting to come ... and stay in my little house ... We rostered it, I said if you've got a job don't come, you'll lose your job,*

> *so we’re looking at things that are realistic, if you’ve got holiday leave and you want to come and stay, take it (Papa).*

Mere discussed her husband and nieces' involvement with her care:

> *He [Winston] is always around. I mean he's not that well himself now. He always participates, I say I can get her [Ngamihi] to come for a change to give you a break, he says no, he's got to be there cos he has the knowledge, plus I forget so much things. I'm very very lucky in that sense, good support system. My niece [Ngamihi] comes in she's not part of anything; she just comes in as family (Mere).*

Ngamihi talked about how she was impressed with Mere and her drive to carry on living life to the fullest, and her bright outlook on her life:

> *Aunty has had a positive attitude (Ngamihi).*

Carolyn discussed how whānau support extends to friends and work colleagues:

> *It's great for me ... we have a son here and we got friends, and that, and even the girls from work, they say if you want a break we’ll come and stay with John ... and keep him out of mischief ... while you go for a break (Carolyn).*

Carolyn is thankful for her work friends with the offer of help when needed. As shown throughout the participants' pūrākau, having a large whānau does not mean whānau support will be available or provided. Commitments and geographical distance are highlighted as barriers hindering the provision of whānau support, for some of the participants. However, the participants have learnt to navigate the changing world influencing whānau support availability and provision.

Medication

Medication is an important part of palliative care and hospice services. All participants that are patients are taking some form of medication. Whānau have been supportive towards the planning, preparation, administration and education of palliative medications. The participants and their whānau have come up with strategies for managing and understanding their medications:

> *I’ve done a chart ... I think it's good anyway, and it's helped the nurses see what's happening when he has to have his medicine and the amount he's having each day. It's a month’s chart, each day, what's he's had and if he's actually had it. So they’ve been able to see a pattern, but I've done one for when mum's away for two and a half weeks. There’s a whole day to a page, it's like a booklet. So we can write everything down about what we are all doing, what he is having and its just easier because sometimes he's not aware of when he's had his last medicine or had his last bit of food, so the chart says it all. Sometimes when they’ve [nurses] changed his medicine instead of telling you what’s the new dosage, they just switch it on the chart; they just rub it out and put it on (Emara).*

Papa admired his daughter’s work of managing his medications:

> *My daughter [Emara] is doing quite well with the medicines ... Emara has been learning and the hospice, they like her, they always ask for Emara because she’s the one that gives me the medicine (Papa).*

Winston has a wealth of knowledge of Mere’s illness, care, and medications. He knew all of her medications and the times that she needed to take them during the day. He also had a good understanding of what medications made her ill, and which medications did not combine well with her other health conditions. Apart from understanding and knowing all of Mere’s medications, he has an acute memory of time and medical procedures that she has had during her illnesses. He discussed his experiences and perceptions of his journey with Mere, before and whilst receiving palliative care and utilising Cranford hospice:

> *She had a double mastectomy in April 2011, so that was the start of the chemo (Winston).*
>
> *Because she’s got kidney problems, this is Neorecormon, but the stuff in it is called Erythropoietin. Cos the kidney, is not producing it, and her haemoglobin level goes down, and normally the kidney produces Erythropoietin to boost the bone marrow to make red cells, the haemoglobin. Because the kidneys not functioning right, she is supposed to have this every week, but it has to warm up first (Winston).*
>
> *So the surgeon arrived at 4.30pm and in two minutes we are going to have to open her up, this is serious, we'll get a scan done, but regardless of the scan we are going to have to open her up. We had a CT scan, we'll do the surgery tomorrow, and he said no this is life threatening. About 6.45pm, they got her into theatre ... scar tissue can grow and this is what had happened, scar tissue had grown, and strangled the bowel and pancreas (Winston).*

Mere has a good understanding of her medicines, but she was more inclined to share her pūrākau in relation to her relationships with various persons she encountered during her journey:

> *We sort of had an idea ... that the codeine and kidneys don't match. So we were aware, and sort of pin pointed it to that. Often with my treatment with the oncologist, her and I have a few little debates on stuff. I believe we are not all the same, it effects us in lots of ways, sometimes a mind set and the medication, well most of it is medication, and I used to say, I've changed that. She didn't like that, which we understand that because that's her job. It’s not for me to say, but I changed it and I found that it worked good for me,*

> *umm, but she reckoned that it wasn't doing any good, so she's the specialist, but I felt better ... when she stopped it I didn't mind (Mere).*

For the whānau members, learning, understanding, preparing, organising, and administrating daily medication routines has been a big part in providing care whānau support. It has been a coping strategy too, which has helped to keep control of some aspects of their life, in an otherwise uncontrollable situation. This has been important considering the inability to control the sense of knowing that death is eminent. Having control over the medications was a distraction from the uncontrollable state of waiting on death.

Discussion

As seen in the extracts, each participant embodies a different Māori reality. For example, tīkanga Māori practice and adherence differed among participants. This could be due to the level of knowledge and understanding of tīkanga Māori possessed by the participants. Indeed, Mead (2003) and Pere (1997) agree there are some people who are highly competent in tīkanga Māori, while others have a lesser understanding, and tīkanga Māori varies from individual to whānau, to hāpu, and to iwi.

The extracts further highlighted the participants varying levels of Māori cultural identity or affinity. Several prominent Maori academics explained why this might be. Rangihau (1975) conceptualised Māori identity from an iwi level. He dismissed the notion of Māoritanga implying that it is an inaccurate measure of culture, and when he reflected upon specific features "of his own cultural heritage, favoured instead the term Tuhoetanga" (Durie, 1994, p.2). He differentiated various unique socio-cultural and historical connections between iwi, pointing out that Māori culture is heterogeneous, and varies from iwi to iwi.

Durie (1995) discussed how demographic, technological and global, cultural interactions have influenced cultural values, beliefs, and practices for Māori. He explained Māori are not homogenous, Māori society is fluid, and Māori individuals may not continue to define their ethnic identity by traditional values or constructs. However, Māori individuals "may or may not enjoy active links with hapū or iwi, or other Māori institutions yet they will describe themselves as Māori and will reject the notion that they are 'less Māori' than their peers" (Durie, 1995. p.15). Furthermore, Durie (1997) stated that “the challenge today is to survive as Māori, to retain a Maori identity, while still being able to participate fully in society and in the communities of the world during these changing times" (p.5). I consider this statement to be as relevant today, as it was sixteen years ago.

As seen throughout the participants' extracts, they discussed the different forms of whānau support. A perception highlighted through the pūrākau, was even though Māori may have large whānau, modern lifestyles differ from the time when whānau were living on the marae, and when kuia and kaumātua were readily available for providing guidance and care. Kaumātua and kuia are acknowledged elders who are respected for their wisdom, and experience, are people to refer to on aspects of te ao Māori, and are charged with the maintenance of Māori knowledge and traditions (Barlow, 1991; Tauroa & Tauroa, 1994; Walker, 2004). They were also valued for their help to care for children and wider whānau networks, as well as contributing to accomplishing useful tasks to the smooth running of a whānau community (Walker, 2004). John discussed how he and Carolyn’s circumstances have changed and evolved with the changing times since growing up on the marae surrounded by their kaumātua and kuia. Durie (1994) pointed out it is highly probable a lot of our kuia and kaumātua will not be capable of providing the level of support that John and Carolyn received when they were growing up. Additionally, he stated kuia and kaumātua "may not be able to count on consistent whānau support. Though Māori by choice, as well as descent, their role within Māori society may be substantially different from the roles currently ascribed to kaumātua" (p. 4).

The participants' extracts spoke solely about Western medications. Traditionally, Māori approached wellness from a holistic stance, where health was considered as total wellbeing (Aboriginal Cancer Care Unit, 2005; Ministry of Health New Zealand, 2005). This involved not just recognising physical health, but acknowledging the importance of mental, emotional, spiritual and family (Prilleltensky, 2005). Durie (1998) and Pere (1982) have formulated frameworks that acknowledge the value of a holistic approach to wellbeing. Durie's (1998) Te Whare Tapa Whā (four walled house) model consists of four elements: taha whānau (family wellbeing), taha hinengaro (mental wellbeing), taha tinana (physical wellbeing), and taha wairua (spiritual wellbeing). Similarly, Pere's (1982) Te Wheke framework is represented by ten elements needed for wellbeing. The head of the octopus represents whānau and the eyes the waiora (total well-being of the individual and family). Each of the eight tentacles represent a different aspect of health: 1) wairuatanga (spirituality); 2) hinengaro (the mind); 3) taha tinana (physical wellbeing); □4) whanaungatanga (extended family); □5) mauri (life force in people and objects); □6) mana ake (unique identity of individuals and family); □7) hā a koro ma, a kui ma (breath of life from forbearers); and□8) whatumanawa (the open and healthy expression of emotion).

These models encapsulate the differences between Western biomedical models of health and Māori concepts of wellness. Therefore, effective understanding of the differences between these two treatment approaches needs to be known to ensure Māori traditional beliefs, values, and practices are not simply displaced by western biomedical understanding, but that they can co-exist (Prilleltensky, 2005). The combined use of both types of expertise can optimize the response to terminal illness and palliative care provision.

Te tatau o te pō: The door of the night

Te tatau o te pō.
The door of the night.

The literal meaning is of this whakataukī is ‘the door of the night’, with the figurative expression of "Pō representing the spirit world" (Brougham, Reed, & Kāretu, 1999, p.33) or "the entrance to the place of departed spirits" (Mead & Grove, 2003, p.391). I choose this whakataukī to symbolise where I envisage the participants to be in their end-of-life care journey. I see them standing at 'the door of the night', contemplating their life journey, and all of the things they have to do before they step through.

This theme looked at the participants' dreams, hopes, desires, and wishes they wanted to achieve before dying. I have chosen to include these extracts of the participants' pūrākau, as all of the patients had a desire to reconnect with Māori traditions upon dying. Terminal illness is bitter sweet. Bitter as there is finality placed on life, but sweet as there is time to plan and aspire to do those last things in life. For some of the participants' finality forced them to think about the future, and for a lot of them time was spent thinking about their final wishes, whilst receiving palliative care or utilising hospice services.

Hui, marae and preparedness

Upon being told, they had a life limiting illness, plans were put in place to accomplish activities for themselves and their whānau, before their death. The participants all talked about holding hui (gathering) with a variety of whānau, friends, committees, and organisations. A hui in this instance means the gathering and assembling of people (Pere, 1997). The realisation that time is ticking, and death may happen any day caused a pragmatic approach to the participants’ thoughts and subsequent actions. Mere talked about a discussion she had had with her niece Ngamihi, and the practicalities of material belongings, planning, and being prepared for what will happen with her belongings:

> *Aunty, you better start de-cluttering, so I said yeah, we have started getting rid, start getting down to lesser things to have around and lesser work (Mere).*

Winston also had plans about when either he or Mere were to die, and how their money would be distributed:

> *We don't know when we are going to die we might finish up in aged care where you have nothing. If I go before her, she is taken care*

> *of, but if I go after her, the bulk of my money will go on towards research, cancer, brain, neurology, etc (Winston).*

The participants discussed their desires to reconnect with their marae, in preparation for their own tangihanga:

> *In December, I’m having a gathering for my immediate family, I only have one son, these are my family, my niece, his son and their kids. More for his [Winston] kids to get to meet my side, because when I ... go back there to be buried, and I might have one day on the marae to give his kids and his moko, they are quite keen to have a Māori experience (Mere).*

Papa was told about a year ago that he has a life limiting illness. Because of this, he had already conducted a number of whānau hui both informing, organising, and delegating responsibilities of his final wishes upon his death:

> *Well I’ve had my own whānau meeting with the kids, which is good, we've moved up another step. I’ve had a meeting with my brother, sisters, and aunties and uncles at the marae. This is what I want, if I had known this when my brother was still alive, ... he didn't do that because he didn't know, and I think that the trip and the journey now ... is a bit easier for everyone. Everybody knows their role. I think it is about organising things, giving people roles (Papa).*

John was prompt to inform his marae committee of his situation:

> *We went to the marae committee ... I think about it now and I laugh, cos it was only a few weeks after [being diagnosed]. The fulla I went to see is a relation of mine...he's on the committee he’s one of the kaumatua he said, “boy I better go see such and such”, and blimey about 9 o’clock that night he’s knocking on the door. He's telling me about everything. I said to him look at the time, I’m not going tomorrow. It was funny (John).*

Emara talked about Papa's acceptance and readiness for death. She discussed how witnessing her father’s preparedness, eased her own feelings and thoughts:

> *Seeing him [Papa] so calm and ready ... he's sick of being sick because he said it's not a life to be living, it’s not living. Seeing him sort of accept what's happening ... it made it easier for me that he's ok. Talking about it [death] made it easier, especially for his brothers and sisters, it made it easier to talk about. In his [Papa] book, we've already organised his order of service book, and there is a photo on there of what people remember of him. Everything has become a lot easier, just talking and planning, and he's become very clear of our thoughts and feelings. So, a lot of his funeral planning is mainly about what mum wanted, and mum was like whatever me and my sister and brother agreed to. So, out of them, it was whatever I wanted, because my sister was like, well she's only going to take over any way (Emara).*

Planning, preparing, holding hui, and reconnecting with their marae has been a positive distraction for all of the participants, from the reality of terminal illness.

Tangihanga: Funeral

Kai hea? Kai hea te pu o te mate? Kai runga, kai raro.
Kai te hikahika nui no Hine-nui-te-Pō

Where is the cause of origin of death? It is above and below.
It is in the organ of Hine-nui-te-Pō.

"This is an old invocation or incantation repeated by the priests of old in order to relocate the breath of life in an apparently dying person" (Best, 1998, p.8).

Tangihanga has been a constant and traditional Māori cultural practice, where whānau, hapū and iwi converge to grieve the death of a loved one (Borell, 2005; Durie, 1995; Mead, 2003; Rangihau, 1992; Tauroa & Tauroa, 1994). Being diagnosed with a terminal illness had given the participants time to plan their own tangihanga. Emara talked about Papa's funeral plans, describing one particular ritual that Papa wanted done and that she has been a part. Within this extract Emara spoke of Papa's preparedness and planning of his funeral preparations:

> *At the moment, I’m doing his [Papa] painting thing that he wants for his lid [of his coffin], and first he said you come up with a design, you do what you want ... then he comes to me, this is design he's had for a while, from when he first went into the hospice, and it was in the journal he had that he used to write in. He drew a design he wanted for his lid, this is my design, can you do this, I like bright colours ... I've got the lid, it’s in the cupboard, it was going to be onto the lid, but now he wants it onto something that will stick onto the lid, because he wants me to keep the painting after (Emara).*

Emara discussed her father's trip to see the funeral director, which included a touch of humour, for a usually sombre experience:

> *Even the funeral director could laugh, and Papa said “will I fit in this box?”, and the funeral director said “it’s ok, I sized you up at the door”, and my dad laughed. The funeral director said he doesn't usually get to meet his clients (Emara).*

John shared once he was told that he had a terminal disease, it appeared logical and pragmatic to visit an undertaker. His pūrākau shows John's search for the right funeral director. He was pleased with his final choice of funeral director, as he was aware and sensitive to the values, beliefs, and practices of Māori tangihanga. John talked about his wish to be cremated and remain close to Carolyn:

> *We went straight to the funeral directors ... we better do this, we better do that ... get things done for her, less things to worry about. They [funeral directors] were really good, they were really really*

> *good. They just took us through what caskets we can have. They [funeral directors] understood the Māori side, they were asking different questions, "are you sure that's what you want done [cremation]?", so they understood too ... We just took our time, and they were thinking that I'm Māori that there might be some resistance [towards the cremation], and I said that's up to me to solve. I was wanting to go back home, for years and years, but in the last couple of years, I haven't been back there for a while. My father is buried there [Rotorua]. There is a spare thing there, plot; I think I'll be fighting my sister for that. So, I didn't really want to go to Rotorua, because I want it to be close for her [Carolyn] you see. That put Taihape out too (John).*

Carolyn also spoke of the therapeutic value that the visit to the funeral director had upon her. As the visit to the funeral directors enabled her to be part of the planning, but also helped her to understand, and it gave her time to process what was happening around her:

> *I'm pleased that we have done that because we have found out a lot ... The funny thing is I actually felt better. One of the girls at work I talk too, I was telling her, and she said "oh my god, I couldn't go through that", and I said "I feel good", and she said "oh do you", and I said "yeah I think it is because when the time comes I know, that I'm prepared" (Carolyn).*

Emara shared a bit of her disapproval for one aspect of Papa's planning:

> *"I'm not for on show and for people to just stare there and look at me", he [Papa] was very upset. Because his brother was the same, his face was more bones than anything, and he didn't want to look like that, and he didn't want people staring at him like that. He's very particular in how he looks, since the last time you saw him, he has gone down hill. If he knows someone is coming, he'll get up and have a shower and get ready, so he needed people to tell him hours before, so he could get ready. It is disrespectful for him for*

> *people to see him like that, so he would present himself ... Knowing he's like that I understand why he didn't want his lid off, but it's still dumb ... so it's still an issue for me. I wanted it to be open. I said to mum he won't be here we could just open it, but thinking about it she was like ... he won't be here you can just do what you feel like, but that one is really something we can't go against. I don't want to lie on a box I want to be able to ... kiss somebody ... I was thinking more for myself. It was a bit sad, but I wasn't caring about anybody else (Emara).*

This was one aspect of her father's planning and preparedness that she was not entirely happy about.

Discussion

As seen throughout the participants' pūrākau, they highlighted their wish to reconnect with their whānau and marae. The marae is one traditional Māori institution that deflects the constant pressure of colonisation and acculturation (Mikaere, 2003; Pere, 1997). Even though Māori may be disconnected from their homelands and resources, tangihanga is a practice that reconnects Māori to their marae (Durie, 1995, 1997; Rangihau, 1992; Tauroa & Tauroa, 1994).

Marae are located on a person's tūrangawaewae. Tūrangawaewae is a place of belonging with deep-seated roots; where one's ancestors have stood before them, a foundation of one's identity, and where a person can move freely in the world knowing that they have this connection (Pere, 1997, 2006). It was highlighted there are now three or four generations of urban Māori, who do not have the same sense of connection to their tūrangawaewae as their parents, grandparents, or great-grandparents had (Durie, 1995; Rangihau, 1992). Those who do not experience this connection to their tūrangawaewae encounter different barriers from their peers who have kept the home fires burning, and "who have remained close to their tribal lands and resources" (Durie, 1995, p. 4-5). These connections, or lack there of, only add to the diversification of Māori as a group, and Māori identity of individuals. An ever-changing environment has meant some of the participants were disconnected from their marae, because of circumstances such as relocation and work commitments, hindering regular access.

Tangihanga has "prevailed as a cultural priority since earliest European contact, despite missionary and colonial impact and interference, and macabre Victorian fascination" (Nīkora, et al., 2010,p. 400). Tauroa and Tauroa (1994) explained tangihanga as a practice that embodies the funeral rites of a person, before the body is laid to rest. They continued by describing some of the rituals associated with tangihanga: the tūpāpaku (deceased) should not be left unaccompanied; whānau and friends will gather; the coffin is left open until the body is finally interred; and, speeches will be made to the deceased (Pere, 1997; Tauroa & Tauroa, 1994). An important aspect of tangihanga is the provision of whānau support for the grieving whānau (Barrett- Aranui, 1999; Pere, 1997). Additionally, tangihanga acknowledges the stages of life, birth, death, and beyond (Te Rangi Hiroa, 1982). This was but a brief and simplistic explanation of a complex Māori practice, involving many facets of tīkanga Māori and kawa of te ao Māori.

As described, general practise for tangihanga is that the casket will be open. Papa had decided that this element of Māori practice would not be adhered to for his tangihanga. Emara discussed her disapproval with Papa's wish to have a closed coffin. It is understandable that Emara has these feelings, as traditionally for Māori the tūpāpaku is taken care of, cherished, spoken to, honoured, whilst whānau and friends are able to mourn around an open casket, before being given back to the earth (Dansey, 1992; Tauroa & Tauroa, 1994).

Within Mere's pūrākau she discussed her concern for Winston’s side of the whānau, as they are Pākehā, and a lot of her decisions and plans were ensuring his needs were acknowledged and met too. A case study conducted by Edge, Nīkora and Rua (2011) investigated the cultural differences between Māori and Pākehā in the context of tangihanga. From the study, it was evident that cultural differences of understanding, values, and practices of tangihanga exist. Even to the point of having experienced different whānau ideologies of cremation or burial. Cremation has and still can be an issue for some Māori to contend with, which John experienced from whānau, and even his Pākehā funeral director was aware of the controversy that can arise when cremation is chosen over burial. Traditionally, Māori have returned to their whānau urupā or ūkaipō for burial with their ancestors, as this is seen as the final committal to Papatūānuku (Earth mother) (Barlow , 1991; Dansey, 1992; Tauroa & Tauroa, 1994). Additionally, Barlow (1991) explained that another reason of the return of the body to their ūkaipō, enables their spouse to find another partner, if they wish too. However, for some Māori there has been a move to being cremated as opposed to being buried, as well as not returning to their ūkaipō, instead favouring to be stay close to whānau and their spouse, as seen in Johns pūrākau. These are other such changes to tīkanga Māori that have evolved with the changing world.

Finally, it might be timely to embrace the changing nature of our Māori traditions and practices. Borell (2005) further reiterated the diversity experienced between the participants and their Māori realities through cultural markers like, their involvement with their marae, ability to converse in te reo Māori, and tangihanga processes. However, she continued by stating these markers alone cannot standardise what an ideal Māori identity may be. Māori identity is fluid, and "how each of us express Māoritanga is the product of a variety of experiences. None of us is today what our ancestors were, and our descendants will not be like us" (Ramsden as cited in Borell, 2005, p.3). I think this sentiment accurately concludes the inability to generalise Māori as a homogeneous group, which was demonstrated throughout the pūrākau of the participants.

Conclusion

This chapter explored the influence of the changing world on tīkanga Māori, Māori tradition, values, beliefs, and practices., which ultimately creates a greater diversification between Māori. These pūrākau illustrated the various barriers that Māori may encounter when navigating palliative care and hospice services in a forever-changing world. From the experiences shared, the participants all have different ways of navigating their way through palliation and hospice services, whilst privileging their cultural identity of 'being Māori'. The participants highlighted whānau support as essential to 'being Māori'. Even if the level of whānau support was diverse amongst participants, it was discussed as an important element nevertheless, and in some cases, taken for granted. Due to the changing times of what te ao Māori may mean to individuals and whānau members, the time may be right where a greater acceptance of palliative care and hospice services by Māori may be realised, perhaps to embrace and take the opportunity to merge new traditions with the old. This chapter explored their pūrākau via two primary themes 1) te ao huirhuri: changing times, and 2) te tatau o te pō: the door of the night. Essentially, diversity among the Māori population needs to be considered in the provision of palliative care and hospice services.

CHAPTER SEVEN: CONCLUSION

Introduction

This thesis has explored the unique experiences and perceptions of three Māori palliative care and hospice patients, and four whānau members. The purpose for sharing their stories was to add understanding to an otherwise unexplored area of Māori and palliation. This chapter reviews the main findings, addresses the research question, and looks at the implications and significance of the research findings. Finally, the limitations are presented with ideas for future research.

Research question

This research set out to answer the question "What are the perceptions and experiences of Māori patients and their whānau of palliative care and hospice services?". Many of the perceptions and experiences spoken about by the participants' were similar to other indigenous populations reported in the literature on palliative care and hospice services. However, there were experiences, perceptions and expectations raised that were distinct to Māori.

Limitations

There are a number of limitations that need to be mentioned. Firstly, it is acknowledged the results of this study impede generalisation, due to the non-probability sampling. However, the rationale for this choice of sample was to conduct a deep investigation into the meanings, relationships, experiences, and perceptions of palliative care and hospice by Māori patients and their whānau. The aim to improve the understanding of complex human issues, and barriers, that come with palliation and hospice accessibility and utilisation by Māori.

Initially, I would have liked to recruit Māori patients receiving palliative care and registered with Cranford hospice only. However, this turned out to be more challenging than expected. Mainly, because of the stage of health, life, and dying that the potential participants were in. But, I am grateful that three patients volunteered to share their pūrākau for this study, as this is a challenging period for them and their whānau, time is precious, and I am grateful that they allowed me into their lives to collect these rich stories.

A final limitation was the lack of literature. Due to the limited research to call upon for my literature review and discussion aspects of my thesis, international literature of colonised indigenous communities were drawn upon to conceptualise parallel similarities needed for the background information to validate and inform others to my research. However, does the similarity of colonial indigeneity through commonalities of marginalization, oppression, land confiscation, cultural assimilation, and psycho-socio-economic inequalities justify its use? I think not. But, this research will aid in filling this gap of the limited literature around Māori and palliation.

Future Research

I feel this research project was a stepping-stone towards further research around Māori and palliation. It prepared a foundation to build future research upon. Since minimal research has been conducted investigating Māori and palliation, there are still many facets to be explored. For example, investigating Māori patients' experiences and perceptions of palliative care and hospice at a national level, and including all hospices. I would achieve this by conducting a similar qualitative interview study of Māori patients' experiences and perceptions of palliative care and hospice at a national level. This will also increase the ability to generalise the findings to a wider population. Another aspect to explore would be, how palliative care and hospice advocacy and literacy programmes could best benefit Māori communities. I would evaluate current palliative care and hospice advocacy and literacy programmes followed by focus group interviews of Māori community members about their perceived knowledge and needs of palliative care and hospice services that would be of benefit. Another aspect I am interested in investigating is the experiences and perceptions of Māori health professionals’ working within palliative care and hospice. For this potential research, I envisage distributing a survey and conducting focus group and individual interviews. Finally, my ultimate research goal is to investigate the realities of an end-of-life care facility run on traditional and contemporary Māori philosophies, values, beliefs, and practices. This would involve a needs analysis to take place, a multidisciplinary consultation process, and interviews of palliative care and hospice health professionals, Māori communities, and whānau who are and who have utilised palliative care and hospice services. Fundamentally, there is a need to increase all research of Māori and palliation, to find strategies that will positively improve the psychosocial health and wellbeing of Māori end-of-life patients and their whānau. Doing so will increase the limited literature that informs governmental support and institutional policy that primarily shapes practice.

Significance

The significance of this research was multifaceted. Firstly, it gave an opportunity to give voice to an otherwise silent area of New Zealand health; furthermore it builds the limited understanding of Māori perceptions and experiences of palliative care and hospice consumer's. Secondly, the research explored barriers and enablers that influence access and utilisation of palliative care and hospice services by Māori patients and their whānau in this region. Thirdly, this study has brought to light the diversity of Māori needs when accessing and utilising palliative care and hospice services. This research will play a small part in informing palliative care and hospice health professionals of the needs of Māori. Ultimately, it can only help improve Māori cultural appropriateness and competence within palliation and hospice. Finally, it has laid the foundation for further research with Māori, palliative care and hospice services. It is hoped that this research project spurs more research to be conducted in this vital and interesting specialised area of New Zealand health services and to add to the limited literature.

Conclusion

Positive perceptions and experience of palliative care and hospice for Māori are more likely to be realised when a coherent picture of Māori realities can be painted. Until then, it is important to avoid drawing conclusions that are based on limited understandings of actual situations or idealised constructions of accessibility and utilisation of palliative care and hospice services by Māori. Access to palliative care and hospice services are a growing focus in the public health sector. As health disparities among minority groups are apparent, the provision of quality end of life should be provided to all individuals regardless of race, ethnicity, or socioeconomic status. A number of complex and often overlapping barriers to accessing and utilising palliative care and hospice were explored. Given the growing population of minority older adults, the availability of high-quality palliative care and hospice services that meets the varied needs of older adults from all cultural backgrounds, races and ethnicities are a priority.

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APPENDICES

Appendix 1: Ethics approval letter

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

10 July 2013

Diane Koti
23 Ngaio Street
Otaki Beach
OTAKI 5512

Dear Diane

Re: HEC: Southern A Application – 13/42
Te Tatau o Te Pō: Māori and palliation

Thank you for your letter dated 2 July 2013.

On behalf of the Massey University Human Ethics Committee: Southern A I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Dr Brian Finch, Chair
Massey University Human Ethics Committee: Southern A

cc Dr Natasha Tassell-Matamua
School of Psychology
PN320

A/Prof Mandy Morgan, HoS
School of Psychology
PN320

Massey University Human Ethics Committee
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Appendix 2: Information sheet

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

TE TATAU O TE PŌ: MĀORI AND PALLIATION
INFORMATION SHEET
The Researcher

Ko Horouta, ko Tainui ōku waka
Ko Hikurangi, ko Pirongia ōku maunga
Ko Waiapu, ko Waipa ōku awa
Ko Ngāti Porou, ko Ngāti Maniapoto ōku iwi
Tihei mauri ora.

Tēnā koe,
Currently I am in my final year as a fulltime Master of Arts in Psychology student at Massey University, Palmerston North, under the supervision of Dr Natasha Tassell-Matamua.

I was born, raised and schooled in Hawkes Bay, and I have a 5-year-old daughter. My initial awareness of palliative care arose from the utilisation of palliative services via Cranford Hospice during my grandmother's final days. Additionally, my interest and knowledge of palliative care grew when I worked as an Administrator at Cranford for a period during 2009 and 2010.

I wish to conduct the research component of my Masters qualification on Māori experiences of palliative care and Hospice services.

Ultimately, I hope to capture current Māori patients' perceptions and understanding of their experiences of palliative care.

What is the study?
This study will explore the experiences of Māori palliative care patients whilst utilising palliative services within the Hawkes Bay region. There is limited research regarding

Māori and palliative care services. Palliative care service demand in New Zealand is predicted to increase. This is presumed mainly due to the growing and ageing New Zealand population (Ministry of Health, 2010). Due to the Māori population being youthful as well as increasing at a faster rate than non-Māori, Māori may be high future users for New Zealand's palliative care services (Ministry of Health, 2010). Consequently, it is pertinent palliative care services, facilities, and health professionals are competent in meeting the needs of Māori.

My specific objectives of this research are to:

1. *Investigate Māori palliative care patients experiences of accessing and utilising palliative care and Hospice services in the Hawkes Bay region; and*

2. *Identify barriers and enablers influencing access and utilisation of palliative care and Hospice services by Māori in this region.*

Ministry of Health. (2010). *Tatau kahukura: Māori health chart book 2010* (2nd ed.). Wellington: Ministry of Health.

What do you have to do?
Although your participation would be valued, you are under no obligation to take part in the study. If, at any point in the research process, you wish to withdraw from the study or do not wish to answer any particular question, you are free to do so. You are also encouraged to ask any questions about the study at any time during your participation.
After being fully informed about the study and agreeing to take part, you will be asked to complete the consent form and an interview time will be organised with you. You may wish to have a next of kin involved in the consent process, as well. This is to ensure your wishes are carried out in regards to ownership and control over your information. They will be the contact person and responsible for your information if you are not able. If you wish to have a next of kin involved in the study, they will need to be available at the interview to give consent and be fully informed about the study.

You will be interviewed at a time and place convenient for you. You must be willing to speak openly, physically and emotionally capable of participating in an interview of 30-60 minutes in length. If, at any time you, need to cease the interview due to fatigue or discomfort this can be done and the interview will be rescheduled for another time that suits you. A list of topics that may be asked are enclosed for you to have a browse over beforehand. The interview will be sound recorded, and you have the right to ask for the audiotape to be turned off at any time during the interview. The interview will be audiotaped and transcribed by myself, solely.

The initial transcription of the audiotaped interview will be sent to you for any amendments or omissions. You will be given a copy of the interpretation of results for your comments or reactions, and if you wish, may receive a copy of the final research report.

Counseling, pastoral or a support person.

If at anytime during the interview you may experience any distress, counselling or pastoral support is available. A whānau kaumatua of the interviewer will be accompanying the interviewer he will be available during the interview. As part of Cranford Hospice services, a pastoral support person is available after the interview if preferred. You are welcome to have a support person or persons accompany you for the interview. You may cease the interview at anytime and reschedule for another time.

Anonymity/ Confidentiality

At all times, your identity will be kept confidential. All identifying information will be removed from the transcripts and the final research report. You may, if you wish to, choose the pseudonym you will be referred to in the transcripts and final research report.

All information gathered in the study will be kept confidential to the research and any publications resulting from it. Remember: you have final control over what information of yours will be included in the study.

Following the interview, the audiotapes will be coded and kept in a secure place for the duration of the study. After the study, you may choose what to do with your tape. The tape can be retained by you, destroyed, or stored in a research archive for future research purposes.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/42. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz

How to contact the researcher and/or supervisor

If at any stage of the research you wish to contact either myself or my supervisor for further information about the study, postal details, email and phone details are as below:

Diane Koti

Phone: 027 273 1723

Email: dmkoti@hotmail.com

Dr. Natasha Tassell-Matamua

Phone: (06) 356 9099 extn 2056

Email: N.A.Tassell-Matamua@massey.ac.nz

Appendix 3: Participant information sheet

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

TE TATAU O TE PŌ: MĀORI AND PALLIATION
Participant information sheet

Full Name:...

Date of Birth:..

Phone number:...

Address:..
....

Email:...

INTERVIEW TIME CHOICE

Please indicate your first preferred time and a second time choice. I will contact you to confirm an interview time.

Would you like the interview to be conducted in Māori? Yes / No (circle one)

	Time			
Date	**10am**	**1pm**	**4pm**	**6.30pm**
Friday 6th of September	■	■	■	
Saturday 7th of September				
Sunday 8th September				■

	Time			
Date	**10am**	**1pm**	**4pm**	**6.30pm**
Friday 13th of September	■	■	■	
Saturday 14th of September				
Sunday 15th September				■

IF YOU WISH TO PARTICIPATE IN THIS STUDY PLEASE COMPLETE AND POST THIS FORM IN THE PREPAID ENVELOPE OR EMAILED IT TO dmkoti@hotmail.com

Appendix 4: Participant consent form

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

TE TATAU O TE PŌ: MĀORI AND PALLIATION

Participant Consent Form – Individual

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me, or my next of kin.

I agree to participate in this study under the conditions set out in the Information Sheet.

Participant signature:______________________________________

Date:________________________

Name:____

Next of kin signature:______________________________________

Date:________________________

Name:____

Appendix 5: Next of kin information sheet

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

TE TATAU O TE PŌ: MĀORI AND PALLIATION

Next of Kin Information Sheet

Full Name:..

Date of Birth:.................................. Phone number:................................

Address:..

..

Email:..

Relationship to the participant:...

Appendix 6: Authority for the Release of Transcript

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

TE TATAU O TE PŌ: MĀORI AND PALLIATION

Authority for the Release of Transcript

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature____________________________ Date_________________________

Name____