Surviving the System

Māori and Pacific whānau coping strategies
to overcome health system barriers

Rachel Melanie Brown

2018

Faculty of Health and Environmental Studies

A thesis submitted to Auckland University of Technology in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD)

Sometimes superheroes wear their capes on the inside

ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), no material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed: _____

Rachel Melanie Brown

ABSTRACT

The value, power and skill of Māori and Pacific whānau and their associated processes are often under-estimated and under-valued within health care. However, collectively, whānau have the expertise and resources that can sustain them in daily life and particularly when one of their members is under threat. Dealing with a child who has a life-threatening medical condition poses a threat to whānau through premature death being imminent and whakapapa being interrupted. Health care engagement processes are critical and can either enhance or inhibit the whānau journey through the health care system.

The objectives of this study were to explore the coping mechanisms of Māori and Pacific whānau who had experience of continual transition and re-entry along the continuum of care who had a child diagnosed with a life-threatening medical condition. Whānau who had repeated health care engagement encounters were considered better able to assess their coping due to care being over longer periods, in diverse environments (for example, primary care, emergency departments) and engaging with multiple people. The study also investigated the role and influence of Ronald McDonald House on Māori and Pacific whānau coping due to this population being the highest users of the Auckland based houses. An Indigenous paradigm underpinned by Māori and Pacific methodologies and qualitative methods is presented in this thesis. Thirty sets of interviews (with collectives and individuals) took place. Twenty sets of interviews were undertaken with Māori and Pacific whānau alongside ten sets of stakeholders.

Findings revealed that while whānau entered the health system with a primary focus on their child, their attention became temporarily and consistently re-directed to dealing with the barriers and distractions to fully participating in their child's health care. Engagement barriers and distractions occurred across four areas: policies and procedures, people and practice, environment, and resources. Whānau not only had to contend with values, ideals and practices that starkly contrasted with their own but they also had to decipher the contradictions entrenched in and between Western dominant health care practice. Coping for whānau in this study, therefore, was less about their child's health and more about surviving the system. To combat barriers, findings revealed whānau utilised coping mechanisms and strategies that aligned with holistic processes. While some system-based supports were found to facilitate coping they were often limited to the point where whānau filled the gap. Coping elements were cultivated stemming from whānau rituals of encounter - roles, functions and processes that were embedded within their own system of care. Whānau became the expert and a critical resource to not only cope with their critically ill child but to engage, facilitate and support optimal health care provision and provide culturally relevant solutions for themselves, other whānau and medical staff. This research confirms that whānau know what they need to be and stay well, and on one level, have the means to implement it. However, it is the barriers, restrictions, racism and lack of resources and support at all levels of the health system and society that impinges on Māori and Pacific whānau benefiting from full participation.

DEDICATION

Dedicated to our son **Raen**, a true superhero.

Also, remembering the journey of our fellow warriors (past and present).

Bumper

Te Amohaere

Kereopa

Ōhia

Malawai

Kathy

Sarn

Papa Ron

Tutekiha

Tukaiora

Luke

Glory

Johnny

Masey Moo Moo

Verno

Colleen

ACKNOWLEDGEMENTS

There are so many people to acknowledge in this journey. Firstly, to **Ātua and Ihu Karaiti** for the experiences and hope that shaped this journey long before this study was even thought of.

AUT Ethics Committee (AUTEC) **14/198** for granting ethics approval and keeping me in check.

To **Beni boi**, yet again you were the chief back patter and babysitter in this second leg of the journey. Although our relationship status has changed, this PhD journey was yours as much as it was mine. Thank you for all that you continue to do for our children and me. I will always love and cherish what we have.

To my supervisors, **Professor Denise Wilson, Dr Amohia Boulton** and **Dr El-Shadon Tautolo** for your belief that I could do this, as well as my dear friend **Dr Nick Garrett**, biostatistician. Thank you all so much for your support and guidance along the way.

I want to acknowledge **Whakauae Research Services and Ngāti Hauiti** for their incredible support and scholarship. The taonga that allowed me to take time away from my full-time job and to write while giving me the means to feed my children in the process. To **Gill** for letting me moan and groan.

To **Mr Lex Davidson, previously CFO - HRC** who paved the way that enabled me to take the time out of my job, before he passed away - Moe mai rā e te rangatira.

To **Dr Mera Penehira** and **Dr Leonie Pihama** who were with us from the first day of our Emergency Department journey and still are. Thank you for continuing to feed our souls, and for showing us, we are not alone in our voyage.

Colossal mihi to my **whānau** who cheered me on along the way picked up the pieces when they broke and glued them back together through love, generosity, kindness and sincere madness.

Huge cheers big ears to my **friends** who gave me encouragement, feedback and loads of food and wine (yes, it's your fault I put on ten kilograms). To my **Rally4Raen** administrators and **all the supporters,** near and far, who embraced our journey, thank you, we needed it.

To our **Wahine Toa Club,** these sessions have been invaluable, may the membership last a lifetime (Sonia, Aroha, Cath, Erena, Jaylene, Ruth, Sandy, Zub). To all the **Māori and Pacific health researchers** who went before me, who fought and continue to fight to pave a safe pathway for us to continue in the mahi. I am forever grateful for what you have achieved. Without you, our position in this world would be even more invisible.

To **Dr Te Kani Kingi** who planted the seed, encouraged, no, demanded that I go and negotiate the space to write and put me in my place when I started to doubt myself (I had never heard you swear until then) thank you!

To **Erena Wikaire** (a.k.a Minimihi) who was my calm throughout the storm, my library and my gentle but powerful voice of reason - it is your turn now.

To **Merlin**, my magician who continued to work your magic through reliability, support and practical advice…and for accompanying me to New York for well needed time out - wahoo!

To **Annemaree Long**, my soul mate, my counsellor, my chief advisor, my most supportive critic. Thank you for all the long and late-night phone calls, the analytical PhD and life-changing sessions, for the laughter and the tears but, most importantly for urging me to face my fears.

To **SKB** for highlighting to me at a time when I was in despair that there is always hope for our people.

It takes a **village** to raise a child, and I thank God for my village people - to my **Waimate whānau** I could not have done this without you guys. Just knowing my kids were well looked after, fed, safe and loved enabled me to continue.

To **Viriama**, our smart and intelligent niece, who took advice and dared to complete her own degree despite the cultural challenges both personal and professional. Awesome stuff from a little girl from Rakz. To our other niece, **Lil Mala** - keep going, you are next!!

To **Vaana banana** for always bringing us complete joy especially at such a heart-wrenching time. I so wish I could be there for you now.

To all the **participants, Ronald McDonald House staff, cultural support services, Child Cancer Foundation and my Advisory Group members**, it's been an exciting process, and together we got there. To **Hilary van Uden** from **HONE proofing** a real star thanks so much for proofing my babble and the quick turnaround.

To my heart and souls, my kaupapa tamariki, **Matangaro, Jerome, Sandy, Lorenzo** and **Ammon** and my mokopuna, **Jax, Xavier, Kairua, Spencer, Neo and Hiwa-Kairangi**. Thank you to all of you for teaching me that whānau comes in all shapes, sizes and colours of the rainbow. To all those who said that **I COULD NOT** do this… Thank you for the drive to ensure I completed yet another mission apparently impossible.

To my **mum** always the role model and the gentle voice of reason.

To my number one critics **Raen** and **Manaia** this is for you… Never forget the struggles our ancestors undertook to give us the life we have and when people say you **CAN'T** …let this and our journey be a constant reminder that **YOU** bloody well **CAN!**

Finally, to Raen,

Thank you for showing us all that we can defy the odds, do the unthinkable, the unexpected and be the miracle

…no matter what…

PREFACE

Ko Taranaki te maunga

Ko Mohakatino te awa

Ko Parihaka te marae

Ko Te Atiawa me Ngāi Tahu oku iwi

Ko Ngāti Mutunga ki Wharekauri/ Ngāti Mamoe ki Waimate oku hapū

Ko Rachel ahau

Tihei Mauri Ora!

This preface allows me to situate myself within this thesis and ride the journey alongside all the whānau who participated as part of it. It allows me to tell part of my own story about the topic. Parts of this section were also included in my Master's thesis which foregrounds my PhD work.

Moulding the clay

I am of Te Atiawa and Ngāi Tahu descent. My parents had me at the young age of 18. Due to my parents' work commitments, I was looked after by my Māori paternal grandparents and lived between Ōtautahi (Christchurch) and Wharekauri (The Chatham Islands). The Chatham Islands were home to both my grandparents, where they lived and met, also at a young age. I am the oldest of sixteen grandchildren, some of whom were also raised alongside me under my grandparents' care. My grandparents were both fluent in reo Māori, but I rarely heard them speak a word. My grandfather was not supportive of things Māori which influenced the way his children and subsequently his grandchildren lived and viewed the Māori world (R. Brown, 2010).

Growing up, I remember through both primary and secondary school being asked if I was Māori, to which I remember reluctantly replying yes in fear of some repercussion. Throughout the various stages of primary and secondary education, I tried my hand at the then termed "Māori club," now appropriately named kapa haka group. I distinctly remember my grandfather's reaction and his exact words when I told him, "Why do you want to learn that bloody rubbish for? It will never get you anywhere." With his reaction and those of other members who told me I was too white to be Māori, I left and dabbled in drama with the white kids where I was told to join the Māori club. For many years, I was left wondering where I would fit in as I never did quite fit into either box (R. Brown, 2010). I went back and forth from living with my grandparents and then my mother. A lot was going on at home at that time (too detailed to add here), so I avoided being there as much as possible. Influenced by family and friends and as part of the avoidance, it was pretty predictable that I would partake in many risky behaviours at a young age.

Home life mixed with risky behaviours affected my schooling, which I used to love, my view of the world and my connection to my family. Due to the behaviours and decisions, I was making at the time (mostly under the influence of whatever came my way) I was beginning to hear the predictions people had for my life. Projections included becoming a young mother, not amounting to anything, living a wasted life, no job and no qualifications.

The kiln

I eventually left the nest, heading overseas at 17 years of age, and when I did finally come home to Christchurch, I was given a chance to head to Auckland for a weekend with two friends. Little did I know that this trip would radically change my direction in life. It also gave me the oomph I needed to silence the negative stories spoken over my life and use them to drive me to rewrite my own story and direct the ending. Since then, I have never left and have been residing in Auckland for over 20 years. After working in retail, I decided to try out tertiary education; I completed my social work qualification, and there a whole new journey started (R. Brown, 2010). The journey helped me learn about the Treaty of Waitangi, being Māori and all the injustices that had occurred and continue to occur. I also learned the reason why my grandfather was so anti things Māori. Social work linked me to my husband, who is of Cook Island/Tahitian descent, and where we spent over 20 years together. Today, I am a mother of seven children (two biological for those trying to work it out) and five beautiful step-children (I hate that term, but people needed detail). I am also a grandmother of six mokopuna. My grandparents have now passed away due to various health issues, all preventable, so I have since learned, with adequate care, information and appropriate assistance (R. Brown, 2010).

A few years ago, my mother, who always claimed she was Pākehā[1], found out she was a descendant of Ngāi Tahu. We both remember my maternal grandfather, who liked to drink at the Workingmen's Club, always saying he had Māori land. He tended to tell a few stories after a beer or two, so we never believed him, especially as both he and my mother had blonde hair and blue eyes. After he died, my aunty stumbled on a book that incorporated some of our family histories that showed the Ngāi Tahu links and names of all our Māori family on that side. Stumbling on this book took my mother and me on another journey of self-discovery (R. Brown, 2010).

I took some well needed time out from social work and was employed at the Ministry of Health, where I discovered more about Māori health issues. I then became employed at AUT University in the Māori Health Research Centre, (later launched as Taupua Waiora, Centre for Māori Health Research), for just under five years, where my journey began into researching Indigenous and Māori health issues. Papers towards my master's qualification helped me to understand the impact of dominant discourses in shaping perspectives, including my own Māori identity. Ironically, although I did very well at the postgraduate study, I was told by someone I had admired that I would never be an academic and research was probably not for me. I had always wanted

---

[1] Pākehā – European/Caucasian/white person

to learn te reo Māori but was discouraged and outraged that I would have to pay for something that should have been rightfully mine in the first place. Once te reo became free, I could no longer complain. I took classes over three years and found it both exhilarating and frustrating at the same time. I vowed that my children would never go through the struggle of learning their languages and, thus, I made it my mission to bring them both up in kōhanga reo (total immersion pre-school) and kura kaupapa (total immersion primary-secondary school). Both of my children became fluent in Māori and, when necessary, speak Cook Island reo (R. Brown, 2010). I have since graduated with a Masters in Health Science (First Class Honours) and went on to be Group Manager, Māori Health Research, at the Health Research Council of New Zealand, following the footsteps of some very high powered, intelligent and politically savvy Māori. I have learned a lot in my journey; one lesson is to use the negative statements people make to drive me to achieve the things that seemingly cannot be obtained. While this is not the best driver for undertaking many things, it has none the less worked for me.

A shiny layer

Māori health research has contributed to who I am today, how I see the world and, in particular, where I now stand as a Māori woman. Knowing and feeling comfortable in my own skin as a Māori has enriched my life and the lives of those around me. As a result, I want to contribute to Māori and Pacific health gains and be part of a solution that results in positive impacts for our people. Hence, the undertaking of this research and the associated qualification. Today I no longer feel apprehensive regarding informing people that I am Māori. I now know it is my whakapapa (genealogy) that determines who I am and not other people's perceptions of who they think I should be (R. Brown, 2010).

On display

I had always wanted to embark on a PhD but could never decide on a topic that I was passionate enough about to embark on a journey for 3-6 years. I also wondered how I would fit this into my already hectic life as well as paying the mortgage and bringing up a family. The masters took a significant toll on both my family and me, physically and emotionally. After submitting my thesis, I was physically exhausted, so I had planned a long weekend away, back home in Christchurch, to catch up and spend some overdue time with my family. On that particular weekend, the September 4th Christchurch earthquake occurred. Little did I know that it was just the beginning of another radical change in our lives. The earthquake was horrific, loud, scary and caused so much heartbreak and destruction, but fortunately, no one was seriously injured or died as a result. My mother lost the beautiful house she had just built on the Kaiapoi river in Canterbury, and I had to leave her to sort out the next steps as I ventured back to Auckland even more weary than when I left.

Upon arrival back in Auckland, I noticed that my son, who was seven at the time, was dragging his leg and holding his hand as if he had just suffered a mini-stroke. I made appointments with my GP who sent me to a paediatrician. My professional medical opinion (joke) was that he probably just needed physiotherapy. We were soon rushed off to get an MRI. We were then told he had a tumour in his brain and were raced to Starship hospital where our ongoing journey

began. Long story short, our son Raen went into surgery (9 hours); we were told that he had a 10% chance of coming through it. Our family was in deep shock and still dealing with the impacts of the earthquake, which now took a back seat. He came through the surgery but spent the next two years re-learning to walk, talk and regain his memory (probably the most devastating effect). We were at Starship Hospital for months, spending most of our time in the High Dependency Unit, then up at oncology as the tumour was cancerous, so chemotherapy and radiotherapy were needed. We were also transferred to the Wilson Home and Hospital for months for intense rehabilitation. After two years of intense rehabilitation, he could finally attend school, but, due to his fatigue, could only manage 2 hours spread across the week.

School hours soon built up and after another year he was back to school full time with a teacher aid (funded by the Child Cancer Foundation for one term then by us for the next three years). Everything was back on track with six monthly MRIs and follow up appointments from 21 services. As he was doing well, MRIs were then put back to yearly. At our first annual appointment, I knew something was not right. There were no explicit symptoms; I know this because I over monitored these. However, it was obvious from the reactions of the health staff that we had built such good relationships with.

We were called into neurosurgery and informed by our neurosurgeon that a tumour had grown back and was aggressive and that further urgent surgery was needed. We were also told that the risks were much higher going in the second time and that he probably would most likely not come out this time. It was near the end of school term and Christmas, and surgery was scheduled for two weeks before Christmas Day. I asked if we could have Christmas with him and let him finish the school term, which took it to 4 weeks. The surgeon said that we would have to make that decision as parents knowing that leaving it that long might make it inoperable. We had till 10 am the next morning to phone and let him know the decision. It was an excruciating 24 hours for our whānau; telling our boy that he had to have surgery again was painfully sad as he did not want it and sat there wailing, telling us so. In the end, the decision was made to have it sooner; we then took our boy back to Christchurch to celebrate life with friends and family. The surgery day came, and going through it a second time was just as excruciatingly painful as the first. He came out of the surgery with limited effects compared to the first, but we were readmitted due to seizures and other complications over time. He is now 15 years old and is attending De La Salle College. He is doing well medically, and we are still followed up by over 20 services. The impact of a tumour affected his eyes, brain, memory, posture, growth and hormones. The treatment affected his teeth, hair, skin and taste. Fortunately, all of this did not affect his positive outlook on life and his huge God-given gift of humour.

It was through attending a Ronald McDonald House (where we spent a lot of time) support group that the PhD came about. While we were admitted over months, I noticed the high numbers of Māori and Pacific children in the wards and their families who were in similar situations. I also noted that these families often had insufficient support, came from outside of Auckland or outside of New Zealand. Many were new to the health system and found it difficult to navigate or understand the process and terminology being used. I also wondered how they coped as I had

great support, knew the health system, had financial flexibility and my work was next door, yet I barely coped.

It was at a Ronald McDonald House meeting that I questioned the numbers and ethnicity of the users of Ronald McDonald House. I was informed that at that time, the highest users of the Auckland houses were Māori and Pacific whānau. I also found out that, at the time, there was no research into the impact of Ronald McDonald House on whānau. After talking with the CEO, who encouraged me to consider some research and told me he would support it, I decided to embark on this journey.

While this is an overview of our journey with our son, there is so much more hidden between the lines of writing: feelings and emotions such as guilt as a parent/mother for not picking up symptoms, and for telling him off for what could have been related to a tumour; for not doing enough and not spending enough time with my other children, and not being there enough for the baby while dealing with this trauma; questions over whether I was making the right decisions; dealing with this issue separately as a couple, and not together, and then having the impact of separation down the track; constantly being on edge when he coughs, breathes or looks different; never quite letting go; hitting the wall a year later because it all caught up with me; feeling constantly exhausted from having people in my house; going to appointment after appointment or having appointments cancelled that took a year to confirm; being told by well-meaning people that I should do this and try this; trying to fit everything in, but also trying to just be present because you never know what might happen and where we might end up in a month or a year; constantly repeating the story, negotiating support so he can feel like a normal part of his community, advocating for him, confronting mediocrity, and setting boundaries which offended some people. These are just some of the raw issues and feelings that I faced, that all whānau face when dealing with a child with a life-threatening medical condition. But through it all comes the strength, vitality and impact of the drawing together of whānau; it is this component of the journey that this PhD is all about.

Priceless artefact

Someone once asked me if I could change one thing in my life, what would it be? They were shocked that I did not say my son's journey. I would change the diagnosis, but the journey itself has totally transformed our lives, the way we think, the way we behave, the decisions we make. It has made an enormous impact on our lives.

I am so grateful for the journey as it has taught me to have gratitude for so much in life.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

GLOSSARY

Āiga	Family (Samoa)
Alofa	Love and respect (Samoa)
Aotearoa	New Zealand
Āriki	High chief/chief (Māori/ Cook Island)
Aroha	Love and respect
Ātua	God(s)
Awhi	To support
Fa'aaloalo	Respect (Samoa)
Fa'a lavelave	Significant event (Samoa)
Fāmili	Family (Tonga)
Fale	House or meeting house (Samoa)
Fa'a Samaoa	Samoan ways incorporated rules/practices/tradition
Famili	Extended family (Tonga)
Fanau	Extended family (Samoa)
Fanau Ola	Optimal Pacific health and well-being
Hale	House or meeting house (Cook Island)
Hapū	Sub tribe connected to larger tribe of iwi
Ihu Karaiti	Jesus Christ
Iwi	Tribe where people affiliate to
Kaiako	Teacher
Kāiga	Family (Tokelau)
Kaitiaki	Guardian/protector
Kapa haka	Cultural expression traditions and practices
Karanga	Calling by women
Kaumātua	Elders or (male elder)
Kaupapa whānau	People connected by a purpose or goal
Kava	Cultural ceremonial beverage
Kawanatanga	Governorship
Kōhanga Reo	Pre-school incorporating Māori cultural practices

Kōpū tangata	Family (Cook Island)
Kura Kaupapa Māori	School incorporating total immersion Māori
Magafaoa	Family (Niue)
Mana	Strength, power, prestige
Marae	Meeting house
Matai	Head of family, village
Mātauranga	Māori knowledge
Ngāi Tahu/Kai Tahu	Tribe and tribal area in the South Island of New Zealand
Noa	To make normal or common
Pākehā	White person
Pōwhiri	Welcome ceremony
Rahui	Ban or restriction
Ringawera	Cook/kitchen worker/organiser
Tagata/Tangata	Person or people
Tapu	Sacred or restricted
Taonga	Something precious or sacred
Tautua	To be of service
Te Atiawa	Tribe of people stemming from Taranaki
Te Reo Māori	The Māori language
Teina	Younger/sibling
Tikanga	Particular way to behave
Tikahanga	The right way (Cook Island)
Tino Rangatiratanga	Self determination
Tohunga	Healer
Tuakana	Older/more knowledgeable or older sibling
Tūpāpaku	Deceased body
Vuvale	Family (Fiji)
Waiata	Song/hymn
Whakapapa	Kinship
Whakapapa whānau	People connected through kinship ties
Whakawhanaungatanga	The building of relationships/ structures of support

Whānau	Extended family and beyond
Whānau ora	Optimal health and well-being
Whānau pani	Those who are grieving and close to the deceased
Whānau Ora	Government initiative/optimal health and well being
Whenua	Land

LIST OF ACRONYMS

ACC	Accident Compensation Corporation
CCF	Child Cancer Foundation
CYFS	Child Youth & Family Service (Ministry of Vulnerable Children
DHB	District Health Board
FCC	Family Centred Care
FDA	Food and Drug Administration
HDU	High Dependency Unit
HPFNZ	Health Promotion Forum of New Zealand
LTMC	Life-Threatening Medical Condition
MCNZ	Medical Council of New Zealand
NICU	Neo-natal Intensive Care Unit
PICU	Paediatric Intensive Care Unit
RMHC	Ronald McDonald House Charities (formally Ronald McDonald House)
RNZCGP	Royal New Zealand College of General Practitioners
SUDI	Sudden Unexpected Death in Infancy
WINZ	Work and Income New Zealand

CHAPTER 1 - INTRODUCTION

In this section, I provide context for the research through a brief overview of the main components concerning the topic of whānau coping. This segment includes my reasons for undertaking this piece of work; personal examples are woven throughout the thesis in shaded boxes and used as a guide to provide further emphasis regarding specific elements. The critical key players, Māori and Pacific peoples, are introduced, as well as their notions of family. Whānau coping is then defined as related to this study as well as an exploration of coping mechanisms and strategies. The discussion includes Māori and Pacific concepts of health and Māori and Pacific current health status. Hospital admission rates for Māori and Pacific children with life-threatening medical conditions (a key criterion of the study) are incorporated, identifying whānau experiences of transitioning for these whānau along the health care continuum (a system of care used to track and treat patients). The position of Ronald McDonald Houses, including associated support services and how they apply to this study, is justified. A summary of key concepts that are explored in more detail further throughout the thesis are presented. I conclude this section by providing an overview of the material presented throughout the remaining chapters.

Statement of the problem

In New Zealand, there are obvious health inequities that exist for Māori and Pacific people. The New Zealand Government continues to struggle to adequately and effectively address health issues that affect Māori and Pacific whānau. Many of these issues come as a direct result of colonisation including Māori and Pacific high hospital admission rates, premature death from preventable conditions and inadequate systems causing delays in diagnoses and treatment. While small gains have been made across the health system (such as, implementing cultural models of health including activity related to cultural safety, cultural competence and cultural responsiveness and increasing Māori and Pacific health workforce participation), Māori and Pacific health disparities remain, with some gaps increasing further (Ajwani, Blakely, Robson, Tobias, & Bonne, 2003; Marriott & Sim, 2015). Factors that contribute to these disparities include racism, inadequate and ineffective systems and processes, lack of cultural responsiveness, competence and safety. Māori and Pacific peoples stem from collective cultures, therefore, whānau (extended family) are integral to their health and being. Limited research exists on how Māori and Pacific as a whānau cope while being admitted into the hospital and even less is known about their coping abilities in relation to their experiences of dealing with a child diagnosed with a life-threatening medical condition. Research that addresses these and other gaps in knowledge and pertains to a whānau coping perspective will be beneficial and contribute to improvements for Māori and Pacific whānau through effective development and implementation of policy and practice including adequate resource and service allocation.

Ronald McDonald Houses are a system-based resource that facilitates support free of charge for families who are dealing with a child who is critically ill. At the start of this research, there were no empirical studies that had been undertaken that looked at the impact of Ronald McDonald

House on family, locally, nationally or internationally. Māori and Pacific whānau are the highest users of the Auckland based Ronald McDonald Houses. Therefore, it was imperative that this research looked at the organisation's role and influence on Māori and Pacific whānau coping. In taking a whole whānau perspective, this research also contributes to gaps in knowledge pertaining to Māori and Pacific men's perspectives, grandparents as primary caregivers and sibling caretaking.

Background to the Study

I am Māori of Te Atiawa, Ngāti Mutunga ki Wharekauri (Chatham Islands) and Kai Tahu (South Island) descent, and, therefore, the research encompasses my background, experiences, values, and culture. It is this worldview that defines who I am and determined how this research was initiated, developed, and implemented. I am not of Pacific descent, nor claim to be. However, my husband and children are Cook Island (Rakahanga/Manihiki/Rarotonga) and Tahitian, hence the inclusion of Pacific whānau in this study. This study stems from our family's journey of dealing with our son's life-threatening medical condition. His diagnosis, a cancerous brain tumour at the age of seven and then again at age ten had significant impacts on our whānau and community. I became extremely aware of the high number of Māori and Pacific whānau dealing with similar situations over the extended period (over a two-and-a-half-year period for the first diagnosis) that we were in Starship Hospital, Wilson Home and Hospital (an acute rehabilitation facility) and residing at Ronald McDonald House (accommodation facilities). It was while being in those settings that I observed and experienced how integral whānau (the extended family support system) is to Māori and Pacific people, particularly when a child is critically ill (Collins & Wilson, 2008; Goodhead & McDonald, 2007; Jansen, Bacal, & Crengle, 2008; T. K. Kingi, 2002). Despite having access to extensive resources (for example, having information, financial flexibility, treatment in the same location, whānau support, flexible working arrangements), and grounded knowledge of the New Zealand health system, I found it difficult to cope. Throughout our journey, we met many whānau who were in similar positions during our Starship Hospital and Ronald McDonald House experiences. Whānau members who had resided at Ronald McDonald House spoke of the support they had received from staff and the services provided. Many whānau, like us, had experienced multiple admissions, surgeries and services. However, some whānau admitted to Starship hospital did not appear to have the same access to information, resources or support. Many of the whānau we met had limited English, were away from their hometowns and countries and were navigating not only foreign lands and languages but also a different system of care while knowing that at any time their child could die. It was through these observations and connections that the following research question was raised.

Research Question

The study sought to answer the question: *How do Māori and Pacific whānau cope when their child is diagnosed with a life-threatening medical condition?*

This research had two main aims:

1. To explore the <u>coping mechanisms and strategies</u> (for example, negative, positive, intentional and unintentional) employed by Māori and Pacific whānau who have experience in navigating the New Zealand health care continuum with a child diagnosed with a <u>life-threatening medical condition.</u>

2. To explore the <u>role and influence of Ronald McDonald House</u>, Auckland, on whānau coping.

In essence, I wanted to explore what whānau drew upon to cope, given that:

- their child was in a critical condition and knowing that death could occur at any time
- they were away from their familiar support systems (whether residing in Auckland or living outside)
- resources were mainly in English and used terminology and jargon that was difficult to understand
- whānau were in foreign environments (land and/or systems)
- whānau have had to navigate the continuum of care that includes multiple services and disciplines, transfers to other hospitals, a variety of treatments, recovery and rehabilitation, much of which takes place external to Starship
- at the time of the commencement Māori and Pacific whānau were the highest users of the Ronald McDonald Auckland-based houses, raising the question, what are Māori and Pacific whānau experiences of this service concerning their coping?

Quantitative and qualitative methods informed by Māori and Pacific methodologies were utilised for this research. Quantitative data was collected through the Ronald McDonald House database systems, Starship Hospital systems and reports and the Ministry of Health National Minimum Data Set (NMDS). While quantitative data was collected, it was decided due to the scope of this thesis that only qualitative data would be included. The quantitative data will be used in separate publications and or further research. Therefore, this thesis only reports the qualitative data. Qualitative interviews were undertaken with Māori and Pacific whānau members as well as support service workers (identified by whānau members themselves). The research comprised of 30 sets of interviews in total.

Māori and Pacific Peoples in Aotearoa

Māori

Aotearoa, New Zealand is made up of two main islands (North Island and South Island) and a series of smaller islands (including, for example, Stewart Island, also known as Rakiura, and the Chatham Islands, also called Wharekauri). Māori are "tangata whenua" (people of the land) of Aotearoa and affiliate to different tribes (iwi) and sub-tribes (hapū) that spread throughout these islands. Colonisation and urbanisation have impacted on the way Māori live, with many no longer residing in the place from which they originate. In 2013, at the commencement of this study, the majority of the Māori population (86.0%) lived in the North Island, with 23.8% residing in the Auckland region (Statistics New Zealand, 2013). Māori children (0–14 years) made up 33.8% of

this population with just under a quarter, 23.7% or 48,033, living in Auckland. According to the 2013 Census (the official count of New Zealand population-based data), Tasman, a region in the South Island, had the highest proportion of children who were Māori, at 36.2% (Statistics New Zealand, 2013). Shifts in the economy, including the rising house market (Auckland is now one of the most expensive places to live), have seen Māori, who once moved to central urban areas for employment and housing, now shifting away from main cities due to the high cost of living in main centres. Three-quarters of the Māori population live outside of the Auckland region. Moves away from their homelands and tribes have resulted in modifications in the makeup of the Māori population. More than half of Māori (53.5% or 320,406 people) now identify with two or more ethnic groups, and one in five (21.3%) Māori now speak more than one language (Statistics New Zealand, 2013).

Pacific

In the context of Aotearoa, "Pacific" is a grouping that refers mainly to immigrants or their descendants from the islands of Samoa, the Cook Islands, Tonga, Niue, Fiji, Tokelau and Tuvalu. Other smaller Pacific groups from western and northern Pacific are also included, such as Papua New Guinea, Solomon Islands, Vanuatu, Palau, Guam, New Caledonia and Tahiti, but are significantly smaller in numbers (Ministry of Social Development, 2009). Each group incorporates its distinct language, culture and history (Bacal & Jansen, 2006). While many Pacific people may reside in their homelands, some Pacific Islands, such as the Cook Islands, Tokelau and Niue, have a special relationship[2] with New Zealand, and their residents are considered New Zealand citizens.

Pacific peoples from other islands come to New Zealand to visit, while others have gained permanent residency (Auckland Regional Council, 2008; Statistics New Zealand, 2014). Those with residency contribute to a significant proportion of the Auckland population, with 66% of the Pacific population of New Zealand as a total living in Auckland urban areas, twice the proportion of the total New Zealand population who live in Auckland (Auckland Regional Council, 2008; Tukuitonga, Bell, & Robinson, 2000). As well, Pacific peoples remain the ethnic grouping with the highest proportion of children (0-14 years) at 35.7% in comparison to European, 19.6%, and Māori, 33.8% (Statistics New Zealand, 2014).

Māori and Pacific are diverse populations living in a range of cultural worlds (such as urban, rural, traditional, contemporary, island, New Zealand or Australia) reflecting various characteristics and contexts (Robson & Ellison-Loschmann, 2016). Differences are attributed to diverse cultural realities including how and where people live, language variances and distinctions in customs, values and beliefs (Bacal & Jansen, 2006). Māori and Pacific peoples ability to adapt to change and live in different worlds signals their tactical characteristics and capacities.

---

[2] New Zealand retains special relationships with its former colonies. The Cook Islands and Niue have "free association" agreements, giving their governments substantial budgetary assistance and their people New Zealand citizenship. In 2012, Tokelau remained a non-self-governing New Zealand territory. Samoa was also under New Zealand jurisdiction from 1920 to 1962, when it gained independence (http://www.teara.govt.nz/en/pacific-islands-and-new-zealand/page-1).

Whānau

For many, the word "family" consists of people connected through bloodlines or kinship. In Western terms, the family often refers to the nuclear or immediate group, comprising parents and their biological children (Social Policy Evaluation and Research Unit [Superu], 2016). For Māori and Pacific people, the connection and meaning of family go much wider. Terms for the family include āiga (Samoan), famili (Tongan) and kōpū tangata (Cook Island Māori). Family incorporates genealogy and lineage that are paramount in most Pacific cultures. These concepts link people together and, equally as important, link them to specific places (Mitaera, 1997; Tamasese, Peteru, & Waldegrave, 1997)

While whānau is a Māori term, in this thesis I also use the term for Pacific people as whānau is widely employed in Pacific documentation across sectors and have similar meanings in some Pacific cultures. For example, the word for extended family in Samoa is translated as *āiga* or *fanau* and can include village and church family (Otsuka, 2009). Furthermore, Whānau Ora/Fanau Ola (a New Zealand Government initiative aimed at reaching optimum health and well-being for individuals and the collective) contains familiarity and has gained favourable influence within Pacific health. Whānau is deliberately used throughout this thesis with the exception of information taken directly from literature, a quote from participants or where Western terms are used.

Whakapapa Whānau

In both traditional and contemporary Māori and Pacific societies, children are a treasured resource with many still being raised and taught through input from the collective (Durie, 1994, 2003; Moeke-Pickering, 1996). The collective can comprise of the wider family members, for example, aunts, uncles, and grandparents who live nearby and share the responsibilities of daily life including the upbringing of a child. For Māori and Pacific peoples, family members may be connected through blood ties and include extended-family members also known as whakapapa whānau (Auckland Regional Council, 2008; Goodhead & Mcdonald, 2007).

Literature confirms that through whakapapa whānau, our identity, teachings, roles and a sense of well-being is formed, nurtured and sustained (Durie, 1994). It is through whakapapa whānau that we perceive our place in the world and learn how to act and react to situations (L. Smith, 1999; Superu, 2016). For many, contemporary New Zealand society living has affected access to whakapapa whānau by separating members from their collective support. For many people, while they have whakapapa whānau they live some distance away from them. Therefore, having an impact by much-needed support not being necessarily readily available at a critical time.

Kaupapa Whānau

For many, whānau also comprises community members, neighbours and close friends, those who may not have kinship ties but have an active link and affiliation, known as kaupapa whānau (Auckland Regional Council, 2008; Lawson-Te Aho, 2010; Superu, 2016; Tibble & Ussher, 2012; T. Walker, 2014).

or fictive kin (Superu, 2016). Kaupapa whānau members recognise the collective as being critical to the individual functioning of whānau members and value both the traditional and contemporary roles that whānau has in the lives of each of its members (Hendricks, 2010). Kaupapa whānau allows the inclusion of individuals who affiliate and identify in other ways, such as having shared interests, an association, or similar goals and values, rather than through a shared heritage (Lawson-Te Aho, 2010; Superu, 2016; Tibble & Ussher, 2012; T. Walker, 2014). Current researchers describe different aspects of kaupapa whānau such as sports teams, kapa haka groups (traditional Māori performing arts), those in learning environments such as te reo classes (Māori language learning) or kōhanga reo pre-school underpinned by Māori processes, protocols and language; (Durie, Fitzgerald, T.K. Kingi, McKinley, & Stevenson, 2002; Hendricks, 2010; Superu, 2016). For Pacific peoples, kaupapa whānau can also include church members, village communities and official community societies (such as other chiefs and leaders). It is important to note that kaupapa whānau are not a substitute for whakapapa whānau but rather an addition that broadens whānaungatanga (support that facilitates and strengthen relationships) and provides perseverance and strength toward whānau values rather than a dilution of them (Superu, 2016).

In times of need, and particularly when dealing with a child with a life-threatening medical condition, other forms of support may be required. Many whānau are dealing with treatment for their child within a system that is not only foreign, but also away from their support structures and hometowns (Jansen & Smith, 2006; Reid, Robson, & Jones, 2000). For example, some Pacific whānau face further additional pressures as English (the language hospital staff use to communicate) is their second language. Having limited English can inhibit their ability to fully access and benefit from mainstream support services (Huakau & Bray, 2000; Zanchetta & Poureslami, 2006).

Because of being at a distance from their usual support structures, whānau are often forced to rely on other support/collectives including wider family members, friends and support services. In situations such as this, it is common to build close relationships with others who share a similar journey, such as other whānau with children in the hospital with life-threatening medical conditions (Barton & Wilson, 2008). These relationships often become a "whānau" and a "culture" in themselves and form when sharing a room, ward or waiting room for extended periods. These connections provide whānau with well-needed support including the sharing of resources, technology and information (for example, sharing food, explaining procedures, or accessing free car parking). Relationships such as these build up the support needed to ask questions and/or seek information from a doctor or specialist (Barton & Wilson, 2008). This support becomes critical, particularly when the hospital environment, terminology and systems are unfamiliar.

Whakapapa and kaupapa whānau are socio-cultural constructs that can differ to varying degrees depending on function and intent. While the two models (whakapapa and kaupapa) construct whānau identity and composition differently, the intent of both is to contribute to the achievement of whānau ora (optimum health and well-being) of the collective. The achievement of whānau ora is by building and strengthening relationships and promoting the collective practices of whānaungatanga (support and structure). Working together to achieve a common goal creates

opportunities for support in action for and by both whakapapa and kaupapa whānau (Durie, 2003; Kahu & Wakefield, 2008; Taiapa, 1995).

For our whānau, contemporary living broadened our whānau horizons. In our situation, whakapapa whānau were the blood connections that came from both parent lines. Kaupapa whānau included very close affiliations with those who may not have blood ties but were integral to our whānau structure to the point we claimed them as our own. For example, the long-standing husbands or wives of those who were connected through blood, those who were whangai (adopted in or out) or step-children. It included "feeding family" (the family that help feed and raise a child as their own alongside parents) and godparents (in some whānau these are blood relatives). Many of our whakapapa whānau lived away from Auckland. Kaupapa affiliations were also varied and connected us through not only a common purpose or goal but also a common person, and not just our child. For example, our colleagues became an integral part of our journey (wives of men I worked with became close friends as they could sympathise with what we might be going through).

School parents, teachers and peers became more than an association; they connected daily with us as parents and with our child. Cook Island church members became regular support and provided a spiritual security net. As well, ex-partners and their family members were closely affected by our journey and were always supportive, as were our various support services that were involved.

Our closest connections, however, were those families experiencing a similar journey to our own. With these people, we found that words were not needed in many situations because they knew our pain as much as they knew most of our needs.

Whānau ability to Cope

Coping in its simplest form is defined as a series of deliberate and focused efforts in which people engage in to minimise the harm (such as physical, psychological, or social) associated with an event or situation (Lazarus, 1999; Lazarus & Folkman, 1984). Both Māori and Pacific people carry with them wide-ranging concepts, traditions, practices, beliefs and values that are shaped by several influencing filters, including culture, upbringing, contexts, environment and experiences, to name a few. It is through these filters that their worlds are moulded, viewed and sculpted. These filters also facilitate their interactions, the resources they use, and their reactions and coping strategies in certain situations.

Coping with a child's life-threatening medical condition poses multiple challenges for all those involved (Bakker et al., 2014; Berube, Fothergill-Bourbonnais, Thomas, & Moreau, 2014; Coad et al., 2015). These challenges include time away from family or work, financial difficulties, transport issues, dealing with various practitioners, departments and trying to understand medical terminology, as well as stress and worry and so on. Literature confirms family members experience many emotions and behaviours when dealing with a child's ill health (Garcia Coll, Meyer, & Brillon, 1995; Goodhead & Mcdonald, 2007; Han, Cho, Kim, & Kim, 2009). For example, a mother's guilt, a breakdown in communication between couples, or a grandmother's grief for

both the grandchild and her child. Coping with a child's life-threatening medical condition continually affects whānau members as individuals, such as a mother, sister or uncle, and as part of the wider family unit including grandparents, parents or siblings. It also affects communities such as school peers, friends, neighbours and church members.

Not coping can further affect whānau members' health and well-being and their ability to assess what may be needed, as well as what may be available as an alternative. Whānau plays an important part in all aspects of everyday life, particularly when a child is seriously sick or facing a life-threatening medical event. It is the whānau that provides crucial social support and access to resources (Bacal & Jansen, 2006; Barton & Wilson, 2008; D. Wilson & Barton, 2012) acting as protective devices and buffers against stress and discrimination encountered (A. Moewaka Barnes, Taiapa, Borell, & McCreanor, 2013; Walters et al., 2011). Whānau is integral to Māori and Pacific health and well-being and, therefore, play a critical role in how they cope.

This study intentionally uses *whānau* as the central focus as it aligns with Māori and Pacific worldviews. This research identifies the impact whānau (roles, functions and structures) has concerning its members' coping with a critically ill hospitalised child. It will look at approaches and practices that may help or hinder whānau engagement (such as being together, discussions and decision making) within the health environment. Whānau, with regard to this study, is socially and culturally constructed, and defined by whānau members themselves, and includes both whakapapa and kaupapa whānau.

Mechanisms and Strategies to Cope

The terms coping mechanisms and strategies are often used interchangeably throughout literature. However, there are definitions that can be usefully applied to define each category. A coping mechanism is described as "an adaptation to environmental stress that is based on conscious or unconscious choices, and that enhances some form of control over behaviour or gives some psychological comfort" (Dictionary.com). The key is that coping mechanisms can be automatically applied either unconsciously or by default. In contrast, a coping strategy is defined as something that is implemented through specific, conscious and deliberate effort, it can be both behavioural and psychological, and is used to control, tolerate, reduce, or minimise stressful events (Watson, Logan, & Tomar, 2008).

Coping in the context of this research is identified by the use of any mechanism or strategy that aids the family to contend with difficulties and, therefore, act to try to overcome them. In relation to this study, a mechanism is identified as something that is applied semi-unconsciously (such as the minimal progression and effort made to undertake something) or by default (for example, crying, debriefing with someone to share the load). A strategy is, therefore, something that is deliberately and consciously put in place (such as writing a journal, getting out of the hospital at regular times during the day or attending counselling sessions). Simply defined, a mechanism can be unconsciously applied, and a strategy is more deliberate in its application.

Regarding my situation, some of the coping mechanisms I relied on were talking with family members or friends who understood health. While I spoke to other people, those to whom I did not have to explain things in great detail brought a sense of relief as I found constant repetition exhausting. I also decided I needed to be near my son and I needed to touch him (in Starship he was in the High Dependency Unit (HDU) for months where he had 24-hour monitoring and where parents could enter at any time day or night but could not stay). I spent most of my time in HDU with my son even though we had a room at Ronald McDonald House. One of the strategies I used while in Starship was to sit outside for at least 10 minutes a day to feel the wind on my face and the sun on my skin (this became a luxury, because, as a parent, I needed to be with my son for all the treatment and rehabilitation he was having). Being hospitalised for months either makes you or breaks you.

Upon being admitted to Wilson Home and Hospital, my son was in an entirely separate part of the hospital from where parents resided, which caused me much stress as access times were strictly enforced. The strategy I used in Wilson Home and Hospital was to request to meet with the head of nursing about the need for parents to see and be near their child. I informed her that parents want to actually parent and be involved in their child's care, and I reiterated that I felt disempowered when that right and role was taken away. I also reiterated that I had not built a relationship or trust with their nursing staff. Therefore, I needed to ensure both my son and me felt comfortable and safe before I would leave him for extended periods in their care. After much deliberation, staff meetings, and approval, they transferred my son to the quarters where I was residing. The move only occurred after telling me three times that the facility was not designed to accommodate this, and that while nursing staff would be available, I would have to do much of the work.

Māori and Pacific Concepts of Health

Māori and Pacific holistic worldviews (including relationships with the physical, emotional, spiritual, and environmental elements) provide indicators of the influences that affect well-being. These indicators contrast starkly with the dominant health system's biomedical worldview that focuses solely on the physical aspects of a disease, illness or associated physiological problems (Weerasinghe & Mitchell, 2007; D. Wilson & Nevelle, 2008). Incorporated within Māori and Pacific views of health is the retention of cultural approaches and increasing (Indigenous) control. Health strategies that have been developed by, for and with Indigenous people have included designs that stem from Indigenous cultural perspectives utilising familiar components, for example, the Medicine Wheel (NNADAP, 2008), Te Whare Tapa Wha (Durie, 1994) and Fonofale (Crawley, Pulotu-Endemann, & Stanley-Findlay, 1995). Family and culture are of importance to Indigenous people. For Pacific people, contributions and obligations toward family, church and community, both in New Zealand and their homelands, play a significant part (Cowley, Paterson, & Williams, 2004; Ministry of Health, 2008; Tait, 2009). Health and well-being, for many Māori and Pacific people, also include other facets such as situation improvements for the collective as well as individuals, for example, language sustainability or revitalisation, support toward education and

employment, or warmer, safer, more appropriate sized housing (Ministry of Health, 2008; M. Ratima, 2001).

Similar to other Indigenous peoples, Māori and Pacific health concepts incorporate an eco-spiritual holistic worldview which is driven by spiritual beliefs, connection to lands, people and other living things (Barton & Wilson, 2008; Bacal & Jansen, 2006; Finau, 1996; Ministry of Health, 2002, 2008). Therefore, for many Indigenous peoples, ill-health is often attributable to the loss of or damage to status or esteem, land and relationships. It can be viewed as fatalistic and spiritual, caused by external forces including ancestral spirits, or present itself in the form of a curse due to a transgression that may have taken place (Lui, 2003; Martinson, 1999), for example, breaking a customary rule or belief or committing an offence. Restoration of good health may include looking at the cause of the problem. Restoration can also comprise confronting a violation, taking particular medicines (for example, traditional or contemporary) or undertaking various rituals such as physical, spiritual, verbal or emotional; (Ministry of Health, 2008).

Māori and Pacific Health Status

New Zealand health statistics show a high percentage of preventable ill-health for Māori and Pacific people in general. Health status, health care and service utilisation have significant implications for Māori and Pacific, in particular, concerning children admitted to a hospital (Ajwani et al., 2003; Cormack, Robson, Purdie, Ratima, & Brown, 2005; Crampton, Jatrana, Lay-Yee, & Davis, 2007; A. Moewaka Barnes et al., 2013; H. Moewaka Barnes et al., 2013; Smedley, Stith, & Nelson, 2003). Māori and Pacific children show high rates of life-threatening medical conditions (such as respiratory conditions and asthma) and hence high rates of admission into hospital paediatric intensive care units, including New Zealand's specialist tertiary hospital – Starship (Bacal & Jansen, 2006; Ministry of Health, 2010b). Contemporary society and the associated stress of modern day living places enormous pressure on families, resulting in breakdowns through separation, distance and isolation from wider members. Documentation of this pressure highlights consequences over time through disparities relating to determinants, particularly low income, unemployment, substandard housing and ill-health (Ministry of Health, 2008; Raphael, 2010; Rasmussen, 2011). Determinants directly influence the health of Māori and Pacific populations, in particular, social and economic factors (Ajwani et al., 2003; Blakely et al., 2006; Howden-Chapman & Cram, 1998).

Within New Zealand, Māori and Pacific peoples predominantly occupy the lower socio-economic groups, live in the poorest communities, dwell in substandard housing, and have low education attainment compared to non-Māori and non-Pacific (Superu, 2016). Poverty and deprivation are active drivers of health outcomes throughout life and are related to family cohesion (Ministry of Health, 2009; H. Moewaka Barnes et al., 2013). Many determinants influence Māori and Pacific health and well-being, and therefore, whānau coping. Determinants that impact health are outlined in more detail in Chapter two – Background.

Māori and Pacific peoples have, on average, the highest health needs of all ethnic groups in New Zealand (Ministry of Health, 2012a, 2012b, 2015a, 2015b; Statistics New Zealand and Ministry of

Pacific Island Affairs, 2011). Extensive disparities exist between the health status of both Māori and Pacific peoples when compared to Pākehā (New Zealand Europeans), and, in some areas, health status disparities continue to widen (Ajwani et al., 2003; Marriott & Sim, 2015). International evidence reveals that Indigenous peoples have reduced access to and/or utilisation of health services (O. R. Gibson & Segal, 2015; Kowal & Paradies, 2010; A. Moewaka Barnes et al., 2013; Wepa, 2016). Research also indicates that even when Māori and Pacific people do access health services, they receive lower quality of care compared to the general population (Crampton et al., 2007; Smedley et al., 2003).

Life-Threatening Medical Conditions

Having a child with a life-threatening medical condition (LTMC) severely impacts the family unit (Rasmussen, 2011; Svavarsdottir & Sigurdardottir, 2006). LTMCs are also termed long-term conditions, chronic conditions and or severe long-term illnesses, life-threatening or life-limiting conditions, to name a few. The Food and Drug Administration (FDA) incorporates key components of these terms in their definition of LTMCs. Descriptions include medical conditions where the likelihood of death is high unless the illness is disrupted (USFDA, 2002), where medical intervention may be successful but also carries a substantial chance of mortality within childhood. Life-threatening conditions involve any condition and/or disease (PedPalASCNET). In this research, an LTMC is considered to include any condition that threatens the life of the child, including communicable diseases (acute); chronic conditions; or short-term, long-term and terminal conditions. For example, LTMCs can include different types of cancers, heart conditions, respiratory conditions, organ failure and other rare disorders. It is important to note that while some LTMCs can be short-term, often the treatment, recovery and follow-up extend over long periods. Throughout this thesis, the terms *life-threatening medical conditions*, *medical conditions* and *conditions* are used interchangeably.

Admission to Hospital

In New Zealand, most of the hospitalisations concerning children under five years of age are due to life-threatening conditions caused by infectious disease (Health Partners Consulting Group, 2012). Sadly, the gap between Māori and Pacific infectious disease admissions and other ethnic groups has increased significantly over the last 20 years, with rates being double that of New Zealand European/other ethnic groups (Health Partners Consulting Group, 2012). In 2011, for every 100 NZ European children hospitalised, there were 251 Pacific and 167 Māori children hospitalised (Child Poverty Action Group, 2012). Pacific children have higher hospitalisation rates (compared to non-Pacific) for numerous conditions including those that are life-threatening, such as respiratory disease, asthma, cellulitis, gastroenteritis, kidney and urinary tract infections (Gillies, Tomlin, Dovey, & Tilyard, 2013; Statistics New Zealand and Ministry of Pacific Island Affairs, 2011). Māori children also experience significant disparities across a range of conditions including dental caries, sudden unexpected death in infancy (SUDI), hospital admissions for assault, and injury mortality (Craig, Jackson, & Yeo Han, 2008). Starship Hospital plays a critical role for Māori and Pacific children because it is New Zealand's only tertiary care hospital for children and young people.

Starship Hospital

Starship Hospital, also known as Starship Children's Health, opened its doors in 1991. It is New Zealand's first hospital built exclusively to address the health needs of children and young people. Children admitted to Starship Hospital usually have severe and complex health conditions (Auckland Doctors, 2017).

Starship Children's Hospital is New Zealand's key specialist children's health facility, treating approximately 100,000 children every year. The hospital incorporates a major teaching centre that aims to lead the nation in paediatric training and research. Facilities include inpatient and outpatient services as well as community-based services such as Community Child Health and Disability Service, Safekids and Paediatric Home Care. At the time of writing this thesis, Starship had nine wards and a capacity of 219 beds. Renovations were occurring to accommodate more patients and to enable improved efficiency in surgical procedures. Besides the main building, Starship has outpatient clinics throughout the Auckland region and is associated with approximately 45 outreach clinics throughout the country. Starship's prime focus is on delivering family-centred care in a child-friendly environment to children and young people throughout New Zealand and the South Pacific (Auckland Doctors, 2013; Starship, 2017e).

The Health Care Continuum

Children with LTMCs are hospitalised more and spend more days in hospital than children with non-life-threatening illnesses. They also contribute to greater proportions of hospitalisations and hospital days of all children admitted, including readmissions. Simon et al., (2010) found that children with chronic conditions comprised 10% of admissions, 25% of hospital days, 40% of hospital charges, 75% to 92% of technology-assistance procedures, and 43% of inpatient deaths among US children in 2006. Children with LTMCs may require a broad range of services and support over an extended period. Multiple services, long and exhaustive appointments, combined with the unique and unpredictable nature of the child's condition can result in complex care and management across an array of health care providers (Kodner, 2009).

The health care continuum includes pathways aimed at maternity, cancer, palliative, mental health and diabetes care, for example. The concept of a continuum involves a system of care that seeks to guide and track patients over time through multiple health services spanning all levels of intensity of care (Evashwick, 1990; HiMSS, 2014). The continuum spans services from pre-diagnosis to discharge and beyond, and covers health care provided from birth to end of life. The continuum includes a broad set of services and may also extend to include home care, accommodation and funding for travel assistance (HiMSS, 2014; Young, Clark, Kansky, & Pupo, 2014).

Whānau Navigation of the Health Care Continuum

Access to and understanding of the necessary services spread across the health care continuum is an important aspect for whānau. Whānau who are dealing with a child with an LTMC tend to experience continual transition and re-entry along the health care continuum (MacMahon & Thomas, 1998; National Multiple Sclerosis Society, 2008). Figure 1 shows four of the multiple

transitions that can occur for whānau. These include a linear process that can incorporate pre-diagnosis, diagnosis, treatment and discharge. Other experiences show whānau that continually transition back and forth through the different stages. Whānau in this position may have multiple health needs that require a range of treatments (such as chemotherapy, radiation, surgeries and rehabilitation) delivered by multiple services for one or more medical conditions. For some whānau, treatment can cause other side effects leading to other diagnoses where additional treatments may be required (Kodner, 2009).
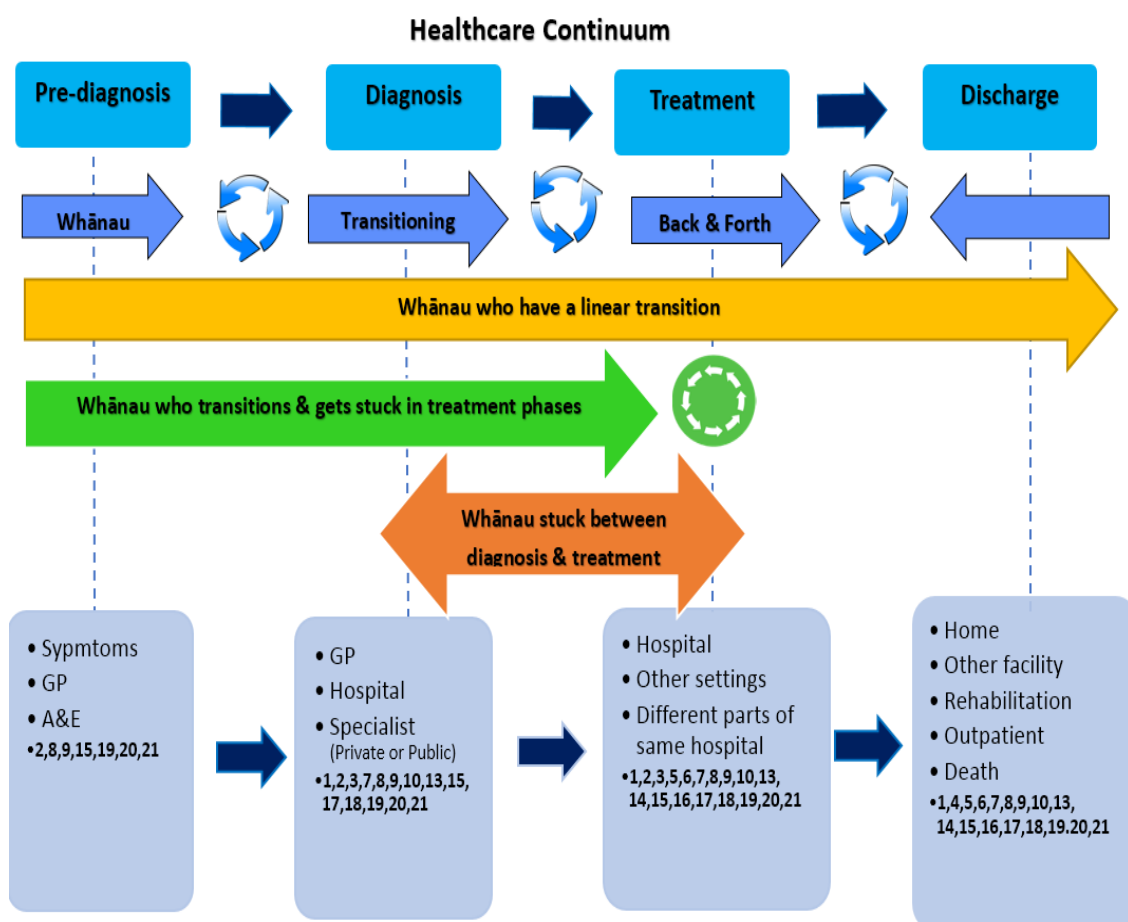
Figure 1. Whānau transitions along the health care continuum.

Table 1 below lists examples of health services connected through a continuum of care. Each service has been allocated a number corresponding to those listed in Figure 1. The numbers are representative of where services may sit along the health care continuum (these may differ between cities and countries). It is important to note that some services may need to be drawn upon multiple times and at different points along the continuum.

Table 1. Services Involved in a Continuum of Care.

Acute health care services (1)	Hospitals (8)	Outpatient services (16)
Emergency departments (2)	Urgent care (9)	Hospices (17)
Inpatient services (3)	Physician practice (10)	Long-term care (18)
Home care (4)	Assisted living (11)	Behavioural health (19)
Visiting nurse services (5)	Skilled nursing facilities (13)	Research (20)
Palliative care (6)	Rehabilitation (14)	Wellness care (21)
Care management (7)	Public health (15)	

Our first encounter with the health care continuum as whānau started with symptoms *pre-diagnosis*. These were a change in personality, falling over, and limited coordination. We went to our GP, who then suggested we see a paediatrician (in the public system the wait was over one month, we had asked to go privately which still took over one week to be seen).

The paediatrician then sent us for an MRI, which was a private facility where the cost, unbeknown to us at the time, was $1000 to get our results. We were in a very privileged position where we could pay the amount through a credit card. It was there that my son was *diagnosed* with a brain tumour. From the MRI, we were sent straight to Starship Hospital for *treatment*. Medications were given, to reduce the swelling in the brain, along with constant monitoring and the scheduling of urgent surgery. Post-surgery we were then *diagnosed* with the cancer element after a tumour was removed and examined. We, therefore, needed *treatment* to deal firstly with the after-effects of brain surgery (loss of memory, loss of ability to walk, loss of speech); physiotherapy, occupational therapy and speech-language therapy became a regular feature. After approximately three months we were then *discharged* from Starship and *admitted* to Wilson Home and Hospital where intensive nursing care and rehabilitation commenced. After several months (timing is a blur) we were then *discharged* from the Wilson Home and Hospital and became an outpatient at Starship Hospital for cancer treatments, (chemotherapy and radiation therapy). During the year of treatments, we were also readmitted to Starship for various issues. Some of the treatments caused severe health reactions, and alternative issues were then diagnosed which needed additional treatments. For example, radiotherapy caused serious teeth problems, and our son had to be admitted removing six of his teeth urgently. Reactions to radiation caused severe headaches, so we were readmitted to Starship for monitoring and further MRIs. Also, results indicated that where a tumour was situated affected my son's sight, therefore, we were admitted to another hospital, Greenlane, for eye surgery. The care continuum for us involved 21 services in total for the two years post first surgery.

Ronald McDonald House

The second aim of this study contributes to understanding the role and influence of Ronald McDonald House, Auckland regarding whānau coping.

The Ronald McDonald Houses[3] are an example of support provided by a non-government organisation. Many whānau who are coping with a child with an LTMC utilise the services of the houses. Ronald McDonald House Charities NZ (RMHC) provides a range of programmes and accommodation to whānau dealing with critically ill children (for example, temporary accommodation near Starship hospital, care mobile [dental treatment] and schooling programmes).

Each year the houses and family rooms accommodate and care for thousands of families whose children are undergoing hospital treatment at Auckland Children's Hospital (Starship), Wellington Hospital or at one of Christchurch's Hospitals (RMHC, 2016a).

RMHC creates, finds and supports programmes that help children live happier healthier lives. Families who have a child admitted to either the Neonatal Intensive Care Unit (NICU), or Paediatric Intensive Care Unit (PICU), or one of the High Dependency Units (HDU) also use Ronald McDonald Family Rooms, which are situated within the hospital complex).

Definitions of Key Concepts

Kaupapa Māori

Kaupapa Māori is a research framework founded on cultural practices that stem back thousands of years (Pihama, 2001). It encapsulates the concepts of "ground rules, customs and the right way of doing things". Kaupapa Māori influences the way Māori think, interact and interpret the world. At the core of kaupapa Māori research is the validation of Māori worldviews and knowledge to frame and define terms of reference, methods of conduct and analysis (Nepe, 1991). Kaupapa Māori research puts Māori at the forefront and ensures processes and outcomes are undertaken appropriately and are of benefit to Māori.

Talanoa

The name talanoa stems from the Tongan language base and is a research approach that is derived from oral traditions (Vaioleti, 2003a, 2003b, 2006). Talanoa is frequently referred to as a conversation that incorporates an exchange of ideas and different aspects of thinking (formal or informal), it is most widely practised by those who live in the Pacific (Capell, 1991). Talanoa is an appropriate approach when researching various issues that affect the people of the Pacific (Fletcher, 2003; Otsuka, 2005; Vaioleti, 2003b, 2006).

Paradigm Net

The paradigm net is an overarching framework that is applied to house the tools needed to undertake the research (Denzin & Lincoln, 2000). It contains some features that are adaptable

---

[3] **Ronald McDonald Houses (RMH)** as they are known elsewhere in the world. In New Zealand many of the RMH's have now amalgamated under Ronald McDonald House Charities (RMHC).

and informed by both Indigenous and Western knowledge. The net holds the researcher's ontological (belief in what is real in the world), epistemological (ways of knowing about reality), axiological (set of morals or ethics) and methodological (how to use modes of thinking to gain more knowledge about the fact) principles. It also contains essential elements to undertake the research (for example, kaupapa Māori and talanoa methodologies, qualitative methods, Western knowledge) that overlap, signalling their flexibility and allowing the researcher to draw on one or a combination, as and when required.

Support Services, Providers, Support Workers and Health Care Staff

Support services, providers, support workers and health care staff are mentioned continually throughout this thesis. Health workers refer to a cluster of people and could include a nurse, doctor, specialist or administrator. In some instances, whānau mentioned the identity of specific roles and organisations. This thesis includes these general terms in the absence of specific names and functions, for example, a doctor or specialist rather than a specialist oncologist.

Thesis Outline

The following describes the order and content of the thesis.

Chapter 1 – The introduction presents a brief overview of the information and context of the research. Presented here are the research question and research aims.

Chapter 2 – The background offers in-depth information regarding Māori and Pacific traditional notions of whānau and the historical influences that sought to change traditional whānau structures over time. The position of Māori and Pacific people is also examined in relation to equity, equality and disparity as well as discussion on the determinants of health and strategies for change.

Chapter 3 – A review of the literature examines research on whānau coping, the impact on whānau roles as well as diverse cultural coping approaches. It highlights current knowledge and identifies gaps in literature and positions the research.

Chapter 4 – The methodology chapter incorporates the research design, drawing on both Western and Indigenous concepts framed within a paradigm.

Chapter 5 – The methods outline the qualitative methods employed to undertake the research. It describes recruitment strategies and participants. Ethical considerations and the establishment of rigour for the research are also included.

Chapter 6 – The findings draw together the strands of data collected to present the analysis of the study. As there were two primary aims of this research, the results are presented in two separate sections. Firstly, barriers and distractions combatted by coping mechanisms and strategies. Secondly, the influence of Ronald McDonald House in relation to whānau coping.

Chapter 7 – The discussion focuses on the interpretation of the results presented in Chapter 6. It highlights key themes arising from the findings and positions this research amongst the current literature.

Chapter 8 – The conclusion draws the work together and summarises the main highlights from the findings, analysis and discussion. The chapter revisits the research question, aims and objectives and identifies the limitations.

Chapter 9 – Recommendations are put forward for consideration and relate to services, practice and staff.

Summary

In this chapter, I have provided context for the study including my reasons for undertaking the research. The information identified Māori and Pacific health as being holistic, integrating relationships with many facets such as physical, spiritual, emotional and environmental. For Māori and Pacific peoples, contributing financially and physically to community plays a critical part in health and well-being. I have explored the notion of family and defined two key whānau concepts: whakapapa whānau and kaupapa whānau. The information has also identified Māori and Pacific health status in that they have on average the poorest health of any other ethnic group in New Zealand. As well, Māori and Pacific children continue to have high hospital admission rates that include life-threatening medical conditions. In relation to the health care continuum, it has been shown that there are complexities for whānau in transitioning the health continuum which is for many not a linear process for those with a critically ill child. The principal aims of the research have been highlighted, and comprise identifying coping mechanisms, and strategies Māori and Pacific whānau utilise when their child is admitted to hospital with an LTMC. As well, as an exploration of the role and influence of Ronald McDonald House on whānau coping.

CHAPTER 2 - BACKGROUND

In this chapter, I address the traditional and contemporary constructs of Māori and Pacific health systems and structures including whānau. Included are the historical influences that have sought to change Māori and Pacific cultural underpinnings and practices over time. A Western concept of family and its diversity is examined through the identification and use of contemporary classifications currently used to shape New Zealand policies and society, as well as significantly influencing health-related behaviour. The information provided takes into consideration Māori and Pacific history, the impact of colonisation, current health status and health needs as well as the distribution of allocated resources. I conclude the background information by examining some of the strategies that have been developed and implemented to reduce Māori and Pacific disparities within the New Zealand health system.

Traditional Constructs of Whānau

Families are a significant socialising influence in people's lives (Superu, 2016) and an important institution for most cultures throughout the world. Family members are also a critical source of support and an essential strategy for coping (Chen & Kennedy, 2005). People view family through their cultural frameworks. Therefore, definitions of family vary depending on peoples' background, culture, beliefs and upbringing (Pihama, 1998; Superu, 2016).

Māori

For Māori, whānau is a cultural construct that both defines and sets Māori apart from other cultures. The essence of whānau derives from a collective dynamic, with internal processes that bring the strength and resilience of its members through collective identity and group effort. Traditionally, whānau was identified as one of the smallest of Māori social structures, usually consisting of three to four generations of extended family members (Moeke-Pickering, 1996). It was common practice for individuals to belong to several different whānau collectives. These collectives incorporated the formation of hapū (a sub-group) and iwi (tribe), all linking back to one eponymous ancestor (Papakura, 1986). Keeping within the confines of their tribal affiliation, each whānau "mixed, divided, rekindled, migrated and established fresh relationships" (Moeke-Pickering, 1996, p. 2). It is these relationships that both acculturated (assimilate the cultural traits of another group) and enculturated (learn the dynamics of their surrounding culture and acquire the appropriate values and norms) whānau into a sense of collective affiliation. The collective, in turn, facilitated pathways for obligatory roles and responsibilities that supported cohesiveness, which was of primary importance (Moeke-Pickering, 1996).

Kruger et al. (2004) stated that whakapapa (kinship ties) forms through sets of relationships, conditional obligations and privileges that determine a sense of well-being between iwi (tribe), hapū (sub-tribe) and whānau (extended family). These reciprocal and mutual obligations act as a source of support for individual members and the collective whānau (Superu, 2016). History

confirms this by identifying that the roles of men and women within a Māori whānau involved whānaungatanga (support and structure) where all living things were interrelated and guided by a principle of balance (Mikaere, 1994). Both men and women played critical roles within the collective whole while supporting interdependence. Early European observer accounts highlight the role of the father as the carer alongside the mother and other family members (Jenkins & Harte, 2011). Every person in the whānau contributed toward the collective good, and it was the collective responsibility to ensure that each respective role was valued and protected (D. Wilson, 2004). Structures of responsibility and accountability to the collective facilitated an environment based on respect and mutual obligations. Whānau raised children together, and structures such as intergenerational living (for example, living with grandparents, aunts or cousins) acted as an accountability source that individual whānau members used as a guide and measurement concerning the upbringing of children (K. Baker, 2010; Superu, 2016). While some of these traditional aspects of whānau remain, unfortunately, consequences stemming from separation, urbanisation and colonisation have impacted severely regarding the current case for many others. Historical influences on whānau such as these are explained further along in this chapter.

Pacific

Likewise, Pacific peoples have always placed great importance on the extended family, church and communities (Koloto, Duncan, de Raad, Wang, & Gray, 2007). The proximity of contact often prioritises Pacific cultural notions of family and household which traditionally meant belonging to a unity of members who have continuing relationships (Cotterell, von Randow, & McTaggart, 2009). Traditional Pacific settings incorporated the development of socio-political structures, cultural and religious frameworks, as well as values associated with economics and parenting. These are based on relationships between people (including the past, present and future), their environment and their gods (Suaalii-Sauni, McTaggart, & von Randow, 2009; Suaalii-Sauni, Tuagalu, Kirifi-Alai, & Fuamatu, 2008). Samoan family life in the 1970s is described as being centred on village life and the hierarchical social system within it (Meleisea & Schoeffel, 1998; Tautolo, 2011). In contemporary New Zealand society, the importance of kinship ties for Pacific peoples is reflected in the primacy placed on extended family, households, and the church, as well as on traditional cultural obligations (Cotterell et al., 2009).

As for Māori and Pacific, grandparents played a vital role in traditional cultural whānau structures and were deemed critical to the well-being and sustainability of the whānau, village, hapū and iwi. Grandparents provided support, knowledge, skills, and resources while helping to raise and nurture children (C. Smith, 2008; Worrall, 2008, 2009a). It was also customary practice for grandparents in Māori and Pacific societies to be the primary caregivers, especially to the first-born grandchild (Hakaoro, 2003; Ka'ai, 2005; C. Smith, 2008; Worrall, 2009a). Within traditional cultural communities, these elders had the right to make decisions regarding the wider whānau and children. For most Māori and Pacific cultures, whānau is considered the greatest asset and central foundation of the collective (Arlidge et al., 2009; Goodhead & McDonald, 2007; Rasmussen, 2011; Superu, 2016; Tukukino, 1985).

Associated with whānau structures are the protocols and practices within it. These protocols and practices are facilitated through specific events (for example, a wedding, funeral or birthday). Examples of cultural processes that are enacted through a series of general patterns include functions such as pōwhiri (process to welcome people) or tangi (funeral) roles, for example, matai/Āriki (chiefs), kaumātua (elders); and processes including karanga (calling), kava ceremony or hui meeting; (Nikora et at 2004). These general patterns can occur for Māori and Pacific whānau whether the event is one of welcoming, farewell, celebration or mourning. Associated practices stem from traditional values, culture and the environment. For example, Fa'a Samoa[4] (adhering to the Samoan way of life) and fa'alavelave[5] (the financial contribution toward significant events) is an integral part of many Samoan whānau lives.

Intergenerational living was normal for our whānau growing up. Due to the demands of my parent's employment (for my mother it was shift work through nursing in Christchurch, and my father was away fishing in the Chatham Islands), and being the eldest grandchild, I was raised with my paternal grandparents who travelled between Christchurch and the Chatham Islands (our homeland). Likewise, it was rare for any of my husband's family to be living in a home with fewer than two generations. Today we live in Auckland, with many of our Cook Island family living nearby; our living circumstances encompass houses situated beside each other (in different suburbs) and daily activities including the sharing of meals and looking after children. Our closest Cook Island environment comprises four houses referred to as the "Waimate village," reflecting the street name and the essence of village life incorporating community living. In our particular whānau, the men play a very hands-on significant role in bringing up and caring for children. In our own home (in a nearby suburb from the village), my father resided with us for over ten years helping to nurture and care for our children. Having my dad there was particularly helpful due to the demands of my employment at a time when travel was constant. Although my dad worked demanding hours for the Power Board, much of it was at night. He would then be home during the day to help look after our children. When he worked, my husband would be home to take over. After the birth of our first child, it was my husband who took paternity leave while I went back to work.

For many Indigenous cultures, including Māori and Pacific, their "social hierarchy incorporates protocols associated with Āriki (high chiefs), tapu (sacredness) tikahanga (doing things right) and mana (power and prestige"; Hunt 2003, p.10). Whānau cultural roles and responsibilities were central to the lives of Māori and Pacific peoples (C. Smith, 2008; Statistics New Zealand and Ministry of Pacific Island Affairs, 2011; Superu, 2016; Worrall, 2008, 2009a).

---

[4] **Fa'a Samoa** is the practice of adhering to the Samoan way of life and is described as family pooling resources under the leadership of the family matai (chief). Everybody has a place and a role and respects that by undertaking the behaviours associated with it. These roles and behaviours are an expectation and are learned and reinforced through daily life and ceremonial events (Families Commission, 2010).

[5] **Fa'alavelave** is the financial contribution toward significant events. It is defined as "anything which interferes with normal life and calls for special activity." In other words, it refers to any huge event in Samoan culture. These events include funerals, weddings, giving of matai titles, births, special birthdays, and building dedications *http://www.mytripjournal.com/travel-716682-birthday-party-tin-fish-family-members-finemats.http://www.samoa.travel/page/faa-samoa-samoan-culture,http://www.samoa.travel/page/faa-samoa-samoan-culture*

Traditional Public Health Systems

Pre-colonisation, Māori and Pacific people lived in a well-developed society that consisted of tribal and village structures. Māori and Pacific people were highly innovative, implementing calculated strategies to survive in harsh environments with limited resources. Within these environments were hierarchical systems that incorporated health, education, justice, spirituality and a common language (Orange, 1987a, 1987b). At the time, Māori and Pacific health systems (or what we would refer to nowadays as a public health system) were well established. For example, systems incorporated uses of water, waste disposal and separation for the ill, dying and dead. A public health workforce was formed as a result of well-respected designated roles. These roles and associated knowledge and practice were often passed down and learnt by successive generations. Jenkins and Harte (2011) noted that, traditionally, children participated alongside their elders in many events including tribal councils. Attendance formed part of children's training, with many undertaking roles of adulthood including those associated with agriculture, medicine, warfare and justice.

Traditional health structures and systems were developed over many generations and were tailored to the environment and the people who lived within it (M. Ratima, 2001). Health systems were based on concepts that were clearly defined and were divided into clean, unclean, safe and unsafe practices. For Māori, these practices come under the concept of tapu and noa[6] that existed within a framework of Māori beliefs and values. Similar concepts existed for Pacific people; for example, Cook Islanders from the Northern groups used the concept of tikahanga, meaning doing things correctly; while this was used in daily living, it was also utilised when someone deviated from protocols or practice into behaviour that could be deemed unsafe.

Examples, where tapu and noa or tikahanga concepts were used, include livestock being looked after away from the everyday living, different uses of water systems (for example cooking versus waste disposal) where ablution blocks were separated from cooking facilities and birthing quarters or infirmaries for the ill or dying came with restrictions on who could enter for quarantine or recovery purposes. A rahui (a ban) is another example where restrictions were put in place for specific lengths of time to protect specific resources (such as fishing areas so replenishment could occur) and to ensure there was enough food to keep people healthy. The beliefs and values, as well as mutual understandings of respect, enabled specific roles and strict protocols to be applied (Durie, 1998). The regulation of such practices protected people from the risk of injury and disease and were critical to maintaining good health.

Each individual within Māori and Pacific whānau had a special place, held a distinct role that performed a certain function all within the confines of the marae/fale or hale (meeting house), village and tribal area. All the roles were valued and respected which made for ease and succession of specific events.

---

[6] **Tapu** is the restrictions and prohibitions put in place to prevent the violation of physical, mental/emotional, spiritual and cultural well-being and maintain dignity and sacredness…
Noa, in the negative sense, is the state of diminished tapu, of weakness and helplessness resulting from violation. In the positive sense, it is the state of freedom of mind and spirit that comes through being acknowledged, restored and healed (Delamere Support Services, p. 2) *f*

Historical Influences – Impacts on Whānau and Health

Colonisation and urbanisation have been the main catalysts for the collapse of Indigenous family systems and health structures. Literature from New Zealand, the Pacific, Australia, Hawaii and Canada all document the radical decline of Indigenous peoples following colonisation (Grant-Mackie, 2007; C. Harris, 2002; Kunitz, 1996; Waldram, Herring, & Young, 2006; Wepa, 2016). With colonisation, came the loss of land, the collapse of traditional health systems, destruction of whānau systems and structures, compounded by the loss of language and cultural practices. New infectious diseases led to death and rapid changes for Indigenous peoples all over the world (Consedine, 2007; Hayes, 2016; Ministry of Health & University of Otago, 2006). Colonial processes and agendas replaced many traditional structures (Pihama, 1998). Colonisation also brought with it one of the most disruptive influences on Indigenous peoples in many countries: the forced removal of children from their families and tribal communities to boarding schools for the explicit purpose of destroying their culture and religion (Billow, 2011). These schools deprived parents and other relatives of their children, who were subjected to brutal treatment both physically and psychologically. The forced removal of children accompanied segregation, separation and death of many Indigenous whānau members along with genocide, stolen generations and confiscation of Indigenous lands (MacDonald & Hudson, 2012; Woolford, 2013).

Having to adapt to new and foreign environments, due to forced removal from their lands, left communities with no economic base, limited access to food sources and informal support networks. Health system changes and the impacts of living in a new land brought with it new forms of disease. Whānau structural changes saw the loss of interdependence and a heavy reliance toward independence (Durie, 1998; Wepa, 2016) through collective support being removed. Women and children became vulnerable, having to rely solely on their husbands or fathers while becoming increasingly isolated from support systems. Christian values replaced collective ones and also determined what constituted being a "good" wife and mother. Economic hardship and adhering to a new value system meant that women worked twice as hard both in and outside of the home to try and adhere to these standards (Wepa, 2016). For men, the new concept of working for an income further undermined traditional gender roles within the whānau structure (Pihama, 1998). Working away from the home base when and where work was available and holding the sole responsibility for the family placed added pressures on an already burdened unit. Destructive behaviours, including violence, increased along with the loss of native languages and diminishing health practices (Kruger et al., 2004; Wepa, 2016).

Family: A Western Construct

The devastation from colonisation and urbanisation inflicted damage to whānau structures, systems and cultural practices. With this destruction, the missionaries introduced a new concept: the nuclear family. This model became entrenched, supported and promoted as "*the* model of civilisation," "ordained by God," "biblical" and "natural" (Pihama, 1998). Western culture became regarded as defining civilisation. Cultural ways of doing things became "primitive, archaic and unacceptable in the public domain" (Arowolo, 2010, p. 2). The nuclear family model contributed

significantly to the redefining of roles within whānau as well as the cultural practices that underpinned them.

Today, nuclear family or "immediate family" classifications have become the benchmark against which families are measured (New Zealand Families Commission, 2005). The nuclear concept of the family usually consists of two generations: parents (mother and father) and their biological children. The focus of these families is on developing and maintaining close relationships between these main individuals, with the extended family tending to be on the periphery (Carteret, 2011; Superu, 2016). Legal and other systems continue to validate the nuclear family concept, thereby failing to account for alternative views and experiences such as Māori and Pacific notions of whānau (Cotterell et al., 2009; Pihama, 1998).

The erosion of whānau support and intergenerational nurturing continues to be a growing concern (C. Smith, 2008; Worrall, 2009a). Many families face difficulties and financial stress which affects their ability to function well as a family (Superu, 2016). Today, smaller family units are promoted, both directly and indirectly, across many sectors. For example, social service systems such as Work and Income New Zealand (which provides employment and financial assistance) financially disadvantage those who may have family members living with them. Likewise, Housing New Zealand has only recently begun providing suitable accommodation for bigger whānau, due to outbreaks of various diseases such as pneumonia, meningococcal disease and tuberculosis which have occurred as a consequence of overcrowding. These outbreaks affect children and have been life-threatening. Further factors in the breakdown of whānau structures include the rising cost of living in urban areas (particularly Auckland) where there is a high population of both Māori and Pacific people. These costs also affect proximity to whānau support structures and include the cost of transport and having to work longer hours. Working longer hours means being away from children and having to pay strangers for childcare (Kukutai & Taylor, 2013; Superu, 2016; Worrall, 2009a), placing additional pressure on family units.

Promotion of smaller more acceptable nuclear family units has taught its members to live separately and privately, promoting a sense of secrecy under the guise of privacy and confidentiality, concepts which were once foreign to Māori and Pacific culture. In contemporary New Zealand society, Māori and Pacific grandparent roles remain active; however, how they connect with their grandchildren varies (C. Smith, 2008; Vai'imene, 2003). For example, Māori and Pacific grandparents may visit New Zealand for extended periods or take children back to other lands at certain times during school holidays, or they may live nearby enjoying proximity and regular connection (C. Smith, 2008; Worrall, 2009a). Many grandparents have now also been forced into becoming primary caregivers. These positions have come as a result of high rates of violence and stress-related addiction issues which have consequently led to more children being in state care (Moyle & Tauiri, 2016). The removal of children has often come about without sufficient whānau input, cultural processes and adequate resource. Removal of children in this manner has caused strained intergenerational relationships, particularly for grandparents who are still coming to terms with being the primary caregiver(s) with limited support (C. Smith, 2008).

Whānau, over time, has gone through massive upheaval and changes because of the direct impacts of both colonisation and urbanisation. The communities people reside, work and socialise in can have a range of direct and indirect health effects (Stevenson, Pearce, Blakely, Ivory, & Witten, 2009). Community conditions, changing environments and workforce demands all have an impact on the health and well-being of whānau as well as on whānau structures. Changes have obstructed the ability of whānau to maintain and sustain some key cultural practices, values and knowledge systems (K. Baker, 2010). It is these that whānau draw on to cope. Consequently, many government social policies, systems and models have served to undermine, reinterpret and redefine what whānau means as well as what it may look like (T. Walker & Porou, 2006). Health is an area where Māori and Pacific whānau are over-represented in negative statistics (such as rates of cancer, mental health and/or suicide), yet many of the models within health (including culturally-based models) are taken out of context, placed in a Western environment, driven from Western perspectives and lack culturally reflective staff in order to implement them fully. Models that contrast with Māori and Pacific worldviews can have significant negative impacts on health and wellness. Foreign concepts, lack of understanding and a lack of health system responsiveness regarding cultural and whānau diversity creates internal conflict and causes stress that can result in poorer health outcomes (R. Harris et al., 2012b; R. Harris et al., 2006b; H. Moewaka Barnes et al., 2013) access and uptake (Ajwani et al., 2003; Cormack et al., 2005; Crampton, Jatrana, Lay-Yee, & Davis, 2007; Jansen & Smith, 2006; Smedley, Stith, & Nelson, 2003).

Equity and Equality

Access to health care services is recognised as an important determinant of the health outcomes of communities (WHO, 2014). Health disparities, or rather health inequities, are defined as differences which are unnecessary and avoidable but also considered unfair and unjust (Braveman, 2010, 2014b; H. Moewaka Barnes et al., 2013). Disparities in health outcomes between Māori and non-Māori have been widely recognised as a major focus for health system improvement in Aotearoa New Zealand (Gauld et al., 2011; Pega, Carter, Blakely, & Lucas, 2012). In accordance with New Zealand government direction since the early 2000s, there has been an ongoing expectation that the New Zealand health system will address and reduce these disparities (King, 2000; King & Turia, 2002; Ministry of Health, 2002, 2015b).

The word *inequities* is now used, as not all inequalities are unexpected and unfair (H. Moewaka Barnes et al., 2013). Equity is an ethical concept where the distribution of resources ensures everyone has at least their minimal requirements. It is important to note that equity does not necessarily mean that resources are shared equally, rather that the relevant required resources are distributed in order for different groups to have equitable health outcomes (H. Moewaka Barnes et al., 2013; Reid & Robson, 2007). For example, those with higher needs may require more resources.

Braveman and Gruskin (2003) define health equity as "the absence of systematic disparities in health or in the determinants of health between different social groups who have varying levels of underlying social advantage/disadvantage" (p. 254). This concept of health equity focuses

attention away from individuals and their health; rather than "victim blaming" (for example, blaming the person for not going to the doctor and not accounting for wider access or racism issues), it monitors how resources, including health services, are distributed to relevant communities and considers the evaluation of processes that determine how resources are shared. Vast differences exist in the health status of populations in various parts of the world (Braveman, 2014a; H. Moewaka Barnes et al., 2013). The distribution of health resources within or across countries is not equal and for many countries does not meet population demand or need.

New Zealand evidence confirms that Māori and Pacific have, on average, the poorest health status of any ethnic group in New Zealand (Kahukura Tatau, 2010; Ministry of Health, 2015a, 2015b). Māori and Pacific children suffer health disparities and inequities at higher rates compared to other children living in New Zealand (Ministry of Health, 2012a). Therefore, according to their high needs, they should have, at a minimum, enhanced access to appropriate health care and facilities that meet their requirements, as well as better and more efficient distribution of adequate resources. Inequities are indicative of poor system responsiveness and reduced quality of care experience (Ministry of Health, 2014a; Pacific Perspectives, 2012). The correlation between deprivation reduced standards of living, and low employment status and ethnicity in Aotearoa has severe impacts on access to health care and health outcomes (Durie, 1998; Robson & Harris, 2007). These impacts influence and affect the resources people draw on to cope effectively.

Determinants of Health

There is international recognition and acceptance that a wide number of determinants influence and impact health. The more common determinants are described as: social, cultural and economic (R. Brown, 2010; Health Promotion Forum of New Zealand [HPFNZ], 2002; WHO, 2008, 2014). While each of the determinants is important in its own right, health is determined at every stage of life by complex interactions, in particular between social and economic factors, the physical environment and individual behaviour (R. Brown, 2010; Dahlgren & Whitehead, 1991; Davies & Macdowall, 2006). New Zealand research highlights the emergence of these factors at different levels including structural, system, organisational and personal (Cormack et al., 2005; M. Ratima et al., 2008). It has been established that the health and well-being of people are influenced by a range of factors both within and outside of the individual's control (Lalonde, 1974; WHO, 1998). More specifically, these factors include income and poverty, employment and occupation, culture and ethnicity, education and housing (R. Brown, 2010; Ministry of Health, 2007; National Health Committee, 1998; M. Ratima, 2001; Superu, 2016). These determinants have both direct and indirect impacts on health, as well as having interconnected effects that build up over lifetimes (Robson, Cormack, & Cram, 2000). These impacts and consequences shape and influence both individual and whānau coping behaviour.

The New Zealand public health system provides free admission to hospital for citizens and residents with acute injury or illness (P. Davis et al., 2013; Rasmussen, 2011). Māori and Pacific children have high rates of illness and mortality (Mills, Reid, & Vaithianathan, 2012), and have

the highest number of admissions to hospital (Bacal & Jansen, 2006; Bathgate et al., 1994; Curtis, Harwood, & Riddell, 2007; Ministry of Health, 2010b; Tukuitonga, Bell, & Robinson, 2000). The health of children is especially sensitive to social determinants, and, in New Zealand, many of the causes for admission stem from decreased family income and ethnicity (Craig, Jackson, Han, & NZCYES Steering Committee, 2007; Raphael, 2010; Rasmussen, 2011). There is also increasing evidence that doctors treat patients differently based purely on ethnicity (Bacal & Jansen, 2006) and that health care systems often neglect to incorporate cultural worldviews and values into health service delivery (Adler & Stewart, 2010; P. Kingi, 2008; Tiatia-Seath, 2008). For Māori and Pacific people, culture is intrinsically linked to whānau with both known to act as buffers to negative stereotypes, racism and discrimination (H. Moewaka Barnes et al., 2013; Walters et al., 2009).

Socio-economic variables such as income, education and occupation effect whānau ability to cope (Calixto & Anaya, 2014). For many Pacific whānau, values regarding collective responsibility, respect and service to others influence how resources are shared and who they are shared with (Superu, 2016). This responsibility denotes that Pacific individuals do not stand on their own, but they are an integral part of an extended family (Koloto & Sharma, 2005; Superu, 2016). Therefore, resources are shared and allocated amongst extended family including their communities in both New Zealand and overseas. For Pacific people, customary financial commitments include donations to the church, financial contributions to their village, projects, or functions that form part of collective health and well-being (Cowley, Paterson, & Williams, 2004; Craig, Taufa, Jackson, & Han, 2008). Samoans experience greater financial pressures that include not only financial commitments associated with the functions referred to above, but also because of their adherence to the cultural concept of fa'a Samoa and fa'alavelave. In relation to many Pacific households, finances were extended to family and church obligations. These obligations would sometimes become more of a priority over immediate household needs (Cowley et al., 2004). For those dealing with a critically ill child, the effects include having to endure additional financial pressures on top of their current financial burdens. Additional costs incurred for whānau in the hospital can include transport-related expenses, such as extra petrol and parking, ongoing medications (some unsubsidised), child care, accommodation and food.

> Our whānau lived in the same city as our admission and treatment, although it was 40 minutes' drive away from Starship Hospital (notwithstanding peak hour traffic). We also had a two-year-old who was cared for by extended whānau who lived further from our house. During treatment times, we had three cars travelling up to Starship in one day. Whānau members would take turns and shifts so my husband and I could return to work as finances were rapidly depleting. Costs incurred by us at this time were for petrol (three cars), parking and food (at the hospital and home). Wilson Home and Hospital is based in Auckland's Northshore, a further 30-40 minutes' drive from Starship Hospital. Additional costs were also incurred having to reside, visit and return home from the Northshore (for the two-year-old) an environment that was even further afield.

Education affects health by improving individual knowledge about health-related topics or issues. Knowledge gives people the confidence to be able to seek out health-related support. Limited

education and/or English as a second language has been found to have significant effects concerning health literacy (Ali, Ferguson, Mitha, & Hanlon, 2014). The Institute of Medicine (2004) report states that health literacy is not only about education but rather the extent to which an individual can obtain, process and comprehend basic health information to make proper health decisions. Studies have shown that people with low-health-literacy levels get less preventive health care such as screening, and tend to use emergency services more frequently (Institute of Medicine, 2004). Individuals with poor health literacy find some issues challenging that others may consider part of a normal routine. For example, getting a repeat prescription, understanding directions for taking medication, reading a health-related pamphlet or, of equal importance, understanding what the doctor is saying (Hixon, 2004). In New Zealand, a qualitative study of elderly Pacific informal caregivers of a young person with an illness found that the more fluent in English caregivers were, the better informed they appeared to be. Furthermore, they found the participants who had the least English fluency appeared to have the lowest medical understanding and minimum knowledge about health services or how to access them (National Health Committee, 1998). Limited fluency in English is not the only barrier to understanding information. The terminology associated with information has also proven to be a barrier for those who are fluent in English (Jordan, Buchbinder, & Osborne, 2010). Better informed decisions are made if people fully understand the information at hand. Families who understand information are better able to balance treatment and care for their child and therefore cope more effectively (Clarke, Davies, Jenney, Glaser, & Eiser, 2005)

While our son was undertaking chemotherapy, a family was flown in from Rarotonga, Cook Islands. The mother had three children with her (one undergoing treatment). The doctor and two nurses were talking to her about treatment for her child in the busy space of the chemotherapy lounge. The mother smiled and kept nodding while the health care staff continued talking. I barely understood what the doctors were saying so I could only imagine what this mother, who was straight off a flight from a foreign country, was <u>not</u> understanding. Like us, she was given a huge white folder (over 100 pages), and she was told to read the information, particularly around the risk of infections during chemotherapy. The family had a young child with them who was coughing (a potential high risk to those undertaking chemotherapy due to weakened immunity). My husband who is Cook Island was present during this time, and I asked him if he thought this mother understood the information given to her by the doctor and nurses. He said no. We knew that the child who was coughing could potentially put our son's health and life at risk. I went to the front desk and asked the receptionist if the big white folder that contained pertinent information was written in any other languages. She said no. My husband then sat with the mother and translated what the doctor had said to the best of his ability. He showed her the section in the book about the risk of infections. The mother was thankful but embarrassed; she got the older child to take the younger one out of the environment. This situation could have been avoided by the foresight of organising a translator to be present (a service offered by the hospital), having the support of another family member present, or by providing resources written in other languages.

Employment has been shown to increase general health and well-being as it provides opportunities for social interaction, community participation, the development of social status, and income (Craig et al., 2008). In New Zealand, many Māori and Pacific work in low-skilled job areas that pay minimum wage. With the costs of living rising, particularly in Auckland (where a high population of Māori and Pacific live), whānau who have a child with a life-threatening medical condition must also cope with having to take extended periods of time away from employment. Moreover, some whānau also have to cope with having to leave their place of employment permanently due to their child's treatment being in another city or country or over extended periods of time (three months and over). Other issues also remain, such as working extra-long hours to make up for time, getting the child to appointments or hospital, or finding alternative childcare for additional children that incur extra costs. It is important to note that Māori and Pacific people's circumstances relating to health, income, education and employment are diverse.

Whānau Diversity

The diversity of Māori whānau is recognised by researchers. The Māori Diversity Framework (Cunningham, 2004) categorises different realities into four distinct groups: the conservative Māori, the integrated Māori, the isolated Māori and the pluralistic Māori (these were Māori who could move easily between both European and Māori worlds[7]). Models, such as the Diversity Framework that uses Māori identity as their basis bring to light not only the diversity across cultures but also within the same culture. The utilisation of distinct Māori models has been labelled a risk making invisible those Māori who do not explicitly possess the traits evident within them and therefore, further marginalising them (Borell, 2005). Borell highlights an important point, particularly regarding the implementation of cultural models within health systems. Issues arise when cultural models are applied out of context; instead of reducing disparities, they could be contributing further to their increase.

As seen by the different ethnic groupings alluded to in Chapter 1, people of the Pacific are also not homogeneous (Bacal & Jansen, 2006). Pacific peoples who have migrated to New Zealand face different realities and issues compared to those who have lived here for more than two generations, and those who are New Zealand born. Connections with their motherland, language and traditions can all vary significantly between families and across generations, with more New Zealand-born Pacific peoples facing tensions between their traditional and contemporary New Zealand ways (Tiatia & Foliaki, 2005). Although the proportion of New Zealand-born Pacific peoples is growing, they still maintain core cultural values that have sustained, nurtured and developed them through the centuries (Craig et al., 2008; P. Kingi, 2008). It is these values, customs and traditions that remain very strong and are actively "lived" out in the contemporary New Zealand context (Koloto et al., 2007). Statistics New Zealand (2014) notes a decline in Pacific migration and the high rate of natural increase (through births in New Zealand) meaning

---

[7] These are described as Māori who fit comfortably in the Māori world, and for example, may be able to speak their language, have consistent connection to their homelands, iwi, hapū and and undertake different cultural roles as and when needed. They can also fit in the Pākehā world have mainstream employment roles, take part in community and government initiatives can converse in political and technical conversations and comfortably take part in Pākehā and Māori societies.

that the Pacific population has changed from a predominantly migrant group to a largely New Zealand-born population. Furthermore, the Auckland region still has the highest proportions of people born in the Pacific Islands (8.3 percent of people living in the Auckland region were born in the Pacific Islands) compared with other parts of New Zealand (Statistics New Zealand, 2013). The changing status highlights the fact that Māori and Pacific people are multifaceted populations who often live simultaneously in a range of cultural worlds (Boulton, 2005). Therefore, if models, policies and systems are to work, they need to recognise, reflect and cater for diversity both within cultures and whānau as well as across them, rather than taking a one-size-fits-all approach.

Strategies for Change

The following section identifies some of the main strategies that have been developed in response to reducing Māori and Pacific disparities. Many of these include components consistent with Māori and Pacific worldviews. While not all stem from a cultural perspective, some strategies outlined have aided the facilitation of change over time within the New Zealand health system. Strategies formed have aimed to improve Māori and Pacific health outcomes.

Te Tiriti o Waitangi/The Treaty of Waitangi.[8]

The Treaty of Waitangi (the Treaty) is New Zealand's founding constitutional document and the major mechanism whereby Māori have sought to have their unique rights addressed. The Treaty is an agreement that was signed between Māori chiefs and the British Crown in 1840 and set the foundation for the British to settle in New Zealand formally. The Treaty intended to lay the ground rules for the relationship between Māori and the British settlers. The Treaty was a base for protections and concerns; however, there are some discrepancies between the Māori and English versions. Discrepancies between the two have been the cause of ongoing debate (R. Brown, 2010).

The three Articles within the Treaty have been analysed for their health implications (HPFNZ, 2002), but need to be considered in conjunction with each other rather than separately. One example of contention is Article 1 of the English version, which provides for transfer of sovereignty from Māori to the Crown while, in the Māori version, the same Article provides for transfer of kawanatanga (translated as governance, or administrative authority), which falls short of sovereignty (R. Brown, 2010; M. Ratima, 2001).

Article 1, kawanatanga (governance), outlines the obligations of the Crown. Kawanatanga allows the Government to govern and provides for the Crown's right to make laws and its obligations to govern by a constitutional process which directly applies to all organisations which draw their authority from the Crown (HPFNZ, 2002). Māori gave up governance of their lands but in return expected to receive benefits from the Government (R. Brown, 2010).

---

[8] **Te Tiriti o Waitangi** is written in the Māori language and was signed by 39 chiefs. The same version was then translated into English (the Treaty of Waitangi) which showed several significant differences in meaning to what the Chiefs agreed to by signing. The differences therefore negatively affected Māori, including sovereignty, health, lands and overall protection.

Article 2 shows that the Queen of England agrees and consents to give the chiefs, hapū and all the people of New Zealand the full chieftainship (tinorangatiratanga) over their lands, villages and possessions. This article provides for Māori to exercise tinorangatiratanga control, authority and responsibility for their affairs, including health. It guarantees to Māori the control of their resources and taonga (those things sacred and precious). One government response to crown obligations has been to support the development of Māori health funders and providers (HPFNZ, 2002).

Article 3 addresses issues of equity and equality and constitutes a guarantee of legal equity between Māori and citizens of Aotearoa (New Zealand). Māori should experience equity in the enjoyment of all benefits of New Zealand citizenship including health. The provision requires the Crown to actively protect and reduce disparities between Māori and non-Māori (HPFNZ, 2002). Māori have a right to monitor the Crown as a treaty partner as the right to good health for Māori is implicit under the Treaty of Waitangi, and therefore health inequalities are in breach of it (Robson & Reid, 2001).

The Treaty of Waitangi and the Articles are strongly associated with determinants of health. Treaty articles provide good government and protection, Māori self-determination and control over their affairs and equity with other people in Aotearoa New Zealand. While the importance of the Treaty of Waitangi as a founding document in New Zealand's political system is currently questionable, Māori rights within it are concrete. Many organisations have tended to identify more with incorporating the principles of partnership, participation and protection that reside within the document. The principles are recognised as interpreting the intentions and spirit of the Treaty arising from the interpretative differences (Ministry of Culture and Heritage, 2005). Under the Treaty of Waitangi, health is a citizenship right to which all should be entitled (Ministry of Health, 2014a).

The Government has a responsibility to manage improvements in the poor health status of New Zealand children (Pacific Perspectives, 2012). Despite this, there is consistent evidence of the ongoing health inequities that exist for both parents and their children, including unmet health needs (Ministry of Health, 2012b). The provision of culturally safe and responsive care is critical for reducing health disparities and inequities for Māori and Pacific populations (Barton & Wilson, 2008; Robson & Harris, 2007). Cultural responsiveness is founded in worldviews, relationships (to people including land and environments), cultural contexts, and links to whatever is deemed as "culturally normal" ways of operating (Werkmeister-Rozas & Klein, 2009). Werkmeister-Rozas and Klein describe cultural responsiveness as a "co-created reality between worker and client" (p. 6). This concept challenges the adoption of one-size-fits-all approaches. In addition to health care practitioners' awareness of their own cultural positions, cultural responsiveness is underpinned by a critical analysis of whānau realities about equity, social justice, rights, intersectionality, and complex interactions that impact their daily lives. (Bellon-Harn & Garrett, 2008; Pauly, MacKinnon, & Varcoe, 2009). T. Walker (2004) identified that to be responsive to individuals, issues need to be investigated within the context of their wider whānau. For both Māori and Pacific people, the accountability to, and the responsibility for, collective whānau and community exceed the over-all focus of health services on individuals (Metge, 2014; Tamasese, Peteru, Waldegrave, & Bush, 2005).

Whānau Ora

Whānau ora has been undertaken by Māori for generations and has only recently become a government initiative implemented to improve the health of New Zealand whānau, hapū and iwi. The initiative is still a work in progress with many organisations in the early phases of implementation development. This approach locates whānau at the centre of decision making and places the well-being of individuals within the context of their whānau. Whānau Ora differs from traditional health approaches that focus solely on the needs of individuals (Te Puni Kōkiri, 2007). As an initiative, it first sets out to reduce inequalities between Māori and non-Māori and takes into account the devastating effects on Māori health that stem from colonisation and the loss of critical determinants such as land, language and social organisations, including whānau structures. The purpose of Whānau Ora is to deliver a service to New Zealand whānau based on Māori cultural values and beliefs with the intention of improving economic, cultural and social well-being (Boulton & Gifford, 2014). Whānau Ora provides a vehicle that facilitates cultural safety alongside culturally-based components and initiatives that could be embraced and fully supported by communities, whānau, hapū, iwi and government (K. Baker, 2010; Hayes, 2016; Turia, 2014).

Secondly, Whānau Ora/Fanau Ola, as an approach, also aligns well with Pacific worldviews and is fast becoming a familiar feature within Pacific health. The Whānau Ora vision for Pacific families is "Prosperity for all Pacific families in Aotearoa/New Zealand by supporting and building āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili, family capability" (Ministry of Health, 2014a, p. 4; Te Puni Kōkiri, 2013). The aims are that Pacific families:

- are prosperous in Aotearoa/New Zealand (for a definition of social and economic prosperity, see Ministry of Pacific Island Affairs, 1999)
- are strong and confident in their Pacific identity
- self-determine what they need in their lives to be successful
- influence decision-making on matters that affect Pacific peoples at all levels

Whānau Ora operates from a strength-based position. The intent is to use the combined strengths of individual members of the whānau in the achievement of collective well-being outcomes, which is then aided and assisted by government-funded services rather than led and directed by them (Gifford & Pirikahu, 2008). The key to Whānau Ora success is the kaiarahi (navigator). The kaiarahi works closely with whānau to identify their specific needs and aspirations, then helps whānau to determine the services that will support them to meet their needs and wants. The Productivity Commission identified that the kaiarahi approach is a key example of an integrated whānau -centred approach supporting seamless health and social services (Te Puni Kōkiri, 2016).

The Whānau Ora outcomes framework is the principal measurement for indicating the success of Whānau Ora. Included in the framework are seven outcomes for whānau. These outcomes are that whānau are:
- self-managing
- living healthy lifestyles
- fully participating in society
- confidently participating in Te Ao Māori (the Māori world)

- economically secure and successfully involved in wealth creation
- cohesive, resilient and nurturing; and
- responsible stewards to their living and natural environment (Te Puni Kōkiri, 2016)

Whānau ora is best shaped and given meaning by those most affected by it (Whānau Ora Taskforce, 2009). Whānau ora is described as holistic and encompassing domains that whānau determine as contributing to their well-being (Cherrington & Masters, 2005). While there are multiple definitions (Boulton, Tamehana & Brannelly, 2013), it is agreed that whānau ora is a fluid concept that contains several elements. Specific elements have been identified as important indicators of whānau ora, and include cohesion, self-sufficiency and the ability of whānau to support itself. T. Walker (2006) adds safety of children as an essential consideration. Components that make up whānau ora include emotional, spiritual, physical and whānau /community/group dimensions. These dimensions are vital to maintaining aspects of a healthy body, mind, spirit and whānau. These elements are outlined within well-known Indigenous, Māori and Pacific models of health and are also contained and maintained within the context of whānau relationships. The belief that underpins these elements is that if one of the components is impacted (for example an individual), it impacts the whānau /community and vice versa (K. Baker, 2010). Whānau Ora as a government initiative is still in its infancy, and while many Māori organisations are heavily focused on its implementation (Boulton, Tamehana & Brannelly, 2013), it is yet to be fully embraced by Western-based practices. In relation to this study, while whānau practice whānau ora at the personal and whānau level, it is yet to be implemented fully as part of secondary and tertiary health environments.

He Korowai Oranga

As New Zealand's Māori health strategy, He Korowai Oranga sets the overarching framework that guides the government and the health and disability sector to achieve the best health outcomes for Māori. The Strategy was updated with input from across the industry during 2013/14 to ensure its relevance for the future. Pae Ora (Healthy Futures) is the Government's vision and aim for the refreshed strategy. It builds on the initial foundation of Whānau Ora (healthy families) to include Mauri Ora (healthy individuals) and Wai Ora (healthy environments). Figure 2 shows the components of the framework as an interactive pyramid.
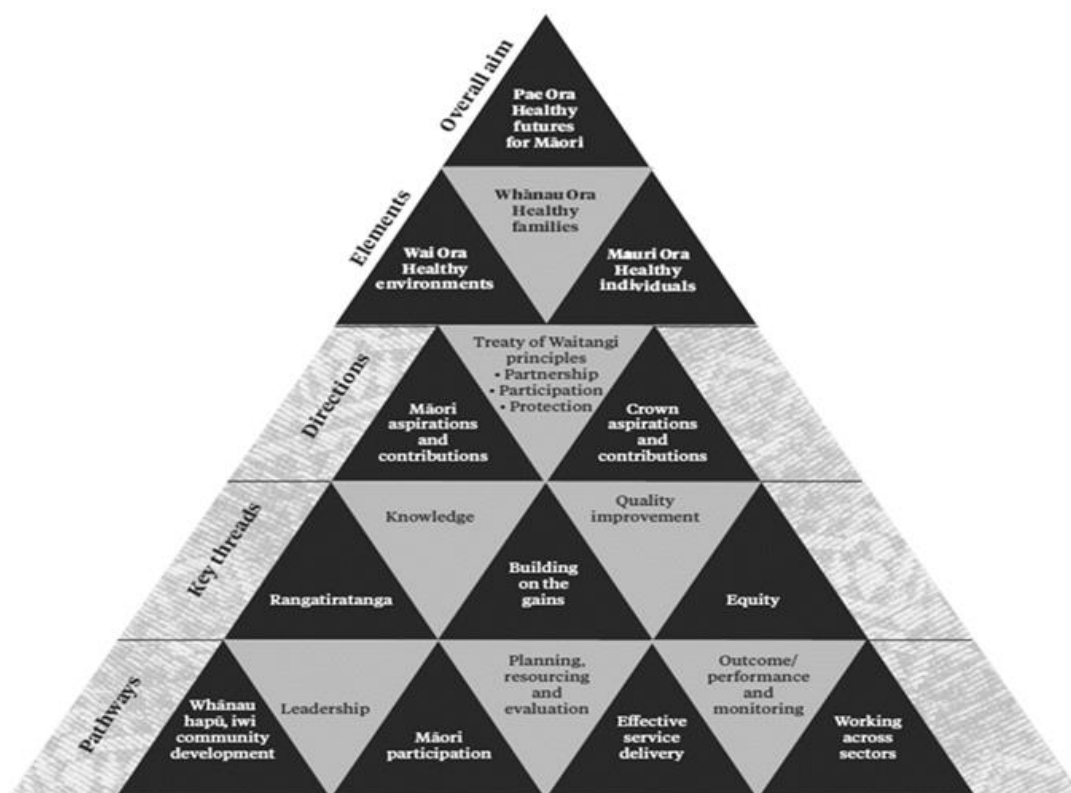
Figure 2. He Korowai Oranga Framework**.**

The elements, directions, key threads and pathways are the health system's guide to improving Māori health and realising Pae Ora – healthy futures. There are four paths that guide the implementation of the strategy:

- supporting whānau, hapū, iwi and community development
- supporting Māori participation at all levels of the health and disability sector
- ensuring effective health service delivery
- working across sectors. (Ministry of Health, 2014b)

The whole of the health and disability sector is responsible for the implementation of He Korowai Oranga.

'Ala Mo'ui: Pathways to Pacific Health and Well-being

'Ala Mo'ui: Pathways to Pacific Health and Well-being 2014–2018 is the Government's national plan for improving health outcomes for Pacific peoples. It is driven by the vision of achieving health equity for all Pacific peoples in New Zealand. That is, all New Zealanders, including Pacific peoples, will lead healthier and more independent lives; the delivery of high-quality health services, in a timely and accessible manner, and the future sustainability of the health and disability sector, will be assured. The Pathway does not offer a comprehensive list of all activities that contribute to improving the health of Pacific peoples. Instead, it sets out the government's priority focus areas for Pacific health in the next four years. The vision of *'Ala Mo'ui* is that: "Pacific

'āiga, kāiga, magafaoa, kōpū tangata, vuvale and fāmili (see footnote 5) experience equitable health outcomes and lead independent lives" (Ministry of Health, 2014a, p. 2)

The New Zealand Health Strategy

The New Zealand Health Strategy sets the direction of health services to enhance the health of people and communities (Ministry of Health, 2016). It was developed with the help of sector leaders, independent reports, and extensive public consultation, and was informed by other government programmes and initiatives.

This strategy pursues equitable outcomes for all New Zealanders. It recognises and respects the principles of the Treaty of Waitangi with more support for all New Zealanders to participate in the sector and in making decisions on services. The second part of the strategy: The Future Direction, outlines a new high-level direction for New Zealand's health system over the next ten years. This direction encompasses five strategic themes: people-powered, closer to home, value and high performance, one team, and smart system (Figure 3). These themes are interconnected. The five themes represent the cornerstones for establishing a health sector that understands people's needs and provides services that are integrated across sectors, focusing on early in life, sustaining wellness, preventing sickness, and providing support for the end stages of life.

Figure 3. Five strategic themes of the New Zealand Health Strategy.

Ministry of Health (2016), Creative Commons Attribution 4.0 International licence.
https://creativecommons.org/licenses/by/4.0/

The New Zealand Health Strategy closely aligns with the New Zealand Disability Strategy, He Korowai Oranga: The Māori Health Strategy, and Ala Mo'ui: Pathways to Pacific Health and Well-being (Ministry of Health, 2016).

Pacific Models of Health

Pacific health care models exist that take different ways of Pacific life into consideration. Pacific models of health are pan-Pacific in nature and appeal to most Pacific groups in New Zealand.

While other models are ethnic specific, they can still have pan-Pacific relevance (Pasefika Proud, 2016). Pacific groups have their distinct language and customs; therefore, it is important that diversity extends to the tools and models developed. These tools are essential in providing culturally relevant approaches, and they aim to promote Pacific health and well-being. Some common Pacific models in circulation include Fa'afaletui (Tamasese, Peteru, & Waldegrave, 1997), the Tivaevae model (Maua-Hodges, cited in HRC, 2014), and Kakala (Helu-Thaman, cited in HRC, 2014), to name a few.

Māori Health Initiatives

Many health initiatives have developed over the years that are distinctly Māori (M. Ratima, 2001). There are also many Māori models and approaches currently used across different areas of health. These include Te Whare Tapa Wha (Durie, 1994), Te Wheke (Pere, 1984), Tatau Tatau (Collins & Hickey, 2006) and the Meihana Model (Pitama et al., 2007). Māori approaches that have been developed are linked to traditional cultural systems, processes and infrastructure. These customary structures support Māori health initiatives together with a variety of Māori-driven health interventions which are also well established. Initiatives such as these are diverse and seek to address a range of issues, from nutrition and physical activity to mental health and addictions (R. Brown, 2010). For example, recently we have seen the re-emergence of initiatives aimed at physical activities directly tailored toward Māori, with a high rate of Māori uptake. For instance, Iron Māori (an iteration of IronMan), Māori Tri-series (triathlon), and Waka Ama (paddling sport). These approaches often incorporate whānau at different levels (through active participation and by supporting others) and concentrate on cultural specific roles and functions (supported by kaumātua, include tamarki, karakia and haka). While these are not directly related to life-threatening conditions, it shows that models and concepts that stem from cultural approaches, incorporate cultural values and are supported by appropriate structures which create cultural context can have significant effects, including health benefits for specific populations.

University Health Programmes

Directly associated with medical settings are culturally-based programmes that facilitate pathways to increase numbers of Māori and Pacific in the health workforce. Literature highlights a critical shortfall of Māori and Pacific health professionals in a number of roles at varying levels. These include front line clinical roles, and decision-making roles, as well as working across the community, secondary and tertiary health care (Curtis, Reid, & Jones, 2014; Curtis, Wikaire, Stokes, & Reid, 2012; M. Ratima et al., 2008). The lack of a culturally reflective workforce of Indigenous and ethnic minority peoples within the health care profession limits the provision of culturally responsive, safe and competent workers who meet the diverse needs of the communities it serves (Curtis et al., 2012; Health Workforce Advisory Committee, 2003). The inability of the health system to respond and the under-representation of Māori and Pacific in the health workforce continues to reinforce deficiencies in cultural understandings and associated practices (Reid & Robson, 2006). A workforce that reflects the patients it cares for brings with its connections, for example, with Pacific communities bring a personal understanding of Pacific issues, as well as specific cultural and language skills (Ministry of Health, 2014a). Lack of cultural

understandings and associated practices have a significant impact on Māori and Pacific health and well-being. These and other influencing factors relative to New Zealand also affect whānau ability to draw upon useful resources (including mechanisms and strategies) to cope effectively with challenging situations. One way in which the situation can improve is through health workforce development programmes aimed at graduate levels such as the Māori and Pacific Admissions Scheme (MAPAS) and the Whakapiki Ake Project (WAP) that are incorporated as part of university-based health and medical programmes.

Medical Training Programmes

Specific to medical settings, Indigenous health frameworks are continuing to be developed and implemented (Wepa, 2016). Pitama, Huria, and Lacey (2014) have had significant influence regarding ensuring cultural safety, and cultural competency is implemented within medical settings. Other models that facilitate similar components include the Hui Process, (Lacey, Huria, Beckert, Gilles, & Pitama, 2011) which provides support and encouragement regarding relationship building with Māori patients. The Meihana Model (Pitama et al., 2007) accounts for history and addresses determinants such as racism, colonisation and migration among other issues alongside practitioner encouragement to seek out Māori patient beliefs, values and experiences (Wepa, 2016). This model also incorporates important mechanisms such as whānau (extended family), tikanga (cultural ways), whenua (land), as well as ahua (personal indicators). The Calgary-Cambridge Model (S. Kurtz, Silverman, Benson, & Draper, 2003) takes quite a different approach by looking at Indigenous patient perspectives alongside the biomedical focus on the disease (Wepa, 2016). These models play an important role in paving the way to enhancing medical students' knowledge and practice of cultural safety and cultural competency. Frameworks such as these, introduced at the early stages of medical training or incorporated within health systems, can promote quality of care for patients and enhance whānau coping. Earlier incorporation of frameworks within medical training, in turn, will facilitate better clinical outcomes.

Cultural Safety

Cultural safety as an initiative came about in the 1980s and was developed to try and challenge nurses' misuse of power and to support healing (Ramsden, 1990; Wepa, 2016; Wright, 1995). The concept of cultural safety has been through many iterations to keep up with the on-going advancements that occur in health care provision. The Nursing Council of New Zealand (2011), in its latest definition, proposed that cultural safety would exist if the cultural needs and well-being of patient or family were satisfied through the interactions of nurses. In New Zealand, all regulated health practitioners under the Health Practitioners Competence Assurance Act (2003) and the Medical Practitioners Act (2007) are required to demonstrate cultural competence annually, of which cultural safety is a core component. While cultural safety has progressed, it has also become somewhat more involved and now extends beyond just the nursing profession. Cultural safety is also instigated in other countries including Australia (C. Baker, 2007), the United Kingdom (De & Richardson, 2008) and Canada (Browne et al., 2009). Cultural competence and cultural safety are key components that aid Māori and Pacific health and well-being, and, specifically, coping with a child with a life-threatening medical condition. Familiarity with staff from

the same or similar culture, and understanding language, traditions and concepts aid in healing practices and act as buffers to negative perceptions and discrimination (H. Moewaka Barnes et al., 2013; Walters et al., 2009). For Māori and Pacific people, the cultural competence of practitioners, and feeling safe culturally, are necessary given their high rates of admission to hospital and are essential if cultural models and concepts of health are to be fully supported and integrated into medical practice.

Pacific Provider Workforce Development Fund

The 'Ala Mo'ui: Pathways to Pacific Health and Well-being 2014–2018 identifies one of the enablers for improving Pacific health as increasing the Pacific health workforce. Pacific health workers have made a significant contribution to New Zealand health care, particularly nurses (Zurn & Dumont, 2008) and non-regulated workers, such as community health workers, health care assistants and caregivers (Samu, Ulugia-Veukiso, & Perese, 2009). The Ministry of Health allocates funding to Pacific providers via the Pacific Provider Workforce Development Fund. The focus is on increasing the Pacific health workforce through a pipeline approach, as outlined in Table 2, below.

Developing the Pacific health and disability workforce also contributes to health and well-being for other New Zealanders. Workforce development (including job creation and skill development) has economic benefits for Pacific individuals, families and communities. Low health literacy is an example of inequity that is experienced by Pacific peoples (Ministry of Health, 2014a). Increasing the Pacific health and disability workforce will contribute to improvements in health literacy (through better understandings, review of health-related documentation and creating a better supportive and familiar environment where queries can be put forward and answered effectively) and the cultural competency of the health and disability sector.

Table 2. Funded Activities to Increase the Pacific Health Workforce

Priorities	Goals	Funded activities
Attract	Increased number of Pacific students taking science subjects in years 11, 12 and 13	Health Science Academies in Auckland
		Mentoring for students studying health-related subjects (i.e., Pacific Orientation Programme at Otago (POPO) mentoring –
Train	Increased number of Pacific students enrolled in a health qualification at a tertiary institution	University of Otago; mentoring – Auckland tertiary institutions)
		Pacific Health and Disability Workforce Awards (scholarships)
Strengthen	Increased number of Pacific workers in the health and disability workforce	Aniva programmes:

Upskill and retain	Increased number of Pacific health professionals advancing in professional and/or clinical development	Pacific nurses – Master of Nursing in Pacific health, master class seminar to Pacific nurses in postgraduate study
		Auckland University of Technology – return to midwifery programme
		Pacific community health worker support
		Professional health organisation support for: Pasifika Medical Association; Aotearoa Tongan Health Workers Association; Cook Islands Health Network; Tongan Nurses Association of New Zealand; Samoan Nurses Association of New Zealand; Pasifikology; Fiji Nurses Association

Ministry of Health & Ministry of Pacific Island Affairs (2010, p. 10)

Patient and Family Orientated

Over the years, various models have been developed and implemented taking into consideration different perspectives of care and treatment. Such models have contributed towards the progression of individual/patient-centred health care to more family-orientated approaches. The approaches outlined in Figure 4 highlight their progressive order. These approaches are the precursor of family-centred care (FCC).

Figure 4. Progressive order of health care approaches.

Family-Centred Care

Family-centred care is described as a partnership approach to the health care decision making between the family and health care provider (Kuo et al., 2012). It supports the notion that family at the bedside enhances a child's recovery (Garvey, Towney, McPhee, Little, & Kerridge, 2004), and is today considered the standard of paediatric health care by many clinical practices, hospitals, and health care groups (Coyne & Cowley, 2007; Darbyshire, 1995; Kuo et al., 2012).

While there is no single consistent definition of FCC, there has been some agreement on its basic features and principles (Mikkelsen & Frederiksen, 2011). Family-centred care has been described as a philosophy of care (Bruce & Ritchie, 1997; Mikkelsen & Frederiksen, 2011) and an approach to planning, delivery and evaluation of health care. It is reportedly based on mutually beneficial partnerships between health care providers, parents (Carmen, Teal, & Guzzetta, 2008) and is underpinned by empowerment and negotiation (Mikkelsen & Frederiksen, 2011). The underlying

principles include information sharing, respect for and honouring difference, partnership, collaboration, negotiation, and care provision within the context of family and community. The principles favour an approach that respects families as integral and co-equal parts of the health system. Curley and Meyer (2001) state that the central tenet of FCC is that the family is constant in the child's life, and is ultimately responsible for ensuring the child's physical, emotional and social needs are met.

A family-centred-care approach is expected to improve the quality and safety of patients' care by helping to foster communication between families and health care professionals. The family includes parents, the patient and any other significant person identified as being part of the family unit. The underlying aim of FCC is that effort is put into incorporating the needs of the whole family, and considering them in decisions about treatment and interventions (Mikkelsen & Frederiksen, 2011; Shields, Pratt, Davis, & Hunter, 2007; Shields, Pratt, & Hunter, 2006). Family-centred care confirms the family systems theory[9] perspective that is caring for a child must be in the context of their whānau. However, there is some criticism that the focus tends to be more centred on the child than family.

The Family Partnership Model

The family partnership model was first developed in the United Kingdom (H. Davis, Day, & Bidmead, 2002). The model is based on establishing relationships and communication with others. It promotes the development of knowledge, skills and techniques for those working with children and their families. It is currently being utilised in New Zealand by The Royal New Zealand Plunket Society (known as Plunket). The Plunket society provides 'well child' services to 90% of children and their families nationwide and captures a lower percentage of Māori children – only 65% in 2010' (Tipa, Wilson, Neville, & Adams, 2015). The family partnership model provides a framework for health professionals to support families who may be considered as vulnerable. The model promotes a supportive parent-centred approach underpinned by the helping process, whereby health professional-parent partnerships aim to achieve positive and beneficial changes in children's health, development, and outcomes (Rossiter, Fowler, Hopwood, Lee, & Dunston, 2011). The principles of the model are to share power, work with parents and to utilise the dual expertise of both parents and health professionals. Importantly, it requires health professionals to display respect, humility, and effective communication (Fowler et al., 2012). Within this model, parents play a significant part.

Summary

This chapter has highlighted the importance of Māori and Pacific whānau structures to their health and well-being and has shown that culture, whānau and health are intrinsically linked. While colonisation has had devastating impacts by eroding whānau structures and radically changing the cultural practices that underpin it, the essence of whānau remains. Whānau sustainability

---

[9] Family system theory (FST) tradition views the entire family in terms of a unit/system instead of a collection of individuals (Ross, Mirowsky, Goldstein, 1990). FST promotes assessing the role of multiple family members as well as the family a whole.

continues in spite of the Western notion of the family still being used as *the* source of measurement as seen throughout various policies, legal and cross-sector systems, including health, education and justice. Whānau sustainability over time has demonstrated Māori and Pacific vitality and strength and for many, their continued commitment to keeping true to traditional whānau cultural practices. For Māori and Pacific peoples, whānau extends past the need of individuals and encompasses the obligations and responsibility to ensure collective health and well-being. Current evidence supports government and health system inability to provide adequate and appropriate resources to meet the needs of population groups. Essentially, the government and health sector are failing to clean up the devastating mess created by colonisation. The consequences of colonisation are reflected in the health status of various populations. Strategies and approaches have been developed over time to help address and, therefore, reduce Māori and Pacific health disparities. Despite progress being made, there is still much work to be done. The diversity and unique characteristics of Māori and Pacific populations, coupled with the effects of social and economic issues, continue to pose a real challenge for the New Zealand government and, therefore, our health system. Documentation highlights the continuation of Māori and Pacific high health needs, high admission rates and the increase in some disparities. The material presented demonstrates that family and culture are integral to Māori and Pacific health and therefore coping, yet while cultural models do exist, deficiencies remain with some disparities continuing to increase.

CHAPTER 3 – LITERATURE REVIEW

Māori and Pacific people show their strength and resilience by facing adversity and challenge while increasingly and disproportionately featuring in statistics for lower socio-economic status, overcrowding, high unemployment, high rate of communicable diseases, and poor educational outcomes (Bacal & Jansen, 2006). Facing such adversities raises questions about what is known about Māori and Pacific whānau coping given their marginalised position, particularly when hospitalisation involves the admission of a critically ill child. In undertaking the literature review, the following questions will be asked:

- How is family defined in literature?
- What evidence is there that includes a whānau coping perspective?
- How does coping with a critically ill child impact on whānau roles, functions and processes?
- Are there different cultural perspectives toward coping with ill health in general and more specifically with a critically ill child?
- How does context impact whānau coping?
- What knowledge gaps are evident regarding whānau coping?

This literature review explores the topic of whānau coping. A search strategy, along with an inclusion and exclusion criteria was used to locate the literature. The chapter concludes by identifying the gaps and explaining how this study builds on existing research while making an original contribution to the growing body of knowledge regarding whānau coping.

Locating the Literature

A wide range of literature was sourced to explore topics related to whānau coping. Broad topics included coping, life-threatening conditions, family, culture, health and health care. Iterations of these categories were identified, narrowed down and sourced. While this thesis is concerned with whānau coping as it pertains to children and life-threatening conditions, it was recognised that these were enormous topics. Therefore, parameters were set, in that this research did not include a full range of coping theories, clinical management, measures or accountabilities. The study excluded children who had disabilities unless the disabled child had a life-threatening medical condition. Individual areas and specific health conditions, for example, oncology, maternity, cancer or health issues about premature babies were also not the emphasis. Instead, it considered whānau coping in relation to their child being admitted or undergoing treatment and care within these key areas. While the research is not aimed at adults, the focus was about whānau coping. Therefore, some of the limited literature that was sourced and included did pertain to adults in hospital-based care. The research intentionally excluded caregiving, concerning the at-home care, as it was coping while in a health care environment (for example, hospital or treatment centre) that was a key focal point. Attention was directed concerning a critically-ill child that was admitted to and utilising hospital services (primarily Starship Hospital).

The research purposefully took an Indigenous collective perspective, which meant that while the literature included here on coping may refer to Western aspects, it is the cultural tenets that were central to this study.

Search Strategy

National and international sources were accessed to inform the literature review. The search included government and non-government documents such as policies, reviews, evaluations and newsletters. Databases searched included CINAHL, EBSCO, Ovid – Cochrane Library, Medline, and Scopus. Grey literature was obtained from books, Google Scholar and other websites that included content, relevant documentation such as protocols and procedures, kaupapa Māori information, Māori and Pacific definitions, examples and statistics. Examples of websites searched included Families Commission, Te Puni Kōkiri, the Ministry of Health, the Health Research Council of New Zealand, LeVaa, Te Atawhai o te Ao, Whakauae Research Services, Ronald McDonald House, Starship Hospital, and District Health Board websites. University-based sites were also accessed to find additional references and studies related to specific areas, such as the Dunedin Longitudinal Study undertaken by the University of Otago.

A search strategy was utilised that contained keywords as outlined in Table 3. Combinations of words were then applied to obtain articles of relevance.

Table 3. Search Strategy Keywords *Strategy Keywords*

Māori	Pacific	Indigenous	Ethnic
Child/ren	Life-threatening	Coping	Life-limiting
Family	Families	Whānau	Extended family
Gender	Family centred	Aboriginal	Paediatric
Grandparents	Siblings	Parents	Pasifika
Cultural	Family Partnership	Caregiver/ing	Step parents
Hospital	New Zealand	Migration	Blended family
Colonisation	Family unit	Health care services	Health Care Continuum
Support	Services	Ronald McDonald House	Patient

Peer Reviewed Journal Articles

Articles accessed were then reviewed by reading the title and abstract to distinguish relevance. The articles that met the following criteria were included in the literature review:

- Peer-reviewed studies
- Published in English
- Published between 2005-2016 (some older publications were used to incorporate relevant history and original studies)
- Took an Indigenous/ethnic perspective
- Included a collective coping perspective
- Related to health
- Included information on the health care continuum and related services
- Included hospital experiences

- Focused on life-threating medical conditions
- Concentrated on a critically ill child(ren)
- Engaged family members in their research

The funnelling of information through the inclusion criteria helped to refine the search by narrowing down topics such as family coping approaches. For example, a search would firstly identify "family coping approaches" then, "following hospitalisation/hospitalisation of a child" or be defined by "additional family members coping excluding parents." Of the articles sourced, many looked at coping approaches and theories. In summary, the search resulted in an abundant amount of literature about parents compared to whānau, with limited literature found on ethnic and other cultures compared to Western-based studies. The search produced information on coping mechanisms and strategies that still drew upon early research and original theorists, for example, Lazarus and Folkman (1984) and McCubbin (1983, 1996). Early works such as these, and others, remain relevant and have been included in this literature review.

The search focused on coping concerning roles within whānau and included parents, siblings and grandparents that were in-line with the study question. The following exclusion criteria were applied:

- Children with non-life-threatening illnesses or medical conditions/disabilities
- At home care or caregiving within the home environments

Document Review – Grey Literature

An extensive range of documents in the "grey literature" was reviewed and accessed for their utility and relevance to this study. While I tried to apply the same criteria to the grey literature as the academic literature, I realised that I needed to be somewhat flexible. In a few cases, time frames required extending as some organisational documents were not current, but information remained relevant. Documents were reviewed if they held pertinent information about Māori and Pacific, children, Starship Hospital, coping and support. Additional documents were retrieved from the Ministry of Health and services that support whānau such as Heartkids, Curekids, Child Cancer Foundation and the Make a Wish Foundation.

Ronald McDonald House, Auckland, contributes to the second objective of this study. Administration staff provided supplementary information relating to history, development, funding, sponsors, published newsletters, family stories, members and affiliations, eligibility, rules and regulations of the houses, changes over the years and future direction.

The findings of both peer-reviewed articles and grey literature on whānau coping are presented here under three categories that include:

- Specific roles within whānau
- Different coping approaches (such as individual, collective and cultural perspectives)
- The coping context (for example, impacts of migration, level of acculturation or whether the physical environment makes a difference).

Whānau Coping

Findings from a New Zealand qualitative study that consisted of 19 primary caregivers with children in paediatric palliative care showed that the most common theme spoken about was having family support. This study included six Māori and one Pacific whānau. The criteria for the study incorporated those who self-identified as primary caregivers and included extended family. The findings highlighted a broad range of support mechanisms that were offered by family, including relief, respite, help with decision making, distraction for caregivers, emotional and physical support, childcare (for the sick child and sibling support) and help with post-death arrangements (Gaab, Owens, & MacLeod, 2012). Findings also revealed that simply having family present was what most whānau wanted. Caregivers also expressed the joy of watching other family members take care of each other. The experiences of caregivers in this research was seen as being heavily intertwined with their whānau. As well, sharing responsibilities enabled better coping for the whole whānau unit (including the patient, siblings, and other children). Additional studies have also found that whānau provide varied forms of support and are central to members coping (S. Edwards, McCreanor, & Moewaka-Barnes, 2007; Monterosso, Kristjanson, & Phillips, 2009), and pivotal to patient well-being (Bellamy & Gott, 2013; Cottle & James, 2008; Frey et al., 2013; McFadden, Campbell, & Taylor, 2014). D. Wilson and Barton (2012), in their intrinsic single case study research (case is embedded within a set of data) that described Māori experiences during hospitalisation, identified that whānau support went a step further in that family members also looked out for other Māori patients by advocating or providing well-needed information when the patient's own family were not able to be present. Meyer, Ritholz, Burns and Truog (2006) suggest that the involvement of the extended family may be a characteristic that is specific to New Zealand. However, other studies on Indigenous and ethnic cultures have identified similar attributes (Ho & Bedford, 2008; Lichtenthal & Kissane, 2008; Superu, 2016).

New Zealand studies examining adult Māori with cancer that included patient and their whānau members in their research, highlighted specific ways in which whānau aided coping. Supports included being with members at appointments and utilising cultural mechanisms such as karakia (prayer/incantation) and waiata (hymn/song; (Dew et al., 2015). Whānau members were found to be fundamental in facilitating a process between clinician and patient, which helped them understand information to enable informed choices and, therefore, cope better (Magnusson & Fennell, 2011; Monterosso & Kristjanson, 2008; Slater et al., 2013; T. Walker, Signal, Russell, Smiler, & Tuhiwai-Ruru, 2008). Slater et al. (2013) found that hospice care whānau identified a spokesperson from within the collective who would take the lead in organising other members to assist with visitor shifts as well as making sure children were looked after and entertained. Whānau also provided a source of support within their own culture, providing sustained cultural practices and understandings (Dew et al., 2015; T. Walker et al., 2008).

While whānau are a great source of support, it is also important to note that strong whānau connections were also found to be a source of tension causing additional stress for some patients and family members (Dew et al., 2015). This stress and tension tended to come with feeling pressured when having to make critical decisions. The pressure was also noted regarding

diagnosis, and not just with individuals but direct impacts were also noticed affecting the whole whānau. Whānau members not only have to come to terms with a loved one facing a life-threatening disease but also, in some cases, the whānau itself (perhaps through genetics) may have to confront the same illness (Dew et al., 2015). Dealing with these wider impacts places additional stress and pressure on whānau further impacting on their coping. Magnusson and Fennell (2011), who examined the role of culture in pain in their qualitative study with 33 Māori participants, also found tensions regarding whānau support. They found while whānau support was welcomed, the number of visitors was exhausting and overwhelming. Patients were also conflicted about not wanting to burden family members but valued having family support at the bedside. These findings exposed a disparity between the "ideal" and the "real," that is, having the availability of whānau to provide support versus the reality of it not being readily accessible due to distance (including family residing overseas). Additional pressure was attributed to limited designated whānau spaces and a lack of understanding from health care staff.

Well-being has been found to include access to both internal assets which are embodied in individuals and external assets which are derived from the standard, societal and structural conditions (H. Moewaka Barnes et al., 2013). Resilience is an internal asset involving an individual's capacity to draw on personal resources. The concept of community or whānau resilience as a collective attribute has gained recent traction in the literature. Whānau resilience is the ability of whānau as a whole to overcome, or to endure, hardship and adversity. A resilient whānau is described as one that can support its members through difficulty (Te Puni Kōkiri, 2009; J. Waiti, 2014). Studies refer to "family hardiness" (Jeong et al., 2016; Stehl et al., 2008; Woodson, Thakkar, Burbage, Kichler, & Nabors, 2015), which is defined as a family's ability to work together and be cohesive as they combat stress and find solutions (McCubbin, Thompson, & McCubbin, 1996). Hardiness is also likened to a type of resilience (Woodson et al., 2015). Research on Indigenous peoples indicates that family and community play a significant role in promoting resilience (Kirmayer, Sehdev, & Isaac, 2009; J. Waiti, 2014). Research with two-spirited people[10] identified associations with internalised colonisation, adverse impacts of historical trauma and contemporary discrimination but also found that family, culture, language and land were important protective buffers that restricted the negative impacts associated with these issues (H. Moewaka Barnes et al., 2013; Walters et al., 2009).

The literature reveals there is a link between coping, resilience and whānau (J. Waiti, 2014). These studies confirm the need to continue building evidence that puts whānau at the centre of research. Whānau voices need to be heard so that appropriate action can be taken. Shudy et al. (2006) undertook a systematic literature review of the impact of paediatric critical illness and injury on families and found several gaps in their review of 115 reports. Gaps were highlighted showing that studies minimally investigated cultural diversity; often excluded fathers' views, perceptions and experiences; most often incorporated Western perspectives; and stemmed mainly from married white mothers. It was also found that much of the research lacked focus regarding alternative coping strategies and interventions about "non-maternal" family members (kaupapa

---

[10] Two-spirited" refers to a person who has both a masculine and a feminine spirit, and is used by some First Nations people to describe their sexual, gender and/or spiritual identity.

whānau), various ethnic groups and non-nuclear families. Upon reflection of the gaps identified here, research is therefore required that incorporates culture and includes males (not just fathers) in different roles, as well as family diversity.

Whānau Roles

The following section focuses on roles within whānau. As the literature search grew, it became apparent that coping literature frequently referred to the term *caregiver* but predominantly considered parents (mother and/or father) in this role. It is important to note that in a New Zealand context, for Māori and Pacific whānau, it is not only the parents that bring up or take care of a child; but is often also the responsibility of several family members.

Impact on Relationships

The impact of dealing with a child who has a life-threatening medical condition can have significant consequences on a couples' relationship. Da Silva, Jacob, and Nascimento (2010), in their integrative review, examined evidence related to the effects of childhood cancer on parents' relationships. In fourteen articles reviewed four common themes existed: difficulty in communication between couples; changes in the couple's relationship during the child's illness; separation (both distance and legal), gender differences in parental stress and coping; and role changes. Other studies also confirmed that communication was a major factor that affected most family relationship roles such as between parents and siblings as well as health professionals (Bacal & Jansen, 2006; Jackson et al., 2007; Leonard, Graham, & Bonacum, 2004). In their systematic review of 34 articles, J. Smith, Cheater, and Bekker (2015) noted that parents perceived that living with a child with a long-term condition placed them at risk of marital breakdowns (Goble, 2004; Hovey, 2005). The primary barrier identified was meeting arduous caregiving commitments that resulted in parents spending limited time together (McGrath, 2001; Sullivan-Bolyai, Rosenberg, & Bayard, 2006), leaving little or no time for intimacy and other leisure activities (Lavee & Mey-Dan, 2003).

Extended hospital stay was also found to have an impact on relationships. Studies undertaken showed that health care facilities that were geographically distant from the family's home or city of origin created further complications. Couples who were separated by distance found it challenging to communicate and engage effectively about important issues (Butt, McGrath, Samra, & Gupta, 2013; McGrath, 2001; Silva-Rodrigues, Pan, Sposito, de Andrade Alvarenga, & Nascimento, 2016). For Māori and Pacific whānau, talking face to face is an important cultural aspect, especially when there are serious decisions to consider. Studies also showed that quality communication, when it occurred, was an important factor in decreasing the burden of the child's illness for parents (Da Silva et al., 2010; Shapiro, Perez, & Warden, 1998). Difficulties in communication frequently appeared in parents' relationships throughout early studies (Lavee & Mey-Dan, 2003; McGrath, 2001; Shapiro et al., 1998) and represented significant problems occurring in handling conflict and showing support and understanding between partners (Duman et al., 2007).

The impact of a child's death in a relationship affects couples as individuals as well as causing changes to their relationship (Rando, 2000). In a systematic review of 24 studies, nine assessed the link between the death of a child and the marital relationship (Albuquerque, Pereira, & Narciso, 2016). Within the review, three population-based studies with large-scale data identified that, in comparison to non-bereaved parents, bereaved parents had higher divorce rates (Lyngstad, 2013; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008; Wengenroth et al., 2014). While many studies highlight adverse impacts of the death of a child on relationships, the qualitative studies reviewed revealed evidence of resiliency and researchers concluded that marriages could endure even after the death of a child (Albuquerque et al., 2016). In these contexts, it was the relationship that acted as a source of support that brought couples closer together (Barrera et al., 2009; Essakow & Miller, 2013; Naef, Ward, Mahrer-Imhof, & Grande, 2017; Paley, 2008; Titus & de Souza, 2011). Other studies also report similar findings where several parents' relationships were strengthened when a child was critically ill. One study states that closeness came by parents having a mutual commitment to meeting their child's needs (Goble, 2004; Ray, 2002). Lavee and Mey-Dan (2003), looked at the marital changes in 35 parents who had children with cancer. They observed the perceived quality of marriage across several dimensions. Results showed that many parents who were dealing with a critically ill-child had better perceptions of their partner's personal and behavioural traits, an increased ability to resolve any conflict that arose, improved interpersonal confidence, and greater flexibility in their relationship. Likewise, in their qualitative study of eight fathers whose child had received treatment through paediatric oncology, Brody and Simmons (2007) attributed a stronger relationship with their wife to the extended amounts of time spent together while taking care of their sick child. Dealing with a critically ill child can have profound impacts on couples' relationships. For some, it brings them closer together but, for others, implications can range from difficulties in communication, distance or separation and divorce. These effects all have broader impacts affecting other family members and their roles within the family unit.

The Role of Grandparents

Research regarding grandparent's involvement in the health care equation of a critically ill and hospitalised child while limited is beginning to advance. The constructivist grounded theory study of Rempel, Ravindran, Rogers, and Magill-Evans (2013) involved 53 participants, 28 of whom were grandparents. The study identified the critical role grandparents played in support of parents who had a critically ill child (Ravindran & Rempel, 2011). Hall (2004a, 2004b), in her phenomenological studies, sought Danish grandparents' experiences of dealing with their seriously ill grandchild. The studies identified in this section all revealed similar outcomes. Grandparents were found to have concern for both their adult child and their grandchild; they worried about the whole family unit and undertook to safeguard family relationships. The research also identified that grandparents were explicit about acknowledging the complexities that occurred within the family but also played a vital role in sustaining family connection. Safeguarding the family included looking after the needs of the parents (as individuals and as a couple) and by taking care of siblings so that parents had sufficient rest, resources including adequate time out.

Hall's (2004a, 2004b) studies further noted that grandparents were not supported in their role by nurses and were often excluded from discussions or procedures, identifying that some were even asked to leave the room or ward. While neither Ravindran and Remple (2010) nor Hall presented findings from grandparents who were primary caregivers, Hall's research indicates how grandparents are impacted by a critically ill child and how their roles can be perceived by health staff within a hospital environment. Cultural contentions were also noted that impact grandparents. From a Western perspective, the grandparents' role is seen as informal, sitting outside the nuclear family or decision-making unit, a role that has no legal rights to make decisions regarding critical health care. From a Māori and Pacific cultural perspective, grandparents are positioned as key decision makers regarding the child and the wider whānau (Ka'ai, 2005; C. Smith, 2008). Thompson, Cameron, and Fuller-Thomson (2013) noted that some Native American grandparents viewed caring for their grandchildren as a right that contributed to the reinvestment in their cultural health and well-being. Native American grandparents in this study drew on the strength from their experiences with cultural disruption to fulfil their roles as caregivers. Drawing from strength helped Indigenous grandparents use the purpose of their caregiving role to mediate the stress of caregiving. Caregiving roles provided grandparents with a sense of empowerment and meaning associated with knowing that they are critical to the wellness of their grandchildren. Indigenous grandparents felt that their care and influence contributed to the rebuilding of cultural traditions and practices (Dennis & Brewer, 2017). What these studies highlight is that the aspects of caregiving that grandparents may find hard were somewhat alleviated by knowing that they were contributing toward a healthier future for their grandchildren.

Sibling Coping

Research conveys that siblings of a critically ill-child often show negative behaviours reflecting the impact on their emotional health and well-being, including anxiety, depression, post-traumatic stress symptoms, poorer quality of life, behavioral difficulties, and/or peer problems (Alderfer, Navsaria, & Kazak, 2009; O'Brien, Duffy, & Nicholl, 2009; Vermaes, van Susante, & van Bakel, 2012). Studies that explore sibling behaviour have linked such difficulties to their experiences with illness, such as witnessing upsetting medical procedures (Alderfer et al., 2009; Vermaes et al., 2012), changes in the health of the sick sibling (Hartling et al., 2014), as well as experiencing similar emotions to their parents, such as anger, grief, guilt, and a feeling of helplessness (Da Silva et al., 2010). Attention-seeking behaviours often contribute to the additional strain impacting all members of the household (Sartore, Lagioia, & Mildon, 2013). Studies also point to problems for siblings stemming from having to take on extra caregiving and or domestic responsibilities as well as assuming a parental role (Boer, Dunn, & Dunn, 2013; Long, Marsland, Wright, & Hinds, 2015). One study noted that these responsibilities often prevented siblings from partaking in a "normal" childhood (Gaffney, 2007). It is important to note that most literature concerning siblings originates from a Western perspective and takes a deficit approach, identifying sibling behaviour as problematic. A few studies referred to sibling caregiving from a cultural viewpoint. McDonald, Cumming, and Dew's (2009) research in New Zealand, using nine case studies, demonstrated consistent themes as to the reasons why children were in the caring role. These comprised

cultural and family expectations, the desire to assist family members and "filling in" when formal support was unavailable. The results showed that sibling caring was the product of a mixture of choice and/or obligation. Hafford (2010) reviewed sibling caretaking aimed at practitioners undertaking assessments that were better culturally informed. She noted that sibling caretaking in immigrant families was engrained in a complex set of risk and protective factors related to migration, applications about family configuration, accessing resources, social supports, and options regarding childcare. There is limited literature available that includes Indigenous, ethnic, Māori and Pacific sibling perspectives including taking on a caregiving role. This thesis will contribute to this body of knowledge by providing a cultural perspective that underpins exploration of whānau coping and the impact of a critically ill child.

Gender Coping

While there has been considerable research undertaken that has identified stressors and coping strategies of caregivers and parents whose children have been admitted to paediatric intensive care units (PICU). The majority have tended to have had a focus on the role of mothers (Foster, Whitehead, Maybee, & Cullens, 2013). Betman's (2006) study, which focused on grief about a child with a life-threatening illness, found "gender differences were assessed based on a well-established bias in grief inventories" (p. 33). This bias, according to Betman, used female grief reactions as the unit of measurement by which male responses were then measured. Betman believed that the male grief response had been inadequately measured taken from historical accounts based on the assumption that men expressed less emotion than women and, therefore, were less affected by situations. Higham and Davies' (2012) ethnographic study of fathers' roles in unplanned hospital care of their child found that while fathers wanted to be physically present, access was primarily determined by their relationship with the child and the mother. Higham and Davies' study found similar findings to the limited early hospital-based studies that included fathers' experiences (Callery, 1997; Coyne, 2006; Darbyshire, 1994; Leinonen, Solantaus, & Punamäki, 2003). Findings confirmed that fathers had a minimal role and were often called in to provide some relief for the mother. Several studies that focused on long-term childhood illnesses also included fathers that were supporting children with conditions such as diabetes (Sullivan-Bolyai et al., 2006), cancer (McGrath & Chesler, 2004) and kidney disease (Swallow, Lambert, Santacroce, & MacFadyen, 2011). These studies showed that along with dealing with the child's condition they also had to contend with the difficulties and restrictions associated with being confined in neonatal and paediatric intensive care (Board, 2004). While there is an increase in research concerning fathers, Isacco and Garfield (2010) claim that "health care research with fathers has focused on severe and atypical situations" (p.111). There is a lack of research addressing fathers' coping in short-stay acute inpatient care, despite there being a largescale trend for fathers to become more involved in all aspects of their children's lives (Flouri, 2005; Lamb, 2000). Research that involves the experiences of both mothers' and fathers' have been compared to those whose child is experiencing long-term illness, for example, Hobson and Noyes (2011), and planned surgery (Tourigny & Lepage, 2004).

Da Silva, Jacob and Nascimento (2010) found that, in general, nurses and other clinicians typically did not attend to the father's needs for emotional support or encourage fathers to take part in decisions affecting their ill child. Coad et al.'s (2015) study found that on several occasions there were reports of consultants talking to the mother only, despite both parents being present. Nishimoto's (1999) study on parents with a child with a cleft palate, which included Pacific Island perspectives, also found that fathers were excluded from health discussions and treated as bystanders or spectators. Katz's (2002) study on parents dealing with a life-threatening childhood illness found fathers felt uninformed, unsupported and isolated from events even when they did appear to help. The limited support for men was more evident when they could not be present during hospitalisations due to work or other family commitments such as looking after additional children. Katz's study was included because it is one that articulated reasons why fathers may not be present during their child's hospital admission. As well, it highlights the additional roles fathers take on outside the hospital environment that also contribute to their child's care (Katz, 2002).

Different variables such as societal expectations and norms, culture and age, for example, shape how people react to stress, and therefore, how they cope (Goodhead & McDonald, 2007; Han et al., 2009). These variables differ for men and women and the role they take on within whānau and society. Variables are likely to play a critical and influential part in the different ways that both men and women cope. It is envisaged that undertaking this study will provide an opportunity to explore how Māori and Pacific men cope while considering societal expectations and cultural assumptions about child rearing and caregiving.

Coping approaches

There are many different schools of thought concerning how people cope and what mechanisms and strategies they may apply in stressful situations. Firstly, individuals possess preferred coping styles that they bring with them to each situation they face. Secondly, coping is contextual and is influenced by an individual's characteristics, by how a person interprets or views how to react to situations (Folkman, 2001). Simply put, it means that while one strategy may work in one situation, it may not be effective in another (Lazarus, 1999). Thirdly, coping is a process of change (Folkman, 2001). Therefore, mechanisms and strategies used may vary over time and between situations (Carver et al., 1989). Lastly, coping is a dynamic process that shifts in nature dependent on the situation and the people involved. Coping may be influenced by changes in circumstances (for example, people, conditions or environment) and/or by the way people react to them (Folkman & Lazarus, 1980; Lazarus, 1986; Lazarus, DeLongis, Folkman, & Gruen, 1985).

The admission of a child to the hospital is a stressful event, and the impacts of these events on caregivers are well noted (Bakker et al., 2014; Berube, Fothergill-Bourbonnais, Thomas, & Moreau, 2014; Coad et al., 2015). High levels of stress and worry impact significantly on caregivers. Given that caregivers of children with life-threatening medical conditions play a central role in the care of the child, the health and well-being of the caregivers themselves need to be considered as an important factor in the ability of the family to cope (Tong, Lowe, Sainsbury, & Craig, 2008). Studies have identified key reasons why many caregivers may find it difficult to

cope. These include the inability to foresee the future and plan, frequent and lengthy hospitalisations, as well as dealing with the possibility that their child might die (Sloper & Beresford, 2006; Tong et al., 2008). In a systematic review of qualitative studies about parents of children who were critically ill, one study found that caregivers likened the experience to "living with a time bomb" (Lewis, 2012, p. 110). These feelings intensified while waiting for treatment outcomes, enduring prolonged intervals between appointments and observing ongoing irregular changes in their child's health condition (Tong et al., 2008). Another cause of caregiver distress included having a lack of control over the situation (Arockiasamy, Holsti, & Albersheim, 2008).

While caregivers can draw on multiple mechanisms and strategies to cope, some are more prominent in literature than others. In searching the literature three major themes were evident that were deemed important to parents' coping:

- Maintaining proximity and frequent contact with their child
- Ensuring access to, and having the understanding of, necessary information including communication
- Support

Regarding proximity, parents identified that they needed to see the child frequently, and wanted to be at the bedside (Dudley & Carr, 2004) or at the very least near the ward or room where their child was located (Jee et al., 2012; Wigert, Berg, & Hellström, 2010).

Regarding health information about a critically sick child, three main issues were identified throughout literature. Firstly, whānau wanted access to information, whether it came from health professionals or sources they could access themselves (Hummelinck & Pollock, 2006; Jee et al., 2012; Kirschbaum, 1989), secondly, they needed to be able to understand it (Jee et al., 2012; Koontz, 2003) and lastly, they wanted good communication from and with health professionals (Koontz, 2003). Research that focused on parents of children with congenital heart disease found that they were not given adequate information about their child's condition, treatment and medical prognosis. Inadequate information caused uncertainty that impacted on their decision-making ability about their child's health status (Chessa et al., 2005; Cheuk, Wong, Choi, Chau, & Cheung, 2004; Lawoko, 2007). Access to resources that hold critical information, such as symptoms, procedures and minimising the risk of infections, enables families to make informed decisions about their child's care (Bacal & Jansen, 2006). Sources of pertinent information need to be easily accessible, up to date, tailored to the needs of specific communities and groups, written in simple language, and not solely based on a Western-centric health professional perspective (Bacal & Jansen, 2006; Jordan et al., 2010; Ministry of Health, 2008; Statistics New Zealand and Ministry of Pacific Island Affairs, 2011). Generic information targeting the wider New Zealand population does not seem to be working well for some population groups (Statistics New Zealand and Ministry of Pacific Island Affairs, 2011). Limited understanding of information often leaves family members attempting to provide interpretations of relevant health information, based on their limited understanding (D. Wilson & Barton, 2012).

International literature shows a link between poor health literacy and poor health outcomes (S.-Y. Lee, Arozullah, & Cho, 2004). Family understanding of pertinent information can enhance early detection of symptoms and intervention related to the condition, which can improve the child's quality of life (Ministry of Health, 2014b). Māori and Pacific peoples have continued to be overrepresented in low literacy statistics (Families Commission, 2009; Hayes, 2016; Statistics New Zealand and Ministry of Pacific Island Affairs, 2011) and evidence points to those who speak English as a second language often have lower health literacy (Huakau & Bray, 2000; Zanchetta & Poureslami, 2006). Given the complexity of care required when dealing with a child with a life-threatening medical condition, access to and understanding of information for Māori and Pacific whānau is critical.

There is a significant correlation between adequate parental coping and clear communication between clinical staff and parents. Research studies revealed that clear communication minimised discrepancies between parents' expectations and reality. Communication is a central element for parents coping when they have a child in PICU (Durall, Zurakowski, & Wolfe, 2012; Jackson et al., 2007). Health outcomes are determined by effective communication and relationships. Communication between health practitioners and whānau can easily be misunderstood and misinterpreted. Moreover, communication failures are a leading cause of patient harm (Bacal & Jansen, 2006; Leonard et al., 2004). Mack and Grier (2004) confirm that the way in which a child's diagnosis is conveyed to parents is crucial to their ongoing experience. Blume's (2014) study on end of life decision-making for a critically ill child with heart disease found that when parents experienced poor communication and insufficient provision of information by medical staff, they related this to poor quality of care. Other studies have found similar outcomes (Dodgson & Struthers, 2005; Reid & Robson, 2007). In reviewing the literature, it became apparent that information and communication played a key role in parents coping with a critically ill child. It was envisaged that, through this research, a better understanding might emerge that is driven from Māori and Pacific whānau perspectives about how information and communication could be improved so it can be fully understood.

Parents with a child admitted to PICU identified that support, encouragement and comfort were essential to their coping. Many parents relied on the belief that there was hope, that their child was getting better, and that health care personnel genuinely cared about the child (Jee et al., 2012). Coad et al. (2015) found that having trust and confidence in both staff and services was important and families related it to the care they received (Dodgson & Struthers, 2005; Reid & Robson, 2007). Good relationships were important not just for the child or young person but the whole family coping (Coad et al., 2015).

Proximity, communication of information and support services play a significant role when a child has a life-threatening medical condition. Relationships with health care and support services staff were also key to coping with some having continued involvement with whānau over lifetimes. This research looks at whānau coping and incorporates views of staff who had supported whānau by playing a significant role throughout their journey.

Ronald McDonald House

At the commencement of this study, there were no studies found in the empirical literature that focused on what impact RMHC (local, national or international) might have on whānau. Today, 11 published impact studies were found and, two literature reviews, which have all been commissioned[11] by RMHC in other countries (Daniel et al., 2013; Franck, Gay, & Rubin, 2013; Giuntoli & Fisher, 2015; Nabors et al., 2013; Sanchez & De Cunto, 2014; Stremler, Dhukai, Wong, & Parshuram, 2011). The studies, in general, looked at the costs associated with accommodation, family interpretation and experiences of RMH (see footnote 3) services and support, and more specifically, research also included the value of family resource rooms within hospitals.

Cultural Perspectives of Coping

Research highlights the importance of culture, upbringing and life experiences in shaping the values, beliefs and practices of individuals, including how they cope under stress (Goodhead & McDonald, 2007; Han et al., 2009). Cultures differ in the endorsement of various values, the structures and roles taken on, and how well-being is promoted (Superu, 2016). In relation to family/ whānau and culture, two key dimensions are identified that illustrate culturally diverse values. These are individualism and collectivism (Hofstede, 2001; Superu, 2016). These dimensions can be identified by the cultural emphasis on an individual's wants and needs (individualism) compared with the group's wants and needs (collectivism).
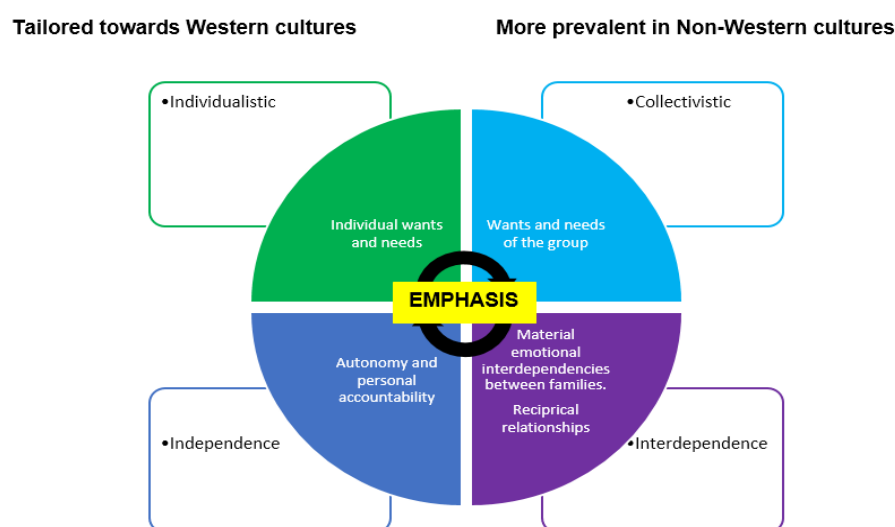
Figure 5. Overarching dimensions relating to family cultural values.

---

[11] A global team of researchers drawn from leading universities, including University of California, San Francisco (UCSF), George Washington University, University of Chicago, as well as from hospitals and research institutions in Hong Kong; Sydney, Australia; the United Kingdom; Buenos Aires, Argentina; Toronto, Canada; and Cincinnati, Ohio; Southern California; Kansas City, Missouri; Minneapolis, Minnesota; and Stanford (Palo Alto, California), U.S., have collaborated to examine the role that the Ronald McDonald House program plays in keeping families together during times of medical crises and enabling family-centred care. These studies, collectively known as the RMHC Impact Study, have demonstrated that the Ronald McDonald House program provides families with emotional and physical comfort and support, improves the child and family hospital experience and improves the child's recovery (RMHC Impact Study, 2016).

Individualistic cultures tend to place less importance on the family as a way for individuals to define themselves. Collective cultures, on the other hand, place great emphasis on loyalty to the group and honouring family obligations (Superu, 2016). Differences between the two are also reflected through independence or interdependence (Kağitçibaşi, 2006). Figure 5 outlines the characteristics of each concept.

Individualism and collectivism are detailed through different family models. **The independent family model** is described as being tailored toward Western, individualistic cultures that tend to live in small nuclear type families (for example, European or non-Indigenous families). These family types tend to place value on money, autonomy and personal accountability while de-emphasising material and emotional independence between members (Kağitçibaşi, 2006; Superu, 2016). Parenting in this model has a focus on child independence and uniqueness, with an emphasis on encouraging a sense of self-worth as distinct from others. There is also a small focus on the importance of interpersonal relationships. Extended family, such as grandparents, aunts, uncles and cousins might have little influence regarding daily life as it pertains to the central family unit (Georgas, 2006). In relation to a child who is hospitalised with a life-threatening medical condition, families in the independent model will most likely come together to support one another; however, decisions regarding medical treatment and care are generally left up to parents.

The family model of interdependence is more prevalent in non-Western, collectivistic cultures where interrelationships and responsibilities are characterised between family members (for example, Indigenous peoples). This model promotes reciprocity rather than personal autonomy and parenting tends to focus on material and emotional interdependencies with obligations to the family (Kağitçibaşi, 2006; Superu, 2016). The importance of conformity and duty is highly valued within this model (Chao, 1995; Chao & Tseng, 2002). For Māori and Pacific whānau, this model is more reflective of their collective nature. In dealing with a child with a life-threatening medical condition, culture and tradition can play an important part. In this model, it is more likely that extended family, community (prominent hierarchy such as church minister, kaumātua, or grandparents) and other supports will aid in the decision making and care of the child.

Families' cultural meanings are critical to understanding how families experience caring for children with special health needs, and consequently how they might manage the demands that come with serious illness (Nishimoto, 1999). Culture plays a role in how families express their distress, for example, a level of somatisation and the extent to which they accept health services (Kirmayer & Young, 1998).

Western perspectives continue to be dominant throughout stress and coping literature. Theories viewed through a Western lens assume that individuals cope to enhance their own health and well-being (M. Y. Wong & Chan, 2006). Thus, coping strategies that support the values of individualistic cultures are considered positive/adaptive, and other coping strategies more aligned to collectivistic societal values are labelled negative/maladaptive (Chun, Moos, & Cronkite, 2006). There is now a growing body of research that examines cultural values and beliefs that influence

people's coping styles and choices including individualism and collectivism (Chen & Kennedy, 2005; Lam & Zane, 2004).

Past research on stress and coping is criticised for ignoring the ongoing context in which stressful events occur (P. T. Wong, Wong, & Scott, 2006). One of the most neglected contexts is culture. Culture is defined by Triandis (1995) as being "highly involved, a system of meaning that continually changes [which] are learned, shared, transmitted and altered from one generation to another" (cited in Chun et al., 2006, p. 31). Statistics New Zealand (2013) defines culture as "the shared knowledge, values, and practices of particular groups" (quoted in Superu, 2016, p. 79). Culture includes lived experiences and how individuals or groups view everyday life, including their attitudes, customs and beliefs (Matsumoto & Fletcher, 1996; Superu, 2016). Lam and Zane (2004) state that since culture is important in shaping the individual and their social environment, then cultural influences will be central in determining what coping behaviours are appropriate and valued in a particular society. Culture, therefore, plays a significant role in dealing with a child with a life-threatening medical condition.

Cultural factors influence the way individuals and families deal with ill-health, and how they make decisions, which in turn impacts on the way they cope. Differences in culture in its broadest sense, for example, race, ethnicity, country of origin, socio-economic status and gender, are present in most health interactions. Culture influences people's thoughts, intentions, expectations, and therefore, behaviour (Superu, 2016). Differences need to be acknowledged and considered as medical decisions are being made. The way different cultures view sickness and health and attribute meaning to the disease will guide their coping behaviour (Vaughn, Jacquez, & Bakar, 2009). Many cultures place a high value on beneficence (to do something for the benefit of others) and non-maleficence (to do no harm). International studies bring to light the collective or family decision-making within health care (Ho & Bedford, 2008; Superu, 2016). For example, in Eastern countries, preserving family harmony in health care decisions and plans has a high priority over individual preferences (Chang & McConkey, 2008; Cong, 2004; Sekimoto et al., 2004; Tsai, 2001). In many cultures, the family becomes the decision-making unit which is based on a relational understanding of autonomy which differs from the individualistic Western perspective. Family-based decision making is dominant in many Asian cultures (Kissane, Lichtenthal, & Zaider, 2008). Similarly, for many Māori and Pacific whānau-based decisions are common. Collective decision making is especially significant when dealing with a child under 16 years of age with a life-threatening medical condition where the parents and whānau have to make critical decisions on the child's behalf.

Part of culture and coping is related to care of the patient and processes regarding it, such as communication and information, which may differ from Western idealisations. For example, in the instance of non-disclosure (mainly negative) where families and or medical professionals choose not to relay information to the patient. Several examples relating to non-disclosure were found in the literature. These examples highlighted how negative disclosure of a patient's health status was found to be disrespectful, impolite and inhumane in some cultures (Frank et al., 1998; Hern, Koenig, Moore, & Marshall, 1998; Kagawa-Singer & Blackhall, 2001; Mitchison et al., 2012). Furthermore, in some cultures, perceptions remain regarding open discussions about illness

provoke unnecessary negativity, anxiety and depression and eliminate any source of hope. There were also beliefs that speaking aloud prompts further deterioration or death (Searight & Gafford, 2005; Vaughn et al., 2009). For some Filipino patients, discussing end of life care is seen as a lack of respect as fate is only determined by God (Yeo & Hikoyeda, 2000). Certain Native American, Filipino, Bosnian (Vaughn et al., 2009) and Chinese cultures (Liu et al., 1999) believe that negative words become self-fulfilling prophecies, and Navajo people place a particularly prominent value on thinking and speaking positively (Carrese & Rhodes, 1995; Vaughn et al., 2009). Many Māori and Pacific whānau rely on traditional forms of healing, church and spiritual-based actions, including speaking positively, as part of coping management (Norris, Fa'alau, Va'ai, Churchward, & Arroll, 2009).

Culture also impacts a family's response to medical illness and the extent to which the family is involved in patient care. For example, Nguyen and Kagawa-Singer (2008) explain that to Westerners, many Asian families may appear to infantilise their family member(s) who are patients'. Chan (2004) highlighted that Chinese family members have authority over the patient and physicians will first discuss medical plans with the family representative. Following on from the family's decision, the patient will then become involved. In a New Zealand context, the influence of the extended family both support and sustain Māori and Pacific people's connection with each other and their culture having an impact on their health (Collins & Wilson, 2008; Goodhead & McDonald, 2007). In these cultures and others there are formal lines of communication, for example, kaumātua, matai/chief, the eldest child, head of the family or those deemed to have the most medical knowledge or understanding (Health Research Council of New Zealand, 2014; Ministry of Health, 2008; T. Walker et al., 2008). Many cultures also assign certain customs and practices to gender-specific roles. For many Australian Aboriginal people, they have often equated health issues as being "men's or women's business" (Women's Health, 2017). For many Māori and Pacific peoples, gender plays a critical role in caring for the sick, particularly when staying overnight in hospital or dressing and bathing their family members – young or old. Little is written regarding cultural taboos[12] associated with family and health care (Central PHO, 2018; Ministry of Health, 2008), an aspect not usually acknowledged within a public hospital environment.

Across many cultures, the concept of protectiveness involves patients themselves or family members choosing to conceal or guard information. Protectiveness enhances coping as it protects against negativity. In a New Zealand study related to pain, Māori were found to be very private about their health worries, only speaking about it with close family. Reasons provided included not talking about their worries being a positive coping strategy to negate negative energy. Others cited negative past experiences with culturally insensitive health care systems and staff, leading them to protect themselves by keeping quiet, not wanting to be a burden or draw any unwanted attention (Magnusson & Fennell, 2011). Thus, highlighting that past negative

---

[12] **Cultural taboos** are unwritten rules of understanding inherent within cultures (although may differ between cultures and family). They commonly involve gender based actions or roles and can be associated with health care, family care such as bathing elderly family members and communication and information (who should be told and who and how the family will be informed).

experiences can shape coping behaviour. Table 4 lists a summary cultural coping perspectives presented in this chapter.

Table 4. Overview of Cultural Coping Mechanisms Related to Health Care Decisions

Cultural perspective	Meaning Associated
Beneficence	An action is undertaken for the benefit of others
Non-maleficence	To do no harm
Collective or family decision making	Family members make a decision either on behalf of the patient or with the patient
Non-disclosure	Where families and or medical professionals choose not to relay information to the patient
Protectiveness	Where the patient themselves or family members choose to guard information by harbouring or concealing it
Primacy of the family	Family decisions are accepted by the patient

Bennett, Smith, and Irwin's (1999) study about preferences for participation in medical decision making showed that in Hong Kong, where both Eastern and Western philosophies of autonomy exist, medical staff firstly consulted with the family, and secondly gave medical information to the patient. Patients accepted the primacy of the family unit and their treatment decisions, including their family's decision to compromise or agree to procedures such as surgery. The main aim of this concept is to alleviate family anxiety or concerns, so they cope better. Bennett et al. (1999) noted that although patients were fully competent to mediate with medical professionals themselves, they perceived family members as their liaisons for information and as advocates in the physician-patient relationship. The family, therefore, played an active role in the informed consent process. In this respect, the family shared the burden of ill health and protected the patient from the health care system. Studies in relation to whānau coping with a child who has a critical illness showed that collectiveness revolved around sharing the burden of illness (with and among family and those outside the family). By collectively drawing on philosophies or activities that added meaning to make sense of the illness or event, such as spiritual guidance or religious activities (McCubbin et al., 1983) helped alleviate the pressure for specific individuals.

Revealed within the literature were a number of studies about cultural coping. Much information was also found that related to Māori and Pacific cultural elements such as aroha (love), whānaungatanga (relationships), and talanoa (discussions using a cultural framework in which they proceed). However, there is a scarcity of information relating directly to whānau coping and, more specifically, dealing with a child who has a life-threatening medical condition.

The Impact of Context on Coping

Unique socio-cultural contexts construct the way in which family members cope with events. People's experiences about particular settings or significant events (negative or positive) can shape the way they view and handle different situations, and therefore, how they react and manage.

Migration

International research recognises the importance, and the impact, migration has on health and coping (Carballo, Divino, & Zeric, 1998; Østbye, Welby, Prior, Salmond, & Stokes, 1989; Sam, 2006; Stanhope & Prior, 1976; Thomson & Hoffman-Goetz, 2009). The health and well-being of a migrant group are determined by many factors, most significantly related to their place of origin, the migration journey and adjusting to the new location of settlement (Borrows, Williams, Schluter, Paterson, & Langitoto Helu, 2011; Tautolo, Schluter, & Paterson, 2015).

The motivation to move to New Zealand from the Pacific Islands for many Pacific whānau was to search for a better way of life including advancing employment and education opportunities. Pacific migrants not only have to negotiate new cultures but also learn to navigate multiple new and diverse systems such as the New Zealand health system. Migrants have done this mostly without the support of familiar social networks, structures and, in many cases, their language (Tautolo, Schluter, Paterson, & McRobbie, 2011). Migration has been shown to have a potentially severe impact on migrant culture-specific patterns including roles such as parenting, responsibilities, decision-making, as well as cognition and practices, for instance, childrearing and coping (Lansford, Deater-Deckard, & Bornstein, 2009). These changes are evident when families migrate from one society to settle in another that is vastly different from their original setting.

Acculturation (the process of cultural change in customs, language, and values resulting from contact between cultural groups) is an additional challenge faced by Pacific migrant whānau. Both migration and acculturation processes can cause significant disruption which directly impacts their health and well-being. When integrating into a new culture, it is often found that socialisation agents in the receiving culture, such as colleagues, church members or health staff, may possess remarkably different images, processes and structures determining health and well-being than those of the culture or country of origin (Roer-Strier, 2001). These factors are attributed to harmful health-related behaviours such as stress, pressure, loneliness, isolation, internal conflict and self-esteem issues, all of which have a significant effect on coping. Adding to this is the immense worry of a child who is critically ill, as well as being away from local resources and supports.

Pacific migrant whānau are required to adjust their ingrained responses including routines associated with the life that was (whether temporary or permanent), to compensate for the cultural differences and disruption of family roles and associated responsibilities of the life that now is. Part of the process comprises making many decisions and rapid changes to their way of thinking as well as trying to retain, modify, translate or reject various processes, language, interpretations and practices that others may take for granted (Tautolo, 2011). Many Pacific whānau have to contend with this constant cultural-negotiation process.

The acculturation gap can affect family cohesion by creating distance between generations (Elliott & Gray, 2000; Lin, Cleary, & Edberg, 2014). The effects impact Pacific migrant children who, as time goes by, may have limited opportunities to participate in and learn about their culture of origin. Thus, causing gradual shifts where migrant parents and their children start to live in different cultural worlds (Birman, 2006a, 2006b). Children tend to adapt and become involved in

their new culture relatively quickly, particularly if they attend school; however, their parents or older generations may find it more difficult to come to terms with a new country, new language and culture (Birman, 2006b). The cultural gap can influence how whānau cope, especially when many Pacific children are often the advocate and translator between health staff and parents, grandparents or siblings who may have limited English.

Māori are also impacted by migration. The alienation of Māori land and the removal of the Māori economic base through colonisation by non-Māori left many whānau little choice but to move from their homelands where they had resided for generations (Hayes, 2016; Hirini & Collings, 2005; Te Puni Kōkiri, 2007). Ongoing positioning of Māori and Pacific peoples as marginalised and disadvantaged groups by dominant non-Māori, non-Pacific social systems have forced both Māori and Pacific peoples to leave New Zealand in great numbers in search of a better way of life in other countries, in particular, Australia. The distance and isolation contribute significantly to the breakdown of traditional and familiar ways whānau previously interacted and connected (Baker, 2010). The financial cost of returning home for events such as tangi (death) and hui (meetings) is unrealistic and unattainable for many urban and overseas whānau. The pressure places extra burdens on members, especially in weighing up the substantial cultural costs of non-attendance. Urbanisation has eroded whānau on the basis that people living in cities or other countries lose their whakapapa links, and are left in a state of suspension. The loss of whakapapa connections contributes to over-representation of Māori negative statistics (Te Rito, 2007), such as mental health, prison and hospitalisation from preventable diseases, both here in New Zealand and in Australia where many Māori and Pacific whānau now reside.

Migration will be a major factor to consider in this research, given New Zealand's special relationship with many Pacific countries where many come under New Zealand citizenship or have obtained residency and the fact that many Māori and Pacific are returning to New Zealand after being away for extended periods of time, living in other lands such as Australia.

Health Care Continuum

It is now established that children with life-threatening illnesses are now living longer than their counterparts who were diagnosed in earlier years (Berry et al., 2013). It is acknowledged that transitional care for these children is far more complicated with more opportunity for problems (Nageswaran, Radulovic, & Anania, 2014). According to Marston and Chambers (2012), the lack of sustainable funding and problems with co-ordination of services means that health care for those with life-threatening medical conditions remains unstable and inequitable. Issues such as these arise from children having multiple clinicians and agencies involved in their care, both in the community and the hospital, and require complex medical care on discharge from the hospital.

It is common for whānau to continuously re-enter and depart the health system at different access points along the continuum (for example, another diagnosis leading to re-admission, more treatment in other facilities, additional medical conditions that need further rehabilitation) depending on the child's condition (refer Figure 1, page 16). For many Māori and Pacific whānau dealing with a child who has a life-threatening medical condition and having to navigate the health system can be an isolating and tremendously challenging experience. Families can be under

excessive stress at any time. Many family members have long and exhaustive experiences of re-entering the health system through different access points over a child's lifetime (Berry et al., 2013).

There were very few studies identified in the literature review that highlighted the stress and coping experienced by whānau throughout re-occurring transitions and entry points into the health care system. Most research focused on specific stages of entry such as diagnosis or admission (Commodari, 2010; Needle, O'Riordan, & Smith, 2009; Wray, Lee, Dearmun, & Franck, 2011), treatment (Choi et al., 2016; Streisand, Kazak, & Tercyak, 2003), or discharge (including death and home care; Aydon, Hauck, Murdoch, Siu, & Sharp, 2017; Fraser, Fleming, & Parslow, 2017). Other literature related to a health care continuum focused on integrated care to reduce costs and maximise outcomes (Øvretveit, 2011). Children with life-threatening medical conditions often experience re-occurring re-entry through the health care continuum over extended periods. In addition to re-entering the system of care along the continuum, whānau cope with other inefficiencies. These include gaps in and between services, poor coordination, difficult transitions, duplications of referral, assessments and services. While a more efficient system would be less exhausting for families, result in better outcomes and reduce costs, it involves much-needed coordination, including both vertical integration, such as from secondary to primary or tertiary to social care, and horizontal integration, for example, across different teams, agencies, or individuals (Peel, Thomas, & Worth, 2013). Within New Zealand, the demand for and cost of health and social care services have both risen dramatically within the last decade. Budget restraints and cuts affect workforce, care and treatment along the health care continuum, therefore making it difficult for a high quality of care to follow (Office of the Auditor General, 2011). While the health care continuum is essential, the approaches to care incorporated within health systems are of equal value. Care approaches contribute to how patients and their whānau with life-threatening medical conditions utilise and interact with the systems along the continuum and whether their experience of coping is enhanced or made worse.

Hospital Experiences

Hospital admission forms part of the health care continuum. Admission can cause great emotional impact with anxiety generated by being away from familiar support networks and facilities such as the home environment. Admission can be a traumatic time for families (Moorey, 2010). Research identifies the timing of admission to a hospital, particularly when unplanned, as the most stressful moment for both parents and children (Macías et al., 2015).

Health environments including hospitals play a significant role in Māori and Pacific health considering their high health need and high admission rates (Bacal & Jansen, 2006; Bathgate et al., 1994; Ministry of Health, 2010b; Tukuitonga et al., 2000). Globally Indigenous peoples experience significant systematic inequalities and consistent disparities, compared to the non-Indigenous population (Bramley, Hebert, Jackson, & Chassin, 2004). Admission into a hospital has often been related to negative and poor experiences for Indigenous peoples. Research highlights numerous accounts of inadequate treatment, along with intensely negative feelings

including an inability to cope (as patients and whānau members), in relation to their health care and, in particular, to hospitalisation (Barton & Wilson, 2008; Jansen & Smith, 2006).

D. Wilson and Barton (2012), found that hospital environments created discomfort, anxiety and stress for Māori rather than a sense of healing. They also found participants felt their cultural needs, including beliefs and practices, were not considered and, therefore, were compromised in exchange for receiving health care.

McGrath (2007) noted that for Australian Aboriginal people, the hospital environment felt to be an unsafe place that caused fear, distress and further hardship. On a spiritual level, Australian Aboriginal people expressed the desire to be near family and to die in their home on their lands which were often far from the hospital and in rural and remote areas. New Zealand research shows that historically Māori reluctance to be hospitalised relates to being away from home or being distanced from whānau, as well suspicion and mistrust about staff, lack of adequate care and the use of foreign medical approaches, including biomedical approaches (Barton & Wilson, 2008; Buck, 1949). Canadian First Nations women described feeling like intruders who were alienated and unable to connect with health professionals (Browne & Fiske, 2001). Research revealed that institutional racism and interpersonal racism, discrimination and structural inequalities had shaped their health care and hospital encounters and had an impact on their ability to cope effectively with them (Barton & Wilson, 2008; Browne & Fiske, 2001).

Like other Indigenous peoples, Māori link culturally appropriate care with the quality of care (Dodgson & Struthers, 2005; Reid & Robson, 2007) and both Māori and Pacific experience of hospital care has been less than optimal (Nikora, Hodgetts, Carlson, & Rua, 2011). Understanding hospital systems and processes, while advantageous for navigating the care continuum was found to be frustrating and challenging due to the complexities involved, including a patronising and paternalistic culture among hospital staff (Cram, Smith, & Johnstone, 2003). Literature shows that Māori and Pacific whānau accessing hospital care for a child with respiratory conditions encountered many difficulties attributed to socio-economic status and health system barriers (Bolitho & Huntington, 2006; Horsburgh, Trenholme, & Huckle, 2002; D. Wilson & Barton, 2012). Moreover, Pacific people, entering the New Zealand hospital system for the first time who were facing language barriers, found navigating and understanding the matrix of care extremely difficult (Arlidge et al., 2009).

Differential quality of care is linked to institutionalised racism, negative stereotypes, victim blaming and deficit explanations (Reid & Robson, 2007). These continue to be voiced by health care staff, particularly when Indigenous people do not respond optimistically to prescribed health interventions (Barton & Wilson, 2008; S. Kurtz et al., 2003). Despite the introduction of both Māori and Pacific primary health care providers, they remain high users of secondary health care services (Statistics New Zealand and Ministry of Pacific Island Affairs, 2011) where they are more likely to be sicker on presentation to health care services, and therefore, more likely to be hospitalised. Māori continue to experience longer and slower pathways through the health care system (Barton, 2008; Kahukura Tatau, 2010; Robson & Harris, 2007), and when they are admitted to hospital they receive a poorer quality of care and are more likely to be discharged

earlier than others (Rahiri, Lauti, Harwood, MacCormick & Hill, 2017; Seneviratne, Campbell, N. Scott, Coles, & Lawrenson, 2015; Kahukura Tatau, 2010; Robson & Harris, 2007).

Māori and Pacific whānau receiving hospital care are also more likely to receive their care from non-Māori and non-Pacific health professionals and, increasingly, from a person from another country. Reports highlighted that health care staff often lacked authentic understanding of the hardship Indigenous people experience and were prone to negative stereotype assumptions (D. L. Kurtz, Nyberg, Van Den Tillaart, & Mills, 2008). It was also reported that many Indigenous patient and family inquiries seemed to inconvenience nurses and doctors, marginalising them further (Dodgson & Struthers, 2005). It was also noted that nurses often treated those with darker skin colour worse (D. L. Kurtz, Nyberg, Van Den Tillaart, & Mills, 2008).

Internationally, investigations are increasing regarding the links between racism, health and well-being (Brondolo, Love, Pencille, Schoenthaler, & Ogedegbe, 2011; Clark, Benkert, & Flack, 2006; Dominguez, 2008; R. Harris et al., 2012b; H. Moewaka Barnes et al., 2013; Paradies, 2006; D. R. Williams & Mohammed, 2013). Research shows that racism has tangible effects on people. These include inequitable access to resources that support good health, such as good quality jobs, housing, education and health care; differential exposure to environmental risks, for example, toxic substances and dangerous properties; direct experiences, such as, assaults, abuse, ethnic genocide; and stress affecting mental health and the body including immune-endocrine and cardiovascular systems (H. Moewaka Barnes et al., 2013; Wepa, 2016). Racism is also a determinant of health (Came, McCreanor, Doole, & Rawson, 2016).

In New Zealand, we have direct evidence linking the personal experience of racial discrimination to poorer health outcomes (R. Harris et al., 2012b; R. Harris et al., 2006a, 2006b; H. Moewaka Barnes et al., 2013) as well as strong links between discriminatory practices toward Māori and the quality of care received (Cram, 2014; R. Harris et al., 2012a; H. Moewaka Barnes et al., 2013; Rumball-Smith, Sarfati, Hider, & Blakely, 2013; Wepa, 2016; D. Wilson & Barton, 2012). Evidence highlights a strong relationship to coping, in that the less able a person is to draw on useful resources that may act as a buffer to racism and discrimination, the more it affects their ability, or rather inability, to cope and, therefore, heal and recover (Brondolo, Love, Pencille, Schoenthaler, & Ogedegbe, 2011; Came, McCreanor, Doole, & Rawson, 2016; Clark, Benkert, & Flack, 2006; Dominguez, 2008; R. Harris et al., 2012b; H. Moewaka Barnes et al., 2013; Paradies, 2006; Wepa, 2016; D. R. Williams & Mohammed, 2013). Thus, poorer health outcomes are associated with an inadequate ability to deal with what is going on. These encounters highlight that while Indigenous, Māori and Pacific people are sicker than their counterparts, they must also contend with the effects and impacts of racism and discrimination as well as contrasting beliefs, values, protocols and processes within health settings. Furthermore, hospital environments were shown to be non-conducive to Indigenous people's healing practices (Barton & Wilson, 2008; Bramley, Hebert, Jackson, & Chassin, 2004; Browne & Fiske, 2001).

The way whānau cope and the mechanisms and strategies they draw upon to do so are important and will help in designing better policy, applying appropriate models of care and implementing effective practice. Whānau dealing with a child who has a life-threatening medical condition face

enormous challenges. The issues include time away from family or work, financial difficulties, transport issues, dealing with multiple admissions, various practitioners, trying to understand medical terminology, as well as the stress and worry that death for their child could occur at any time. Difficulties and challenges have an influence on the whole family as well as the members within it (Rasmussen, 2011; Svavarsdóttir & Örlygsdóttir, 2006; Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010). Coping with a child's critical illness is a contextual family experience in which the experiences of one family member influence the entire family system (Miller & Caughlin, 2011; Revenson, 2003).

While literature recognises the family as heterogeneous (Beckman & Bristol, 1991; Garcia Coll et al., 1995) and its members as interconnected (Collins & Wilson, 2008; Miller & Caughlin, 2011), very few studies focused on *family coping.* Instead, issues viewed through a family lens (Raffensperger, 2012), or those who took a "whole family" perspective (Leadbitter, 2008; Raffensperger, 2012) had most often been informed by parents, or in many cases were taken from a mother's perspective. This is in spite of literature confirming that responding to the family as a whole, while maintaining an awareness of the individuals' needs, is more likely to enhance positive family outcomes (Friebert & Huff, 2009; Hung et al., 2014; Newman & Grauerholz, 2002; Thomas, Sampson, & Zhao, 2003). Despite this being recognised, the assessment of children within the context of their families is generally not undertaken (Sloper & Beresford, 2006).

While family-focused studies about a child who had a life-threatening medical condition were located, discrepancies were found. Many articles sourced incorporated the word *family* in the title and on further investigation *family* was found to equate to parents only (Foster, Whitehead, & Maybee, 2010; Pai, Bhaduri, Jain, Kumar, & Sethi, 2008; Rasmussen, 2011), and were based on the "nuclear family" model (Donalek, 2009; Rasmussen, 2011). M. Brown, Small and Palmer (2008) undertook a systematic literature review of studies focusing on critically ill children. The review included a study that incorporated 1,200 Finnish adolescents with a chronic condition (Kyngäs & Rissanen, 2001). The findings suggested that the term family, regarding a critically ill child, should extend past traditional concepts to include significant others such as nurses or those who contribute to the support of the family or the patient (M. Brown, Small, & Palmer, 2008). Their findings identified that nurses who had built a relationship with the patient aided compliance in managing their illness and improved their health outcomes. This study was included as it was one of the very few Western-focused studies that aligned with the concept of kaupapa whānau (Kyngäs & Rissanen, 2001). The M. Brown et al., (2008) review labelled the role of extended family members as "stand-in caregivers," and reiterated that flexibility in defining family within the health context is needed because families are anything but traditional. They supported the view that the description of the family should include supportive medical personnel. Nevertheless, while Brown et al., acknowledged the incorporation of family presence and significant others, they failed to provide a breakdown of who that entailed. The description of family roles in this study may have been useful to determine who whānau considered as significant in supporting them with a critically ill child.

Descriptions such as "reconstituted" or "blended" families are Western concepts that are used throughout literature. In New Zealand, evidence points to much of the data collected on families

being associated with, defined and dominated by, "household" (those living in a single house or unit) based studies. The term household is commonly referred to as being the economic unit of production (Cribb, 2009; Families Commission, 2012; Superu, 2016). Table 5 provides current New Zealand terms used in documentation relating to family makeup.

Table 5. Family Type and Characteristics

Family type	Characteristics
Nuclear/Immediate family	Usually, two generations consisting of heterosexual parents and biological children
Reconstituted/Blended/Stepfamilies	Where one or both parents have children from a previous relationship, but they have combined to form a new family. The parents may or may not then have children with each other.
Extended family/ whānau	The family, which extends beyond the nuclear family to include grandparents and other relatives. It can also include non-biological members and those who may be members of a community (sports team, church, kōhanga reo)
Fictive kin/Kaupapa whānau /Stand in	Describes forms of kinship relationships based on neither blood ties or marriage
Whakapapa whānau	Those related through blood ties and a common ancestor
Household	Those defined as a family by living in a single unit

Source: Adapted from Families Commission (2008, 2009) and Superu (2016).

These definitions have become a subject of debate for many New Zealand policy makers, analysts and statisticians (Superu, 2016; Tibble & Ussher, 2012). The Status of Families Report (Superu, 2016) presented outcomes based on a full range of control variables regarding household-based family type. Results revealed that household had no bearing on how people described who belonged to their whānau. These indications suggest that units of analysis such as household-based measures are an insufficient substitute for the more complex set of relationships that exist within whānau. Both the nuclear family model and household-based definitions reject Māori and Pacific values including their worldviews about whānau (Cram & Pitama, 1998; Cunningham, Stevenson, & Tassell, 2005; Superu, 2016). Household-based data also fails to provide meaningful levels of analysis to inform policy regarding whānau due to lack of culturally-informed data (Superu, 2016).

In New Zealand, policies continue to reflect Western concepts of the family. Definitions of family within many policies often discount that, for Māori and Pacific, whānau are complex, multifunctional institutions based on distinct cultural principles and meanings (Superu, 2016). Māori and Pacific whānau place a significant emphasis on the wider collective being both whakapapa and kaupapa whānau. As well, extended family members are valued and seen as a fundamental part of the primary family unit and are intrinsically linked to their health and well-being (Arlidge et al., 2009; Rasmussen, 2011; Superu, 2016).

Summary

In this chapter, I have discussed the key strategies used to locate the literature and clarify their inclusion. The questions raised at the beginning of the chapter have been answered. Families are mainly defined according to the Western definition of a nuclear family with particular emphasis on parents. The roles within a whānau were shown to be significantly affected by the impact of

hospitalisation and a member being critically ill. However, there is insufficient explicit information available on whānau coping approaches with much of implied. While roles within whānau were shown to change to some extent, for example, the primary caregiver role (at home and in the hospital), the functions and processes (for example, leadership, decision-making, support) of whānau remained strong. Scoping of the literature revealed a number of cultural coping perspectives that were distinctly different from Western coping approaches. These perspectives included independence and interdependence as well as individualism and collectivism. Research also highlighted specific cultural coping methods including, for example, beneficence and protectiveness. The context in which whānau cope was shown to be highly significant impacting not only on *how* they cope but *what* they had to cope with in addition to ill-health. Additional barriers included: racism, discrimination, a foreign environment and access to critical resources. Deficiencies regarding whānau focused studies have been highlighted as well as research about the roles grandparents, men/fathers and the role culture plays in relation to whānau coping. Mechanisms and strategies deemed as important to the way whānau cope with a child with a life-threatening medical condition have been examined. Circumstances that impact the way Māori, Pacific and other Indigenous people cope, including context, experiences and perspectives, have also been considered.

Gaps identified in the literature signal areas to which this research can make an original contribution. In summary, the areas identified are:

- A whole whānau coping perspective
- Grandparents as primary caregivers of a child with a life-threatening medical condition
- A cultural perspective on sibling coping with a critically ill and hospitalised child
- Coping from a cultural and gender-based (men) perspective
- The role and influence of Ronald McDonald House on whānau coping
- Whānau coping with re-occurring admissions and transitions along the health care continuum
- Culturally informed data

Based on these gaps, and as previously mentioned, this thesis will look at whānau coping mechanisms and strategies utilised in dealing with a child who is hospitalised with a life-threatening medical condition. The identification of these areas has helped to inform the research approach, specifically the methodology and methods which are outlined in-depth in the next chapter.

This thesis takes into consideration the unique and diverse realities of Māori and Pacific whānau such as being away from their familiar support systems, cities and countries. It also explores different whānau compositions and the impacts of dealing with a child who has a life-threatening medical condition at an individual level, for example, as a mother, sister or grandmother, as well as part of the wider whānau group, for example, grandparents, siblings or parents. The research also set out to identify the role of culture in whānau coping given that the majority of health practice is shaped by Western influences. As part of whānau coping, this study incorporated Māori and

Pacific men's views about coping with a child who has a life-threatening medical issue, providing both a gender and cultural perspective – also an identified gap in the current literature.

CHAPTER 4 - METHODOLOGY

In this chapter, I outline the theoretical positioning of the research and the principles that underpin and guide research activity. A description is provided of the overarching framework – the Paradigm Net that supports and houses the key components of kaupapa Māori and Pacific (talanoa) methodologies and associated methods.

The Interface

Historically, concern has been raised about the legitimacy of Western paradigms as the broader framework for research among Indigenous peoples (T. K. Kingi, 2002). L. Smith (1999) noted the many implications resulting from Western researchers researching Indigenous people. These implications can be significant as Western and Indigenous ways are based on different sets of cultural values and alternative concepts such as space and time. They can also include different theories of knowledge and language that may be highly specialised. Worldwide efforts by Indigenous peoples towards self-determination have resulted in debates about research, including intellectual ownership, community control, participation, and partnership, as well as appropriate research processes and outcomes (Durie, 1999a, 1999b; L. Smith, 1999). Māori and other Indigenous peoples alike have struggled to assert their rights to determine their own future in their own ways. In health research, Indigenous people continually voice their concerns, heavily criticising Western research (Durie, 1999b; Soutar, 2000) in relation to Indigenous peoples which in the past has too easily affirmed colonial practices (McGregor, Bayha, & Simmons, 2010). Western research has often served to alienate and misinterpret different cultures and societies. Mis-interpretation occurs when those cultures and societies are viewed through the lens of Western norms and morals (T. K. Kingi, 2002).

Research at the Interface

Social science researchers have been known to use traditional paradigms and approaches (positivist versus interpretivist approaches and the kaupapa Māori/Māori-centred dichotomy) to frame their research. Often this has resulted in researchers having to choose one approach over another forcing them to consider only one line of positioning. Durie (2004) developed a framework coined "research at the interface". The research at the interface framework describes the practice that many Indigenous scientists and researchers have adopted of accessing both Western and Indigenous knowledge pools to gain traction for the betterment of their people (Boulton, 2005). The framework provides a foundation for integrating Western and Indigenous methodologies and knowledge without compromising the integrity of either approach. While debates regarding the validity and superiority of scientific versus Indigenous knowledge continue; more researchers are beginning to use the interface between the two.

The Paradigm Net

The research presented in thesis draws on a similar framework by way of a Paradigm Net (the Net) (Denzin & Lincoln, 2000). Boulton (2005) noted that the paradigm net helps us move beyond utilising competing approaches. The Net allows the researcher to draw on the most appropriate research means from both traditional social science research practices and other cultural traditions and customs to answer the research question. In my mind, the Net made sense as I thought it to be unrealistic for this research not to be informed by or to incorporate both Indigenous and Western views and knowledge, given Māori and Pacific history and the ongoing impacts of colonisation. As well, health environments, whānau, university settings and research procedures are still heavily driven by Western processes. While this research and the practices associated with it places Indigenous knowledge and practice at the forefront of this thesis, I am acutely aware that it is still heavily influenced by Western worldviews.
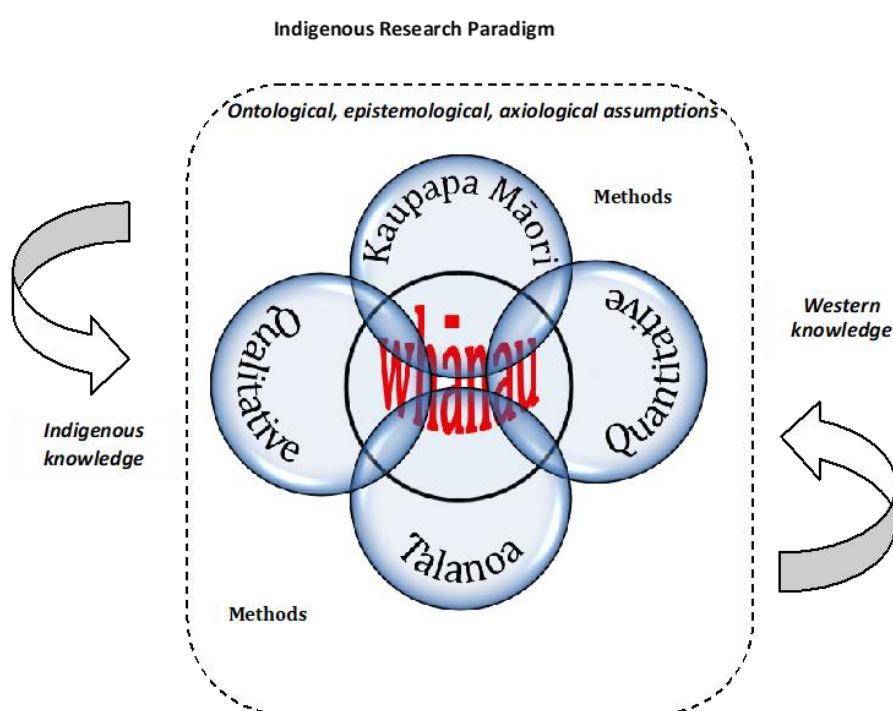
Figure 6. The paradigm net.

(Adapted from Denzin & Lincoln, 2000; Durie, 2004)

Figure 6 shows the location of my research project within the wider world of social science and Indigenous knowledge activity. This figure incorporates a collection of research tools presented as a paradigm net (the overarching framework), it forms part of the methodology and includes a representation of Durie's (2004) research at the interface. The methods within the net have been employed with the utmost respect, putting whānau aspirations of wellness at the forefront. Contained within are key elements that interact, purposely overlapping, signalling the ability of the researcher to draw on one or a combination of these approaches as required, as well as use the "toolkit" of methods each approach brings. Consistent with Indigenous approaches and the reality of life for many, the paradigm net also takes into consideration the researcher's experiences, background, values and culture. It is these combined elements that affect the type

of research questions asked, how the researcher is involved in the topic, and what tools are used to discover answers (Denzin & Lincoln, 2000).

The research carried out within this paradigm is consistent with Indigenous values, holistic views and diverse realities. Indigenous research frameworks have often been used in studies as a vehicle of decolonisation for Indigenous peoples, who were subject to Western colonisation (Vudiniabola, 2011). As Indigenous ways of knowing and sharing knowledge are context-specific, there is no single Indigenous methodology. There are, however, shared common principles and assumptions (Koster, Baccar, & Lemelin, 2012; K. Ratima & Ratima, 2003). The paradigm net contains the researcher's ontological (belief of what is real in the world), epistemological (ways of knowing about reality), axiological (set of morals or ethics) and methodological (how to use ways of thinking to gain more knowledge about reality) assumptions (Denzin & Lincoln, 2000).

Ontological, Epistemological, Axiological Assumptions

The **ontological** assumptions about the nature or form of reality, and, therefore, what can be known about it, stem from a multiplicity of socially constructed realities. These are multi-layered connections that humans have with the environment, and the cosmos, including the living and the non-living (Chillisa, 2012; McGregor et al., 2010). It is based on the collective relationship where the whole is greater than the sum of its parts, and the collective good is more valued than individualism (Chilisa, 2012). An Indigenous ontology takes into account reciprocity, whereby we receive, therefore, we must give (Hart, 2010). It includes spiritual and physical influences (Boulton, 2005; Cajete, 2000; Rice, 2005) and has an emphasis on the connections between health and broader social, economic, cultural and historical factors (Durie, 1998; T. K. Kingi, 2002; L. Smith, 1999).

For this research, Māori and Pacific whānau sat at the centre. Therefore, a collective, holistic approach was considered. As well, diverse realities were accounted for alongside beliefs, customs and the contemporary makeup of whānau.

Epistemological assumptions are concerned with the nature of the relationship between the knower or would-be knower, and what can be known. In an Indigenous paradigm, these assumptions stem from the belief that knowledge is fluid, and derives from many sources, often not recorded in written form but passed down from generation to generation. Sources may include teachings, stories, traditions, visions, dreams, songs, myths and legends (Hart, 2010; J. Lee; 2009). Indigenous epistemology is based on the understanding that knowledge is relational, involving a connection with humans, the world, the past, present and future, and all of creation (S. Wilson, 2001). It takes into account the traditional and contemporary and utilises both Indigenous and Western knowledge.

In relation to this research, it is acknowledged that Māori and Pacific people hold many forms of knowledge and that by using appropriate cultural methods this knowledge will flow forward once trust has been established. Relationships built on trust are especially important given that the use of cultural coping mechanisms may not be overtly recognised but more intrinsically utilised and, therefore, may not be recorded in Western literature. Various forms of coping may be drawn upon

through other methods and resources, such as moteatea (hymns), whakataukī (proverbs) and include stories of old (J. Lee, 2009).

The **axiological** assumptions refer to keeping true to the cultural beliefs, values and practices that guide the ethics of the research. These assumptions include ensuring the research has positive benefits for communities, involves a reciprocal research process that respects people and their environments (Boulton, 2005; Cram, 2001), while maintaining accountability throughout the research process and beyond (L. Smith, 1999). Axiological assumptions allow for the incorporation of self-reflection and self-awareness, enabling the ability to change how we think, act, feel and behave in a way that may better benefit the people and the research process (Garvey et al., 2004). Indigenous research paradigms reflect multiple realities, contexts (for example, historical, cultural and social) and worldviews (Krauss, O'Brien, & Brus, 2001; Otsuka, 2005; S. Wilson, 2001). They are dynamic, evolving and can continually adapt to contemporary challenges (Bear, 2000; Henderson, 2000; Pihama, 2001).

As this thesis initially derived from personal experiences, it was important that self-reflection and self-awareness were incorporated to ensure whānau stories were captured most respectfully. Each family had different realities; some whānau were brought up in traditional ways, others came to New Zealand and had to adapt and change as they assimilated into New Zealand culture. Other whānau did not know their traditional ways and lived solely in contemporary contexts not knowing their language, land of origin or their whakapapa (genealogy). While I acknowledge I had a similar journey and experience and that I could empathise with whānau, I ensured that their journey was of utmost importance. Whānau were given space to tell their story, from their worldviews and their experiences. Taking into account ontological, epistemological and axiological assumptions, the framework for the research was developed to account for diverse realities such as those in which Māori and Pacific whānau live.

It is important to note that the approaches within the paradigm net are not meant to compete nor take away from each other, but rather provided the means to undertake the research in culturally appropriate and unique ways that aim to benefit all involved. Kaupapa Māori methodology acknowledges Māori worldviews and approaches, both traditional and contemporary. The paradigm net takes into consideration a holistic view of health and well-being and incorporates the environment, spirituality and whānau as individuals and as a collective. Talanoa recognises and accounts for Pacific aspirations, and acknowledges the impact of colonisation and migration on Pacific peoples. It takes into consideration the different Pacific nations, languages, histories and protocols. Within this research, the process of talanoa was used to firstly promote the appreciation of Pacific whānau and their associated titles, functions and roles. It was important that these functions were highly valued and recognised as playing a vital part within their communities and societies. Understanding the importance of hierarchy within Pacific societies and within whānau aids in building rapport and trust enabling conversations to flow. Talanoa stems from a strengths-based position, and therefore both Māori and Pacific whānau within this research were positioned as an expert knowledge holder and valuable contributor in shaping the research process and outcomes.

Both kaupapa Māori and talanoa cater to diverse Māori and Pacific realities and different socio-cultural contexts and recognises the continual impact of colonisation while highlighting Māori and Pacific strength and uniqueness.

Western knowledge and research techniques are also incorporated within this research to cater for diverse whānau realities, the continuing impacts of colonisation (for example, loss of land, language and traditional practices), as well as Western practices that have become embedded within Māori and Pacific whānau lives. The research is also health-based and focuses on the New Zealand public health system – a Western-based environment (hospital) where high numbers of Māori and Pacific whānau receive health-related care.

By modifying Denzin and Lincoln's (2000) version of the paradigm net, whānau are positioned at the very core. Utilising culturally appropriate research paradigms and methodologies ensured that whatever context whānau were in, they would feel a sense of familiarity. Setting the right tone for the research was important to validate Māori and Pacific whānau experiences pertaining to their journey of dealing with a child who has a life-threatening medical condition.

Kaupapa Māori

Origins and Concepts

Kaupapa Māori as a research framework is still considered relatively new. However, it is founded on cultural practices that stem back thousands of years (B. Jones, Ingham, Davies, & Cram, 2010; Pihama, 2001). Taki (1996) stated that kaupapa is derived from keywords and their conceptual bases. She explains further that the word 'kau' can be described as a process and uses examples of "to disclose" or "appearing for the first time." H. W. Williams (1985) took the term slightly further giving examples of its different translations including 'ka u' as representing an articulate sound, breast of a female, arrive, reach, be firm and place of arrival, while the term "papa" is used to mean ground or foundation base. Putting these definitions together, kaupapa encapsulates the concepts of "ground rules, customs and the right way of doing things".

S. Walker (1996) discussed kaupapa as the explanation that gives meaning to the "life of Māori". He believed that it is the base on which the superstructures of te ao Māori (the Māori world) may be viewed. Nepe (1991) discussed kaupapa Māori in relation to the development of kura kaupapa Māori (Māori cultural-based teachings) and stated that it is the "conceptualisation of Māori knowledge" that has been developed through oral traditions. Nepe situated Māori knowledge specifically within te reo Māori (Māori language base) and noted that it should not be confused with Pākeha knowledge or general knowledge that has been translated into Māori. Kaupapa Māori knowledge has its origins in a metaphysical base that is distinctly Māori (Nepe, 1991). It is this, according to Nepe, which influences the way Māori people think, interact and interpret the world. Māori knowledge validates the Māori worldview and is owned and controlled by Māori through te reo, highlighting an intrinsic link between the two. The link is shown by the "significance of kaupapa Māori as an educational intervention system in ensuring the survival of kaupapa Māori

knowledge and te reo Māori" (Nepe, 1991, p. 4). Without these stances, te reo and Māori knowledge systems may have been dismissed and lost.

In a contemporary context, the terms kaupapa Māori, tikanga Māori, mātauranga Māori and Māoritanga are used interchangeably. The term kaupapa Māori is now widely applied across a range of organisations and sectors. It has become entrenched as part of the official discourse that appears in a range of documents spanning health, justice, social development, education and employment. While it has materialised as a theory, its parameters are not always clearly defined. Kaupapa Māori challenges, questions and critiques Western hegemony as "mainstream" and Māori ways as the "other" or "less" than another (Pihama et al., 2002). At the core of kaupapa Māori is the right to be Māori, and being Māori for us is "mainstream" or normal.

In essence, the origins of kaupapa Māori are shown by its diversification through different understandings, meanings and contexts. For some, it is associated with significant shifts and movements in history, and for others, it is based on a Māori way of life or their experience in the world. While for many it is solely grounded in te reo Māori, for others its foundations are based in whakapapa, whenua and mātauranga. What the origins show is that the term and concept of kaupapa Māori cannot be broken down into a single simplified meaning or definition. Kaupapa Māori is based on experiences in time, it is diverse and has different meanings underpinned by diverse beliefs, realities and understandings relative to different people and groups.

Kaupapa Māori Research

A key development area in kaupapa Māori is that of kaupapa Māori research. Mead (1996) describes kaupapa Māori research as a social project weaving in and out of Māori cultural beliefs and values. As it has done in education, kaupapa Māori research offers a counter-hegemonic approach to Western forms of research and dominant Western research paradigms. The influence of kaupapa Māori in Māori research and academic developments has been evident throughout the years. A starting point for discussions was at the 1998 Te Oru Ranghau Conference held at Massey University. This conference provided a platform for varying and challenging views regarding kaupapa Māori and its use in research. Throughout the conference the diverse ways in which Māori utilised kaupapa Māori was highlighted resulting in its validity within research.

At the core of kaupapa Māori research is the validation of Māori worldviews and knowledge to frame and define terms of reference, methods of conduct and analysis (Nepe, 1991; Pihama, 2001; L. Smith, 1999). It is also about power and control of knowledge (Te Awekotuku, 1991). As there is considerable diversity amongst Māori, there is no one definitive way, or right way, of conducting kaupapa Māori research (Glover, 2002). M. Ratima (2001) agrees that the nature of the relationship between the researcher and participants is interactive, acknowledging the values of the researcher in influencing the research. Furthermore, K. Ratima and Ratima (2003) pointed out that Māori consider knowledge to be culturally bound, and hence, values-based. This position emphasises interaction as fundamental between the researcher and participant, as well as the responsibility of the researcher as a repository of material and a guardian of information (Irwin, 1994). Penehira (2011) stated that to identify as a kaupapa Māori researcher one would explicitly

identify this position at the very beginning and provide sound rationale. Penehira further believed that alongside the methodology, the analysis will confirm that position and that the findings will ultimately add to Māori and/or Indigenous self-determination.

L. Smith (1999) described and outlined some working principles of kaupapa Māori research which include: whakapapa (knowledge and experience handed down through generations), te reo (Māori language), tikanga Māori (Māori ways of doing), rangātiratanga (self-determination) and whānau (incorporating the diversity of family). L. Smith (2000) raised several questions that may need to be considered as the basis of kaupapa Māori research. These are:

- What research do we want to carry out?
- Who is the research for?
- What difference will it make?
- Who will carry the research out?
- How do we want the research to be done?
- How will we know it is a worthwhile piece of research? (L. Smith, 2000, p. 239)

While there is no universal definition for kaupapa Māori research, a number of themes have been agreed upon that outline its essential features. These include interconnectedness, Māori potential, Māori control, collectivity, Māori identity, relationships and transformation (Bevan-Brown, 1998; Bishop, 1997; Pihama, 2001; L. Smith, 1999). It is important to note that not all Māori who undertake research do so practising kaupapa Māori. There are also ongoing debates about who can conduct kaupapa Māori research and whether Pākehā can positively contribute and participate.

Talanoa

Talanoa is a holistic approach to engaging in rich and meaningful dialogue. The underpinning philosophies and traditions that surround talanoa enable people to engage in social conversation and allows for rich contextual and inter-related information to surface as co-constructed stories. It is this collective relationship that then leads to critical discussions and or knowledge creation (Vaioleti, 2006). Talanoa originated from the Tongan language base and is a derivative of oral traditions. Superficially, talanoa is oftent referred to as a conversation, a talk, an exchange of ideas or thinking (formal or informal). Historically, Pacific cultures, like many other Indigenous cultures, relied on the spoken word as a form of contract or agreement. For many Indigenous cultures, formal written language came about only when European settlers arrived. Before this, communication was solely based on oratory and verbal negotiations which have deep traditional roots in many Indigenous cultures (Otsuka, 2005; Schmidt, 1988; Tavola, 1992; Vaioleti, 2003b). As a research method, talanoa is seen as a trustworthy, relevant approach. It is widely supported by the Pacific Island nations, because of the meaningful engagement of those who are connected through the research process (Vaioleti, 2003b). The concept of talanoa, is similar for Tongans, Samoans and Fijians as well as other nations situated in the Pacific (Latu, 2009), although local variations may differ. As talanoa is universal in its application, it is fast becoming a more familiar practice across sectors (for example, health, social work and education) within New Zealand

(Prescott, 2008; Ramacake, 2010; Tiatia-Seath, 2014). It is considered to be an appropriate approach when investigating various issues that affect the people of the Pacific (Fletcher, 2003; Otsuka, 2005; Vaioleti, 2003b).

Talanoa sits particularly well with Māori and other Indigenous oral tradition communities (Vaioleti, 2006). Talanoa's flexibility provides opportunities to probe, challenge, clarify and re-align. It allows for the creation and dissemination of valid and up-to-date knowledge because the shared outcome of what talanoa has integrated and synthesised will be contextual, not likely to have been already written or subjected to academic critique (Vaioleti, 2006). Talanoa is consistent with how data was analysed in this research by using a bottom-up approach (as explained in the data analysis section). A bottom-up approach allowed the data to determine the story, rather than it being pre-determined.

Relationships and respect are seen to be the foundation on which most Pacific activities are built (Morrison, Vaioleti, & Veramu, 2002). Like kaupapa Māori, talanoa requires researchers to partake deeply in the research experience, unlike some Western paradigms where objectivity and distance are regarded as key to determining the "truth" or in the establishment of facts (Theory of Knowledge, 2017). Similarities exist to kaupapa Māori methodology, where talanoa's philosophical base is collective, oriented towards defining and acknowledging Pacific aspirations while developing and implementing Pacific theoretical and methodological preferences for research (Vaioleti, 2006). Talanoa validates the experiences and ways of Pacific peoples' in Aotearoa and is known to remove the distance between researcher and participant providing a relationship and a human face that participants can relate to. The approach allows the participants more control over the direction and focus of the conversations (Fletcher, Parkhill, Fa'afoi, & Morton, 2006). Talanoa facilitates reciprocal relationships between the researcher and participant and allows for open communication so stories can be told and experiences shared.

To effectively implement research practice that is of benefit to the participants, a series of guiding principles were used. Table 6 outlines each principle and how they were initiated throughout the research with Māori and Pacific whānau members.

Table 6. Principles that Underpinned the Research

Kaupapa Māori	Pacific	Application in Research
Aroha ki te tangata - respect for people in general and specifically those involved in the research.	**Relationships/Alofa*** - to develop, cultivate, and maintain principled relationships	Respecting whānau members and the trauma they are experiencing. Understanding their vulnerability within a foreign environment (hospital). Taking into consideration their stress, roles, whānau makeup and gender (grandparents, kaumātua, same-sex couples).
He kanohi kitea - being present and accountable.	**Meaningful engagement** - to conduct ethical research with Pacific peoples there must be meaningful engagement.	Ensuring face to face contact was undertaken at a time convenient to whānau. Being available and following up with those who participated in the research. Acknowledging participants as partners in the research process.
Titiro, whakarongo, kōrero - Firstly, listen carefully before speaking, be receptive and always be open to new learnings.	**Rights** - research should not be detrimental to research participants, as individuals, as members of a community, or as members of an identified ethnic group. All research relationships are embedded with both rights and responsibilities to the other.	Taking time to sit, listen and prompt where necessary. Knowing whānau have a right to be heard, to express without judgement. Knowing I have a responsibility to the whānau I engage with.
Manaaki ki te tangāta - to look after people	**Reciprocity/Tautua*** – should be a principle for research relationships. It should be demonstrated in practical ways.	Ensuring the environment was comfortable and safe and as free from distractions as possible. Understanding that they might get upset and allow emotions to take their natural course. Following up to ensure they had support or what they needed after the interview.
Kia tupato - ensuring caution, with words, actions, behaviours, data and processes.	**Protection** - primary knowledge that is based on experience and expertise belongs to the research participants and should be acknowledged as such. Where appropriate, researchers should uptake protective measures that will safeguard Indigenous Pacific knowledge	Ensuring participants stories were primary. When participants were upset asking them if they wanted to stop, turn off the recorder or take a break. Ensuring I remained professional when familiar names of doctors or nurses came up where there were concerns or issues of care.

		and knowledge holders appropriately.
Kaua e takahia te mana o te tangāta making sure not to trample on the mana (dignity) of people, and be uplifting (mana-enhancing).	**Balance** - balance is critical when practising the ethical principles of Pacific research. Any research partnerships formed with Pacific peoples should be equitable and fair for both parties, engendering symmetry in the balance of power.	Accepting diversity, different cultural practices and languages. Understanding that whānau I talk to may have differing views. Promoting the strengths of whānau members through a hard time.
Kia mahaki to remain humble	**Respect/Fa'aaloalo*** - The relationship between the researcher and the research participant is based on respect for the inherent value of each human being.	Being open to learning, remembering I am in a privileged position to be part of their journey. Remembering I am teina (the learner) they are tuakana (the teachers).

(*Adapted from Cram, 2009; Health Research Council of New Zealand, 2014; Lui, 2003; L. Smith, 1999) *Samoan equivalent*

Summary

In this chapter, I have discussed the theoretical positioning of the research and the overarching framework of the paradigm net. The guiding principles that underpinned the research, along with examples, have been outlined. As well, the methodologies of kaupapa Māori and talanoa have been explained and deliberated in relation to this research, along with personal understandings and experiences. The following chapter will describe the research methods used in this study. The methods utilised have been informed by the previous background context, literature review, and this methodology chapter.

CHAPTER 5 - METHODS

In this chapter, I explain relevant information regarding how the research was undertaken. It includes how data was collected, who was involved and what approaches were used to answer the research question. The key activities that helped ensure the research process was rigorous are also represented. Researcher reflexivity is discussed by exploring my insider/outsider dichotomy. Ethical,[13] cultural and physical safety considerations are explained as well as the strategies employed to minimise risks. Lastly, I conclude the chapter by discussing the dissemination strategies with a focus on potential approaches for the future.

Limited information was available about Māori and Pacific whānau who were dealing with a child with a life-threatening medical condition. Therefore qualitative methods were appropriate to explore this topic in-depth from a whānau perspective. Also, I wanted to gain an understanding of how Māori and Pacific whānau cope within the context of a Western-based health environment – hospital. Henwood and Pidgeon (1994) confirm that the strength of qualitative research is its ability to capture the participants' reality through their experiences. Table 7 outlines an overview of the methods undertaken within the research as identified in this chapter.

Qualitative methods used in this research project included:

- Participant interviews with whānau (individual and/or group)
- Stakeholder interviews (health practitioners, family support workers, cultural support groups)
- Document review

---

[13] Ethical approval was sought through the AUT Ethics Committee (AUTEC **14/198**) before any research was undertaken (Appendix A).

Table 7. Overview of Methods Undertaken

Method	Māori	Pacific
Consultation	• Hui with Māori researchers • Community groups • Advisory group members • Ngāi Tahu Research Consultation Committee • Ngāti Whātua (Clay Hawke)	• Hui with Pacific whānau, • Community church leaders (Cook Island, Niue) • Pacific Advisory members • Community members
Engagement	**Interviews** • Pre-contact (phone or face to face) • Face to face **Recruitment** • Māori domains (Māori and Indigenous research conferences, symposiums and hui, Auckland, Whanganui) • Māori cultural support services (Starship and Auckland Hospital) • Support services (Kaimahi) • Runanga	**Interviews** • Pre-contact (phone or face to face) • Face to face **Recruitment** • Church-based meetings • Pacific cultural support (Starship and Auckland Hospital) • Support services (Pacific support workers)
Practice	• Karakia • Te Reo • Kaumātua involvement • Koha • Kaumātua • Iwi leaders • Waiata • Kai (stakeholder)	• Minister and matai/Āriki involvement • Prayers • Words in different languages utilised in information and conversation • Koha • Interpreters offered
Analysis	• Māori lens through Māori researchers, kaumātua, Māori advisory group members, Māori Supervisors and whānau	• Pacific lens through Pacific supervisor, Pacific advisory group members and whānau
Safety	• Māori advisors • Supervisors • Peer support • Māori researchers • Mai ki Tamaki	• Pacific supervisor • Cook Island/Tahitian whānau • Pacific Advisors • Pacific health researchers
Dissemination	• Hui • Health and cultural-specific conferences • Pamphlets, summaries • Symposiums • Reports • Kumara vine (word of mouth) • Support meetings • Marae-based presentations • Community-based presentations	• Support meetings • Community group meetings • Pamphlets • Word of mouth • Church meetings • Family meetings • Family gatherings

Consultation

Before planning the research, I undertook consultation with my whānau, with relevant iwi and Pacific communities, and the key stakeholders. The consultation took place in various forms including whānau, iwi, Pacific, stakeholder and advisory group engagement. The initial consultation for this project occurred with my whānau (Māori - Te Atiawa ki Wharekauri and Kai Tahu), and my husband's whānau Cook Island (Rakahanga/Manihiki/Rarotonga) and Tahitian

who gave their approval to go ahead with the research. It was critical to get their buy-in and approval as this research is as much their journey, as it is mine. They were my backbone and primary support through our journey with our son and this PhD.

Iwi consultation occurred with Ngāti Whātua ki Orākei (Appendix B) who are the mana whenua (Māori who have authority over a particular location) to the area where Starship Hospital and Ronald McDonald House Auckland are situated. Out of respect for my own Iwi, although they have authority in other parts of Aotearoa, and to let them know what I was doing, I sought advice from a prominent and well-respected woman in our tribe, Professor Khyla Russell (Appendix C). Professor Russell suggested I also write to the Ngāi Tahu Research Consultation Committee at Otago University to gain their support for the research (Appendix D).

The Pacific consultation took place with Mr Popo Ben (Cook Islands representative and King of Rakahanga), and Mr Tolu Makakona (Nuiean representative and prominent church elder; Appendix E). Unfortunately, the Tongan representative with whom I had a connection became seriously ill. Samoan consultation came by representation on the advisory committee through Ms Atitala Ah Yek and my Pacific supervisor (Cook Island and Samoan) Dr El-Shadan Tautolu. At the time of the research, I was employed by the Health Research Council of New Zealand. Therefore, I had access to both prominent Māori and Pacific health research committees and their respective members. AUT Univerisity, where this research is hosted, also provided access to Māori and Pacific researchers through the various research centres based there.

Before any formal project interviews took place, I undertook several informal preliminary conversations and meetings with parents at support groups and with various support services staff (for example, Ronald McDonald House staff, Child Cancer Foundation staff, ward nurses, my own GP and a rehabilitation specialist). The intention of these conversations was to help gain a sense of how people would react to the research, assist in defining the research question and gauge their willingness to participate.

At a local support group, I posed a question to those present regarding coping mechanisms. The feedback was overwhelming, with people who wanted to tell their story and who knew other people who would also want to share their journey. The support agencies involved in this initial consultation were national-based agencies and, therefore, could potentially help recruit participants in different regions. Feedback from those conversations indicated that participation in the research would be a healing process for those who had a chance to share their experiences and identify their coping mechanisms. Commentary revealed that the study would provide an opportunity for whānau members to share their journey, help others and give back. These meetings provided the basis for the development of the inclusion/exclusion criteria (Appendix F).

Stakeholders and the Ronald McDonald House staff were supportive and welcomed the research. In undertaking some preliminary investigations, it became apparent at the time that there were no current empirical studies that explored how Ronald McDonald House locally, nationally or internationally impacted on whānau. The Chief Executive of Ronald McDonald House Auckland confirmed this and welcomed the research for the Auckland area. He gave his full support for staff time, documentation and provision of data to inform the study (Appendix G).

Advisory Group

An advisory group was set up to help guide the research, and to provide support and cultural advice. The advisory group consisted of seven members with various roles, experience and backgrounds. There were four Māori and three Pacific members. Advisory group member backgrounds included social work, Ronald McDonald House representative, general practitioner (GP), kaumātua, Starship cultural support, Pacific community representative and a patient advocate with Health and Disability Commission experience. The establishment of a terms of reference document (Appendix H) enabled me to provide feedback and updates as well as seek advice or support on any issues that arose. Members where practical attended set meetings as a group but were also approached individually for advice that related to their individual roles and expertise. Members also put forward suggestions and had input into data collection tools and recruitment strategies. Members who were not available for meetings or advice usually recommended an alternative person or pathway to follow up. This was usually communicated by phone or email.

The consultation processes undertaken, while they took some time they were well worth the effort. All who were consulted with, approved and supported the project. The advisory group mandated the project, myself as the researcher, and informed the study's design. An example of advisory input into the design was the translation of information. The original intent was to translate all information into different languages. However, the advisory group felt rather than translate information; the real need was to keep the information jargon-free and easy to read. It was also recommended that access to interpreters be incorporated as part of the study. This advice was taken on board. Advisory group members, alongside supervisors, also helped with iterations of information sheets to ensure information was easy to understand.

Researcher Networks for Recruitment

As part of the consultation process, whānau were identified by using researcher networks and advertising. Support service staff determined that they would help advertise the research and promote information within their respective services. Copies of the information sheet (Appendix I), consent form (Appendix J), pre-thinking sheet (Appendix K) and advertisement (Appendix L) were provided for dissemination. As part of my wanting to give back to various charities, I took part in media activities (including newsletters, website articles, events and promotions). Media involvement enabled wider promotion of the research. My PhD supervisors and colleagues were also supportive, indicating whānau within their circles and regions that may be willing to take part. It was agreed from the onset that whānau would not be approached directly but rather given relevant information so they, themselves, could decide to contact the researcher if they were willing to take part. A 0800 number was set up through Taupua Waiora, Centre for Māori Health Research, AUT (where the research was hosted) in recognition that cost may be an issue for participants. At the time of recruitment, my work was based nationwide and included Waikato, Whanganui and Christchurch. Considering this opportunity, recruitment was extended to these regions. I also informed those who were interested in helping to recruit whānau and stakeholders about the inclusion/exclusion criteria for this research.

Relating Kaupapa Māori and Talanoa to the Research

Firstly, for me, kaupapa Māori is not just a theory or "practice" it is an intrinsic part of who I am. Therefore, to relate kaupapa Māori to this project, I need to relate it to me first. While I am Māori and not Pacific, talanoa is also a part of who I have become and how my children are. Being married to a Cook Islander for over 23 years and being part of his culture, traditions and homelands have influenced the reality I have lived.

Kaupapa Māori, for me, is not just used in research, on paper or in my workplace from 9 am to 5 pm. Kaupapa Māori is a lifeform that encompasses who I am and what I believe in through my everyday life. The underpinning principles of kaupapa Māori, such as manaakitanga (hospitality, generosity), and tika (to do what is deemed right), are the same for me whether I am at work or home, although practices may differ (for example, using more reo while at work than home or vice versa). In undertaking this research, I have considered Māori diverse realities (how and where Māori live) and acknowledged the on-going impacts of colonisation and the marginalised position Māori are in as a result. Kaupapa Māori within this project accounts for Māori whānau narratives, and ensures their voices are heard. The guiding principles, support and accountability, as well as the beliefs of the researcher, will ensure that the project has outcomes that are of benefit to Māori whānau. These principles also underpin talanoa. Talanoa is intrinsic to many Pacific whānau ways of living and being (Vaioleti, 2006). Due to its inherent nature, many Pacific people find it difficult to articulate exactly what talanoa is (Fa'avae, Jones, & Manu'atu, 2016).

While I can read about what talanoa is, my experience of talanoa stems from being part of a Pacific whānau, culture and community for over 20 years. This experience has enhanced my understanding of talanoa, particularly the unstructured structure of discussions, both formal and informal (Prescott, 2008), the relevant hierarchal positions and practices (Prescott, 2008; Robie, 2013; Vaka, Brannelly, & Huntington, 2016) in leading discussions, and, equally important, the behind-the-scenes support and leadership presented especially by Pacific women (which is not widely written about). Talanoa is respectful of positions, people and power, believing that whatever the end outcome, that is what it will be (Prescott, 2008; Vaioleti, 2006). In essence, talanoa draws on its structural processes which are culturally and spiritually determined (Vaioleti, 2006). Talanoa, in my experience, is directed both by courage and humility and it exemplifies collective activity both in thought (thinking about others either negative or positive) and in action (wanting and making something happen as a result of discussions). Talanoa is preserved in time with participants believing the result, whatever that is, will happen when it happens (Farrelly & Nabobo-Baba, 2012; Robinson & Robinson, 2005). Talanoa, for this research, takes into account Pacific whānau narratives which are led by a Pacific whānau structure of dialogue (taking into account values, positions within whānau and community). It accounts for Pacific diverse realities and acknowledges their Indigenous position in their homelands (talking about where they are from, their upbringing practices and traditions). It takes into account that Pacific people are manuhiri (visitors) and, therefore, some would say, teina (those who we need to nurture and look after) while in our lands. For me as the researcher and being tangata whenua (person of the land) it is part of my duty to awhi (support) and manaaki (look after them).

In relation to this research, talanoa and kaupapa Māori are initiated, led and supported by those who want the best outcomes for whānau and include the researcher, stakeholders and whānau themselves. Both methodologies ensure there is respect for all involved. The processes involved in both approaches not only acknowledge the past but honour Māori and Pacific ancestors and history. Kaupapa Māori and talanoa both embrace and recognise different forms and levels of culture, people and whānau. It is these principles, along with the support with which I surround myself (Māori and Pacific whānau, supervisors, mentors, academics, kaumātua, community, and other researchers), that helps me to understand better the whānau we work with. As well, this approach helps to ensure that I am respectful, open and embracing to others and not just with regard to the research. It is this support that gives me the courage to challenge systems, processes, beliefs and behaviours that have an impact on whānau, whether in research, health, or my professional or personal life. While deeply and firmly rooted in links to the past, for me both approaches acknowledge their rightful political place at policy, community and whānau levels. I am grateful for all those who have fought in the past and continually fight so our whānau might struggle less in the future. Those that have paved the way have ensured that cultural methodologies remain a firm, true and valid part of the research.

Both talanoa and kaupapa Māori methodologies encompass practices and beliefs that are present; they are fluid, reflective and evaluative. The approaches are flexible and enduring, allowing ongoing transformation to occur.

Transformation has been shown through the many avenues in which talanoa and kaupapa Māori are now being used (for example, academia, traditional meetings, research and health). This research, through these methodologies, can

- draw on links to the past (such as stories, myths, legends, whakatauki, dreams and visions),
- utilise cultural practices (for example, waiata, karakia, haka and moteatea),
- have links to the spirit world (honouring and acknowledging God, Ātua, Jesus, our ancestors, our whānau who have passed on),
- have links to the environment (our lands, beach, being near water, near our sacred burial grounds)

Also, this research can embrace the ever-changing world of technology such as video calling, Skype and social media (such as Facebook and Instagram). My research approach took into consideration migration, urbanisation and the social determinants of health. Through the overarching framework of the paradigm net, the processes used were eclectic in nature and included traditions and languages; as well, death was acknowledged, especially when a child had passed on, as this was a stark reality for whānau within this research. The flexibility and use of methods allowed for the contemporary realities of whānau, their lived experiences, knowledge and views of the world in the context of coping with a child with a life-threatening medical condition to be at the forefront. These methodologies allowed for self-determination in that it was the participant's story that was to be validated, their experiences that count, and used their definition of whānau, alongside processes that helped identify their methods of coping.

For Māori and Pacific people, the concept of health is holistic and cannot be separated from their historical, cultural, economic, political, and environmental circumstances (Durie, 1998). As well, it incorporates physical, spiritual, mental and social well-being and their ability to participate fully in family and community life (Bacal & Jansen, 2006). Māori and Pacific have shown their strength and resilience through their very survival and ability to thrive continually, considering the adverse impacts of colonisation and immigration. It is the strength, agility and flexibility of such whānau that formed the very basis of this research. Therefore, it was imperative whānau, and whakawhānaungatanga (relationships) sat at the core of this work, and, as the researcher, I sought positive outcomes for collectives by promoting the strengths of Māori and Pacific whānau and their culture (Porsanger, 2004). The research process I used embraced the relationships and interactions by valuing reciprocity while upholding my responsibility and obligations and honouring those involved in the research, their worldviews, knowledge, culture and traditions (Bishop, 1997; Porsanger, 2004; L. Smith, 1999). Most importantly, the research aimed to validate Māori and Pacific aspirations making positive, relevant and practical differences for whānau (L. Smith, 1999; Vaioleti, 2006) who were dealing with a child's life-threatening medical condition.

Inclusion/Exclusion Criteria

Parents at support groups and Ronald McDonald staff helped develop the inclusion and exclusion criteria. The inclusion criteria for whānau recruited into this study included:

- whānau who are of Māori and/or Pacific Island descent; and
- who had a child who was diagnosed with a life-threatening medical condition; and their child was a short term (approx. 3 months) medium term (6 months to one year) to long-term patient (over one year) and may have a terminal condition. It also involved whānau whose child had died; and,
- who had accessed hospital-based services and had been admitted to Starship Hospital within the last five years (between 2008 and 2013).

The exclusion criteria were aimed at whānau whose child was newly diagnosed or who had recently passed. The exclusion was in recognition that they were likely to be coming to terms with the diagnosis or death and, therefore, managing a high level of stress and anxiety. This was implemented for two reasons (1) as a protective mechanism so whānau could grieve, and therefore, have more time to try and come to terms with the situation; and (2) it was anticipated that whānau might not be able to clearly articulate their coping mechanisms and strategies due to the rawness of the situation.

Qualitative Data Collection

Interviews

Face-to-face interviewing was deemed the best methodological way to collect data (Boulton, 2005). All participant interviews were held kanohi ki te kanohi (face to face). In keeping with the cultural values of the project, For Māori and Pacific peoples, meeting face to face is determined

as a relevant and accountable relationship aspect (Milroy, 1996) and has been viewed as being the gold standard in qualitative interviewing (Cachia & Millward, 2011). All interviewees were adults (over 16 years of age). Interviews took place in English as offers for an interpreter were declined. Interviews varied in length, ranging from 60-110 minutes.

Semi-structured interviews give participants the opportunity to discuss issues that are important to them and accounts for issues that the researcher may not have anticipated (Patton, 2002). Interview schedules (Appendix M and N) were used to guide and nurture participants in telling their story (Rubin and Rubin, 2011) and both (whānau and stakeholder schedules) were developed with input from PhD supervisors and the advisory group. The whānau interview schedule was tested with my family members (a Cook Island male and a Māori elder), and the stakeholder interview schedule was tested on a colleague (a Māori female who worked in the health sector). Both schedules were then refined and tested with two Māori researchers until both the researcher and supervisor felt satisfied that (a) the schedules would adequately capture the appropriate data, and (b) the sequencing of questions allowed for logical flow (Braun & Clarke, 2013). The schedules also provided a framework for some consistency across all interviews.

Interviewing techniques were also practised and refined, in particular, opening and summarising the interviews. Techniques aided in highlighting any gaps and asking any follow-up questions (Kvale & Brinkmann, 2009). Questions were open-ended as much as possible to enable participants to talk freely without being limited by a question that required a yes or no answer. Polit and Hungler (1995) stated that semi-structured interviews are best used when reassurance is needed specifically related to areas covered in interviews. Semi-structured interviews also allow for themes to be easily traced. Questions were open enough to allow for diverse views to be expressed and captured. Whānau were given a pre-thinking sheet as practice interviews revealed some difficulty in identifying how they coped. Stakeholders were given specific themes to consider before the interview. These themes were related to the identification of similarities and differences in coping and of additional support that could be provided to help whānau cope that may be currently absent.

Before the interviews commenced, the research project information was reiterated to participants, and the information sheet and consent forms were briefly discussed; participants were also given the opportunity to ask questions and seek clarity on any issues before proceeding. All interviews were audio recorded with the written consent of each participant. The first interview question was, "Can you tell me about your family's journey?" This question allowed whānau to start their story where they felt comfortable. For example, some whānau chose to start with the diagnosis while others started with being discharged from hospital after several months of treatment. Overall, the interview structure remained consistent with whānau telling me about their journey, how they coped and what mechanisms and strategies they used. Prompts were used throughout such as "tell me a bit more about that" or "who else played a significant part?" Mostly, minimal encouragers were displayed, like nodding my head while they were talking, assisting people to continue. At the completion of each interview, participants could ask questions, clarify any issues and add any information they felt they wanted to contribute. Each member received a $50 supermarket voucher in appreciation of their time and contribution to the research.

Interviews were spread out to allow the researcher to facilitate the process of transcription and allowing time to then better absorb the data. No more than two interviews were held in one day (Hallowell, Lawton, & Gregory, 2004), as it was emotionally and physically draining for me as the researcher. Interview audio files were uploaded onto a computer immediately after each session. Data was secured with a password. I then transcribed the audio files which allowed for data absorption and familiarity. Each transcript was then checked by me and given back to those interviewees who had indicated they wanted to receive them. This process enabled participants to change, delete or correct any part of the interview. No participants came back with changes.

It is important that the method used be culturally appropriate to the target audience. Chillisa (2012) terms these Indigenous methods: the extent to which research methods and measures are tailored to the culture of the research. In this case, the methods used were culturally appropriate to the target audience - Māori and Pacific whānau. Within the context of this study, I used Māori and Pacific words within information sheets, advertisements and during conversations, for example, using greetings such as kia ora, talofa or mahi (work) or moe (sleep). Interview venues were selected, so they were convenient for whānau (being close to hospital or wards or occurring within private meeting rooms). The language was kept simple and jargon-free throughout the process, including information given out and during interviews. I acknowledged each whānau member's role as well as the time and knowledge they were giving in telling their story (for example, kaumātua, matai/chief or church minister). The culture and homeland of whānau were always considered (particularly since many whānau resided outside of Auckland and, in some cases, New Zealand), as being away significantly affected their coping.

In understanding the process of talanoa, I allowed significant time to talk about general activity, build trust and rapport, and gain a better understanding between whānau, as interviewees and me, as the interviewer. The result of this process was that we became a "whānau" connected through their story, feelings and experiences. I kept in mind the importance of giving respect to relevant communities that formed a significant part of the whānau journey (this included church, marae or kōhanga reo, for example). Where a child had passed away, there was always an acknowledgement of the child in the present tense as whānau involved held the belief that the child is still with us. Interviews proceeded by asking members how they would like to start and finish their interview (most used karakia [prayer/incantation] or expressions of thanks and gratitude). These processes and protocols formed part of a natural process that occurred and were shared between the researcher and whānau member(s).

Participants were reassured that participant information would be kept confidential and non-identifiable. In two cases, whānau assured me that they felt comfortable if we wanted to use their names, as it was a means of helping others in similar positions. Participants welcomed a collective approach whereby they could bring other members with them to be part of the interview (some took this up). It was also important to be comfortable with emotions being displayed while whānau told their story. When emotions arose, I let whānau determine whether to proceed with the interview or not. Other cultural practices were also encouraged as part of the interview process, for example, bringing in support whānau, readings, bringing special mementoes, photos, songs and kai (food). While, in a formal sense, this was an interview process, for whānau and the

researcher, it was also a journey of storytelling and healing. The process validated whānau as a significant coping mechanism, a support and resource that enhanced their endurance, both individually and collectively.

Participants

Patton (1990) states that qualitative interviewing starts with the thinking that other people's perspectives are meaningful. The goal is to get people talking about their perspectives and experiences, to capture their language and concepts (Seidman, Rubin, Rubin, & Dilley, 2004). Māori and Pacific whānau members individually and collectively provided a primary data source for this study. Stakeholder interviews (Appendix M) were also integral in contributing to the understanding of whānau coping.

Recruitment

Accessing whānau to be part of the project was in some ways made easier by still being part of support groups post-treatment, having sustained connections with various charities and maintaining contact with whānau with whom we had built close relationships. In the context of the research, I felt it was important to include whānau who lived in other regions. The inclusion was due to my observations of whānau being away from their hometowns, and therefore leaving their support systems, which seemed significant to their coping. The simplest way to capture those who were away from their hometowns was through Ronald McDonald House. I had already established with the Chief Executive and relevant staff that Māori and Pacific whānau were the highest users of their three Auckland-based houses (N. Judd, personal communication, 2013).

Whānau

As the research was whānau-centred, interviews looked at how whānau coped on two levels: an individual level (for example, as a female, father or partner) and as part of the wider group (including, siblings, couples, men or grandparents). I conducted whānau interviews (Appendix N) either as individuals or as a group, determined by whānau themselves.

Twenty sets of whānau interviews were undertaken over a 4-month period. Eight whānau interviews were conducted with Pacific whānau and 12 interviews with Māori whānau. Seven males took part, four of whom were of Pacific descent (Cook Island and Samoan). The majority of interviews were undertaken as individual interviews (n=14) and the remaining as group interviews (n=6). Group interviews varied in number comprising between 2-4 members.

Whānau were made up of both Māori and Pacific members. Māori within this study included those who were Auckland based and those who resided in other parts of the country (for example, Whanganui, Waikato, Christchurch and Tokoroa), or in other countries (such as Australia). Māori participants were also a mix of both rural and urban, younger and older generation, and comprised a combination of whānau roles (such as mothers, grandparents and step-parents) and functions (for instance, kaumātua/elder, tohunga/healer and kaiako/teacher). These roles and functions are significant to how Māori whānau operate in general and particularly when a child is critically ill.

Pacific peoples in this research included both New Zealand citizens and permanent residents, those who lived in New Zealand and those who, at the time of admission, were residing in their homelands or other lands (for example, Cook Islands, Samoa, Australia). Pacific peoples in this study comprised different roles (for example, grandparents, fathers, aunts) as well as holding various functions and stature in their communities (such as matai/chief, king or church minister). These roles and duties are deemed relevant to the Pacific culture and are significant to their family structures and systems.

The age of whānau members ranged between 22 and 66 years. The types of conditions whānau were dealing with included; different types of cancers, brain tumours, heart conditions, immune deficiencies, organ failure and perforated appendix. Over half of the participants indicated that they had qualifications including degrees, masters and one had a PhD.

All whānau who were interviewed had resided at RMHC (an unintended consequence) and were asked three main questions regarding their utilisation of the houses and or the family rooms. RMHC questions formed part of a full schedule of interview questions pertaining to whānau coping. Questions specifically related to RMHCs were:

1. Did you use Ronald McDonald House or family rooms?

   Yes - (go to question 2)

   No - tell me what you know about RMHC

2. Tell me about the role RMHC played for you and your family

3. Is there anything more or different you would like to see RMHC do in the future?

Questions about RMHC were scheduled for the latter part of whānau interviews. However, nearly all whānau raised the topic without prompting. Whānau who raised the subject earlier than anticipated signalling the significant role RMHC played throughout their journey in dealing with their critically ill child.

All 30 sets of participants interviewed knew about Ronald McDonald House. All 20 sets of Māori and Pacific whānau interviewed for this report had resided at one of the Auckland-based homes. Some whānau had also been accommodated in Ronald McDonald houses in other cities. The frequency of stay varied for each whānau, with some having stayed numerous times at the Auckland based houses over extended periods, while others were accommodated once. The length of their stay ranged from one month to just under one year. Figure 21 shows the most extended stay for 2016.

Stakeholders

Stakeholders were defined as those who had an interest and who had supported whānau through their journey. Given that treatment and support for whānau dealing with a child who had a life-threatening medical condition can last for extended periods of time, stakeholders operate in powerful positions to observe how whānau cope, what mechanisms they use, (whether negative, positive, intentional or unintentional) and what strategies they draw on. Whānau interviews were

undertaken before stakeholder interviews, and hence a preliminary analysis was completed that informed the stakeholder interview process. The analysis enabled me (as the researcher) to identify and explore any glaring gaps in information or think further regarding issues that arose. This process assisted in developing additional questions that needed to be asked of stakeholders.

Stakeholder Recruitment

Stakeholders were initially identified through whānau members. Whānau members identified services that had been a significant support through their journey, including the Child Cancer Foundation, Heartkids, Make a Wish Foundation, Ronald McDonald House, and Starship Hospital staff. I had also established a rapport with these services through the duration of our whānau journey. Stakeholders were approached by phone, email or in person. Information was provided before meeting and time was agreed on to undertake the interviews. All stakeholders were interviewed face to face at a place that was convenient for them (this included a hospital meeting room, cafe, work meeting rooms, or at their office). Ten sets of stakeholder interviews were undertaken in total.

Stakeholders were identified using snowball sampling. Whānau did not identify clinicians to interview (this is not to say clinicians were not supportive, but rather, those people that were identified to interview stood out more to whānau). While original recommendations came from whānau, stakeholders themselves also identified potential people. In some cases, they would bring another person to the interview with them. For example, one Pākehā stakeholder interviewee thought it would be beneficial to bring her Pacific colleague to provide a Pacific viewpoint. Stakeholder participants represented a range of ethnic backgrounds and roles. Stakeholders self-identified as the following ethnic backgrounds. The three male stakeholders were all Māori, and the seven female stakeholders were: Zimbabwean, Māori, Pakeha, Samoan. Two sets of interviews were completed as collectives (comprising two and six members, respectively) and eight interviews were with individuals. Stakeholders' roles include Ronald McDonald House managers, Starship and Auckland Māori cultural support staff, Ronald McDonald House and Starship administrators, Child Cancer Support service managers, social worker and support service coordinators. At the time of the research, the Pacific Cultural Support team were unavailable to contribute due to significant staff shortages. Stakeholders were asked to consider how different whānau cope; what strategies and mechanisms they draw upon; what the differences are regarding gender, culture, and age, for example; and, what the similarities or unique strategies might be. Stakeholders were also asked to identify whether there were ways that services could better support whānau to cope, and what they considered was working well.

Six out of ten stakeholder participants held intimate knowledge related to the second objective Ronald McDonald House. Four stakeholders were employed across the RMHC organisation (between the two houses and family rooms), in different roles, while two were employed within Starship and had a close working relationship with both RMHC frontline staff and whānau. Other key stakeholders were aware of the organisation but did not necessarily hold detailed organisational knowledge.

All stakeholders were asked a range of questions regarding whānau coping (Appendix M) including whether they referred whānau to RMHC.

Qualitative Data Analysis

The analysis took place when the data from the interviews (whānau and stakeholder) were deemed as reaching saturation (no new data was being generated; (Morse, 1995; Sandelowski, 1995). Qualitative analysis is interpretive in that it tries to gain a greater understanding of the data by exploring meaning at a deeper level (Braun & Clarke, 2013).

Qualitative data from the research were analysed using inductive thematic analysis. The analysis involved different stages including analysing information from:

- whānau interviews
- stakeholder interviews
- documents, newsletters, contracts and websites
- Ronald Mcdonald database
- Memos or field notes which contained observation notes and personal reflections

Inductive Thematic Analysis

Thematic analysis is a systematic approach to identifying, analysing themes and reporting patterns that emerge from the data about the question being researched (Braun & Clarke, 2013). It seeks to examine commonalities, differences and relationships (W. Gibson & A. Brown, 2009; Harding, 2013). The inductive thematic analysis adopts a bottom-up approach. This approach allowed the data in this research to tell the story rather than following pre-determined ideas that may have come from other sources. While it is not shaped by existing theory, it does take into account the impact of the researcher's standpoint, disciplinary knowledge and epistemology (Braun & Clarke, 2013). Thus the approach is compatible with talanoa and kaupapa Māori processes.

Through inductive thematic analysis, the participants' narrative was the primary source of data. The interview transcripts were examined manually and then coded according to themes found in the data. These were then sorted into sets of preliminary categories and split into different themes (including similarities, differences or negotiating). The following section outlines the process of how codes, categories and themes transpired. The coding and thematic analysis were undertaken and discussed alongside my primary supervisor. Te roopu taukoko was also undertaken. Te roopu tautoko is support gained as a group. It is a collective process where other people also undertake a small section of analysis to see if similar or differing themes appear. Two Indigenous researchers participated in te roopu taukoko (one Māori and one Metis - Indigenous to Canada), together these researchers looked at six transcripts. Most of the coding resulted in being similar across all the transcripts with some minor differences. These differences were then discussed and agreement sort on either a new code or to add it to an existing one. Ongoing hui and korero occurred with researcher peers, and to incorporate Pacific views, Pacific advisory members,

Pacific whānau members and my Pacific supervisor were part of Pacific analysis. The consistency helped me to check in, re-validate along the way and further frame the write up of the findings.

Coding

Inductive thematic coding involves a process of identifying aspects of the data that relate specifically to the research question. Braun and Clarke (2013) identify two main approaches to coding in pattern-based forms of qualitative analysis. The approaches are selective coding and complete coding. Selective coding involves identifying a corpus of instances of the phenomena and then removing them with the purpose of data reduction. Complete coding identifies anything and everything of interest or relevance to answering the research question within the entire dataset. Complete coding was utilised in the analysis of this research.

The process I used for complete coding included:

- initial coding
- categorising
- identification of themes
- classification of overarching themes

All transcripts were read and excerpts coded by colour distinguishing different areas such as family, hospital, or Ronald McDonald House for example. A code or term was then associated with the text, for example, roles, cultural or negative. Research notes were added in blue and thoughts or queries to pursue were added in red. The thoughts, notes and queries formed a memo and helped with the analysis in that it contained information (to further stimulate thinking at a later time) or an action (to be done). Memos were valuable to the process, particularly in refining the analysis. Two examples of memos and coded excerpts are provided in Figure 7.

[Researcher Notes] Role: Māori mother/grandmother – youngest but the leader of the family, a sick child is whangai has five other children. Speaks te reo, teacher, well known in her community, the husband is a teacher and is well known in the NZ rep sports arena.

85	is my experience not talking about other parents but it's, it's the fact that I've got kids older than some
86	of the nurses here and a good example is one of the speech therapist, she comes in and tells me, oh
87	this is how you set up your baby, this is how you feed the baby and when I asked her how she was, she
88	was just in her 20s and then she has no kids, I've got kids, I've been feeding them even my siblings,
89	my brothers and sisters I've looked after and nephews, nieces, but do you see it, I understand the feel
90	what they've been trained to but to actually experience being a father or a mother, to have kids, to look
91	after kids it's a 24 hour thing, it's quite different and I was even told by one of the consultants here, I've
92	been staying here too long. This is where our issue was because they said I should get, go out of the
93	hospital, cause up in here's too long, I said that's none of their business, that's my decision and my
94	wife's. You're medical, that's you focus on that and focus your energy on my son. If he's ok, I'm fine,
95	if he's not, I'm not happy, simple as that. But saying, we're like you're over dedicated, we see you as
96	an over dedicated dad. I said to myself, look you say that to a person who's broken somewhere, go
97	home, have a break, you don't say to us parents, it's our life time thing with our kids, that's why we
98	make the decisions and it sounds like your trying dictate how we live our life. So ever since then, those
99	ones have a few issues with them, they do not take the parents advice at times, if, if they, somehow it
100	feels like it falls on deaf ears, cause Arthur he's never hungry cause he's on a continuous feed. The
101	only problem he's got is his nappy, a wet nappy or a number two nappy or he's fighting it sleeping and
102	that the only time you hear his voice, if he's very upset then something is wrong with him, he's sick but
103	I've ..?.. time and time again to these, the nurses, every nurse that comes, they don't take care of my?
104	and it's the money?, I eventually had after all this time put down my foot and I told one of the young
105	doctors there, I don't want you here, cause just said to me he's single, no wife, no kids, no girlfriend,

[Researcher notes] Role: Samoan father – Matai/teacher/lives in Samoa/elder and church choirmaster (imp roles) well respected in communities speaks three different languages. Had to leave Samoa urgently when the wife was pregnant with a baby, has two daughters under 12 who have just flown over, so they are finally together. Limited supports in Aux as NZ family in South Island.

Figure 7. Examples of data excerpts.

Initial coding came from reading data from the transcripts, highlighting areas deemed relevant and important to consider, and assigning an initial code to it. Initial coding is seen above in Figure 7. Examples of the range of codes used are seen in Table 8.

Table 8. Overview of Data Codes

Codes
Men/women
Communication/information
Proximity
Cultural
Spiritual
Shaped by experiences
Negative coping
Protective coping
Older/younger
Out of their control

Table 9 Outlines the **categories** that codes were then assigned under. Categories came about by grouping the codes into specific groups. Some codes could sit in multiple categories.

Table 9. Example of Data Categories

Categories
Men/women = Gender
Older/ younger = Generational
Communition/Information/resources = Engagement
Māori
Grandparent(s)
Pacific = Pacific men
Whānau = Collective
Individual = Personal/physical
Organisational = Other hospitals/Starship/RMH House
System = Health system

Table 10 shows the identification of the themes that became apparent by comparing codes with categories and the excerpts.

Table 10. Example of Coded Themes

Themes
Whānau coping context
System engagement barriers
Facilitators
Coping mechanisms
Coping strategies
Resources available
System supplied resources
Gaps/limitations
Whānau initiated resources
Fill the gaps

The coding process also took into consideration: roles, context, and similarities and differences. The roles whānau members had in relation to the child were also considered (for example, aunty, uncle, or father). Identifying their roles in relation to the child helped when analysing the data by confirming the broad relationships that Māori and Pacific members constitute as whānau so analysis could identify if and how these impacted on whānau coping. Commonalities and differences were then examined within and across transcripts where additional themes transpired specific to certain categories, for example, the generational differences in using social media as a support strategy and cultural assumptions that pertained to Pacific men. Table 11 shows codes

and themes that were re-analysed and refined. The merging of codes and categories formed three overarching themes that became the basis for my analysis, as identified in Table 11.

Table 11. Overarching Themes

Overarching themes
Whānau context for coping
Coping resources
Surviving the system

Validation of Findings

Observations and field notes were also kept to help with context, thoughts and feelings during interviews. Using a journal after interviews had been completed helped me to process information, highlight issues or interesting observations it also helped me to debrief and somewhat let go of the emotion associated with interviews. I have labelled journal entries as memos (see Table 12).

Table 12. Memoing

Memo: 1
It's interesting that most of the participants identify the cleaners and receptionists as being a significant support throughout their journey (those that have been going through treatment for long periods of time). Also, a point to note is that these supports are the only few brown faces within the health environment and have been in their respective roles for many years.
Memo: 2
Gender perspectives are interesting; while many of the women identified that their partner being around wasn't that helpful to the everyday care of their sick child, the men interviewed identified that they knew they didn't or couldn't do much but felt they needed to be physically present.
Memo: 3
Men seemed to be discouraged from caring for the child within HDU and PICU. Men identified when they gave their partner a break or wanted to be with the child, health care staff would tell them to have a break or would take over from what the men were doing (feeding, changing, bathing). The Pacific men felt offended when they were told they needed a break from their child or the hospital.

Once the data analysis had been completed, preliminary findings were then presented back to participants and stakeholders at various hui, conferences and symposiums. This feedback process was critical for a number of reasons. It allowed participants to remain involved, provide comment and validate or critique the findings. Feedback received was sometimes in a public forum, by way of further questioning about certain categories. Other times it was in private during a tea break or after a presentation. For example, questions were asked about how whānau cope when they have to prepare for their child's death, or whether they could suggest a solution to help resolve the lack of support and or information given to them by health professionals. In some instances, more information or recommendations of whom to talk further with were offered. Most times, participants nodded during the presentation in support of the findings; others would

publically agree by giving their experiences and or highlighting how the interview helped them heal by talking about their child and the journey.

In response to feedback, I would answer as honestly as possible about what was found through the research. If I did not have the answer, I would validate that what participants had said was an important issue that could be explored in the future. In one meeting, I had to keep reiterating the scope of the study as there was general excitement about how the research could have been expanded. Overall, audiences were happy with what was presented; there was no negative feedback or controversy regarding what the findings were or what was presented. Table 13 shows an example of validation.

Table 13. Validation - Community-based Symposium in Whanganui

Validation: 1 – Community-based symposium in Whanganui
Findings were validated through participants nodding in agreement. Some of the audience agreed by sharing their own similar experiences. Stakeholders present also shared that issues raised were not new, bringing to light there have been little changes in the health system over a number of years. Limited changes were most evident in relation to the lack of a Māori and Pacific health workforce, the involvement of men/fathers in the care of sick children and the lack of cultural responsiveness within the hospital environment.

Document Analysis

At the start of the research, high quantities of documents were obtained that were deemed relevant to the research. However, the interview analysis facilitated the narrowing down of documents and information within them. Document data became targeted informed by participant interview information. The analysis of documents (key service articles, website information, newsletters and other supplementary information) was undertaken manually using thematic content analysis (Crabtree & Miller, 1992; Patton, 1990; Yin, 1994). This process allowed for the careful description of data and the development of categories. Documents and supplementary information were analysed against similar codes and categories presented from interviews. This process enabled the data to be organised around consistent key themes. These documents were primarily viewed to confirm or show contrast compared with interview data and to review service and support information and identify gaps that may affect whānau coping. Documents were also viewed and analysed for their cultural content (for example, is the service or support culturally defined, does it talk about cultural responsiveness or is there information that specifically pertains to Māori and Pacific whānau?).

Ethical Considerations and Issues

Ethical approval was sought through the AUT Ethics Committee (AUTEC **14/198**) before any research was undertaken (Appendix A). The research was also guided by the following ethical frameworks:

- Te Ara Tika: Guidelines for Māori Research Ethics and Guidelines for Researchers on Health Research Involving Māori (Putaiora Writing Group, 2010)
- Pacific Health Research Guidelines (Health Research Council of New Zealand, 2014)

- Pacific and Māori principles that underpin the research project (see Table 6, page 76)

Guidelines were read and adhered to throughout the development and duration of the project. Examples include consultation, feeding back to participants along the way and using cultural processes and resources. As well, principles within these core documents were incorporated as part of the design. I also consulted with other Māori and Pacific researchers who shared their experiences and knowledge. Additional readings were obtained and read which contributed to identifying ethical issues to be considered while reiterating the importance of positive engagement, partnership and participation with communities such as these (HRC, 2014; MCNZ, 2016). It was these readings and support that promoted my consciousness toward developing a checklist protocol (Appendix O) that was a constant reminder and source of safety for all. The protocol kept me grounded in relation to where I stood as the researcher and ensured that confidentiality, consent and safety were priorities at each stage of the research, in particular, the interviews

Information sheets contained relevant information that enabled Māori and Pacific whānau and stakeholders to be fully informed about the study and their rights in relation to it. That is, they could choose to be involved and or withdraw at any time. Information was also explicit regarding how and where information would be kept, such as their consent form and interview information. Participants were informed that their consent form and information were filed separately, and only the supervisors and I would have access to it.

In research, it is common to talk about the data destruction timeframe and process. However, I was conscious that using words such as destroying *their* information or stories about their critically ill child and their journey was culturally insensitive and disrespectful. Instead, I talked about the university's process of protection of people's data in general so that it cannot be used by anyone else without permission in the future. I reiterated to whānau that the university's *copy* of the interview information would be made obsolete after a certain length of time, but they would have their copy of their interview story as well; after they will receive a summary report that includes information from participant stories.

Hard copies of the transcripts are stored in a locked cabinet within Taupua Waiora, Centre for Māori Health Research, AUT. These were coded and separated from consent forms. Electronic copies were also coded and stored on the computer with a password. Codes are kept in a locked draw separate from transcripts. All data, including consent forms, are to be retained for six years according to the ethical requirements. After this time, destruction of the data will occur as per AUT processes.

Confidentiality is an important issue in research and forms a major part of ethics approval processes. Before undertaking the research, discussions were held with advisory group members regarding identifying versus non-identifying data. Historically, Māori and Pacific peoples have contributed significantly to Western-led research studies about them and have often not been acknowledged (T. K. Kingi, 2002; L. Smith, 1999). There was agreement that before dissemination, an additional discussion and strategy meeting would be held where people involved in the research would be fully acknowledged if they agreed. I informed participants about

confidentiality and that their information (despite consent to use names) would remain anonymous in the write-up. Anonymity was kept as permission had not been granted by all participants. However, the researcher has acknowledged all whānau participants, stakeholders and other contributors whenever the research is talked about.

Cautionary Measures

As a whānau member and researcher, I was acutely aware that my participants were a vulnerable group of people and, therefore, cautionary measures were put in place. Free counselling sessions were negotiated for this research project with the AUT Counselling Centre. This measure was put in place in recognition that telling their stories could trigger emotions and memories for whānau that needed to be worked through. I also understood that whānau might not have necessarily been offered counselling during their journey nor perhaps had the means to undertake it (due to financial, time or access restrictions). There was also an appreciation, from my experience, that triggers could come on any time post interview. Therefore, time frames regarding when counselling sessions could be initiated were extended to cover the duration of the research project (three years) and not just the interview phase itself (four months). Kaumātua, church ministers and other cultural support resources such as interpreters were also organised. This support came through input from the advisory group and was also offered post interviews.

As whānau stories were primary, it was paramount that they were put at the forefront. Prior to interviews taking place, preliminary contact was made on at least two occasions with relevant whānau members. A quarter of interviewees were contacted face to face, specifically if I was in the area where whānau were staying. In most circumstances (due to distance and location), this contact occurred by phone (or both). Pre-contact with whānau before the interview was positive as it provided for a deeper and quicker rapport when it came time to undertake the interview itself. The first form of contact was to make an initial introduction (for example, to introduce myself, provide a summary of the research and check that they met the inclusion criteria). Fortunately, all potential participants met the criteria and no-one needed to be excluded. The second point of contact (usually a day or two before the interview) was to confirm and remind whānau of the time and place to meet. Through experiences of having a child with a life-threatening medical condition, I understood that things could change at any given moment. There were three interviews out of the 20 that needed to be rescheduled. The preliminary contact with whānau also included discussion about obtaining their written informed consent for interviewing and audio recording.

Obtaining Informed Consent

A consent form was sent out with the information sheet to participants if time allowed. Therefore, when it was time to meet face to face they were well aware of what needed to be signed. Some whānau members had it prepared and signed; others were happy to fill out the form at the time of the interview. I would always ask if they would like a copy. If they agreed we would fill out two, so I could give one to them straight away (there was not always access to a photocopier or

printer). I also understood that access to email and printing for these whānau was limited and or expensive, particularly if they were in the hospital.

As the researcher, I needed to maintain respect for whānau members' time to ensure I did not take them away from their child for too long. I would check in with whānau members during the interview as time went on or I would read cues (whānau looking at the clock, restlessness or signs of agitation). I would then either ask if they needed to go or move toward finishing the interview session.

Cultural, Power and Familiarity Considerations

In qualitative research, it is acceptable to interview people you know (Braun & Clarke, 2013), this is known as acquaintance interviews (Garton & Copland, 2010). As a precaution (in case I knew some of the interviewees) ground rules were set to help ensure the safety of participants and their information. These included reassuring whānau that I would keep their information confidential and any information written would be non-identifiable. As I had personally experienced a similar journey to whānau members, I knew how raw and vulnerable whānau could be even after five years post-treatment. I understand that no whānau accessed the free AUT counselling service. However, one family did use the Consult Liaison Service (counselling service offered through Starship Hospital) at the hospital, and another family who was already attending counselling and support elsewhere utilised that as support in relation to their interview. I also suggested to whānau that the support service that they were involved with (such as Child Cancer Foundation), if they chose, could be made aware that they were involved in the study. Informing whānau support was in recognition that issues could arise. In 13 of the 20 interviews, people cried, highlighting the continual rawness of the journey. All of them declined to stop the interview and wanted to carry on talking. In most instances, we just took a moment and then continued. A couple of hours after the interview I called the whānau members who were interviewed or in some cases sent a text (negotiated at the end of the interview) to see if participants were okay and whether further support needed to be implemented. In two cases, mothers explained that they had never spoken of the impacts of the journey before. In one case where a child had passed, the mother said she had boxed all the child's keepsakes and that the interview gave her the strength to look through them (something she had not done since the child's death).

Different aspects were considered in relation to interviewing whānau members. These included familiarity, vulnerability and distress of participants, cultural considerations including language and taboos (being a female interviewing a male), power relations, and ensuring that the participant's story is primary.

Starship Hospital is the main children's hospital and support groups and treatment, including rehabilitation for life-threatening medical conditions are limited. Therefore, it was only natural that I would be familiar with health professionals, wards and support services that were discussed in the interviews. When familiar names came up during interviews, I tried to remain as neutral as possible (in some circumstances, participants had negative experiences with some staff members who I knew).

As the researcher, I was also aware of the different power relations that could potentially exist as the interview process proceeded. Namely those participants who may have seen me as an expert in an area (Braun & Clarke, 2013), especially since the research was associated with a university. I also understood that some whānau members might have thought I had additional information that could help them access entitlements they were seeking (for example, Work and Income New Zealand [WINZ] support, travel assistance, and access to housing). There was also potential for whānau members to see me as a Pākehā (European) due to my light-coloured skin, which could cause whānau members to relay information differently by holding back due to the perceived power dynamic. Being aware of this and having some predetermined strategies, such as making it clear I was Māori as well as providing relevant information such as hospital social worker names and numbers and relevant pamphlets, helped alleviate concerns. In most cases, whānau were the experts and had sourced appropriate resources for themselves.

Safety

All interviews took place during the day with most in a relatively public space (ward, meeting room, work environment, support service private room or café). I was particularly conscious of this when interviewing Pacific men. To cover all bases and to ensure the safety of the researcher, a research safety protocol was developed (Appendix P). As part of the plan, I was to let my supervisor know when, where and what time I would be conducting an interview. I would then text or phone her to let her know that I had finished. If I had not contacted her within a time limit of 2 hours, she would phone me to ensure I was safe. I also had access to the AUT Counselling Centre and my support services person. I found it most useful to record my feelings and what issues arose for me in a journal. Part of my process was to do karakia before the interview and afterwards, either with participants or without them. In most cases, the participants would facilitate karakia themselves. After particularly difficult interviews I would either engage in physical activity or sit quietly by water, depending on what was needed at the time.

The risk of physical harm to participants was minimal within this study. However, there was potential for emotional or psychological harm due to the very nature of the topic if a child had passed away. These risks were minimised, where possible, by offering support (kaumātua, cultural support and counselling), encouraging other whānau to attend and be part of the interview, and contacting them post interview.

Making Participant Stories Primary

While my story and experience influenced the research processes, I ensured that the participants' stories were central. As the researcher, I kept to this notion, and if the participant wanted to talk further about some aspects of my journey, I ensured the interview was complete, and stopped the audio recording and made particular reference to "now that your interview has ended" prior to conversations. On three occasions, we agreed to an alternative time and day to meet to follow-on discussions. Meeting on an alternative day when possible helped ensure the process and conversation were kept separate and kept the participant's story as the primary source of the interview. The research process and in particular the participant interviews will always hold a

significant place in my life. I felt honoured that whānau wanted to be part of the research and that they gave their time to share their stories.

Dissemination

Keeping participants and interested parties informed continues to be a critical part of this research. This process allows parties to see progress and be involved in the findings and, therefore, implement them (Jahnke & Taiapa, 1999). L. T. Smith (1996) stated that feeding back to participants and communities demonstrates accountability and reciprocity and that after any study, research should be available to report to participants in a culturally appropriate manner (Bishop & Glynn, 1992).

Dissemination has occurred in relation to this project in several ways, in both written and oral forms. Participants are regularly updated via email, conversations at support groups, meetings and through relevant media sources (for example, newsletters, social media, and websites). Formal feedback sessions have occurred by way of conference presentations, symposiums, community and stakeholder meetings. Results will also be written into summary reports, community notices, and practically through the provision of a booklet, as suggested by interviewees. It is anticipated that the results and outcomes will be disseminated as widely as possible across different domains and through different sources of media. Dissemination will be appropriate to specific communities. For example, I will utilise a different format for Māori and Pacific communities, such as newsletters, booklets, hui and summaries. Peer-reviewed journal articles will be published, and reports will be written utilising different forms of media (for example, AUT, Māori media, Pacific media, social media, newsletters). Hui has also taken place in various regions (Waikato, Auckland and Whanganui) and this will continue to occur.

Rigour

Ensuring rigour or the "truthfulness" of the data that is collected in any project is a critical focus. Mays and Pope (1995) highlighted that qualitative research is often criticised for lacking "scientific rigour" as concerns lie with ensuring the data and the analysis are credible and transferable. Rice and Ezzy (2002) suggest rigour takes a postmodern perspective and consider it as an ethical and moral task that is focused on liberation or political actions. In relation to Māori and Pacific health research, rigour needs to also focus on the commitment to culturally congruent practices of data collection and analysis, and the need to understand that undertaking the research will contribute in a positive way to the development of Māori and Pacific aspirations, outcomes and ways of being and living (Boulton, 2005).

The study used snowball sampling to identify those who possess characteristics relevant to the social phenomenon being studied (Mays & Pope, 1995). For this research, there were two samples. The first included Māori and Pacific whānau members who were dealing with a child who had a life-threatening medical condition. Inclusion/exclusion criteria were applied to ensure consistency in whānau taking part (Appendix F). The second sample included stakeholders who supported these whānau members through their journey, as identified by whānau themselves. Mays and Pope (1995) note that this form of sampling does not establish a representative sample,

but rather allows exploration of an aspect relevant to the research. As well, it allows the researcher to select participants who hold important sources of knowledge.

According to Billups (2014), to help establish credibility the researcher needs to develop close familiarity with participants to engage them and gain a better understanding of their perspective and or behaviours. Relationships with participants were built as much as possible before interviews being undertaken, either by phone or face-to-face contact. Building a relationship was an easy process as we already shared a connection through the phenomenon of interest – having a child with a life-threatening medical condition.

As part of triangulation, multiple data sources were used (such as interviews, journals, document and database review) to produce greater depth and breadth of understanding, corroborate findings and build a more holistic picture. Methods triangulation (Cohen & Crabtree, 2006) occurred within the research, which included interviews undertaken with two sets of data sources as explained above, and keeping a research journal that enabled me to keep track of themes, observations, thoughts, feelings, ideas and decisions that occurred throughout the research process. Documents and databases were trawled to verify information from interviews and identify possible gaps in services and systems that could enhance whānau coping. For example, an interview might reveal that there is a lack of culturally representative staff within the organisation. Database and documents may highlight staffing numbers, ethnicity and roles. Observations formed part of the journaling process. If I observed that a question made someone uncomfortable, I would write it down to process the possible associated reasons and consider changing the format or excluding it next time I undertook an interview.

Researcher Reflexivity

Many traditional perspectives of Western-derived research have stemmed from a position that in order to undertake research "properly" it must be conducted in an impartial or objective way (Braun & Clarke, 2013; Penehira, 2011).

I did conduct this piece of research bearing in mind my position of 'being so close' to the subject matter. I also considered the fact that my personal experiences will influence parts of the research by being deeply embedded in the research area, topic and questions. The preliminary strategies incorporated to combat potential issues were:

- Being explicit that the research topic stemmed from my own personal journey
- Being open about the initial questions which were developed from my own experiences
- I re-looked at the questions and answers given and then asked myself did that happen in our journey and I noted the answer
- I journaled the comparisons and noted my own journey compared to participants
- Comparing my own journey and experiences with participants and realising while there were some similar experiences there were more differences (for example, the majority of participants did not have a close relationship with health care staff they encountered. I had mostly great, close relationships to the point specialists gave me their cell phone numbers and email addresses)

- Re-analysing data at different intervals during the overall research timeframe (one month after data collections, six months after and then at one year) to ensure it was participant stories that were at the forefront and not my own. Taking a second and third look at the data also gave me insight into whether time made a difference to my feelings, emotions and therefore the analysis

In re-analysing the data I found that the categories and codes remained the same but the way I shaped the writing of the analysis was different. As I was more removed from the emotional intensity of interviews due to time, I found that my writing went from deficit-based (having no hope) to a more solid factual-strengths based position (there is always hope, and whānau will do what it takes to get through). In writing up, I also made a clear distinction between my journey and experience through grey shaded boxes compared to the majority of text related to participant experiences.

The strategies I used above were also useful when reflecting on contrasting methodologies such as those underpinning this research (kaupapa Māori and talanoa) that require the researcher to be subjective and situated "inside" the research, removing layers of objectivity. According to Penehira (2011), subjectivity, in kaupapa Māori terms, is necessary for the research to be deemed valid. It is this subjective or insider approach that provides a way of viewing, engaging and analysing data. Insider research enables viewing the research from the inside, from a whānau perspective, (Charmaz, 2014; Wepa, 2016). In doing this, the researcher needs to be part of the subject or subject group. Subjectivity is advantageous, particularly given the injustices documented throughout history, such as past research being conducted *on* Indigenous peoples rather than *with* or *alongside* them (T. K. Kingi, 2002; Penehira, 2011; L. Smith, 1999).

Using Indigenous approaches allowed me to be part of the subject and subject research group (K. Ratima & Ratima, 2003). My insider position took the form of varying roles. I was **a parent** of a child with a life-threatening medical condition, I was **Māori,** and our whānau had both **Māori and Pacific ancestry.** As well, I could identify with other whānau members who had **similar experiences** (regarding admission, transfers, treatment and experiences with support services). These insider positions allowed me to connect deeply with other whānau.

As a **parent**, I had rapport, particularly with women as I could share and, importantly, not just understand but know what they may be experiencing. The connection with these women occurred in different ways. Sometimes it was about health or support service staff who gave whānau information regarding the study. They would relay to whānau that I too, had similar experiences and was now doing research. In other circumstances, members would recognise me from the ward or support services so there would be an automatic connection where little of my own experience needed to be exchanged. At other times when I made first phone contact with whānau members, I would relay that I had been in a similar position with a sick child. I was always conscious of keeping my story brief, ensuring that the research was guided by participants' experiences, not mine. These insider positions helped me to build trust and later opened the door as these people became whānau participants in the research study. As these connections were deepened by experiences and familiarity, a high level of trust was gained relatively quickly. As

many of these whānau are involved in areas of health in which I work, communities I am involved with and charities I support, the reciprocal nature of our relationships will extend beyond the research project. Reciprocal relationships also ensure that I remain accountable to these participants and the services that support them. I included my tribal affiliations on information sheets and business cards, to make it explicit that I am Māori. Some authors have agreed that being a Māori researcher is critical to undertaking kaupapa Māori research (Bishop, 1998; Pihama, 2001; G. H. Smith, 1997). While being Māori was advantageous for this research I could see that it could also be quite complex, depending on the form of research, audience and topic. Penehira (2011) alludes to the tribal nature of Māori communities, which contain a myriad of roles, responsibilities and positions. These complexities can increase for Māori researchers with extended interactions.

The Māori researcher position may also change depending on the nature of relationships, for example, tuakana (being older or holding more knowledge) versus teina (being younger and learning new knowledge). In different environments over the course of a research project, positions such as these have a bearing as they may change depending on the participant and nature of the project. A Māori researcher may be a tuakana (seen as a leader, older, wiser) in one interview and a teina (seen as emerging, a learner or student) in another, depending on where the researcher positions themselves and who is being interviewed (for example, a kaumātua or a professor). As a Māori researcher, I positioned myself as teina, as I was learning new knowledge from those deemed experts (whānau). Complexity did arise, as I had to see whānau members in two ways. I saw them as kaupapa whānau, participants who reminded me of my close relationship with them. However, I was also pulled as they were participants in a research study. To keep grounded I surrounded myself with other experienced and well-grounded Māori researchers. I kept connected with kaumātua and whānau and constantly journaled reflections and issues. I had two Māori supervisors and one Pacific supervisor with whom I have good relationships. I knew I could be open and honest with them about any part of the research (personal and professional).

I made **Pacific** connections, firstly through project information given to whānau. Providing a space for Pacific whānau to share their views as Pacific people attracted them to the research. Two interviews revealed that the Pacific flavour (in the advert and using Pacific language) engaged them. Revealing our Pacific whānau heritage came by way of either initial contact with whānau members or during the interview process. For example, on one occasion, a Pacific interviewee expressed his frustration at being in the hospital ward for over three months, and they still could not pronounce his name. He said I was lucky to have a simple name. I revealed my children's last name to him, and the difficulty ward staff had in pronouncing it. The interviewee and I made an instant connection by having a similar experience. My advisory group members held a wealth of cultural information. As well, my Cook Island/Tahitian family, who are rooted in their culture, languages and traditions, kept the participants and me safe. Their investment in the research aided the design, development and dissemination phases.

The outsider positions I held in relation to the research were **PhD student, non-Pacific person** and **researcher**. Putting in place precautions as previously mentioned ensured these positions

did not cause significant issues. Interestingly, what I perceived as an outsider position became an insider position. **The position of PhD student** made unexpected connections, particularly with Pacific fathers interviewed. These men were educated and not only wanted to participate in their story, but knew it would have an educational impact that they promoted and supported. Peer supervision (from others doing a PhD) and support groups such as "Mai ki Tamaki" a support initiative for Māori PhD students, helped with any issues that arose with being a PhD student. While issues did not arise for me, it was helpful to hear of those where they had concerns. As a group, we identified strategies to keep grounded and safe as students in the research.

In analysing Pacific data, I utilised my Pacific Advisory Group members, one Pacific whānau member and a Pacific researcher. These people helped to confirm or further the analysis to a deeper level from a Pacific perspective. One example is regarding a discussion that took place pertaining to negotiating cultural space (using their own language, having their support people around, having information in their language, having people who they identify with and understand their ways without having to educate them) within the hospital environment. While I solely concentrated on the hospital environment what my Pacific support people were saying was that Pacific people have to do this every day in every space they occupy and that it is a constant for them. The information created new insight for me as the researcher. My Pacific supervisor was tasked with the primary role of overseeing the final analysis and write up of the findings and results to ensure the Pacific data was fairly and accurately represented.

Being a **non-Pacific** person did not explicitly raise issues that I was aware of. Being Māori was evident in information given to participants prior (my name and tribal information were explicit in all research forms, information sheets and cards). I would also say "kia ora" during phone calls as the first point of contact. I also think that whānau wanted to tell their story and the important issue for them at the time was that they felt comfortable to be able to do so. The comfort was evident in the lengthy interviews and rich data they produced. The role of the **researcher** did not come across as an issue for whānau. In hindsight, I think it was because I positioned myself as one of the whānau members having a similar experience, not as a researcher with knowledge or aggressively wanting their data. Some stakeholders, however, constantly referred to me as "that" researcher if they forgot my name. These occurrences were rare, and I just gently reminded those stakeholders of my name and gave them a card with my details.

At times, I did feel a slight pressure as there were expectations from outsiders (other stakeholders, students and academics) that the project would make huge differences for Māori and Pacific whānau and therefore contribute positively to each community's development. A number of times during the research I felt disheartened about how this would be achieved considering the impacts of racism, colonisation and general lack of responsiveness toward Māori and Pacific peoples within the health system. To help alleviate this feeling, I referred to my strategies including supervision, journalling and peer contact. I also found feeding back to stakeholders helpful as every meeting generated a positive outcome. For example, Ronald McDonald House now has an enormous welcome sign using Māori language, regularly seeks support and advice, and eagerly awaits the results. While these are examples of little impacts in the whole scheme of things, the

ideas came from discussions and interviews that were undertaken with Māori and Pacific whānau, and the feedback was implemented.

This project has further grounded me as Māori, parent, whānau member, student and researcher. The goal of all these roles is to make a difference to my people. This process has taught me that you can strive to make big changes, but need to ask "do they make a difference?" Sometimes it is the small steps that can have huge impacts.

Summary

In this chapter, I have outlined the general research approach, specific methods that were employed as part of the research process. It also highlighted the very real and dynamic ethical, cultural and personal considerations that impact on the research, research processes, researcher and participants. While these can have a negative impact, protocols and guidelines helped to alleviate tensions and identified potential risks and appropriate solutions. The design of the study puts Māori and Pacific whānau at the forefront and incorporates tools combining both Western and Indigenous knowledge and methods under a paradigm net. The study design validated Māori and Pacific whānau voices and experiences through their narratives about their journeys. This research aims to draw on and support both Māori and Pacific aspirations by contributing to positive health outcomes.

CHAPTER 6 - FINDINGS

In this chapter, I present the findings from the research study. The two primary sources of qualitative data for this section stemmed from 30 sets of participant interviews and grey literature sourced from various documents and websites reviewed. Key documents and websites included: Starship Hospital, District Health Boards (DHBs) and Ronald McDonald House websites, reports, referral forms, newsletters and pamphlets. A small number of photographs have also been incorporated to emphasise key points in the data. Data are combined within this section and addresses the two objectives of the study. These were to explore:

1. The coping mechanisms and strategies employed by Māori and Pacific whānau who had experience in navigating the New Zealand health care continuum with a child who has a life-threatening medical condition.

2. The role and influence of Ronald McDonald House, Auckland on whānau coping.

The findings are presented in two separate sections and are set out according to the above objectives. Quotes have been incorporated that were deemed to fit with the relevant themes and may not reflect equal representation between stakeholders and whānau members.

Coping Mechanisms and Strategies

Coping mechanisms and strategies that whānau employed stemmed from four emergent themes: context for family coping, barriers and distractions, drawing on resources which incorporates both system-based resources and whānau initiated resources. The overarching theme, the **context for whānau coping** explains how Māori and Pacific whānau prepared themselves in order to cope with their critically ill child in different environments (GP clinics, emergency departments). Analysis of data then mainly focuses on hospitalisations and hospital experiences. Within these contexts, whānau assumptions and expectations are evident in that they expected their care to be positive and straightforward. In entering the health care system, whānau were confronted with several **barriers and distractions** which took time and energy away from focusing solely on their critically ill child. Whānau looked for support in combating these obstacles by drawing upon available resources. Resources incorporated those that were system-based (such as services, information and environments) and those that were whānau initiated. **System-based resources** which, while found to be helpful, in some instances provided additional burden and frustration through their limitations and gaps. **Whānau-initiated resources** included coping mechanisms and strategies that were holistic incorporating spiritual, cultural, and environmental elements as well as negative and/ or positive.

To get the support whānau needed while transitioning through the health system, two further sub-themes were explicit. It was found that **whānau fill the gap** by searching for or drawing on their resources to get their needs met and therefore cope. While dealing with their critically ill child was a whānau primary focus, findings identified that this emphasis had inadvertently shifted by having

their main source of concentration consistently and temporarily diverted toward **surviving the system** as shown in Figure 8. The following section provides detail of each theme, along with sub-themes, incorporating excerpts from participant interviews and examples from grey literature.
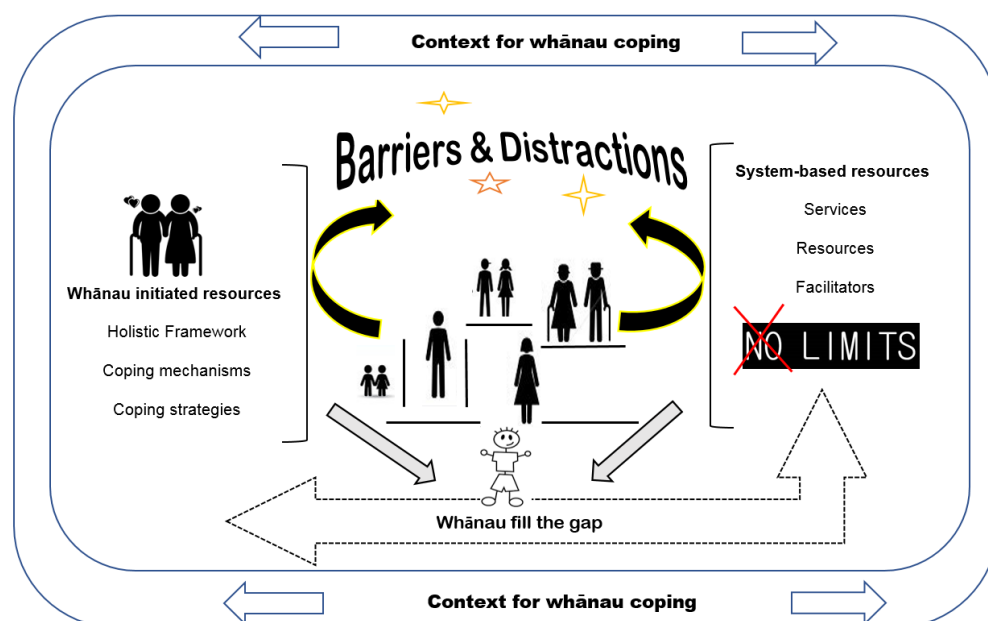
Figure 8. Surviving the system.

Whānau Coping Context

Even before a child is diagnosed with a life-threatening medical condition the lead-up in dealing with signs and symptoms related to something being seriously wrong, placed enormous stress and worry on whānau in this research. Presented within the data were several explicit expectations and assumptions that were held by many whānau regarding health care in general. Whānau expected to receive care and treatment at the time when they first presented their child as being seriously sick. Whānau also anticipated receiving care in their local hospital and being treated respectfully. The reality of health care engagement for whānau within this study was, in most cases unexpected. Six of the whānau highlighted presenting their sick child to the various health clinics and emergency departments and being sent away with pain relief (Panadol) only to return on several occasions as the child's health deteriorated.

> *So, come November after going to four different doctors we were told that he has a virus, he has a tummy bug, here is some medication. I would go back three days later and say it is not working. I was getting frustrated. I ended up taking him….to emergency almost every second day towards the middle of November. I was starting to lose hope as every time I went back to A and E I knew very well I was going to get this same friggin doctor and he will make the same diagnosis, and we will be sent home with Panadol. (WI.002)*

Other whānau expressed knowing something was wrong, asking questions and not getting answers. Their frustration and the deterioration of their child caused them to act defensively to try and get any satisfactory action and answers. In some circumstances, whānau got second and third opinions as indicated above by participant two. Additional opinions sometimes resulted in doctors (particularly in small towns and due to locums [fill in doctors], who were based out of

109

town) coming to the same conclusions. Whānau expressed that these conclusions would occur by reading the clinical notes and without checking the child. Other action taken that facilitated a pathway for diagnosis, as indicated by whānau, was making a scene.

> *We went to our hospital three times that month. We went there the first time, she got given an ice-block, and we were sent home. The second time, they kept her in for a couple of hours and gave her fluid and third time I kicked up a big stink and wouldn't leave until someone saw her. I felt she was a hassle to them, and I was a hassle to them because they called the security guard on me [be]cause that's how much of a scene I made, but she couldn't walk, I had to push her in a pram, and I couldn't carry her because she was heavy, she couldn't go toilet, she hadn't gone to toilet for days, and she had turned green, but they were still sending us home. The surgeon came in and looked at her didn't even touch her, and he started pushing her bed to the operating room because she needed to get her appendix removed [be]cause it had burst, and that's why she had turned green. (WI.018)*

With hospitalisation being inevitable, whānau organised themselves so they could focus on the child and their journey through a range of expected care and treatments. Coping with the burden that their child may die put whānau into survival mode (do all that we can to survive at this moment). The findings highlight whānau routines being radically disrupted and everything becoming secondary to the child's medical treatment in the hope of the child surviving.

> *All I could do was focus on the now, all that mattered was doing what was needed for him, whatever that was. He was the focus everything else was put to the side. (WI.001)*

A significant contribution to whānau disruptions was having to cope with treatment not being undertaken locally but at hospitals outside their region and, in some cases, their country. Transferring to different environments was due to lack of skills and expertise within local hospitals, and the need for specialised staff and equipment which were housed in bigger or main urban centres. The critical and urgent nature of a life-threatening medical condition often left whānau ill-equipped and ill-prepared (physically, financially, and emotionally), particularly as all whānau admissions to hospital in this research came as a result of an emergency crisis. Whānau identified having to rapidly leave their hometowns and having their child admitted in up to three different hospitals before getting treatment at Starship. Out of the 20 sets of whānau interviewed, 15 resided in locations outside of Auckland (Christchurch, Whanganui, Tokoroa, and Waikato) including four who had come from other countries (Australia, Samoa and the Cook Islands).

Being distanced from homelands and familiar support systems added to whānau pressures. Also, whānau coping was further compromised by the different worldviews and experiences (Western versus Māori and Pacific, Island born and raised versus New Zealand born and or raised) that often came into collision between whānau and hospital staff, processes and procedures, as well as the environment itself. Lack of a culturally reflective workforce and noticeably limited cultural support and cultural competence within hospital environments and associated services contributed toward lack of understanding, negative and judgemental assumptions. These consequences impacted specific cultural mechanisms and therefore disrupted key support toward whānau coping with a child with a life-threatening medical condition. These included:

- Māori and Pacific gender and generational roles
- Māori and Pacific whānau structure and designated member functions
- the importance of collective support (including community)
- Māori and Pacific whānau processes (such as hui, decision making, karakia, waiata)
- culturally appropriate care and communication

The context of whānau coping incorporated not only having to deal with a child who was critically ill but also factors that impact on getting a diagnosis and therefore treatment. Whānau highlighted being unprepared in having to deal with the critical nature of the situation but also the impact of the disempowering engagement process encountered within various health environments. Disengagement included not being listened to, being sent away and having to make a scene to get taken seriously. On top of that, not having a choice as to where the child would go for treatment. Whānau were forced to leave their hometowns and, in many of the cases, transfer to other foreign environments where values, beliefs and practices clashed, further impacting on whānau coping. The following section outlines some of the barriers and distractions whānau experienced while trying to participate in the provision of health care for their seriously ill child.

Barriers and Distractions

The barriers and distractions identified from the data all stem from four key areas of engagement with whānau (Figure 9). These were: whānau engagement with policies and procedures (especially inconsistencies and models of care), people and practice (particularly communication and including racism), the hospital or service environment (namely the location, design and culture) and resources (specifically services and information). Racism was found to sit across all four areas of engagement. It was discovered that the four key areas while distinct also interconnect, impacting each other. For example, a policy may impact procedures which in turn impact people and their practice. In relation to a barrier, the same notion applies. A barrier experienced by whānau at the policy level may affect barriers then experienced at the organisational and or practice level.
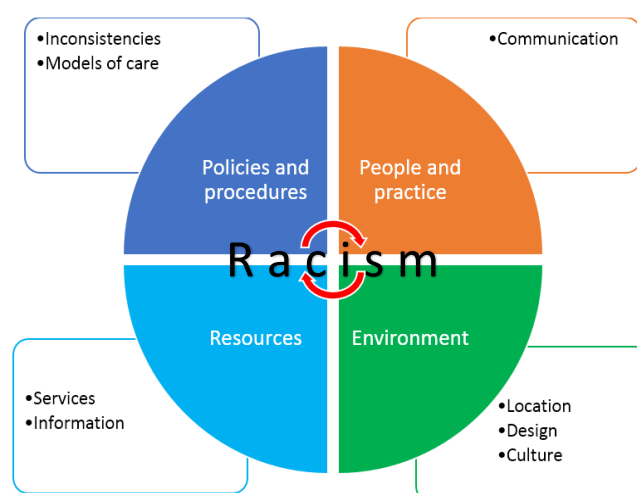
Figure 9. Whānau engagement barriers

Policies and Procedures
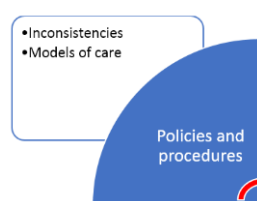
Figure 10. Policies and procedure engagement barriers.

Whānau were found to be coping with the impacts of policy decisions that affected their participation in their child's care. All whānau identified barriers that stemmed from policies made or procedures implemented. While whānau understood the need for guidelines and rules, barriers were created by inconsistencies that occurred within and across DHBs. Participant 5 alludes to travelling (flying) with a minor when having to have treatment in a different location away from home.

> DHBs have different rules about whether or not you can have someone travel with you, so when we go down to Wellington, they will not cover travel costs for you to take somebody with you. For some reason, Wellington is really tough around a whole lot of things, and they won't allow another person. (WI.005)

For whānau, having to make life or death decisions and being the only one caring for the child without support impacted on them practically, emotionally and physically. Whānau noted how hard it was in general dealing with a seriously ill child with support, let alone when they were the only person. The physical and emotional impacts of 24/7 care and worry were found to inhibit many whānau abilities, including, eating, thinking and being able to stay well themselves. Interestingly, eight of the women who were interviewed and who were the main caregiver for the child while in the hospital(s) indicated that they became unwell, some to the point of being admitted to the hospital themselves. Participant 5 identified her past experiences of being the sole support:

> It's absolutely horrific because you can't get away from the bedside and you need two. Two people need to be there. Otherwise, you can't get the rest, you can't get a proper meal, and you can't sleep. When it is just me, it's double the load 24/7 and doubly hard. (WI.005)

The above quote also highlights that while whānau know what keeps them well, as noted in this example as support, rest, good food and sleep – the barriers to maintaining their wellness while in the support role are often compounded by rules and regulations that restrict effective strategies being implemented at a practical level. Despite being told that only one support person can travel, in the National Travel Assistance (NTA) guidelines, there are noted exceptions. The guidelines state that:

Additional funding for a second support person may be approved when:

1. a second support person is required to:

- make clinical decisions, or
- learn technical skills for ongoing care (i.e., dialysis),

2. a child client is in a critical condition, or
3. a second support person is required to be present to decide whether to proceed with surgery (Ministry of Health, 2014c).

A letter signed by the specialist explaining why it is necessary to have two support people present will be required prior to the approval of a second support person (Ministry of Health, 2014c).

Whānau who needed to travel did so under strenuous circumstances; therefore, seeking out information was not high on their survival agenda in the first instance. The few who knew about the guidelines did not have time to get specialist to sign off and wait for approval. While many whānau did fit the criteria, it was not until well down the track or their third or fourth admission that they realised or implemented the support available through NTA, including claiming mileage and accommodation. It was also found that some entitlements were paid on reimbursement only, so whānau had to pay for some things upfront. Accommodation costs under the NTA can only be paid up to $100 per night and must be from an approved DHB provider. In central Auckland, whānau stated, there was minimal quality accommodation near the hospital under the amount stipulated. RMHC also state that it costs $120 per night to accommodate a family within one of their houses (RMHC, 2017). Whānau who found out NTA information were mostly informed by other whānau members whom they had met within the hospital system. These whānau were given their information by health authorities, showing that there were inconsistencies in the relaying of information between DHB's to different whānau.

Whānau talked about the exhaustion associated with dealing with a child with a life-threatening medical condition, but wider implications were also found. While whānau understood the practicalities and implications of Starship's rule[14] of only permitting one parent to stay the night, issues were raised of being stressed, feeling alone and worrying in case something happened, with the child dying in the night.

> *Only allowing one parent to stay and your child is on his death bed is a hard call. It's hard for the parent who stays because of stress and worries and equally hard on the parent who leaves. Imagine the guilt and self-blame of not being there if the child died in the night and it's not your fault it was because the rule is you can't both be there. I think there needs to be some exceptions. For us, I just told my husband to stay with us, and we will deal with it when they try and kick us out. (WI.017)*

Doing what whānau felt was right for them and their child, sometimes went against the rules. Whānau were constantly weighing up the risks of breaking the rules versus aligning with their beliefs, values and practices relating to what is right for the child. For Māori and Pacific whānau,

---

[14] At Starship Child Health, we understand how important it is for your child to have a parent or caregiver staying with them whenever possible. We provide overnight accommodation in the ward for **one** parent or caregiver to stay with their child. Brothers and sisters cannot stay in the wards. This is due to space restrictions and the need for staff to be able to get to the patient quickly and easily at all times. The nominated caregiver must be over the age of 16 and capable of looking after themselves. The nominated parent or caregiver will be provided with breakfast only each day, and will have to make their own arrangements for lunch and dinner. https://www.starship.org.nz/patients-parents-and-visitors/your-childs-hospital-or-daystay-admission/staying-with-your-child/

being left alone with a child who is at risk of dying goes against cultural practice. Whānau reiterated not wanting to leave the child alone and finding it difficult when they have been pulled away for various reasons or forced to have a break. Whānau talked about their difficulty in leaving the child unaccompanied or with staff with whom they had not yet built a trusting relationship. Whānau identified processes such as these as going against what they believed. One Māori parent reiterated the custom practised in her iwi.

> *We don't leave the tūpāpaku (deceased) alone so why would we want to leave our living sick child alone and with people she doesn't know while in a place she doesn't recognise?... that would impact and probably make her even sicker (WI.022)*

Likewise, Pacific whānau found it difficult being left alone, recognising the impact it had on their well-being.

> *Just having someone there with me the whole time I needed that and when there wasn't anyone there or if XX had gone to work or something I kinda felt like um…just not well. (WI.007)*

The one support person rule was found to be inconsistent with Starship's philosophy of family-centred care (FCC). Documents reviewed were explicit in highlighting the importance of FCC in health-related care. The terms family and whānau are noted on family-centred care documents, implying that the organisation recognises the difference between the two concepts (Starship, 2017b); however, inconsistencies were noted. In certain documents family-centred care was seen to acknowledge both parents and primary caregivers, again recognising the difference between the two terms (Kidshealth, 2015), and in others, while the term whānau is utilised, care is focused on the parents, as noted on Starship's Paediatric Intensive Care Unit web page (Starship, 2017d).

> *Family Centred Care is the dominant philosophy of the unit and staff care for critically ill children in partnership with the child's family/whānau. **Parents' **presence at the bedside of their critically ill child is accepted as the norm, and **parents** are not asked to leave for any procedures ranging from the insertion of intravenous lines to resuscitation.*

While FCC implies family involvement in health care, decisions and discussions and policies include the words "working with whānau and caregivers" daily practice, alternative policies and the environment seem more to exclude them. Documents and philosophies such as these shape health behaviour and while inconsistencies exist in various policies they were also found to translate into practice.

For our family, we had some expectations that our world views would collide with medical views having both worked in social work and health-related fields. It was part of our role to advocate for whānau to get their voices heard in different situations so in some ways we were already armoured up to a point ready for battle. The surprise was how inconsistent and contradicting the Western rules regarding health engagement were. While I realised early on that minor inconsistencies were evident, mainly among people informing us what other people could do for us. I did not realise until I put pen to paper and fingers to the laptop just how incongruent different policies, information, practice and models actually were. Inconsistencies were not only between different policies and practice but in and between the same policies, same practices and within the same environments (DHB and Starship). Examples include: fitting the criteria for reimbursement for travel to treatment every day but being told we didn't meet it by the clinician. We took the form, got it filled in at each session and obtained reimbursement for kilometres travelled. The amount itself was only small, but it really helped us out. Not being given the option for an oncology parking permit, reading the sign, asking for it, being declined by the receptionist. Asking the Oncologist about the criteria who questioned the receptionist as to why we were refused. We were then given a permit for a month (usually only given out daily or weekly). Being told on our move from Starship (which sits under Auckland District Health Board) to Wilson Home and Hospital (that sits under Waitemata District Health Board) that I would be in the same room as my son, something I was looking forward to (in Starship HDU parents/caregivers cannot be accommodated). On arrival, we were not housed in the same room nor the same living quarters. In meeting with the managers or nursing staff and having to seek approval about an 'unwritten' rule no one could find, he was reluctantly moved into my room, but supports were taken away as a consequence (I had to do all his personal care myself). The above practice highlights differing world views within health care. For me and many other whānau in this study, the undertaking of our child's care such as bathing, dressing and toileting was an honour, not a consequence as I hadn't been able to fully participate as a parent in this role for so long.

People and Practice

Figure 11. People and practice engagement barriers.

Nearly all the men in the study talked about a time when they were caring for their child either full time or by giving their whānau member a break where the nurse or doctor had encouraged them to leave in some way. In some cases, nurses, particularly those who worked in PICU or HDU, would just take over while the men were changing, feeding, bathing or just being with their child.

At other times men revealed that they were over-encouraged to have a break. Some Pacific men talked about their experiences in facing the negative assumptions of health care staff. Pacific men found that some nurses were quite explicit about their beliefs around Pacific culture. Nurse's beliefs consisted of Pacific men not wanting to get involved in the upbringing and care of their children and that it was the women's role to do so. Pacific men expressed being offended when they were discouraged from participating in the care of their child. Participant 6 tells of his experience.

> *I was even told by one of the consultants here, that I've been staying here too long and I should go and get out of the hospital. I didn't decide to be here for over a year I had no choice. I said, "that's none of your business, that's my decision, me and my wife's". I said, "you're medical, so you focus on that and focus your energy on my son". "If he's ok, I'm fine, if he's not, I'm not happy, simple as that". But then they would say that I am over dedicated, "we see you as an over dedicated dad" they said. I don't even know what that means maybe other fathers are not so dedicated but to me, this is what we do, to me its normal to be here with my son. (WI.006)*

Pacific men also described feeling a sense of powerlessness when doctors would wait to speak to their wives/partners or limit what information doctors would give to them. Encounters highlighted that when their partners did arrive doctors would often only talk to her, despite them being present. What this highlighted for the men was that doctors too must have the same ideology as nurses about Pacific men and caregiving.

> *The specialists would always ask me when was my wife was coming back so they could tell her things. When we were there together, the doctors would only speak to her. (WI.024)*

> *I would go up to intensive care to relieve my wife who had been there for two days with no sleep. The nurses would say to me when I was doing things for my baby, "leave it I'll do it". Out of respect for the nurses and their job, I would just leave it. My wife would then ask me questions about did our son drink much or sleep and I would have to tell her that the nurse said to leave it for them to do. To be honest, I felt a bit redundant as a parent. (WI.003)*

In contrast, some women in the study felt they were frowned upon when they took a break. Upon returning to the bedside even when their male counterpart was there, they could feel the nurses' attitude and annoyance. Women spoke of dealing with comments from nurses about what actions had been done in her absence reiterating the inconvenience caused by her leaving.

> *I was gone for 10 minutes I had to go and get forms signed from the social worker and came back to a bitchy nurse who said that the doctor came to see me but left as I wasn't around and he was too busy to wait. I had waited all bloody morning for the doctor and left my husband there in case he came who by the way was supposed to come at 7.30 am it was going on 12. The nurse knew that too. I just walked out and cried. (WI.017)*

Other whānau members also emphasise their concerns. Primary caregivers for children (including grandparents, aunties and step-parents) talked about how they were also often excluded from health discussions, and left feeling discredited, with some not being allowed on wards until visiting

hours. Despite society's "acceptance" of contemporary whānau makeup (for example, civil unions, blended whānau), health system processes were still found to be bound by the nuclear concept of family (mother, father and biological children). Family in a health sense was demonstrated by grandparents and those who had whangai children (cultural adoption); while they had raised these children, they were not legally able to make critical health decisions without biological parent permission. A grandparent who was the primary caregiver relays her vivid memory about making critical health decisions for her mokopuna (grandchild).

> *My grandson was really bad, it looked like they would need to do an operation as he was going downhill fast and we were in the hospital, and they said that our next step is surgery. I was texting my daughter madly because they needed her authority. They said to me "you can't give it, we need it from a parent". I was trying to find her, I couldn't find her, and I was thinking this just can't happen again. I was not wanting to do a legal process I didn't want to go through the courts and get legal custody of him. As a whānau, we can do this, and we can sort it out ourselves, but that incident forced me to go through a court process. (WI.005)*

The above quote describes the emotional anguish whānau felt in being forced into positions that culturally disrupt whānau processes. Other whānau relayed similar experiences where the system did not cater for grandparents to visit outside visiting hours. One whānau highlighted that while in some instances they were allowed in to see their dying grandchild it had to be constantly negotiated alongside the use of cultural mechanisms such as healing practices of karakia (prayers) and waiata (songs).

> *Mum and Dad were always there every night and every morning for karakia. I had to negotiate this with the nurses and had to make sure they told the other staff as well, as it was outside the visiting hours. Our son would often ask my dad to stay on. So, my dad would happily sit there for four or five hours. He would just sit without talking, and that is what our son loved. But again, I had to negotiate a lot of that. (WI.002)*

Grandparents who were not primary caregivers were also noted to be the main source of support within whānau. Grandparents provided practical support such as helping with other children, providing respite and delegation of tasks to other whānau members within the hospital and keeping things running at home. They were found to be a wealth of knowledge, exuding a sense of wisdom and calmness to those who were stressed and, equally importantly, providing a sense of healing to the child.

> *They wouldn't let my mum into the ward as she wasn't a parent, but she was my son's parent he kept asking for her, but she had to wait for visiting hours. I needed her to be there as the doctors were coming to relay information on options for his cancer treatment. She has a background in nursing so she would know what they were saying. Her not being there caused me mega stress which then caused my son some distress. (WI.017)*

Communication

Communication was the most common barrier talked about by all participants. The barriers for whānau related to how information was relayed, what was relayed, where it was relayed, and who it was relayed to.

Information relayed to whānau about diagnosis and treatment was rarely straightforward and simple. Whānau talked about health staff using technical terminology that they did not understand, phrases such as *evidence-based*, and *clinical trials* and pointing out how certain procedures are done overseas. As well, specialist roles and functions such as *oncologist*, *haematology*, and *neurology* versus *neurosurgery* were also confusing for whānau. Not being able to remember the specialist name or their role and function caused whānau added stress. Similarly, information in pamphlets or books (such as the chemo book) given to whānau were just as confusing, too long or simply unappealing.

> *We were told that he was at stage 4 and he had a 20% chance of survival and then they rattled off all the names that were associated with his cancer. That meant nothing to me and then handed me this big fat white folder that I never ever went past page 1. They also suggested that if we had questions to get back to him. I thought oh yeah whatever. He went on and basically gave a crash course in what the treatment will be like for him and the fact that he will be part of a 54-week regime. We were also told that it's standard practice in other countries and I thought oh yeah. (WI.002)*

Other issues were for those for whom English was their second language; there was little support in the way of resources in other languages or offers of a translator, despite the DHB clearly stating that it is the patients' right to have access to this service (Starship, 2017g). Lack of access to adequate resources left whānau trying to interpret, relay and understand information mainly from their limited knowledge base of the subject matter. Other whānau highlighted the negative focus of communication which was deemed offensive.

> *We were given a 1% chance that baby will live, that's what they said, and one of the workers actually gave us another hospital option - termination, that's what they gave us, no hope, no positives. (WI.006)*

Another form of communication whānau found insensitive and insulting, was referring to their child as their diagnosis. Whānau took this practice as a sign of disrespect in not learning the child's name but also making them feel like their child was the disease.

> *My grandson obviously had some special diagnosis as medical students were accompanying the specialists every visit. They kept referring to my grandson as the "pineal germ cell teratoma". My daughter was very courageous she kept saying to them "his name is XX ! and he is 7", to make them see he is a human being, not a lab rat. (WI.001)*

Where communication took place was also an issue for whānau. Whānau identified diagnosis by the bedside, in hallways and corridors or other places with limited privacy. As well, time was an issue; some doctors would state that they had limited time, blurt out information and then move on. Lack of privacy and time did not allow whānau to take in the information or ask questions. It also did not allow for whānau to prepare themselves. Māori and Pacific whānau talked about not

wanting to impinge on doctors' time, with the majority of whānau feeling that they shouldn't ask questions.

> *I was standing by my son's bed when the doctors came. We were in a busy ward room. One doctor within 1 minute of being there just told me, oh yes, he has cancer. I was shocked but conscious of trying not to react badly and scare my son. (WI.017)*

> *We were standing in the corridor part when she just blurted out "so his tumour is quite big" and I said to her "what are you talking about?". "What do you mean a tumour?" So all of that and by the time she blurted it out that it's cancer (it's so vivid now) I collapsed on the floor, but I managed to recompose myself quickly before my whānau saw me then I went around to the whānau room, as there were other people in the other rooms. (WI.002)*

Many of the Māori and Pacific whānau identified certain roles within their whānau where lines of communication were to be relayed. It was noted that roles differed between whānau. In some cases, it was the parent, in others, it was kaumātua, church minister or the oldest child.

For some it was gender specific, for example with a daughter, it was the mother or elder sister, while for other whānau it was the one who had the most medical knowledge. In some circumstances, whānau wanted to hear it directly from the doctor.

> *I always say if you want to talk to me by myself then nope or if they are planning yet another operation for my son nope… I have told them "I'm not gonna sit with you guys while my wife isn't here, and you're gonna wait, I'm not gonna sign those consent forms until my wife gets here. It's best for you guys to tell her". (WI.006)*

Whoever the line of communication went through was usually also the person who would communicate with the wider family.

> *I said to her [the doctor] "you do not tell anyone, there's a process to this and I will tell my own family". (WI.002)*

In many situations, whānau wanted collective support when being communicated with but, in most cases, this was not offered. When collective support did occur, it was often initiated by whānau members themselves.

> *I said to them "wait; I need to get my mum and husband, they need to hear this". I just turned away and went in and got them, so they [doctors] had no choice. My mum and husband came in, and lucky they were there as all I heard was cancer he is going to die. My mum later relayed what the doctor had said and talked about options for treatment. I said to her "OMG; I didn't hear any of that!" (WI.017)*

> *My mother in law was a nurse I wanted her to hear the health information I trusted her to put it in words we could understand. (WI.003)*

Receiving devastating news in isolation, while already coping with other issues, impacted on whānau members' emotions and focus. As identified by participant 17, while she only heard certain aspects of the diagnosis, it was whānau members who reminded her of wider information

and the decisions that needed to be made for treatment options. Being exhausted and emotionally drained impacted on being able to make informed decisions. Therefore, whānau support helped to alleviate pressures. In some situations, having whānau support was declined by doctor's due to timing, and, in most cases, doctors and specialists failed to facilitate it. While collective support was not actively promoted, there were a few indications that some doctors did offer to tell family members later. While this was a compromise, it meant that individual whānau members carried the burden by themselves until other members could be adequately informed. In circumstances where the burdened whānau member relayed the information to whānau, it was found that questions and queries that arose overwhelmed the informed whānau member further. The intensity of being in these situations brought feelings of guilt and inadequacy for not knowing answers. This burden often remained with whānau members as they felt not able to "annoy the doctor".

The Environment
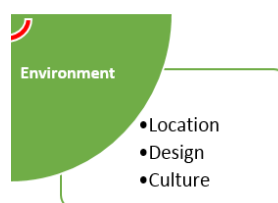
Figure 12. Environment engagement barriers.

Location

The environment played a big part in whānau coping. While most whānau identified having had at least some sort of support to draw on, what was consistent throughout the data was that much of it was not immediately accessible. Reasons identified were around distance and costs. The location of Starship Hospital in Auckland, situated in the upper North Island, created barriers of distance away from whānau familiar support systems and environments.

With regard to whānau supporting those admitted to Starship over long periods, it was found that many Māori and Pacific whānau were not in a position financially to afford them the ability to travel long distances at short notice. In fact, most of the whānau interviewed were also not well placed financially to deal with the child's on-going admissions, and the associated costs, given that treatment of life-threatening medical conditions mainly stemmed from a crisis point and went on for extended periods of time.

The central city location of Starship impacted on whānau finances through petrol, parking (free parking is time-limited – 60 minutes, with traffic agencies constantly patrolling) and the cost of buying food (the nearest supermarket was at least a 25-minute walk away in Newmarket, one of the most expensive suburbs). All whānau found parking to be a barrier.

> *Parking…we got in on the 29th that was on Sunday morning, then Monday we came for the scan and the following Monday my wife in her pregnancy was admitted, they asked if she can come in to be observed and she was here for over 5 weeks, about 7 weeks before treatment, and it cost me over 800 bucks*

in parking and tickets. I asked them "do you have anything that could help us?"… They said "no". I found out later from other families that they could have given me a parking permit or a subsidy letter to reduce the cost. I was also told that at 11.30 at night the arm of the car park goes up until the next morning so you can get out for free. (WI.003)

We had a parking permit, but we had two cars you could only use it for one, and they were very strict on this. We had to swap cars often due to car seats and kids, so the other car we had to pay to park even though there was only one car there at one time. (WI.017)

Design

The design of hospitals was also raised as a barrier to whānau fully participating in the provision of care for their child. Whānau highlighted issues with there being limited or no space to meet privately and discuss issues and make decisions. It has already been identified that whānau were told private and pertinent information by bedsides and corridors, corresponding with a lack of spaces to meet. Lack of whānau -designated spaces in waiting rooms and ward rooms caused spillovers in corridors where health staff would get annoyed. Whānau did note that while in some hospitals there were whānau -designated spaces they were often occupied by staff who were holding meetings or were kept locked (see Figure 13).

I needed some space to clear my head and remembered seeing a sign that said whānau room. I went there it was locked and had a sign saying, please keep locked. I went to reception to ask for the key. They didn't know who had it. I asked them to call security to unlock it; they never came, so I sat back in the waiting room that was full of other people. (WI.017)

Figure 13. Barriers to accessing whānau designated spaces*.*

Stakeholders interviewed mentioned there being whānau-designated meeting rooms and being able to use them. Whānau themselves did not know they could access them or where they were. While these rooms were available, bookings had to be made in advance through a booking system that staff initiated, on behalf of the whānau.

Up at the hospital, there are some meeting rooms that can be used for whānau meetings; we can get in touch and try and organise them to be used. (SI.010)

In most cases, whānau could not predict when they needed to use a meeting room, with many discussions occurring ad-hoc. The annoyance of staff at whānau being present seems to mainly emerge from inadequate provision of whānau spaces. Ward rooms held only one or two small chairs. Some rooms had no pull-down beds as highlighted on the website. "If you are staying on the ward with your child, you will be provided with a bed or tilt away bed that folds up, depending on the available space. Linen and pillows are provided" (Starship, 2017e). While some whānau had access to lazy boy chairs to sleep in next to their child, others had nothing, resulting in them sleeping in the same bed with their child which is frowned upon within a Western environment. The size and space of the hospital affected how staff reacted.

> *We were asked to wait in the waiting room down the hall. I had to laugh; it was tiny; it had a two-seater couch and a tv that did not work. Well, there were already five people squashed on the couch including the arms, and three different whānau spread tightly around the wall and on the floor. Like five other whānau we waited in the corridor where the nurses got pissed off at us all. Not because we were disruptive but because we were apparently in the way. (WI.011)*

> *Waiting in that tiny waiting room and security came in as the nurses had called them because we were too noisy. (WI.003)*

Culture

The clash in cultural world views was evident throughout the data. Three types of culture were evident from the interviews: hospital or medical culture, Western culture and Indigenous culture. While medical and Western cultures mostly aligned, there was an obvious clear separation when it came to Indigenous.

The makeup of the health workforce was a common topic of conversation that stemmed from interviews. The notable lack of a culturally reflective workforce was seen at all levels.

> *I have noticed that three-quarters of the medical staff in three hospitals we have been in, they're all either from the UK or overseas. I think to myself what do they understand about our culture, culture-wise because the two things they really need to look is the cultural aspects and the religious aspects and that's what is lacking here. (WI.006)*

Whānau also bore the brunt of cultural misunderstandings. Examples have already been highlighted, of whānau being seen as an annoyance rather than support, primary caregivers being disregarded and the unacceptable use of cultural mechanisms such as karakia (prayer) as well as cultural practices such as sleeping in the same bed. While much of the hospital culture went against Māori and Pacific worldviews, most whānau felt they had to "accept and comply" out of fear of repercussion impacting on the quality of their child's care.

Also noted was the general lack of cultural responsiveness. The environment was described as being white and clinical with limited connection to different cultures including very limited signage in other languages. Starship promotes cultural support services on its website "The Kai Atawhai, and Pacific Family Support staff can provide cultural support" (Starship, 2017f). Cultural support

services, while they existed, were overloaded and under-resourced, often not able to see whānau who needed support.

> *I've gone from covering two wards to eight because staff have left and they have not been replaced. We have one person covering the whole of Starship, there used to be five. (SI.016)*

For some whānau, cultural support services were the only connection with their culture while they were admitted. Whānau talked about cultural support not being offered, with some not knowing they even existed. Others remember meeting someone at the emergency department but had no contact while admitted. For whānau who requested support, it was through nursing staff and usually right before a life-threatening operation. Whānau would want karakia (prayer) done if their family or support were not around at the time of the operation. In two cases, support never came. While one whānau attributed the absence to the inability of the cultural support team, the other wondered if the nurse had even put the request forward. Other whānau highlighted that their interaction with cultural support was when the nurse determined it, often at a crisis point, creating a negative situation, which was often reached due to cultural misunderstandings.

> *Sometimes if health care staff had of called us [cultural support] in earlier, situations with whānau could have been handled much better and dealt with much easier. I don't know why they wait so long to call. (SI.015)*

Whānau were also party to in-house politics when cultural support was called in by ward staff and used as security to tell whānau they were too noisy, or there were too many at the bedside. The mi-representation of cultural support not only caused tension between the two health services but, for whānau, it gave a negative impression of what the service actually offered. It also highlighted the ignorance of the staff and the disregard for the value of cultural support services within the hospital environment.

The lack of cultural responsiveness caused other barriers for whānau that were connected to cultural taboos. Cultural taboos were instances where cultural beliefs and practices were compromised due to ignorance or lack of understanding or by the environment not being conducive to catering for their existence.

Pacific cultural taboos were noted by whānau.

> *My son shared a ward room with a young, sick Tongan girl about ten who was being looked after by her sister who wasn't much older than 13. My husband was going to come and give me a break for a night as I hadn't slept for days, but for him to come in and share a room with these girls was a cultural no-no!. (WI.017)*

Whānau also talked about staff imposing their beliefs and practices on them, not fully understanding their implications at a cultural level.

> *The staff were trying to get me to have a break from looking after my son. They told me that they wanted my wife to come and take over. Being from Samoa and having limited support, my wife was at our accommodation looking*

*after my teenage daughters. I told them the right place for me is here with my
son, the right place for my wife is looking after the girls that's how it is. (WI.006)*

While interpreting services are offered through the DHB, there were instances noted when staff asked and expected whānau to translate private health information to other whānau of the same culture. The use of whānau for this purpose disregarded cultural issues about gender and family structures. It also dismissed the functions where certain people within whānau do the translating and relaying of information to their family members. Whānau talked about tensions around whether they should comply or not.

*I know some of the Pacific men here have been asked by staff to take part in
other family's medical discussions and translate some sensitive information.
It's just not appropriate they need to approach and go through the family.
Some of these men felt pressured and wondered what would happen if they
didn't do it and queried the effect on their child's care. I know the translating
was ok, but when it's like sensitive and private information that needs to be
given to a mum and her elderly parents about their child, Ummm no that was
not right there are some things you wouldn't tell those old people, well not
from someone outside of the family and definitely not like that in that
environment, that needs to come from their family representative. (WI.012)*

The processes involved in accessing the hospital interpreting services, as seen on the DHB website, seemed time-consuming, therefore most likely ruling out usage in an emergency. The website outlines what is needed to be able to book the services, as seen in Figure 14.

To request any of the ADHB Interpreting Services you must have an account or be registered, if you have not please *register* now¶

If you have registered, you need to complete the online booking form;¶

- → You can ring us at 0800 559 555 for Telephone Interpreting Only;¶
- → ADHB Interpreter Service will confirm you booking according to your preferred notification method noted on your user profile or *booking form*,¶
- → You will be provided with a Job number on your confirmation form and also on your online *booking list*¶

NOTE:¶

- → You are required to complete the booking form accurately for the service to process, with language, date, time, duration, location of appointment etc, Incorrect information may result in a call out of cost to pay in interpreter incorrectly assigned;¶
- → See *cancellation policy* for more details¶

BEFORE MAKING A BOOKING, YOU NEED TO¶

- → Ascertain the spoken, written or sign language requirement;¶
- → Ascertain the client's gender preference;¶
- → Ascertain which type of interpreting service is suitable for the situation. ¶

Figure 14. Processes to book interpretation services.

Ironically, the website states:

Interpreting services can be arranged for people who are hearing impaired or do not speak English as a first language. Arrangements can be made through the nurse in charge of the ward or department, or you can ask for an interpreter when confirming an

outpatient clinic or day stay appointment by telephone. (Auckland District Health Board, n.d.-b)

Those needing to use the interpreting services are most likely not going to understand this information as it is in English; therefore, they might not access the website at all.

In other situations, whānau took it upon themselves to translate, in certain situations such as children having no support around them at the time. These situations occurred mainly in the ED or recovery units when parents were on their way up to the hospital or making their way back to the ward.

> *There was a Samoan boy, who had the stroke and the boy had very limited English, so a translator was needed [be]cause they need to get him to CT urgently and they couldn't get one quickly, so they got the security guard [be]cause he was kicking all over, they needed to control him, he was scared he didn't know where he was and he wasn't with anyone as he came in from school. So, I went up to the charge nurse and told her I'm family I will translate she got permission from someone (family) on the phone who was on the way in. It took me three minutes, just to calm him down and establish a way of communication [be]cause of the stroke on the right side, I said to him in Samoan "you know, you are frustrated right now [be]cause you can't speak, you're not thinking straight, so all I need to do is establish some form of communication, you blink your eye once if you understand", he does that, then I said "blink your eyes twice if you don't understand me". He did the same thing, "if you want attention [be]cause your left hand is still moving, open it like that, so you get some", so once we did that, I said to the doctor "what do you need him to know?". They took him for a CT scan then he had to go to theatre urgently, but he was calm. (WI.006)*

Participant six recalls being present during other events, which had occurred regarding cultural situations which were due to misunderstandings and lack of system resources.

> One of the Samoan dads came in, his daughter went to the theatre he was told to go, and they will phone him to come back after the operation. He went to Manurewa where he had a family. They say things and Islanders will just do it; some won't challenge. Well, wrong move, that girl, she was seven, her father is the only person she's known, [be]cause the mother died a couple of years back. Yep, sure enough, the father was there, baby was in PICU, she comes around at about half eleven, no father there, she then starts pulling the wires and everything, yep, then they called the father as she was in hysterics and he had only just got to Manurewa and had to turn around to come all the way back. The dad called me, asked if I could go downstairs talk to her in our language just to calm her down, so I went downstairs and calmed the girl down, and then when they came back, I had some food for them, these are the things they need to look at putting in place. (WI.006)

Resources
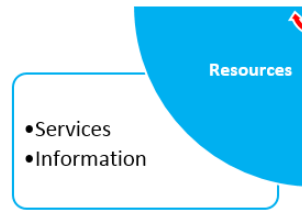
Figure 15. Resource engagement barriers.

The main barrier identified by whānau regarding resources was the constant lack of transparency regarding information and services. Whānau consistently raised issues of "not knowing" or not being offered publicly available services. Whānau mentioned hearing about certain services at a later date having realised they had met the criteria for support. While whānau did access some services, the issue of the lack of transparency was also consistent within these services as revealed by participant 2.

> *My support worker would always say when she came to visit us "if you need anything at all just ask". Every time I would say… "but I don't know what you offer so I don't know what to ask for". That was it through our whole time up there. I am not one to ask for anything, and she realised that in the end and we never explored that further. (WI.002)*

> *I found out later what I could get from the Foundation. I know they kept offering to support me, but it was always in code. They were never actually explicit about what they give out. In the end, they gave me petrol and supermarket vouchers as well as coffee vouchers for up at the hospital which was a godsend. I'm not sure why they can't just say this is what you can get. (WI.024)*

Whānau also realised that other well-needed services were available within the hospital environment but remained unidentified until it was too late. Whānau talked about spending much time away from their child trying to navigate the Work and Income New Zealand (WINZ) social system for support. Appointments took days, sometimes weeks, and travelling long distances only to be told to come back with different signatures and forms.

> *I just went to WINZ and did everything, yeah took all my stuff with the housing form but um I just found out later from the social worker here, there's a WINZ person here that helps families who are admitted. They sit at outpatients three times a week, so people don't have to go to an office. I never knew that no one said a thing and I still can't see that information anywhere. (WI.006)*

In looking for documentation, no specific on-site WINZ support information was found, only addresses for WINZ locations and information pertaining to forms. The lack of general information was also noted, such as parking and associated permits and criteria, accommodation options, café locations and hours, and spaces whānau can access such as the chapel and Ronald McDonald Family Rooms. While whānau knew bits of information, it was a mission for whānau to easily access useful details. Often, the lack of transparency would lead to misconceptions for whānau. For example, hospital social workers were mistaken for CYFS (Children, Youth and Family Service – Statutory Child Services), social workers. Whānau believed that accepting vouchers or food parcels could lead to CYFS involvement as a result.

Some families I know have been asked by staff if they want to take the food package they've got, some of them said we know once we've received those, it goes on our record and the Salvation Army then goes straight to CYFS. (WI.006)

Other barriers to receiving information were due to whānau not being able to understand it as it stemmed from medical speak, or was not available in other languages, was too long and unappealing (no pictures or pictures that had no connection for whānau). In some circumstances, incorrect information was being relayed before transfer to Starship.

Sometimes the no information or misinformation comes from the transferring DHB. We go around like a headless chook trying to tee them back up with co-ordinators back at their local DHB, you know, so if processes and correct information was done better at that point before they came up, it would make their journey here probably less problematic for them. (SI.016)

Lack of transparency caused some whānau to be seen as demanding resources because they were misinformed by health care staff, other DHBs or told by other whānau what they had received, not realising that their situation was unique and therefore entitlements differed.

Racism

The findings have highlighted racism at different levels and across all engagement areas of the health system. Clear treatment differences were noted by whānau particularly between ethnic groups. Interactions with health staff and being in the hospital for extended periods contributed to whānau intimate knowledge and evaluation of their surroundings over time. Differences ranged in the way they were treated, the language used, and resources offered, along with assumptions made. A Pacific father whose son had been admitted for over a year highlighted the differences he had felt and witnessed.

They look at us Island people, they think we don't know anything, and sometimes some racial issues come in. I do see how differently they treat us brownies from the whites… Māori or Pacific Islanders. (WI.006)

God, sometimes they treat us like we are dumb Islanders, I have a masters for God's sake. (WI.024)

Other whānau who were party to the politics within the organisation relayed what they had experienced and how people had tried to confront it head-on.

An incident occurred with a Māori mum who had a very sick baby and a Pākehā family who also had a child admitted. The Pākehā family complained that the Māori mum was making too much noise in her room. One of the other fathers who was Samoan was in the very next room to her, and he was asked by the charge nurse if he heard anything that night. He had said he didn't hear anything and queried if he couldn't hear it then, how could they? [Pākehā family] There was no meeting or negotiation they just moved this mum she was put elsewhere. After this had happened, he [Samoan man] told them [management] that what they did was wrong. He then said to the management involved "did you take their [Pākehā] word as gospel because of the colour of their skin or is it [be]cause of their money?" (WI.012)

While instances of racism and discrimination were noted, what was also evident was that whānau felt a sense of guilt or remorse for just thinking or stating it and would rationalise why staff behaved in certain ways. Rationalised behaviour was seen by whānau putting their own treatment aside as they felt that despite negative and derogatory comments or behaviour they had got a desired outcome in the end. Outcomes varied from receipt of specific information, answers to questions, access to support services or gentler physical handling of their child.

> *It was the Pākehā nurse I found really, really rude, just abrupt … oh in saying that she was probably just tired. (WI.018)*

> *We've had some really bad treatment um…but I think…well, to tell you the truth, the bad treatment I'd say is probably less about the individuals and more about the stress of their loads. (WI.005)*

Summary

Barriers and distractions have been summarised over the four key connecting areas of policies and procedures, people and practice, the environment and resources. Barriers and distractions impacted on the way whānau received, perceived and reacted when engaging with health care systems, processes and people often causing misunderstandings leading to undue stress, additional pressures and a victim blaming mentality (blame the patient). The findings have shown that health care engagement can either hinder or enhance whānau experience having wider implications on whānau roles, functions and processes including gender, generational, and cultural mechanisms that contribute to whānau ability to cope sufficiently.

Drawing on Resources

Coping, for Māori and Pacific whānau, relied upon them drawing on accessible and available resources. Whānau relied on two main sets of resources that stemmed from system-based resources and whānau-initiated resources. System-based resources were mainly seen as facilitators that contributed positively to whānau coping. However, they were also found to have limitations and gaps which sometimes added to whānau burden. Whānau-initiated resources were found to be based on coping mechanisms and strategies employed under a holistic framework incorporating six elements: spiritual, cultural, environmental, emotional, physical and whānau. Māori and Pacific whānau employed positive, negative and protective coping mechanisms and strategies.

System-Based Resources – Facilitators

System-based resources are supplied within the health system itself. They include various support-related services, practical and tangible items (vouchers, gifts), facilities (such as equipment and environments) and the forming of trusting relationships. These were seen as facilitators of whānau coping.
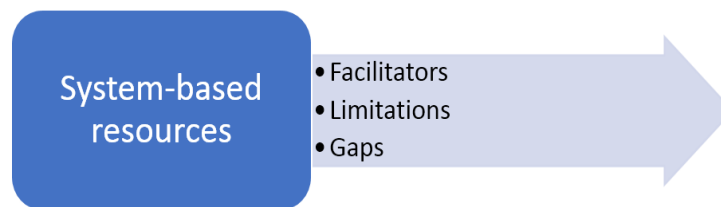
Figure 16. Indicators of system-based resources.

Support services and staff who were available and accessible seemed to meet some needs at different levels. For example, accommodation needs were met as best as possible through Ronald McDonald House, Te Whare Awhina[15] or by services accessing cheap but quality motels. Financial assistance through vouchers was always appreciated by whānau, particularly as finances were tough for many. System-based services identified in this study where those that facilitated whānau coping over and above wards and condition-related services. Services included: Ronald McDonald House, Child Cancer Foundation, Canteen, Consult Liaison Services (hospital counselling), Heartkids, Cultural Support Services, Radio Lollypop, Hospital Grandmothers and Volunteers, the Northern Health School and the Palliative Care Team.

> *So over and above the CCF providing the odd voucher here and there and petrol money for mum or whoever to come and go, the palliative care team did the same. So, when mum and Dad were ready to go home and leave us here, they gave them grocery vouchers too and some for my daughter for our house when they got home. They gave about $150 worth of petrol vouchers for the car to get home. They were amazing. (WI.002)*

Practical and tangible resources included vouchers for petrol or food for whānau. Others talked about support services that had given items in luggage bags: luxury toiletries, blankets, thermometers, teddy bears, magazines and books. Retreats and holiday homes were also offered when and if the child recovered. For some, however, whānau resources came in the way of practical help that made their journey a little easier by enabling them to just get on with daily life.

> *A nanny in oncology she just needed help more practically, like accessing and being shown how to use the washing machine. (SI.012)*

The recognition of not just practical support but emotional support and understanding received from services was articulated by many whānau and particularly by those affected by the Christchurch earthquakes.

> *As soon as people knew we were at Starship due to the earthquakes and heard that we were also dealing with our losing our whānau house, they were so supportive, and I felt that they just understood. We received lots of support, people in Christchurch who were dealing with their own losses and devastation were so giving. We had parcels and fundraising arrive. Staff at Starship and the services we were involved with were really compassionate*

---

[15] Te Whare Awhina is located on the Auckland City Hospital site. It operates under Māori tikanga/protocols and is available to whānau/family who meet the entry criteria. Accommodation is short term and primarily for whānau who live outside of the Auckland region and have a family member in hospital. Whānau living in the Auckland region who are supporting an acutely ill patient will be considered on a case by case basis. Patients are not eligible for accommodation. Bedding, towels, and laundry are provided. A kitchen is available but families must supply their own food. A small fee may be charged if you are not eligible for a Ministry of Health subsidy. All bookings are through the ward clerk.

about the impact the earthquake had on us. We were just so embraced. (WI.001)

While those who were flown in from other countries and regions recognised the difficulty in being away from their home lands and support systems, they also emphasised appreciation for being under a high-quality health care system. Their appreciation stemmed from whānau experiences with other institutions that were deemed ill-equipped to provide quality care.

As we got to Starship, it was like wow! You know, doctors and nurses everywhere, support was right there, yes it was foreign to us but you know we could keep up and we could understand and um yeah… XXX hospital in comparison was absolutely traumatic…it was a horrible place…it was actually disgusting. (WI.008)

By 10 o'clock we were on our way to Starship, as soon as we got there I felt more comfortable, the baby was improving, literally, as soon as we walked in the door, they just knew how to treat her. (WI.018)

We come from Samoa, we've been here almost a year now in this hospital, and my son was diagnosed, we didn't know he had a heart problem. Back home, I guess it's just the lack of resources and the expertise why they couldn't pick up his heart problem but … it was only when we got here, we had the first scan, and then we were told. (WI.006)

The environment of Starship was noted as being well equipped, not only with highly technical and advanced machinery but also in the way of people power as well. Whānau equated these things to the quality of care.

And there was a room full of people, they were ready for her, she was really, really unwell as soon as she entered the world but there must have had about 15 people ready to treat her and all the high-tech equipment. (WI.004)

Good relationships with both support service and health care staff were an important factor to whānau coping. Developing and maintaining good relationships enabled trust to build. Whānau identified trust as staff doing what they said they would do, keeping consistent contact and supplying what they said they would, such as printed information, practical assistance and items or relevant contacts. Trust became an important factor in whānau being able to leave the room, take a break and relax more. Whānau talked about being able to tell over time if staff were genuine in their care for their child, as many had experienced patronising comments.

I remember the doctor saying to me when I was upset, "Look, I know what you are going through." That made me madder. I said to him, "Do you? Is your child at risk of dying? Have you been let go from your job, as you had to be in another city? Are you worried you can't pay your mortgage? Are you exhausted? ... No .. So don't tell families that you know what they are going through!" Hmm, needless to say, I never saw him again, and that lovely doctor wrote that I was a neurotic mother on my son's file. One of the nurses who I had a good relationship with reluctantly showed it to me. (WI 017)

Part of whānau evaluation of staff being genuine stemmed from whether they interacted fully with their child on a level their child could understand and enjoy. Whānau equated good trusting relationships with high quality of care, irrespective of the facility they were in.

> *Our neurosurgeon was great; he talked to our boy who was seven on his level. He even got down on his knees to be at the same height as my son's wheelchair. He visited us every day and came in on his day off. When I said to him I thought it was your day off; he said, "yes, it is, but I kept thinking about XX and wanted to see him". He was awesome, approachable and gave us such good care. (WI.019)*

While whānau were grateful for all the resources and support that was supplied, there were limitations and gaps noted within services. Whānau reiterated that a culturally reflective workforce was a gap across most services impacting on Māori and Pacific whānau through lack of understanding of beliefs and practices. Whānau deemed cultural support as important given the fragile nature of the child and the imminent risk of death, yet the cultural support services were already overburdened and under-resourced. As well, cultural support was used by health care staff as security to control whānau.

Limitations within services included age restrictions and eligibility and, as a result, being referred on to an additional service. Hours of operation also provided limitations as the majority of services only operate between certain hours and cover a huge area, which then impacts on time with the whānau in need. During the day whānau usually have to attend treatments and a full regime of recovery and rehabilitation activities with their child, so many cannot fit in additional appointments. There were also waiting lists for some services. Therefore, some whānau never got a chance to engage. Restrictions on how many times whānau could access the service and or resources was also raised as an issue, especially for whānau who are in the hospital for long periods of time. Many whānau also highlighted being offered services at the beginning, which is an already overwhelming time, but then nothing in the middle where they are more likely to be needed.

Simple but practical information was still lacking, including exactly what services could supply to whānau, as well as medical information being put across simply and plainly, including in other languages. Whānau felt that the hidden information in general across health was an added burden to whānau energy and time as they had to go and search for it themselves.

Whānau appreciated the support services offered and undertaken and many understood that the staff themselves were doing the best they could with what they had, given the systemic difficulties they too had to often deal with.

Whānau-Initiated Resources – Coping Mechanisms and Strategies

Whānau-initiated resources

Holistic
Negative/positive
Protective
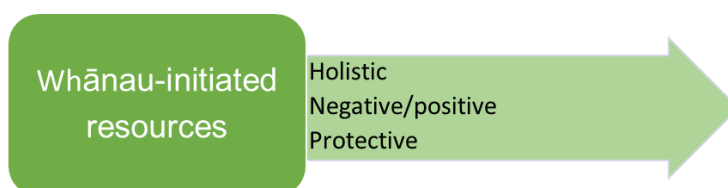
Whānau-initiated resources consisted of coping mechanisms (implemented semi-unconsciously or by default) and strategies (implemented specifically and intentionally). These were drawn upon from what whānau already possessed or had at their disposal, specifically searched for or intentionally put in place. The coping mechanisms and strategies that whānau had employed through their experiences of navigating and transitioning through the health care continuum were found to be influenced both positively and negatively by a range of impact factors. The factors that had an impact on whānau included the barriers, distractions and facilitators identified in the previous sections, as well as external factors (factors out of people's control) such as dealing with the impact of an earthquake, having to reside away from familiar supports, the death of family member or an additional child's hospital admission. Whānau-initiated resources are grouped into coping mechanisms and strategies and are categorised under a holistic framework containing six key elements: spiritual, cultural, environmental, psychological, physical and whānau /personal (see Figure 18).
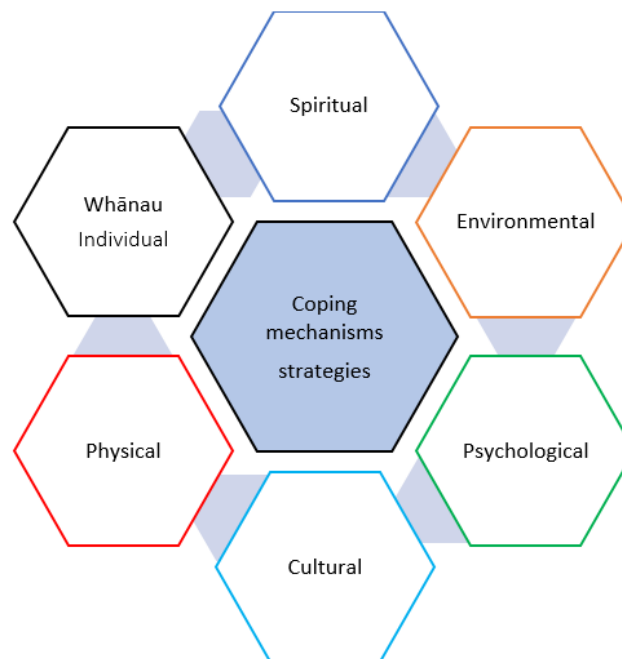
Figure 18. Interacting elements of whānau coping.

Coping mechanisms and strategies may also overlap between elements. For example, karakia (prayers or incantations) can be categorised as both spiritual and cultural. Likewise, photos and mementoes can be spiritual, cultural and environmental. While this is recognised, mechanisms and strategies are not repeated throughout this section.

Spiritual

Spirituality as a coping mechanism was a common theme among all whānau. However, it was represented in different ways. Whānau revealed feeling scared and lost and needing strength. Representation of spiritual reliance came through beliefs in higher powers such as God, Jesus,

Ātua and Mary. Whānau would call on their tīpuna (people who had passed) for guidance as well as kaumātua (elders). Reliance on church and church members was identified by both Māori and Pacific whānau, as well as actions such as prayer, having faith and hope. Searching for meaning was also common as was knowing that life and death contributed toward a bigger purpose. Some whānau talked about being tested and searching for a reason as to why this may have occurred. Other spiritual essences were having the child die at home which was seen as positive and comforting, as well as speaking to the child believing they are still present, even in death (see Table 14).

Table 14. Spiritual Coping Mechanisms and Strategies

Mechanisms	*Strategies*	*Examples*
Spirituality Feeling scared A sense of loss Needing strength Gratitude	Prayer	*I wasn't even scared, and that was just through prayer. You know, I prayed religiously I just prayed and prayed and prayed, and I just felt no fear... I didn't. (WI.008)*
	Call on higher powers	*I made my pact with God right from the beginning you know, I left it up to God. (WI.006)*
	Looking for meaning	*Many families believe that there's a bigger purpose to this. (SI.021)*
	Having faith/hope	*That's what this journey did for me it made me have faith. I read the word for today, and I feel that's what made me have faith and be strong and stay positive. The focus on that he is going to come out. There is thinking about it, and then there is believing, and I believed. (WI.003)*
	Child dying at home Child still present in death	*So, we decided to take him straight home, well, he passed just around midday. I think it was, but we managed to rally all the family over. (WI.002)*

Gratitude was a consistent theme that whānau drew upon, no matter what the outcome was for their child or at what stage they were in their journey. Whānau had gratitude for what they had, taking on the lessons learned through their journey such as the value of family and time and celebrating smaller milestones more often rather than waiting for big ones. Whānau were thankful for a range of things such as having a great health system and support from services, community and whānau. Many whānau highlighted the significant changes they had made to their lives both as individuals and collectives such as changing eating habits and routines, moving houses, changing jobs and becoming less materialistic.

> *It has definitely opened our eyes a lot and just made us stronger people and just more humble. It's made me more humble because I was more of a keeping up with the Joneses kinda girl, but when he got sick, it made me realise there are more important things than being materialistic. (WI.007)*

It was also found that the older generation tended to have set routines and patterns aligning with spirituality. Set times for karakia/prayers seemed to be early in the morning and then at night around about 6 pm. While many whānau prayed individually and privately, some whānau relied on other sources such as their church or cultural group to undertake particular ceremonies or prayer-related sessions. Spirituality ceremonies were also restricted within the hospital for multiple reasons. Whānau accepted compromise regarding the lighting of candles, incense and having to adopt alternative rituals. Sometimes spiritual connection required quiet with no disruptions, and as there were limited whānau spaces to do so, whānau found it difficult.

Environmental

Whānau conveyed that many of their coping mechanisms and strategies were related to different environments. Environmental coping included connections to lands, buildings, houses and items within them. Table 15 outlines the environmental coping mechanisms and strategies Māori whānau identified.

Table 15. Environmental Coping Mechanisms and Strategies

Mechanism	Strategies	Examples
Environmental Yearning for home Wanting the familiar	Finding a place	*Most of the time, if the time is right I would go up to level six where the chapel is, so I spend a bit of time there, and I played the piano that's there, so that's my way of de-stressing (WI.006)*
	Getting outside Having a smoke	*I'm a smoker, and you would think that because of my heart baby that I wouldn't, I would have given it up and I did think about it, I thought I could, but I didn't. As sad as it sounds, it was all I had, that was my three minutes alone, that gave me ah I don't know what it was, time, just to go out and have a cigarette, that was the only time I was away (WI.004)*
	Bringing mementos	*I brought my awa with me. I bottled it and brought it to keep me connected to home (WI.004)*
	Eating 'our' food Negotiation	*Just to be able to cook our own food, what we wanted was so great, I'll never moan about cooking again (WI.024)*
	Breaking the rules	

Whānau related environmental coping to the outdoors, including gardens, parks, walks, weather and associated elements. Coping strategies put in place stemmed from being away from their homelands and support and being in a foreign environment.

Smoking was identified by whānau as a negative strategy, although it gave them time out and a sense of refreshment. The smokers' corner was identified as a support group. Even whānau who didn't smoke assembled there for support. It was a place where familiar faces would be, and it was away from the ward. Whānau found the smokers' support group a place to find out

information, release stress, find comfort and get questions answered. It also provided connection and consistency where whānau knew where to find people and knew what times they would be there (including when the child was sleeping and after meals). Participant ten notes what she saw in her experience of working with whānau who had children that were critically ill.

> *One of the other mothers mentioned that she liked going out to the smoking area in the hospital even though she didn't smoke as that's where you could have deep conversations with other like-minded parents and it was a great release. (SI.010)*

Environments were important to whānau in that they either hindered or enhanced their coping. Some whānau searched for connection within the environment they were in, for example, the smokers' support group, while others rebelled in some way. Whānau talked about being encouraged to keep kids away from their sick child due to the risk of infection. Breaking the rules for many whānau was a way of coping. Many whānau spoke of their realisation later in their journey of their sick child needed other children around them. For some whānau in dealing with the end of life, they put the child's need first, and the sickness became secondary.

> *Toward the end, I didn't worry too much if our other kids had colds, etc. because it was more about him. I worried about that later as it was about trying to get him some normality. (WI.002)*

Other parents talked about kids needing to be with kids and that it made their child feel like a normal child as kids still treated them the same. Whānau identified that it was the adults that tended to limit and treat the child like they are sick.

> *He was still the annoying cousin to her not some sick half dead kid. He responded well, so we let other kids just come and see him despite what the doctors said. (WI.017)*

Other acts of rebellion were breaking the one parent rule or standing firm in negotiating cultural health practices such as karakia.

Psychological

Coping mechanisms and strategies that fall under this category are outlined in Table 16. These methods pertained to emotions and feelings, thinking and perceptions. It also includes the forming of ideas and implementing strategies to initiate some sort of action, either positive or negative. Actions varied depending on situations and resources; some implemented what they determined as positive strategies for coping (such as writing, seeking information and helping others), while the negative actions were seen by whānau as their inability to cope (such as smoking, anger, crying or not being able to ask questions).

Table 16. Psychological Coping Mechanisms and Strategies

Mechanism	Strategies	Examples
Psychological Mistrust Fear	Comply/don't ask questions	*I just did what they asked even if I didn't agree (WI.003)*
Experiences shape behaviour	Make a complaint	*We went through that process of complaint um, and all I wanted from them, which I got, was an apology. (WI.019)*
	Implement a service - Translation - Advocacy for others - Safety	*I go out of my way; there was a nanny she needed to go up the road late at night I went with her just to keep her company. (WI.006)*
Trust	Be more relaxed Have time out Focus	*Family around me provide safety I can trust them they know me and my child well. (WI.017)*
Form perceptions	Don't ask questions	*We didn't know any better, doctors were just gods. (WI.002)*
Protection	Withhold information	*I didn't think to prepare my mum for it; it was a bit harder in the end. I didn't show her the book; I don't think she would have wanted to have looked at it. (WI.004)*
Expression	Holding on to emotion	*I had to be strong for my family for my wife. (WI.003)*
	Letting go of emotion	*If you asked how I coped I would say I didn't I just kept crying all the time. (WI.022)*
		Xx was always angry. (WI.002) *We have had incidents of violence. (WI.010)*
Powerlessness	Taking control	*I had to reclaim my role as the parent. (WI.017)*
		I journaled as a way to tell his story, and in case any of my kids have kids with the same condition. (WI.004)
Measurement	How far we have come	*My way of coping is thinking of how well he is now, what he has been through and what the outcome has been. It could have been so much worse. That all helps but at the time and with the earthquakes and the stress associated with that, it's like being in post-traumatic stress. (WI.001)*
Intuition Knowing something was wrong	Heeding to signs and symptoms	*I knew something was wrong I just knew it. (WI.004)*
		He was losing weight we kept getting sent home I got another opinion, and I'm thankful I did. (WI.002)

In several circumstances, whānau implemented protective strategies. These were strategies that whānau thought would protect someone, but they often caused issues later down the track. Whānau revealed withholding information the doctor had told them from their wife or partner and that when the information was finally revealed it caused mistrust and issues in the relationship. Not informing the child of details so as not to scare them ended up making the child more anxious and unprepared. In another case, a sister tried to hide her own good news, thinking that she should not share it while her sister's boy was fighting for his life.

> *My mum had told me that my nephew had won a big award in Australia. I asked my sister why she didn't tell me that. She said, "because your son is fighting for his life, do you need to hear about how good my life is right now?"… I said to her "I actually need to hear positive stories. I need to feel that there is a sense of normal outside of these four walls". (WI.017)*

Taking back control was a way whānau could feel they had some power over their often-powerless journey. Whānau would become advocates for themselves and others, seek out information, make to-do lists, or help out with cleaning (support service offices, or ward room kitchens). Some would become allies to ward staff and teach them about cultural elements.

> *Then I talked about some of the cultural considerations that they might think about when they are talking to families in a similar way. There was a head nurse up there, and she would often come and talk to me regarding the cultural stuff. I thought that was really cool. (WI.002)*

What was evident is that some whānau thought they did not cope; however, whether the psychological coping was negative or positive, it was still the way in which whānau managed to cope in order to survive within a foreign system.

Cultural

Cultural aspects were focused on roles and functions, such as elders, leaders, nurturers and cooks; and processes and practices, including grieving, tuakana/teina (older helping younger), and kaitiaki (being the overseer for specific people) as indicated in Table 17. For whānau, coping stemmed from what they knew, and what had shaped them, including both negative and positive experiences.

The structures within whānau held primary position when there was support available. The respect for designated roles such as kaumātua or grandparents, siblings, as well as the youngest and eldest member was evident from data. Each whānau member had a role, and the majority of whānau knew their roles well. Some roles were to undertake cultural functions such as karakia or lead in making critical decisions, while for others, it was to nurture and look after other members, or keep the home fires burning with fundraising, or driving people to and from the hospital. For older participants, the matriarchal and patriarchal roles were very clear. Responsibilities for others if they were not well-defined, would soon become clear through delegation (usually by the older guiding, the younger). Adult siblings were recognised as providing pivotal support toward the critically ill-child or their caregiver. Provision of support came by looking after additional children, assuming responsibility for the sick child so the caregiver could have break and supply financial

(paying bills, transport and accommodation), emotional (talking, giving advice, listening), cultural (making decisions, speaking in their own language, undertaking cultural rituals and routines) and physical (cooking and cleaning) support. Child siblings irrespective of age contributed in many ways by making the ill child feel 'normal' rather than sick while carrying out some of the usual sibling routines including arguing, playing or just being physically together.

My younger sister played a significant part in our journey. Despite her living, in another country, she left her own young family, a business and a job to come and support us. My sister was very close to my son, so his sickness impacted greatly on her. Although culturally she was classed as teina (the younger) I had looked up to her as the successful, wiser, and more talented sister. Living out of the country for many years did not alter her cultural role in supporting, leading, delegating and organising. Her role did not stop when we were discharged either. While she returned to her own home and family between her and my mother (who also lived in another city), they took turns providing regular shifts which occurred approximately every three weeks to continue with supporting our recovery. Our whānau roles continued to function despite distance and time away from each other.

Through this journey, I realised that the roles, practices and processes that occurred in our whānau were embedded. I do not ever remember having an explicit conversation about what these roles, practices and processes entailed. Rather we just knew through our respective upbringings and seeing and being with others who were like-minded, what was expected of us.

Cultural mechanisms and strategies were found to be implemented by all whānau interviewed, but in different ways and to varying degrees. While some whānau had limited physical support, they made up for it by searching for the familiar. Presented in Table 17 are the cultural mechanisms, and strategies whānau drew up on in order to cope.

Table 17. Cultural Coping Mechanisms and Strategies

Mechanism	Strategies	Examples
Cultural Roles and functions Processes and practice	Tuakana/teina	*The older nurse took me under her wing and showed me how to use the machines. I then showed other younger mums. (WI.004)*
	Kaumātua	*Just having Papa XX around was so reassuring; our old people they just have this way about them. My mum just flocked to our kaumātua she said she found a sense of safety. (WI.017)*
	Matai/Āriki Church Minister/elders	*When the matai came to see us he was from a village next to ours it was like being connected to home again. He also brought his church minister. (WI.006)*
	Waiata sessions	*Having waiata sessions all singing together and playing the guitar, my son responded to that; it was positive and uplifting. Some of the other whānau would come and join us each night. (WI.001)*
	Moteatea	*People were starting to sing songs and my sister in law had composed a waiata for him. Talking about his bravery and all that sort of thing it was a bilingual song. So, they were busy singing away, and while the song was playing, he passed. (WI.002)*
	Practice	*My uncle was a bit worried about my breast milk being in the ward fridge with everybody else's food so he bought a little beer fridge so I could keep baby's stuff separate. (WI.004)*
	Language	*Being able to speak in our mother tongue was healing in itself. Whether it was with my own family or other families. You don't realise how much you miss it until you are far away from it. (WI.002)*
	Functions	*My sisters, they worked out the schedules for visits and breaks for us they sorted out who would do what like cooking and washing. (WI.003)*

Whānau deliberately searched for families and staff of a similar culture. They ended up becoming a support for each other by, looking after each other's children, sharing food, practices and conversations in their mother tongue. Whānau supporters embraced those who had little to no cultural or physical support.

> *I would look at the ward admission board or the Ronald McDonald Family Room board to see if there were familiar names. I would then make a point of*

introducing myself to these families and sharing information and knowledge that I thought would be helpful. (WI.017)

Whānau also talked about strong relationships made with cleaners, tea ladies, orderlies and receptionists. Whānau highlighted that these people were some of the only brown faces that they had contact with during their journeys. The relationships were formed over time, and through many admissions, as these people tended to stay in their roles for many years.

The cleaners, orderlies and the tea ladies were great, all brown faces. The cleaner was a wealth of information she knew everything she gave us more support than our support person. She was so approachable and had been there for years. We befriended her from the last two admissions. (WI.021)

The security guards were great I used to get to know them when I went out for a smoke or was up during the night. One guy, he was a kaumātua he was fantastic with families offered help, carried things, gave us lifts to the House which was a long way for my mother to walk. Families felt safe when he was on. (WI.017)

Searching for cultural familiarity occurred even for those who were young and brought up away from their homelands and whānau. The younger generation would also seek cultural familiarity, mainly through other whānau in similar situations or support service staff. For whānau, cultural familiarity was a space where they felt a sense of normality and could just be.

I remember XX instantly made a relationship and a connection with a local Māori mum going through the same journey with her baby; she was a bit older… She was 43 at the time…Yeah, and you know XX [my sister] was 16 when she was admitted and had a baby [with heart complications], and she was just another blanket of support for us, [be]cause culturally… You know we could connect, and she was up at the hospital by herself most days because her husband had mahi (work) and the kids were at school so yeah it was/that was…We got really close, yeah!…. that was a really special um bond to have, just really pulled us up and into line as well…yeah!… She was cool…that was amazing support…yeah. (WI.008)

Cultural familiarity came about even if the whānau were of a different culture, as related above by the sister of a young Samoan/Cook Island participant. The majority of whānau talked about searching for connection and most found it with other whānau also admitted with critically ill children. Support and relief also came by just venting frustrations with someone who understood their cultural reality. Discussing their frustrations or differences and having someone understand regarding practice and approaches from health staff that differed from their own culture helped them feel validated.

Just talking with XX about the different care compared to what our own culture is used to took the load off. I thought it was just me I was being paranoid and crazy and ungrateful but to get that backing made me realise I wasn't nuts, things were radically different, and my feelings were actually functioning alright. (WI.025)

Culture was relied upon by all whānau interviewed. Stakeholder participants also reiterated the importance of culture in whānau coping even though their agencies were not able to provide it.

Where services could not provide adequate cultural support, whānau soon found it through other means.

Physical

Table 18 demonstrates mechanisms and strategies were found that related to the physical aspects of whānau. These included elements that affected the body (such as exercise or lack of it) and sleep. It also included touch and proximity to the child and relying on whānau support. Other mechanisms and strategies included the use of technology such as social media.

Table 18. Physical Coping Mechanisms and Strategies

Mechanism	Strategies	Examples
Physical Feeling constrained	Getting outdoors	*I made it my mission to get outside for at least ten mins a day. I just needed fresh air and light. (WI.005)*
Needing to vent/inform	Facebook	*My daughter would put things on Facebook, which I found quite difficult. I couldn't go and look at it. But like she was saying that was her way of telling everybody without going over and over and over it again. But that's a modern thing that Facebook. (WI.001)*
Feeling distant and alone	Being near	*I needed to be near my son to smell and touch him it was hard not being able to sleep by him. (WI.017)*
		Family is very important during a crisis. I was talking to my brother, and he was telling me being distanced made him suicidal, and it was family being near that pulled him together. (WI.003)
		My niece who I was looking after had just started school when they were up at Starship and cause my sister goes to everything for her kids; she never missed anything, so I think that was pretty hard for her, so we just recorded the day and then sent it up. (WI.011)
Exhaustion	Not sleeping or eating	*Everyone was worried about me [be]cause I was pregnant and I wasn't eating properly. (WI.007)*

The inability to get outside the hospital, let alone exercise, caused distress for some whānau. Whānau strategies for getting exercise incorporated walking stairs instead of taking lifts or walking up and down the wards over and over. Technology usage was more favoured by the younger generation than the older. Facebook, FaceTime and Skype were the main tools utilised by whānau. Social media enabled connection and the ability to keep people information without the need to constantly repeat information. As well, social media became a tool to keep track of the journey. The diminishing of physical abilities was also apparent over time with the likes of

exhaustion, lack of sleep and some being unable to eat. Whānau support, in most cases, helped to reduce these issues as well; whānau found innovative ways that worked for them.

Whānau/Individual

Whānau and individual level mechanisms and strategies related to the impact on whānau themselves as a collective and as an individual member. Strategies included being together, giving back in some way, as well as planning and adjusting to the on-going issues throughout their journey (see Table 19).

Table 19. Whānau/individual Coping Mechanisms and Strategies

Mechanism	Strategies	Examples
Whānau/individual Collectivism	Grieve together	*We were all together when he went in for his operation we all cried together as a whānau. (WI.017)*
Giving back	Volunteering/charity work	*I give to the organisations that helped us; we volunteer to give back and show our appreciation. (WI. 008)*
	Building a foundation	*We decided that maybe this is the beginning of another journey and that's how the foundation was birthed I guess. Since the foundation, we have done about three presentations in schools just to raise awareness, and we support other whānau going through the journey. (WI.002)*
Planning and preparation	Putting money aside	*I was always looking ahead in case there is the next visit, so I put money away to take care of things I take a little bit out every week. (WI.004)*
Adjusting	Changing plans to fit with the child	*I can't take my son home to Samoa cause it's risky, so our short-term plan is five years here to live for, move everything, drop everything and move here for his sake and then at the same time try to accommodate my two girls [be]cause they are only young. (WI.006)*
Becoming the expert	Knowing all the medications, machines, symptoms and solutions	*I will look after him, just send someone to do his obs[ervations] I can do his obs and write it down and give it to one of your nurses cause I've got to the point now I've learned everything even the machines. (WI.006)*
Changing roles	Becoming the main caregiver	*My husband became the main caregiver at home he worked and took care of the other children. When I got home it remained like that really he got used to it, and I went with it. (WI.024)*

The flexibility of whānau was shown by them adapting to the child's journey so openly and willingly. Whānau just got in and did what needed to be done even if it meant shifting countries, cities or changing lifestyle behaviours. Becoming the expert for whānau went beyond just doing the health care job, it included hooking up machines, changing dressings and tubes and distributing medications. Expertise was needed in caregiving, reading and assessing the child

and knowing when things were not right emotionally and physically. Expertise also included being able to talk to the child and relay information and procedures so the child could understand.

After months of watching his medication, it suddenly changed. I questioned why the change stating this medicine was not my son's. The nurse informed me that it certainly was his and that I lacked the qualifications to determine otherwise. I refused to give it to him until his chart was checked. The nurse returned with my son's 'normal' medication and no apology. On follow up with another nurse she said it was the wrong medication which was methadone. My mother was a methadone specialist as part of her working role and on further investigation found out the dosage. She carefully but aggressively informed me that if I had given it to my son, it would have killed him. I instantly made a complaint that I never heard back from even on follow up. Like us, whānau found it challenging to deal with a clash of different views. The difficulty for whānau is how do you try and understand clashes that occur within one worldview, that is not your own, but has a severe impact on your child, and comes with societal expectations that the system holds *the* expertise.

Whānau reiterated that health care staff being unable to relate to the child or undertake procedures in a child-friendly manner was a source of contention.

> *On one level, everything was really good, it was the specialists that would be a worry, so depending on their ability to deal with children [be]cause I saw some very bad behaviour from specialists who I think just really needed more training around how to work with children. It's a different set of expertise needed then working with adults. (WI.005)*

On a similar note, older whānau members who had more life and family experience were taken back when younger staff with no children would be sent in to tell them how to care for their children.

> *So, she comes in and tells me, oh this is how you set up your baby, this is how you feed the baby and when I asked her how old she was, she was just in her 20s and that she has no kids. I've got kids; I've been feeding them even my siblings, my brothers and sisters I've looked after them and nephews, nieces, So it just makes me mad. I understand they were trained to do a job but to actually experience being a father or a mother, to have kids, to look after kids it's a 24-hour thing, not a 9-5 thing. (WI.006)*

Whānau/individual level coping mechanisms and strategies ranged vastly. Small things made the difference, such as not having to repeat things over and over, while others were big and included major life decisions. What was discovered was the flexibility of whānau and what they will do to keep the child as happy, safe and secure as possible.

Summary

In dealing with a child with a life-threatening medical condition, whānau drew on two sets of resources: system-based resources and whānau-initiated resources. While system-based resources were seen as facilitators, their limitations and gaps were yet another issue that whānau had to cope with. Coping mechanisms and strategies employed by whānau were mainly found to

be put in place as a result of, and the reaction to, system engagement barriers and distractions, as well as resource limitations and gaps.

Whānau Fill the Gap

What the data revealed overall was that while there were system-based supports put in place that were meant to help whānau deal with their child with a life-threatening medical condition, they were limited. Table 20 outlines the gaps and limitations that came about from analysis of the data and highlights how whānau filled the gap.

Table 20. Addressing Limitations and Gaps

Limitation and gaps	Whānau-initiated resource
Initial engagement of health care non-responsive to whānau	*Advocate for themselves by making a scene, stand, or complaint* *Continue to ask questions* *Challenge behaviour* *Get 2nd opinion* *Keep going back*
Lack of whānau support due to restriction in rules/policies	*Whānau pull finances, take time off* *Travel long distances to support* *Whānau become the support for other whānau* *Share resources and knowledge*
Lack of transparency of information and services	*Seek out information* *Research into services* *Breakdown information for ease of understanding, share information, pool information*
Lack of cultural responsiveness	*Whānau become translator and or interpreter* *Whānau become cultural advocates* *Whānau provide cultural services to staff and other whānau* *Whānau become the direct line of communication for other whānau* *Share whānau roles and functions with other whānau* *Whānau search for cultural connections and become a liaison*
Models of care	*Whānau become advocates of whānau-centred care* *Whānau-centred care practitioners* *Whānau implement cultural models of care*
Lack of culturally reflective workforce	*Whānau become the health experts in health care, equipment, medications and child needs* *Whānau advise doctors/nurses* *Whānau teach cultural understandings to staff* *Whānau implement cultural understandings with other whānau*
Limited service hours	*Whānau are open 24/7*
Limited resources	*Whānau provide food, accommodation, transport*
Inconsistencies and unreliability	*Whānau provide safety, stability and consistent support through routine, roles, function and delegation*
Racism	*Whānau provide identity and refuge* *Whānau provide counselling services by way of kaumātua/tuakana/teina support*

Limitations and gaps have been identified from previous sections alongside whānau -initiated resources. These resources bridged a pathway toward better and more effective endurance within the health environment that was not conducive to Māori and Pacific whānau coping. Findings show that whānau provided resources not only to cope with their own journey but also to enable others to cope with theirs. Where the health system and associated support services were lacking, whānau more than filled the gap.

Summary

Whānau, in essence, provided their own cultural health support system by drawing on their pool of resources to respond to barriers, distractions, limitations and gaps identified at health-system, organisational and whānau /individual levels. Resources drawn upon were wide-ranging and included practical (such as money, clothing food), manpower (including sharing support, providing security), services (for example, translation, advocacy, cultural advice), and cultural support (language, karakia, waiata, kaumātua).

The Role and Influence of Ronald McDonald House, Auckland.

This section relates to research objective two that looks at the role and influence of Ronald McDonald House Charities (RMHC), Auckland on whānau coping. RMHC was found to be a significant facilitator toward whānau coping. Whānau within the research study identified specific influences that enhanced their coping abilities while residing within its premises. RMHC was found to encompass whānau both in policy and in action, through dedicated support by passionate and caring front line[16] staff. These actions enriched whānau by providing unique experiences tailored to their situations and needs. While whānau had positive experiences, they also identified some alternative options for consideration that may further enhance RMHC as a service in meeting the needs of whānau from different cultures. The findings from the research pertaining to RMHC specifically are grouped into two main themes: the **role and influence on whānau coping,** including sub-themes of embracing the notions of whānau, staffing and support and experiences; and **whānau recommendations for optimal service** (Figure 19).

Figure 19. The influence of RMHC on whānau coping.

Context

RMHC Auckland comprises two houses (Grafton Mews and Domain House). The houses cater to the needs of those whānau with a hospitalised child who live out of Auckland. Family rooms are also available on Level 3 of Starship Hospital, which are a semi-shared (shared bathrooms, lounge and kitchen area), supportive clinical-free facility (Giuntoli & Fisher, 2015).

The family rooms provide accommodation for those who have children admitted into one of the intensive care units, including the neonatal intensive care unit (NICU), paediatric intensive care unit (PICU) and the high dependency unit (HDU). RMHC's core programme component is the Ronald McDonald Houses that provide free accommodation and support to families. RMHC also

---

[16] Frontline roles are those that work directly on a day to day basis in supporting families

includes support for schooling and other health-related programmes through their houses and their care mobile which offers oral health treatments. RMHC's mission is to keep families together so that they will be better placed to cope helping their children to heal (Ronald McDonald Charities New Zealand, 2016a).

RMHC aim is for the "houses to be a home away from home based on familiarity and routine that is provided in a homelike environment (Ronald McDonald Charities New Zealand, 2016c.). The Ronald McDonald Impact Study highlights that in 2016 support was provided to 3,722 families, including 41,698 nights of accommodation (see Figure 20) (RMHC, 2016d).

Figure 20. RMHC number of families and accommodation for 2016.

Reprinted with permission RMHC (2016)

Figure 21. Number of nights for the longest family stay in 2016.

Reprinted with permission (RMHC, 2016)

Embracing the Notion of Whānau

Similar to Starship Hospital, RMHC supports the model of the family centred care (FCC). FCC is incorporated within RMHC's vision, which states: "As pioneers of providing family centred care, RMHC continually strives to be part of the solution to improving the lives of hospitalised children and their families" (Ronald McDonald Charities New Zealand, 2016a). RMHC describes their definition of family as "caregivers (parents, step-parents, grandparents, foster parents, occasionally aunts or uncles) of patients, and their siblings (brothers or sisters or half brothers and sisters)" (Ronald McDonald Charities New Zealand, 2016c). RMHC, as an organisation, is relatively unique in that it openly and explicitly accounts for extended family members (whānau), including those not connected by blood - also known as kaupapa whānau (see chapter 1 for full definition). A stakeholder participant relays an example of the support Pacific whānau often bring when residing at RMHC.

> *Pacific families believe heavily in prayer, and they get their minister from their church that comes in with them sometimes. They normally do have someone with them it could be an uncle; there's usually a spokesperson for the family that comes around with them as well. (SI.010)*

The inclusion of extended family members is significant given the finding within the full study that primary caregivers and other family members who were not the parents often felt excluded, disregarded and restricted in different hospital situations when caring for their critically ill child. As well, a primary finding was for Māori and Pacific peoples, having whānau support was essential to their coping. When children with life-threatening conditions are hospitalised over extended periods, it is not always possible for both the parents to be there especially since primary caregivers often must return to or find alternative employment. In these situations, additional whānau members become a significant resource, and cultural processes within Māori and Pacific whānau often include a family leader, support or spokesperson. Two whānau identify the importance to them of having additional support.

> *You definitely need two people at least, and it can't always be a partner as we often know partners work or one person has to stay working, so it needs to be whoever else in the whānau who can go. (WI.005)*

> *It was so helpful just being able to have my family be able to stay and take turns looking after my son and me. (WI.017)*

Many whānau talked about taking shifts, being part of schedules to give parents/caregivers a break. RMHC allowed whānau members to adequately fulfil their role and functions by providing a space where their fellow members could reside, rest and recuperate.

> *That's what I liked about RMHC; they did not pre-determine who your whānau were. I mean modern day families are made up of all sorts nowadays. (WI.001)*

Having whānau around them supports Māori and Pacific peoples' ability to cope better. The environment, staff and philosophy of RMHC encompass whānau and their support, and therefore, helps improve their quality of life to better place them to deal with their circumstances.

Many family members raised their experiences regarding RMHC's flexibility in accommodating theirs and different family members' needs. An example, as shown below, is that where and when possible, the family would be offered a bigger room to cater for different dynamics at different times (if available).

> *We were a Polynesian family, grieving and bringing the family together on weekends was like gold. You know having mum and dad we needed them [be]cause we were so young and vulnerable. RMHC was open to those pathways of having that support. When mum and dad would come, it would be with the other three kids. When they [RMHC staff] could, they would move us to bigger rooms, so we had enough beds. (WI.021)*

Staff raised how RMHC is committed, where possible, to improvements particularly regarding ongoing changes in the accommodation setup to cater to the ever-changing family dynamics. Given the evidence witnessed and experienced by staff, whānau and the researcher of constant ongoing additions and changes to the Auckland-based houses, it was apparent that RMHC consistently reviews its position, policies and processes to better cater to the needs of its

consumers. The following informant reported how identifying potential changes to meet family needs formed part of her role.

> *Modern demographics don't fit the mum dad and two kids model anymore. We're more and more multi-cultural especially in Auckland, so we have to look at how we sort and model our rooms, we get separated parents and children that are brought up by grandparents you know that sort of thing, parents with new partners and so we have to try and make all that work. (SI.015)*

Changes in demographics over the years can be shown in two snapshots from the RMHC database (see Figure 22 and Figure 23). The figures highlight Pacific and Māori numbers by region, diagnosis and occupancy (nights at RMHC and by number of families). While the numbers have certainly increased for Māori and Pacific populations, it is also important to note that although the collection of data, particularly by ethnicity, has improved over the years, it is still a work in progress. At the start of this research in 2013, RMHC was committed to ongoing improvements in their collection of ethnicity data and were working on collecting iwi and hapū information. RMHC statistical data for this research was only collected for the years 2009-2014. Consideration is needed in interpreting snapshot data without its full context, a more detailed paper relating to statistical content including the National Minimum Data set information obtained as part of this research is currently in progress.

Whānau commented on the changes that they have seen over time in other areas of RMHC. One change was the implementation of regular shuttle runs to the supermarket, which whānau expressed made life much easier. Shuttle runs were particularly helpful for those who were from out of town, unfamiliar with Auckland, had little money and no transport. RMHC initiated the supermarket shuttle runs, which came about from an identified need and developed further as the demand increased.

> *So, there is a grocery run on a Thursday where a volunteer driver comes to take anybody who wants to go shopping, but there was a need for another one. A new run started about two years ago, going on Tuesday mornings, taking people, anybody who wants to go to the likes of Countdown. (SI.009)*

Facilities and Equipment

RMHC facilities were rated as being of high quality by all whānau interviewed. Its location and proximity to Starship Hospital allowed for 24-hour access to their children. Whānau described the environment as having a nice feel that provided a sanctuary away from the ward setting and demanding hospital environment. All whānau felt that the houses were very welcoming.

> *You were made to feel you could use the place. It really felt like it was a place for you, your family and the child. (WI.001)*

Users of the houses entered by a swipe card allocated and all those who were interviewed mentioned that 24-hour support was available. Comments regarding the 24-hour support highlighted that physical safety and security was of high importance for whānau while their child was in the hospital.

Whānau members talked about the contrast between the hospital environment and RMHC. Māori and Pacific whānau raised in the general findings of frequently feeling disempowered, redundant and disregarded as a parent/caregiver on different occasions on the wards. Whānau also felt that at times in the hospital they did not have a role, due to nurses performing most of the child's care, or members being excluded from health discussions or decisions. Many whānau found RMHC a much-welcomed relief where they could retain some sense of normality and feel reinstated in their various whānau roles. Whānau felt they could replenish themselves by being in an environment that welcomed other family members, rather than feeling they were in the way. Whānau were also grateful to be near other whānau in similar situations and company of supportive and caring staff.

Pacific Families

2009

Cook Islander

Diagnosis by region	Occupancy	Families
Cardiac	3	1
Pacific Islands (exc. Tahiti)	3	1

Samoan

Diagnosis by region	Occupancy	Families
Neurology	1	1
Auckland	1	1
Orthopaedic	2	1
Wellington (incl Kapiti & Hut	2	1
Respiratory	94	11
Hawkes Bay	94	11

Tongan

Diagnosis by region	Occupancy	Families
Cardiac	9	2
Auckland	9	2
Respiratory	2	1
Auckland	2	1

2014

Cook Islander

Diagnosis by region	Occupancy	Families
Cardiac	243	11
Auckland	87	4
Southern Region South Island	140	4
Wellington (incl Kapiti & Hutt)	16	3
Medical	28	4
Auckland	1	1
Pacific Islands (exc. Tahiti)	21	1
Southern Region South Island	6	2
Neonatal (NICU)	11	1
Waikato	11	1
Neurology	14	3
Auckland	2	1
Hawkes Bay	12	2
Oncology	16	9
Waikato	16	9
Orthopaedic	7	2
Manawatu (includes Horowhenua)	7	2
Psychological (CFU)	3	1
Lakes (Rotorua/Taupo)	3	1
Respiratory	67	6
Auckland	11	1
Pacific Islands (exc. Tahiti)	29	1
Wellington (incl Kapiti & Hutt)	27	4
Surgical	11	1
Lakes (Rotorua/Taupo)	11	1
Unknown Diagnosis	1	1
Auckland	1	1

2014 Continued

Pacific Islander

Diagnosis by region	Occupancy	Families
Cardiac	128	18
Auckland	18	4
Manawatu (includes Horowhenua	6	4
Overseas Other (exc. Pacific)	44	1
Pacific Islands (exc. Tahiti)	44	8
Wellington (incl Kapiti & Hutt)	16	1
Ear, Nose & Throat	1	1
Northland	1	1
Liver & Kidney	3	2
Nelson/Marlborough	2	1
Wellington (incl Kapiti & Hutt)	1	1
Medical	80	9
Auckland	80	9
Neonatal (NICU)	92	3
Auckland	13	1
Northland	40	1
Pacific Islands (exc. Tahiti)	39	1
Neurology	10	4
Auckland	9	3
Pacific Islands (exc. Tahiti)	1	1
Oncology	102	2
Pacific Islands (exc. Tahiti)	102	2
Respiratory	6	2
Auckland	6	2
Surgical	80	6
Auckland	10	1
Northland	45	1
Wellington (incl Kapiti & Hutt)	25	4
Unknown Diagnosis	1	1
Northland	1	1

Tahitian

Diagnosis by region	Occupancy	Families
Cardiac	90	18
Tahiti	90	18
Oncology	58	1
Tahiti	58	1

2014 Continued

Tongan

Diagnosis by region	Occupancy	Families
Cardiac	96	16
Auckland	71	10
Hawkes Bay	2	1
Pacific Islands (exc. Tahiti)	21	4
Southern Region South Island	2	1
Ear, Nose & Throat	2	1
Auckland	2	1
Kidney	9	2
Northland	9	2
Liver & Kidney	28	2
Southern Region South Island	28	2
Medical	109	8
Auckland	109	8
Neonatal (NICU)	15	3
Auckland	15	3
Neurology	65	13
Auckland	50	9
Nelson/Marlborough	3	2
Pacific Islands (exc. Tahiti)	12	2
Orthopaedic	12	4
Auckland	1	1
Gisborne (Tairawhiti)	4	1
Manawatu (includes Horowh	7	2
Respiratory	50	10
Auckland	33	7
Canterbury	16	2
Hawkes Bay	1	1
Surgical	13	4
Auckland	13	4
Unknown Diagnosis	12	4
Auckland	8	3
Pacific Islands (exc. Tahiti)	4	1

Vanuatu

Diagnosis by region	Occupancy	Families
Cardiac	226	12
Overseas Other (exc. Pacific)	131	5
Pacific Islands (exc. Tahiti)	95	7

2014 Continued

Samoan

Diagnosis by region	Occupancy	Families
Antenatal / Prenatal	18	2
Taranaki	12	1
Wellington (incl Kapiti & Hutt)	6	1
Cardiac	251	24
Auckland	193	14
Manawatu (includes Horowhen	10	2
Pacific Islands (exc. Tahiti)	10	3
Taranaki	14	2
Wellington (incl Kapiti & Hutt)	24	3
Ear, Nose & Throat	45	6
Auckland	6	2
Canterbury	2	1
Hawkes Bay	33	2
Wellington (incl Kapiti & Hutt)	4	1
Kidney	1	1
Hawkes Bay	1	1
Liver	117	9
Auckland	1	1
Nelson/Marlborough	2	2
Waikato	114	6
Medical	46	13
Auckland	36	11
Waikato	5	1
Wellington (incl Kapiti & Hutt)	5	1
Neonatal (NICU)	108	3
Auckland	108	3
Neurology	47	13
Auckland	37	10
Waikato	10	3
Oncology	236	38
Auckland	1	1
Hawkes Bay	64	20
Wellington (incl Kapiti & Hutt)	171	17
Orthopaedic	4	1
Auckland	4	1
Respiratory	81	16
Auckland	52	14
Wellington (incl Kapiti & Hutt)	29	2
Surgical	16	10
Auckland	6	3
Bay of Plenty	5	3
Gisborne (Tairawhiti)	4	3
Northland	1	1

Figure 22. Snapshot of RMHC Pacific occupancy 2009 and 2014.

2009

Maori — Diagnosis by region	Occupancy	Families
Cardiac	**184**	**49**
Auckland	56	13
Hawkes Bay	11	2
Pacific Islands (exc. Tahiti)	39	19
Tahiti	77	14
Wellington (incl Kapiti & Hu	1	1
Liver & Kidney	**93**	**9**
Nelson/Marlborough	93	9
Medical	**23**	**6**
Auckland	20	4
Northland	2	1
Waikato	1	1
Neonatal (NICU)	**108**	**13**
Auckland	69	6
Lakes (Rotorua/Taupo)	17	3
Pacific Islands (exc. Tahiti)	1	1
Waikato	21	3
Neurology	**225**	**30**
Auckland	89	18
Lakes (Rotorua/Taupo)	37	4
Pacific Islands (exc. Tahiti)	99	8
Oncology	**8**	**1**
Gisborne (Tairawhiti)	8	1
Orthopaedic	**29**	**6**
Pacific Islands (exc. Tahiti)	9	2
Wellington (incl Kapiti & Hu	20	4
Psychological (CFU)	**13**	**2**
Lakes (Rotorua/Taupo)	13	2
Respiratory	**161**	**26**
Auckland	32	11
Hawkes Bay	15	3
Lakes (Rotorua/Taupo)	13	4
Pacific Islands (exc. Tahiti)	97	6
Waikato	2	1
Wellington (incl Kapiti & Hu	2	1
Surgical	**180**	**28**
Auckland	99	17
Manawatu (includes Horow	1	1
Pacific Islands (exc. Tahiti)	17	2
Taranaki	2	1
Waikato	35	2
Wellington (incl Kapiti & Hu	26	5

2014

Maori — Diagnosis by region	Occupancy	Families
Antenatal / Prenatal	**54**	**9**
Lakes (Rotorua/Taupo)	8	2
Northland	17	4
Taranaki	15	2
Waikato	14	1
Cardiac	**1077**	**164**
Auckland	137	28
Bay of Plenty	69	12
Canterbury	38	6
Gisborne (Tairawhiti)	4	2
Hawkes Bay	21	5
Lakes (Rotorua/Taupo)	187	13
Manawatu (includes Horowhenua)	42	3
Nelson/Marlborough	15	3
Northland	180	28
Southern Region South Island	14	2
Taranaki	88	13
Waikato	153	28
Wellington (incl Kapiti & Hutt)	70	13
Whanganui	59	8
Ear, Nose & Throat	**37**	**18**
Auckland	11	4
Canterbury	3	1
Lakes (Rotorua/Taupo)	4	2
Nelson/Marlborough	6	1
Northland	6	4
Taranaki	3	2
Waikato	2	2
Wellington (incl Kapiti & Hutt)	1	1
Whanganui	1	1
Kidney	**175**	**26**
Bay of Plenty	17	1
Canterbury	9	3
Gisborne (Tairawhiti)	16	2
Northland	94	13
Taranaki	24	5
Waikato	7	1
Wellington (incl Kapiti & Hutt)	8	1
Liver	**519**	**27**
Auckland	84	2
Bay of Plenty	188	5
Gisborne (Tairawhiti)	42	3
Lakes (Rotorua/Taupo)	3	2
Taranaki	6	4
Waikato	19	1
Wellington (incl Kapiti & Hutt)	1	1
Whanganui	176	9

2014 continued

Maori — Diagnosis by region	Occupancy	Families
Medical	**206**	**69**
Auckland	48	13
Bay of Plenty	30	10
Gisborne (Tairawhiti)	13	8
Hawkes Bay	13	3
Lakes (Rotorua/Taupo)	17	4
Manawatu (includes Horowhe	4	1
Northland	42	17
Southern Region South Island	1	1
Taranaki	2	1
Waikato	33	10
Wellington (incl Kapiti & Hutt)	3	1
Neonatal (NICU)	**841**	**43**
Auckland	266	10
Bay of Plenty	2	1
Gisborne (Tairawhiti)	21	1
Hawkes Bay	127	2
Lakes (Rotorua/Taupo)	17	2
Northland	368	25
Wellington (incl Kapiti & Hutt)	15	1
Whanganui	25	1
Neurology	**1178**	**211**
Auckland	142	31
Bay of Plenty	80	25
Canterbury	6	2
Gisborne (Tairawhiti)	33	12
Hawkes Bay	164	19
Lakes (Rotorua/Taupo)	180	26
Manawatu (includes Horowhe	84	15
Nelson/Marlborough	1	1
Northland	124	26
Southern Region South Island	26	4
Taranaki	37	7
Waikato	216	35
Wellington (incl Kapiti & Hutt)	9	1
Whanganui	76	7
Oncology	**1924**	**332**
Bay of Plenty	584	88
Gisborne (Tairawhiti)	73	21
Hawkes Bay	242	19
Lakes (Rotorua/Taupo)	92	25
Northland	541	89
Southern Region South Island	8	5
Taranaki	69	14
Waikato	243	57
Whanganui	72	14

2014 continued

Maori — Diagnosis by region	Occupancy	Families
Psychological (CFU)	**249**	**61**
Bay of Plenty	45	9
Gisborne (Tairawhiti)	11	2
Hawkes Bay	4	1
Lakes (Rotorua/Taupo)	65	20
Manawatu (includes Horowhenua)	4	1
Northland	6	1
Taranaki	12	2
Waikato	102	25
Rehabilitation	**4**	**2**
Auckland	4	2
Respiratory	**963**	**131**
Auckland	90	17
Bay of Plenty	168	36
Canterbury	7	2
Gisborne (Tairawhiti)	24	3
Hawkes Bay	91	12
Lakes (Rotorua/Taupo)	28	7
Northland	95	19
Taranaki	51	10
Waikato	130	13
Wellington (incl Kapiti & Hutt)	24	7
West Coast of South Island	243	1
Whanganui	12	4
Surgical	**402**	**108**
Auckland	8	5
Bay of Plenty	15	5
Gisborne (Tairawhiti)	32	16
Hawkes Bay	15	6
Lakes (Rotorua/Taupo)	4	4
Manawatu (includes Horowhenua)	15	7
Northland	121	33
Southern Region South Island	27	5
Taranaki	18	9
Waikato	140	14
Wellington (incl Kapiti & Hutt)	4	2
Whanganui	3	2
Unknown Diagnosis	**83**	**16**
Auckland	15	5
Bay of Plenty	6	2
Canterbury	13	1
Gisborne (Tairawhiti)	3	2
Hawkes Bay	6	2
Lakes (Rotorua/Taupo)	28	2
Waikato	1	1
Wellington (incl Kapiti & Hutt)	11	1

2014 continued

Maori — Diagnosis by region	Occupancy	Families
Liver & Kidney	**606**	**44**
Auckland	2	1
Bay of Plenty	27	7
Hawkes Bay	5	3
Lakes (Rotorua/Taupo)	4	2
Manawatu (includes Horowhenua)	226	2
Northland	13	8
Taranaki	263	7
Waikato	57	11
Wellington (incl Kapiti & Hutt)	5	1
West Coast of South Island	2	1
Whanganui	2	1
Ophthalmology	**5**	**4**
Gisborne (Tairawhiti)	1	1
Southern Region South Island	4	3
Orthopaedic	**437**	**124**
Auckland	4	4
Bay of Plenty	49	12
Gisborne (Tairawhiti)	32	15
Hawkes Bay	27	13
Lakes (Rotorua/Taupo)	111	21
Northland	152	39
Waikato	59	17
Whanganui	3	3

Figure 23. Snapshot of RMHC Māori occupancy 2009 and 2014

The use of cooking facilities enabled members to realign to their caregiving roles. Cooking, supplying, nurturing and hosting affiliated with food is an important aspect of Māori and Pacific culture. Staff interviewed, mentioned they felt sorry for family members who had been up early to go to the hospital and had been there all day, and then came back and cooked. While this seems like a daunting task, for some, it is a way of relaxing or re-aligning, as alluded to earlier.

Some whānau members mentioned that cooking distracted them from what was going on for a short time, and were grateful because it did not take much emotional effort.

> *Making food was a no-brainer, it helped me not think for a moment about what was going on (WI.017)*

> *When your 'normal' is turned on its head, you will take anything to get that sense back.. cooking which was not my favourite past time became something I looked forward to at the end of the day… it provided some sense of 'normal' (WI.003)*

Other RMHC environmental amenities reiterated by whānau included:

- suitably sized clean, high-quality accommodation (where the family were together),
- having access to a computer and wifi (to stay connected to other whānau), and
- other health-based equipment, such as breast pumps.

The following participant relays how having access to support, and adequate equipment helped her feel like a "real" mum after the birth of her severely sick baby.

> *I couldn't breast feed baby; she was too sick. I didn't feel like I had a role as a mother. I couldn't really touch her she was all wired up and in an incubator. I felt much better knowing that I could at least pump some milk. I had a hand pump which took so long I felt like giving up, but RMHC staff were so supportive, they supplied a machine for us. They treated me like I was a real mum and I felt like I finally could play that part even though it was small. (WI.008)*

The facilities allowed for whānau roles and functions to continue, a primary coping mechanism as indicated by many other whānau. The cooking facilities were deemed important for Māori and Pacific whānau, identifying the importance of food and its association with not only daily life but with ceremony (birthdays, treatment milestones), process (cooking for the family or others, being part of "normal" routine like having dinner) and rituals (giving thanks for food, eating together, sitting down at a table to eat).

Having a child admitted to hospital impacts on whānau and communities. Given the critical nature of the child, important family decisions needed to be made. For Māori and Pacific peoples, the collective rather than individuals usually made decisions. Given the identified lack of whānau-designated spaces at the hospital, including a table to sit at, RMHC provided the space where whānau systems and structures could be maintained, such as family gatherings, meetings, sitting together and making decisions over food. A staff member confirms the importance of family talking and being together.

> *Sometimes for families, they get all the whānau in and sit down and talk about what the doctors have said. We understand that so we do allow them to do that. (WI.010)*

Whānau acknowledged relevant hui (meetings) being undertaken, utilising familiar cultural processes such as karakia (prayer), whānaungatanga (connections and relationships) and kai (food). The process incorporated members who were in prominent positions (including Matai, family leaders and kaumātua) who could take their rightful place, as there was a space that enabled them to participate.

> *We had to make some really tough decisions as a family, not only for our boy that was admitted but for the goings on at home too. It was good that we could cook our food, sit together and then hui about what we would do going forward. This is what we would have done up at home. (WI.017)*

> *Some big decisions were made at that table over a cuppa, and you needed one big enough for whānau to be able to make those decisions and you know, culturally we need to feed them, or at least have a cup of tea, it's all part of it. (WI.001)*

A significant influence on whānau coping through RMHC concerned whānau finances. Provision of free accommodation and support afforded many whānau the ability to be able to focus more on their child rather than on their finances or lack of (even if for a short time). Accommodation and transport-related costs were a significant barrier and distraction for those who had the experience of paying. The central city location of Starship impacted on whānau finances through petrol, parking (free parking is time-limited – 60 minutes, with traffic agencies constantly patrolling) and the cost of buying food. All whānau in this study found parking to be a barrier.

Whānau highlighted the relief RMHC gave them, not only for accommodation but also for having space (Grafton) where they could park their car while staying there and still be close to the hospital. These provisions saved money in petrol costs and alleviated stress, especially for rural whānau, in dealing with Auckland traffic. Access to parking at the hospital and the costs associated were highlighted as a major concern. The overall support, including shuttle, runs to supermarkets and access to cooking facilities and food, reduced financial stress and burden. It gave many some reprieve and allowed them to progress with other things while knowing the home front was okay.

> *When we didn't have RMHC accommodation and had to pay for it, we had lots of difficulties in keeping the home fires burning. You know paying the rates and the power bill at home that sort of stuff. Now since being here, it has helped us a lot we could get on track again. (WI.003)*

Staffing and Support

RMHC staff played a significant role in whānau coping, particularly frontline staff. While names are usually kept confidential in research, certain whānau asked if the thesis could name the RMHC workers who significantly influenced their lives. Nearly all whānau mentioned the endless support and compassion of Christine and Jax. Other people regularly identified throughout conversations as making an impact were Alan and Bridgette. Whānau who had become a familiar

feature at RMHC, through multiple admissions over extended periods, commented on how the staff went 'above and beyond' their role and scheduled hours. The identification of staff being passionate in their roles was evident by their long-term commitment to their jobs, the whānau and the children.

> *The staff they are amazing people, you know really, what Christine and her staff do, they really, make you feel at home, and they also take half of that pressure away from you when you go in there. [Be]cause when you go in there, and you see a smiley face, you know, a simple smile, it just peels off all that frustration you've got or tiredness, and they do understand they do look out for you. (WI.006)*

Caregivers found that RMHC frontline staff were highly skilled in their assessment of what whānau needed at the time. Some whānau required intense support at different times and stages, while others needed tangible practical help (like the breakdown of technical information, how to use the washing machine or oven). Some identified as just needing a timeout and the space to be alone

> *You know the staff just knew what we needed. I don't know how well, probably because they deal with families all day every day, but they could read when I needed to talk or when I needed to be left. They were really good at gauging that. (WI.002)*

> *My son had deteriorated I was exhausted. My family relieved me for a bit. I went to the family room I needed to get away from the ward I sat in the family rooms closed my eyes and fell asleep. I woke up, and I had a pillow and blanket on me. I was surprised that the staff didn't wake me to tell me not to sleep there, they just let me do what I needed to do. (WI.017)*

It was also noted that whānau felt that RMHC processes and staff worked with them rather than against them. Instances of flexibility and patience were revealed with employees taking the time to meet, sit and discuss issues that arose with and for whānau. In other health environments, whānau had encountered ridged inflexible processes that intimidated and disempowered them. This participant reiterates RMHC's philosophy in action.

> *It is not about us it is about them. We are a house, and like all homes, there are standards and rules, but again we need to work with families to know what works for them. So, we look at those things, we try and take the right approach. Then we work with them. We are not superb, and we don't know what every culture does or needs but we are open, and we are quite flexible and respectful of different cultures. (SI.010)*

Whānau were consistent in explaining that they knew that RMHC frontline staff supported whānau at significant milestones and events, like eyebrows and hair growing back after treatment, and coming through complicated surgeries. RMHC staff provided comfort through difficult times. It was evident through interviews with whānau and staff that RMHC workers were immersed in and part of whānau (a culturally relevant and appropriate way to be), because of their provision regarding ongoing long-term support. Support was noted at pertinent times, including through healing and recovery, dying and death, and post-death. Having RMHC staff attend their child's funeral was highly significant both for the family and provided a sense of closure for the staff. A participant

relayed some of her experiences about being involved in some of these situations and dealing with parents having to cope with such difficulty.

> *You get some that just say ok there is no more treatment, so we are going to send you home. Your child is going to have a month or so to live which is the worst part as well. I don't like that part, but I understand it. I do understand it. I just said goodbye to another teenager recently. It isn't the most pleasant experience. It's sad and losing a baby as well. And the babies that pass here even the previous evening was eating and sitting in the high chair putting chocolate on his face and then the next morning he was gone you know. In here you are involved in it all. So, it's pretty sad seeing parents in agony running everywhere saying help my child, but he had already passed. I've had to do CPR on babies. (SI.010)*

Given what staff go through alongside whānau it is important that the organisation provide adequate support to ensure staff are not overloaded, not leaning toward burn out or become hardened to family situations. While some formal mechanisms have been put in place, consistent ongoing review of these supports to ensure they are sufficiently tailored to meet staff need will be critical.

Volunteers also played a significant role in whānau journeys. Whānau highlighted the many events in which volunteers would be involved, including cooking dinners, bigger celebrations such as Christmas parties, mid-winter Christmas celebrations, fun runs and other activities. Whānau also gave back, supporting RMHC by fundraising themselves, volunteering or joining in the events to help raise awareness and funds. RMHC hosts 763 regular house volunteers (RMHC, 2016d).

Experiences

Whānau experiences of RMHC were, in general, very positive. Fathers who had resided at RMHC spoke of the need for them to be just near their child. Men often stated that even if they did not do much while they were there, proximity to the child was important to them.

All men within this study highlighted the impact of the child's situation on them, recognising that most often they could not adequately articulate their feelings, sometimes causing them to be aggressive, angry or just blocked off. What aided in their coping was seeing other men in similar situations and having a space to share. Given the dominant female nursing profession, and what whānau deemed a mainly unapproachable hierarchy of doctors and specialists in hospitals, the presence of the RMHC male staff members were seen by nearly all whānau interviewed as highly positive.

Men stated that being able to sit with the male staff member and talk about relevant issues was helpful. In some situations, they could let off steam, and in others, no words were needed to be exchanged as there was a male form of understanding that was naturally exchanged. In some instances, men reiterated that meeting with other males or the RMHC male staff member became a regular feature. For some, they likened meetings to being on the paepae (a particular place that speakers gather).

It started when one dad came down, and we had a heart to heart about something. While we were talking, another dad came down, a Pākehā fella who had a Māori partner, and so we sat out there, and it became a thing because other dads would come down we started likening it to sitting on the paepae. It was a place to sit down, shoot the breeze for an hour. It was good. (SI.009)

These meetings allowed men to be open with some identifying the tension felt in being responsible for keeping the home fires burning and their need to be physically present. They highlighted a sense of powerlessness being away from their place of employment where they felt needed, fulfilled and in control but at the same time wanting to be part of their child's health care equation or at least near it.

Yes, the men they're like fish out of the water especially when all their normal support networks and the things that they can cope with have been removed and also being isolated from that, they have to cope in a place that's strange to them without their usual male mates. (SI.009)

Employment, or being away from it, was a primary concern for men and being in a space with people who understood that helped them to cope. During interviews, some men raised that in normal family home circumstances it took a long time for them to build up their current 'mateships', and therefore, being away and not having familiar support was extremely hard for them.

Participants and researcher observations raised a noticeable lack of men on staff particularly front line staff, as well as a limited workforce that reflected the cultural groups using RMHC, at all levels, including board and management levels.

RMHC they need more ethnic diversity they need more Māori and Pacific Island, workers. From me being here a long time, I see a lot of French [Tahitians], … Tongans … The Samoans and those from Vanuatu … There are a lot more Pacific patients getting flown over. (WI.006)

While numbers of Māori and Pacific whānau residing at RMHC has increased over the years, the need to better cater to their cultural needs will be imperative. Whānau indicated that the frontline staff do their best with the resources that they have. RMHC staff identified wanting and needing more training as well as more culturally diverse workers. The front-line staff, as much as possible, tried to fill the cultural gaps as best as they can or call on additional hospital-based resource. RMHC management recognised and acknowledged the importance of cultural input for whānau and had previously initiated training for staff.

We're becoming more and more conscious of what we need to do around cultural components and it's something that our staff would be keen for is some more training around Māori and Pacific culture. We have had some morning teas with Kaiatawhai and Pacific Support, but I think there's probably some more practical learning that we could provide our staff with. (SI.015)

It was noted that RMHC staff have a particularly heavy reliance on the cultural support person (Kaiatawhai) associated with Starship. Frontline staff identified their close relationship with the Kaiatawhai but were also conscious that this role had reduced from five people to one person,

covering the whole of Starship. Whānau and staff highlighted instances where they asked to talk to someone from their cultural background

> *We have people asking to speak to a Māori or Pacific person so I will usually phone cultural support. (SI.012)*

Whānau interviews were explicit regarding their appreciation for RMHCs and the staff. While they were grateful for the service provided, they also made suggestions that may further enhance whānau experiences of RMHC.

Whānau Recommendations for Optimal Service

Whānau indicated a preference for having a cultural presence within the houses so they could initiate the contact themselves.

> *Yes, culture, having multicultural support, we didn't have it at first but when we did that was just a shining light. When you are around it, you take it for granted but put in a different environment without it… No its what everyone needs. I know we can't all be you know supported in that way I see some of our whānau in the house, and they separate themselves. Having cultural support in the house or on the RMHC team would be a great asset to both the staff and the families. (WI.023)*

As well as cultural support, whānau identified that having a liaison person as a support who understands first-hand what whānau have to go through as well as how to navigate the health system and associated services. Having this person might take pressure off frontline staff who were dealing with issues that were in some instances beyond their dedicated role

> *The staff are great, but we need like a family liaison person, that knows what the family's going through. A parent that has been there knows what's going on, because I tell you, I probably know more about this hospital than the [hospital] staff. I've been here so long; you get to know this hospital. It needs to be more than someone that does 9-5 pm they need to have lived experience; what we need is a parent liaison not just at RMHC but the hospital or someone that knows both well and can solely support a family with things along with accommodation. (WI.006)*

Other cultural elements recognised by whānau as being more helpful included more signs in different languages. A significant barrier for whānau, raised earlier in the thesis, was the inability to understand information because English was their second language or the use of highly technical language and jargon. Whānau who reside at RMHC are in a vulnerable position, particularly if their child has low immunity and is at high risk of infections. While there were signs alerting whānau about certain regulations and health procedures (for example, please wash your hands, use the hand sanitiser, please let staff know if you have been exposed to… or a virus is currently in circulation, please….), these were all in English. Whānau expressed that important signs in other languages would be helpful and might facilitate better compliance.

> *I noted the faces staying here many who did not speak English very well. I noticed all the signs and that they were in English. I noticed people not using*

the hand sanitiser or not signing in as asked to on the sign. It might be that they don't understand the sign. (WI.017)

Alongside signs in different languages, whānau also highlighted feeling better connected if the environment reflected elements of the different cultures of people who utilise it. Whānau indicated that they would like to have seen ethnic art pieces on walls so they could have a better sense that they were connected to the environment.

It would be great to see Māori or Indian art, a mix together. If anything, it would be good to have some reflection of the families that use the environment. (WI.001)

Whānau highlighted some key factors that would enhance their stay at RMHC and their coping. Reflective of RMHC's own review and evaluation of its processes and practice, it was noted that in the family rooms a new sign had been recently suspended that included a Māori greeting (Figure 24).

Figure 24. Family room welcome sign.

In searching the RMHC website, Māori designs were also noted on different web pages (Figure 25). As well, RMHC newsletters reflect the nature and diversity of the whānau who utilise the houses through their whānau stories.
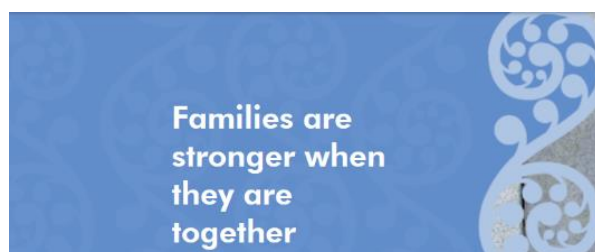

Figure 25. Website Māori patterns.

One of the hurdles identified for the Grafton house was the steep hill that needed to be conquered on the way to the hospital. Grandparents commented on the difficulty both going up and down

given their age and energy. As well, parents also found this an issue, especially those who had additional smaller children, prams or frail children

> *For grandparents raising grandchildren, a lot of are older as well, some have disabilities in which case or difficulties, so there's no way they will be able to walk up the hill …We had to get taxis to get up and down that hill. (WI.005)*

Staff too recognised the difficulties and, in some circumstances, had provided different modes of transport. Volunteer drivers have been trialled but are hard to secure with some days not being needed at all. Staff currently supply a limited amount of taxi chits (through sponsorship) and have a dedicated driver one-half day a week. RMHC recognises that this is still a work in progress and are trying to find a suitable solution.

Other comments raised regarding enhancing whānau coping was the connection to water. Whānau identified that the ideal would be to have a water feature as a representation of healing, given that access in Auckland to a body of water is some distance taking time away from their child.

For larger whānau, there was the suggestion of a bigger room or space that could be used as marae-style accommodation space (not huge but bigger than just a bedroom). This type of accommodation style could cater for whānau who have more members, particularly those who are dealing with the end of life care and needed to be near the hospital.

While a new private orientation meeting room has been purpose built (Grafton) and whānau have access to it if needed, it has been suggested that a dedicated whānau meeting room(s) would be useful and could be operated on a booking system hour by hour. Having a designated appropriate meeting room(s) with basic cup of tea facilities would provide some privacy and take the pressure off the RMHC kitchen and dining areas.

Whānau (two years prior) had initially recommended the utilisation of a dedicated workspace, with whānau mentioning they had used the family rooms' "quiet space" to undertake work, make calls and hold small meetings while they were at the hospital. Whānau who had been admitted for long periods of time identified that while their work was flexible (that is, they could still work away from the office), the space to put it in practice was limited. Other whānau also mentioned that it would be ideal for siblings or the child to do their school work in and for whānau who were undertaking study (three were identified in this study). It is great to see that Grafton house now has a dedicated business hub that is well utilised (as noticed when the researcher recently visited).

Private lounges were also discussed during this research, to provide a semi-private space where whānau could just sit together, particularly those dealing with the end of life care for their child. Whānau identified that sometimes they just didn't want to interact at those times with others outside of their own. More private spaces was also supported by Giuntoli and Fisher (2015) where similar findings noted that whānau need both communal and private spaces in which whānau could have time on their own. On the last visit to Grafton House, a new lounge area had been built that incorporated some semi-private functional areas that whānau now fully utilise alongside

a dedicated play room for children that can be viewed from the new lounge space and the business hub.

Regarding the family rooms, many whānau said they would like it if the lounge area could be open a bit later for whānau residing there, so they could unwind and not disturb their partner if one had difficulty sleeping, and could talk and catch up with other whānau. One whānau mentioned that small television sets in the rooms, with headsets, might also aid carers to wind down, relax more or provide surrogate company for those without support. Table 21 outlines all the recommendations put forward by whānau.

Table 21. Whānau Recommendations

More culturally reflective staff
Cultural support person be attached to RMHC
Parent Liaison
Signs in other languages
Ethnic art
Shuttle to get up and down the hill to the hospital
Marae style or bigger room to accommodate more significant whānau
Water feature
Dedicated work space
Semi-private lounge
Dedicated Meeting room(s)
Family room - TVs
Family room lounge open longer hours for RMHC whānau only

Summary of Findings

Whānau enter the health system with a set of expectations that their engagement will be a positive and straightforward process. Whānau enter the journey focused on coping with their critically ill child, only to be confronted with a barrage of barriers and distractions. Energy is put toward overcoming the difficulties preventing whānau from fully participating in their child's health care provision

The barriers and distractions stemmed from health care engagement at four levels: policies and procedures, people and practices, the environment, and resources. Inconsistencies in policies and models of care at the health system level were found to ripple down through organisations, having impacts on both staff and patients. Health care practice, including rules and regulations, inhibited whānau ability to be active participants in their child's care. As well, communication from health care staff was found to starkly contrast with family-centred care policies and Māori and Pacific needs and preferences. Māori and Pacific whānau were found to be affected by racism and discrimination across all four levels of engagement. The location and design of the organisational environment (hospitals) was not was not conducive to whānau involvement, with many members bearing the brunt of staff annoyances for spilling into corridors or having more than one visitor. A lack of transparency regarding resources was found, including whānau not

being informed about services and information that they were entitled to which could have made their journey much easier.

System-level resources were found, on the one hand, to facilitate whānau coping and, on the other, to provide further barriers for whānau through their limitations and gaps. In dealing with their critically ill child and the barriers associated with their active participation, whānau employed a range of coping mechanisms and strategies. Resources that were whānau initiated (sought after, supplied or learned) became the main source of provision. It was found that whānau drew upon a wide range of methods that sat under a holistic framework incorporating spiritual, cultural, physical, environmental, psychological and whānau-level aspects.

Coping mechanisms and strategies were found to be positive or negative and/or protective. Whānau-initiated resources became system-collective resources as those that were provided were found to be wanting in some areas. Whānau filled that gap by providing services, support and information to staff, and other whānau, as well as trying to cope themselves.

While the main aim of the research was to identify specific Māori and Pacific whānau coping mechanisms and strategies, what became apparent was not so much how they coped but what they were coping with. That is, even before diagnosis they had to cope with systemic barriers that failed to provide a straightforward, direct and appropriate pathway for them to fully engage in their child's health care provision. As well as coping with the risk of their child dying, they were in a foreign environment that prevented familiar support systems being implemented that could enhance whānau coping, lessen whānau stress and alleviate some of the health staff burdens.

The findings from the research have revealed that the challenges faced by whānau can be divided into three main categories:

- Stresses and challenges associated with having a seriously ill child who is hospitalised;
- Challenges and stresses placed on whānau by the system which make their journey more difficult (physical barriers such as location and access to resources); and,
- Challenges and stresses placed on whānau by the system which are related to ethnicity (including systemic racism or cultural (in) competence and/or deprivation).

In order to cope with these whānau drew on different coping mechanisms and strategies for each with some overlapping.

The following chapter will provide a discussion about relevant key findings, providing contrast and or endorsement from existing literature. The discussion chapter will also explore the implications for present and future health service support and health care practice.

CHAPTER 7 - DISCUSSION

The study set out to explore the coping mechanisms and strategies of Māori and Pacific whānau who had experience in navigating the health care continuum with a child diagnosed with a life-threatening medical condition. The analysis of the findings revealed that although whānau entered the health system with a primary focus on dealing with their child's ill-health, their attention became re-directed having to cope with the barriers to fully engaging and participating in their child's health care provision. Engagement barriers and distractions occurred across four areas: policies and procedures, people and practice, environments and resources (see Figure 9, page 107). To combat barriers, whānau utilised mechanisms and strategies that aligned with holistic processes and were deemed positive, negative and or protective. While *how* whānau coped was an important factor for this research, the discussion is tailored to focus on *what* it was that whānau were coping with (a significant finding that emerged from the analysis). System-based resources were found to facilitate whānau coping they were often limited to the point where whānau drew upon their own resources to make up for the shortfall (Figure 26). Whānau were shown to be an essential resource that cultivated critical elements needed to not only cope with their critically ill child but to navigate the intricacies and complexities of a seemingly volatile health care system. The collective strength and power of whānau were demonstrated by their ability to engage in optimal health care while also providing culturally relevant solutions for themselves, other whānau and medical staff. The discussion focuses on three major themes: surviving the system, whānau filling the gap and implications for health care practice.

Surviving the System

Surviving the system is one of three major themes discussed in this chapter and contains information that addresses a number of key areas including barriers to health care engagement; the clash of worldviews; encountering difference, and the marginalisation of whānau roles. Surviving the system also discusses the contradictions within the health system and the need to address inequitable access to critical resources.

Surviving the system for whānau in this study came as an unexpected consequence of their health care engagement. In seeking medical care for their child, whānau expectations were that they would be embraced by medical staff and presented with a clear pathway that facilitated appropriate assistance and support toward their child's diagnosis, treatment and/or recovery. Findings revealed that while whānau focused on and geared up for coping with the implications surrounding their child's critical illness they also had to deal with several other unanticipated barriers.

Barriers consisted of firstly, trying to obtain appropriate care (being taken seriously, being seen, getting second and third medical opinions and undergoing an actual examination) secondly, being able to fully engage in the care equation (being fully informed of details, treatments and given all potential possibilities), and thirdly, finding appropriate supports (relevant resources, suitable services and understandable information) in order to cope with radical change and disruption to

their lives (such as, having to promptly move away from home and support, dealing with the critical nature of the illness and being in a number of foreign environments). Findings indicate that while survival mode took root contending with initial engagement barriers set a negative precedent, putting whānau in a defensive position. Literature confirms similar experiences of whānau which impacted their on-going health care experience (Barton & D. Wilson, 2008; Jansen & Smith, 2008; McKinney, 2006).

Barriers encountered encroached on precious time and attention taking the focus away from their child. One of the most unanticipated and most significant barriers for whānau in this research study was not only surviving within a health care environment where worldviews starkly contrasted with their own but having to try and decipher the embedded contradictions that occurred in and between dominant Western health care practice. Attempts to interpret such encounters in an environment that lacked adequate cultural responsiveness and cultural competence left whānau feeling vulnerable and therefore unsafe.

The implications of contradictory practice and being in an unsafe environment had significant impacts on Māori and Pacific whānau within this study including diminishing expectations of being in a place of healing and recovery due to experiencing multiple issues. D. Wilson and Barton's (2012) research support similar findings where Māori patients found that being in the hospital created discomfort, anxiety and stress for them rather than a place where healing could occur. Likewise, other Indigenous hospital experiences have included negative descriptions such as feeling like an 'intruder', 'alienated' and 'disconnected'. These descriptions reveal how foreign the hospital environment and associated practices are for many who were admitted (Browne & Fiske, 2001

Clash of Worldviews

The clash of worldviews and therefore cultural values, practices and traditions within hospitals derive from the original intent of their establishment. Health systems, in particular hospitals, were seen as clinical environments constructed and driven by Western concepts, ideals and values. History informs us that the notion of health care stems back to the 1800's where colonisation brought with it the re-arrangement of traditional health care systems. Hospitals were set up as environments that not only housed solely Western approaches but promoted health care as a way to "civilise" the "natives" (Salesa, 2001; Waitangi Tribunal, 2001). Similar approaches remain today with non-Western patients bringing with them their worldviews, which starkly contrast with Western ones (Browne & Fiske, 2001; T.K. Kingi, 2002; L. T. Smith, 1999). The hospital as a clinical environment continues to embrace the origins on which it was founded favouring Western values while seemingly disregarding differing alternatives.

Western medicine has been described as having its own culture comprised of history, language, codes of conduct, roles and expectations, methods and technologies (Putsch & Joyce, 1990). Findings revealed that for whānau the Western biomedical culture brought with it a hierarchy; doctors were seen as gods, distance from the patient and their family seemed to be the norm,

time was of the essence, family support was a hindrance requiring extra effort and time to engage and; the patient was often referred to as their disease. Much debate continues regarding the dissimilarities between the biomedical classification of "*disease"* and the patient's personal and social experience of "*illness".* It has been proposed that the inability to deal with illness has been a major failing of biomedicine" (Putsch & Joyce, 1990, p. 1050)*.* Studies have shown that patient, and family needs vary widely. Therefore, some factors need to be considered in facilitating adequate health care. These include the family's cultural heritage; ancestral worldviews; language preference; degree of acculturation; access to society's resources and institutions; socio-economic status; exposure to poverty and other life stressors in the context of racism, prejudice and discrimination (Curley & Meyer, 2001; McDonald et al., 2009; Mikkelsen & Frederiksen, 2011; Woolford, 2013).

Indigenous peoples have been required to adapt and accept Western ideas, values, norms and practices dating back pre-1800's. However, this is neither acknowledged nor recognised within the Western health system. Furthermore, the Western health system does not allow for reciprocation concerning the actions of Māori by allowing for Māori cultural values and processes to be readily practised (a point discussed further on within this chapter). Thus, for many Māori and Pacific whānau to access the necessary health care they need, a compromise must be made; one which is usually characterised as asymmetric and one-sided.

Encountering Difference

The National Primary Medical Care Survey reported that clinicians who have a limited rapport with their Pacific patients are likely to order fewer tests and therefore refer patients to specialists less often despite their more significant and complex health needs (Bacal & Jansen, 2006; Tukuitonga, 2013). There were also strong links to self-reported experiences of racial discrimination identified, leading to a range of adverse health outcomes (Bacal & Jansen, 2006; Ministry of Health, 2008; Statistics New Zealand, 2007). In contrast, health professionals who were more familiar with their patient's cultural heritage were likely to offer more improved patient care (Bacal & Jansen, 2006; LaVeist & Nuru-Jeter, 2002) including alternative pathways and better access to resources**.** The findings gleaned from whānau in this study support earlier work which noted that relationships with health care staff were an important indicator of quality of care (Anhang Price et al., 2014; Dodgson & Struthers, 2005; Franck et al., 2013; Isaac, Zaslavsky, Cleary, & Landon, 2010; Robson & Reid, 2001).

Findings confirmed that health systems, including associated resources, were still being tailored for clinician ease. The results highlight multiple examples where clinicians were also over-represented in power dynamics and where the distribution of well-needed resources was mainly at their mercy. A referral to RMHC for accommodation must come via health staff such as a doctor, DHB staff member or social worker (RMHC, 2016c). Incorporating additional family members, other than mothers, in health care discussions and decision making was dependent on whether health staff, primarily the clinician, actively pursued it. In this research, whānau incorporation was mainly actioned by whānau members themselves. The active discouragement

of fathers in the care of their child and clinicians feeling threatened when their practice was brought into question, to the point security was called; or clinicians negatively labelling vulnerable family members (with terms such as over-dedicated, neurotic and emotional), all raise serious questions regarding power and control. As does the archaic notion, still being played out in the 21st century, that whānau need to gain permission and negotiate cultural healing practices such as the use of karakia (prayer/incantation) or 24-hour access to grandparents at the bedside.

The interpreting services were another fundamental resource found to be primarily set up to meet the needs of health staff over those of the patient, with patients having to pre-book with an allocated registration number through the medical team. The DHB web page states, "A 24-hour service is available through wards/departments for those patients who require it. Bookings are made through ward/department staff on behalf of the patient. The interpreter service for GPs and their patients is open from 8 am – 4.30 pm" (Auckland District Health Board, 2017). While there are indications that there is a 24-hour service available the findings revealed two instances where interpreting services were needed rapidly but were absent with one being out of business hours. Questions are then raised as to whether financial considerations might be prioritised over patient need. The National Travel Assistance guidelines regarding having a second support person to travel with a minor required clinician sign off, as did many other critical resources. Whānau in the study did, however, highly praise the Starship Hospital social workers' service for their engagement with whānau, and in gaining access to many of these resources in a quick, timely and efficient manner. However, limitations remained due to their workload, restrictions regarding business hours, the perception that they were associated with and part of CYFS, and the fact that there were mainly Pākehā women in the role (an additional barrier for many Māori and Pacific whānau members). There was evidence from the findings that many Māori and Pacific whānau were unlikely to approach a doctor, specialist, or even a social worker, to get the necessary sign off for critical resources. Indications were that many whānau did not know about resources that would have been helpful, raising further questions about equity and access. The inequities within this research were a reflection of poor system responsiveness and reduced quality of care for Māori and Pacific whānau (Pacific Perspectives, 2012).

The Marginalisation of Whānau Roles

Grandparents

New Zealand literature points to the continual increase of the high numbers of New Zealand Māori and Pacific grandparents (Collins & Wilson, 2008; National Health Committee, 2009; Nikora, Karapu, Hickey, & Te Awekotuku, 2004) who assume full-time care of children (C. Smith, 2008; Worrall, 2009b). It is estimated that 10,000 children are in kin/ whānau care (Worrall, 2009b); it is acknowledged that these numbers are not exact as many whānau are under informal arrangements. Within this study, informal arrangements relating to Māori and Pacific grandparents as primary caregivers were seen as a legitimate cultural construct (Hakaoro, 2003; Ka'ai, 2005; Worrall, 2008), as well, grandparents formed an important part of intergenerational living (Baker, 2010; Superu, 2016). In these whānau, grandparents had all the rights, even more

so than parents when it came to making decisions for mokopuna (grandchildren) and overseeing the health and well-being of the whole whānau (Ka'ai, 2005; National Health Committee, 2009; C. Smith, 2008). As part of cultural roles and functions shared care as a collective practice was common among the Māori and Pacific whānau interviewed. Shared care consisted of sharing in, and supporting, the care of the child through the entirety of their journey. Sharing in the child's care took place within the hospital and home environments (whether full or part of the time). As well, supporting them to and at appointments or by initiating action behind the scenes such as fundraising activity, cooking, taking part in hui, or church-related services that centred around the child's well-being. Grandparents were an essential and familiar feature with critically ill hospitalised Māori and Pacific children.

While grandparents played a significant role within whānau in this research, from a Western perspective and within the hospital system, grandparents were often disregarded (Hall, 2004a, 2004b; Rempel et al., 2013). Findings revealed grandparents feeling forced to apply for legal power to be able to make critical health decisions for their child. Having to go through court procedures not only disrupted whānau processes but impacted on the grandparents' well-being as it not only went against their cultural beliefs and role within the whānau but took additional finances and a physical toll on their health. Research confirms the problematic position grandparents looking after grandchildren are often in, having to navigate and negotiate both public and private realms, including health domains, family and statutory services as well as other obligations, both personal and cultural (Cass, 2007; Hendricks, 2010). In contrast to the hospital, grandparents who resided at RMHC talked about their acceptance and validation within the organisation which had important significance for Māori and Pacific whānau (and other cultures). Endorsement of traditional and contemporary whānau roles within RMHC made whānau members feel better and therefore were found to be in a better position to be able to care for themselves and the child (Nabors et al., 2013; Sanchez & De Cunto, 2014).

The findings signified that traditional roles such as grandparents came with accompanying duties which were supported from outside of the whānau. Participants highlighted support that came from their various iwi, church, and specific cultural groups with which grandparents had close associations. Outside support (for example, kōhanga reo, Māori Women's Welfare League, Cook Island Associations, church groups) were vital in maintaining cultural practices. These types of supports also sustained whānau and contributed to collective health and well-being. Additional support showed that for Māori and Pacific grandparents within this study, health and well-being and therefore enhanced coping came in many forms. Having reciprocal relationships with these groups, enhanced not only the child's well-being but their own. Literature confirms instances of community resilience where drawing on resources in different forms helps people overcome and endure (Te Puni Kōkiri, 2009; J. Waiti, 2014). There is little written about the additional commitments and activities Māori and Pacific grandparents undertake such as contributing to whānau, hapū and iwi, community, village, land, church and marae (National Health Committee, 2009; C. Smith, 2008) in general and, more specifically, while dealing with a child in their care who has a life-threatening medical condition.

It has been noted that the demands of looking after a critically ill child while trying to maintain their health and well-being by actively participating in society can inhibit grandparents from seeking support for their own health needs (Collins & Wilson, 2008; Nikora et al., 2004, C. Smith, 2008). Health needs included medical care, information on receiving entitlements for grandchildren, and practical support that aids them to cope better when raising grandchildren (Hendricks, 2010; National Health Committee, 2009). One of the significant issues, found in the literature, for elderly Pacific caregivers was their duty, desire and willingness to look after the children in their care. However, their advancing years meant that often their physical capacity did not match the level of care that was required, particularly regarding a seriously ill-child (National Health Committee, 2009). Māori and Pacific grandparents in this study played a critical role in looking after the whānau health and well-being. Nurturing the health of members included being the primary caregiver and looking after siblings, travelling long distances to support whānau while putting their own needs aside for the collective well-being. Grandparents putting their own needs aside was evidenced by them travelling long distances over short periods of time (5 – 7-hour drive) and who had been in the Christchurch earthquake and had lost their house. Despite being frail, or emotionally, physically and financially exhausted, grandparents continued to play an active and critical part in the health care equation of their critically ill child. Additional pressures such as even thinking about seeking legal advice, court action and formal legal arrangements would take a further toll on their health and therefore impact on the well-being of the child.

Siblings

Siblings within this research played a critical role in all aspects of the child's health care journey. Siblings included those of the child, those of the parents and those of other whānau members who came to support the whānau in need. Findings indicated that sibling roles and functions were seen as significant to whānau coping. Siblings including those who were younger would become the protectors, leaders and initiators of aspects of care, including health care, child care, and physical care through organising, transportation, cooking and supplying food. It was often the siblings of caregivers and parents who became the family communicator and in many instances the primary support. Literature indicates that siblings of children with a life-threatening medical condition were prone to taking on duties that were deemed beyond their responsibility removing aspects of having a "normal" childhood (Gaffney, 2007). Other studies have also highlighted negatively associated sibling behaviours (Alderfer, Navsaria, & Kazak, 2009; O'Brien, Duffy, & Nicholl, 2009; Vermaes et al., 2012). Within Māori and Pacific whānau, particular to this study, the sibling role was seen as an honour, which provided support, protection and generosity. It was often the adult sibling who took time off work or left their job to support the whānau with the sick child or who was the trusted guardian to keep the home fires burning (such as feeding and looking after additional children, animals, elderly parents and maintaining routines in order to keep some normality for others around them). In Māori and Pacific culture, the roles taken on by siblings were not seen as a burden but rather as fulfilling and purposeful. Within this study, it was found that irrespective of what was going on around them, siblings of the sick child coped positively. Interpretations suggest this was due to whānau members who cared for them is closely associated with their daily lives, were a natural part of their shared care and/or where possible

included the sibling in the regularity of the health care equation. Siblings were also seen as being vital to the ill child's quality of life. In contrast to other studies where hiring a stranger to care for a sibling has been related to adverse sibling behaviour (Burns, 1984; Simon, 1993) and not being included led to attention seeking impacting their emotional wellbeing (Alderfer et al., 2009; Sartore, Lagioia, & Mildon, 2013; Vermaes et al., 2012). Another Western view is to see the caregiving role as a liability or an avenue blocking an individual's wants or needs (Kağitçibaşi, 2006; Superu, 2016). For Māori and Pacific whānau within this study, sibling roles were culturally based deriving from collective responsibility that was related to their cultural context (Hafford, 2010).

Males/Fathers

While father involvement in parenting has been conceptualised in the international literature much of it has been based on Western experience (Ball, 2010 cited in W. Edwards and M. Ratima, 2014). Contrary to Western societal and health care expectations, Pacific men in the study were seen to defy and challenge health care staff's discriminatory expectations and attitudes. This was done by both Māori and Pacific men being actively attentive with some taking over the full-time care of their child while in hospital. The primary role shown by these men confirm early European accounts which found that traditionally men within whānau contributed significantly toward supporting, caring and raising children (Jenkins & Harte, 2011). Despite this, findings revealed that fathers were often discouraged by medical staff and were left feeling unsupported, a common theme found through several studies (Katz, 2002; Nishimoto, 1999; Silva-Rodrigues et al., 2016).

Some whānau who had been transitioning through the health system over extended lengths of time saw fit to challenge both the overt and subtle racist remarks, including correcting nurses' ill-informed ideals about Pacific men and caregiving. Despite confrontation being stressful, some whānau believed it was a way to shift staff attitudes. Regardless of how passive whānau were in doing this, they were often met with aggressive consequences, particularly Pacific men (such as doctors calling security or having them trespassed). Some whānau believed that confronting negatively associated behaviour and having conversations that challenged the beliefs and conduct of health care staff were appropriate. Many others, however, while desirous of confronting these negative attitudes and behaviours did not due to the fear that to do so it would cause repercussions for their child's health care. The consequences however in not addressing issues particularly for men often-caused internal conflict with some admitting to blocking off or having to deal with their aggression.

Strong indications from findings revealed that RMHC staff support along with the environment which provided proximity to their child (Franck et al., 2013; Jee et al., 2012; Wigert, Berg, & Hellstrom, 2010) made the hospital engagement all the more bearable for whānau. These feelings were particularly evident for men. The limited number of males in the regulated workforce other than doctors or specialists specifically Māori and Pacific were also noted. The male presence on RMHC staff was remarked on by whānau and identified as being particularly important to men's coping providing a spirit of comradery. Grandmothers especially recognised that having a Māori male present on staff enhanced their coping by fitting with their cultural norms, giving them a

sense of security, familiarity and leadership. Conversely, the number of male staff at RMHC while it has increased is still very low in numbers, particularly in front line roles.

Whānau Fill the Gap

The second main theme *Whānau fill the gap* incorporates discussion on what it means to have access to whānau support for participants dealing with a critically ill child. This section concentrates on the reliance of whānau as a crucial resource and highlights the tactical strategies participants utilised when their own whānau could not be accessed. Strategies within this research stemmed from three areas: (1) what whānau had already in their possession and at their disposal including service-based resources; (2) what they had explicitly searched for, and, therefore, (3) what they had intentionally put in place. As Māori and Pacific whānau views are holistic; it was only natural, however unintentional, that their mechanisms and strategies would also take a holistic approach, confirming a long-standing affiliation between good health and connections to lands, spirit, environments and people (Durie, 2011; Huakau & Bray, 2000; Mark & Lyons, 2010; Waitangi Tribunal, 2001). Communication of information is deliberated expanding on key identified areas that stemmed from the findings. Whānau were shown to be fundamental experts linking all elements within this research together. Whānau were found to be the most relied upon and trusted coping mechanism and strategy utilised while transitioning along the health care continuum.
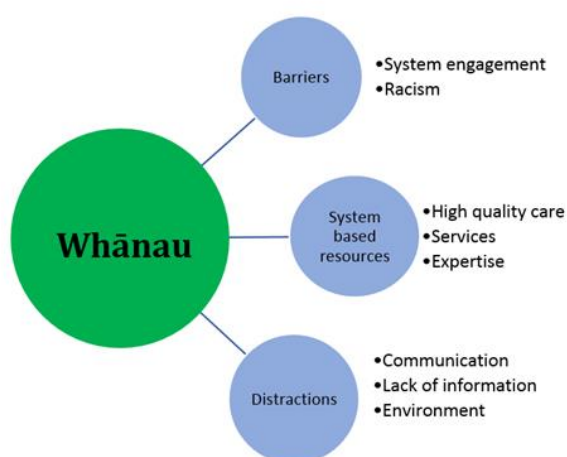
Figure 26. Filling the gap.

While in simplest terms, whānau could be interpreted as a set of people who are connected through different means, within this research the evidence shows that the significance is far deeper. For Māori and Pacific people dealing with a child with a life-threatening medical condition, whānau was their essence and life stream. It was the umbilical cord that intrinsically linked them to their culture, their lands, emotions and their spiritual connections, even though they may have been physically far from them.

Throughout this research, whānau were exposed as an organic living system comprising a myriad of cultural processes, roles and functions that were of primary importance to their coping. The

processes, roles and functions were presented through diverse forms and applications of whānau. Pihama and Penehira (2005) identify that the contemporary makeup of whānau is significantly different from how our ancestors may have viewed it. There are now multiple constructions of family, which are culturally, politically and socially influenced (Pihama, 1998). There are more single-parent households and blended whānau that have been created by new relationships. It is revealed that there are now more multigenerational whānau, civil unions and transgenerational models in which grandparents, uncles, and aunts are more commonly acting in the position of the primary caregiver (Pihama, 1998; Pihama & Penehira, 2005; Superu, 2016). The diversity shows that family structure is increasingly recognised as heterogeneous (Lamanna, Riedmann, & Stewart, 2014; Widmer, 2016), thereby adding a different dimension to the impact of the critical illness of a child (Miedema, Hamilton, Fortin, Easley, & Matthews, 2010). While society is aware, and in various forms is accounting and adapting to whānau contemporary composition (for example, gender neutral toilets, signs and information in different languages, culturally significant logos and pictures), resistance remains; the New Zealand health system is one such place where active advancement is still yet to be made.

Searching for the Familiar

Findings indicate a heavy reliance on whānau members and cultural resources including processes and protocols to cope effectively. For whānau who did not have easy access to either of these resources, they actively searched for a substitute. Whether it was people of the same culture, different culture but similar values, or a similar situation, what whānau wanted was an environment that provided some familiarity and therefore a source of comfort. Even those who were young and not closely associated with their Indigenous ancestry noticed the absence of familiarity when put in a foreign environment over an extended period. A three-year evaluation project that looked at access barriers to health care services for young Māori women and their tamariki on the West Coast of the South Island also identified that although they were disconnected from their whānau, they wanted cultural input, support and to learn about their identity and whakapapa (genealogy). They also wanted services to incorporate cultural values and practice (Whakauae, 2017). Similar findings were found in the same area regarding maternity services seven years prior (F. Waiti, 2009). Wepa (2016) found that Māori whānau who struggled to be involved in health care created social processes to address the disconnection between health care providers, patients and whānau. Studies have also shown that similar processes were used by whānau to keep themselves culturally and spiritually safe (Egan et al., 2014; Wepa, 2016). Magnusson and Fennell (2011) found whānau support at the bedside to be a source of tension for adult members admitted to the hospital. The tension was due to whānau adding additional pressure for the patient in various ways. A question stemming from this research is whether much of that burden was the patient not wanting the presence of whānau to bother or annoy health care staff and therefore reap the consequences as a result or whether the patient was trying to protect whānau members. Practical application of Family Centred Care (FCC) including appropriate whānau designated spaces and cultural competence might have alleviated some of that anxiety for the patient.

Whānau in this research kept themselves and others culturally safe by searching for other whānau, looking for/negotiating culturally-based support, and building relationships with support workers, cleaners, or security staff who met elements of whānau familiarity criteria. These people became kaupapa whānau (connected through a common goal) and often filled the gap where cultural roles were absent. For example, findings show whānau sought support from older ones who in turn, became like kaumātua/elders and mother figures to the whānau. Kyngas and Rissanen's (2001) research found that medical personnel also became like family to patients within their study. Evidence through interviews with whānau and staff revealed that RMHC workers became immersed in and part of whānau which fits with culturally appropriate constructs. Much of this was because of their provision regarding on-going long-term support and the trust built between members as they confronted critical and severe battles.

Whānau within this study not only searched for cultural familiarity but took on additional cultural roles such as kaitiaki (guardian and protectors) in support of others through implementing their provision of cultural support and advocacy. D. Wilson and Barton (2012), also noted similar research findings where Māori, during hospitalisation, looked out for other Māori patients by advocating or providing much-needed information. The fact that whānau were not only searching for but providing cultural familiarity within the health environment highlights that a severe lack of cultural responsiveness still exists. Whānau interviewed for this study were in the hospital for extended periods at a time and during that time encountered very few 'brown faces' apart from other patients and their family. The paucity of Māori and Pacific Island staff identified in this study alone emphasises the urgent need to develop the Māori and Pacific health workforce at all levels of the health sector.

Implementing Familiar Cultural Practice

Māori and Pacific whānau cultural practices originate from traditional behaviour. The values associated within whānau have been honoured through time and continue to be rationalised through the art of oratory and auditory means, and are reinforced by repeated enactments and re-lived through historical narratives (Nikora et al., 2010; Vaioleti, 2003a, 2003b, 2006). Familiar processes are recognised in many traditional practices, in which there is a "general pattern that brings order and predictability during a time of critical emotional upheaval, grieving and healing" (Nikora et al., 2010, p. 400). Nikora et al. further allude to the predictability and familiarity of processes whereby people are informed and prepared for what is yet to emerge, an important aspect of coping. Māori and Pacific whānau continue to draw on traditional processes and protocols for different events such as death, life, weddings and birthdays. While the events themselves may vary the practices within remain the same. For example, a karanga or (call) can occur at a number of different events, but the underlying intention remains the same which is to call the people on or toward, for something significant. It is a sign of welcome and is the start of connecting different parties, so they work together as one toward a common goal.

Despite the hospital environment not being conducive to whānau cultural processes and practices it was evident from the findings that Māori and Pacific whānau continued to draw upon what they knew. This included reliance on whānau roles, traditional practices that occurred within whānau

and familiar cultural patterns which were integrated and utilised as their own system of care. Interpretation of the findings brought to light the following exemplars.

The whānau pani (grieving family) was seen by the whānau members who were impacted by the trauma of their critically ill child. **The karanga** (the call) related to whānau informing other whānau about the child's admission to hospital and related treatment. **Āriki/matai and kaumātua** (elders) including grandparents were called upon as they were essential to family decision making and support. **Koha** (gifts) came from contributions of food, money, vouchers and support from various whānau, services and their communities. As well, whānau had with them **taonga** (special mementoes) that made them feel connected to ancestors (past and present), lands, spirits, and home environments. The **manuhiri** (visitors) played a role in supporting the whānau pani by assisting them to grieve by undertaking emotional and practical support. The **ringawera** (cooks/helpers) manifested as people organising and preparing food, schedules, transport and other preparations. **Tuakana and teina** relationships (older and younger siblings) took their designated roles in supporting or providing leadership and guidance. Church ministers and other prominent people were critical in meeting whānau pani emotional and spiritual needs, and **hui** (meetings) took place to discuss and make important decisions. Much of the hui were held off-site in homes and community venues due to lack of adequate space within hospital environments. These cultural processes were drawn on as they were familiar, reliable, stable and safe. While standard cultural practices were conducive to whānau coping, they were also disrupted by the hospital environment, policies and practice. Whānau pani (the grievers), whose role in the traditional process is just to grieve while supported by others, undertook several additional roles and functions through default as the system would not cater for the alternative. The roles assumed by whānau pani included **ringawera** (cook/organiser, information gatherer), **kai korero** (speakers to doctors and family members) and **kaitiaki** (guardians and protectors for theirs and other whānau). Cultural specific mechanisms such as **karakia** (prayer/incantation) **and waiata** (songs) were limited by having to negotiate for them or by them being prohibited altogether. The **marae** (whānau designated spaces), where **hui** could be held, within the hospital environments, were inaccessible or not conducive to meet whānau needs.

Findings highlight that, when compared with the hospital environment, RMHC practices and processes enabled whānau cultural practices to be actively and positively sustained. RMHC environments were identified by whānau as being better able to provide a space that allowed to a significant degree some regular "family" functioning to occur. For some whānau, RMHC was seen as a type of marae where they could have their whānau with them and therefore fulfil some of their cultural based roles, functions and practices. Interestingly, while there was no mention of whānau being given information about marae including Te Whare Awhina while in Starship, they did raise it as a recommendation for RMHC where an ideal would be to incorporate "a marae type space". While literature highlights the extensive attempts in the past to eliminate whānau out of their cultures through colonisation, urbanisation, racism, stolen generation and genocide (Came et al., 2016; H. Moewaka Barnes et al., 2013; Wepa, 2016;) this research confirmed that despite limitations and restrictions, cultural obligations, responsibilities and practices are still very much

intact (L. Smith, 1999), and were imperative to whānau coping (S. Edwards et al., 2007; Monterosso et al., 2009).

Communication of Information

Role processes and functions within whānau were also critical regarding communication and information. These processes ranged from how information was communicated, to whom it was relayed and where communication took place. While whānau indicated they did not understand much of the information given to them, highlighting, amongst other issues, the terminology used by clinicians, no evidence was found from the findings as to whether health care staff followed up with whānau to find out if they fully understood the information relayed. It was also evident that whānau were reluctant to approach the doctor to seek out further understanding despite doctors offering this. Wepa (2016) found, through her theoretical sampling with experts in the field of health literacy, that whānau were not following instruction, not taking the right medications and therefore not getting the expected results. However, it was also found that health workers were not checking to see if whānau understood what was required. Research has pointed to the importance of patients having a clear understanding of information relevant to their health (Dodgson & Struthers, 2005; Robson & Reid, 2001). Similarly, the findings have identified the importance of access to, understanding, and delivery of information to whānau coping. Whānau related clear and understandable information and communication from health care staff including building good relationships with quality of care.

Understanding the roles, functions and processes within whānau helps to ensure better communication. Knowing who to communicate with, and empowering the whānau to decide this, enables not only better understanding but also compliance (Day, 2009; Osborne, 2008; Wepa, 2016). Communication is a reciprocal process, requiring both parties to be actively engaged and, according to Osborne (2008), creates a setting for teaching and change to occur. Berkman et al. (2004) supported and encouraged the idea of bringing whānau members to health-related appointments, especially when medications were discussed. Berkman et al. recognised that family helped ensure that relevant questions were asked and adequate answers were provided and understood. Whānau within this study were not encouraged to have a whānau member present during discussions. It was found at times when a doctor went to inform other family members that whānau discouraged this drawing on their own past negative experiences of previous doctors' and the communication processes that had transpired.

Restrepo and Davis (2003) stated that cultural perspectives become more real to health staff when they fully engage with patients, creating tolerance, empathy and therefore more culturally responsive care. J. Lee (2009) identified the importance of pūrākau (storytelling transpired by oral traditions), as a culturally relevant way of communicating. Pūrākau allows for messages and experiences to be conveyed in a way that keeps with cultural notions. Jansen, Bacal and Buetow (2011) found that having whānau support at the time information is relayed, regardless of health literacy levels, reduced stress for whānau which aided better coping while transitioning through the health care system. Whānau within this study took extra time, energy and effort to seek out additional information and the support required to understand it so they could try to make informed

critical decisions. Given that miscommunication is linked to patient harm (Bacal & Jansen, 2006; Leonard et al., 2004), and that the way in which a child's diagnosis is conveyed shapes whānau ongoing health care experiences (Mack & Grier, 2004), it is critical to ensure that information is relayed appropriately and understood when dealing with a child who has a life-threatening medical condition.

Online health information (for example, Starship, RMHC) was found to be in English using technical terminology; it takes some skill for even the most technically advanced and health knowledgeable person to find specific information required. Highly technical online systems and health-based information incorporating specialist terminology are commonplace throughout the hospital system. At the most basic level, whānau want effective communication that is understood while being surrounded by support. The respect for designated roles around lines of communication was often not considered from a clinician viewpoint. Evidence suggests that in many areas of health, Pacific peoples do not have adequate information (Craig, Jackson, & Yeo Han, 2008; Huakau & Bray, 2000; S.-Y. Lee et al., 2004; Ministry of Health, 2008; Zanchetta & Poureslami, 2006). Having a limited understanding of information makes it difficult to make fully informed decisions. Also, there is an acceptance that public health information needs to be tailored to the needs of specific community groups. The Pacific Health Report noted that promoting positive messages and controlling negative influences will contribute toward better health outcomes for Pacific peoples (Statistics New Zealand, 2002).

Not all information is deemed difficult to understand, and some traction has been made. Better and more effective information now exists in different areas and has been tailored to meet the needs of specific groups. Communication cards, for example, have been developed with patients, whānau, clinical staff and the interpreting services. Cards are available in 12 different languages and are free to download. Communication cards contain particular sets of icons that patients can use to communicate their immediate needs, wants or concerns. The icons used on cards follow a hierarchy similar to the well-researched concept of intentional rounding (consisting of regular checks, structured process and dedicated time to identify and address the patient need). Communication cards focus on priority needs: pain, elimination, positioning, environment and personal needs or possessions (Auckland District Health Board, 2017). It is hoped that these cards will improve the safety and quality of care for some patients who may not be able to communicate effectively. The cards are designed by the Design for Health and Well-being Lab. Figure 27 shows a communication card in the Samoan language.

Figure 27. Samoan communication card.

Findings also indicated that information for whānau dealing with a child with a life-threatening medical condition needed to be reinforced at different times and through various means. Whānau were found to help reinforce information that might not have been entirely comprehended due to stress or shock at the time of it being presented (Berkman et al., 2004; Jansen et al., 2011). Written information containing pictures and language that is tailored to specific communities, using phrases and wording that they can connect with and relate to, is promoted as being effective (Bacal & Jansen, 2006).
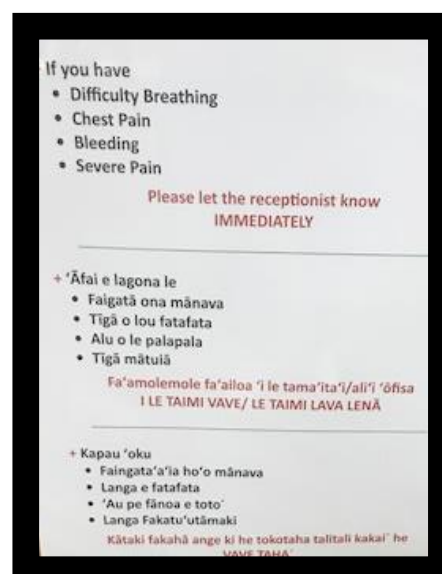
Figure 28. Examples of information tailored to various communities.

Obtained with permission (Nursing, Otara Family and Christian Health Centre, 2017)

The National Cervical Screening Programme (NCSP) has several pamphlets that are tailored to different communities, including Māori and Pacific. Figure 28 shows a case of wording and pictures that are matched to their intended audience. In the example below, the NCSP shows an image of a Māori woman and uses Māori words (wahine – women; Figure 29).
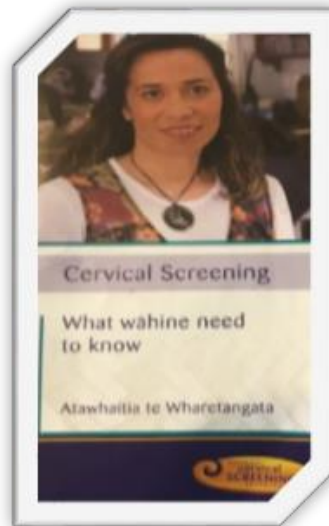
Figure 29. National Cervical Screening Programme pamphlet.

Having whānau members verbally reinterpret and re-emphasise pertinent information at relevant times will also have significant effects. Stakeholders confirm their contribution toward helping whānau understand information, emphasising the need for reinforcement at different points of the journey. Whānau within the study wrote journals and diaries or simply wrote down relevant information so they could process it further at a time more convenient for them.

Participants identified relying on whānau members who had the capacity and capability to undertake additional research and the energy and language with which to break down the information further in an understandable format. What the findings revealed was that whānau needed a mix of information systems that could work for differing levels of understanding and ages. Three forms of communication have been identified: written (hardcopy), verbal (face to face) and through electronic means. Overall, communication also needed to be appealing and engaging.

Written and Personalised Information

The Brooklyn's Love Foundation, set up by the Patea whānau to help other whānau going through the journey with a critically ill child, has initiated the development of a whānau booklet (Brooklyn's Love Foundation, 2013). The booklet is aimed at the whānau the Foundation supports, who are dealing with a child with cancer.

The initiation of the booklet stemmed from the Patea whānau 's journey and the whānau being inundated with information over the first few days of their own son's diagnosis. The booklet is still

in development and will be tailored and provided to whānau. The booklet will hold critical information, incorporate ideas, questions to consider as well as list useful resources. Most importantly the book is developed by whānau for whānau. In many instances, it is difficult for whānau to quickly obtain pen and/ or paper especially when timing regarding doctor's rounds can be unpredictable. The stress related to circumstance can cause memory loss with many well-intended questions not being asked and the risk of overload resulting in information loss. Many of the whānau who participated in this study learned over time to consistently write down information. Writing a journal (some through social media sites such as Facebook or Instagram) was also a way of coping by venting, searching for information and informing other whānau of occurring events. Social media was also a mechanism where whānau did not have to repeat information, an additional exhausting feat.

Child Cancer Foundation (CCF) undertakes communication through storytelling in an alternative way. The beads of courage programme is a registered, therapeutic programme. "Each bead represents a treatment (for example chemotherapy, injections, scans); an experience (hair loss, isolation, fever) or milestone (completion of treatment)." (CCF, 2017) The programme provides the opportunity for the child to tell their significant story representing their physical journey and courage while dealing with cancer. Each bead represents some aspect of the journey, from diagnosis to discharge and everything beyond and between. CCF also supply sibling beads, confirming a whānau approach acknowledging that siblings are also affected by the journey (CCF, 2017).

Face to Face – Verbal

For Māori and Pacific whānau, particularly the older generation, oratory and face to face communication is deemed highly important, culturally relevant and necessary. While a whānau information booklet is in development, there seems to be a desire for information to also be relayed face to face. Whānau identified feeling patronised by staff who communicated that they knew what whānau were going through although they had not had a child in the same position. The lack of transparency of resources, including services and information, as well as understandings, could well be provided by someone who has experienced the journey, knows the systems and understands well what whānau need. One interviewee identified wanting a parent liaison, while others identified wanting someone who understands their journey. The emphasis on the parent liaison related more to the need for someone who has been through the journey themselves so they could empathise with whānau.

A parent liaison could also help navigate whānau through the health and support services and systems. While navigators are not a new position within hospitals, what whānau require on top of the navigation is deep and reassuring understandings. Currently, some whānau members and staff may facilitate this function to varying degrees and lengths; for example, RMHC staff, CCF staff, social workers and nurses. However, no one person or role is a designated position, specifically in place to serve this purpose. Therefore, whānau are having to consult multiple people, not knowing fully who does what. In some instances, and as indicated in the findings,

whānau themselves have taken on this role, integrating advocacy, navigation, security, cultural support, and facilitation both to whānau and staff.

Whānau Ora navigators (kaiarahi) have been instrumental at the community level and are seen as key to an integrated whānau-centred approach to health (Te Puni Kōkiri, 2007). Whānau Ora is currently being implemented in various ways across many DHBs. While Māori and Pacific peoples have been undertaking whānau ora before colonisation, implementing it into practice while confined by Western rules through government funding outputs and different environments has had its fair share of challenges. Whānau Ora navigators are also located at some DHBs. Whanganui DHB has named these navigators 'haumoana'. The haumoana role model "whānau /family-centred care by working alongside staff to foster staff confidence in working with Māori whānau; participate in multidisciplinary teams and discharge planning and work with whānau /families to advocate and navigate to improve and self-determine their health journey" (Whanganui District Health Board, 2017). Cultural support services also undertake whānau ora within their roles but are becoming are rare commodity within DHBs. Whānau ora navigators will be a welcome addition for whānau across all hospitals. However, the implementation will most likely come at the cost of either losing or redefining other forms of cultural support already implemented.

Electronic Resources

The move to paperless systems within health seems more and more attainable with patient portals and health passports being developed and initiated. Electronic-based information is being integrated at a fast rate within our society. What will be needed is a system that is tailored to the needs of the health population.

Whānau as the Expert

Literature and the findings acknowledged that families become the "expert" in their child's health care, during protracted periods of hospitalisation, having to step into the roles of many health care professionals providing specialist treatment within the hospital and within the home environment (Kirk & Glendinning, 2002). Interviews highlighted some whānau as having extensive knowledge of health, culture and bringing up children (not just their own). Some who had been highly educated held prominent positions within sectors, communities, cultures and countries. Participants had vast amounts of experience in dealing with health systems (for example, up to four different hospitals and over 20 services involved) over extended periods of time, in various parts of the country and sometimes in different countries. Some of the Pacific men talked about how they had become experts in their child's care over the extended periods that they had been in the hospital. In the provision of health care, the clinician is often driven by the medical culture. It has also been noted that clinician-based views can be further prejudiced by their background, values, and social class. As well, training and teachings toward their qualification(s) create a sense of superiority and authority for them where society learns that the doctor holds all the power and knowledge (Putsch & Joyce, 1990).

Whānau in the study highlighted that their experience, skills and knowledge were not considered valid by health care staff, despite knowing the procedures, medications, treatment regime, and their child, well enough to assess reactions and behaviours to particular situations. These feelings are often a result of patient views, context and culture being overlooked, excluded and deemed invalid (Putsch & Joyce, 1990). In some situations, whānau would raise issues aligning with their intuition, sometimes on several consecutive occasions. Often these issues were regarding something being seriously wrong with their child. Whānau talked about not getting answers to questions or being treated with disrespect and disregard. Interestingly, while health staff failed to endorse whānau knowledge and skills at one level, at another level, it was shown that specific whānau were often called upon by health care staff with an expectation they would provide advocacy and translation. Health care staff were seen to rely on whānau to provide skills that they either did not possess or could not adequately, appropriately and efficiently access. Whānau reliance has been supported by the findings of Williams et al. (2003) where solutions provided by whānau were often culturally related, including language and appropriate access to information. While it was found that staff acknowledged and drew upon whānau cultural knowledge whānau are still not seen as holding valued 'health' knowledge. These findings reiterate the lack of health system cultural responsiveness and the impact the gap has on both health care staff and patients.

Roles and functions within Māori and Pacific whānau in the study were seen to be highly regarded by their respected members (Moeke-Pickering, 1996; Superu, 2016) The respect for roles is not only recognised within whānau but also pertains outside of the whānau. Cultural tensions were noted when young health staff came in to inform older Pacific men (who had children and grandchildren), in particular, how they should care, hold or feed their child. Two of the Pacific men in the study felt offended given that young staff were giving them advice regarding children when they lacked life experience and had no children themselves. Likewise, doctors would inform fathers that they needed to go and have a break from their child or spend time out as a couple; Pacific men found this offensive for two main reasons: (a) the way it was communicated which was negative and implied their child was the problem; (Frank et al., 1998; Hern, Koenig, Morroe & Marshall, 1998; Mitchison et al., 2012) and, (b) particularly, Pacific men, saw the doctors in their role to be responsible for the medical care of the child, not for the parents' psychological or marital situation. Further to this, findings highlighted some societal expectations being played out in the health care environment. The general expectation from health care staff was that mothers/women would care for the child and stay in the hospital. With this expectation, it was found that women were more frequently drawn upon and seen as being central to discussions regarding the care and treatment of their child, even when other whānau were present (Coad et al., 2015). Particular societal expectations and attitudes were reflected, such as nurses being "surprised" to see Pacific men, in particular, attending to their child or acting as primary caregivers. Interviews highlighted the "subtle" discouragement of dads being involved in their child's care (Da Silva et al., 2010). Men also expressed the behaviour of nurses, particularly in intensive care units, as over-encouraging dads to leave. Tensions were also raised when specialists had limited understanding and experience in talking to and treating children, often treating children as though they were adults (speaking in a language the child did not understand or unintentionally harshly treating

them with equipment), causing the child and whānau considerable stress which consequently led to mistrust.

Implications for Health Care Practice

The final theme discusses the *implications of the study* relevant to models of care, particularly family centred care and the incorporation of cultural models within health. This section emphasises the importance of culture not only within the health system but in and across other sectors that impact health care practice and therefore health outcomes. This segment concludes by identifying approaches that are critical to making a difference in Māori and Pacific health outcomes.

Models of Care

Family-centred care (FCC) is the philosophy that underpins Starship Hospital, as promoted on their websites and throughout relevant documents (Starship Hospital, Children's Hospital Health: Auckland District Health Board, Starship Paediatric Intensive Care Unit - PICU). FCC is considered the pinnacle of paediatric health care by many clinical practices, hospitals, and health care groups (Abraham & Moretz, 2012; Moretz, 2010). While the concept and intention are great, there seems to be a division between the ideal and what can be effectively implemented within the practice. For FCC to be effective, all parties involved, including whānau, need to agree, have clear understandings, and be supported to make the best decisions and have the best outcomes for both the child and their family. Findings in this study revealed little discussion, let alone consultation, with whānau members and if and when consultation did occur, it was whānau - initiated. Shared care for Māori and Pacific whānau was a common element throughout literature (Collins & Wilson, 2008; Ka'ai, 2005; Moeke-Pickering, 1996; National Health Committee, 2009) and evident in findings. FCC promotion within a hospital environment, particularly when there is a chance of extended stay, needs to account for the differing whānau members, structures, roles and functions. Across some countries, health-care decisions are not just left to one or two people (for example, parent or spouse) or just to the physician (Chang & McConkey, 2008; Kissane et al., 2008; Tsai, 2001). Cultural context, family structure, process and protocols need to be taken into consideration when health care decisions are made. If there is a collective decision-making process then, where and when possible, sufficient time must be afforded so that the family can make the necessary decisions they feel best to meet patient and family health care needs. While some decisions, especially regarding children, need to be made quickly, a collective decision can still be achieved. For this to occur, however, there needs to be a willingness on the part of clinicians to offer or account for this by providing their time, appropriate space and other resources such as an interpreter or support services.

While the family is defined in many studies to broadly include social relations (Arnett, 1995; Shields et al., 2007; Solar & Irwin, 2007), it has been found that overall, informants in studies on coping and FCC have mainly consisted of women. According to Mikkelsen and Frederiksen (2011), this indicates that FCC has been built on a narrow understanding of the term family as it primarily constitutes knowledge formed from the views of mothers. Furthermore, the disregard for

cultural constructs that relate to FCC is barely mentioned within FCC literature and is even scarcer within practice. The absence of an appropriate space for family meetings has been associated with higher levels of anxiety and depression for ICU families (Azoulay et al., 2001). Discussions at the bedside have also raised concerns, and conversation with physicians in hallways or waiting rooms not only violates the privacy of the patient but also disturbs other families who overhear (Durral et al., 2012). There is also a lack of information about the FCC model of care in general within practices. While Starship mentions FCC on their web page, limited information is found as to what it means for the facility, its staff and the whānau themselves, or how FCC is implemented. Starship documents related to FCC care utilise the term "whānau and caregivers" but then relate their practice to the parent(s). It might be helpful if practices made it clear and were transparent regarding their FCC practice, just like other information portrayed within the hospital environment such as patient rights, mission statement and core values.

The findings showed that FCC was not transparent at the patient and whānau levels within hospital environments nor was it evident in practice. Adherence to the principles of FCC appeared to be at the discretion of the clinicians. While Starship promotes FCC, it is uncertain how the staff are trained or oriented to facilitate and use it within their practice and with whānau. Mikkelsen and Frederiksen (2011) recognised that implementing a generic Westernised model into environments that have high numbers of non-Western patients will always be difficult without sufficient resources (time, staff, training and understanding). Notwithstanding that, the medical staff themselves are less enthused about dealing with the whole family, often talking to the mother even when specifically asked to address others or the whole family (Corbett & Callister, 2000; Gay, Pronovost, Bassett, & Nelson, 2009). Also, and in contrast to the best intention of family-centred care, the hospital environment is not conducive toward family bedside care, in particular in a New Zealand context for Māori and Pacific larger, extended and blended whānau. Services were found to be tailored toward parents and or child only; there were limited resources and services available that cater to different cultures and their associated languages (Huakau & Bray, 2000). Despite its name and intent, family-centred care within the hospital seemed to support more short-term intensive care, reinforcing both the traditional construct of the family unit as comprising parents (mother and father) and their child(ren), or focusing specifically on the child (Barton & Wilson, 2008; Lawlor & Mattingly, 1998).

Similar to Starship Hospital, RMHC supports the notion of the FCC model. FCC is incorporated within RMHC's vision, and their definition of family is clearly visible within policies, on websites and translated into daily practice through the organisation's staff. For whānau who have children with a life-threatening medical condition, care is usually extensive, over long periods and therefore there is a likelihood that more whānau will be involved. For Māori and Pacific peoples, decisions were usually made with the collective rather than individuals. Given the identified lack of whānau -designated spaces at the hospital whānau, where-ever possible, utilised, the existing space within RMHC to ensure whānau systems and structures could be maintained, such as family gatherings, meetings, sitting at a table and making collective decisions over food (an important component in many cultures). It was also noted that whānau felt that RMHC processes and staff worked with them rather than against them with whānau citing instances of flexibility and patience

revealing staff taking the time to meet, sit and discuss issues that arose with and for whānau. In other health environments, whānau disclosed ridged inflexible processes that intimidated and disempowered them. Family-centred care within RMHC was evident resulting in the model being translated from policy into practice. This was seen by its distinct positioning of placing whānau at the centre of their vision and mission. As well whānau were central throughout key strategic documents and websites and through the conduct and practice of their staff and by tailoring the environment to meet the on-going changing needs of contemporary family make-up. This confirms that as FCC is not implemented well within the hospital that it then extends beyond the hospital setting (Shields et al., 2012). One of the key aspects of RMHC for whānau in this research was that whānau themselves determined who their family was rather than having to fit with a pre-determined unsuited concept.

Shields (2010) argued that it would be better for countries to develop and tailor their own culturally appropriate models of care that could include elements and principles of FCC rather than to implement models from elsewhere or try to fit a generic version. Several models of care, including "home-grown" models, have been presented in the background to this thesis. The key emphasis of these models and strategies is that the whole of the health and disability sector is responsible for their implementation. For example, the Ministry of Health's (2014b) He Korowai Oranga refreshed framework highlights four pathways as a guide to improving Māori health and realising Pae Ora – healthy futures. Two of the pathways include:

- supporting Māori participation at all levels of the health and disability sector
- ensuring effective health service delivery (Ministry of Health, 2014b)

Similarly, Ala Mo'ui: Pathways to Pacific Health and Well-being is driven by the vision of achieving health equity for all Pacific peoples in New Zealand. It also includes within the plan the delivery of high-quality health services in a timely and accessible manner (Ministry of Health, 2014a). Other cultural models such as Te Whare Tapa (Durie, 1982) and Fa'afaletu (Tamasese et al., 1997) and Whānau Ora (Whānau Ora Taskforce, 2009) are also utilised both across health at different levels (including community, DHB and government). While these models incorporate culturally relevant elements and words, what matters is whether they are effective in practice. Strategies are only as good as the people, funding, policies or an organisational culture that actively implements them. Cultural models that are developed within a Māori and Pacific context, driven by cultural values, traditions and practices, are done so with the best intentions. However, what fails to be accounted for is that such models are often taken out of their original context; applied in a Western system (such as the hospital) where cultural elements are re-defined to fit with Western ideals and understandings (family vs whānau and parents vs caregivers); and become implemented according to Western values. While intentions seem reasonable, they lack cultural reinforcement and understanding. A lack of a culturally reflective workforce and or cultural competence of the current workforce then bastardises these models even further to the point where they become tokenistic, having little real value in reducing disparities for Māori and Pacific whānau. While gains have been made in some areas, particularly regarding specific cancers (McLeod et al., 2010), there is evidence that Māori and Pacific health disparities in many other areas remain slow, with some gaps widening further (Ajwani et al., 2003; Marriott & Sim, 2015).

Cultural safety, which came out of nursing in the 1980's, has been seen to have made significant traction in the nursing profession in New Zealand and beyond. Cultural safety is now being implemented in countries such as Canada, Australia and the United Kingdom (C. Baker, 2007; Browne et al., 2009; De & Richardson, 2008). In New Zealand, under the Health Practitioners Competence Assurance Act (2003) and the Medical Practitioners Act (2007) it is now a requirement that all regulated health practitioners must be able to demonstrate cultural competence, annually of which cultural safety is a core component. Despite the gain in cultural safety implementation there continues to be little effect regarding Māori and Pacific whānau experiences within hospitals (Davis et al., 2006; McKinney, 2006: D. Wilson & Barton, 2012), highlighting that a significant gap still exists. Both Mckinney (2006) and Wepa (2016) identify that the lack of a 'caring' component within medical care is partly responsible.

Recognising the Importance of Culture

Variables that impact on Māori and Pacific health and health decision making for whānau are huge and include family makeup, connection or disconnection from family or lands, as well as the impacts of a family's current living environment and context (Borell, 2005; L. Williams, Labonte, & O'Brien, 2003). For Pacific whānau, the variable of immigration also plays a critical part in their role in New Zealand society. Cultural influences are central to determining coping behaviours and play a significant role in dealing with a child with a critical health condition (Lam & Zane, 2004). Whānau noted the under-representation of Māori and Pacific within the health workforce across health system environments including support related services and at all levels within the study. The absence of Indigenous and ethnic minority peoples within the health workforce limits the provision of culturally receptive, safe and competent workers who meet the differing needs of the communities it serves (Cram, 2014; Curtis et al., 2014; Curtis et al., 2012; Health Workforce Advisory Committee, 2003; M. Ratima et al., 2007, 2008). Currently, the limited culturally reflective workforce was seen to exist at all levels of RMHC Auckland, including board and management levels. RMHC management identified the need for cultural based training, while RHMC staff observed that a more culturally reflective workforce would enhance service and whānau resource. While culture is deemed an important aspect of health for many Indigenous peoples, unsurprisingly cultural responsiveness has been found to pose some challenges for medical and support service organisations and their staff. Searight and Gafford (2005) state that with increasing diversity in society, the challenge for physicians (and support service roles) has been in learning the cultural factors that influence patients' responses to medical issues. For RMHC the willingness to do something to improve their cultural responsiveness is apparent, and some small-scale gains evident by the conclusion of this study. Beyond these minor gains the organisation seemed at a loss in how, or what, they could effectively and efficiently execute. To support cultural input and advice to the organisation, several key recommendations have been put forward and further detailed (see Chapter 9 - Recommendations).

While it is acknowledged that cultural guidelines exist in many health environments (Kagawa-Singer & Blackhall, 2001), the challenge, according to Searight and Gafford (2005), is to find resources that tell health care staff how these guidelines can be applied directly to patient care.

Many physicians are unfamiliar, whether by choice or ignorance, with common cultural beliefs and behaviours regarding physician-patient communication, medical decisions and other important aspects of care. Cross-cultural circumstances have often magnified the differences between patient and clinician views. The system and those that contribute toward its on-going embedded practice fail to recognise and deal with perceptions of ill-health that differ from those of the biomedically trained staff. Perceptions such as these can thwart attempts at identifying problems and therefore inhibit the development of any form of an effective solution (Putsch & Joyce, 1990). A contributing factor to consider is that in the past culturally-based aspects have not been a core part of the medical curriculum or medical training (Kripalani, Bussey-Jones, Katz, & Genao, 2006; Wikaire, 2015). In some instances where cultural elements had been incorporated, there was found to be a disconnection between the implementation within a programme setting versus applying cultural reflections in practice (McKinney, 2006). The incorporation of cultural elements into medical training is not a new phenomenon; many Indigenous advocates have been pushing for its inclusion for years (Durie, 1999; Ramsden, 1990). While some traction has been gained over these years, in many cases cultural competency training within the medical curriculum has only been offered as an elective (i.e. such training is not mandatory); is only delivered outside of medical school timetables; and is not properly accounted for within the curriculum nor part of the overall qualification (Flores, Gee, & Kastner, 2000). Cultural competence, cultural safety and cultural understandings are everyone's responsibility. While having a culturally reflective workforce helps facilitate all those things, the responsibility and the load need to be first acknowledged and secondly, actively shared. To do so, specific strategies are needed that are fully endorsed and implemented at several levels so that over time changes will occur within the health culture.

The concept of a pipeline has been identified in studies regarding recruitment into training programmes that support health workforce development (Acosta & Olsen, 2006; Curtis et al., 2012; Ministry of Health and Ministry of Pacific Island Affairs, 2010; M. Ratima et al., 2008). These studies reflect the need for pre-secondary support to facilitate recruitment and retention of Māori and Pacific in the health and disability workforce. The recruitment of Māori and Pacific peoples into health workforce training programmes has also been assisted by effective programmes such as the Māori and Pacific Admission Scheme (MAPAS), Whakapiki Ake Programme (WAP), Vision20/20, Te Rau Puawai and Hauora Māori Scholarships, for example. While programmes such as these have been successful, they are also driven by high demand (D. Edwards, Friedman, & Pearce, 2013; S. Edwards et al., 2005; Poole, Moriarty, Wearn, Wilkinson, & Weller, 2009; Wikaire, 2015).

Multiple challenges for Māori and Pacific students, particularly those undertaking health and related medical study in their first year at the university, have also been raised (Curtis et al., 2015; Curtis et al., 2012; Madjar, McKinley, Deynzer, & Van der Merwe, 2010; Sopoaga et al., 2013; Wikaire, 2015). Challenges include cultural isolation, racial discrimination, and being overwhelmed by being engulfed in large predominantly Western institutions (Curtis et al., 2012; Madjar et al., 2010; M. Ratima et al., 2008). To support Māori and Pacific retention, and therefore the growth of the health workforce, attention is required in these first crucial years (Wikaire, 2015).

While there has been traction alongside promotion and support within various institutions that enhance Māori and Pacific health workforce participation, we need to be mindful of the full impacts on Māori and Pacific health workers. The sole reliance on the Māori and Pacific workforce to meet and provide the cultural needs of the patients they serve or the staff and providers they work for may confine and further marginalise them to the point of burnout. Consequences stemming from burnout such as conflicts, exhaustion through overload leading to ill-health, being let go or resignation has been modelled by many Māori and Pacific workers, not only in health but across other sectors (Staniforth, Fouché, & Beddoe, 2014).

This research found a heavy reliance on the cultural support teams that sat in both Auckland and Starship hospitals. It was shown that workloads were high and resources remained low. The study also highlighted how cultural support teams became the cultural responsibility of all staff. Cultural support staff worked across system, organisation, community and patient levels. The multiple accountabilities toward themselves, their whānau and Māori as a collective (Carlson, Barnes, & McCreanor 2017; Elder, 2008; M. Ratima et al., 2007) saw them work extra hard over long hours. Overtime was often not paid as people in these roles often regarded helping whānau as part of their cultural duty and responsibility. While they were a critical resource for whānau and heavily relied upon by staff and community, they were also completely undervalued within the health system. Similar experiences have occurred across other workforce areas including community support workers and whānau ora navigators (Boulton, Gifford, & Potaka Osborne, 2009). The undervaluing by the system of staff who hold additional skills that are not recognised as 'health' often lead to the point of staff burn out and/or resignation and staff who have left are not replaced. For cultural based support within the hospital, their initial integration within and part of multidisciplinary teams attached to specific wards ceased to exist. Not being part of critical teams isolates and detaches the service; their heavy daily workloads, critical role and cultural functions are concealed and therefore easily dismissed within the larger health system matrix.

A primary example occurred in June 2017 where we saw the Lakes District Health Board's decision to dismantle their cultural team, Te Hunga Manaaki. The team were integral in bridging relationships between clinical staff and Māori patients and their whānau, and an extensive evaluation of the team's performance, incorporating over 50 interviews of clinical, nonclinical and service users, revealed overwhelming support for the service (Radio New Zealand, 2017). Anecdotally, it is suggested that the DHB's unrealistic expectations of Te Hunga Manaaki were to improve inequalities in Māori and non-Māori health, a feat that no DHB in the country has been able to achieve (T.K. Kingi cited in Radio New Zealand, 2017). The response from the DHB was that the decision was made as part of their commitment to improving health equity (Radio New Zealand, 2017). Considering the inequitable access to Western resources for Māori and Pacific whānau, as indicated through this thesis, this raises the question of whether getting rid of the very limited cultural-based resources will improve or further enhance equity, particularly for Māori and Pacific populations.

Despite cultural-based resources being removed in some areas, more recently alternative and necessary strategies have been implemented at some levels. Such resources include the continuation and extension to cultural-based curriculum and models within university health

programmes and across medical schools including professional bodies, and health provider levels.

The Medical Council of New Zealand (MCNZ) has recently released its publication *Good Medical Practice* (MCNZ, 2016). The publication serves as a foundation document that outlines standards that form part of the MCNZ function as directed under section 118(i) of the Health Practitioners Competence Assurance Act 2003. Standards include clinical competence, cultural competence and ethical conduct for doctors. The MCNZ has also issued publications in association and consultation with Mauri Ora Associates that are solely directed at the provision of care to Māori and Pacific patients (Bacal & Jansen, 2006; 2010), and they also provide a statement of cultural competence. The MCNZ have been involved in cultural competence since 1998, after reviewing their policies and statements in consideration of the Treaty of Waitangi. Professor Sir Mason Durie was also influential regarding the idea of developing cultural competence standards, about positive outcomes for patients and generating improvement for public health and safety (Adams, 2011).

The Royal New Zealand College of General Practitioners (RNZCGP), as part of their professional development programme, have introduced a minimum number of credits relevant to cultural competence and/or Māori health in line with MCNZ requirements and the College's Māori strategy (The Royal New Zealand College of General Practitioners, RNZCPG: Continuing Professional Development Programme 2014-2017). The 3-year programme requires participants, amongst other tasks, to "spend at least two hours on activities that are related to developing cultural competence, particularly Māori cultural competence, or contribute differently to the development of Māori health" (p. 10), and for the annual programme spend at least one hour. The time and effort allocated seem insignificant compared to the state of Māori and Pacific health, but it is a start.

Alongside other programmes and organisations, the medical schools at the Auckland University and the University of Otago have been instrumental in implementing models and curriculum that not only teach about Indigenous health but raise the students' critical consciousness about their cultural values and how they might reflect on their practice. Models such as these are being incorporated into programmes to ensure cultural safety, and cultural competency occurs within medical settings (Curtis et al., 2014; R. Jones, 2011; Lacey et al., 2011; Pitama, Huria, & Lacey, 2014; Pitama et al., 2007). Models that form part of medical curriculum support and encourage relationship building with Indigenous patients, take into account history, addressing racism, colonisation, migration and marginalisation as well encouraging practitioners to seek out Māori patient beliefs, values and experiences, alongside other important mechanisms such as whānau, tikanga (ways) and whenua (land). As well, immersion programmes have been implemented where medical students experience living and working in specific Māori and Pacific communities (Sopoaga et al., 2013; Wikaire, 2015).

Cultural misunderstandings and unconscious bias contribute significantly to the state of Māori and Pacific health. Bacal and Jansen (2006) report that integrating cultural with clinical competence will lead to better outcomes through improved communication, making treatment more acceptable

and enhancing adherence to treatment plans. A better understanding of cultural perspectives on health and culturally competent services can improve responsiveness to health needs. As well, measuring clinician performance in the delivery of services (ACC, 2004; Baxter, 2002; Crengle, 2000) to Māori and Pacific peoples is well overdue (Bacal & Jansen, 2006). Models and programmes such as these that are being implemented throughout professional bodies, organisations and universities directly impact the health workforce and put the responsibility and some of the workloads back on non-Māori and non-Pacific medical students and health workers. Models such as these are critical to making a difference in Māori and Pacific health.

At one level, the government implements strategies to try to reduce disparities but at a practical level removes a critical resource that whānau identify as making the difference, such as patient navigators, cultural support teams, and cultural advisors. Currently, while government strategies acknowledge the different pathways of support needed for Māori and Pacific peoples, they still end up with a one-size-fits-all approach with some tokenistic cultural elements that sit within it. The strategies mentioned, including models of care, recruitment, facilitation and retention of the health workforce, and government-initiated strategies across health and education, seem to be occurring in small pockets (some having encouraging results) with some operating in complete isolation. It must also be recognised that despite the availability of guidelines and model programmes (American Medical Student Association, 2007; Beagan, 2003), not all cultural competence education will be effective in improving the attitudes and skills of all health professionals (Beach et al., 2005).

In evaluating the strategies incorporated within this thesis, it became obvious that some health-related/government strategies align, some build on other strategies and some overlap. While all are well-intended and are making critical differences, big and small, it will take some time before these differences have a significant effect. Given the state of Māori and Pacific health, time is something we do not possess. The approaches might work faster and better if there was a dedicated, coordinated approach. A current stocktake of effective programmes will be useful and, support from government critical. A co-ordinated cohesive approach to strategies that incorporate cultural safety, cultural competency and critical consciousness implementation across sectors starting with health and education utilising what is already in place will be beneficial. In the past, Te Kete Hauora, a business unit of the Ministry of Health would have taken a leadership role in driving initiatives such as these. Considering again, the recent disestablishment of this Māori policy team there are limited avenues keeping the government in check regarding addressing institutional racism and its Treaty obligations (Came cited in S. Harris, 2017). Institutions such as Te Kete Hauora provided exposure to the differences between Māori and Pacific health and the health of other dominant groups (Wikaire, 2015). Having critical cultural resources dismantled in the name of equity reduces accountability and responsibility toward Māori and Pacific health. Taking away resources that provide support and accountability to and for Māori and Pacific peoples continue to benefit dominant groups' further reducing Māori and Pacific health inequities from visibility and priority.

Summary

While there are limited studies in the literature that focus on a whole whānau coping perspective, this research has demonstrated and confirms that coping with a child with a life-threatening medical condition is a contextual family experience where the encounters of one family member influences a whole family system (Miller & Caughlin, 2011; Revenson, 2003). The value, power and skill of whānau and its associated processes are hugely underestimated and undervalued by health practitioners. Māori and Pacific whānau in this research were placed in a vulnerable position where they were at the mercy of those who held power. The journey experienced by whānau who were transitioning along the health care continuum involved patience, flexibility and adaptability, with some whānau noting up to three or four previous hospital admissions before getting to Starship, as well as intense treatments, infections, discharges and readmissions. Maintaining resilience and building up strength came in the many forms of whānau.

The clash of worldviews brought with it different ideals about coping. For Māori and Pacific whānau their ideal was drawing on support which brought with it strength that enhanced their coping. Alternative views in the literature regard the need for assistance as an indication of submission to weakness and therefore not being reliant on support was a sign of pride and self-sufficiency rather than a facilitator to coping (M.Y. Wong & Chan, 2006). These constant conflicts saw Māori and Pacific whānau practices and processes, while intrinsically strong, sometimes worn down through having to continually battle with and rely on a foreign and contrasting set of systems, values and practices. As well, whānau were working overtime negotiating and providing a much-needed resource for other whānau and staff. The very system that set out to physically heal the child, in many cases caused infection and made whānau spiritually, emotionally and culturally unwell.

Whānau obtained respite at the Ronald McDonald Houses. The organisation was found to be both a positive influence and a primary facilitator of whānau coping with much of its service filling critical gaps at health system and organisational levels. RMHC, as an organisation, was found to be transparent, actively translating their philosophy of family-centred care into practice. FCC was demonstrated by embracing and supporting whānau (extended family) and their wider networks and therefore enhancing whānau coping abilities. RMHC supported Māori and Pacific whānau by validating the differing roles and functions along with key processes and practices. The constant reflection and review of policies, procedures and practice to try and meet on-going consumer need and the provision of high-quality environments and facilities made whānau feel that they had some sense of normality by being remarkably cared for, particularly at a time of intense stress, worry and exhaustion. The care, compassion and skill of front line staff made whānau feel welcomed, as the staff were adept at tailoring support to each family's unique experiences and needs. While whānau were very optimistic and grateful for RMHC, they also felt that whānau coping could be further enhanced by recommending some additional resources for consideration. RMHC is in a powerful position to take the lead in role modelling its FCC approach. The researcher commends the organisation and management for having the courage to explicitly identify their target audience (whānau) through theory and practice. The researcher noted the readiness and openness of RMHC to implement changes at a fast rate over the period of this

research (3 years). By implementing relevant cultural initiatives especially partnering with iwi and incorporating Pacific organisational input would enhance RMHC work even further. A separate more detailed report outlining findings and interpretations has been written and provided to RMHC as part of this PhD.

The information in this chapter has brought to light in more detail some of the gaps and limitations that whānau had to contend with regarding service-based resources. While whānau are expected to make critical decisions for their critically ill child, issues of power and control remain in both decision making (for example, who gets to be involved, told and participate) and the fair and equitable distribution of critical resources (including who gets what and how). The low socio-economic position of Māori and Pacific whānau is further deepened by costs associated with being hospitalised away from their home base and support systems. RMHC was found to significantly relieve financial burdens in many areas (including food, accommodation and parking). Financial burdens such as this concerned whānau causing a considerable impact on their ability to cope (Daniel et al., 2013; Stremler, Dhukai, Wong, & Parshuram, 2011).

Being critically ill, in most cases, cannot be pre-determined and may not be experienced between regular business hours nor follow a clear sequential process. Critical engagement, including having access to resources, needs some degree of flexibility particularly if it is sudden, requiring treatment in foreign locations, multiple locations and in foreign languages. This research confirmed literature that shows the link between racism and health and well-being (Brondolo, Love, Pencille, Schoenthaler, & Ogedegbe, 2011; Clark, Benkert, & Flack, 2006; Dominguez, 2008; R. Harris et al., 2012b; H. Moewaka Barnes et al., 2013; Paradies, 2006; D. R. Williams & Mohammed, 2013). The inequitable access to critical resources including the u2017se of cultural resources (system-based and whānau initiated), as well as the direct differential treatment experiences, foreign environments and lack of understanding of information impacted on the health and well-being of parents, caregivers and therefore whānau (H. Moewaka Barnes et al., 2013; Wepa, 2016). This study also confirms the role racism plays as a determinant of health (Came, McCreanor, Doole, & Rawson, 2016; R. Harris et al., 2012b; R. Harris et al., 2006a, 2006b H. Moewaka Barnes et al., 2013).

Despite these systemic barriers, whānau utilised and relied on the skills and resources they had at their disposal to fill the gaps, providing a buffer and defence to the limitations, shortfalls and barriers and therefore further enhancing their ability to cope. In this research, it was apparent in the hospital environment that it was the structure of whānau that facilitated effective coping pathways (not only for themselves but for other whānau and health care staff). The capacity to change with the context and times indicated that whānau as a vital cultural institution is highly adaptable which, according to L. Smith (1999), has been of pure necessity, not choice. While many whānau within the study were away from their homelands and familiar support systems, with limited members being present, their need for the familiar enhanced their resourcefulness in finding compatible alternatives. Where the physical presence of whakapapa whānau was absent, kaupapa whānau filled the role. Whānau cultural practices, roles and functions were critical to whānau surviving the system and fully participating in their child's care. The research confirms that coping with a child's critical illness impacts the whole family and not just its members but also

the structures, roles and functions incorporated within it (Miller & Caughlin, 2011; Revenson, 2003). Evidence from this research has shown the vitality and strength of Māori and Pacific whānau demonstrating their skill and resourcefulness as well as their exceptional ability to walk in multiple worlds.

There is limited research that looks at Māori and Pacific whānau coping pertaining to a child with a life-threatening medical condition. The use of kaupapa Māori and talanoa methodologies foregrounds Māori and Pacific worldviews and realities. The research outlines the barriers to whānau fully engaging in their child's care, and captures their coping mechanisms and strategies as a collective in order to combat barriers. Whānau were shown to draw on their own holistic system of care which included rituals of encounter; whānau processes, roles and functions. The findings of the study contribute to explaining how whānau survive the system despite it not being set up to cater to Māori and Pacific whānau needs. The study contributes to the work in the Whānau Ora space by providing evidence that whānau can self-manage, self-determine, and can articulate what they need to be healthy. The research reiterates that whāhau are cohesive, resilient and nurturing. The study highlights the impacts of determinants including racism, economic position, and health literacy (amongst others) that hinder whānau leading optimal healthy lives. The research demonstrates the vitality and strength of the whānau collective. The mechanisms and strategies drawn upon to overcome health system barriers enhanced whānau coping so they could fully participate in optimal health care provision for their critically ill child.

.

CHAPTER 8 - CONCLUSION

In this thesis, I have sought to answer the research objectives pertaining to Māori and Pacific whānau who were navigating the New Zealand health system while dealing with a child who has a life-threatening medical condition.

The research echoes evidence about racism and its impact on health (Barton & Wilson, 2008; Browne & Fiske, 2001; H. Moewaka Barnes et al., 2013; Walters et al., 2009; R. Harris et al., 2012a; 2012b). Racism, as identified in this thesis, also included structural factors such as power structures including specific people, positions, practice and policies. Moreover, racism was found to exclude, diminish and disempower key members of whānau and their associated cultural processes that promote and facilitate Māori and Pacific healing practices. These key issues remain of critical importance for whānau in being able to fully participate in their child's health care in a way that is conducive to their holistic needs.

The New Zealand health system reflects ongoing colonising processes. At a structural level, the government implements a top-down approach (i.e. government-sector-organisation-community-whānau) through strategies that are disjointed and have limited efficient and practical application at the whānau /patient level. System-based resources, while bountiful, were met with a multitude of barriers. Cultural resources incorporated within hospitals (such as cultural teams, Māori and Pacific workforce and cultural health models being implemented and visible through practice), while scarce, were further restricted by the very system that housed them. Māori and Pacific whānau were willing and able to draw upon their own system of care to meet their needs, but often came up against considerable difficulties. The dominance of the biomedical culture within a publicly-funded health system environment remains, with clinicians holding much of the power to either enhance or inhibit access to and distribution of, much-needed resources, effective models of care and culturally relevant and safe practice. Additional burdens are placed on whānau in not only having to deal with a critically-ill child, in a foreign environment away from their support systems but having to contend with diverse world views and health system inconsistencies across policies and practice. The environment in which health occurs needs to change. It is no longer acceptable for cultural elements to be added on as fragmented parts of programmes built on deficit approaches. In order for whānau to fully participate in the health system and society it will take:

- a focus on identifying and eliminating racist processes and outcomes
- increasing cultural competence of both the health workforce and the system
- increasing Māori and Pacific workforce at all levels
- a co-ordinated, supported and well-funded approach

There is evidence that transformation is occurring through various mechanisms that contribute toward health equity through a bottom-up approach (i.e. whānau -community-organisation-sector-government). These pathways highlight another version of *whānau filling the gap*, making the limited resources work to meet the needs to survive within various systems. These solutions are

being driven by Māori and Pacific peoples themselves in varying roles (for example, through teaching, clinical practice and management) using diverse methods (such as implementing cultural elements throughout university health programmes, medical schools and professional bodies).

Whānau within this research exhibited amazing resourcefulness in drawing upon innovative and familiar strategies to get their needs met despite having to work twice as hard and costing twice as much. Searching for the familiar and utilising what they had at their disposal became key to **surviving the system**. Cultural practices, processes and roles played a vital part in enhancing whānau coping. Whānau were seen to provide practical solutions to system-based problems that not only affected vulnerable whānau but their health care practitioners. This thesis has highlighted that whānau know what they need, to be and stay well, and, on one level, have the means to implement it. However, it is the barriers, restrictions, racism and lack of resources and support at all levels of the health system and society that impinges on Māori and Pacific whānau benefiting from full participation.

Original Contribution

Shudy et al. (2006) identified several gaps in their systematic literature review of 115 reports related to paediatric critical illness and injury on whānau. These included; cultural diversity of whānau, fathers and other member's perspectives additional to mothers, cultural perspectives, as well as alternative coping strategies and the incorporation of kaupapa whānau. While some traction has been made ten years on in some areas, gaps remain.

This research study contributes to, and builds on the limited existing literature regarding family/ whānau and coping. As well, it confirms and supports work currently being undertaken and implemented such as Whānau Ora. Cultural perspectives have been captured across many areas of this research. A non-deficit approach to sibling coping has been incorporated highlighting sibling contribution to the health and well-being of the whānau. The study also included the critical position of grandparents and recognised their role as primary caregivers outlining the difficulties they face within a Western-based hospital system. Māori and Pacific men revealed their experiences in relation to dealing with the hospital systems and processes as well as negative cultural assumptions from health care staff. Māori and Pacific whānau perspectives were presented in relation to the role and influence of Ronald McDonald House (a current gap in literature). The research confirms the multitude of barriers that exist for Māori and Pacific whānau when accessing health care, showing that whānau structures, processes and protocols are critical and an integral part of their coping and healing processes. The study has identified the various forms of communication and information that Māori and Pacific whānau require. It also provided a picture of whānau coping from those who had experience transitioning along the health care continuum. These whānau were well versed in encountering multiple admissions, staff, treatments and information while also dealing with inconsistencies in health care policies that impact on practice and therefore Māori and Pacific participation in health care provision. The research also demonstrated that whānau know what is needed to be well and stay healthy,

drawing on their own system of care to fill the gap, making up for the shortfalls at all levels of the health care system. In summary, the research provides a whole whānau coping perspective that incorporates views stemming from culture, gender, age, roles and functions within both traditional and contemporary whānau.

Meeting the Research Objectives

The study aimed to address two primary objectives:

1. What are the coping mechanisms and strategies employed by Māori and Pacific whānau who have experience in navigating the New Zealand health care continuum with a child with a life-threatening medical condition? and

2. What is the role and influence of Ronald McDonald House, Auckland on whānau coping?

The study's objectives were met by utilising qualitative methods informed by a paradigm net that incorporated Kaupapa Māori, and talanoa methodologies were employed for this research. The research was undertaken to ensure that Māori and Pacific whānau were at the forefront, allowing for effective engagement that enhanced the richness of data. Participants were a valid part of the whole research process and were kept up to date and informed throughout the study's duration. The researcher was also guided by both professional and personal support people who enabled the research to be carried out with integrity, honesty and credibility.

Limitations

Participant numbers for this study included 20 sets of whānau and ten sets of stakeholder participants. Numbers of men who took part were Māori (n=3) and Pacific (n=4). Greater male participation would enhance any future studies, particularly looking at a more extensive number and range of different Pacific cultures. Only two Pacific whānau came from out of New Zealand; it would be beneficial for any further research to consider incorporating research participants who were more widespread. Incorporating a larger, more extensive group would enhance the data and add more depth to the findings.

While those that were deemed supportive to whānau on their journey were interviewed, it would also be advantageous to incorporate those that contribute toward whānau challenges in the health system. Interviews of this type would then inform recommendations for the improvement of relevant services.

While my own specialists were happy to be interviewed, they were not identified by the participating whānau (a primary driver for this research). No clinicians were interviewed as part of this research. Further research may be enhanced by adding a clinician perspective. Interviewing clinicians would be beneficial considering their contribution regarding cultural responsiveness, cultural competence and cultural safety.

The Next Step

The next step in relation to this research will be to write up papers pertaining to the quantitative data collected and concentrate on publishing specific areas stemming from qualitative research within this study. In moving forward, an application will be submitted to try and obtain funding to develop and trial the hospital companion device (see recommendations) with a range of whānau who have been through a similar journey as part of postdoctoral research. It is hoped that the hospital companion can be developed and trialed with whānau and staff through Ronald McDonald House, Auckland, who provide a central location for a range of whānau with an international mix. It is also anticipated that the device could be trialled through Ronald McDonald Houses, Auckland, as a starting point

On a Personal Note

As a personal reflection at the end of this thesis, I think back on two significant journeys. The first, experiencing twice the transition along and navigation through the New Zealand health care continuum while being ever so conscious that my child might die. The second, re-living the experience 20 times over through interviewing and writing up findings from other whānau who had experienced a similar journey. In all honesty, both journeys brought with them a series of tears, sadness and a sense of loss. The grief was only partly due to our similar journeys and experiences but, mostly due to the racism that was found to exist at all levels of the health sector. The power behind the whānau produced strength, authority, resilience, consciousness and healing. I, like many others, entered the health system focused solely on doing what I could for my son so he would hopefully recover, despite the odds, and be as well as he could be. I knew the battle was hard and long, and it still is.

What I failed to realise, like so many other whānau in that situation at the time, was that the battle was made even more difficult by the systemic barriers I encountered to fully participate in his care. I truly struggled with this when it emerged from analysis of the data. I felt that as I was involved in Māori health research and has previously been a social worker for many years, I should have seen this implication at the time and done something about it then. In talking this out with my supervisor and mentor, she relayed to me that I too at the time was merely just trying to **survive the system**. This thesis is my step to doing the *something* on behalf of the twenty whānau interviewed and thousands of others that have and are still battling; this is for you!

Starship
Radiation
Optometrist
Paediatrician
Consult-Liaison
Speech-Language-Therapy E.D
Wilson-Home-and-Hospital
Surgery-two Neurology
Radiation
H.D.U Surgery-one Dental
MRI EAP
Peadiatric-Rehabilitation
Speech-Language-Therapy
Child-Cancer-Foundation
Northern-Health-School
Ronald-McDonald-House
Cultural-Support
Chemo Endocrinology
Koru-Care Chiropractor

CHAPTER 9 - RECOMMENDATIONS

This section outlines the wider application of the research findings with suggested recommendations that could improve Māori and Pacific whānau participation in their child's health care journey. While recommendations are directed at specific parts of the health system, they can also be applied generally.

Hospital and Related Services

Many barriers whānau experienced could be easily resolved by good will, better resources and practical application.

Recommendations include:

Clarity and Transparency of Information

Provide clear and transparent information in relation to critical resources and services. Provide information in a format that is engaging and understandable. Include information in other languages in verbal, written (hard copy), and electronic, via websites, form.

Build effective patient/whānau-practitioner relationships through the practical application of models of care at patient and whānau levels. Incorporate the family (which usually implies more than one individual) in quality discussions and decisions regarding their child's health care.

Investigate supplying personalised booklets for whānau that they could write in. Given that stress associated with their situation can cause them to forget as well, and that whānau usually arrive in an emergency and may not get time to leave the hospital, and given that bookshops within hospitals often contain expensive items.

Communication

Extend communication toward more than one family member even if they get involved by phone, so that there are at least two sets of eyes and ears hearing information.

Have a better efficient process for after-hours interpreting service particularly regarding an emergency. Better and more effective culturally appropriate communication and information will enable the whānau to be better informed to make critical decisions for their child. Consistencies and transparency in information across all levels will alleviate confusion and take the pressure off an already burdened workforce.

Relay information, as positively as possible in every circumstance. Refrain from referring to the child as their disease or condition and, when recommending caregivers have a break, refer to "having a break from the hospital or ward" rather than from the child itself, as it is deemed offensive.

A recommendation from the researcher is to have information hubs or Hospital Companions as seen in many Westfield malls. These incorporate touch screen monitors that contain relevant information such as maps that inform you where you are and how to get to a specific location and are similar to self-check-in kiosks used at the airport. A prototype based on touch screen interactive monitors could be developed and implemented within hospitals and relevant services (see Figure 30). The difference being these should be designed by patients and their whānau and be placed at appropriate locations within the hospitals, by lifts for example, or ideally on wards and or by cafes. Information hubs presented in touch screen form could be tailored to information 'whānau' identify as helpful and useful during their journey. They could also contain the information in different languages and have links to audio and visual material (similar to YouTube but on a smaller scale). Information in various languages is currently limited on health websites. The software and information (as it contains no personal information) could also be uploaded to a personal mobile device so whānau can have 24-hour access without leaving their child's bedside. The software would enable whānau to enter pertinent information on their devices, such as appointment times, names of specialists or addresses. The hospital companion would be developed with input from whānau, RMHC staff and a group comprising multi-cultural health workforce staff. The hospital companion is currently being discussed with the hope of further development as part of a postdoctoral research project.

Figure 30. Hospital Companion prototype

(R. Brown & Mills, 2017)

The findings highlight a wide range of information that whānau sourced to enhance their coping. Examples that could be integrated into the Hospital Companion are outlined in Table 22.

Table 22. Hospital Companion Sources of Information

Locations and maps	Outline
Internal wards, departments, support, marae, chapel, chaplain, kaumātua cafes, ATM, WINZ support, pharmacy, book shop	Where locations are situated, distance in minutes between locations, directions to each one.
External eateries, supermarket, ATM, banks, post shop, parks, transport modes, reviewed close quality accommodation options with reasonable prices	

Services and entitlements	
WINZ support, National Travel Assistance social work, Child Cancer Foundation, Ronald McDonald House,	Hours of service, phone numbers, addresses, what they can help with. Who to contact, how to get a referral.

Definitions	
Oncology or Oncologist Onkolagest	Phonetic spelling could be used to pull up a definition. Phonetic spelling could also occur in different languages. Information could also be sourced regarding who are the oncologists at the hospital, with a photo (this way if whānau forget a name they may well recognise a face).

The companion could also "push" notifications[17] such as wards in transition due to renovations, alternative and closer parking options, all in the language of the patient. As this research did not focus solely on the information needs of whānau, further research will be needed to identify specific user needs and information regarding their usability. Information and communication are a vital part of the health care equation. The transferability of information is needed in ways that patients can access it, understand it and usefully apply it. The three forms of information identified from findings (written, face to face and electronic) including the Hospital Companion, parent liaison/navigator and tailored written information can enhance whānau understanding of particular concepts or terms as they can be tailored to whānau needs and requirements.

Cultural Competency and Models of Care

Cultural competency and FCC training form part of an orientation package at Starship. Given the number of Māori and Pacific whānau who enter hospital systems, it would be advantageous for all staff, especially those from overseas, to know and expect that Māori and Pacific children come with a whānau (an extended family), they are collective and that they embrace shared care as part of that system.

---

[17] A **push notification** is a message that pops up on a mobile device.

Cultural context, family structure, process and protocols need to be taken into consideration when health care decisions are made. If there is a collective decision-making process then, where and when possible, sufficient time must be afforded so that the family can make the necessary decisions they feel best to meet patient and family health care needs. While some decisions, especially regarding children, need to be made quickly, a collective decision can still be achieved. For this to occur, however, there needs to be a willingness on the part of clinicians to offer or account for this by providing their time, appropriate space and other resources such as an interpreter or support services.

Ensure there is some form of cultural understanding, particularly around whānau shared care, collective values and practices, this will enhance not only practitioner understanding but also whānau relationships and better quality of care.

Acknowledge grandparents as key supports, and in many circumstances, the primary caregivers of the child and critical decision makers within whānau.

Recognise men do want to be actively involved in their child's care (despite challenges to be able to do so, such as having to work).

Acknowledge whānau have a voice, are skilled and knowledgeable, albeit different, and that they can make a significant contribution to care. It is hard enough for whānau who already feel guilty for the child being sick.

Recognise and support roles and functions within whānau acknowledging they play a critical part in health for Māori and Pacific whānau

It might be helpful if practices made it clear and were transparent regarding their FCC practice, just like other information portrayed within the hospital environment such as patient rights, mission statement and core values.

Whānau Designated Spaces

Review whānau designated space opportunities to see what is accessible and appropriate to meet both whānau and staff needs. The allocations of appropriate sized whānau -designated spaces could take the pressure off corridors and bedsides. The ability to use the space for meetings and cultural practices such as waiata and karakia brings resolution to a number of identified issues.

Policies and Health Sector

Recommendations include

A Co-ordinated approach

Consider a co-ordinated approach to enhance the critical and effective work already identified and implemented through universities, health programmes, medical schools and professional bodies to combat racism and provide a health workforce that genuinely embraces cultural diversity and understands history, context, backgrounds, positions and experiences.

Review of the National Travel Assistance Programme

Review the National Travel Assistance Programme particularly accommodation supplements to ensure it adequately meets whānau needs more effectively and efficiently.

Ronald McDonald House Charities

It is recommended that RHMC:

The Incorporation of Cultural Elements

Incorporate the Treaty of Waitangi throughout documentation and policies outlining how RMHC New Zealand makes meaningful commitment and contribution towards its implementation within the organisation.

Form a partnership with Ngāti Whātua collective who are the mana whenua of the area in which both RMHC Houses and Starship are located. A partnership is particularly pertinent as history identifies the land in which both the hospital and Houses are situated was gifted by the iwi (Disability Support Advisory Committee, 2016). A dedicated paid position as part of the partnership would be advantageous for both parties, providing cultural support, professional development, advice and potential business, sponsorship, links with other iwi and whānau-based opportunities. Likewise, for other RMHC around the country; for example, in Christchurch, establish a partnership with Ngāi Tahu, which would be advantageous for both parties.

As part of the recognition of the history and gifting of land and in consultation with Ngāti Whātua RMHC could name a wing/floor within their houses acknowledging the iwi or their tipuna (ancestors).

Reconsider Board positions to include members that reflect RMHC end user ethnicity.

Form Pacific related partnerships and relationships both inside Starship and externally, for example, Pacific Family Cultural Support, LeVa, AUT Pacific Island Family Study and community organisations near the houses and hospitals.

Establish an advisory group that is reflective of the ethnic makeup of whānau to assist staff and the organisation in tailoring policies, newsletters, pamphlets, and the environments to better reflect the cultural diversity of consumers. As well, provide advice at board and management levels regarding issues of relevance.

Small but effective steps would be to support and promote cultural language weeks, align activity for whānau with cultural celebrations (for example, Matariki, Diwali) and cooking by, for, and with culturally diverse whānau.

In addition to partnering with iwi, have an RMHC dedicated cultural support person in a paid position that is present in the houses, so whānau and staff have sufficient access to a well-needed resource.

Provide culturally relevant staff training as identified by staff members themselves.

Continue to make "culture" a regular part of organisation activity by incorporating wording and other associated icons into promotional and routinely developed resources and general correspondence.

Provide opportunities for whānau to be creative with, and share their culture through for example, once a month having a dedicated slot where whānau can teach, cook, share and join in (for example host different performances and/or different cultural events).

Ethnicity Data Collection

Continue with improvements regarding the collection of ethnicity data. A suggestion would be to align with ethnic groupings as outlined in the Ministry of Health's (2017) Ethnicity Data Protocols for the Health and Disability sector.

Increased Opportunities

Given the limited male staff presence, provide more opportunities for men to participate in and possibly lead initiatives within RMHC.

Create cultural opportunities that provide both healing, support, relaxing and learning such as, weaving, storytelling/story time for children utilising a similar process to Hospital Grandparents (Starship, 2017h).

Signage and Information

Continue to provide information including signage in different languages.

Ensure transparency of information within the hospital environments, particularly regarding the family rooms, location, day space, service and hours.

Implement, where realistically possible, the recommendations from whānau as per RMHC findings that included: more culturally reflective staff, signs in other languages, ethnic art, shuttle up and down the hill, marae-style room, dedicated meeting room, water feature, family room televisions, more extended lounge hours for family room residents.

Include feedback/suggestions regarding cultural elements within satisfaction surveys.

Areas for Further Research

As there were limited men involved in this study (seven), a suggestion would be to undertake more research that involves male experiences in the care of a life-threatening medical condition, including uncles, grandfathers, brothers, step-dads and fathers. It is particularly recommended to include Māori and Pacific men's viewpoints as there is a dearth of information that highlights their experiences and perspectives generally, and in particular, in relation to a child with a life-threatening medical condition.

The child's world view throughout the journey is a critical aspect to study. While this research gathered some information on the child's experience through the eyes of whānau, children were

not talked to directly due to ethics processes surrounding interviews. A recommendation to talk to children in these situations will help fill the gaps in this area.

While this research also intended to capture whānau who did not reside at RMHC, it was not the case. Research that includes whānau who met criteria but did not reside at RMHC will be able to add to data breadth. These whānau could provide insight into additional accommodation services or further inform research regarding reasons as to why their stay did not transpire.

At home care is an important topic to research given that supports take time to implement on discharge and whānau leave a system where they are wrapped in service and health care support for their child.

Research into the re-integration of the child to school was raised as an issue throughout interviews but was not the focus of this research. Limited supports were identified by whānau in relation to re-integration, and therefore further research on the topic would be valuable.

Research into the cost-benefit associated with RMH in relation to whānau being accommodated would be useful for both DHB, RMHC and whānau.

Research into the cost for whānau of transferring to hospitals outside their regions would be of interest and how this compares to the National Travel Assistance support given.

More research into the impacts of migration and dealing with the health system would be beneficial as there are some significant issues that need to be addressed and catered for.

APPENDICES

The following appendices reflect the original title of the project: ***Eat? Pray? Love! - What are the mechanisms and strategies Māori and Pacific whānau use to cope when confronted with a child's life-threatening medical condition***? *The title was changed on submission to reflect a more accurate description as revealed through findings and interpretations.*

Appendix A - AUT Ethics Approval Letter

E T H I C S   A P P R O V A L   L E T T E R

AUTEC
SECRETARIAT

29 July 2014

Denise Wilson
Faculty of Health and Environmental Sciences

Dear Denise

Re Ethics Application: **14/198 Eat? Love? Pray? What are the mechanisms and strategies Māori and Pacific whānau use to cope when confronted with a child's life-threatening medical condition?**

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

Your ethics application has been approved for three years until 29 July 2017.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/researchethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 29 July 2017;

- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/researchethics. This report is to be submitted either when the approval expires on 29 July 2017 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

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

Cc: Rachel Brown rbrown@hrc.govt.nz

Appendix B - Ngāti Whātua Ōrākei Consultation

30 October 2013

Mr Clay Hawke

Education Manager

Ngāti Whātua Maia Ltd

Tena koe e Clay

Re: Research project: Eat? Love? Pray! How do Māori and Pacific whānau cope when confronted with a child's life threatening medical condition?

Taranaki te maunga
Mohakatino te awa
Parihaka te marae
Te Atiawa mea Kai Tahu oku iwi
Ngāti Mutunga mea Tuahiwi oku hapu
Ko Rachel ahau

I wanted to let you know as Ngāti Whātua ki Ōrākei of my research intentions in fulfilling my PhD. I have condensed the information to outline the research aims, design and consultation. I am happy to provide additional information if you require it. I can also provide the ethics application intended for submission for AUT Ethics Committee (this is currently sitting with my supervisors).

Lay summary of the research proposed
The goal of my study is to explore how Māori and Pacific whānau cope when confronted with a child's life-threatening medical condition. The study will aim to (a) identify how whānau maintain well-being, and what coping mechanisms and or strategies are used and put in place (negative, positive, intentional, and unintentional); (b) consider the cultural implications of these; and (c) examine the impact services and resources may have had throughout the journey. 'Whānau' for the purposes of this study will include members that played a significant role in the child's journey and include kaupapa-based whānau (determined by whānau members themselves). The study will utilise a whānau centred research framework stemming from a 'whole family' perspective. It will look at how whānau members cope on two levels: an individual level (e.g. as a female, mother, partner, brother, grandmother) and; as part of the wider whānau group (e.g. as siblings, couples, parents, grandparents). The research will include Māori and Pacific families who have had access to Ronald McDonald House Auckland and Family Rooms and those who have not.

The context of the study stems from a personal journey of dealing with my child's life-threatening medical condition. At the age of seven my son was diagnosed with a cancerous brain tumour. It is through this personal journey that I realised that despite having extensive access to relevant resources, coping for me was at a bare minimum. The resources I had access to were, information, financial flexibility, treatment in the same location, good whānau support, flexible working arrangement, and having grounded knowledge of the New Zealand health system.

Over the long period of time that we were in Starship Hospital I became aware of the high number of Māori and Pacific whānau dealing with similar situations. Many of whom did not have the same access to information, resources and support. I began to question how do these whānau cope?

Potential areas that are of interest or concern for Māori
The project is focused on the strengths and abilities of whānau . The main outcomes are; for whānau to be the centre of the research, and that they contribute toward developing relevant and culturally appropriate whānau determined resources. The project aims to also work alongside services such as Ronald McDonald House to better meet the needs of Māori and Pacific families. The project is Māori led and is guided by an advisory group made up of relevant Māori and Pacific members. The project supervisors āre well respected in their fields and will provide overall guidance and mentorship of the applicant.

Design of the study
The research will be whānau centred (Jones, Ingham, Davies, & Cram, 2010) and will aim to provide a whole family perspective. It will look at the complexities for whānau of dealing with a child with a life-threatening medical condition in order to draw on their strengths and abilities. It will be informed by an Indigenous research paradigm underpinned by Māori and Pacific methodologies that incorporate Māori and Pacific beliefs, values and knowledge. It will utilise both quantitative and qualitative methods and adopt the analogy of a paradigm 'net' (Denzin & Lincoln, 1994; 2000), which brings together multiple components, including whānau, kaupapa Māori, talanoa, quantitative and qualitative approaches, as deemed relevant to the research and the participants.

Recruitment
Preliminary consultation with Starship, Ronald McDonald House staff and families through support groups confirm many people are ready and willing to talk about their journey once they have come to terms with the initial diagnosis and treatment has commenced. I observed similar indications from families in the hospital environment and from my own personal experience.

Whānau interviews
Up to 25 whānau will be recruited utilising purposeful sampling. It is envisaged that the majority of whānau members will be recruited through Māori and Pacific networks, Ronald McDonald House external and internal newsletters, Ronald McDonald family rooms networks and support groups, Starship's oncology, neurology and cardiac ward notice boards, Child Cancer Foundation and Make a Wish support networks, as well as my own personal networks formed through our journey. Most importantly participation will be voluntary. As whānau live in different cities, it is envisaged that the researcher will travel to interviews in their home towns. Whānau may wish to be interviewed in Auckland if they are here for specific appointments can be arranged prior.

Ronald McDonald House staff and parents at support groups helped to identify possible inclusion and exclusion criteria. **Inclusion criteria**: The inclusion criteria for whānau recruited into the study will include: whānau who are of Māori and/or Pacific Island descent, have a child that was diagnosed with a life-threatening medical condition, and be a medium to long-term patient who has utilised Starship Hospital within the last five years. **Exclusion criteria**: The exclusion criteria will include whānau whose child is newly diagnosed or recently passed in recognition that they are still coming to terms with the diagnosis or death and are under immediate undue stress.

Stakeholder interviews
Stakeholder interviews will be based on snowball sampling stemming mainly from recommendations from Ronald McDonald House staff, Child Cancer Foundation support workers, whānau members and Starship hospital staff.

I am currently enrolled at AUT as a provisional PhD student. I am well supported by my own whānau, and that of my husband's family who are Cook Island/Tahitian. I have three supervisors, Associate Professor Denise Wilson (Ngāti Tahinga – Tainui) who is Director for Taupua Waiora, Centre for Māori Health Research and has a background in nursing, Māori health and women's health; Dr Amohia Boulton (Ngāti Ranginui, Ngāi te Rangi, Ngāti Pukenga) is Co-Director for Whakauae Research Services in Whanganui and has expertise in governance, Māori health, health services and qualitative research and; Dr Elshadan Tautolo (Cook Island/Samoan) whose expertise is in Pacific health, family and men's studies. The research will also be guided by an Advisory Group made up of Māori and Pacific members. Members include kaumātua and Māori health researcher - Mr Tom Ruakere (Te Atiawa), clinician/researcher - Dr Matire Harwood (Ngā Puhi), whānau representation - Mr Popo Ben (Cook Island), Ronald McDonald House staff – Mrs Christine Marino (Ngāti Porou) and community person - Ms Jean Waters (Ngāti Kuri/Ngāti Kahu) and Pacific Community Worker - Ms Atitala Ah-yek (Samoa).

Collaborations
Ronald McDonald House and Family Rooms, Auckland (three locations) see letter attached from Chief Executive Mr Wayne Howett.

Consultation
Consultation has taken place with members of the Advisory Group, and I have also written to Mrs Naida Glavish via Ms Helen Wihongi, Research Advisor for Auckland and Waitemata District Health Boards, The Ngāi Tahu Research Consultation Group c/- Mr Mark Brunton, Research Advisor, Otago who will let me know if I need to also advise Te Runanga o Ngāi Tahu. An ethics application will be submitted to the AUT Ethics Committee prior to any research commencing.

Potential funding bodies
AUT University
Ministry of Health – Hauora Scholarships
Lotteries Commission

I welcome your input, advice and/or guidance regarding this research and can be contacted at the email and phone numbers below.

Nga mihi nui

Rachel Brown
rbrown@hrc.govt.nz
021933326

Appendix C - Ngāi Tahu – Representative Iwi Consultation

From: Khyla Russell [mailto:Khyla.Russell@op.ac.nz]
Sent: Tuesday, 13 May 2014 10:54 a.m.
To: Brown, Rachel
Subject: Fwd: Ethics for PhD

Kia ora Rachel,
Just a quick check in to acknowledge that you have followed up on my advice during our discussion on your research.
As part of the e,thics process, I suggested as a courtesy, that you get in touch with Mark Brunton at Otago University in his role regarding research consultation & ethics process for Ngai Tahu.

That body is made up of six appointees from the Otago Papatipu Runaka and constitute the Ngai Tahu Research Consultation Committee.
Though it was not a requirement by you to undertake this, it does give the Iwi information on their members and the research in which they are engaged.

As you have whakapapa to Ngai Tahu (Kai Tahu south of the Waitaki) it is a worthwhile & mutually beneficial to have undertaken.
This is especially important to the Iwi since your Tahu whakapapa sees you firmly placed in the centre of our rohe potae.

We regularly gain insight in the increasing numbers of our Iwi members at the very highest level of education & research.

No reira, I wish you every success on your confirmation path & will keep in touch as your PhD progresses Rachel.

Kati ra i konei e hine, tae noa ki te wa tauatahi hei tutaki a tinana mai.

Nahaku noa ,
Khyla

Professor Khyla Russell
Otago Polytechnic

Appendix D - Ngāi Tahu Research Consultation Committee

30 October 2013

Ngai Tahu Research Consultation Committee
Centre for Māori Development
University of Otago
P.O. Box 56
DUNEDIN

Tena koe e Mark

Re: Research project: Eat? Love? Pray! How do Māori and Pacific whānau cope when confronted with a child's life-threatening medical condition?

Ko Taranaki te maunga
Ko Mohakatino te awa
Ko Parihaka te marae
Ko Te Atiawa mea Kai Tahu oku iwi
Ko Ngāti Mutunga mea Tuahiwi oku hapu
Ko Rachel ahau

I have recently spoken to Professor Khyla Russell who suggested that I let you know of my research intentions in fulfilling my PhD. Professor Russell also said that you would be able to let me know whether you would recommend that I also write to Te Runanga o Ngai Tahu.

I have condensed the information to outline the research aims, benefits, design and consultation. I am happy to provide additional information if you require it.

Aims
The goal of my study is to explore how Māori and Pacific whānau cope when confronted with a child's life-threatening medical condition. The study will aim to (a) identify how whānau maintain well-being, and what coping mechanisms and or strategies are used and put in place (negative, positive, intentional, and unintentional); (b) consider the cultural implications of these; and (c) examine the impact services and resources may have had throughout the journey. 'Whānau' for the purposes of this study will include members that played a significant role in the child's journey and include kaupapa-based[18] whānau (determined by whānau members themselves). The study will utilise a whānau centred research framework stemming from a 'whole family' perspective. It will look at how whānau members cope on two levels: an individual level (e.g. as a female, mother, partner, brother, grandmother) and; as part of the wider whānau group (e.g. as siblings, couples, parents, grandparents). The research will include Māori and

---

[18] Based on Metge (1995) and refers to people who come together for a common purpose.

Pacific families who have had access to Ronald McDonald House[19] Auckland and Family Rooms and those who have not.

The context of the study stems from a personal journey of dealing with my child's life-threatening medical condition. At the age of seven my son was diagnosed with a cancerous brain tumour. It is through this personal journey that I realised that despite having extensive access to relevant resources, coping for me was at a bare minimum. The resources I had access to were, information, financial flexibility, treatment in the same location, good whānau support, flexible working arrangement, and having grounded knowledge of the New Zealand health system.

Over the long period of time that we were in Starship Hospital I became aware of the high number of Māori and Pacific whānau dealing with similar situations. Many of whom did not have the same access to information, resources and support. I began to question how do these whānau cope?

Benefits
This research has the potential to benefit multiple groups. Preliminary consultation with Ronald McDonald House staff and **whānau** members at support groups identified that being able to tell their story, share their experience, and look back and identify how they coped (or not) through particular phases of their journey can be a transformative process, even for those who have experienced a death of a child. It may aid them to be better equipped to cope in a variety of situations in the future both as an individual and as part of the family group. Secondly, the strategies identified may be a useful resource for others going through similar situations by confirming and relating experiences, strategies and resources (negative, positive, cultural, spiritual). Culture is an important element of health for Māori (Wilson & Barton, 2012) and Pacific (Medical Council of New Zealand, 2010) and can be overlooked, disregarded or neglected by health professionals or even families themselves when dealing with a Western-based health system (Wilson & Baker, 2012). Given the high negative health statistics for Māori and Pacific, it is critical that this research results in practical outcomes for families.

Health professionals will benefit by gaining a better understanding of the different family make-up, coping abilities and the varying strategies (particularly those that may be culturally associated). As well, having whānau-determined resources will enable better understanding for whānau members and health professionals, and therefore, more effective transition through and along the health care continuum.

Ronald McDonald House and Family Rooms staff and stakeholders will benefit on both a national and international level by the provision of information to better meet the needs of their service users, ,in particular, Māori and Pacific families; and identify any potential service gaps and possible future prospects while highlighting service benefits and advantages. It will provide a baseline for building evidence, as currently there are no studies in the published empirical literature that focus on the impact Ronald McDonald House (local, national and international) has on families. In addition, it will provide information for Ronald McDonald House for improvement of services to better meet the needs of their highest Auckland service users (Māori and Pacific).

Communities will benefit by becoming more aware of Ronald McDonald House and what families go through in order to better support, understand and provide assistance toward local families, including accessing relevant resources for Māori and Pacific.

---

[19] Ronald McDonald House Auckland mainly caters to families who live outside of Auckland and the Family Rooms cater to families whose children are in Paediatric Intensive Care Unit (PICU), Intensive Care Unit (ICU) or a High Dependency Units (HDU).

Researchers will benefit by having a study that looks at coping from a family perspective that relates to Māori, Pacific, children and life-threatening medical conditions. This will directly benefit the **child** and/or family of focus in their on-going journey.

In summary, the research will be translated into meaningful outcomes for Māori and Pacific whānau and their communities by development of; practical, cultural and relevant whānau - determined resources to: (a) help others in similar situations, and (b) provide assistance (training, toolkit, information) to health professionals and support service staff to better meet the needs of families. The research addresses a significant health issue looking at dealing with a child with a life-threatening medical condition, as well; it addresses current identified gaps pertaining to: a whole family perspective involving extended/blended families within the health system, Māori, Pacific and life-threatening medical conditions. In addition, it builds an evidence base for Ronald McDonald House on the impact it has on families and in particular; tailoring services to better meet the needs of service users. This can also be translated to other services and organisations in the future.

Design of the study
The research will be whānau centred (Jones, Ingham, Davies, & Cram, 2010) and will aim to provide a whole family perspective. It will look at the complexities for whānau of dealing with a child with a life-threatening medical condition in order to draw on their strengths and abilities. It will be informed by an Indigenous research paradigm underpinned by Māori and Pacific methodologies that incorporate Māori and Pacific beliefs, values and knowledge. It will utilise both quantitative and qualitative methods and adopt the analogy of a paradigm 'net' (Denzin & Lincoln, 1994; 2000), which brings together multiple components, including whānau, kaupapa Māori, talanoa, quantitative and qualitative approaches, as deemed relevant to the research and the participants.

Recruitment
Preliminary consultation with Starship, Ronald McDonald House staff and families through support groups confirm many people are ready and willing to talk about their journey once they have come to terms with the initial diagnosis and treatment has commenced. I observed similar indications from families in the hospital environment and from my own personal experience.

Whānau interviews
Up to 25 whānau will be recruited utilising purposeful sampling. It is envisaged that the majority of whānau members will be recruited through Māori and Pacific networks, Ronald McDonald House external and internal newsletters, Ronald McDonald family rooms networks and support groups, Starship's oncology, neurology and cardiac ward notice boards, Child Cancer Foundation and Make a Wish support networks, as well as my own personal networks formed through our journey. Most importantly participation will be voluntary.

Ronald McDonald House staff and parents at support groups helped to identify possible inclusion and exclusion criteria. **Inclusion criteria:** The inclusion criteria for whānau recruited into the study will include: whānau who are of Māori and/or Pacific Island descent, have a child that was diagnosed with a life-threatening medical condition[20], and be a medium to long-term patient who has utilised Starship Hospital within the last 5 years. **Exclusion criteria:** The exclusion criteria will include whānau whose child is newly diagnosed or recently passed in recognition that they are still coming to terms with the diagnosis or death and are under immediate undue stress.

---

[20] Life threatening for the purposes of this study means a medical condition that has at *some stage* threatened the life of the child and includes, short term, long term and terminal conditions. The study will also capture whānau who have lost a child to a life threatening medical condition.

Stakeholder interviews

Stakeholder interviews will be based on snowball sampling stemming mainly from recommendations from Ronald McDonald House staff, Child Cancer Foundation support workers, whānau members and Starship hospital staff.

I am currently enrolled at AUT as a provisional PhD student. I am well supported by my own whānau, and that of my husband's family who are Cook Island. I have three supervisors, Associate Professor Denise Wilson (Ngāti Tahinga – Tainui) who is Director for Taupua Waiora, Centre for Māori Health Research and has a background in nursing, Māori health and women's health; Dr Amohia Boulton (Ngāti Ranginui, Ngāi te Rangi, Ngāti Pukenga) is Co-Director for Whakauae Research Services in Whanganui and has expertise in governance, Māori health, health services and qualitative research and; Dr Elshadan Tautolo (Cook Island/Samoan) whose expertise is in Pacific health, family and men's studies. The research will also be guided by an Advisory Group made up of Māori and Pacific members. Members include kaumātua and Māori health researcher - Mr Tom Ruakere (Te Atiawa), clinician/researcher - Dr Matire Harwood (Ngā Puhi), whānau representation - Mr Popo Ben (Cook Island), Ronald McDonald House staff – Mrs Christine Marino (Ngāti Porou) and community person - Ms Jean Waters (Ngāti Kuri/Ngāti Kahu) and Mental Health and Addictions Working - Ms Atitala Ah-yek (Samoa).

Consultation has taken place with members of the Advisory Group and I have also written to Mrs Naida Glavish via Ms Helen Wihongi, Research Advisor for Auckland and Waitemata District Health Boards, The Ngāi Tahu Research Consultation Group and Mr Clay Hawke, Ngāti Whatua o Orakei. An ethics application will be submitted to the AUT Ethics Committee prior to any research commencing.

I am happy to have your input, advice and or guidance around this research and can be contacted at the email and phone numbers below.

Nga mihi nui

From:	Mark Brunton <mark.brunton@otago.ac.nz>
Sent:	Tuesday, 3 June 2014 11:13 a.m.
To:	Brown, Rachel
Subject:	RE: Ngai Tahu Research Consultation Committee feedback

Kia ora Rachel

Just back from three weeks leave and wading through the hundreds of emails. The Committee thought your approach, consultation and discussion with the relevant people in order to conduct this safely and in a cultu relevant way is to be commended.

Nāhaku noa, nā
Mark Brunton

MARK BRUNTON • KĀI TAHU, KĀTI MAMOE, WAITAHA
KAIWHAKAHAERE RAKAHAU MĀORI – RESEARCH MANAGER MĀORI
UNIVERSITY OF OTAGO • PO BOX 56 • DUNEDIN 9054, NEW ZEALAND
T: 03-479-8738 | C: 021-798-737 | E: mark.brunton@otago.ac.nz

Te Irika o Te Wharawhara Te Raki – Office of Māori Development
Office of the Vice-Chancellor

From: Brown, Rachel [mailto:RBrown@hrc.govt.nz]
Sent: Tuesday, 3 June 2014 10:38 a.m.
To: Mark Brunton

Appendix E - Pacific Consultation

13 May 2014

To Whom It May Concern

I am writing to inform you that the Cook Island community of Rakahanga – Manihiki support the research Ms Rachel Brown is intending to undertake as part of her PhD. We believe that her research will benefit Pacific communities and families that need support when their child is suffering from a life-threatening medical condition and are utilizing the New Zealand health system. We wish her well in her research and we aim to support it in any way possible.

Signed

Popo Bob Ben Ioakimo

Chairman - Rakahanga Sports
Committee Member – Rakahanga Henua

15 May 2014

As part of the Niue Church Community I am writing to confirm my support for Rachel Brown to do research that will help Pacific families who have been in hospital and been supported by Ronald McDonald House in relation to their sick child. I believe the research will be beneficial for all families especially Pacific.

Signed

Tolu Makakona

Appendix F - Inclusion/Exclusion Criteria

Inclusion/exclusion criteria

The inclusion criteria for whānau recruited into this study included:

- whānau who are of Māori and/or Pacific Island descent; and

- who had a child that was diagnosed with a life-threatening medical condition; and

- their child was a medium to long-term patient; and

- who accessed Starship Hospital within the last 5 years.

The exclusion criteria included whānau whose child was newly diagnosed or recently passed. This was in recognition that they were likely to be coming to terms with the diagnosis or death, and therefore, managing a high level of stress and anxiety.

Appendix G - Ronald McDonald House CE Support

Ronald McDonald House
AUCKLAND

10 May 2013

To Whom it may concern,

Re: Commitment of Support for Rachel Brown's PhD Study

On behalf of the Ronald McDonald House Auckland Trust I would like to express not only our support for Rachel's study, but our enthusiasm for it.

We are committed throughout its duration to provide whatever data, family contact, staff interview, supporting documentation or other needs which may arise, so far as we are able to, in a prompt timeframe for her.

Our organisation is service-led, and we are both encouraged by, and grateful for the research and insight, which will come from Rachel's work; and how this will be able to assist us in continuing to improve our service offering for the good of the New Zealand community.

Thank you and should you have any questions please don't hesitate to contact myself directly on 09 365 8302, or Stephanie who is Rachel's contact point on 09 365 8316.

Thank you.

Yours sincerely,

Wayne Howett
Chief Executive Officer

Eat? Love? Pray! (ELP)

Advisory Group

Terms of Reference

Version {2} {2013}

Background/Context

The goal of this study is to explore how Māori and Pacific whānau (family) cope when confronted with a child's life-threatening medical condition. The study will aim to (a) identify how whānau maintain well-being, and what coping mechanisms and or strategies are used and put in place (e.g. negative, positive, intentional, and unintentional); (b) consider the cultural implications of these; and (c) examine the impact services and resources may have had throughout the journey. 'Whānau' for the purposes of this study will include members that played a significant role in the child's journey and include kaupapa-based[21] whānau (determined by whānau members themselves). The study will utilise a whānau centred research framework stemming from a 'whole family' perspective. It will look at how whānau members cope on two levels: an individual level (e.g. as a female, mother, partner, brother, grandmother) and; as part of the wider whānau group (e.g. as siblings, couples, parents, grandparents). The research will include Māori and Pacific families who have had access to Ronald McDonald House[22] Auckland and Family Rooms and those who have not.

As the people involved in this study will be of both Māori and Pacific descent, it is necessary that the appropriate knowledge systems, tools and processes inform the research. Incorporation of these will appropriately guide the research and ultimately result in culturally relevant and practical outcomes for Māori and Pacific whānau .

Roles and functions of the ELP Advisory Group

The ELP Advisory Group will:

- provide strategic leadership and guidance to the PhD student Rachel Brown in the development, implementation and dissemination of the research project Eat?Love? Pray!
- provide cultural advice, support and assistance throughout the duration of the project
- assist in the promotion of a culture of community, health and well-being
- monitor identified and emerging risks and advise on their prevention, mitigation and management
- recognise barriers and enablers to whānau, the researcher and the project, and assist in developing initiatives to address these
- identify cultural needs

Role of individual group members

The role of the individual members of the ELP Advisory Group includes:

---

[21] Based on Metge (1995) and refers to people who come together for a common purpose.

[22] Ronald McDonald House Auckland mainly caters to families who live outside of Auckland and the Family Rooms cater to families whose children are in Paediatric Intensive Care Unit (PICU), Intensive Care Unit (ICU) or a High Dependency Units (HDU).

- attending regular meetings as outlined below

Once confirmation and approval has been granted
This first meeting will allow the researcher to update members on the research plan and on any changes that have been suggested. I will also use this time to seek advice and input on the ethics application including the interview schedule and consent forms. The meeting will also provide the opportunity for advisory committee members to raise any specific processes the researcher needs to think about and implement prior to data collection. Finally, this will also be a time for advisory group members to confirm their membership for on-going meetings.

Prior to data analysis
At this meeting, I will to report back on how the data collection method went, what issues if any were identified, and report on preliminary findings from the interviews.

To report back draft findings
The advisory group will then be convened once I have written up the draft findings. This will identify any potential risks posed from information that may not have been identified already, gaps or other considerations.

General

Membership

The ELP Advisory Group shall be comprised of:

Expertise regarding recruitment, interviewing, tikanga and risks and safety issues. Members of the group were recruited to ensure that all aspects of the research were covered, including whānau , Māori, Pacific, clinical, service and community representation.

Members	Representation
Ms Jean Waters	Māori/Community/Elder
Mr Tom Ruakere	Kaumātua/Māori health researcher
Dr Matire Harwood	Clinician, researcher
Ms Christine Marino	Ronald McDonald House staff
Mr Popo Ben	Whānau/Pacific/elder/community
Ms Atitala Ah-Yek	Pacific /whānau /Mental Health and Addictions Support Worker

Membership profiles

- **Ms Jean Waters (Ngāti Kuri/Ngāti Kahu) - Māori community/elder representative (CHAIR)**
  Jean Waters previously held the position of Patient Advocate under the Health and Disability Commission. She has experience in working with whānau within the health system and is currently a Justice of the Peace and a Funeral Director. Jean brings her many years of community experience and working with whānau coping with stressful and difficult situations to this advisory group. Jeans guidance will support the researcher and ensure whānau are not put at risk.

- **Mr Tom Ruakere (TeAtiawa) - Māori health researcher**
  Mr Tom Ruakere is a Māori health researcher currently based at AUT. He brings his Māori community expertise as well as his knowledge and experience of working in the health sector and with families coping with sick children. Tom has had many years' experience in working within Starship Hospital, as part of the cultural team and Wilson Home and Hospital where families (including those with life-threatening medical conditions) are admitted for intense rehabilitation. Tom will provide advice on tikanga within the context of the study, ensuring appropriate protocols are adhered to. He will also have input at stages of recruitment and analysis and ensure any cultural issues have been considered

- **Dr Matire Harwood (Ngā Puhi)** - **Clinician/researcher**
  Dr Harwood is Clinical Director for Tamaki Health care, a Māori-led PHO in Auckland, and has just completed her doctorate in rehabilitation medicine. Her work experience encompasses the fields of general practice, Hauora Māori, neuro-rehabilitation (stroke and traumatic brain injury) and respiratory medicine. She is Deputy Chair for Te Ohu Rata o Aotearoa (Māori Medical Practitioners Association), sits on the Board for Asthma and Respiratory Foundation for New Zealand, and served nine years on regional Health and Disability Ethics Committees. Dr Matire Harwood is a practising clinician and has experience in research and governance. Matire brings her medical and research knowledge to the project. Her skills and abilities as well as her networks will be of much value to the research.

- **Ms Christine Marino (Ngāti Porou) - Ronald McDonald House representative**
  Christine Marino is the Manager for Ronald McDonald Family Rooms, Auckland. Christine has been in this role for seven years and has first-hand knowledge of families dealing with children with life-threatening medical conditions. Her knowledge and networks of families, Ronald McDonald House, and community, is an asset to the research. Christine will help guide the recruitment process ensuring families are comfortable in participating, before during and after the interviews. Christine will also contribute greatly to the development of the interview questions and feedback at participant sessions.

- **Ms Atitala Ah-Yek (Samoa) - Pacific/ whānau representative**
  Atitala Ah Yek is a trained, qualified Art Therapist. Atitala has worked in the Counties Manukau region for over ten years with Māori and Pasifika clients and families. Atitala is currently employed at Oyssey House as Mental Health and Addictions practitioner within the residential alcohol and drug service.

- **Popo Ben (Cook Island) - Whānau representative/elder/community**
  Popo Ben is well known in the South Auckland Cook Island community. He represents Manahiki and Rakahanga Islands and is the Chair of the Rakahanga Sports Club. Popo Ben in his role in the community has been involved with several families with seriously sick children who have been admitted to Starship Hospital and have utilised Ronald McDonald House. Popo is happy to be part of the advisory group and support the research.

Other members may be included in the group as required.

Chair/Convenor

The group will be chaired by Ms Jean Waters.

Agenda items

All agenda items will be forwarded to the PhD student Rachel Brown by close of business ten working days prior to the next scheduled meeting.

The agenda, with attached meeting papers, will be distributed at least five working days prior to the next scheduled meeting.

Minutes and meeting papers

The minutes of each ELP Advisory Group Meeting will be prepared by PhD student Rachel Brown

Full copies of the minutes, including attachments, will be provided to all ELP Advisory Group Health and Well-being Working Group members no later than five working days following each meeting.

Frequency of meetings

The ELP Advisory Group Health and Well-being Working Group will meet three times a year at a time/day/month as agreed

Quorum requirements

A quorum will be half the regular membership plus one

Review

The effectiveness and membership of the ELP Advisory Group will be reviewed after 12 months.

Participant Information Sheet

Date Information Sheet Produced:

13 June 2014

Project Title

Eat? Love? Pray! What are the mechanisms and strategies Māori and Pacific whānau use to cope when confronted with a child's life-threatening medical condition?

An Invitation

Kia ora, Kia orana, Malo e lelei, Talofa lava, Ni sa bula vinaka, Fakalofa lahi atu.

My name is Rachel Brown; I am Māori of Te Atiawa and Ngāi Tahu descent. I am currently studying towards my PhD at Taupua Waiora, Centre for Māori Health Research at AUT. I am being supervised by Associate Professor Denise Wilson (Ngāti Tahinga – Tainui), Dr Amohia Boulton (Ngāti Ranginui, Ngāi te Rangi, Ngāti Pukenga) and Dr El-Shadan Tautolo (Cook Island/Samoa). This research will contribute toward my PhD qualification, but it is also a subject dear to my own heart, having had a child that was diagnosed with a life-threatening medical condition.

I would like to invite you to take part in this study about how you and your family (whānau /Āiga) coped during the child's journey. For my study, life-threatening means a medical condition that has at *some stage* threatened the life of a child and includes short-term, long-term and terminal conditions. This condition may or may not still be affecting your child today.

If you are a Māori or Pacific family member who has had or known a child diagnosed with a life-threatening medical condition in the last 5 years, and the child has been admitted to Starship Hospital, I would like to talk to you about how you and your family coped. You and/or your family's participation in this study, is voluntary, and you can choose to withdraw your information or yourself from the research at any time.

What is the purpose of this research?

The purpose of this research is to explore how you as Māori and Pacific family members cope when dealing with a child's life-threatening medical condition. I intend to identify the strengths and abilities families have through this journey with their child. I also want to seek information on coping that may be helpful to other families in similar situations. I am hoping that through this research health professionals, services and families may have a better understanding of Māori and Pacific coping mechanisms and strategies. This may help them to tailor services and care to better meet Māori and Pacific needs. It is likely that publications, presentations and resources will be an outcome of this research,, in this case, any personal information will not be identifiable.

How was I identified and why am I being invited to participate in this research?

We are contacting you as you may have indicated that you and/or your family wish to be involved in the study. You may have seen the advertisement in selected newsletters or on noticeboards through support organisations or you may have been told through your support networks or other family members. We are looking at talking to Māori and Pacific families that have dealt with a child with a life-threatening medical condition and have utilised Starship Hospital in the last five years. We are excluding any families whose child is newly diagnosed or has recently passed. We recognise that families are still coming to terms with this and do not want to place any further stress on them.

What will happen in this research?

If you are a Māori or Pacific family member that has been involved with a child with a life-threatening medical condition who has utilised Starship in the, last five years, then I will make contact with you to arrange to meet to talk with you and possibly other family members about your journey.

This will take approximately 60-90 minutes and will be recorded to ensure I have accurate information. You can bring a support person with you and/or other whānau /Āiga members who may also wish to participate. We can meet and talk at a place of your choosing, and I can also arrange a translator if you would like to talk in your own language. This choice is yours. These details will need to be confirmed prior to meeting so I can ensure the place, time and resources are available. You can choose to talk as a group (up to 4 people maximum at one time to ensure everyone has a chance to have their say) or you can talk one person at a time on the same or a different day. Everyone who agrees to be involved will need to sign a consent form giving permission for me to talk to them and to involve their information in the research.

Over the time of, the research, there will be opportunities for me to meet with you again to ensure that I have recorded and written your story correctly. It will also be a chance for you to be updated about where the research is at and ask any further questions.

You will be given a $50 voucher as a token of appreciation in recognition of your time and input into the research.

What are the discomforts and risks?

I realise that telling your story can be very distressing and it may bring up different feelings related to both you and your child's journey. At any time, you can stop the recording of your story, and you can choose to withdraw your information. We can take a break or make another time if you wish to continue. You will be given numbers of support people that may be able to help if things come up before, during or after the interview (this will be at no cost to you). AUT Counselling Services can offer, this service, and I can also contact your support person through any of the participating support agencies (if you wish).

If you need to contact AUT Counselling Services you can phone the AUT free calling number **0800 288 864**. You will need to ask for the counselling service or alternatively you can call them direct (09) 921-9992 City or (09) 921-9998 North Shore. They will need to know your contact details and that you are part of this research. More information can be found at the following website address www.aut.ac.nz/students/student_services/health_counselling_and_well-being.

What are the benefits?

The benefits of being involved in this research are to help other families like yours in similar situations, and to provide information that will help toward the development of resources. It may also help health professionals and support services to tailor services and practice to better meet Māori and Pacific family needs.

How will my privacy be protected?

Your privacy will be protected by your information being coded so that it is unidentifiable to anyone else except me as the researcher and my supervisor Associate Professor Denise Wilson. You will be given a chance to see what you have said in your interview and can change or withdraw any information at any time. Please note your ethnicity, gender and age bracket may be used in the report. This is an example; Māori male aged over 40 years of age.

What are the costs of participating in this research?

It is anticipated that in telling your story may take some time, a timeframe of between 60-90 minutes has been estimated. This may take longer depending on how many people are present and want to be part of your interview. Another time can be scheduled if you want to talk further.

What opportunity do I have to consider this invitation?

Contact, will be made, and information will be sent to you for your consideration at least three weeks prior to making an appointment to meet. At the time of the appointment I can go through the information with you, and at any time you can consider withdrawing from the research.

How do I agree to participate in this research?

A copy of the consent form will be sent to you with all the information you will need. Once a time has been confirmed I will go through the information and the consent form. You will need to sign the consent form. This gives permission for me as the researcher to talk with you and record your information. All those that want to be involved will need to sign a consent form.

Will I receive feedback on the results of this research?

There will be different opportunities to get feedback at different times of the research. These will be outlined in the consent form where you can pick a range of different options on how you would like to receive this. Examples of options include; attendance of hui/meetings, newsletter, email, or text.

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

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Associate Professor Denise Wilson via email dlwilson@aut.ac.nz or by phoning (09) 921- 9999 extension 7392

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz (09)*, 921 9999 extension 6038.

Whom do I contact for further information about this research?

Researcher Contact Details:
Rachel Brown
021 933326 or on
0800 XXX XXX *(waiting on a 0800 to be established through Taupua Waiora)*
Email: māoriandpacificresearch@gmail.com

Project Supervisor Contact Details:

Primary Supervisor:	Secondary Supervisor:
Associate Professor Denise Wilson	Dr Amohia Boulton
Taupua Waiora Centre for Māori Health Research Services	Whakauae Research
Faculty of Health and Environmental Sciences, AUT	Whanganui
Email: denisel.wilson@aut.ac.nz amohia@whakauae.co.nz	Email:

Phone: (09) 921 – 9999 ext 7392   Phone: (06) 3476772
0800 AUT UNI (**0800** 288 864)

Pacific Supervisor:
Dr El-shadan Tautolo
Associate Director, Pacific Islands Families (PIF) Study
Email: dtautolo@aut.ac.nz
Phone: (09) 09 921 9999 ext. 7527
0800 AUT UNI (**0800** 288 864)

Consent Form

AUT
UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Project title: **Eat? Love? Pray! What are the mechanisms and strategies Māori and Pacific whānau use to cope when confronted with a child's life-threatening medical condition?**

Project Supervisor: **Associate Professor Denise Wilson**

Researcher: **Ms Rachel Brown**

○ I have read and understood the information provided about this research project in the Information Sheet dated 13 June 2014.

○ I have had enough time to consider the information and have been provided with an opportunity to ask questions and to have them answered.

○ I understand that notes will be taken during the interviews and that they will also be recorded and transcribed (written word for word).

○ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

○ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

○ I agree to take part in this research.

○ I wish to be kept updated about the progress of the research   Yes ○   No○
by email ○ txt ○ newsletter ○ hui/meeting ○ or other please identify
_____

○ I wish to receive a copy of the report from the research (please tick one): Yes ○   No ○

Participants signature:

....……………………………………………………………

Participants name:

....……………………………………………………………

Participants contact details (if appropriate):

…………………………………………………………………………………………..

…………………………………………………………………………………………..

…………………………………………………………………………………………..

………………………………………………………………………………………..

Date:

Parent/Guardian

Consent Form

AUT
UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Project title: **Eat? Love? Pray! What are the mechanisms and strategies Māori and Pacific whānau use to cope when confronted with a child's life-threatening medical condition?**

Project Supervisor: **Associate Professor Denise Wilson**

Researcher: **Ms Rachel Brown**

○ I have read and understood the information provided about this research project in the Information Sheet dated 13 June 2014.

○ I have had enough time to consider the information and have been provided with an opportunity to ask questions and to have them answered.

○ I understand that notes will be taken during the interviews and that they will also be recorded and transcribed (written word for word).

○ I understand that I may withdraw my child/children and/or myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

○ If my child/children and/or I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

○ I agree to my child/children taking part in this research.

○ I wish to be kept updated about the progress of the research   Yes○   No○
by email ○ txt ○ newsletter ○ hui/meeting ○ or other please identify
_____

○ I wish to receive a copy of the report from the research (please tick one): Yes○   No○

○ I have read and understood the information provided about this research project in the Information

Child/children's name/s :..…………………………………………………………………

Parent/guardian's signature:............…………………………………………………….

Parent/guardian's name:...............…………………………………………………………

Parent/guardian's contact details (if appropriate):

…………………………………………………………………………………………..

…………………………………………………………………………………………..

…………………………………………………………………………………………..

Date:

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

Whānau pre-thinking sheet
Some things to think about before the interview

Think about

What are the things that got you and your whānau through or helped you manage throughout your journey

Here are some examples;
- coffee
- having a family member there with you
- knowing your other children are being looked after
- taking a walk
- getting a massage
- being near the water
- prayer
- reading

1. Think about the **strengths** you saw in one another
   - For example, what strengths did you see in the child's mother/grandmother/uncle

2. Think about what this journey has taught you as an individual and as a whānau
   - For example 'life is too short' or 'whānau time is more valuable now.'

3. Can you think of something that symbolizes this journey?
   - For example, a phrase, song, verse, a child's favourite toy, a colour or a significant place

Appendix L - Research Project Advertisement

Māori and Pasifika input into research

Kia Ora, Kia Orana, Malo e Lelei Talofa, Ni Sa Bula Vinaka

Are you of Māori or Pasifika descent?

Have you or your family dealt with a child with a life-threatening medical condition?

A condition that has at some stage threatened the life of the child – short, medium or long term

Have you been involved with Starship Hospital because of the child's condition?

Has Starship involvement been in the last 5 years?

If you have answered YES then we would like to invite you to take part in this research. The research will look at the strengths of families and how they cope while dealing with a child's life-threatening medical condition.

Contact: **Rachel Brown**
0800 XXX or 021933326
Email: maoriandpacificresearch@gmail.com

Appendix M - Stakeholder Interview Schedule

Stakeholder Indicative Questions

1. Tell me a bit about your role and how you work with families who are dealing with a child with a life-threatening medical condition

2. Tell me how you see how families cope through this time

3. What are some of the coping mechanisms or strategies you see them use

4. What are some of the unique strategies you may have seen

5. Do mechanisms and strategies differ for different cultures

6. What are the strengths you see in the individuals/families

7. What stands out to you about the families who are coping with a child with a life-threatening medical condition

8. Is there anything you can identify that may aid families better in these situations (health system, services, resources)

9. Do you refer families to RMH or any other service during your contact with them?

Appendix N - Whānau Interview Schedule

Questions for participants

The aim is for questions to be open-ended as much as possia ble

1. Tell me a bit about your family (makeup, e.thnicity, etc.)

2. Tell me about your child's journey

3. Tell me how you or your whānau /community managed/got through (during this time) (would you see this as a strength/ coping mechanism)

4. Tell me how this impacted on you as a …(mother, brother, sister)

5. How did this impact on you as part of the wider whānau?... (parents, grandparents, siblings, negative, positive, cultural impacts

6. Who are the people who played a significant role in your child's journey? (family, community, church, school)

7. What helped you cope during this time (services, social media, support)

8. What was not helpful to you/your whānau

9. What was valuable for you/your whānau in regard to this journey? (Lessons learned, life is too short,).

10. Tell me what strengths you saw in each other (as a couple, whānau, as a mother, grandmother)

11. Tell me about any information/resources/services you found useful.

12. How did these help you? (if not mentioned above)

13. Was/is there anything different (positive or negative) that you would have found helpful (regarding information/services/resources)?

14. Did you use Ronald McDonald House or Family rooms (? (see if they raise this above)

    - if **No** – What do you know about RMH or Family rooms?

    - if **Yes** – tell me about the role RMH played for you and/or your family.

15. Is there anything more or different you would like to see RMH do in the future? (water feature, special garden)

16. Lastly, is there something significant that symbolizes your journey (photo, toy, phrase, description) – Rainbow, bead, blanket

17. Is there **anything** you would like to add?

Appendix O - Check List Protocol

Things to remember…	√	Notes
Karakia (me)		
Is the interviewee male or female? Older/younger? Individual or group?		
Is an interpreter needed?		
Has the research been clearly explained?		
Has a time/day/venue been set?		
What follow up needs to done prior?		
Have I got the necessary tools/resources needed?		
What cultural resources might be needed?		
Check consents explained and signed		
Check how and what participants want their feedback/transcripts/reports		
Opening and closing of interviews		
What safety protocols are needed to be implemented?		
Check koha obtained		
Whānau story first		
Ensure whānau are empowered to share/stop		
Ask if they need anything further – show phone number/counselling number		
Check up later esp if interview was upsetting		
Write my observations/feelings		
Share with supervisor/counsellor to debrief		
Karakia (me)		

Appendix P - Researcher Safety Protocol

Researcher Safety Protocol

Where possible the researcher will undertake to interview whānau members and stakeholders in a privately public place (e.g. Ronald McDonald Family Rooms – quiet room, Ronald McDonald House library, café or public library).

It is noted that this is will not always be possible, and this safety protocol will be used for alternative venues such as private homes.

A. Physical Safety

- The researcher will where indicated by the family take a kaumātua/kuia or translator with her to interviews. This will be discussed on contact to set up an interview and will be pre-arranged with permission of the family (Confidentiality forms will be signed).
- The researcher will inform the primary supervisor of the schedule for the interviews, including time, date, address and who will be interviewed.
- The researcher will use phone/text the supervisor pre-and post-interview. If the researcher fails to call or text post-interview, the supervisor will call the researcher. If there is no reply within 15 minutes, the supervisor will notify the Police.

B. Emotional Safety

- The researcher might be emotionally at risk if the interview was particularly difficult. In these situations, the researcher will request a debriefing session with the supervisor.
- The researcher will also have in place her own support network, including access to the Consult Liaison Team through Starship and AUT Counselling Services to deal with particularly difficult issues that may arise.

Approved by the Auckland University of Technology Ethics Committee on type the date on which the final approval was granted AUTEC Reference number type the AUTEC reference number

REFERENCES

Abraham, M., & Moretz, J. G. (2012). Implementing patient- and family-centred care: Part I-Understanding the challenges. *Pediatric Nursing, 38*(1), 44-47.

ACC. (2004). Summary Guidelines on Māori Cultural Competencies for Providers. Wellington: ACC.

Acosta, D., & Olsen, P. (2006). Meeting the needs of regional minority groups: The University of Washington's programs to increase the American Indian and Alaskan native physician workforce. *Academic Medicine, 81*(10), 863-870. http://dx.doi: 10.1097/01.ACM.0000238047.48977.05

Adams, J. (2011). Building cultural competence: The Medical Council's direction. *Best Practice Journal 37*, 18-21. Retrieved from http://www.bpac.org.nz/BPJ/2011/august/cultural _comp.aspx

Adler, N. E., & Stewart, J. (2010). Health disparities across the lifespan: Meaning, methods, and mechanisms. *Annals of the New York Academy of Sciences, 1186*(1), 5-23. http://dx.doi:10.1111/j.1749-6632.2009.05337.x

Ajwani, S., Blakely, T., Robson, B., Tobias, M., & Bonne, M. (2003). *Decades of disparity: Ethnic mortality trends in New Zealand 1980-1999.* Wellington, New Zealand: Ministry of Health and University of Otago.

Albuquerque, S., Pereira, M., & Narciso, I. (2016). Couple's relationship after the death of a child: A systematic review. *Journal of Child and Family Studies, 25*(1), 30-53. http://dx.doi:10.1007/s10826-015-0219-2

Alderfer, M. A., Navsaria, N., & Kazak, A. E. (2009). Family functioning and posttraumatic stress disorder in adolescent survivors of childhood cancer. *Journal of Family Psychology, 23*(5), 717. http://dx doi10.1037/a0015996

Ali, N. K., Ferguson, R. P., Mitha, S., & Hanlon, A. (2014). Do medical trainees feel confident communicating with low health literacy patients? *Journal of Community Hospital Internal Medicine Perspectives, 4*(2). http://dx.doi.org/10.3402/jchimp.v4.22893

American Medical Student Association. (2007). *Promoting, reinforcing, and improving medical education culture and diversity curriculum.*

Anhang Price, R., Elliott, M. N., Zaslavsky, A. M., Hays, R. D., Lehrman, W. G., Rybowski, L., . . . Cleary, P. D. (2014). Examining the role of patient experience surveys in measuring health care quality. *Medical Care Research and Review, 71*(5), 522-554. http://dx.doi10.1177/1077558714541480

Arlidge, B., Abel, S., Asiasiga, L., Milne, S. L., Crengle, S., & Ameratunga, S. N. (2009). Experiences of whānau /families when injured children are admitted to hospital: A multi-

ethnic qualitative study from Aotearoa/New Zealand. *Ethnicity & Health, 14*(2), 169-183. http://dx.doi.org/10.1080/13557850802307791

Arnett, J. J. (1995). Broad and narrow socialization: The family in the context of cultural theory. *Journal of Marriage and the Family*, 617-628. http://dx.doi.org/10.2307/353917

Arockiasamy, V., Holsti, L., & Albersheim, S. (2008). Fathers' experiences in the neonatal intensive care unit: A search for control. *Pediatrics, 121*(2), e215-e222. http://dx.doi10.1542/peds.2007-1005

Arowolo, D. (2010). The effects of Western civilisation and culture on Africa. *Afro Asian Journal of Social Sciences, 1*(1), 1-13.

Auckland Doctors. (2013). *Starship Children's Hospital health: Auckland District Health Board.* Retrieved from http://www.aucklanddoctors.co.nz/hospitals/starshipchildrenshospital/

Auckland District Health Board. (2017). *Support Services*. Retrieved from http://www.adhb.health.nz /our-services/support-services/-Interpretingservices

Auckland District Health Board. (n.d.-a). *Communication cards*. Retrieved from http://www.adhb.health.nz/health-professionals/resources/communication-cards/

Auckland District Health Board. (n.d.-b). *How to request a service.* Retrieved from https://interpreters.adhb.govt.nz/(S(p5i2d4liklvxffnoh4qeflvp))/RequestAService.aspx

Auckland Regional Council. (2008). Economic Futures for the Auckland Region. Author

Aydon, L., Hauck, Y., Murdoch, J., Siu, D., & Sharp, M. (2017). Transition from hospital to home: Parents' perception of their preparation and readiness for discharge with their preterm infant. *Journal of Clinical Nursing.* http://dx.doi.org/10.1111/jocn.13883

Azoulay, E., Pochard, F., Chevret, S., Lemaire, F., Mokhtari, M., Le Gall, J.-R.,Schlemmer, B. (2001). Meeting the needs of intensive care unit patient families: A multicenter study. *American Journal of Respiratory and Critical Care Medicine, 163*(1), 135-139. https://doi.org/10.1164/ajrccm.163.1.2005117

Bacal, K., & Jansen, D. (2006). *Best outcomes for Pacific peoples: Practice implications*. Retrieved from https://www.mcnz.org.nz/news-and-publications/guides-and-booklets/

Baker, C. (2007). Globalization and the cultural safety of an immigrant Muslim community. *Journal of Advanced Nursing, 57*(3), 296-305. http://dx.doi10.1111/j.1365-2648.2006.04104

Baker, K. (2010). *Whānau Taketake Māori: Recessions and Māori resilience: A report for the Families Commission*. Wellington, New Zealand: Families Commission. http://dx.doi:10.1111/j.1365

Bakker, A., Van der Heijden, P. G., Van Son, M. J., van de Schoot, R., Vandermeulen, E., Helsen, A., & Van Loey, N. E. (2014). The relationship between behavioural problems in preschool children and parental distress after a paediatric burn event. *European Child & Adolescent Psychiatry, 23*(9), 813-822. http://dx.doi10.1007/s00787-014-0518

238

Ball, J. (2010). Indigenous fathers' involvement in reconstituting "circles of care". *American Journal of Community Psychology* 45(1-2), 124-138.Bacal, K., & Jansen, D. (2010). *Best outcomes for Pacific Peoples: Practice implications*. Wellington, New Zealand: Medical Council of New Zealand. http://dx.doi10.1007/s10464-009-9293

Barrera, M., O'connor, K., D'Agostino, N. M., Spencer, L., Nicholas, D., Jovcevska, V., Schneiderman, G. (2009). Early parental adjustment and bereavement after childhood cancer death. *Death Studies, 33*(6), 497-520. http://dx.doi10.1080/07481180902961153

Barton, P. (2008). *'A kind of ritual Pakeha tikanga'–Māori experiences of hospitalisation: A case study* (Unpublished master's thesis). Massey University, Albany, New Zealand.

Barton, P., & Wilson, D. (2008). Te kapunga putohe (the restless hands): A Māori centred nursing practice model. *Nursing Praxis in New Zealand, 24*(2). **DOI**: http://dx.doi.org/10.1016/j.nepr.2011.12.004

Bathgate, M., Alexander, D., Mitikulena, A., Borman, B., Roberts, A., & Grigg, M. (1994). *The health of Pacific Islands people in New Zealand.* Wellington, New Zealand: Public Health Commission.

Baxter, J. (2002). *Barriers to health care for Māori with known diabetes: A literature review and summary of the issues.* Te Roopu Rangahau Hauora a Ngai Tahu.

Beach, M. C., Price, E. G., Gary, T. L., Robinson, K. A., Gozu, A., Palacio, A., Bass, E. B. (2005). Cultural competency: A systematic review of health care provider educational interventions. *Medical Care, 43*(4), 356-373.

Beagan, B. L. (2003). Teaching social and cultural awareness to medical students: "It's all very nice to talk about it in theory, but ultimately it makes no difference." *Academic Medicine, 78*(6), 605-614. http://dx.doi10.1186/1472-6963-7-15

Bear, L. L. (2000). Jagged worldviews colliding. In M. Battiste (Ed.), *Reclaiming Indigenous voice and vision* (pp. 77-85). Vancouver, Canada: UBC Press. http://dx.doi10.1080/09515070802066847

Beckman, P. J., & Bristol, M. M. (1991). Issues in developing the IFSP: A framework for establishing family outcomes. *Topics in Early Childhood Special Education, 11*(3), 19-31. http://dx.doi.org/10.1177/027112149101100304

Bellamy, G., & Gott, M. (2013). What are the priorities for developing culturally appropriate palliative and end-of-life care for older people? The views of health care staff working in New Zealand. *Health & Social Care in the Community, 21*(1), 26-34. http://dx.doi:10.1111/j.1365-2524.2012.01083

Bellon-Harn, M. L., & Garrett, M. T. (2008). Vision: A model of cultural responsiveness for speech-language pathologists working in family partnerships. *Communication Disorders Quarterly, 29*(3), 141-148. https://doi.org/10.1177/1525740108315879

Bennett, K., Smith, D. H., & Irwin, H. (1999). Preferences for participation in medical decisions in China. *Health Communication, 11*(3), 261-284.

 http://dx.doi.org/10.1207/S15327027HC110308

Berkman, ND., DeWalt, DA., Pignone, MP., Sheridan, SL., Lohr, KN., Lux, L., Bonito, AJ. (2004). Literacy and health outcomes. *Evidence Report/Technology Assessment, 87*, 1-8.

Berry, J. G., Hall, M., Hall, D. E., Kuo, D. Z., Cohen, E., Agrawal, R., Neff, J. (2013). Inpatient growth and resource use in 28 children's hospitals: A longitudinal, multi-institutional study. *JAMA Pediatrics, 167*(2), 170-177. http://dx.doi10.1001/jamapediatrics.2013.432

Berube, K. M., Fothergill-Bourbonnais, F., Thomas, M., & Moreau, D. (2014). Parents' experience of the transition with their child from a pediatric intensive care unit (PICU) to the hospital ward: Searching for comfort across transitions. *Journal of Pediatric Nursing, 29*(6), 586-595. http://dx.doi10.1016/j.pedn.2014.06.001

Betman, J. (2006). *Parental grief when a child is diagnoised [ie diagnosed] with a life-threatening chronic-illness: The impact of gender, perceptions and coping strategies* (Unpublished master's thesis). University of Canterbury, Christchurch, New Zealand.

Bevan-Brown, J. (1998). By Māori, for Māori, about Māori–is that enough. T. P. *Hauora (Ed.), Proceedings of Te Oru Rangahau: Māori Research and Development Conference* (pp. 231-246). Palmerston North, New Zealand: Massey University.

Billow, R. H. (2011). *A qualitative investigation of the strategies used by a sample of Native American older adults to cope with race-related stressors* (Unpublished doctoral dissertation). University of Montana.

Billups, F. (2014). The quest for rigor in qualitative studies: Strategies for institutional researchers. *The NERA Researcher*.

Birman, D. (2006a). Acculturation gap and family adjustment: Findings with Soviet Jewish refugees in the United States and implications for measurement. *Journal of Cross-Cultural Psychology, 37*(5), 568-589. http://dx.doi10.1177/0022022106290479

Birman, D. (2006b). Measurement of the" acculturation gap" in immigrant families and implications for parent-child relationships. In M. Bornstein & L. Cotes (Eds.), *Acculturation and parent child relationships: Measurement and development* (pp. 113-134). Mahwah, NJ: Erlbaum. http://dx.doi10.1177/0265407506064207

Bishop, R. (1997). Māori people's concern about research into their lives. *History of Education Review, 26*(1), 25-41.

Bishop, R. (1998). Freeing ourselves from neo-colonial domination in research: A Māori approach to creating knowledge. *International Journal of Qualitative Studies in Education, 11*(2), 199-219. http://dx.doi.org/10.1080/095183998236674

Bishop, R., & Glynn, T. (1992). He Kanohi Kitea: Conducting and evaluating educational research. *New Zealand Journal of Educational Studies*, 125-135.

Blakely, T. J., Harding, J. S., Mcintosh, A. R., & Winterbourn, M. J. (2006). Barriers to the recovery of aquatic insect communities in urban streams. *Freshwater Biology, 51*(9), 1634-1645.

Blume, E. D., Balkin, E. M., Aiyagari, R., Ziniel, S., Beke, D. M., Thiagarajan, R., Wolfe, J. (2014). Parental perspectives on suffering and quality of life at end-of-life in children with advanced heart disease: An exploratory study. *Pediatric Critical Care Medicine, 15*(4), 336-342. http://dx.doi10.1097/PCC.0000000000000072

Board, R. (2004). Father stress during a child's critical care hospitalization. *Journal of Pediatric Health Care, 18*(5), 244-249. http://dx.doi.org/10.1016/j.pedhc.2004.06.003

Boer, F., Dunn, J., & Dunn, J. F. (2013). *Children's sibling relationships: Developmental and clinical issues*. Psychology Press http://dx.doi10.2307/353189

Bolitho, S., & Huntington, A. (2006). Experiences of Māori families accessing health care for their unwell children: A pilot study. *Nursing Praxis in New Zealand, 22*(1), 23. http://dx.doi0.1111/j.1365-2702.2011.04042

Borell, B. (2005). Living in the city ain't so bad: Cultural identity for young Māori in South Auckland. In J. Liu, T. McCreanor, T. McIntosh, & T. Teaiwa (Eds.), *New Zealand identities: Departures and destinations* (pp. 191-206). Wellington, New Zealand: Victoria University Press.

Borrows, J., Williams, M., Schluter, P., Paterson, J., & Langitoto Helu, S. (2011). Pacific Islands families study: The association of infant health risk indicators and acculturation of Pacific Island mothers living in New Zealand. *Journal of Cross-Cultural Psychology, 42*(5), 699-724. https://doi.org/10.1177/0022022110362750

Boulton, A. (2005). *Provision at the interface: The Māori mental health contracting experience* (Unpublished doctoral thesis). Massey University, Palmerston North, New Zealand. http://dx.doi:0.1111/j.1467- 9299.2009 .01784

Boulton, A., & Gifford, H. (2014). Whānau Ora; He whakaaro a whānau: Māori family views of family well-being. *International Indigenous Policy Journal, 5*(1). http://dx.doi10.18584/iipj.2014.5.1.1

Boulton, A**,** Gifford, H., & Potaka Osborne, M. (2009). Realising Whānau Ora Through Community Action: The Role of Māori Community Health Workers. *Education for Health*, Volume 22, Issue 2, pp: 188-188. http://dx.doi10.1177/109019819702400409

Boulton, A., Tamehana, J., & Brannelly, P. (2013). Whānau-centred health and social service delivery in NZ: The challenges to, and opportunities for, innovation. MAI Journal: A New Zealand Journal of Indigenous Scholarship, 2(1), 18 - 32. http://dx.doi10.1111/j.1467-9299.2009 .01784

Bramley, D., Hebert, P., Jackson, R. T., & Chassin, M. (2004). Indigenous disparities in disease-specific mortality, a cross-country comparison: New Zealand, Australia, Canada, and the United States. *New Zealand Medical Journal, 117*(1207), U1215. http://dx.doi10.1111/j.1753-6405.2009.00355

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*: Thousand Oaks, CA: Sage. http://dx.doi10.4236/ojdm.2013.31001

Braveman, P., & Gruskin, S. (2003). Defining equity in health. *Journal of Epidemiology & Community Health*, *57*(4), 254-258.

Braveman, P. (2014a). What are health disparities and health equity? We need to be clear. *Public Health Reports, 129*(Suppl 2), 5-8. http://dx.doi10.1177/00333549141291S203

Braveman, P. (2014b). What is health equity: and how does a life-course approach take us further toward it? *Maternal Child Health J, 18*(2), 366-372. http://dx.doi10.1007/s10995-013-1226-9

Brody, A. C., & Simmons, L. A. (2007). Family resiliency during childhood cancer: The father's perspective. *Journal of Pediatric Oncology Nursing, 24*(3), 152-165. http://dx.doi10.1177/1043454206298844

Brondolo, E., Love, E. E., Pencille, M., Schoenthaler, A., & Ogedegbe, G. (2011). Racism and hypertension: A review of the empirical evidence and implications for clinical practice. *American Journal of Hypertension, 24*(5), 518-529. http://dx.doi10.1038/ajh.2011.9

BrooklynsLove Foundation. (2013). *BrooklynsLove.* Retrieved from http://www.sporty.co.nz /brooklynbattle /BrooklynsLove-Foundation/BrooklynsLove

Brown, M. H., Small, L., & Palmer, N. N. (2008). Does family involvement and psychosocial support influence coping in teenage patients who have congenital heart disease? *Pediatric Nursing, 34*(5), 405. http://dx.doi10.1177/1359105312471569

Brown, R. M. (2010). Organisational pre-requisites to fund, implement and sustain Māori health promotion in a primary care setting. (Unpublished master's thesis). Auckland University of Technology, New Zealand

Brown, R,. & Mills, M. (2017). Hospital Companian Prototype: Draft plan for development of an information system for whānau . Auckland, New Zealand.

Browne, A. J., & Fiske, J.-A. (2001). First Nations women's encounters with mainstream health care services. *Western Journal of Nursing Research, 23*(2), 126-147. http://dx.doi10.1177/1049732310385824

Browne, A. J., Varcoe, C., Smye, V., Reimer-Kirkham, S., Lynam, M. J., & Wong, S. (2009). Cultural safety and the challenges of translating critically oriented knowledge in practice. *Nursing Philosophy, 10*(3), 167-179. http://dx.doi10.1111/j.1466-769X.2009.00406.x

Bruce, B., & Ritchie, J. (1997). Nurses' practices and perceptions of family-centred care. *Journal of Pediatric Nursing, 12*(4), 214-222. DOI: 10.1016/S0882-5963(97)80004-8

Buck, P. H. (1949). *The coming of the Māori*. Wellington, New Zealand: Māori Purposes Fund Board. http://dx.doi10.1525/aa.1950.52.3.02a00110

Burns, C. E. (1984). The hospitalization experience and single-parent families. A time of special vulnerability. *The Nursing clinics of North America*, *19*(2), 285-293.

Butt, M. L., McGrath, J. M., Samra, H. A., & Gupta, R. (2013). An integrative review of parent satisfaction with care provided in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 42*(1), 105-120. http://dx.doi10.1111/1552-6909.12002

Cachia, M., & Millward, L. (2011). The telephone medium and semi-structured interviews: A complementary fit. *Qualitative Research in Organizations and Management: An International Journal, 6*(3), 265-277. https://doi.org/10.1108/17465641111188420

Cajete, G. (2000). Indigenous knowledge: The Pueblo metaphor of Indigenous education. *Reclaiming Indigenous voice and vision*, 181-191.

Calixto, O.-J., & Anaya, J.-M. (2014). Socio--economic status. The relationship with health and autoimmune diseases. *Autoimmunity Reviews, 13*(6), 641-654. http://dx.doi10.1016/j.autrev.2013.12.002

Callery, P. (1997). Caring for parents of hospitalized children: A hidden area of nursing work. *Journal of Advanced Nursing, 26*(5), 992-998. http://dx.doi10.1046/j.1365-2648.1997.00387

Came, H., McCreanor, T., Doole, C., & Rawson, E. (2016). The New Zealand Health Strategy 2016: Whither health equity? *The New Zealand Medical Journal, 129*(1447), 72-77. http://dx.doi10.1016/j.socscimed.2014.01.055

Capell, A. (1991). *A new Fijian dictionary*. Suva, Fiji: Government Printer.

Carballo, M., Divino, J. J., & Zeric, D. (1998). Migration and health in the European Union. *Tropical Medicine & International Health, 3*(12), 936-944. http://dx.doi10.1046/j.1365-3156.1998.00337

Carlson, T., Barnes, H. M., & McCreanor, T. (2017). Kaupapa Māori evaluation: A collaborative journey. *Evaluation Matters—He Take Tō Te Aromatawai, 3*(2017), 67-99. https://doi.org/10.18296/em.0023

Carmen, S., Teal, S., & Guzzetta, C. E. (2008). Development, testing, and national evaluation of a pediatric patient-family-centred care benchmarking survey. *Holistic Nursing Practice, 22*(2), 61-74. http://dx.doi10.1097/01

Carrese, J. A., & Rhodes, L. A. (1995). Western bioethics on the Navajo reservation: Benefit or harm? *Jama, 274*(10), 826-829. http://dx.doi10.1001/jama.274.10.826

Carteret, M. (2011). Culture and family dynamics. *Dimension of Culture*: *Cross-Cultural Communications for Health care Professionals.* Retrieved from http://www.dimensionsofculture. com/2010/11/culture-and-family-dynamics/

Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of personality and social psychology*, *56*(2), 267.

Cass, B. (2007). Exploring social care: Applying a new construct to young carers and grandparent carers. *Australian Journal of Social Issues, 42*(2), 241-254. http://dx.doi10.1002/j.1839-4655.2007.tb00052

Central PHO. (2018.). Central PHO: *Pacific cultural guidelines.* Retrieved from http://www.centralpho.org.nz/Portals/0/Publications/Health Services/Pacific Cultural Guidelines (Central PHO).pdf

Chan, H. M. (2004). Informed consent Hong Kong style: An instance of moderate familism. *The Journal of medicine and philosophy*, *29*(2), 195-206.

Chang, M. Y., & McConkey, R. (2008). The perceptions and experiences of Taiwanese parents who have children with an intellectual disability. *International Journal of Disability, Development and Education, 55*(1), 27-41. http://dx.doi10.1080/10349120701827961

Chao, R. (1995). Chinese and European American cultural models of the self reflected in mothers' childrearing beliefs. *Ethos, 23*(3), 328-354. http://dx.doi10.1525/eth.1995.23.3.02a00030

Chao, R., & Tseng, V. (2002). Parenting of Asians. *Handbook of Parenting, 4*, 59-93.

Charmaz, K. (2014). *Constructing grounded theory*. Thousand Oaks, CA: Sage. http://dx.doi10.3928/01484834-20120402

Chen, L., & Kennedy, C. (2005). Cultural variations in children's coping behaviour, TV viewing time, and family functioning. *International Nursing Reveiw, 52*, 186-195. http://dx.doi10.1111/j.1466-7657.2005.00419

Cherrington, L., & Masters, B. (2005). *Literature review of Māori models of health and Indigenous injury prevention and health promotion interventions.* Wellington, New Zealand: Accident Compensation Corporation.

Chessa, M., De Rosa, G., Pardeo, M., Negura, D. G., Butera, G., Giamberti, A., . . . Carminati, M. (2005). What do parents know about the malformations afflicting the hearts of their children? *Cardiology in the Young, 15*(2), 125-129. http://dx.doi10.1017/S1047951105000284

Cheuk, D., Wong, S., Choi, Y., Chau, A., & Cheung, Y. (2004). Parents' understanding of their child's congenital heart disease. *Heart, 90*(4), 435-439. http://dx.doi10.1136/hrt.2003.014092

Child Cancer Foundation. (2017). *Beads of courage.* Retrieved from https://www.childcancer .org.nz/get-support/beads-of-courage/

Child Poverty Action Group. (2012). So many sick Māori and Pacific children: The Government must do more. Retrieved from http://www.cpag.org.nz/news/media-release-childrens-social-health-monitor/

Chillisa, B. (2012). *Indigenous research methodologies*. London, England: Sage. http://dx.doi:10.4102/aej.v1i1.44

Choi, E. K., Yoon, S. J., Kim, J. H., Park, H. J., Kim, J. Y., & Yu, E. S. (2016). Depression and distress in caregivers of children with brain tumors undergoing treatment: Psychosocial factors as moderators. *Psycho-Oncology, 25*(5), 544-550. http://dx.doi10.1002/pon.3962

Chun, C.-A., Moos, R. H., & Cronkite, R. C. (2006). Culture: A fundamental context for the stress and coping paradigm. In P. Wong, L. Wong, & W. Lonner (Eds.), *Handbook of multicultural perspectives on stress and coping* (pp. 29-53). New York, NY: Springer. http://dx.doi10.1007/0-387-26238-5_2

Clark, R., Benkert, R. A., & Flack, J. M. (2006). Large arterial elasticity varies as a function of gender and racism-related vigilance in black youth. *Journal of Adolescent Health, 39*(4), 562-569. http://dx.doi10.1016/j.jadohealth.2006.02.012

Clarke, S. A., Davies, H., Jenney, M., Glaser, A., & Eiser, C. (2005). Parental communication and children's behaviour following diagnosis of childhood leukaemia. *Psycho-Oncology, 14*(4), 274-281. http://dx.doi10.1002/pon.843

Coad, J., Kaur, J., Ashley, N., Owens, C., Hunt, A., Chambers, L., & Brown, E. (2015). Exploring the perceived met and unmet need of life-limited children, young people and families. *Journal of Pediatric Nursing, 30*(1), 45-53. http://dx.doi10.1016/j.pedn.2014.09.007

Cohen, D., & Crabtree, B. (2006). Triangulation. In Robert Wood Johnson Foundation (Ed.), *Qualitative Research Guidelines Project*. Retrieved from http://www.qualres.org/HomeTria-3692.html

Collins, A., & Hickey, H. (2006). *The role of whānau in the lives of Māori with physical disabilities*. Wellington, New Zealand: Families Commission.

Collins, A., & Wilson, G. (2008). *Māori and informal caregiving. A background paper prepared for the National Health Committee.* Retrieved from thehub.superu.govt.nz/sites/default/files/43047 _Māori-informal-caregiving-apr08_0.pdf. http://dx.doi.org/10.1016/S0277-9536(98)00421-3

Commodari, E. (2010). Children staying in hospital: A research on psychological stress of caregivers. *Italian Journal of Pediatrics, 36*(1), 40. http://dx.doi10.1186/1824-7288-36-40

Cong, Y. (2004). Doctor-family-patient relationship: The Chinese paradigm of informed consent. *The Journal of Medicine and Philosophy, 29*(2), 149-178. https://doi.org/10.1076/jmep.29.2.149.31506

Consedine, B. (2007). *Historical influences: Māori and the economy*. Wellington, New Zealand: Te Puni Kōkiri.

Corbett, C. A., & Callister, L. C. (2000). Nursing support during labor. *Clinical Nursing Research, 9*(1), 70-83. http://dx.doi10.1177/105477380000900106

Cormack, D., Robson, B., Purdie, G., Ratima, M., & Brown, R. (2005). *Access to cancer services for Māori.* Wellington, New Zealand: Ministry of Health.

Cotterell, G., von Randow, M., & McTaggart, S. (2009). Pacific families now and in the future: Changing Pacific household composition and well-being 1981–2006. Wellington, New Zealand: Families Commission.

Cottle, E.-M., & James, J. E. (2008). Role of the family support person during resuscitation. *Nursing Standard, 23*(9), 43-47. http://dx.doi10.7748/ns2008.11.23.9.43.c6719

Cowley, E. T., Paterson, J., & Williams, M. (2004). Traditional gift giving among Pacific families in New Zealand. *Journal of Family and Economic Issues, 25*(3), 431-444. http://dx.doi10.1023/B:JEEI.0000039949.35285.20

Coyne, I. (2006). Consultation with children in hospital: Children, parents' and nurses' perspectives. *Journal of Clinical Nursing, 15*(1), 61-71. http://dx.doi10.1111/j.1365-2702.2005.01247.x

Coyne, I., & Cowley, S. (2007). Challenging the philosophy of partnership with parents: A grounded theory study. *International Journal of Nursing Studies, 44*(6), 893-904. DOI: http://dx.doi.org/10.1016/j.ijnurstu.2006.03.002

Crabtree, B. F., & Miller, W. L. (1992). *Doing qualitative research.* Paper presented at the Annual North American Primary Care Research Group Meeting, 19th, May, 1989, Quebec, PQ, Canada. DOI http://dx.doi10.1097/00006199-199507000-00011

Craig, E., Jackson, C., Yeo Han, D., & NZCYES Steering Committee. (2007). *Monitoring the health of New Zealand children and young people: Indicator handbook*. Retrieved from http://www.paediatrics.org.nz/nzcyes/. http://dx.doi10.1136/bmj

Craig, E., Jackson, C., Yeo Han, D. (2008). *The health of Pacific children and young people in New Zealand: 2007 overview report*. Retrieved from www.paediatrics.org.nz/nzcyes/

Craig, E., Taufa, S., Jackson, C., & Han, D. (2008). *The health of Pacific children and young people in New Zealand*. Retrieved from http://www.paediatrics.org.nz/nzcyes/

Cram, F. (2001). Rangahau Māori: Tona tika, tona pono: The validity and integrity of Māori research. In M. Tolich (Ed.), *Research ethics in Aotearoa New Zealand* (pp. 35–52). Auckland, New Zealand: Pearson Education.

Cram, F. (2009). Maintaining Indigenous voices. In D. M. Mertens & P. E. Ginsberg (Eds.), *The handbook of social research ethics* (pp. 308-322). Thousand Oaks, CA: Sage. http://dx.doi.org/10.4135/9781483348971.n20

Cram, F. (2014). *Improving Māori access to health care: Research report*. Wellington, New Zealand: Ministry of Health.

Cram, F., & Pitama, S. (1998). Ko toku whānau, ko toku mana. In V. Adair & R. Dixon (Eds.), *The family in Aotearoa New Zealand* (pp. 130-157). Auckland, New Zealand: Addison Wesley Longman.

Cram, F., Smith, L., & Johnstone, W. (2003). Mapping the themes of Māori talk about health. *The New Zealand Medical Journal*, *116*(1170), 1-7. DOI: http://dx.doi.org/10.11157/anzswj-vol24iss3-4id124

Crampton, P., Jatrana, S., Lay-Yee, R., & Davis, P. (2007). Exposure to primary medical care in New Zealand: Number and duration of general practitioner visits. *The New Zealand Medical Journal, 120*(1256), 69-79. Retrieved from http://www.nzma.org.nz/journal/120-1256/2582/

Crawley, L., Pulotu-Endemann, F. K., & Stanley-Findlay, R. T. (1995). *Strategic directions for the mental health services for Pacific Islands people*. Wellington, New Zealand: Ministry of Health.

Crengle, S. (2000). The development of Māori primary care services. *Pacific Health Dialog*, *7*(1), 48-53.

Cribb, J. (2009). Focus on families: New Zealand families of yesterday, today and tomorrow. *Social Policy Journal of New Zealand, 35*, 4-16.

Cunningham, C. (2004). *The new Māori and Māori health*. Retrieved from http://www.massey.ac.nz/massey/fms/Te Mata O Te Tau/2004 Events/Powerpoint pdf presentations/The new Māori & Māori Health.pdf

Cunningham, C., Stevenson, B., & Tassell, N. (2005). *Analysis of the characteristics of whānau in Aotearoa. Report prepared for the Ministry of Education.* Wellington, New Zealand: Ministry of Education.

Curley, M., & Meyer, E. (2001). Caring practices: The impact of the critical care experience on the family. In M. A. Curley & P. A. Moloney-Harmon (Eds.), *Critical care nursing of infants and children* (2nd ed*., pp. 47-67). Philadelphia, PA: WB Saunders*.

Curtis, E., Harwood, M., & Riddell, T. (2007). *Hauora: Māori standards of health IV. A study of the years 2000–2005.* Wellington, New Zealand: University of Otago.

Curtis, E., Reid, P., & Jones, R. (2014). Decolonising the academy: The process of re-presenting Indigenous health in tertiary teaching and learning. In F. Cram, H. Phillips, P. Sauni, & C, Tuagalu (Eds.), *Māori and Pasifika higher education horizons* (pp. 147-165). Bingley, England: Emerald Group. http://dx.doi10.1108/S1479-364420140000015015

Curtis, E., Wikaire, E., Stokes, K., & Reid, P. (2012). Addressing Indigenous health workforce inequities: A literature review exploring 'best' practice for recruitment into tertiary health programmes. *International Journal for Equity in Health, 11*(1), 13. http://dx.doi10.1186/1475-9276-11-13

Curtis, E., Wikaire, E., Jiang, Y., McMillan, L., Loto, R., & Reid, P. (2015). A tertiary approach to improving equity in health: Quantitative analysis of the Māori and Pacific Admission Scheme (MAPAS) process, 2008–2012. *International Journal for Equity in Health, 14*(1), 7. https://doi.org/10.1186/s12939-015-0133-7

Da Silva, F. M., Jacob, E., & Nascimento, L. C. (2010). Impact of childhood cancer on parents' relationships: An integrative review. *Journal of Nursing Scholarship, 42*(3), 250-26. http://dx.doi10.1111/j.1547-5069.2010.01360.x

Dahlgren, G., & Whitehead, M. (1991). *Policies and strategies to promote social equity in health. Background document to WHO-Strategy paper for Europe.* Stockholm, Sweden: Institute for Future Studies.

Daniel, G., Wakefield, C., Ryan, B., Fleming, C., Levett, N., & Cohn, R. (2013). Accommodation in pediatric oncology: Parental experiences, preferences and unmet needs. *Rural and Remote Health, 13*(2), 2005. http://dx.doi10.1089/jayao.2015.0059

Darbyshire, P. (1994). *Living with a sick child in hospital: The experiences of parents and nurses*. London, England: Chapman & Hall. http://dx.doi10.1016/j.pedn.2008.03.010

Darbyshire, P. (1995). Family-centred care within contemporary British paediatric nursing. *British Journal of Nursing, 4*(1), 31-33. https://doi.org/10.12968/bjon.1995.4.1.31

Davies, M., & Macdowall, W. (2006). *Health promotion theory: Understanding public health*. New York: Open University Press.

Davis, H., Day, C., & Bidmead, C. (2002). *Working in partnership with parents: The parent adviser model*. London, England: Psychological Corporation.

Davis, P., Lay-Yee, R., Dyall, L., Briant, R., Sporle, A., Brunt, D., & Scott, A. (2006). Quality of hospital care for Māori patients in New Zealand: Retrospective cross-sectional assessment. *The Lancet, 367*(9526), 1920-1925. http://dx.doi.org/10.1016/S0140-6736(06)68847-8

Davis, P., Milne, B., Parker, K., Hider, P., Lay-Yee, R., Cumming, J., & Graham, P. (2013). Efficiency, effectiveness, equity (E 3). Evaluating hospital performance in three dimensions. *Health Policy, 112*(1), 19-27.

Day, V. (2009). Promoting health literacy through storytelling. *The Online Journal of Issues in Nursing, 14*(3), 6. http://dx.doi10.3912/OJIN

De, D., & Richardson, J. (2008). Cultural safety: An introduction. *Paediatric Care, 20*(2), 39-44.

Delamere Support Services. (n.d.). *Tikanga guidelines*. Retrieved from http://delamoresupport.co.nz/file /dss_tikanga_guidelines_issue-1.pdf

Dennis, M. K., & Brewer, J. P. (2017). Rearing generations: Lakota grandparents' commitment to family and community. *Journal of Cross-Cultural Gerontology, 32*(1), 95-113. http://dx.doi10.1007/s10823-016-9299-8

Denzin, N. K., & Lincoln, Y. (2000). *Qualitative research*. Thousand Oaks CA, 413-42. http://dx.doi10.1111/j.1365-2648.2001.0472a.x

Dew, K., Signal, L., Davies, C., Tavite, H., Hooper, C., Sarfati, D., Cunningham, C. (2015). Dissonant roles: The experience of Māori in cancer care. *Social Science & Medicine, 138*, 144-151. http://dx.doi10.1016/j.socscimed.2015.06.008

Dictionary.com. (n.d.). *Coping mechanism*. Retrieved from http://www.dictionary.com/browse/coping-mechanism

Disability Support Advisory Committee. (2016). Disability Support Advisory Committee Meeting Minutes. Retrieved from http://www.adhb.health.nz/assets/Documents/About-Us/Board-agendas-and-minutes/2016/DSAC/Open-DSAC-Meeting-Pack-24-August-2016.pdf

Dodgson, J. E., & Struthers, R. (2005). Indigenous women's voices: Marginalization and health. J*ournal of Transcultural Nursing, 16*(4), 339-346. http://dx10.1177/

Dominguez, T. P. (2008). Race, racism, and racial disparities in adverse birth outcomes. *Clinical Obstetrics and Gynecology, 51*(2), 360-370. http://dx.doi10.1097/GRF.0b013e31816f28de

Donalek, J. G. (2009). When a parent is chronically ill: Chronic fatigue syndrome. *Nursing Research, 58*(5), 332-339. http://dx.doi10.1097/NNR.0b013e3181ac156f

Dudley, S. K., & Carr, J. M. (2004). Vigilance: The experience of parents staying at the bedside of hospitalized children. *Journal of Pediatric Nursing, 19*(4), 267-275. http://dx.doi:10.1016/j.pedn.2004.05.008

Durall, A., Zurakowski, D., & Wolfe, J. (2012). Barriers to conducting advance care discussions for children with life-threatening conditions. *Pediatrics, 129*(4), e975-e982. doi:10.1542/peds .2011-2695

Durie, M. (1994). Whaiora. *Māori health development*.

Durie, M. (1998). *Whaiora: Maōri health development*. Auckland, New Zealand: Oxford University Press. http://dx.doi10.1177/003231870005200113

Durie, M. (1999a). Kaumatautanga reciprocity: Māori elderly and whānau. *New Zealand Journal of Psychology, 28*(2), 102. http://dx.doi/abs/10.1080/08111146.2014.994740

Durie, M. (1999b). *Te Pae Mahutonga: A model for Māori health promotion. Health Promotion Forum of New Zealand Newsletter* 49, 2-5 December.

Durie, M. (2003). *Nga kahui pou: Launching Māori futures*. Huia Publishers.

Durie, M. (2004). Understanding health and illness: Research at the interface between science and Indigenous knowledge. *International Journal of Epidemiology, 33*(5), 1138-1143. https://doi.org/10.1093/ije/dyh250

Durie, M. (2011). *Nga tini whetu: Navigating Māori futures*: Wellington, New Zealand: Huia Publishers.

Durie, M., Fitzgerald, E., Kingi, T.K., McKinley, S., & Stevenson, B. (2002). *Māori specific outcomes and indicators.* Palmerston North: Te Puni Kōkiri the Ministry of Māori Development.

Edwards, D., Friedman, T., & Pearce, J. (2013). Same admissions tools, different outcomes: A critical perspective on predictive validity in three undergraduate medical schools. *BMC Medical Education, 13*(1), 173. https://doi.org/10.1186/1472-6920-13-173

Edwards, S., McCreanor, T., & Moewaka-Barnes, H. (2007). Māori family culture: A context of youth development in Counties/Manukau. *Kōtuitui: New Zealand Journal of Social Sciences Online, 2*(1), 1-15. http://dx.doi.org/10.1080/1177083X.2007.9522420

Edwards, S., McManus, V., & McCreanor, T. (2005). Collaborative research with Māori on sensitive issues: The application of tikanga and kaupapa in research on Māori sudden infant death syndrome. *Social Policy Journal of New Zealand, 25*, 88.

Edwards, W., Ratima, M. (2014). Engaging Māori fathers: a literature review – father involvement, Māori in parenting. Taumata Associates.

Egan, R., Doherty, J., Albert, T., Llewellyn, R., Walsh, C., Kerslake, P., Atkinson, K. (2014). *He Kāhui Kōrero Taumahatanga o te Mate Pukupuku. Cancer stories project.* Dunedin, New Zealand: Dunedin School of Medicine, University of Otago

Elder, H. (2008). Ko wai ahau? [Who am I?] How cultural identity issues are experienced by Māori psychiatrists and registrars working with children and adolescents. *Australasian Psychiatry, 16*(3), 200-203. http://dx.doi10.1080/10398560701875199

Elliott, S., & Gray, A. (2000). *Family structures: A report for the New Zealand Immigration Service*. Wellington, New Zealand: New Zealand Immigration Service.

Essakow, K. L., & Miller, M. M. (2013). Piecing together the shattered heirloom: Parents' experiences of relationship resilience after the violent death of a child. *The American Journal of Family Therapy, 41*(4), 299-310. http://dx.doi10.1080/01926187.2012.701590

Evashwick, C. J. (1990). Older adults: A growing market for ambulatory care services. *The Journal of Ambulatory Care Management, 13*(2), 1-14.

Ezzy, D. (2002). *Qualitative analysis: Practice and innovation*. Crows Nest, Australia: Allen & Unwin. http://dx.doi10.1177/009430610403300185.

Fa'avae, D., Jones, A., & Manu'atu, L. (2016). Talanoa'i 'A e Talanoa - Talking about Talanoa: Some dilemmas of a novice researcher. *Alternative: An International Journal of Indigenous Peoples, 12*(2), 138-150. http://dx.doi10.20507/AlterNative.2016.12.2.3.

Families Commission. (2005). *Families with dependent children: Successful outcomes*. Wellington, New Zealand: Families Commission.

Families Commission. (2009). *Whānau Strategic Framework 2009-2012*. Wellington, New Zealand: Author.

Families Commission. (2012). *New Zealand families today: A brief demographic profile*. Wellington, New Zealand: Author. Retrieved from http://www/.familiescommission.org.nz /publications/briefs-and-statistics/newzealand-families-today.

Farrelly, T., & Nabobo-Baba, U. (2012). *Talanoa as empathic research.* Paper presented at the International Development Conference (3-5 December). Auckland, New Zealand.

Finau, S. A. (1996). Health, environment and development: towards a Pacific paradigm. *Pacific Health Dialog*, *3*, 266-278.

Fletcher, J. (2003). *Tales and talanoa: Using a culturally appropriate methodology to research the experiences of Pasifika and Māori second chance tertiary learners.* Unpublished paper, Christchurch College of Education.

Fletcher, J., Parkhill, F., Fa'afoi, A., & Morton, M. (2006). Poto he Anga: Collaboration and consultation in Pasifika research. *Qualitative Research Journal, 6*(1), 36-50. https://doi.org/10.1108/14439883200600003

Flores, G., Gee, D., & Kastner, B. (2000). The teaching of cultural issues in US and Canadian medical schools. *Academic Medicine, 75*(5), 451-455. http://dx.doi10.1097/00001888-200005000-00015

Flouri, E. (2005). *Fathering and child outcomes.* Hoboken, NJ: Wiley. http://dx.doi10.1002/9780470713228

Folkman, S. (2001). Revised coping theory and the process of bereavement. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 563-584). Washington, DC: American Psychological Association. http://dx.doi.org/10.1037/10436-024

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 219-239. http://dx.doi.org/10.2307/2136617

Foster, M. J., Whitehead, L., & Maybee, P. (2010). Parents' and health professionals' perceptions of family centred care for children in hospital, in developed and developing countries: A review of the literature. *International Journal of Nursing Studies, 47*(9), 1184-1193. http://dx.doi.org/10.1016/j.ijnurstu.2010.05.005

Foster, M. J., Whitehead, L., Maybee, P., & Cullens, V. (2013). The parents', hospitalized child's, and health care providers' perceptions and experiences of family-centred care within a pediatric critical care setting: A metasynthesis of qualitative research. *Journal of Family Nursing, 19*(4), 431-468. http://dx.doi10.1177/1074840713496317

Fowler, C., Rossiter, C., Bigsby, M., Hopwood, N., Lee, A., & Dunston, R. (2012). Working in partnership with parents: The experience and challenge of practice innovation in child and family health nursing. *Journal of Clinical Nursing, 21*(21-22), 3306-3314. http://dx.doi10.1111/j.1365-2702.2012.04270

Franck, L. S., Gay, C. L., & Rubin, N. (2013). Accommodating families during a child's hospital stay: Implications for family experience and perceptions of outcomes. *Families, Systems, & Health, 31*(3), 294-306. http://dx.doi10.1037/a0033556.

Frank, G., Blackhall, L. J., Michel, V., Murphy, S. T., Azen, S. P., & Park, K. (1998). A discourse of relationships in bioethics: Patient autonomy and end-of-life decision making among elderly Korean Americans. *Medical Anthropology Quarterly, 12*(4), 403-423. http://dx.doi10.1525/maq

Fraser, L. K., Fleming, S., & Parslow, R. (2017). Changing place of death in children who died after discharge from paediatric intensive care units: A national, data linkage study. *Palliative Medicine.* https://doi.org/10.1177/0269216317709711

Frey, R., Gott, M., Raphael, D., Black, S., Teleo-Hope, L., Lee, H., & Wang, Z. (2013). 'Where do I go from here'? A cultural perspective on challenges to the use of hospice services. *Health & Social Care in the Community, 21*(5), 519-529. http://dx.doi10.1111/hsc.12038

Friebert, S., & Huff, S. (2009). NHPCO's pediatric standards: A key step in advancing care for America's children. *NewsLine.* Retrieved from https://www.nhpco.org/quality/nhpco%E2%80%99s-standards-pediatric-care. http://dx.doi.org/10.1016/j.pedhc.2016.04.013

Gaab, E., Owens, R. G., & MacLeod, R. (2012). Communicating about prognosis with young people. *Journal of Palliative Care, 28*(3), 186.

Gaffney, M. (2007). *A research study of young carers: The development of a recording tool for agencies to identify young carers.* Wellington, New Zealand: Ministry of Health.

Garcia Coll, C. T., Meyer, E. C., & Brillon, L. (1995). Ethnic and minority parenting. In M. Bornstein (Ed.), *Handbook of parenting: Volume 4: Social conditions and applied parenting* (pp. 1-20). Mahwah, NJ: Erlbaum.

Garvey, G., Towney, P., McPhee, J., Little, M., & Kerridge, I. (2004). Is there an Aboriginal bioethic? *Journal of Medical Ethics, 30*(6), 570-575. http://dx.doi10.1136/jme.2002.001529

Gauld, R., Al-wahaibi, S., Chisholm, J., Crabbe, R., Kwon, B., Oh, T., Sohn, S. (2011). Scorecards for health system performance assessment: The New Zealand example. *Health Policy, 103*(2), 200-208. http://dx.doi0.1016/j.healthpol.2011.05.016

Gay, E. B., Pronovost, P. J., Bassett, R. D., & Nelson, J. E. (2009). The intensive care unit family meeting: Making it happen. *Journal of Critical Care, 24*(4), 629, e1-12. http://dx.doi10.1016/j.jcrc.2008.10.003

Georgas, J. (2006). Families and family change. In J. Georgas, J. W. Berry, F. J. van de Vijver, Ç. Kagitçibasi, & Y. H. Poortinga (Eds.), *Families across cultures: A 30-nation psychological study* (pp. 3-50). Cambridge, England: Cambridge University Press.

Gibson, O. R., & Segal, L. (2015). Limited evidence to assess the impact of primary health care system or service level attributes on health outcomes of Indigenous people with type 2 diabetes: A systematic review. *BMC Health Services Research, 15*(1), 154.

Gibson, W., & Brown, A. (2009). *Working with qualitative data.* Thousand Oaks, CA: Sage. http://dx.doi.org/10.4135/9780857029041

Gifford, H., & Pirikahu, G. (2008). *Engaging Māori whānau: evaluation of a targeted parenting programme.* Wellington: Families Commission.

Gillies, T. D., Tomlin, A. M., Dovey, S. M., & Tilyard, M. W. (2013). Ethnic disparities in asthma treatment and outcomes in children aged under 15 years in New Zealand: analysis of national databases. *Primary Care Respiratory Journal, 22*(3), 312.

Giuntoli, G., & Fisher, K. (2015). *Ronald McDonald family rooms: Literature review*. Sydney, Australia: Social Policy Research Centre, University of New South Wales. http://dx.doi.org/10.1007/s10995-011-0751-7

Glover, M. (2002). *Kaupapa Māori health research methodology*. Auckland, New Zealand: Applied Behavioural Science, University of Auckland.

Goble, F. G. (2004). *The third force: The psychology of Abraham Maslow*. Chapel Hill, NC: Bassett.

Goodhead, A., & McDonald, J. (2007). *Informal caregiver's literature review*. A report prepared for the National Health Committee Health Services Research Centre. Wellington, New Zealand: Victoria University of Wellington.

Grant-Mackie, D. (2007). In our own right: Black Australian nurses' stories. Review. *Contemporary Nurse, 24*(1), 107-108.

Hafford, C. (2010). Sibling caretaking in immigrant families: Understanding cultural practices to inform child welfare practice and evaluation. *Evaluation and Program Planning, 33*(3), 294-302. http://dx.doi10.1016/j.evalprogplan.2009.05.003

Hakaoro T. H. (2003). Cook Islanders in Australia. In R. Crocombe & M. Crocombe (Eds.), *Cook Islands Culture*. Suva, Fiji: Institute of Pacific Studies and Cook Islands.

Halapua, W. (2003). *Tradition, lotu, and militarism in Fiji*: Fiji Institute of Applied Studies. http://dx.doi.org/10.11157/anzswj-vol22iss4id175

Hall, E. O. (2004a). A double concern: Danish grandfathers' experiences when a small grandchild is critically ill. *Intensive and Critical Care Nursing, 20*(1), 14-21. http://dx.doi.org/10.1016/j.iccn.2003.10.005

Hall, E. O. (2004b). A double concern: Grandmothers' experiences when a small grandchild is critically ill. *Journal of Pediatric Nursing, 19*(1), 61-69. http://dx.doi10.1016/S0882-5963(03)00143-X

Hallowell, N., Lawton, J., & Gregory, S. (2004). *Reflections on research: The realities of doing research in the social sciences*. Berkshire, England: McGraw-Hill Education. DOI: 10.1177

Han, H. R., Cho, E. J., Kim, D., & Kim, J. (2009). The report of coping strategies and psychosocial adjustment in Korean mothers of children with cancer. *Psycho-Oncology, 18*(9), 956-964. http://dx.doi10.1002/pon.1514

Harding, J. (2013). *Qualitative data analysis from start to finish*. Thousand Oaks, CA: Sage.

Harris, C. (2002). *Making native space: Colonialism*, *Resistance, and Reserves in British Columbia.* Vancouver, Canada: UBC Press. http://dx.doi10.2307/25149464

Harris, R., Cormack, D., Tobias, M., Yeh, L.-C., Talamaivao, N., Minster, J., & Timutimu, R. (2012a). The pervasive effects of racism: Experiences of racial discrimination in New

Zealand over time and associations with multiple health domains. *Social Science & Medicine, 74*(3), 408-415. http://dx.doi10.1016/j.socscimed.2011.11.004

Harris, R., Cormack, D., Tobias, M., Yeh, L.-C., Talamaivao, N., Minster, J., & Timutimu, R. (2012b). Self-reported experience of racial discrimination and health care use in New Zealand: Results from the 2006/07 New Zealand Health Survey. *American Journal of Public Health, 102*(5), 1012-1019. http://dx.doi10.2105/AJPH.2011.300626

Harris, R., Tobias, M., Jeffreys, M., Waldegrave, K., Karlsen, S., & Nazroo, J. (2006a). Effects of self-reported racial discrimination and deprivation on Māori health and inequalities in New Zealand: cross-sectional study. *The Lancet, 367*(9527), 2005-2009. http://dx.doi10.1016/S0140-6736(06)68890-9

Harris, R., Tobias, M., Jeffreys, M., Waldegrave, K., Karlsen, S., & Nazroo, J. (2006b). Racism and health: The relationship between experience of racial discrimination and health in New Zealand. *Social Science & Medicine, 63*(6), 1428-1441. http://dx.doi:10.1016/j.socscimed.2006.04.009

Harris, S. (2017). AUT study finds Māori voices being cut from health sector *New Zealand Herald*. Retrieved http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11888605

Hart, M. (2010). Colonization, Social Exclusion, and Indigenous Health. *The social determinants of health in Manitoba*, 91-102.

Hartling, L., Milne, A., Tjosvold, L., Wrightson, D., Gallivan, J., & Newton, A. S. (2014). A systematic review of interventions to support siblings of children with chronic illness or disability. *Journal of Paediatrics and Child Health, 50*(10), 26-38. http://dx.doi10.1111/j.1440-1754.2010.01771

Hayes, R. (2016). Whānau Ora: A Māori health strategy to support whānau in Aotearoa. *Whitireia Nursing & Health Journal, 23*, 25-29.

Health Partners Consulting Group. (2012). *Metro-Auckland Pacific population health profile*. Retrieved from http://www.health.govt.nz/publication/metro-auckland-pacific-population-health-profile

Health Promotion Forum of New Zealand. (2002). *TUHA-NZ: A Treaty understanding of Hauora in Aotearoa-New Zealand*. Retrieved from www.hpforum.org.nz

Health Research Council of New Zealand. (2014). *Pacific Health Research Guidelines 2014*. Auckland, New Zealand: Author.

Health Workforce Advisory Committee. (2003). *The New Zealand health workforce: Future directions–Recommendations to the Minister of Health 2003*. Wellington, New Zealand: Ministry of Health.

Helu-Thaman. Kakala (n.d.). In *Pacific Health Research Guidelines*. Auckland: Health Research Council of New Zealand.

Henderson, J. Y. (2000). Ayukpachi: Empowering Aboriginal thought. In M. Battiste (Ed.), *Reclaiming Indigenous voices and vision* (pp. 248-278). Vancouver, Canada: UBC Press.

Hendricks, A. (2010). *Changing roles: The pleasures of being a grandparent in New Zealand. A Families Commission Report*. Retrieved from http://www.superu.govt.nz/publication/changing-roles-pleasures-and-pressures-being-grandparent-new-zealand

Henwood, K., & Pidgeon, N. (1994). Beyond the qualitative paradigm: A framework for introducing diversity within qualitative psychology. *Journal of Community & Applied Social Psychology, 4*(4), 225-238. http://dx.doi.org/10.1177

Hern, H. E., Koenig, B. A., Moore, L. J., & Marshall, P. A. (1998). The difference that culture can make in end-of-life decisionmaking. *Cambridge Quarterly of Health care Ethics, 7*(1), 27-40.

Higham, S., & Davies, R. (2012). Fathers' roles when their child is in hospital. *Nursing Times, 109*(35), 26-27. http://dx.doi10.1111/j.1365-2648.2012.06131.x.

HiMSS. (2014). Meaningful use, HIE and the continuum of care. Retrieved from http://www.himss.org /meaningful-use-hie-and-continuum-care

Hirini, P. R., & Collings, S. C. (2005). *Whakamomori, He Whakaaro, He Kōrero Noa*. Wellington, New Zealand: Ministry of Health. http://dx.doi.org/10.1007/s40596-017-0813-2

Hixon, A. L. (2004). Functional health literacy: Improving health outcomes. *American Family Physician, 69*(9), 2077-2078.

Ho, E., & Bedford, R. (2008). Asian transnational families in New Zealand: Dynamics and challenges. *International Migration, 46*(4), 41-62. http://dx.do10.1111/j.1468-2435.2008.00471.x

Hobson, L., & Noyes, J. (2011). Fatherhood and children with complex health care needs: Qualitative study of fathering, caring and parenting. *BMC Nursing, 10*(1), 5. https://doi.org/10.1186/1472-6955-10-5

Hofstede, G. (2001). *Culture's consequences: Comparing values, behaviors, institutions, and organizations across cultures.* Thousand Oaks, CA: Sage. https://doi.org/10.1177/031289620202700105

Horsburgh, M., Trenholme, A., & Huckle, T. (2002). Paediatric respite care: A literature review from New Zealand. *Palliative Medicine, 16*(2), 99-105. http://dx.doi10.1191/0269216302pm515oa

Hovey, J. K. (2005). Fathers parenting chronically ill children: Concerns and coping strategies. *Issues in Comprehensive Pediatric Nursing, 28*(2), 83-95.

Howden-Chapman, P., & Cram, F. (1998). *Social, economic and cultural determinants of health* (National Health Committee: Health determinants programme. Background paper 1). Wellington, New Zealand: Ministry of Health.

Huakau, G., & Bray, A. (2000). *"Talking disabilities" from a Pacific perspective*. Dunedin, New Zealand: Donald Beasley Institute.

Hummelinck, A., & Pollock, K. (2006). Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counseling, 62*(2), 228-234. http://dx.doi.org/10.1016/j.pec.2005.07.006

Hung, K. J., Tomlinson, M., le Roux, I. M., Dewing, S., Chopra, M., & Tsai, A. C. (2014). Community-based prenatal screening for postpartum depression in a South African township. *International Journal of Gynecology & Obstetrics, 126*(1), 74-77. http://dx.doi10.1016/j.ijgo.2014.01.011

Hunt, E. (2003). *Rarotonga & the Cook Islands*. Footscray, Australia: Lonely Planet.

Institute of Medicine. (2004). *Health literacy: A prescription to end confusion.* Washington, DC: The National Academies Press. https://doi.org/10.17226/10883

Irwin, K. (1994). Māori research methods and processes: An exploration. *Sites Journal, 28*, 25-43.

Isaac, T., Zaslavsky, A. M., Cleary, P. D., & Landon, B. E. (2010). The relationship between patients' perception of care and measures of hospital quality and safety. *Health Services Research, 45*(4), 1024-1040. http://dx.doi10.1111/j.1475-6773.2010.01122.x

Isacco, A., & Garfield, C. F. (2010). Child health care decision-making: Examining "conjointness" in paternal identities among residential and non-residential fathers. *Fathering, 8*(1), 109. http://dx.doi.org/10.3149/fth.0801.109

Jackson, A. C., Stewart, H., O'Toole, M., Tokatlian, N., Enderby, K., Miller, J., & Ashley, D. (2007). Pediatric brain tumor patients: Their parents' perceptions of the hospital experience. *Journal of Pediatric Oncology Nursing, 24*(2), 95-105. http://dx.doi10.1177/1043454206296030

Jahnke, H., & Taiapa, J. (1999). Māori research. In C. Davidson & M. Tolich (Eds.), *Social science research in New Zealand: Many paths to understanding* (pp. 39-50). Auckland, New Zealand: Pearson Education.

Jansen, P., Bacal, K., & Buetow, S. (2011). A comparison of Māori and non-Māori experiences of general practice. *The New Zealand Medical Journal (Online)*, *124*(1330).

Jansen, P., Bacal, K., & Crengle, S. (2008). He Ritenga Whakaaro: Māori experiences of health services. *Hospital*, *200*, 30-7. http://dx.doi10.1111/j.1365-270.2011.04042.x

Jansen, P., & Smith, K. (2006). Māori experiences of primary health care. *NZFP, 33*(5), 298-300. http://dx.doi10.1111/j.1365-2702.2011.04042

Jee, R. A., Shepherd, J. R., Boyles, C. E., Marsh, M. J., Thomas, P. W., & Ross, O. C. (2012). Evaluation and comparison of parental needs, stressors, and coping strategies in a pediatric intensive care unit. *Pediatric Critical Care Medicine, 13*(3), e166-e175. http://dx.doi10.1097/PCC.0b013e31823893ad

Jenkins, K., & Harte, H. M. (2011). *Traditional Māori parenting: An historical review of literature of traditional Māori child-rearing practices in pre-European times.* Auckland, New Zealand: Te Kahui Mana Ririki. http://dx.doi10.1080/14725869908583801

Jeong, A., Shin, D. W., Kim, S., Yang, H. K., Shin, J. Y., Park, K., Park, J. H. (2016). The effects on caregivers of cancer patients' needs and family hardiness. *Psycho-Oncology, 25*(1), 84-90 http://dx.doi10.1002/pon.3878

Jones, B., Ingham, T., Davies, C., & Cram, F. (2010). Whānau Tuatahi: Māori community partnership research using a Kaupapa Māori methodology. *MAI review, 3*(1), 1-14. http://dx.doi10.1186/1471-2458-13-228

Jones, R. (2011). Te Ara: A pathway to excellence in Indigenous health teaching and learning. *Focus on Health Professional Education: A Multi-Disciplinary Journal, 13*(1), 23-34.

Jordan, J. E., Buchbinder, R., & Osborne, R. H. (2010). Conceptualising health literacy from the patient perspective. *Patient Education and Counseling, 79*(1), 36-42. DOI: http://dx.doi.org/10.1016/j.pec.2009.10.001

Ka'ai, T. M. (2005). Te Kauae Maro o Muri-ranga-whenua (The jawbone of Muri-ranga-whenua). *PORTAL Journal of Multidisciplinary International Studies, 2*(2). http://dx.doi.org/10.5130/portal.v2i2.92

Kagawa-Singer, M., & Blackhall, L. J. (2001). Negotiating cross-cultural issues at the end of life: You got to go where he lives. *Jama, 286*(23), 2993-3001. http://dx.doi10.1001/jama.286.23.2993

Kağitçibaşi, Ç. (2006). Theoretical perspectives on family change. In J. Georgas, J. W. Berry, F. J. van de Vijver, Ç. Kagitçibasi, & Y. H. Poortinga (Eds.), *Families across cultures: A 30-nation psychological study* (pp. 72-89). Cambridge, England: Cambridge University Press. http://dx.doi.org/10.1017/CBO9780511489822.004

Kahu, M., & Wakefield, B. (2008). *Haumanu taiao o ihumanea: A collaborative study with Te Tai o Marokura Kaitiaki group* (Unpublished doctoral dissertation). Lincoln University, Christchurch, New Zealand.

Kahukura Tatau, N. (2010). *Māori health chart book 2010*. Wellington, New Zealand: Ministry of Health.

Katz, S. (2002). When the child's illness is life-threatening: Impact on the parents. *Pediatric Nursing, 28*(5), 453. https://doi.org/10.12968/ijpn.2006.12.12.22544

Kidshealth. (2015). *Family-centred care*. Retrieved from https://www.kidshealth.org.nz/principle-3-family-centred-care

King, A. (2000). *The New Zealand Health Strategy*. Wellington, New Zealand: Ministry of Health.

King, A., & Turia, T. (2002). *He Korowai Oranga*. Wellington, New Zealand: Ministry of Health.

Kingi, P. (2008). Viewpoint: Cultural determinants of health. In E. Craig, S. Taufa, C. Jackson, & D. Y. Han (Eds.), *The health of Pacific children and young people in New Zealand: Introduction, viewpoints and executive summary* (pp. 11-15). Auckland, New Zealand: New Zealand Child and Youth Epidemiology Service.

Kingi, T., K. (2002). *Hua oranga: Best health outcomes for Māori* (Unpublished doctoral thesis). Massey University, Wellington, New Zealand.

Kirk, S., & Glendinning, C. (2002). Supporting 'expert' parents: Professional support and families caring for a child with complex health care needs in the community. *International Journal of Nursing Studies, 39*(6), 625-635. http://dx.doi.org/10.1016/S0020-7489(01)00069-4

Kirmayer, L. J., & Young, A. (1998). Culture and somatization: Clinical, epidemiological, and ethnographic perspectives. *Psychosomatic Medicine, 60*(4), 420-430.

Kirmayer, L. J., Sehdev, M., & Isaac, C. (2009). Community resilience: Models, metaphors and measures. *International Journal of Indigenous Health, 5*(1), 62. http://dx.doi.org/10.18357/ijih51200912330

Kirschbaum, M. S. (1989). Needs of parents of critically ill children. *Dimensions of Critical Care Nursing: DCCN, 9*(6), 344-352.

Kissane, D., Lichtenthal, W. G., & Zaider, T. (2008). Family care before and after bereavement. *Omega-Journal of Death and Dying, 56*(1), 21-32. http://dx.doi0.2190/OM.56.1.c

Kodner, D. L. (2009). All together now: a conceptual exploration of integrated care. *Healthcare Quarterly (Toronto, Ont.), 13*, 6-15.

Koloto, A., & Sharma, S. (2005). *Pasifika women's economic well-being study: Final report.* New Zealand: Ministry of Women's Affairs.

Koloto, A., Duncan, I., de Raad, J., Wang, A., & Gray, A. (2007). *Pacific housing experiences: Developing trends and issues.* Wellington, New Zealand: Centre for Housing Research Aotearoa New Zealand.

Koontz, V. S. (2003). Parental satisfaction in a pediatric intensive care unit (Unpublished master's thesis). Marshall University, Huntington, WV. Retrieved from http://mds.marshall.edu/etd/695

Koster, R., Baccar, K., & Lemelin, R. H. (2012). Moving from research ON, to research WITH and FOR Indigenous communities: A critical reflection on community-based participatory research. *The Canadian Geographer/Le Géographe Canadien, 56*(2), 195-210.

Kowal, E. E., & Paradies, Y. C. (2010). Enduring dilemmas of Indigenous health. *Med J Aust, 192*(10), 599-600.

Krauss, T. D., O'Brien, S., & Brus, L. E. (2001). Charge and photoionization properties of single semiconductor nanocrystals. *The Journal of Physical Chemistry B, 105*(9), 1725-1733. http://dx.doi10.1021/jp0023415

Kripalani, S., Bussey-Jones, J., Katz, M. G., & Genao, I. (2006). A prescription for cultural competence in medical education. *Journal of General Internal Medicine, 21*(10), 1116-1120. http://dx.doi10.1111/j.1525-1497.2006.00557.x

Kruger, T. (2004). *Transforming whānau violence: A conceptual framework: An updated version of the report from the former Second Māori Taskforce on Whānau Violence*. Wellington, New Zealand: Te Puni Kōkiri.

Kruger, T., Pitman, M., Grennell, D., McDonald, T., Mariu, D., Pomare, A., Lawson-Te Aho, K. (2004). *Transforming whānau violence: A conceptual framework. An updated version of the report from the former Second Māori Taskforce on Whānau Violence* (2nd ed). Auckland, New Zealand: New Zealand Family Violence Clearing House.

Kukutai, T., & Taylor, J. (2013). Postcolonial profiling of Indigenous populations. Limitations and responses in Australia and New Zealand. *Espace Populations Sociétés. Space Populations Societies, 2012*(1), 13-27. http://dx.doi10.4000/eps.4812

Kunitz, S. J. (1996). *Disease and social diversity: The European impact on the health of non-Europeans*. New York, NY: Oxford University Press. http://dx.doi10.1525/maq.1997.11.2.264

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centred care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal, 16*(2), 297-305. http://dx.doi10.1007/s10995-011-0751-7

Kurtz, D. L., Nyberg, J. C., Van Den Tillaart, S., & Mills, B. (2008). Silencing of voice: An act of structural violence: Urban Aboriginal women speak out about their experiences with health care. *International Journal of Indigenous Health, 4*(1), 53. DOI: http://dx.doi.org/10.18357/ijih41200812315

Kurtz, S., Silverman, J., Benson, J., & Draper, J. (2003). Marrying content and process in clinical method teaching: Enhancing the Calgary–Cambridge guides. *Academic Medicine, 78*(8), 802-809 http://dx.doi10.1097/00001888-200308000-00011

Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the craft of qualitative interviewing*. London, England: Sage. http://dx.doi.org/10.1108/QRJ-02-2015-0015

Kyngäs, H., & Rissanen, M. (2001). Support as a crucial predictor of good compliance of adolescents with a chronic disease. *Journal of Clinical Nursing, 10*(6), 767-774. http://dx.doi10.1046/j.1365-2702.2001.00538.x

Lalonde, M. (1974). A New Perspective on the Health of Canadians: A Working Document= Nouvelle Perspective De La Sante Des Canadiens. http://dx.doi.org/10.1590/S1020-49892002000900001

Lacey, C., Huria, T., Beckert, L., Gilles, M., & Pitama, S. (2011). The Hui process: A framework to enhance the doctor-patient relationship with Māori. *The New Zealand Medical Journal, 124*(1347). http://dx.doi10.1001/jama.1995.03520280069043

Lam, A. G., & Zane, N. W. (2004). Ethnic differences in coping with interpersonal stressors: A test of self-construals as cultural mediators. *Journal of Cross-Cultural Psychology, 35*(4), 446-459. http://dx.doi10.1177/0022022104266108

Lamanna, M. A., Riedmann, A., & Stewart, S. D. (2014). Marriages, families, and relationships: Making choices in a diverse society (12th ed.). Stamford, CT: Cengage Learning. http://dx.doi10.1136/bmj.38279.705336OB

Lamb, M. E. (2000). The history of research on father involvement: An overview. *Marriage & Family Review, 29*(2-3), 23-42. http://dx.doi.org/10.1300/J002v29n02_03

Lansford, J. E., Deater-Deckard, K. D., & Bornstein, M. H. (Eds.). (2009). *Immigrant families in contemporary society.* New York, NY: Guilford Press. http://dx.doi10.1525/aeq.1983.14.1.05x1181k

Latu, M. (2009). *Talanoa: A contribution to the teaching and learning of Tongan primary school children in New Zealand.* Auckland University of Technology,

Lavee, Y., & Mey-Dan, M. (2003). Patterns of change in marital relationships among parents of children with cancer. *Health & Social Work, 28*(4), 255-263.

LaVeist, T. A., & Nuru-Jeter, A. (2002). Is doctor-patient race concordance associated with greater satisfaction with care? *Journal of Health and Social Behavior 43*(3), 296-306.

Lawlor, M. C., & Mattingly, C. F. (1998). The complexities embedded in family-centred care. *American Journal of Occupational Therapy, 52*(4), 259-267. http://dx.doi10.5014/ajot.52.4.259

Lawoko, S. (2007). Factors influencing satisfaction and well-being among parents of congenital heart disease children: development of a conceptual model based on the literature review. *Scandinavian Journal of Caring Sciences, 21*(1), 106-117. http://dx.doi10.1111/j.1471-6712.2007.00444.x

Lawson-Te Aho, K. (2010). *Definitions of whānau : A review of selected literature.* Wellington, New Zealand: Families Commission.

Lazarus, R. S. (1999). Hope: An emotion and a vital coping resource against despair. *Social Research*, 653-678.

Lazarus, R. S., DeLongis, A., Folkman, S., & Gruen, R. (1985). Stress and adaptational outcomes: The problem of confounded measures. *American Psychologist, 40*(7), http://dx.doi10.1037/0003-066X.40.7.770

Lazarus, R. S., & Folkman. S. (1984). *Stress, appraisal, and coping.* New York: Springer. https://doi.org/10.1017

Leadbitter, H. (2008). *Whole family pathway: A resource for practitioners.* Retrieved from https://www.childrenssociety.org.uk/sites/default/files/whole-family-pathway_0.pdf

Lee, J. (2009). Decolonising Māori narratives: Pūrākau as a method. *MAI Review, 2*(3), 79-91. http://dx.doi:0.1177/1049732306297905

Lee, S.-Y. D., Arozullah, A. M., & Cho, Y. I. (2004). Health literacy, social support, and health: A research agenda. *Social Science & Medicine, 58*(7), 1309-1321.

Leinonen, J. A., Solantaus, T. S., & Punamäki, R. L. (2003). Parental mental health and children's adjustment: The quality of marital interaction and parenting as mediating factors. *Journal of Child Psychology and Psychiatry, 44*(2), 227-241.

Leonard, M., Graham, S., & Bonacum, D. (2004). The human factor: The critical importance of effective teamwork and communication in providing safe care. *Quality and Safety in Health Care, 13*(suppl 1), i85-i90. http://dx.doi10.1136/qshc.2004.010033

Lewis, H. (2012). *Experiences of biographical disruption at critical moments in the lives of young adults with childhood renal failure: A comparative study of adults aged 16-30 with prepubertal and postpubertal onset ERF* (Unpublished doctoral thesis). University of Surrey, England.

Lichtenthal, W. G., & Kissane, D. W. (2008). The management of family conflict in palliative care. *Progress in Palliative Care, 16*(1), 39-45. http://dx.doi10.1179/096992608X296914

Lin, S., Cleary, S. D., & Edberg, M. (2014). *Assessing the Impact of family status, family cohesion, and acculturation on youth violence among immigrant Latinos* [Poster]. Washington, DC: The George Washington University. Retrieved http://hsrc.himmelfarb.gwu.edu/researchdays _2014/1/

Lui, D. (2003). *Family: A Samoan perspective.* Keynote presentation to the SF National Conference, Christchurch. Mental Health Commission

Liu, J. M., Lin, W. C., Chen, Y. M., Wu, H. W., Yao, N. S., Chen, L. T., & Whang-Peng, J. (1999). The status of the do-not-resuscitate order in Chinese clinical trial patients in a cancer centre. *Journal of Medical Ethics, 25*(4), 309-314. http://dx.doi.org/10.1136/jme.25.4.309

Long, K. A., Marsland, A. L., Wright, A., & Hinds, P. (2015). Creating a tenuous balance: Siblings' experience of a brother's or sister's childhood cancer diagnosis. *Journal of Pediatric Oncology Nursing, 32*(1), 21-31. http://dx.doi0.1177/1043454214555194

Lyngstad, T. H. (2013). Bereavement and divorce: Does the death of a child affect parents' marital stability? *Family Science, 4*(1), 79-86. http://dx.doi10.1080/19424620.2013

MacDonald, D. B., & Hudson, G. (2012). The genocide question and Indian residential schools in Canada. *Canadian Journal of Political Science/Revue Canadienne de Science Politique, 45*(2), 427-449. https://doi.org/10.1017/S000842391200039X

Macías, M., Zornoza, C., Rodriguez, E., García, J. A., Fernández, J. A., Luque, R., & Collado, R. (2015). Impact of hospital admission care at a pediatric unit: A qualitative study. *Pediatric Nursing, 41*(6), 285.

Mack, J. W., & Grier, H. E. (2004). The day one talk. *Journal of Clinical Oncology, 22*(3), 563-566.

MacMahon, D., & Thomas, S. (1998). Practical approach to quality of life in Parkinson's disease: The nurse's role. *Journal of Neurology, 245*(Suppl.1), 19-22. http://dx.doi10.1007/PL00007732

Madjar, I., McKinley, E. A., Deynzer, M., & Van der Merwe, A. (2010). *Beyond the first hurdle: Student persistence beyond the first semester of university study*: Auckland, New Zealand: University of Auckland, Faculty of Education.

Magnusson, J. E., & Fennell, J. A. (2011). Understanding the role of culture in pain: Māori practitioner perspectives of pain descriptors. *The New Zealand Medical Journal, 124*(1328).

Mark, G. T., & Lyons, A. C. (2010). Māori healers' views on well-being: The importance of mind, body, spirit, family and land. *Social Science & Medicine, 70*(11), 1756-1764. http://dx.doi10.1016/j.socscimed.2010.02.001

Marriott, L., & Sim, D. (2015). Indicators of inequality for Māori and Pacific people. *Journal of New Zealand Studies*, (20), 24. Marsden, J., & Chambers, L. (2012). International Aspects. In A. Goldman, R. Hain, & S. Liben (Eds.), *Oxford textbook of palliative care for children* (2nd ed., pp. 458-470). Oxford, England: Oxford University Press. http://dx.doi10.1080/10428230902871173

Marston, J., & Chambers, L. (2012). International aspects. In *Oxford textbook of palliative care for children* (pp. 458-470). Oxford University Press, Oxford.

Martinson, K. (1999). *Literature review on service coordination and integration in the welfare and workforce development systems*. Washington, DC: Urban Institute. Retrieved from http://www.urban.org/url.cfm?ID=408026

Matsumoto, D., & Fletcher, D. (1996). Cross-national differences in disease rates as accounted for by meaningful psychological dimensions of cultural variability. *Journal of Gender, Culture, and Health, 1*, 71-82.

Maua-Hodges, T. (n.d.). The Tivaevae model (2014) In *Pacific Health Research Guidelines*. Auckland: Health Research Council of New Zealand.

Mays, N., & Pope, C. (1995). Rigour and qualitative research. *BMJ: British Medical Journal, 311*(6997), 109-112. https://doi.org/10.1136/bmj.311.6997.109

McCubbin, H. I., McCubbin, M. A., Patterson, J. M., Cauble, A. E., Wilson, L. R., & Warwick, W. (1983). CHIP. Coping health inventory for parents: An assessment of parental coping patterns in the care of the chronically ill child. *Journal of Marriage and the Family*, 359-370. http://dx.doi.org/10.1080/02739610802437202

McCubbin, H. I., Thompson, A. I., & McCubbin, M. A. (1996). *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice*. Madison: University of Wisconsin-Madison, Center for Excellence in Family Studies.

McDonald, J., Cumming, J., & Dew, K. (2009). An exploratory study of young carers and their families in New Zealand. *Kōtuitui: New Zealand Journal of Social Sciences Online, 4*(2), 115-129.

McFadden, P., Campbell, A., & Taylor, B. (2014). Resilience and burnout in child protection social work: Individual and organisational themes from a systematic literature review. *The British Journal of Social Work, 45*(5), 1546-1563. http://dx.doi10.1093/bjsw/bct210

McGrath, P. (2001). Caregivers' insights on the dying trajectory in hematology oncology. *Cancer Nursing, 24*(5), 413-421. http://dx.doi10.1097/00002820-200110000-00014

McGrath, P. (2007). 'I don't want to be in that big city; this is my country here': Research findings on Aboriginal peoples' preference to die at home. *Australian Journal of Rural Health, 15*(4), 264-268. http://dx.doi10.1111/j.1440-1584.2007.00904.x

McGrath, P., & Chesler, M. (2004). Fathers' perspectives on the treatment for pediatric hematology: Extending the findings. *Issues in Comprehensive Pediatric Nursing, 27*(1), 39-61. http://dx.doi.org/10.1080/01460860490279545

McGregor, D., Bayha, W., & Simmons, D. (2010). "Our responsibility to keep the land alive": Voices of Northern Indigenous researchers. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health, 8*(1), 101-123.

McKinney, C. (2006). *Māori Experiences of Hospital Care in Auckland: An Exploratory Study* (Unpublished Master of Public Health Thesis). University of Auckland, New Zealand.

McLeod, M., Harris, R., Purdie, G., Cormack, D., Robson, B., Sykes, P., ... & Walker, N. (2010). Improving survival disparities in cervical cancer between Māori and non-Māori women in New Zealand: a national retrospective cohort study. *Australian and New Zealand journal of public health, 34*(2), 193-199.

Mead, L. (1996). *Ngā aho o te kākahu mātauranga: The multiple layers of struggle by Māori in education* (Unpublished doctoral thesis). University of Auckland, Auckland, New Zealand.

Medical Council of New Zealand. (2016). *Good medical practice*. Retrieved from https://www.mcnz.org.nz/assets/News-and-Publications/good-medical-practice.pdf

Meleisea, M., & Schoeffel, P. (1998). Samoan families in New Zealand: The cultural context of change. In V. Adair & R. Dixon (Eds.), *The family in Aotearoa New Zealand* (pp. 158-178). Auckland, New Zealand: Addison Wesley Longman.

Metge, J. (2014). *New growth from old: The whānau in the modern world*. Wellington, New Zealand: Victoria University Press. http://dx.doiorg/10.1080/03468759608579326

Meyer, E. C., Ritholz, M. D., Burns, J. P., & Truog, R. D. (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. *Pediatrics, 117*(3), 649-657. http://dx.doi10.1542/peds.2005-0144

Miedema, B., Hamilton, R., Fortin, P., Easley, J., & Matthews, M. (2010). "You can only take so much, and it took everything out of me": Coping strategies used by parents of children with cancer. *Palliative & Supportive Care, 8*(2), 197-206. http://dx.doi10.1017/S1478951510000015

Mikaere, A. (1994). Māori women: Caught in the contradictions of a colonised reality. *Waikato L. Rev., 2,* 125. http://dx.doi/10.1177/1077801216638766

Mikkelsen, G., & Frederiksen, K. (2011). Family-centred care of children in hospital: A concept analysis. *Journal of Advanced Nursing, 67*(5), 1152-1162. http://dx.doi10.1111/j.1365-2648.2010.05574.x

Miller, L., & Caughlin, J. (2011). Cancer in the family. In M. Craft-Rosenberg & S.-R. Pehler (Eds.), *Encyclopedia of Family Health* (pp.123-127). Thousand Oaks, CA: Sage. https://doi.org/10.1186/1471-2458-12-3

Mills, C., Reid, P., & Vaithianathan, R. (2012). The cost of child health inequalities in Aotearoa New Zealand: A preliminary scoping study. *BMC Public Health, 12*(1), 384. https://doi.org/10.1186/1471-2458-12-384

Milroy, S. (1996). Māori women and domestic violence: The methodology of research and the Māori perspective. *Waikato Law Review, 4*(1), 58-76.

Ministry of Culture and Heritage. (2005). *Made in New Zealand. The Treaty of Waitangi*. Retrieved from http;//www.treatyofwaitangi.govt.nz

Ministry of Health. (2002). *He Korowai Oranga: The Māori health strategy*. Wellington New Zealand: Author.

Ministry of Health. (2007). *Whānau Ora health impact assessment*. Wellington New Zealand: Author.

Ministry of Health. (2008). *Improving quality of care for Pacific peoples*. Wellington New Zealand: Author.

Ministry of Health. (2009). *A Focus on the Health of Māori and Pacific Children: Key findings of the 2006/07 New Zealand Health Survey*. Wellington: Ministry of Health.

Ministry of Health. (2010a). *Kōrero Mārama: Health literacy and Māori results from the 2006 Adult Literacy and Life Skills survey.* Wellington New Zealand: Author.

Ministry of Health. (2010b). *Mortality and demographic data 2010*. Wellington New Zealand: Author.

Ministry of Health. (2012a). *The Health of New Zealand children 2011/12: Key findings of the New Zealand Health Survey*. Wellington New Zealand: Author.

Ministry of Health. (2012b). *Tupu Ola Moui: Pacific health chart book*. Wellington New Zealand: Author.

Ministry of Health. (2014a). *Ala Mo'ui: Pathways to Pacific health and well-being 2014–2018*. Wellington New Zealand: Author.

Ministry of Health. (2014b). *The guide to He Korowai Oranga – Māori Health Strategy.* Wellington New Zealand: Author.

Ministry of Health. (2014c). *National Travel Assistance Scheme.* Retrieved from http://www.health.govt.nz/our-work/hospitals-and-specialist-care/national-travel-assistance-scheme

Ministry of Health. (2015a). *Health and independence report*. Wellington New Zealand: Author.

Ministry of Health. (2015b). *Update of the New Zealand Health Strategy: All New Zealanders live well, stay well, get well: Consultation draft*. Wellington New Zealand: Author.

Ministry of Health. (2016). *New Zealand Health Strategy: Future direction.* Wellington New Zealand: Author.

Ministry of Health, & University of Otago. (2006). *Decades of disparity III: Ethnic and socio-economic inequalities in mortality, New Zealand, 1981 - 1999*. Wellington, New Zealand: Ministry of Health, University of Otago.

Ministry of Social Development. (2009). *Focus on families: New Zealand families of yesterday, today and tomorrow shortcutting policy: From concept to action for family-centred communities.* Retrieved from https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj35/social-policy-journal-35.pdf

Mitaera, J. (1997). Pastoral care and the "real world context" of Cook Islanders in Aotearoa New Zealand. In P. Culbertson (Ed.), *Counselling issues and South Pacific communities.* Auckland, New Zealand: Accent Publications.

Mitchison, D., Butow, P., Sze, M., Aldridge, L., Hui, R., Vardy, J., Goldstein, D. (2012). Prognostic communication preferences of migrant patients and their relatives. *Psycho-Oncology, 21*(5), 496-50. http://dx.doi10.1002/pon.1923

Moeke-Pickering, T. M. (1996). *Māori identity within whānau: A review of literature.* Hamilton, New Zealand: University of Waikato.

Moewaka Barnes, A., Taiapa, K., Borell, B., & McCreanor, T. (2013). Māori experiences and responses to racism in Aotearoa New Zealand. *Mai Journal: A New Zealand Journal of Indigenous Scholarship, 2*, 63-77. http://dx.doi10.1080/01419870802302272

Moewaka Barnes, H., Barnes, A. M., Baxter, J., Crengle, S., Pihama, L., Ratima, M. M., & Robson, B. (2013). *Hapū ora: Well-being in the early stages of life*. Auckland, New Zealand: Whāriki Research Group, SHORE and Whāriki Research Centre, Massey University. Retrieved from http://www.health.govt.nz/publication/hapu-ora-well-being-early-stages-life

Monterosso, L., & Kristjanson, L. (2008). Supportive and palliative care needs of families of children who die from cancer: An Australian study. *Palliative Medicine, 22*(1), 59-69. http://dx.doi10.1177/0269216307084608

Monterosso, L., Kristjanson, L., & Phillips, M. (2009). The supportive and palliative care needs of Australian families of children who die from cancer. *Palliative Medicine, 23*(6), 526-536. http://dx.doi10.1177/0269216307084608

Moorey, S. (2010). Unplanned hospital admission: Supporting children, young people and their families: Effective communication between staff and families is crucial in addressing

anxieties that follow a child's unexpected hospital stay, says Simone Moorey. *Paediatric Nursing, 22*(10), 20-23. http://dx.doi10.7748/paed2010.12.22.10.20.c8133

Moretz, J. G. (2010). Strengthening patient-and family-centred care: Learning through webinars. *Pediatric Nursing, 36*(3), 168-170.

Morrison, S., Vaioleti, T., & Veramu, J. (2002). Participatory approaches to learning and training. In: Commissioned report for the European Commission, Soqosoqo ni Vakamarama, Nabua, Fiji.

Morse, JM. (1995). The significance of saturation. *Qualitative Health Research*, *5*(3), 147-149.

Moyle, P., & Tauri, J. M. (2016). Māori, family group conferencing and the mystifications of restorative justice. *Victims & Offenders, 11*(1), 87-106. http://dx.doi10.1080/15564886.2015.1135496

Nabors, L. A., Kichler, J. C., Brassell, A., Thakkar, S., Bartz, J., Pangallo, J., Lundy, H. (2013). Factors related to caregiver state anxiety and coping with a child's chronic illness. *Families, Systems, & Health, 31*(2), 171-180. http://dx.doi10.1037/a0031240

Naef, R., Ward, R., Mahrer-Imhof, R., & Grande, G. (2017). A world shared–a world apart: The experience of families aft http://dx.er the death of a significant other late in life. *Journal of Advanced Nursing, 73*(1), 149-161. http://dx.doi10.1111/jan.13107

Nageswaran, S., Radulovic, A., & Anania, A. (2014). Transitions to and from the acute inpatient care setting for children with life-threatening illness. *Pediatric Clinics, 61*(4), 761-783. http://dx.doi.org/10.1016/j.pcl.2014.04.008

National Health Committee. (1998). *The social, cultural and economic determinants of health in New Zealand: action to improve health.* Wellington, New Zealand: National Advisory Committee on Health and Disability.

National Health Committee. (2009). *Qualitative study of elderly Pacific informal caregivers.* Wellington, New Zealand: Author.

National Multiple Sclerosis Society. (2008). *Continuum of care.* Retrieved from http://www.nationalmssociety.org/For-Professionals/Clinical-Care/Managing-MS/Continuum-of-Care

Needle, J. S., O'Riordan, M., & Smith, P. G. (2009). Parental anxiety and medical comprehension within 24 hrs of a child's admission to the pediatric intensive care unit. *Pediatric Critical Care Medicine, 10*(6), 668-674. http://dx.doi10.1097/PCC.0b013e3181a706c9

Nepe, T. M. (1991). *E Hao Nei E Tenei Reanga, Te Toi Huarewa Tipuna: Kaupapa Māori, an Educational Intervention System.* University of Auckland.

Newman, D. M., & Grauerholz, E. (2002). *Sociology of families* (2nd ed.) Thousand Oaks, CA: Sage.

Nguyen, T.-U. N., & Kagawa-Singer, M. (2008). *Overcoming barriers to cancer care through health navigation programs.* Paper presented at the Seminars in Oncology Nursing. http://dx.doi10.1016/j.soncn.2008.08.007

Nikora, L. W., Hodgetts, D., Carlson, T., & Rua, M. (2011). Māori and medications: What happens when the pills go home? *Alternative: An International Journal of Indigenous Peoples, 7*(2), 87-99. http://dx.doi10.1177/117718011100700202

Nikora, L. W., Karapu, R., Hickey, H., & Te Awekotuku, N. (2004). *Disabled Māori and disability support options.* Hamilton, New Zealand: Māori & Psychology Research Unit, University of Waikato, and Ministry of Health. http://dx.doi0.1186/1744-603-5-13

Nikora, L. W., Te Awekotuku, N., Rua, M., Temara, P., Maxwell, T. K., Murphy, E., Moeke-Maxwell, T. (2010). Tangihanga: The ultimate form of Māori cultural expression: Overview of a research programme. Retrieved from http://researchcommons.waikato.ac.nz/handle/10289/7968

Nishimoto, P. A. (1999). *Exploring the role of family appraisal and coping with caregiver stress: the experience of caring for children with cleft lip and palate* (Doctoral dissertation, University of Hawaii at Manoa).

NNADAP. (2008). Concerns, issues and emerging requisites for undertaking needs assessment in First Nations: International Symposium of needs assessment and needs-based planning for substance use services and supports. Toronto:The National Native Addictions Partnership Foundation.

Norris, P., Fa'alau, F., Va'ai, C., Churchward, M., & Arroll, B. (2009). Navigating between illness paradigms: Treatment seeking by Samoan people in Samoa and New Zealand. *Qualitative Health Research, 19*(10), 1466-1475. http://dx.doi10.1177/1049732309348364

Nursing Council of New Zealand. (2011). *Standards and guidelines for nurses.* Retrieved from http://www.nursingcouncil.org.nz/Publications/Standards-and-guidelines-for-nurses

O'Brien, I., Duffy, A., & Nicholl, H. (2009). Impact of childhood chronic illnesses on siblings: A literature review. *British Journal of Nursing, 18*(22). http://dx.doi10.12968/bjon.2009.18.22.45562

Office of the Auditor General. (2011). *Progress in delivering publicly funded scheduled services to patients.* Retrieved from http://www.oag.govt.nz/2011/scheduled-services

Orange, C. (1987a). An exercise in Māori autonomy: The rise and demise of the Māori War Effort Organization. *Aboriginal Peoples*, 237.

Orange, C. (1987b). *The Treaty of Waitangi: A historical overview*. Wellington, New Zealand: Bridget Williams Books.

Osborne, H. (2008). In other words: Tools of change: Telling and listening to stories. *On Call.* Retrieved from http://healthliteracy.com/2008/10/16/telling-stories/

Østbye, T., Welby, T., Prior, I., Salmond, C., & Stokes, Y. (1989). Type 2 (non-insulin-dependent) diabetes mellitus, migration and Westernisation: The Tokelau Island migrant study. *Diabetologia, 32*(8), 585-590. http://dx.doi10.1007/BF00285332

Otsuka, S. (2005). *Talanoa research: Culturally appropriate research design in Fiji.* Paper presented at the International Education Research Conference, Melbourne Australia.: http://dx.doi.org/10.11157/anzswj-vol22iss4id175

Øvretveit, J. (2011). *Evidence: Does clinical coordination improve quality and save money? Volume 1.* London, England: The Health Foundation.

Pacific Perspectives (2012). Pacific *Health Workforce Service Forecast. Report to Health Workforce New Zealand and the Ministry of Health.* Unpublished report. http://dx.doi.org/10.1787/888932524051

Pai, M. S., Bhaduri, A., Jain, A. G., Kumar, V., & Sethi, S. (2008). The experiences of mothers of pediatric surgery children: A qualitative analysis. *Journal of Pediatric Nursing, 23*(6), 479-489. http://dx.doi10.1016/j.pedn.2007.08.016

Paley, N. (2008). *Partners in grief: Couples' narratives of the transition from pediatric palliative care into bereavement* (Unpublished master's thesis)*.* University of British Columbia, Vancouver, Canada. http://dx.doi10.14288/1.0054465

Papakura, M. (1986). *Makereti: The old-time Māori*. Auckland, New Zealand: New Women's Press.

Paradies, Y. (2006). A systematic review of empirical research on self-reported racism and health. *International Journal of Epidemiology, 35*(4), 888-901. https://doi.org/10.1093/ije/dyl056

Pasefika Proud. (2016). *The profile of Pacific peoples in New Zealand.* Retrieved from http://www.pasefikaproud.co.nz/assets/Resourcesfordownload/PasefikaProudResource -Pacific-peoples-paper.pdf. http://dx.doi:10.1111/1753-6405.12491

Patton, M. Q. (1990). *Qualitative evaluation and research methods.* Thousand Oaks, CA: SAGE.

Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work, 1*(3), 261-283. http://dx.doi10.1177/1473325002001003636

Pauly, B. M., MacKinnon, K., & Varcoe, C. (2009). Revisiting "who gets care?": Health equity as an arena for nursing action. *Advances in Nursing Science, 32*(2), 118-127. http://dx.doi10.1097/ANS.0b013e3181a3afaf

PedPalASCNET. (n.d.). *Children, families and pediatric palliative care research.* Retrieved from http://pediatricpalliative.com/children-families/

Peel, C., Thomas, S., & Worth, P. (2013). Developing an integrated care pathway: The process and its application to neurological conditions. *British Journal of Neuroscience Nursing, 9*(6). https://doi.org/10.12968/bjnn.2013.9.6.292

Pega, F., Carter, K., Blakely, T., & Lucas, P. (2012). In-work tax credits for families and their impact on health status in adults. *Cochrane Database Syst Rev, 7*. http://dx.doi10.1002/14651858.CD009963.pub2

Penehira, M. (2011). *Mouri Tu, Mouri Moko, Mouri Ora! Moko as a well-being strategy* (Unpublished doctoral thesis)*.* University of Waikato, Hamilton, New Zealand.

Pere, R. (1984). *Te oranga o te whānau: The health of the family.* Paper presented at the Hui Whakaoranga: Māori health planning workshop.

Pihama, L. (1998). Reconstructing meanings of family: Lesbian/gay whānau and families in Aotearoa. In V. Adair & R. Dixon (Eds.), *The family in Aotearoa New Zealand* (pp. 179-207). Auckland, New Zealand: Addison Wesley Longman.

Pihama, L. (2001). *Tihei mauri ora: Honouring our voices. Mana Wāhine as a Kaupapa Māori Theoretical Framework* (Doctoral thesis). University of Auckland, Auckland, New Zealand. Retrieved from http://www.tutamawahine.org.nz/tihea_mauri_ora

Pihama, L., Cram, F., & Walker, S. (2002). Creating methodological space: A literature review of Kaupapa Māori research. *Canadian Journal of Native Education, 26*(1), 30.

Pihama, L., & Penehira, M. (2005). *Building baseline data on Māori, whānau development and Māori realising their potential.* Auckland, New Zealand, Te Puni Kōkiri.

Pitama, S., Huria, T., & Lacey, C. (2014). Improving Māori health through clinical assessment: Waikare o te Waka o Meihana. *The New Zealand Medical Journal, 127*(1393), 107-119. http://dx.doi10.177.1043659614523991

Pitama, S., Robertson, P., Cram, F., Gillies, M., Huria, T., & Dallas-Katoa, W. (2007). Meihana model: A clinical assessment framework. *New Zealand Journal of Psychology, 36*(3), 118-125. http://dx.doi10.1111/j.1753-6405.2011.00702

Polit, D., & Hungler, B. (1995). Essentials of Nursing Research: Methods, Appraisal, and Utilisation (5th ed.). Philadelphia, PA: Lippincott. https://doi.org/10.7748/ns2008.04.22.32.30.b745

Poole, P. J., Moriarty, H. J., Wearn, A. M., Wilkinson, T. J., & Weller, J. M. (2009). Medical student selection in New Zealand: Looking to the future. *The New Zealand Medical Journal, 122*(1306), 88-100.

Porsanger, J. (2004). An essay about Indigenous methodology. *Nordlit: Special Issue on Northern Minorities 15*(2004), 105-120. http://dx.doi.org/10.1139/y95-099

Prescott, S. M. (2008). Using talanoa in Pacific business research in New Zealand: Experiences with Tongan entrepreneurs. *Alternative: An International Journal of Indigenous Peoples, 4*(1), 127-148. https://doi.org/10.1177/117718010800400111

Putaiora Writing Group. (2010). *Te Ara Tika guidelines for Māori research ethics: A framework for researchers and ethics committee members*. Auckland, New Zealand: Health Research Council of New Zealand.

Putsch R. W., III, & Joyce, M. (1990). Dealing with patients from other cultures. In H. K. Walker, W. D. Hall, & J. W. Hurst (Eds.), *Clinical methods: The history, physical, and laboratory examinations* (3rd ed.). Boston, MA: Butterworths.

Radio New Zealand. (2017). *Hundreds protest axing of Lakes DHB cultural unit*. Retrieved from http://www.radionz.co.nz/news/te-manu-korihi/333039/hundreds-protest-axing-of-lakes-dhb-cultural-unit

Raffensperger, M. (2012). *From our perspective: Exploring the strength and resilience of families that include a parent with a disability*. Wellington, New Zealand: Families Commission.

Rahiri, J. L., Lauti, M., Harwood, M., MacCormick, A. D., & Hill, A. G. (2017). Ethnic disparities in rates of publicly funded bariatric surgery in New Zealand (2009–2014). *ANZ Journal of Surgery*. http://dx.doi/10.1111/ans.13997

Ramacake, S. (2010). Fijian social work practice. *Aotearoa New Zealand Social Work, 22*(4), 38-43 http://dx.doi.org/10.11157/anzswj-vol22iss4id175

Ramsden, I. (1990). Kawa whakaruruhau – cultural safety in nursing education in Aotearoa: Report to the Ministry of Education. Wellington: Ministry of Education. http://dx.doi10.1002/14651858

Rando, T. A. (Ed.). (2000). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers*. Champaign, ILL: Research Press. http://dx.doi.org/10.1016/S0882-5963(01)70014-0

Raphael, D. (2010). The health of Canada's children. Part III: Public policy and the social determinants of children's health. *Paediatrics & Child Health, 15*(3), 143-149. https://doi.org/10.1093/pch/15.3.143.

Rasmussen, S. (2011). *Stories families/ whānau tell to describe care by nurses within hospital: A narrative analysis* (Unpublished master's thesis), Auckland University of Technology, Auckland, New Zealand. http://dx.doi10.1186/1472-6963-10-333

Ratima, K., & Ratima, M. (2003). *Māori public health action: A role for all public health professionals*. Wellington, New Zealand: National Health Committee.

Ratima, M. (2001). *Kia uruuru mai a hauora: Being healthy, being Māori: Conceptualising Māori health promotion* (Doctoral thesis). University of Otago, Dunedin, New Zealand.

Ratima, M., Brown, R. M., Garrett, N. K., Wikaire, E. I., Ngawati, R. M., Aspin, C. S., & Potaka, U. K. (2007). Strengthening Māori participation in the New Zealand health and disability workforce. *Medical Journal of Australia, 186*(10), 541-543. http://dx.doi10.1111/1753-6405.12029

Ratima, M., Brown, R., Garrett, N., Wikaire, E., Ngawati, R., Aspin, C., & Potaka, U. (2008). *Rauringa Raupa: Recruitment and retention of Māori in the health and disability*

workforce. Retrieved from http://www.health.govt.nz/publication/rauringa-raupa-recruitment-and-retention-Māori-health-and-disability-workforce

Ravindran, V. P., & Rempel, G. R. (2011). Grandparents and siblings of children with congenital heart disease. *Journal of Advanced Nursing, 67*(1), 169-175. http://dx.doi10.1111/j.1365-2648.2010.05482.x

Ray, S. (2002). 'Those whom God hath joined together': Bondage metaphors and marital advice in early modern England. In K. Boyd McBride (Ed.), *Domestic arrangements in early modern England* (pp. 15-47). Pittsburgh, PA: Duquesne University Press.

Reid, P., & Robson, B. (2006). The state of Māori health. *State of the Māori nation: Twenty-first-century issues in Aotearoa.* Auckland, New Zealand: Reed.

Reid, P., & Robson, R. (2007). Understanding health inequities. In B. Robson & R. Harris. (Eds.), *Hauora: Māori standards of health IV. A study of the years 2000–2005* (pp. 3–10). Wellington, New Zealand: Te Ropu Rangahau Hauora a Eru Pomare.

Reid, P., Robson, B., & Jones, C. (2000). Disparities in health: Common myths and uncommon truths. *Pacific Health Dialog, 7*(1), 38-47.

Rempel, G. R., Ravindran, V., Rogers, L. G., & Magill-Evans, J. (2013). Parenting under pressure: A grounded theory of parenting young children with life-threatening congenital heart disease. *Journal of Advanced Nursing, 69*(3), 619-630. http://dx.doi10.1111/j.1365-2648.2012.06044.x

Restrepo, E., & Davis, L. (2003). Storytelling: Both art and therapeutic practice. *International Journal for Human Caring, 7*(1), 43-48.

Revenson, T. A. (2003). Scenes from a marriage: Examining support, coping, and gender within the context of chronic illness. In J. M. Suls & K. A. Wallston (Eds.), *Social psychological foundations of health and illness* (pp. 530-559). Malden, MA: Blackwell. http://dx.doi.org/10.1002/9780470753552.ch19

Rice, B. (2005). Seeing the world through Aboriginal eyes: A four-dimensional perspective on human vs non-human values, culture and relationships on Turtle Island. Winnipeg, Canada. Aboriginal Issues Press.

Robie, D. (2013). The 'talanoa' and the tribal paradigm: Reflections on cross-cultural reporting in the Pacific. *Australian Journalism Review, 35*(1), 43.

Robinson, D., & Robinson, K. (2005). *"Pacific ways" of talk: Hui and talanoa*. Wellington, New Zealand: New Zealand Trade Consortium.

Robson, B., Cormack, D., & Cram, F. (2000). Social and economic indicators. In B. Robson & R. Harris. (Eds.), *Hauora: Māori standards of health IV. A study of the years 2000–2005* (pp. 21-32). Wellington, New Zealand: Te Ropu Rangahau Hauora a Eru Pomare.

Robson, B., & Ellison-Loschmann, L. (2016). Māori and cancer care in Aotearoa/New Zealand–responses to disparities. *European Journal of Cancer Care, 25*(2), 214-218. http://dx.doi10.1111/ecc.12472

Robson, B., & Harris, R. (Eds.). (2007). *Hauora: Màori Standards of Health IV. A study of the years 2000–2005*. Wellington, New Zealand: Te Ropu Rangahau Hauora a Eru Pomare.

Robson, B., & Reid, P. (2001). *Ethnicity matters: Māori perspectives*. Wellington, New Zealand: Statistics New Zealand.

Roer-Strier, D. (2001). Reducing risk for children in changing cultural contexts: Recommendations for intervention and training. *Child Abuse & Neglect, 25*(2), 231-248. http://dx.doi10.1016/S0145-2134(00)00242

Rogers, C. H., Floyd, F. J., Seltzer, M. M., Greenberg, J., & Hong, J. (2008). Long-term effects of the death of a child on parents' adjustment in midlife. *Journal of Family Psychology, 22*(2), 203. http://dx.doi10.1037/0893-3200.22.2.203

Ronald McDonald House Charities New Zealand. (2016a). About Us. Retrieved from https://rmhc.org.nz/about/.

Ronald McDonald House Charities New Zealand. (2016b). *Keeping families close.* Retrieved from https://rmhc.org.nz/

Ronald McDonald House Charities New Zealand. (2016c). Ronald McDonald House Auckland. Retrieved from https://rmhc.org.nz/house/auckland/

Ronald McDonald House Charities New Zealand. (2016d). *Ronald McDonald House Impact Report 2016*. Ronald McDonald House Charities.

Ronald McDonald House Charities. (2017). *Ronald McDonalld House Charities Newsletter.Volume 2, (page 4).*

Rossiter, C., Fowler, C., Hopwood, N., Lee, A., & Dunston, R. (2011). Working in partnership with vulnerable families: The experience of child and family health practitioners. *Australian Journal of Primary Health, 17*(4), 378-383. http://dx.doi10.1071/PY11056

Rubin, H. J., & Rubin, I. S. (2011). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage. http://dx.doi.org/10.4135/9781452226651

Rumball-Smith, J., Sarfati, D., Hider, P., & Blakely, T. (2013). Ethnic disparities in the quality of hospital care in New Zealand, as measured by 30-day rate of unplanned readmission/death. *International Journal for Quality in Health Care, 25*(3), 248-254. http://dx.doi10.1093/intqhc/mzt012

Salesa, T. D. (2001). 'The power of the physician': Doctors and the 'dying Māori' in early colonial New Zealand. *Health and History, 3*(1), 13-40. http://dx.doi10.2307/4011139

Sam, D. L. (2006). Acculturation: Conceptual background and core components. In D. L. Sam & J. W. Berry (Eds.), *The Cambridge Handbook of acculturation psychology* (pp. 11-26).

Cambridge, England: Cambridge University Press. http://dx.doi.org/10.1017/CBO9780511489891.005

Samu, K., Ulugia-Veukiso, A., & Perese, L. (2009). *Pacific Non-Regulated Health Workforce Study Phase 1: Executive summary.* Auckland, New Zealand: University of Auckland.

Sanchez, C., & De Cunto, C. (2014). Quality of life in children with chronic diseases and their caregivers staying at the Ronald McDonald House. *Archivos Argentinos de-Pediatria*. http://dx.doi.org/10.5546/aap.2014.eng.231

Sandelowski, M. (1995). Sample size in qualitative research. *Research in nursing & health*, *18*(2), 179-183.

Sartore, G., Lagioia, V., & Mildon, R. (2013). Peer support interventions for parents and carers of children with complex needs. *The Cochrane Library.* http://dx.doi10.1002/14651858.CD010618

Schmidt, A. (1988). *Language in a Fijian village: An ethnolinguistic study* (Unpublished doctoral thesis). Australian National University, Canberra, Australia.

Searight, H. R., & Gafford, J. (2005). Cultural diversity at the end of life: Issues and guidelines for family physicians. *American Family Physician, 71*(3). http://dx.doi:10.1111/j.1468-232X.2010.00598.x

Seidman, I., Rubin, H. J., Rubin, I. S., & Dilley, P., . (2004). Interviews and the philosophy of qualitative research. *The Journal of Higher Education, 75*(1), 127-132. http://dx.doi10.1353/jhe.2003.0049

Sekimoto, M., Asai, A., Ohnishi, M., Nishigaki, E., Fukui, T., Shimbo, T., & Imanaka, Y. (2004). Patients' preferences for involvement in treatment decision making in Japan. *BMC Family Practice, 5*(1), 1. https://doi.org/10.1186/1471-2296-5-1

Seneviratne, S., Campbell, I., Scott, N., Coles, C., & Lawrenson, R. (2015). Treatment delay for Māori women with breast cancer in New Zealand. *Ethnicity & health*, *20*(2), 178-193. http://dx.doi10.1080/13557858.2014.895976

Shapiro, J., Perez, M., & Warden, M. J. (1998). The importance of family functioning to caregiver adaptation in mothers of child cancer patients: Testing a social ecological model. *Journal of Pediatric Oncology Nursing, 15*(1), 47-54. http://dx.doi10.1016/S1043-4542(98)90007-8

Shields, L. (2010). Questioning family-centred care. *Journal of Clinical Nursing, 19*(17-18), 2629-2638. http://dx.doi10.1111/j.1365-2702.2010.03214.x

Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: A review of qualitative studies. *Journal of Clinical Nursing, 15*(10), 1317-1323.

Shields, L., Pratt, J., Davis, L., & Hunter, J. (2007). Family-centred care for children in hospital. *Cochrane Database Syst Rev, 1*. http://dx.doi10.1002/14651858.CD004811

Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J., & Pascoe, E. (2012). Family-centred care for hospitalised children aged 0-12 years:A systematic review of quasi-experimental studies. JBI Library of Systematic Reviews, *10*(39), 2559-2592. http://dx.doi10.11124/jbisrir-2011-341

Shudy, M., de Almeida, M. L., Ly, S., Landon, C., Groft, S., Jenkins, T. L., & Nicholson, C. E. (2006). Impact of pediatric critical illness and injury on families: A systematic literature review. *Pediatrics, 118*(Suppl 3), S203-S218. http://dx.doi10.1542/peds.2006-0951

Silva-Rodrigues, F. M., Pan, R., Sposito, A. M., de Andrade Alvarenga, W., & Nascimento, L. C. (2016). Childhood cancer: Impact on parents' marital dynamics. *European Journal of Oncology Nursing, 23*, 34-42. http://dx.doi10.1016/j.ejon.2016.03.002

Simon, K. (1993). Perceived stress of nonhospitalized children during the hospitalization of a sibling. *Journal of pediatric nursing, 8*, 298-298. http://dx.doi10.1177/1367493508096203

Simon, T. D., Berry, J., Feudtner, C., Stone, B. L., Sheng, X., Bratton, S. L., & Srivastava, R. (2010). Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics, 126*(4), 647-655. http://dx.doi10.1136/bmj.b4411

Slater, T., Matheson, A., Davies, C., Tavite, H., Ruhe, T., Holdaway, M., & Ellison-Loschmann, L. (2013). 'It's whānaungatanga and all that kind of stuff': Māori cancer patients' experiences of health services. *Journal of Primary Health Care, 5*(4), 308-314. http://dx.doi.10.1177/1049732316656161

Sloper, T., & Beresford, B. (2006). Families with disabled children: Social and economic needs are high but remain largely unmet. *BMJ: British Medical Journal, 333*(7575), 928. http://dx.doi.org/10.1136/bmj.39017.633310

Smedley, B. D., Stith, A. Y., & Nelson, A. R. (2003). *Institute of Medicine, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. Unequal treatment: confronting racial and ethnic disparities in health care.* Washington, DC: National Academies Press. https://dx.doi.org/10.17226/10260

Smith, C. (2008). *Māori grandparents: Raising mokopuna fulltime.* Paper presented at the Traditional Knowledge Conference 2008 Te Tatau Pounamu: The Greenstone Door.

Smith, G. H. (1997). *The development of kaupapa Māori: Theory and praxis.* Auckland, New Zealand: University of Auckland. https://dx.doi:10.1080/13645570600916049

Smith, J., Cheater, F., & Bekker, H. (2015). Parents' experiences of living with a child with a long-term condition: A rapid structured review of the literature. *Health Expectations, 18*(4), 452-474. https://dx.doi10.1111/hex.12040

Smith, L. T. (1996). *Ngā Aho o Te Kakahu Mātauranga: The multiple layers of struggle by Māori in education.* Auckland, New Zealand: University of Auckland.

Smith, L. T. (1999). *Decolonising methodologies. Research and Indigenous peoples.* London, England: Zed Books. http://dx.doi.org/10.1080/09614524.2013.790946

Smith, L. T. (2000). Kaupapa Māori research. In M. Battiste (Ed.), *Reclaiming Indigenous voices and vision* (pp. 225-247). Vancouver, Canada: UBC Press.

Social Policy Evaluation and Research Unit. (2016). *Families and Whānau Status Report 2016*. Wellington, New Zealand: Author.

Solar, O., & Irwin, A. (2007). *A conceptual framework for action on the social determinants of health. Discussion paper.* WHO Commission on Social Determinants of Health. http://dx.doi10.4236/ojpm.2014.49081

Sopoaga, F., Zaharic, T., Kokaua, J., Ekeroma, A. J., Murray, G., & van der Meer, J. (2013). Pacific students undertaking the first year of health sciences at the University of Otago, and factors associated with academic performance. *The New Zealand Medical Journal, 126*(1384), 96-108.

Soutar, M. (2000). *Ngāti Porou leadership: Rāpata Wahawaha and the politics of conflict:" Kei te ora nei hoki tātou, me tō tātou whenua": a thesis presented for the degree of Doctor of Philosophy in Māori Studies at Massey University, Palmerston North, New Zealand.* Massey University,

Stanhope, J., & Prior, I. (1976). The Tokelau Island migrant study: Prevalence of various conditions before migration. *International Journal of Epidemiology, 5*(3), 259-266. https://doi.org/10.1093/ije/5.3.259

Staniforth, B., Fouché, C., & Beddoe, L. (2014). Public perception of social work and social workers in Aotearoa New Zealand. *Aotearoa New Zealand Social Work, 26*(2/3), 48-60. http://dx.doi.org/10.11157/anzswj-vol26iss2-3id42

Starship Children's Health. (2017a). Retrieved from http://en.wikioedua.org/wiki//Starship _Children%27s_Health

Starship. (2017b). *About us.* Retrieved from https://www.starship.org.nz/for-health-professionals /clinical-services-at-starship/paediatric-intensive-care-service-picu/about-us/.

Starship. (2017c). *Philosophy and values.* Retrieved from https://www.starship.org.nz/for-health-professionals/interested-in-working-at-starship/nursing-staff/philosophy-and-values/ https://www.starship.org.nz/

Starship. (2017d). *Starship Paediatric intensive care unit (PICU).* Retrieved from https://www.starship.org.nz/patients-parents-and-visitors/directory-of-services/Intensive-Care-Unit-PICU/

Starship. (2017e). *Staying with your child.* Retrieved from https://www.starship.org.nz/patients-parents-and-visitors/your-childs-hospital-or-daystay-admission/staying-with-your-child/

Starship. (2017f). *Support Groups.* Retrieved from *https://www.starship.org.nz/patients-parents-and-visitors/whats-at-starship/your-a-z-of-resources-and-facilities/support-groups/.*

Starship. (2017g). *Your rights.* Retrieved from https://www.starship.org.nz/patients-parents-and-visitors/your-rights/

Starship. (2017). *Hospital Grandparents.* Retrieved from https://www.starship.org.nz/patients-parents-and-visitors/whats-at-starship/your-a-z-of-resources-and-facilities/hospital-grandparents/

Statistics New Zealand. (2002). *Pacific progress: A report on the economic status of Pacific peoples in New Zealand.* Wellington, New Zealand: Author.

Statistics New Zealand. (2007). *Tokelauan people in New Zealand: 2006.* Wellington, New Zealand: Author.

Statistics New Zealand. (2013). *Census QuickStats about culture and identity*. Wellington, New Zealand: Author.

Statistics New Zealand. (2014). *Demographics of New Zealand's Pacific population*. Wellington, New Zealand: Author.

Statistics New Zealand and Ministry of Pacific Island Affairs. (2011). *Health and Pacific peoples in New Zealand*. Wellington, New Zealand: Authors.

Stehl, M. L., Kazak, A. E., Alderfer, M. A., Rodriguez, A., Hwang, W.-T., Pai, A. L., Reilly, A. (2008). Conducting a randomized clinical trial of an psychological intervention for parents/caregivers of children with cancer shortly after diagnosis. *Journal of Pediatric Psychology, 34*(8), 803-816. http://dx.doi10.1093/jpepsy/jsn130

Stevenson, A., Pearce, J., Blakely, T., Ivory, V., & Witten, K. (2009). Neighbourhoods and health: A review of the New Zealand literature. *New Zealand Geographer, 65*(3), 211-221. http://dx.doi10.1111/j.1745-7939.2009.01164.x

Streisand, R., Kazak, A. E., & Tercyak, K. P. (2003). Pediatric-specific parenting stress and family functioning in parents of children treated for cancer. *Children's Health Care, 32*(4), 245-256. http://dx.doi.org/10.1207/S15326888CHC3204_1

Stremler, R., Dhukai, Z., Wong, L., & Parshuram, C. (2011). Factors influencing sleep for parents of critically ill hospitalized children: A qualitative analysis. *Intensive and Critical Care Nursing, 27*(1), 37-45. http://dx.doi10.1016/j.iccn.2010.11.001

Suaalii-Sauni, T., McTaggart, S., & von Randow, M. (2009). *Pacific families now and in the future: A qualitative snapshot of household composition, well-being, parenting and economic decision-making among Pacific families in Auckland, 2008.* Wellington, New Zealand: New Zealand Families Commission.

Suaalii-Sauni, T., Tuagalu, I., Kirifi-Alai, T., & Fuamatu, N. (2008). *Su'esu'e Magoni: In search of fragrance: Tui Atua Tupua Tamasese Ta'isi and the Samoan Indigenous Reference*. Apia, Samoa: Centre for Samoan Studies, National University of Samoa.

Sullivan-Bolyai, S., Rosenberg, R., & Bayard, M. (2006). Fathers' reflections on parenting young children with type 1 diabetes. *MCN: The American Journal of Maternal/Child Nursing, 31*(1), 24-31. http://dx.doi:10.2337/diacare.22.5.713

Svavarsdóttir, E. K., & Örlygsdóttir, B. (2006). Comparison of health-related quality of life among 10-to 12-year-old children with chronic illnesses and healthy children: The parents' perspective. *The Journal of School Nursing, 22*(3), 178-185. https://dx.doi.org/10.1177/10598405060220030901

Svavarsdottir, E. K., & Sigurdardottir, A. O. (2006). *Developing a family-level intervention for families of children with cancer.* Paper presented at the Oncology Nursing Forum.

Swallow, V., Lambert, H., Santacroce, S., & MacFadyen, A. (2011). Fathers and mothers developing skills in managing children's long-term medical conditions: How do their qualitative accounts compare? *Child: Care, Health and Development, 37*(4), 512-523. https://dx.doi10.1111/j.1365-2214.2011.01219.x

Taiapa, J. (1995). *Ta Te Whānau Ohanga*: The economics of the whānau : Cultural survival at fiscal expense. *He Pukenga Korero*, 1(1). https://dx.doi:10.1111/j.1471

Tait, R. (2009). An outcomes framework for Pacific peoples in New Zealand: Report for the Ministry of Pacific Island Affairs. Retrieved from https://www.parliament.nz/resource/0000165828

Taki, M. (1996). *Kaupapa Māori and contemporary iwi resistance* (Unpublished master's thesis). The University of Auckland: Auckland, New Zealand.

Tamasese, K., Peteru, C., & Waldegrave, C. (1997). *The new morning: A qualitative investigation into Samoan perspectives on mental health and culturally appropriate services: A Research project carried out by the Family Centre*. Lower Hutt, New Zealand: The Family Centre. https://dx.doi10.1080/000486700782

Tamasese, K., Peteru, C., Waldegrave, C., & Bush, A. (2005). Ole Taeao Afua, the new morning: a qualitative investigation into Samoan perspectives on mental health and culturally appropriate services. *Australian & New Zealand Journal of Psychiatry, 39*(4), 300-309. https://dx.doi10.1080/000486700782

Tautolo, E.-S. (2011). *Pacific fathers cultivating the future: The health of Pacific fathers and their influence upon and involvement with their children.* Auckland, New Zealand: Auckland University of Technology.

Tautolo, E.-S., Schluter, P. J., & Paterson, J. (2015). Pacific father involvement and early child behaviour outcomes: Findings from the Pacific Islands families study. *Journal of Child and Family Studies, 24*(12), 3497-3505. https://dx.doi10.1007/s10826-015-0151-5

Tautolo, E.-S., Schluter, P. J., Paterson, J., & McRobbie, H. (2011). Acculturation status has a modest effect on smoking prevalence among a cohort of Pacific fathers in New Zealand. *Australian and New Zealand Journal of Public Health, 35*(6), 509-516. https://dx.doi10.1111/j.1753-6405.2011.00774.x

Tavola, H. (1992). Race is not the only issue in education in Fiji. *Directions: Journal of Educational Studies, 14*(2), 34-40.

Te Awekotuku, N. (1991). *He tikanga whakaaro: Research ethics in the Māori community: A discussion paper*. Wellington, New Zealand: Ministry of Māori Affairs.

Te Puni Kōkiri. (2007). *How Whānau Ora is different*. Retrieved from https://www.tpk.govt.nz/en/whakamahia/whānau-ora/about-whānau-ora

Te Puni Kōkiri. (2016). *Whānau Ora*. Retrieved from https://www.tpk.govt.nz/en /whakamahia/whānau -ora/

Te Puni Kōkiri. (2009). *Rangahau Tükino Whänau: Mäori research agenda on family violence.* Retrieved from https://www.tpk.govt.nz/documents/download/262/tpk-Māori-research-agenda.pdf

Te Puni Kōkiri. (2013). *Request for proposal RFP: Whānau Ora Commissioning Agency for Pacific Families.* Retrieved from https://www.tpk.govt.nz/_documents/rfp-whānau -ora-commissioning-agency-for-pacific-families.pdf

Te Rito, J. S. (2007). Whakapapa and whenua: An insider's view. *MAI Review LW, 1*(3), 8.

Theory of Knowledge. (2017). *How do we acquire knowledge in the human sciences?* Retrieved from http://www.theoryofknowledge.net/areas-of-knowledge/the-human-sciences/how-do-we-acquire-knowledge-in-the-human-sciences/

The Royal New Zealand College of General Practitioners. (2013). Continuing professional development programme 2014-2017. Retrieved from https://oldgp16.rnzcgp.org .nz/assets/documents/Training-and-Beyond/MOPS-and-CPD-Online-Programme-2014-2017.pdf

Thomas, M., Sampson, H., & Zhao, M. (2003). Finding a balance: Companies, seafarers and family life. *Maritime Policy & Management, 30*(1), 59-76. http://dx.doi.org/10.1080/0308883032000051630

Thompson, G. E., Cameron, R. E., & Fuller-Thomson, E. (2013). Walking the red road: The role of First Nations grandparents in promoting cultural well-being. *The International Journal of Aging and Human Development, 76*(1), 55-78. http://dx.**doi**: http://dx.doi.org/10.2190/AG.76.1.c

Thomson, M. D., & Hoffman-Goetz, L. (2009). Defining and measuring acculturation: A systematic review of public health studies with Hispanic populations in the United States. *Social Science & Medicine, 69*(7), 983-991.

Tiatia, J., & Foliaki, L. (2005). *Draft 4: Pacific Cultural Competencies Framework for District Health Boards.* Unpublished report.

Tiatia-Seath, J. (2014). Pacific peoples, mental health service engagement and suicide prevention in Aotearoa New Zealand. *Ethnicity and Inequalities in Health and Social Care, 7*(3), 111-121.

Tiatia-Seath, J. (2008). *Pacific cultural competencies: A literature review*. Wellington, New Zealand: New Zealand Ministry of Health.

Tibble, A., & Ussher, S. (2012). *Kei te pēwhea tō whānau? Exploring whānau using the Māori Social Survey.* Wellington, New Zealand: Statistics New Zealand.

Tipa, Z., Wilson, D., Neville, S., & Adams, J. (2015). Cultural responsiveness and the family partnership model. *Nursing Praxis in New Zealand, 31*(2), 35-50.

Titus, B., & de Souza, R. (2011). Finding meaning in the loss of a child: Journeys of chaos and quest. *Health Communication, 26*(5), 450-460. http://dx.doi.org/10.1080/10410236.2011.554167

Tong, A., Lowe, A., Sainsbury, P., & Craig, J. C. (2008). Experiences of parents who have children with chronic kidney disease: A systematic review of qualitative studies. *Pediatrics, 121*(2), 349-360. http://dx.doi10.1542/peds.2006-3470

Tourigny, J., Ward, V., & Lepage, T. (2004). Fathers' behaviour during their child's ambulatory surgery. *Issues in Comprehensive Pediatric Nursing, 27*(2), 69-81. http://dx.doi.org/10.1080/01460860490451804

Tsai, D. F.-C. (2001). How should doctors approach patients? A Confucian reflection on personhood. *Journal of Medical Ethics, 27*(1), 44-50. http://dx.doi.org/10.1136/jme.27.1.44

Tukuitonga, C. (2013). Pacific peoples in New Zealand. In I. M. St George (Ed.), *Cole's medical practice in New Zealand* (12th ed., pp. 67-72). Wellington, New Zealand: Medical Council of New Zealand,

Tukuitonga, C., Bell, S., & Robinson, E. (2000). Hospital admissions among Pacific children in Auckland, 1992-97. *New Zealand Medical Journal, 113*(1116), 358-361.

Tukukino, H. (1985). *Māori families.* Paper presented at the New Zealand Child Abuse Prevention Society Seminar, Hamilton, New Zealand.

Turia, T. (2014). *Whānau Ora achievements report*. Retrieved from https://www.tpk.govt.nz/en/a-matou-mohiotanga/whānau -ora/whānau -ora-achievements-report

U.S. Food and Drug Administration. (2002). *Guidance for industry: Information program on clinical trials for serious or life-threatening diseases and conditions.* Retrieved from https://www.fda.gov/downloads/regulatoryinformation/guidances/ucm126838.pdf

Vai'imene, G. (2003). *Api'i: Culture in education*. Rarotonga, Cook Islands: Cook Islands Culture, Institute of Pacific Studies and Cook Islands Extension Centre, University of the South Pacific, Suva and Rarotonga, in association with Cook Islands Cultural and Historical Places Trust and the Ministry of Cultural Development.

Vaioleti, T. (2003a). *Talanoa: Opportunity for cultural learning in research for Pacific and Indigenous peoples in New Zealand: Can invalid methods produce valid findings.* Paper presented at the Learning Conference, London.

Vaioleti, T. (2003b). *Talanoa research methodology: A perspective on Pacific research.* Paper presented at the Power, Politics and Practise-Pasifika Educators Conference, Auckland.

Vaioleti, T. (2006). Talanoa research methodology: A developing position on Pacific research. *Waikato Journal of Education, 12*(1), 21-34. http://dx.doi10.13140/RG.2.1.2202.8887

Vaka, S., Brannelly, T., & Huntington, A. (2016). Getting to the heart of the story: Using Talanoa to explore Pacific mental health. *Issues in Mental Health Nursing, 37*(8), 537-544. http://dx.doi10.1080/01612840.2016.1186253

Vaughn, L. M., Jacquez, F., & Bakar, R. C. (2009). Cultural health attributions, beliefs, and practices: Effects on health care and medical education. *The Open Medical Education Journal, 2*(1), 64-74.

Vermaes, I. P., van Susante, A. M., & van Bakel, H. J. (2012). Psychological functioning of siblings in families of children with chronic health conditions: A meta-analysis. *Journal of Pediatric Psychology, 37*(2), 166-184. http://dx.doi10.1093/jpepsy/jsr081

Vudiniabola, A. (2011). *The Fijian diploma of nursing curriculum: An Indigenous case study of a curriculum change* (Unpublished doctoral thesis). Massey University, Palmerston North, New Zealand.

Waitangi Tribunal. (2001). *The Napier hospital and health services report*: Legislation Direct.

Waiti, F. (2009). Te Tai o Poutini Haputanga. West Coast.

Waiti, J. T. (2014). *Whakaoranga whānau: A whānau resilience framework* (Unpublished doctoral thesis). Massey University, Wellington, New Zealand. http://dx.doi10.1016/j.appet.2014.07.005

Waldram, J. B., Herring, A., & Young, T. K. (2006). *Aboriginal health in Canada: Historical, cultural, and epidemiological perspectives*. Toronto, Canada: University of Toronto Press. https://doi.org/10.3138/cbmh.25.2.543

Walker, S. (1996). *Kia tau te rangimarie: Kaupapa Māori theory as a resistance against the construction of Māori as the other.* Auckland, New Zealand: University of Auckland.

Walker, T. (2014). Whānau-Māori and family. In *Te Ara, the Encyclopedia of New Zealand*. Retrieved from www.TeAra.govt.nz/en/whānau -Māori-and-family

Walker, T., & Porou, N. (2006). Whānau is whānau . *Blue Skies Report, 8*, 06.

Walker, T., Signal, L., Russell, M., Smiler, K., & Tuhiwai-Ruru, R. (2008). The road we travel: Māori experience of cancer. *The New Zealand Medical Journal (Online), 121*(1279). http://dx.doi10.1111/j.1365-2702.2011.04042.x

Walters, K. L., Mohammed, S. A., Evans-Campbell, T., Beltrán, R. E., Chae, D. H., & Duran, B. (2011). Bodies don't just tell stories, they tell histories: Embodiment of historical trauma among American Indians and Alaska Natives. *Du Bois Review: Social Science Research on Race, 8*(1), 179-189.

Walters, K. L., Stately, A., Evans-Campbell, T., Simoni, J. M., Duran, B., Schultz, K., & Guerrero, D. (2009). "Indigenist" collaborative research efforts in Native American communities. In

A. Rubin Stiffman (Ed.), *The field research survival guide* (pp. 146-173). New York, NY: Oxford University Press. http://dx.doi10.1093/acprof:oso/9780195325522.003.0008

Watson, J. M., Logan, H. L., & Tomar, S. L. (2008). The influence of active coping and perceived stress on health disparities in a multi-ethnic low income sample. *BMC Public Health, 8*(1), 41. https://doi.org/10.1186/1471-2458-8-41

Weerasinghe, S., & Mitchell, T. (2007). Connection between the meaning of health and interaction with health professionals: Caring for immigrant women. *Health Care for Women International, 28*(4), 309-328. http://dx.doi.org/10.1080/07399330601179794

Wengenroth, L., Rüegg, C. S., Michel, G., Essig, S., Ammann, R., Bergstraesser, E., & Kuehni, C. (2014). Life partnerships in childhood cancer survivors, their siblings, and the general population. *Pediatric Blood & Cancer, 61*(3), 538-545. http://dx.doi10.1002/pbc.24821

Wepa, D. (2016). *Struggling to be involved: A grounded theory of Māori whānau engagement with health care* (Unpublished doctoral thesis). Auckland University of Technology, Auckland, New Zealand. http://dx.doi10.016.h.sicscuned.2013.04.00710

Werkmeister-Rozas, L., & Klein, W. C. (2009). Cultural responsiveness in long-term-care case management: Moving beyond competence. *Care Management Journals, 10*(1), 2-7. http://dx.doihttps://doi.org/10.1891/1521-0987.10.1.2

Whakauae Research Services. (2017). Mana Tamariki, Mana Mokopuna, Mana Whānau: Evaluation Report. Whakauae Research Services.

Whānau Ora Taskforce. (2009). *Whānau Ora: A whānau -centred approach to Māori well-being.* Wellington, New Zealand: Ministry of Social Development.

Whanganui District Health Board. (2017). Retrieved from https://wdhb.org.nz/content/page/family-navigator/m/0/pre/3320/

Widmer, E. D. (2016). *Family configurations: A structural approach to family diversity*. Routledge

Wigert, H., Berg, M., & Hellström, A. L. (2010). Parental presence when their child is in neonatal intensive care. *Scandinavian Journal of Caring Sciences, 24*(1), 139-146. http://dx.doi10.1111/j.1471-6712.2009.00697

Wikaire, E. I. (2015). *Data speaks: Predictors of success in tertiary education health study for Māori and Pacific students.* Auckland, New Zealand: University of Auckland.

Wikipedia. (2017). Cook Islands culture. Retrieved from https://en.wikipedia.org/wiki/Culture_of_the _Cook_Islands

Williams, B. (1985). *Case study of Māori action against Conzinc Rio Tinto.* Paper presented at the Global Meeting on Environment and Development, Nairobi.

Williams, D. R., & Mohammed, S. A. (2013). Racism and health I: Pathways and scientific evidence. *American Behavioral Scientist, 57*(8), 1152-1173. http://dx.doi10.1177/0002764213487340

Williams, H. W. (1985). *A dictionary of the Māori language* (7th ed.). Wellington, New Zealand: Government Printer.

Williams, L., Labonte, R., & O'Brien, M. (2003). Empowering social action through narratives of identity and culture. *Health Promotion International, 18*(1), 33-40. https://doi.org/10.1093/heapro/18.1.33

Williams, P., Gray, M. A., Ka'ai, T. M., Moorfield, J. C., Mcpherson, K. M., Weinstein, P., & Nacey, J. (2003). Māori men's perceptions and experiences of health seeking for prostate health problems in New Zealand. *Pacific Health Dialog, 10*(2), 71-78Wilson, D. (2004). *Ngā kairaranga oranga: The weavers of health and well-being: A grounded theory study* (Unpublished doctoral thesis). Massey University, New Zealand.

Wilson, D., & Barton, P. (2012). Indigenous hospital experiences: A New Zealand case study. *Journal of Clinical Nursing, 21*(15-16), 2316-2326. http://dx.doi:10.1111/j.1365-2702.2011.04042.x

Wilson, D., & Nevelle, S. (2008). Nursing their way not our way: Working with vulnerable and marginalised populations. *Contemporary Nurse, 27*(2), 165-176. http://dx.doi10.555/conu.2008.27 .2.165

Wilson, S. (2001). What is an Indigenous research methodology? *Canadian Journal of Native Education, 25*(2), 175-179.

Wittenberg-Lyles, E. M., Goldsmith, J., Ragan, S. L., & Sanchez-Reilly, S. (2010). Medical students' views and ideas about palliative care communicatio training. *American Journal of Hospice and Palliative Medicine, 27*(1), 38-49. http://dx.doi10.1177/1049909109347327

Women's Health. (2017). *Infographic Question 4: answers.* Retrieved from http://www.whealth.com.au/documents/publications/cthg-infographic-question4-answers.pdf

Wong, M. Y., & Chan, S. W. (2006). The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing, 15*(6), 710-717. http://dx.doi10.1111/j.1365-2702.2006.01297.x

Wong, P. T., Wong, L. C., & Scott, C. (2006). Beyond stress and coping: The positive psychology of transformation. In P. Wong, L. Wong, & W. Lonner (Eds.), *Handbook of multicultural perspectives on stress and coping* (pp. 1-26). New York, NY: Springer.

Woodson, K. D., Thakkar, S., Burbage, M., Kichler, J., & Nabors, L. (2015). Children with chronic illnesses: Factors influencing family hardiness. *Issues in Comprehensive Pediatric Nursing, 38*(1), 57-69. http://dx.doi10.3109/01460862.2014.988896

Woolford, A. (2013). Nodal repair and networks of destruction: Residential schools, colonial genocide, and redress in Canada. *Settler Colonial Studies, 3*(1), 65-81. http://dx.doi.org/10.1080/18380743.2013.761936

World Health Organization. (1998). *The World Health report: 1998: Life in the 21st century: A vision for all: Executive summary.* Geneva, Switzerland: Author. Retrieved from www.who.int/whr/1998 /en/whr98_en.pdf d http://dx.oi10.12691/ajeid-1-4-4

World Health Organization. (2008). *Closing the gap in a generation: health equity through action on the social determinants of health: Commission on Social Determinants of Health final report*: Geneva, Switzerland: Author.

World Health Organization. (2014). *Social determinants of mental health.* Geneva, Switzerland: Author

Worrall, J. (2008). Kin care: Understanding the dynamics. *Social Work Now, 40*(3), 4-11.

Worrall, J. (2009a). *Grandparents and whānau /extended families raising kin children in Aotearoa/New Zealand.* Auckland, New Zealand: Grandparents Raising Grandchildren Trust.

Worrall, J. (2009b). When grandparents take custody-changing intergenerational relationships: The New Zealand experience. *Journal of Intergenerational Relationships, 7*(2-3), 259-273. http://dx.doi.org/10.1080/15350770902851106

Wray, J., Lee, K., Dearmun, N., & Franck, L. (2011). Parental anxiety and stress during children's hospitalisation: The StayClose study. *Journal of Child Health Care, 15*(3), 163-174 http://dx.doi10.1177/1367493511408632

Wright, T. (1995). Understanding cultural safety. *Nursing New Zealand, 1*(6), 22.

Yeo, G., & Hikoyeda, N. (2000). Cultural issues in end-of-life decision making among Asians and Pacific Islanders in the United States. In K. L. Braun, J. H. Pietsch, P. L. Blanchette (Eds.), *Cultural Issues in End-of-Life Decision Making* (pp. 101-126). Thousand Oaks, CA: Sage.

Yin, R. (1994). Case study research: Design and methods. Beverly Hills, CA: Sage. http://dx.doi10.3138/cjpe.30.1.108

Young, B., Clark, C., Kansky, J., & Pupo, E. (2014). *Definition: Continuum of care.* Retrieved from http://www.himss.org/definition-continuum-care

Zanchetta, M. S., & Poureslami, I. M. (2006). Health literacy within the reality of immigrants' culture and language. *Canadian Journal of Public Health/Revue Canadienne de Sante'e Publique*, S26-S30. http://dx.doi.org/10.17269/cjph.97.1523

Zurn, P., & Dumont, J.-C. (2008). *Health workforce and international migration: Can New Zealand compete?* (Vol. 19). Paris, France: OECD. http://dx.doi10.1371/journal 2010