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Māori whānau experiences of rheumatic fever: reflections of social and structural inequity

Hannah Margaret Burgess

Abstract

Background: Rheumatic fever is a devastating illness that poses a significant burden to Māori in Aotearoa (New Zealand). Despite well-established treatment and prevention interventions, Māori face inequitable rates of rheumatic fever, recurrent rheumatic fever, and rheumatic heart disease. Little is known about the persistence of these inequities for Māori.

Aims: This research sought to understand the lived experiences, knowledge and perspectives of Māori who have experienced recurrent rheumatic fever or re-hospitalisations for rheumatic fever and their whānau, in the Counties Manukau District Health Board (CMDHB) region of Tāmaki Makaurau (Auckland).

Methods: Whānau interviews informed by a Kaupapa Māori research methodology were employed to ascertain whānau experiences of rheumatic fever. Māori living within the CMDHB region who have experienced a recurrence of rheumatic fever or re-hospitalisations for rheumatic fever and their whānau were invited to participate in this research. Five interviews were undertaken with four different whānau, one participant chose to be interviewed alone. A total of 10 people participated in this research. A semi-structured interview schedule was used to guide data collection. Data was analysed using thematic analysis.

Findings: Four metathemes were identified from the interviews: whānau living contexts, whānau experiences in the health system, impacts of rheumatic fever, and the overarching importance of whānau. The findings of this research indicate that whānau were living in contexts of deprivation that significantly affected their access to health services. Health services did not meet the needs of whānau, and whānau received substandard care from healthcare providers. Poor communication and rapport from healthcare professionals was an important element that determined whānau experiences of healthcare. Rheumatic fever significantly impacted the lives of whānau, and whānau members played an important role in the experiences of those suffering from rheumatic fever, especially in mitigating negative experiences.

Conclusion: This research suggests that the health system plays an important role in contributing to ongoing rheumatic fever inequities for Māori. The health system is not responsive to the living contexts in which Māori access healthcare services and this needs to be urgently addressed. The findings of this research necessitate action to be taken that frames the health system itself as a locus for change.
Acknowledgements

Ko Ruapehu me Matauhipo ngā maunga, ko Whanganui me Waimarino ngā awa, ko Te Ātihaunui-ā-Pāpārangi me Ngāti Tūwharetoa ngā iwi, ko Hannah Burgess ahau.

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To my friends who have become whānau. Kamaia, of all of my acknowledgements, yours is the hardest to put into words. You are my rock. The aroha and energy you have provided me during this time has been pivotal to my spiritual and emotional growth, without which I could not have written this thesis. Stephany, again it is hard to put into words what you have contributed to this journey, you have given me life at such crucial times, thank you. Sophie, thank you for providing me with political/life guidance, and helping me to articulate my radical thoughts. And William, thank you for keeping me going.

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<tbody>
<tr>
<td>Aotearoa</td>
<td>New Zealand</td>
</tr>
<tr>
<td>Hapū</td>
<td>Sub-tribe</td>
</tr>
<tr>
<td>Hauora</td>
<td>Health, wellbeing</td>
</tr>
<tr>
<td>Hui</td>
<td>Meetings</td>
</tr>
<tr>
<td>Iwi</td>
<td>Tribe</td>
</tr>
<tr>
<td>Kai</td>
<td>Food, to eat</td>
</tr>
<tr>
<td>Kaumātua</td>
<td>Elder</td>
</tr>
<tr>
<td>Kanohi ki te kanohi</td>
<td>Face to face</td>
</tr>
<tr>
<td>Karakia</td>
<td>Prayer, incantation</td>
</tr>
<tr>
<td>Kaupapa Māori</td>
<td>Māori ideology</td>
</tr>
<tr>
<td>Kaupapa</td>
<td>Purpose, agenda, issue</td>
</tr>
<tr>
<td>Kāwanatanga</td>
<td>Governance</td>
</tr>
<tr>
<td>Koha</td>
<td>Gift</td>
</tr>
<tr>
<td>Kura Kaupapa Māori</td>
<td>Māori immersion primary school</td>
</tr>
<tr>
<td>Mana motuhake</td>
<td>Authority, self governance</td>
</tr>
<tr>
<td>Manaakitanga</td>
<td>Hospitality, kindness, support</td>
</tr>
<tr>
<td>Māori</td>
<td>The Indigenous peoples of New Zealand</td>
</tr>
<tr>
<td>Marae</td>
<td>Meeting house</td>
</tr>
<tr>
<td>Mātauranga</td>
<td>Knowledge, wisdom</td>
</tr>
<tr>
<td>Mihi whakatau</td>
<td>Brief introductions</td>
</tr>
<tr>
<td>Pākehā</td>
<td>New Zealander of European descent</td>
</tr>
<tr>
<td>Tangata whenua</td>
<td>Local people, indigenous people</td>
</tr>
<tr>
<td>Tauiwi</td>
<td>non-Māori New Zealander</td>
</tr>
<tr>
<td>Te ao Māori</td>
<td>The Māori world, Māori society</td>
</tr>
<tr>
<td>Te reo Māori</td>
<td>The Māori language</td>
</tr>
<tr>
<td>Te Tai Tokerau</td>
<td>Northland region of New Zealand</td>
</tr>
<tr>
<td>Te Tiriti o Waitangi</td>
<td>The Treaty of Waitangi</td>
</tr>
<tr>
<td>Tikanga</td>
<td>Customs, protocol</td>
</tr>
<tr>
<td>Tino rangatiratanga</td>
<td>Absolute sovereignty, self-determination</td>
</tr>
<tr>
<td>Whakapapa</td>
<td>Genealogy</td>
</tr>
<tr>
<td>Whakawhanaungatanga</td>
<td>A process of establishing relationships</td>
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<tr>
<td>Whānau</td>
<td>Family</td>
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ix
**List of Abbreviations**

<table>
<thead>
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<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AWHI</td>
<td>Auckland Wide Healthy Homes Initiative</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>CMDHB</td>
<td>Counties Manukau District Health Board</td>
</tr>
<tr>
<td>CNOS</td>
<td>Canadian National Occupancy Standard</td>
</tr>
<tr>
<td>CYF</td>
<td>Child, Youth and Family</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
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<tr>
<td>GAS</td>
<td>Group A streptococcus infection</td>
</tr>
<tr>
<td>NZ</td>
<td>New Zealand</td>
</tr>
<tr>
<td>OR</td>
<td>Odds Ratio</td>
</tr>
<tr>
<td>PHO</td>
<td>Primary Health Organisation</td>
</tr>
<tr>
<td>RFPP</td>
<td>Rheumatic Fever Prevention Programme</td>
</tr>
<tr>
<td>RNZCGP</td>
<td>Royal New Zealand College of General Practitioners</td>
</tr>
<tr>
<td>RR</td>
<td>Risk ratio</td>
</tr>
<tr>
<td>UAHPEC</td>
<td>University of Auckland Human Participants Ethics Committee</td>
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<tr>
<td>WINZ</td>
<td>Work and Income New Zealand</td>
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</table>
1 Introduction

This research sought to explore the lived experiences, knowledge and perspectives of Māori patients and their whānau who have experienced recurrent rheumatic fever or re-hospitalisations for rheumatic fever in the Counties Manukau District Health Board (CMDHB) region of Tāmaki Makaurau (Auckland). This chapter begins by providing a brief overview of rheumatic fever. The research context, research question, and research objectives will then be outlined and. The chapter concludes with an overview of the thesis structure of this thesis.

1.1 Rheumatic fever context

Rheumatic fever is a preventable disease that is caused by an auto-immune response to a highly contagious Group A streptococcus (GAS) throat infection. If left untreated, rheumatic fever can result in permanent heart damage and premature mortality. Globally, rates of rheumatic fever have decreased dramatically in developed countries and rheumatic fever is now rarely seen in affluent population groups (Carapetis, Steer, Mulholland, & Weber, 2005). This decrease in prevalence of rheumatic fever has been due to improved living conditions over the past century and an increase in medical technology and healthcare (Carapetis, Steer, et al., 2005; Seckeler & Hoke, 2011). Recent international data shows that rates of rheumatic fever are currently highest among Māori (the indigenous peoples of Aotearoa) and Pacific1 people in Aotearoa (New Zealand) (Milne, Lennon, Stewart, Vander Hoorn, & Scuffham, 2012a), and Aboriginal peoples of Australia (Parnaby & Carapetis, 2010).

Rheumatic fever and its sequela, RHD, pose a significant burden to Māori in Aotearoa. Significant inequities in rheumatic fever prevalence exist between Māori, Pacific, and non-Māori non-Pacific peoples and these inequities are widening (Gurney, Sarfati, Stanley, Wilson, & Webb, 2014; Milne et al., 2012a; Milne, Lennon, Stewart, Vander Hoorn, & Scuffham, 2012b). Rheumatic fever predominantly affects children with Māori aged five to 14 years being 20 times more likely to be diagnosed with rheumatic fever than non-Māori

1 The term ‘Pacific’ refers to a heterogeneous composite of peoples with Pacific nation ancestry and / or ethnicity, born or living in Aotearoa (A. Gray, 2001a).
non-Pacific peoples (Milne et al., 2012a). Māori are also more likely to suffer from recurrences of rheumatic fever and to be re-hospitalised due to rheumatic fever (Spinetto, Lennon, & Horsburgh, 2011). High rates of recurrence significantly increase the likelihood of developing rheumatic heart disease (RHD) and/or dying (Carapetis, McDonald, & Wilson, 2005). Recent data shows that RHD mortality rates are 5-10 times higher for Māori and Pacific peoples compared to non-Māori non-Pacific (Milne et al., 2012b).

Addressing rheumatic fever is currently a health priority in Aotearoa. In 2012, the government identified reducing rates of rheumatic fever as one of ten priority areas for the public health sector to address (Ministry of Health, 2015b). The Ministry of Health has implemented the Rheumatic Fever Prevention Programme (RFPP) since 2011, which aims to reduce rheumatic fever through the prevention of strep throat infections. The government has since invested NZ$65 million in addressing rheumatic fever nationally (Ministry of Health, 2016). The Government also has an imperative to address rheumatic fever inequities as signatories to Te Tiriti o Waitangi (Te Tiriti) (Reid, 2011).

High rates of rheumatic fever and rheumatic heart disease within Māori and Pacific populations have long been attributed to higher rates of deprivation, household crowding and poor access to healthcare (Jaine, Baker, & Venugopal, 2011). Treatment and prevention initiatives are well established and have contributed to the reduction of rheumatic fever in Aotearoa as a whole (Heart Foundation of New Zealand, 2006). However, despite clear evidence of ongoing rheumatic fever inequities and a marked reduction of rheumatic fever in non-Māori non-Pacific populations, Māori still face a heavy burden of rheumatic fever (Milne et al., 2012a). Persistent rheumatic fever inequities indicate a system-wide failure to meet the needs of Māori with rheumatic fever. Little is known about the mechanisms through which Māori rheumatic fever inequities persist. Despite quantitative reporting of rheumatic fever statistics, there is a paucity of qualitative evidence exploring rheumatic fever. The voice of Māori patients and their whānau has seldom been gathered and research that seeks to understand the persistence of rheumatic fever inequities from the whānau perspective is warranted if we are to reduce rates of rheumatic fever and its ongoing impact on Māori.
1.2 Research context

The research presented in this thesis was undertaken as part of a larger Ministry of Health funded project. In 2014, research funded by the University of Auckland was undertaken to explore Māori whānau perspectives of recurrent rheumatic fever and RHD in Te Tai Tokerau (Northland), Aotearoa. Ten whānau with a total of 36 participants were included in this research. The preliminary findings of the Te Tai Tokerau research were published in a report to Northland DHB (A. Anderson, Mills, Eggleton, Henare-Toka, & Palmer, 2015). The study was extended to inform a larger national project in 2015, funded by the Ministry of Health, which explored both Māori and Pacific experiences of recurrent rheumatic fever and re-hospitalisations for rheumatic fever and silent rheumatic heart disease. The introduction of the national project extended the exploration of these issues into the CMDHB region. The research presented in this thesis was informed by the 2014 study in Te Tai Tokerau and presents data from the CMDHB arm of the larger 2015 project.

1.3 Research question

This research posed the question: What are the lived experiences, knowledge and perspectives of Māori and their whānau who have experienced recurrent rheumatic fever or re-hospitalisations for rheumatic fever?

1.4 Research objectives

This research utilised a qualitative Kaupapa Māori approach to exploring the experiences of Māori patients (and their whānau) who have had recurrent rheumatic fever or re-hospitalisations for rheumatic fever within the CMDHB region of Tāmaki Makaurau. The objectives of the research were:

- To explore whānau perspectives of rheumatic fever including their perceptions, feelings and understandings of the illness.
- To understand the relationships, experiences and contact whānau have had with healthcare services.
- To understand whānau experiences of interacting with health professionals, including how rheumatic fever information was communicated to whānau.
- To identify information that can be used to inform the development of approaches to reduce Māori rheumatic fever inequities.
1.5 Thesis structure

This thesis consists of six chapters. This chapter outlines the research context, question and aims. The subsequent chapters are organised in the following way:

Chapter two provides background information on the policy context for rheumatic fever in Aotearoa, what is already known about rheumatic fever and Māori, the inequities that exist in Aotearoa, and more broadly, understanding the potential reasons for the inequities that exist between Māori and non-Māori. Current gaps in knowledge are summarised.

Chapter three, methodology and methods, introduces the methodological approach to the research that informs the study. The chapter outlines Kaupapa Māori Theory, its dynamic and evolving nature, and the Kaupapa Māori research methodology used to approach the research. The whānau interview method used to collect data, and thematic analysis technique used to analyse data are then described.

Chapter four presents the results of the whānau interviews. Firstly, the chapter provides a brief description of the participants with rheumatic fever and their whānau. The chapter will then outline the whānau experiences of rheumatic fever, organised into four meta-themes: whānau living contexts, experiences in the health system, impacts of rheumatic fever, and the overarching importance of whānau.

Chapter five, the discussion, will critically discuss the findings of the research in the context of available literature. The strengths and limitations of the research are also presented.

Chapter six concludes the thesis. Recommendations are made that draw on the findings of this research to inform health service delivery for Māori with rheumatic fever, and health related policy. Concluding comments are also provided.

1.6 Summary of introduction

This chapter has given a broad overview of the research topic and the context in which this research was undertaken. This chapter began by providing a brief overview of rheumatic fever and highlighted the need to not only address inequities in rheumatic fever prevalence for Māori but also to better understand Māori experiences of rheumatic fever in order to inform future action. The research context, the research question, and the research
objectives were then outlined. Increased detail on the background of rheumatic fever and Māori is provided in the following chapter.
2 Background

2.1 Introduction

This chapter provides background information on issues relevant to the research as informed by existing literature. The first section introduces the policy context of rheumatic fever. The second section provides an overview of rheumatic fever and secondary prophylaxis. The third section outlines rheumatic fever inequities and the fourth section outlines understandings of rheumatic fever inequities. Lastly, gaps in current knowledge are presented.

Rheumatic fever is a preventable illness that is caused by an auto-immune response to a GAS throat infection, which is a highly infectious illness. If left untreated, rheumatic fever can result in permanent heart damage and premature mortality (Carapetis, McDonald, et al., 2005). The burden of rheumatic fever is ongoing as treatment regimens are recommended to persist monthly for at least 10 years after initial diagnosis. Evidence shows that rates of rheumatic fever have seen a significant decrease in developed countries around the world, and rheumatic fever is now rarely seen in affluent population groups (Carapetis, Steer, et al., 2005; Seckeler & Hoke, 2011). However, the rates of rheumatic fever persist for Māori and Pacific peoples in Aotearoa (Oliver, Pierse, & Baker, 2015). Addressing rheumatic fever is a policy imperative within Aotearoa. Rheumatic fever is known to be associated with socio-economic deprivation; however, deprivation cannot fully account for the stark inequities seen (Gurney et al., 2014). There are significant gaps in current knowledge regarding rheumatic fever for Māori. While broader literature can provide some insight into reasons why Māori rates of rheumatic fever remain inequitably high, a detailed investigation of Māori experiences of rheumatic fever is needed.

2.2 Policy context

There is a policy imperative to address rheumatic fever in Aotearoa. In 2012, the Government identified ten 'Better Public Services' targets for the public sector to achieve over the proceeding five years. These targets are seen as priority areas in Aotearoa. Reducing the incidence of rheumatic fever is one of these ten priorities (Ministry of Health, 2015b). The Ministry of Health established the RFPP in 2011 to prevent rheumatic fever (Ministry of Health, 2016). The programme was expanded significantly in 2012 following
the introduction of the rheumatic fever Better Public Services target. The Government has since invested over $65 million to identify and trial new initiatives to reduce the rheumatic fever rates throughout Aotearoa (Ministry of Health, 2016). The RFPP has three main strategies to reduce rheumatic fever rates and delivers a number of initiatives for each:

1. Increase awareness of rheumatic fever, what causes it and how to prevent it
2. Reduce household crowding and therefore reduce household transmission of strep throat bacteria within households
3. Improve access to timely and effective treatment for strep throat infections in priority communities.

The RFPP was implemented in the 11 District Health Board (DHB) areas with the highest incidence of rheumatic fever hospital admissions (including CMDHB). It is recognised by the CMDHB RFPP that addressing rheumatic fever is a complex task (Counties Manukau District Health Board, 2013). As a result, current interventions are multifaceted. The focus for rheumatic fever prevention thus far has been mainly on primary prevention i.e. addressing GAS throat infections. Nationally, a Rheumatic Fever Awareness Campaign was launched to address strategy one (i.e. increase awareness). In CMDHB, Auckland Wide Healthy Housing Initiative (AWHI) and Mana Kidz are two key initiatives that address strategies two and three respectively (Counties Manukau District Health Board, 2013).

The 2015 Rheumatic Fever Awareness Campaign, developed by the Ministry of Health and Health Promotion Agency, targets high risk regions including CMDHB (Ministry of Health, 2016). This campaign aimed to increase the awareness of rheumatic fever in the community and encourage parents and caregivers to respond to their child’s sore throat by getting every sore throat checked by a doctor or nurse at free community-based sore throat clinics (Vermillion Peirce et al., 2015). This awareness campaign was focused on helping to increase parents’ knowledge of the link between sore throats and rheumatic fever and the serious heart damage that it can cause, as well as the importance of seeking medical help as soon as possible for a sore throat. The campaign consisted of mass media including national television and targeted regional media promotions in areas where rheumatic fever incidence is highest (Vermillion Peirce et al., 2015).

---

2 The health system in Aotearoa is signified by DHBs. DHBs are funded by the Ministry of Health and are responsible for funding health services for their respective geographical regions (Cumming et al., 2014).
AWHI is a service that aims to identify and improve households with children at risk of rheumatic fever (Alliance Health Plus, 2014). AWHI was established in late 2013 with the key focus to reduce crowding for families with children at high risk of developing rheumatic fever. AWHI offers interventions to address household crowding and subsequently reduce the spread of GAS. These interventions involve free curtains and insulation, applications to Housing New Zealand (the Government organisation charged with providing housing solutions) to change family housing situations, and working with Work and Income New Zealand (WINZ) to obtain additional financial assistance for families (Alliance Health Plus, 2014).

Mana Kidz is a free, nurse-led, school-based programme that provides comprehensive healthcare for children in the CMDHB region (P. Anderson et al., 2016). This programme aims to improve access to primary healthcare services by delivering a primary care package to children in primary and intermediate school settings. Sore throat swabbing services have been established in 61 schools. Each school clinic has a registered nurse and whānau support worker who provides healthcare including rheumatic fever prevention services (P. Anderson et al., 2016).

### 2.2.1 Te Tiriti O Waitangi

As tangata whenua (indigenous peoples) of Aotearoa, Māori have a right to equitable health outcomes (Reid, 2011). This right is afforded to Māori by Te Tiriti, the document that signifies the relationship between Māori and the Crown (Orange, 2015). Te Tiriti stated that Māori would retain tino rangatiratanga (sovereignty); that the Crown were afforded kāwanatanga (governance); and, that Māori were promised all of the rights and privileges as British citizens (Orange, 2015). Reid (2011, p. 39) contends that kāwanatanga entails "good governance" that is "fair, just and ethical", an expression of which is equity. Good governance would therefore entail equitable health outcomes. On this premise, health inequities are evidence that the government is failing to uphold its obligations as stated within Te Tiriti (Reid, 2011). As signatories to Te Tiriti, the government has an imperative to reduce health inequities for Māori.

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3 Work and Income New Zealand is a service provided by the Ministry of Social Development that provides financial assistance and employment services throughout Aotearoa (Ministry of Social Development, 2016a).
2.3 Rheumatic fever

Rheumatic fever is an autoimmune reaction to a GAS throat infection that can result in an inflammatory response to the central nervous system, heart, joints, or skin (Carapetis, McDonald, et al., 2005). Recurrent episodes of rheumatic fever occur when an individual is re-infected with GAS and can lead to the development of RHD. RHD is a progressive condition that results in scarring and significant damage to the heart valves, and can cause a heart attack and premature death (Marijon, Mirabel, Celermajer, & Jouven, 2012). Secondary prevention of rheumatic fever is of significant importance as it prevents recurrences of rheumatic fever, and RHD. The persistence of rheumatic fever recurrences is said to be due to the failure of secondary prevention (Heart Foundation of New Zealand, 2006). In the following section an overview of rheumatic fever and rheumatic fever recurrences is provided including descriptions of group A streptococcus (GAS) throat infections and RHD. The secondary prevention of rheumatic fever is then outlined.

2.3.1 An overview of rheumatic fever

Group A streptococcus infection

GAS is a bacteria that can lead to throat infection, sometimes termed GAS pharyngitis or 'strep throat' (Heart Foundation of New Zealand, 2012, 2014). GAS is a highly contagious bacteria that spreads through direct contact with infected individuals (Ralph & Carapetis, 2012). Common symptoms include a sore throat, fever and enlarged lymph nodes. If left untreated, GAS throat infections can lead to rheumatic fever (Cunningham, 2000).

GAS throat infections are diagnosed through throat swabs for cultures of GAS. This method of diagnosis is effective and remains the ‘gold standard’ for diagnosing GAS throat infections in Aotearoa (Heart Foundation of New Zealand, 2014). It is important to note that approximately two-thirds of patients with rheumatic fever present as asymptomatic and therefore do not complain of having a sore throat and do not seek medical assistance. This context limits the potential for primary prevention strategies via throat swabbing (Carapetis, McDonald, et al., 2005; Veasy, Tani, & Hill, 1994).

GAS throat infections are treated with a course of antibiotics. Effective treatment generally consists of a ten-day course of oral penicillin V or amoxicillin to target GAS infection within the pharynx (Heart Foundation of New Zealand, 2014; World Health Organization, 2004). Treating GAS can prevent an initial attack of rheumatic fever from developing and can help
control the spread of infection (Robertson, Volmink, & Mayosi, 2005). GAS treatment is commonly referred to as the primary prevention\(^4\) of rheumatic fever (World Health Organization, 2004). If a sore throat is treated within nine days the onset of rheumatic fever is preventable (Robertson et al., 2005). If left untreated or if failure to comply to treatment occurs, the risk of GAS infection developing into rheumatic fever increases significantly (Lennon, 2004).

**Rheumatic fever**

Rheumatic fever is an autoimmune reaction to GAS (Cunningham, 2000). The process by which GAS pharyngitis leads to rheumatic fever is relatively poorly understood but is believed to have an autoimmune basis (Carapetis & Zühlke, 2011). GAS causes an acute generalised inflammatory response that affects the heart, joints, skin, and the central nervous system. Initial symptoms vary between cases and include painful joints, fever, and involuntary muscle movement (Carapetis, McDonald, et al., 2005; Cunningham, 2000). Rheumatic fever symptoms generally occur three weeks after a GAS throat infection. Individuals suffering from rheumatic fever can become very unwell and require hospitalisation (Heart Foundation of New Zealand, 2006).

**Diagnosis**

Rheumatic fever is determined by a clinical assessment as there is no single diagnostic laboratory test that can confirm diagnosis (Heart Foundation of New Zealand, 2006). Knowledge and recognition of symptoms of rheumatic fever are particularly important to health professionals as common features of rheumatic fever are often delayed or atypical (Heart Foundation of New Zealand, 2006). The modified Jones (1944) criteria (Dajani et al., 1992) is the diagnostic tool currently used to diagnose rheumatic fever in New Zealand (Heart Foundation of New Zealand, 2006). The Jones criteria divides clinical features of rheumatic fever into major and minor manifestations\(^5\) that are based on their prevalence and specificity (Table 2) (Dajani et al., 1992; T. Jones, 1944). Diagnosis of rheumatic fever requires the presence of two major symptoms or one major and two minor manifestations (Heart Foundation of New Zealand, 2006).

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\(^4\) Primary prevention is a strategy that seeks to prevent disease occurring in the first instance rather than treating it once it has developed (Heart Foundation of New Zealand, 2009).

\(^5\) Major manifestations are those that make the diagnosis more likely while minor manifestations are indicative of a rheumatic fever diagnosis but inadequate to confirm diagnosis (T. Jones, 1944).
Table 1. The major and minor manifestations of rheumatic fever

<table>
<thead>
<tr>
<th>Major manifestations</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthritis</td>
<td>Inflammation of the joints</td>
</tr>
<tr>
<td>Carditis</td>
<td>Inflammation of the heart tissue</td>
</tr>
<tr>
<td>Sydenham’s chorea</td>
<td>Rapid, uncoordinated jerking movements</td>
</tr>
<tr>
<td>Subcutaneous nodules</td>
<td>Lumps under the skin</td>
</tr>
<tr>
<td>Erythema marginatum</td>
<td>Ring shaped rashes around limbs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Minor Manifestations</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthralgia</td>
<td>Joint pain</td>
</tr>
<tr>
<td>Fever</td>
<td>Increased body temperature (≥38 degrees Celsius)</td>
</tr>
<tr>
<td>Elevated acute phase reactants</td>
<td>Elevated acute-phase proteins in response to inflammation</td>
</tr>
<tr>
<td>Prolonged P-R interval</td>
<td>Changes to heart rate</td>
</tr>
</tbody>
</table>

Sourced from: Heart Foundation of New Zealand (2006, p. 18)

**Treatment**

The main priority after presentation is confirming a diagnosis. At this stage, health professionals are responsible for a range of treatment interventions including: secondary prophylaxis; education; dental referral; notification to the public health register; and, informing the patient’s general practitioner (GP) (Heart Foundation of New Zealand, 2006; Ministry of Health, 2014b).

Treatment of rheumatic fever is centred on two tenets, firstly the treatment of symptoms, and secondly, prevention of recurrence, which is referred to as secondary prevention (Heart Foundation of New Zealand, 2006). The secondary prevention of rheumatic fever is outlined in Section 2.3.2. The National Heart Foundation (2006) recommends treatment within a hospital for individuals who are likely to have rheumatic fever (first episode or recurrence) after the onset of symptoms. Treatment for the symptoms of rheumatic fever are provided in Table 2, and are outlined in detail in the *New Zealand Guidelines for Rheumatic Fever: 1. Diagnosis, management and secondary prevention* (Heart Foundation of New Zealand, 2006).

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6 Secondary prevention aims to reduce the impact of a disease (slowing its progression or its sequelae) that has already occurred (Heart Foundation of New Zealand, 2006).
### Table 2. Treatment options for rheumatic fever

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Treatment option(s)</th>
</tr>
</thead>
</table>
| Arthritis / arthralgia | • Course of Sylicates / Non-steroidal anti-inflammatory drugs to ease pain and inflammation  
|                    | • Paracetamol can also be used for mild arthralgia                                |
| Fever             | • Can be treated with salicylate therapy                                           
|                    | • Fever alone can be treated with paracetamol                                     
|                    | • Low-grade fever may not require treatment                                       |
| Carditis / heart failure | • Bed rest                                                                         
|                    | • Anti-failure medication (E.g. Diuretics, angiotensin-converting-enzyme inhibitors)  
|                    | • Valve surgery (repair or replacement)                                           |
| Chorea            | • Mild or moderate chorea does not require any specific treatment, as it is benign and self-limiting  
|                    | • If severe, anti-chorea medication is available but risks not fully understood    |

Adapted from: Heart Foundation of New Zealand (2006, p. 24-26).

Prior to a patient being discharged from hospital, outpatient follow-up care should be initiated. The frequency and duration of clinical follow-up is dependent on local capacity and an individual’s clinical needs (Heart Foundation of New Zealand, 2006). Long term measures for treating rheumatic fever include secondary prevention through continuous administration of antibiotics, case notification to the local rheumatic fever register and the co-ordination of community services to ensure follow up, education, and contact management (swabbing household contacts) (Heart Foundation of New Zealand, 2006).

Damage to the heart in rheumatic fever patients is thought to severely increase the risk of suffering myocardial infarction (heart attack), which can be brought on from even a mild increase in physical exertion. Hence, bed rest is recommended for patients diagnosed with rheumatic fever, with a duration dependent on the severity of carditis. Guidelines for activity levels outlined by The National Heart Foundation (2006) are provided in Table 3. Ambulation should be gradual and as tolerated by the individual. Those with severe carditis may never be able to return to full activity. Thus, rheumatic fever can have significant long term effects on children, their ability to play in sports and can potentially mean months away from school (Heart Foundation of New Zealand, 2006).
Table 3. Guide for activity levels for rheumatic fever patients

<table>
<thead>
<tr>
<th>Activity</th>
<th>Arthritis alone</th>
<th>Mild Carditis</th>
<th>Moderate Carditis</th>
<th>Severe Carditis</th>
</tr>
</thead>
<tbody>
<tr>
<td>In hospital</td>
<td>1-2 weeks</td>
<td>2-3 weeks</td>
<td>4-6 weeks</td>
<td>2-4 months</td>
</tr>
<tr>
<td></td>
<td>Mobilise freely</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>as tolerated</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House arrest (activity</td>
<td>1-2 weeks after</td>
<td>2-3 weeks</td>
<td>4-6 weeks</td>
<td>2-4 months</td>
</tr>
<tr>
<td>and school work from</td>
<td>discharge</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>home)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>2 weeks</td>
<td>2-4 weeks</td>
<td>1-3 months</td>
<td>2-3 months</td>
</tr>
<tr>
<td>Full activity (sport)</td>
<td>After 6 weeks</td>
<td>After 3 months</td>
<td>After 3-6 months</td>
<td>Variable</td>
</tr>
</tbody>
</table>

Sourced from: The Heart Foundation of New Zealand (2006, p. 25).

The duration of hospital stay is determined by the clinical response and improvement in inflammation. Most cases of rheumatic fever without severe carditis can be discharged from hospital after approximately two weeks (Heart Foundation of New Zealand, 2006). The length of hospital stay is also partly dependant on the social and home circumstances and in some cases may be advisable to prolong the hospital stay until recovery is well advanced (Heart Foundation of New Zealand, 2006).

Recurrent rheumatic fever

Episodes of rheumatic fever are classified as either initial attacks (no known past history of rheumatic fever) and recurrent attacks (an episode in a person with a known past history of rheumatic fever) (Heart Foundation of New Zealand, 2006). Recurrent rheumatic fever occurs in individuals who have previously had rheumatic fever and are re-infected with GAS. Recurrent episodes significantly increase the chance of developing RHD because recurrences of rheumatic fever can increase carditis (Carapetis, McDonald, et al., 2005). People who have had rheumatic fever previously are at greater risk of further rheumatic fever episodes (Carapetis, McDonald, et al., 2005; Sliwa et al., 2010). Given that the 1992 Jones criteria (Dajani et al., 1992) was only intended for use with the initial attack of rheumatic fever, the World Health Organisation (WHO) has provided additional guidelines for the application of the Jones criteria for recurrent episodes of rheumatic fever specifying that recurrences of rheumatic fever should be diagnosed when one major or several minor manifestations are present (World Health Organization, 2004). Greater sensitivity rather than specificity of diagnosis is warranted as recurrences are the major cause of further heart
damage (N. Wilson, Voss, Morreau, Stewart, & Lennon, 2013; World Health Organization, 2004).

The protocols for treatment of recurrences of rheumatic fever are similar to the previously mentioned cases of rheumatic fever. In addition to this it is recommended that reasons for a recurrent attack are investigated (Heart Foundation of New Zealand, 2006). Hospitalisation may be required considering that recurrent attacks can worsen in severity, with variation in symptom severity being seen in different patients (Carapetis, McDonald, et al., 2005; Heart Foundation of New Zealand, 2006).

**Rheumatic heart disease**

If not treated properly, rheumatic fever can develop into RHD. The pathogenesis of this transition remains largely elusive (Ralph & Carapetis, 2012). Cardiac inflammation (the inflammatory response to GAS) can affect the valves of the heart, the outer sac (the pericardium) and the inner lining (the endocardium) of the heart by causing scarring and deformation of heart tissue (Marijon et al., 2012). The most common site of damage is the heart valve (particularly the mitral valve) (Marijon et al., 2012). Carditis occurs a few weeks after the initial episode of rheumatic fever in about 50 per cent of patients (Marijon et al., 2012). It is recommended that all patients with suspected or definite rheumatic fever undergo echocardiography to identify evidence of carditis (Heart Foundation of New Zealand, 2006). Although the initial attack of rheumatic fever can lead to severe heart damage (and then lead to RHD), RHD mostly stems from cumulative valve damage caused by episodes of recurrent rheumatic fever (Carapetis, Steer, et al., 2005; Marijon et al., 2012).

RHD can cause complications such as heart failure, atrial fibrillation (abnormal heart rhythm), ischaemic embolic events (blood clots), and infective endocarditis (inflammation of inner tissues of heart due to bacteria that restricts blood flow) (Marijon et al., 2012). In the absence of appropriate intervention, RHD can lead to a heart attack and premature death (Carapetis, Walker, Kilburn, Currie, & MacDonald, 1997; Marijon et al., 2012). Current RHD treatment regimens (indicated in Table 2) depend on the severity of heart damage and are directed at addressing symptoms and complications (i.e. medical management of heart failure, atrial fibrillation, ischaemic embolic events and infective endocarditis). In severe cases, interventional treatment (i.e. heart surgery) is required (Heart Foundation of New Zealand, 2006).
2.3.2 The secondary prevention of rheumatic fever

Secondary prevention of rheumatic fever involves the continuous administration of secondary prophylaxis in order to prevent recurrences of rheumatic fever (World Health Organization, 2004). Secondary prophylaxis involves the continuous administration of antibiotics, usually intramuscular benzathine penicillin every 28 days to prevent rheumatic fever through the reinfection of GAS (Spinotto et al., 2011). The provision of secondary prophylaxis effectively reduces episodes of recurrent rheumatic fever, hospitalisations and surgical procedures (such as cardiac valve replacement) (Manyemba & Mayosi, 2002). Secondary prophylaxis effectively reduces the rapidity and severity of RHD (Feinstein, Stern, & Spagnuolo, 1964; Majeed, Batnager, Yousof, Khuffash, & Yusuf, 1992).

The recommended guideline for the use of secondary prophylaxis is every 28 days (Heart Foundation of New Zealand, 2006; Spinotto et al., 2011) and must continue for a minimum of 10 years. The duration is dependent on a variety of factors such as: age; clinical patterns (presence or absence of carditis or RHD and severity of carditis or RHD); environment (likelihood of GAS exposure); and, time since last episode of rheumatic fever (Heart Foundation of New Zealand, 2006). The New Zealand recommendations for the duration of secondary prophylaxis are provided in Table 4 (Heart Foundation of New Zealand, 2006).

Table 4. The New Zealand recommendations for the duration of secondary prophylaxis

<table>
<thead>
<tr>
<th>Category</th>
<th>Duration of prophylaxis</th>
</tr>
</thead>
<tbody>
<tr>
<td>All persons with rheumatic fever with no or mild carditis</td>
<td>Minimum of 10 years after most recent episode of rheumatic fever or until age 21 years (whichever is longer)</td>
</tr>
<tr>
<td>All persons with rheumatic fever with moderate carditis</td>
<td>Minimum of 10 years after most recent episode of rheumatic fever or until age 30 years (whichever is longer)</td>
</tr>
<tr>
<td>All persons with rheumatic fever with severe carditis</td>
<td>Minimum of 10 years after most recent episode of rheumatic fever or until age 30 years (whichever is longer), and then specialist review for consideration of the need for continuation of prophylaxis, probably lifelong.</td>
</tr>
</tbody>
</table>

Sourced from: Heart Foundation of New Zealand (2006, p. 35)

The first course of secondary prophylaxis should be administered in hospital (Heart Foundation of New Zealand, 2006). This is said to be beneficial as information about the illness and management can be given. It is recognised that effective communication between healthcare providers and families is important for effective treatment of rheumatic fever.
The Heart Foundation (2006) signifies that all patients and their whānau should have a good understanding of rheumatic fever, and the reasons for secondary prophylaxis, and consequences of missing monthly dosages (Heart Foundation of New Zealand, 2006).

Ongoing secondary prophylaxis is administered by district nurses7 (or community / public health nurses) in CMDHB. Some DHBs (such as Lower Hutt and Canterbury) provide secondary prophylaxis in primary care settings (Heart Foundation of New Zealand, 2006). For children, secondary prophylaxis can occur at school, home or in a workplace (Heart Foundation of New Zealand, 2006). Once a patient leaves school, treatment and care is usually facilitated through primary health providers or home visits depending on individual needs and local capacity (Heart Foundation of New Zealand, 2006; Spinetto et al., 2011). Secondary prophylaxis is co-ordinated by local rheumatic fever registers in Aotearoa.

Rheumatic Fever Registers

Rheumatic fever registers co-ordinate the delivery of secondary prophylaxis and aid penicillin delivery by the secondary prophylaxis providers (Heart Foundation of New Zealand, 2014). The Auckland Acute Rheumatic Fever Register (established in 1982) is a population-based register covering 60 per cent of New Zealand rheumatic fever registrations (Heart Foundation of New Zealand, 2006). If patients do not receive their regular prophylaxis they are actively sought by district nurses and Community health workers for up to three months, after which they are deactivated on the rheumatic fever register (Spinetto et al., 2011).

The use of rheumatic fever registers such as the Auckland Acute Rheumatic Fever Register has been proven to help reduce reoccurrences of rheumatic fever within a New Zealand context by co-ordinating community delivery (McDonald, Brown, Noonan, & Carapetis, 2005; Spinetto & Lennon, 2006). For example, Spinetto et al. (2011) evaluated the safety and effectiveness of long-acting penicillin administered every 28 days to prevent recurrences of rheumatic fever using the register data. In this study, patients were referred to a population-based delivery programme of secondary prophylaxis, where district nurses delivered secondary prophylaxis every 28 days (Spinetto et al., 2011). This study found this

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7 A district nurse (also known as a community nurse or public health nurse) is a nurse that provides care and treatment to patients inside their homes, or schools, as well as in clinics. They deliver bicillin injections to patients in CMDHB (Heart Foundation of New Zealand, 2006).
method of delivery was safe and effective. Additionally, it was found that of the 360 identified cases, 20 recurrences occurred in 19 people between 1993-1999, and that 55 per cent of recurrences occurred because the secondary prophylaxis was discontinued prematurely. According to Spinetto et al. (2011) delivering secondary prophylaxis continues to be a major challenge. It is noted that transient living patterns of patients, or shifting and leaving no forwarding address creates follow-up difficulties. Spinetto et al. (2011) also found that partnership between nurses and community health workers was beneficial given that community health workers have local community and cultural knowledge. A national rheumatic fever register has been proposed to co-ordinate the delivery of secondary prophylaxis across Aotearoa, but this has yet to be actioned due to concerns around governance and funding capacities (Lennon, 2010).

2.4 Rheumatic fever inequities in Aotearoa

As described above, the process of rheumatic fever diagnosis, treatment and the prevention of ongoing complications and recurrences is relatively well understood. Given that Aotearoa is a rather well developed country internationally, it is particularly concerning that high rates of rheumatic fever are affecting Māori. This section provides the epidemiology of rheumatic fever in Aotearoa, highlighting the extent to which rheumatic fever inequities persist.

Despite a government commitment to addressing rheumatic fever in Aotearoa, Māori and Pacific rates of rheumatic fever remain among the highest in the world with rheumatic fever largely affecting peoples of Māori and Pacific ethnicity in Aotearoa. Māori and Pacific peoples make up over 90 per cent of all cases of rheumatic fever in Aotearoa (Gurney et al., 2014; Milne et al., 2012a; Oliver et al., 2015).

Rheumatic fever predominantly affects children (Ralph & Carapetis, 2012). Between the years 2000 to 2009, Māori and Pacific children accounted for 95 per cent of new cases of rheumatic fever in Aotearoa. During this period incidence rates per 100 000 for children aged between 5 – 14 years for Māori was 40.2 (95% Confidence Interval [CI] 36.8, 43.8) and 81.2 (95% CI 73.4, 89.6) for Pacific compared to 2.1 (95% CI 1.6, 2.6) for non-Māori non-Pacific peoples (Milne et al., 2012a). While the incidence of rheumatic fever has significantly decreased for non-Māori non-Pacific over time, rates for Māori and Pacific are increasing (Figure 1) (Milne et al., 2012a). Figure 1 demonstrates that rheumatic fever incidence rates
increased by 79 per cent and 73 per cent for Māori and Pacific children, respectively, whilst declined by 71 per cent for non-Māori non-Pacific.

![Figure 1](image.png)

**Figure 1.** Annual index cases and incidence rates for acute rheumatic fever in 1993–2009 for children 5 to 14 years of age. (▲)Pacific (■)Māori and (●) non-Māori non-Pacific (Milne et al., 2012a).

Milne et al. (2012a) also found that CMDHB had the highest mean annual incidence rate of rheumatic fever (93.9 per 100 000) (Milne et al., 2012a). This provided further rationale for undertaking this research within CMDHB.

Moreover, Milne et al. (2012a) found that incidence rates of rheumatic fever in Aotearoa increased greatly with the degree of socio-economic deprivation according to the New Zealand Deprivation Decile (NZDep)\(^8\). Recently, Gurney et al. (2014) found that from 2010 to 2013, populations living in the most deprived areas were more than 30 times as likely to be diagnosed with rheumatic fever compared to populations residing in the least deprived areas of Aotearoa. Gurney et al. (2014) stratified disease incidence by deprivation decile and ethnicity in Aotearoa and found that Māori and Pacific remain substantially more likely to

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\(^8\)NZDep is an index of relative socio-economic deprivation, The NZDep is detailed in Section 2.5.1.
be affected by this disease than European and Asian ethnic groupings regardless of NZDep decile (Figure 2).

Figure 2. Age-standardised incidence of acute rheumatic fever (2010-2013), by deprivation quintile and ethnic group (Gurney et al., 2014).

As well as high rates of initial rheumatic fever incidence, Māori also have high rates of rheumatic fever recurrences. From 1973 to 1982 (prior to the introduction of systematic prophylaxis delivery), recurrence rates in Māori were 40 per cent compared to 22 per cent in non-Māori (Remenyi et al., 2010). A review of cases from the Auckland rheumatic fever register from 1993 to 1999 found that although the total recurrence rates had reduced significantly from the 1980s (from 22 per cent to 5.5 per cent), almost all of the recurrences found were in Māori and Pacific people (Spinetto et al., 2011). Jaine, Baker, and Venugopal (2008) analysed hospitalisation data from 1996 to 2005 and identified an average of six recurrences of rheumatic fever per year from 1996 to 2005 of which 34 recurrences were Māori, 23 were Pacific peoples, and four were New Zealand European and Others. The persistence of recurrent rheumatic fever suggests a failure of secondary prevention for Māori and Pacific within New Zealand contexts (Webb & Wilson, 2013). Jaine et al. (2008) note that classifications of recurrences are problematic using hospitalization data, and that it is possible that some recurrences could have been classified as first admissions.
Unlike rheumatic fever, RHD is not a notifiable condition (Heart Foundation of New Zealand, 2006). Milne et al. (2012b) reported that from 2000 to 2007 there were an average of 159 deaths per year coded with RHD as the underlying cause. After adjusting for age, RHD mortality rates were 5 to 10 times higher for Māori and Pacific peoples compared to non-Māori non-Pacific (Milne et al., 2012b). From 2000 to 2007, the mean age at death from RHD was 58 years for Māori and 56 years for Pacific compared to 80 years for non-Māori non-Pacific (Milne et al., 2012b).

It is important to note that the Ministry of Health has since reported a decrease in rheumatic fever cases between 2014 and 2015 (Ministry of Health, 2015b); however, analysis of this data has not yet been published. Moreover, rheumatic fever is known to be under-reported, in both hospitalisation data and register data, which means that the true rates of rheumatic fever could be higher (Oliver, Pierse, & Baker, 2014). It has also been previously noted that official datasets often undercount Māori (Harris et al., 2007; Ministry of Health, 2015c). Therefore, the ethnic inequities presented in this section may potentially be larger than reported.

Overall, this evidence suggests that Māori (and Pacific) peoples are experiencing multiple inequities through the healthcare system that specifically relate to rheumatic fever. Higher rates of initial rheumatic fever diagnosis, rheumatic fever recurrence, RHD, RHD mortality and a shorter life expectancy for Māori when compared to non-Māori (and non-Pacific) indicate a system wide failure to meet the needs of Māori with rheumatic fever. Exploration of additional information that pertains to Māori engagement with healthcare and broader determinants of health can provide insight into ways by which higher rates of rheumatic fever may be operating.

## 2.5 Understanding rheumatic fever inequities

This section provides an overview on issues relevant to understanding Māori rheumatic fever inequities including inequities in rheumatic fever recurrences and RHD. This section is organised into four parts. The first three parts: (1) differential access to the socio-economic determinants of health, (2) differential access to healthcare, and (3) differences in the quality of care received, are considered to be three pathways through which ethnic inequities in health occur (C. Jones, 2001; Reid & Robson, 2007). Each pathway will be discussed using relevant literature, in order to contextualise for what is happening for Māori and associated rates of rheumatic fever. Lastly, the overarching role that racism is likely to
play in creating and maintaining differential access to the socio-economic determinants of health as well as differential access to and quality of healthcare is explored and definitions provided. This is consistent with the context of rheumatic fever in Aotearoa and the increasing recognition of the role of racism as an important determinant of health outcomes (Krieger, 2003; Paradies, Williams, Heggenhougen, & Quah, 2008; Reid & Robson, 2007; Williams, 1997; Williams & Mohammed, 2013).

A paucity of evidence specific to Māori rheumatic fever inequities exists. National and international literature pertaining to rheumatic fever and socio-economic determinants of health using quantitative data is available; however, literature seldom seeks to understand the experiences of patients. The scope of the literature reviewed for this research project was therefore broadened to include relevant literature associated with Māori health inequities and Māori experiences in healthcare settings for other illnesses (such as cancer and heart disease).

2.5.1 Access to social determinants of health

The socio-economic determinants of health refer to the social and economic conditions in which people live that influence health, such as education, employment, housing, income and deprivation (Marmot & Wilkinson, 2005). It is well documented that Māori are significantly worse off with respect to social determinants of health than non-Māori, and that this has a significant impact on the health inequities faced by Māori (Blakely, Tobias, Atkinson, Yeh, & Huang, 2007; Ministry of Health, 2015c; Robson, Cormack, & Cram, 2007). There is evidence that rheumatic fever is associated with the socio-economic determinants of health. In particular, factors that have been identified as contributing to rheumatic fever in the literature include household crowding, housing quality and socio-economic deprivation (Atatoa-Carr, Lennon, & Wilson, 2008; Heart Foundation of New Zealand, 2009; Jaine et al., 2011; Kerdemelidis, Lennon, Arroll, Peat, & Jarman, 2010).

Household crowding

Household crowding is a term generally used to mean that a household has fewer bedrooms or less space than acceptable for the number of people residing (M. Baker, McDonald, Zhang, & Howden-Chapman, 2013; A. Gray, 2001b). The mechanisms through which household crowding directly affects health includes children sharing a bed or bedroom associated with increased physical contact and / or poor hygiene practices (M. Baker et al., 2013; A. Gray, 2001b). Crowded housing has long been linked with increased infectious disease
transmission in Aotearoa (especially those spread by respiratory route, such as GAS throat infections) (M. Baker, Goodyear, Telfar Barnard, & Howden-Chapman, 2006; M. Baker et al., 2000; Jaine et al., 2011). The Canadian National Occupancy Standard (CNOS) is a common index measure used in research in Aotearoa (M. Baker et al., 2006; A. Gray, 2001b) because it is measurable with census data. The CNOS measures people per room in a household, age and gender of children, and the relationships of occupants. It states that no more than two people should share a room, unless under the age of five or of the same sex, and that couples may share a room (Canadian Mortgage and Housing Corporation, 1992).

The association between household crowding and the incidence of rheumatic fever within Aotearoa is strong (jaine et al., 2011). Evidence from an ecological study that combined hospitalisation data between 1996 to 2005 with data from the 1996 and 2001 censuses found a positive association between household crowding and the incidence of rheumatic fever (jaine et al., 2011). Rates of rheumatic fever increased with increasing quintiles of household crowding. The quintile with the most household crowding had 23 times the rate of rheumatic fever compared to the quintile with the least household crowding. This effect remained after controlling for age, ethnicity, household income, and the density of children in the neighborhood. These results suggest that household crowding is an independent factor associated with rheumatic fever. Whilst this is the largest reported study investigating risk factors for rheumatic fever in Aotearoa the authors note that other confounding factors related to socio-economic determinants of health such as low education level, and unemployment (which were not accounted for in the study) may also explain their findings (jaine et al., 2011), there is also extensive international evidence that shows an association between crowded housing and rheumatic fever (Adanja, Vlajinac, & Jarebinski, 1987; Gordis, Lilienfeld, & Rodriguez, 1969; F. Gray, Quinn, & Quinn, 1952; Grover et al., 1993; Longo-Mbenza et al., 1998; Zaman et al., 1997).

In Aotearoa, housing remains a critical health and social issue affecting Māori (Flynn, Carne, & Soa-Lafoa’i, 2010). In 2006, four times as many Māori households as New Zealand European households were crowded and the proportion of the Māori population living in crowded households was six times greater than for the New Zealand European population (Flynn et al., 2010). Household crowding is an important issue in CMDHB. The CMDHB region represents the highest proportion of Māori living in crowded houses in the country (Ministry of Health, 2014a). In 2013, Māori households were twice as likely as non-Māori households to be classified as crowded, with 4 719 homes needing at least one additional bedroom, and affecting 28 788 people in the Counties Manukau region. Residents of Māori
households were 47 per cent more likely than others to be living in crowded conditions (Robson et al., 2015).

**Housing quality**

There is some evidence to suggest that rheumatic fever is associated with poor quality housing (F. Gray et al., 1952; Thakur, Negi, Ahluwalia, & Vaidya, 1996; Vlajinac, Adanja, & Jarebinski, 1988; Vlajinac, Adanja, Marinković, & Jarebinski, 1991). Definitions of quality vary between studies internationally and involve measures such as dampness, coldness, availability of running water and levels of deterioration. A case control study involving 148 patients with rheumatic fever in Yugoslavia explored socio-economic factors and rheumatic fever using conditional logistic regression analysis and found a positive association between home dampness and rheumatic fever (Risk Ratio (RR) = 2.4, p=0.008) (Vlajinac et al., 1991). This study also found that deterioration of dwelling had no independent effect on rheumatic fever and that this variable correlated with other socio-economic factors (Vlajinac et al., 1991). Analysis of international evidence by Kerdemelidis et al. (2010) states that due to the measures of quality of housing varying greatly between international studies (and varying levels of significant findings) it is difficult to generalise these to an Aotearoa context (Heart Foundation of New Zealand, 2009). Hence, the contribution of housing quality to Māori rheumatic fever is so far generally inconclusive.

**Deprivation**

Socio-economic deprivation describes access to material and social resources (Atkinson, Salmond, & Crampton, 2014). Deprivation is defined as a “state of observable and demonstrable disadvantage relative to the local community or wider society or nation to which an individual, family, or group belongs” (Townsend, 1987, p. 125). People can be said to be deprived if they lack the social and material conditions, activities and facilities that are required by the societies they belong to (Townsend, 1987). The NZDep is a common way of measuring deprivation and was developed for use as a tool to research the social and economic determinants of health (Atkinson et al., 2014). The index combines eight dimensions of deprivation measured by the New Zealand Census including: access to telecommunications and internet; income; employment; qualifications; home ownership; support; living space; and, access to transport (Atkinson et al., 2014).

Epidemiological studies from Aotearoa previously presented in Section 2.4 also indicate the association between rheumatic fever and deprivation (Gurney et al., 2014; Jaine et al., 2011;
Milne et al., 2012a) Jaine et al. (2011) found a marked and increasing gradient of rheumatic fever rates with deprivation, with the most deprived quintile exhibiting rates 17 times that of the least deprived quintile. The relationship between deprivation (or similar measures such as socio-economic status and poverty) and rheumatic fever has also been explored internationally with similar findings (Al-Sekait, Al-Sweliem, & Tahir, 1990; Bhave, Kinikar, Sane, Agarwal, & Amdekar, 1991; Gordis et al., 1969; Longo-Mbenza et al., 1998; Zaman et al., 1997). The geographic variation of rheumatic fever in Aotearoa also align with geographic areas of deprivation (Jaine et al., 2008). The area of CMDHB is a deprived region with proportionally more people in the most deprived section of the population than the national average (Robson et al., 2015). Ninety-four per cent of the people in Otara (a suburb in the CMDHB region) and 78 per cent of the people in Mangere (another suburb in the CMDHB region) live in the two most deprived NZDep deciles in Aotearoa (Nakhid, 2009).

Despite evidence for a strong association between deprivation and rheumatic fever, the Aotearoa-based epidemiological studies discussed describe how Māori health inequities persist even after controlling for deprivation (Gurney et al., 2014; Milne et al., 2012a). Reid, Robson, and Jones (2000) refer to this phenomenon as the ‘outcome gap’ whereby Māori health outcomes are worse than Pākehā at all levels of deprivation. The higher rates of rheumatic fever seen for Māori regardless of deprivation decile indicate that while deprivation may be an important factor in rheumatic fever incidence and recurrence, it does not fully account for the inequities Māori experience.

2.5.2 Access to healthcare

Access to healthcare is a broad concept. In this section ‘access to’ healthcare is referred to as the factors or characteristics that influence the contact or use of healthcare, qualified by need for care (Levesque, Harris, & Russell, 2013). It is noted that differential access to primary healthcare, associated with the costs of primary healthcare services, may be contributing to ethnic disparities of rheumatic fever in Aotearoa (Kerdemelidis et al., 2010; Ministry of Health, 2014b; Webb & Wilson, 2013).

There is a lack of research internationally that has explored experiences of accessing healthcare for rheumatic fever. However, one relatively recent study explored barriers to secondary prophylaxis for RHD in Jimma, Ethiopia using a grounded theory approach (Petricca, Mamo, Haileamlak, Seid, & Parry, 2009). The aim of the study was to identify factors that influenced the treatment seeking behaviour of rheumatic fever / RHD patients...
and their caregivers. The researchers completed 33 semi-structured interviews with 19 adult patients with RHD, 10 caregivers of pediatric RHD, one adult patient with rheumatic fever, and three caregivers of children with rheumatic fever. Caregivers were included due to their large influence over the health-seeking behavior of their child. This research identified cost as a significant barrier to accessing treatment. Financial barriers associated with treatment included price, travel, and opportunity costs associated with taking time off work to attend medical follow-up appointments. The financial burden of travelling long distances and paying for medications acted as a deterrent in seeking treatment (Petricca et al., 2009). The findings from this study may be useful to inform the current research; however, they may not be directly applicable to urban settings in Aotearoa. Despite this potential limitation, Petricca et al. provide useful evidence that signifies the importance of cost to rheumatic fever given the frequent and ongoing follow-up treatment required for secondary prevention in Aotearoa.

Within the context of Aotearoa, the previously introduced research into whānau experiences of rheumatic fever undertaken in Te Tai Tokerau by Anderson et al. (2015) provides evidence that a lack of access to healthcare was a significant barrier to uptake of secondary prophylaxis. Anderson et al. (2015) identified that financial barriers affected whānau access to healthcare for rheumatic fever. Whānau in this study often chose to go directly to a hospital emergency department rather than seek primary care due to avoid having to pay the financial cost of seeking primary care services. This process resulted in long hospital waits and delays in seeking care.

Among literature exploring Māori healthcare experiences for other health problems (e.g., cancer and heart disease), financial access is cited as an important factor contributing to avoidable morbidity (Cormack, Robson, Purdie, & Ratima, 2005; Cram, 2014b; Ellison-Loschmann & Pearce, 2006; Jansen, Bacal, & Crengle, 2009; Jansen & Smith, 2006; Kerr, Penney, Moewaka Barnes, & McCleanor, 2010; Penney, McCleanor, & Moewaka Barnes, 2006). Jansen et al. (2009) explored Māori experiences of health services from a Kaupapa Māori perspective through 10 hui (meetings) with a total of 86 participants. The researchers found that cost of health services, including physically getting to the service (e.g., location, transport, and having to take time off work), was a concern for Māori. Māori participants noted that although they desired a GP visit, they were unable to access primary healthcare because of cost of services and pharmacy prescriptions. Time off work and childcare were also considered cost barriers to accessing healthcare for Māori (Jansen et al., 2009). Financial barriers for Māori accessing healthcare were also found in a study exploring Māori
access to cancer services (Cormack et al., 2005). Semi-structured interviews with 39 cancer service providers (including Māori health providers) were analysed alongside a literature review and review of available data. This research found that cost was a major barrier to cancer care for whānau and that cost was linked to the socio-economic position of whānau.

Availability of transport is a known issue that affects access to healthcare for Māori and includes: a lack of vehicle ownership; insufficient public transport infrastructure; limited money for petrol and / or public transport (A. Anderson et al., 2015; Cormack et al., 2005; Cram, 2014b; Lee & North, 2013; Penney et al., 2006; Slater et al., 2013). Transport barriers are commonly associated with economic cost and transport is also a variable in the NZDep measure (Atkinson et al., 2014). Slater et al. (2013) completed 12 face-to-face semi-structured interviews with Māori cancer patients and their whānau to explore their experiences with cancer services. The researchers found that travel was a significant barrier to cancer services that was related to financial burdens. In addition, the study found that many Māori experienced difficulty accessing affordable transport even when travelling short distances. Anderson et al (2015) also noted that whānau often did not own a vehicle or could not afford petrol for their vehicles to access rheumatic fever care.

Difficulties for Māori to access healthcare is also evident in findings from the 2014/15 NZ (New Zealand) health survey (Ministry of Health, 2015a). The 2014/15 NZ Health Survey (n = 13,497 adults and 4754 children) found that Māori had a greater level of unmet need for primary healthcare than non-Māori, that the disparity was greater for children, and that cost was an important factor impeding access. Of note, one in three Māori adults (33 per cent) had an unmet need for primary healthcare. In addition, Māori adults and Māori children were more than twice as likely to have had an unfilled pharmacy prescription due to cost as non-Māori adults and non-Māori children after adjusting for age and gender differences. Lack of transport was a reason for not visiting a GP in this study. Of note, lack of transport was patterned by deprivation (Ministry of Health, 2015a).

2.5.3 Quality of healthcare

Māori experience differential quality of healthcare in Aotearoa compared to non-Māori (Crengle, Lay-Yee, Davis, & Pearson, 2005; Jansen et al., 2009). An important element of quality of care demonstrated in the literature is communication with Māori, the absence or substandard nature of which results in poor quality care (A. Anderson et al., 2015; Arlidge et al., 2009; Cram, Smith, & Johnstone, 2003; Jansen et al., 2009; Jansen & Smith, 2006; Slater et
Poor quality care resulting from biases held by health providers that inform their behaviours with Māori patients is also recognised as an element of poor quality of healthcare that contributes to Māori inequities in health outcomes (Jansen et al., 2009; Penney et al., 2006; Penney, Moewaka Barnes, & McCreanor, 2011). The National Primary Medical Care Survey (a nationally representative study of the characteristics of over 200 GPs, their practices and their patients) found quantitative evidence of differential treatment of Māori as a group (Crengle et al., 2005). Results indicated that doctors reported lower levels of rapport, ordered fewer tests and investigations, made fewer referrals, and spent less time with Māori patients when compared to non-Māori patients. These disparities are extremely concerning given that Māori experience a higher burden of disease compared to non-Māori (Crengle et al., 2005; Reid & Robson, 2007).

**Communication and rapport**

Healthcare providers are responsible for providing information to patients and whānau about illnesses, treatment and prevention. It is critical that whānau understand their illness. This is explicitly recognised in the Heart Foundation of New Zealand (2006) *Guidelines for Rheumatic fever: 1. Diagnosis, Management and Secondary Prevention*. The Heart Foundation of New Zealand (2006) states that “effective communication between health staff and families is important” (p. 37) for improving adherence secondary prophylaxis and that “at the time of diagnosis, it is essential that the disease process be explained to the patient and their family” (p. 27).

From a Māori perspective, communication between patients and health professionals is an important dimension of quality of healthcare (Cram et al., 2003). Communication significantly affects Māori health, and it is not always effective for adequate (A. Anderson et al., 2015; Arlidge et al., 2009; Cram et al., 2003; Jansen et al., 2009; Jansen & Smith, 2006; Slater et al., 2013; D. Wilson & Barton, 2012). Jansen and Smith (2006) argue that the greatest impact on patient satisfaction and effectiveness in primary healthcare is the communication skills of the provider.

Arlidge et al. (2009), interviewed eight Māori, eight Pacific, and seven Pākehā whānau to investigate experiences of hospitalisation due to injury. The study found that Māori commonly reported inadequate communication and information from healthcare providers. Māori whānau in this study indicated the importance of needing to understand the
treatment, diagnoses and possible effects of rheumatic fever on their children. However, whānau were not given a substantial amount of information necessary for them to understand what was happening. This lack of communication caused frustration. The lack of information also made it difficult for whānau to navigate the health system. In contrast, Pākehā in this study were satisfied with the services, and felt they had sufficient information to comprehend their circumstances (Arlidge et al., 2009).

D. Wilson and Barton (2012), as a part of a case study, undertook 10 interviews with Māori who had been hospitalised in order to understand hospitalisation experiences for Māori, including actions and interactions in the complexity of hospitals. It was found that poor communication and lack of information about care and treatment was a common occurrence for Māori resulting in a mistrust of healthcare providers. Poor communication was again, characterised by Māori as a lack of information given by health professionals.

A Kaupapa Māori study exploring Māori experiences in accessing and utilising healthcare for Ischaemic Heart Disease (IHD) in Te Tai Tokerau interviewed twenty five Māori with IHD (Penney et al., 2006). Penney et al. (2006) found that negative experiences tended to arise from the relationship that participants experienced with health professionals, including communication. Unsatisfactory healthcare was tied to poor communication and a lack of information, leaving the patient feeling misunderstood, and therefore feeling that their needs were not being met. These participants expressed a desire for positive relationships, and rapport building with their healthcare providers (Penney et al., 2006).

Alongside communication, rapport is another common theme in literature pertaining to Māori experiences of healthcare. Rapport is described as the relationships between patients and doctors, signified by the ability to communicate, meaning “whether or not information was provided and understood, and whether or not the interaction was friendly” (Cram et al., 2003, p. 4). Good communication builds rapport (Jansen et al., 2009). In a qualitative research project interviewing 28 Māori about their experiences of interacting with healthcare settings, rapport was seen as vital to the quality of care for study participants (Cram et al., 2003). Components of rapport identified in this research included the doctor taking time to listen, communicating with understandable language, taking an interest in whānau health history, and engaging with the patient to deliver a collaborative style of healthcare. In the previously mentioned study by Slater et al. (2013), Māori cancer patients described having difficulty building rapport with whānau due to frequent changes of staff members, which lead to gaps in information and support for their treatment.
**Provider bias and differential treatment**

Biases held by health providers can positively or negatively shape the quality of care received by health professionals. van Ryn et al. (2011, p. 201) state that bias “includes generally negative feelings and evaluations of individuals because of their group membership (prejudice), overgeneralised beliefs about the characteristics of group members (stereotypes), and inequitable treatment (discrimination)”. Provider bias can be associated with patient gender, age, socio-economic status, and ethnicity (Smedley, Stith, & Alan, 2003; van Ryn et al., 2011). Biases can be explicit (conscious and intentional) or implicit (unconscious and unintentional) (Dovidio et al., 2008). International research indicates that prejudice and stereotypes can significantly influence the clinical decision making of health providers, increasing the likelihood of discriminatory behaviours and poor quality care (Smedley et al., 2003; van Ryn et al., 2011). Bias can shape provider communication, warmth and information giving. Also, biases can be exacerbated under high cognitive stress and time pressures (Dovidio, Kawakami, & Gaertner, 2002; Smedley et al., 2003; van Ryn et al., 2011; van Ryn & Fu, 2003). Provider beliefs (informed by prejudice and stereotypes) about individuals can influence their interpretation of symptoms and decision-making processes about treatment; resulting in differential treatment (discrimination) (van Ryn et al., 2011).

Differential treatment has been reported in qualitative studies exploring Māori experiences within healthcare settings (Arlidge et al., 2009; Dew et al., 2015; Jansen et al., 2009; Penney et al., 2006). Anderson et al. (2015) reported that whānau experiencing rheumatic fever in Te Tai Tokerau, spoke of experiences of discrimination within primary care where they felt they were being judged by the geographic area they lived in, their physical appearances and their behaviours. Jansen et al. (2009) described how negative perceptions held against Māori patients by providers lead to treatment that was rough and disrespectful. Poor communication and information (outlined previously) is a recurring signifier of discriminatory care in research that gathers Māori experiences of healthcare (Arlidge et al., 2009; Jansen et al., 2009; Penney et al., 2006; D. Wilson & Barton, 2012). Penney et al., (2006) and D. Wilson and Barton (2012) both describe Māori patients attributing experiences of poor communication to their ethnicity. Māori participants in these studies also made observations of Pākehā being communicated with to a higher standard, which raised concerns about quality of care.
In Aotearoa, differential treatment for Māori has also been well documented in quantitative research (Harris et al., 2012a, 2012b; Harris et al., 2006a, 2006b). Harris et al. (2012b) examined the relationship between racial discrimination and health service use and experience. This was done using 2006/07 New Zealand Health Survey data (n = 12488 adults). The relationship of reported experiences of racial discrimination in healthcare (unfair treatment by a health professional) and in other domains (personal attack, unfair treatment in work and when gaining housing) to breast and cervical cancer screening was analysed using logistic regression. It was found that experiences of racial discrimination by a healthcare professional were significantly associated with lower participation in cervical (odds ratio [OR] = 0.51; 95% CI = 0.30, 0.87) and breast (OR = 0.37; 95% confidence interval [CI] = 0.14, 0.996) cancer screening among Māori women. Significant associations were also found between experiences of racial discrimination and all negative patient experience measures. Patients who reported an experience of racial discrimination by a healthcare professional were significantly more likely to report that they were not always listened to carefully, that they did not always have information fully discussed with them, and that they were not always treated with dignity and respect.

There is additional evidence of negative feelings towards Māori by health professionals found in research from the provider perspective (McCreanor & Nairn, 2002a, 2002b; Penney et al., 2006; Penney et al., 2011). McCreanor and Nairn (2002) undertook 25 semi-structured interviews with tauiwi (non-Māori) GPs, in order to investigate the ways in which they talked about health. The data were analysed through critical discursive analyses. It was found that non-Māori GPs held negative perspectives of Māori. For instance, some GPs tended to blame Māori for their negative health outcomes, in a way that legitimised and normalised health inequities. In particular, blame for non-compliance was placed on Māori. GPs perceived Māori health behaviours as poor, in that Māori choose not to follow prescribed treatment regimes, nor attend follow up appointments.

2.5.4 Racism

Racism is increasingly being recognised as an important determinant of health inequities (Krieger, 2003; Paradies et al., 2008; Reid & Robson, 2007; Williams, 1997; Williams & Mohammed, 2013). Racism reflects the concept of superiority with a belief that some ‘races’ or ethnic groups are more superior than others (Harris et al. 2006). Racism is noted for its justification of “institutional and individual practices that create and reinforce oppressive systems of race relations and inequality between racial or ethnic groups” (Harris et al.
Racism can vary in form and type and there are multiple definitions and forms of racism described (Krieger, 2003; Paradies et al., 2008; Reid & Robson, 2007; Williams, 1997; Williams & Mohammed, 2013). For the purposes of this thesis, three levels of racism described by Camara Jones will be used to inform understandings of the rheumatic fever context in Aotearoa. Camara Jones (2000) identifies three characterisations or manifestations of racism: institutionalised, personally-mediated and internalised (C. Jones, 2001).

Jones (2000, p.1212) states that institutionalised racism refers to “differential access to the goods, services, and opportunities of society by race” and manifests as access to material conditions such as education, housing and employment. It also manifests as access to power. Additionally, there is no identifiable perpetrator, but rather institutionalised racism is embedded in the structures of society and societal norms (C. Jones, 2001). Robson and Reid (2001) contend that institutionalised racism is an important mechanism perpetuating health inequities. The distribution of disease is driven by social disadvantage that is structurally produced. The importance of institutional drivers of health outcomes is recognised in internationally literature (C. Jones, 2001; Krieger, 2003; Paradies et al., 2008; Williams, 1997; Williams & Mohammed, 2013), and within Aotearoa (Harris et al., 2006b; Reid & Robson, 2007; Reid et al., 2000).

Personally mediated racism refers to “prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race” (C. Jones, 2000, p. 1212-1213). Personally mediated racism is condoned by societal norms, and can manifest as disrespect, avoidance, and devaluation. Such manifestations lead to poor quality care. Personally racism manifests at the interpersonal level, thus provider bias and differential treatment are forms of personally mediated racism.

Internalised racism is defined by Jones as “acceptance by members of the stigmatised races of negative messages about their own abilities and intrinsic worth” and can manifest as embracing elements of the dominant culture over one’s own and accepting societal norms that marginalise them (C. Jones, 2000, p. 1213).

9 Jones (2000) states that ‘race’ refers to a social (as opposed to biological) construct that encapsulates the effects of racism
All three levels of racism described by Jones (2000) are evident in the three pathways leading to the ethnic inequities in health and rheumatic fever outlined in this section i.e. differential access to socio-economic determinants of health, differential access to healthcare and differential quality of healthcare received (C. Jones, 2001; Reid & Robson, 2007).

### 2.6 Gaps in current knowledge

A number of gaps within current knowledge have been identified. Firstly, here is a lack of qualitative literature pertaining to rheumatic fever. Qualitative research, broadly speaking, attempts to gather meaning as opposed to frequency (Patton, 1990). Qualitative research is valuable as a means to informing and improving health policy and service provision, especially when there is a lack of information about experiences of access to and quality of healthcare for people with high health needs, such as indigenous populations (World Health Organization, 2000). While there is evidence describing rheumatic fever inequities, attempts are seldom made to ascertain information, stories, and experiences from those living with the illness. Reid et al. (2000) note that the description of inequities in Aotearoa is frequent, but that there is a concerning lack of attempts at understanding these inequities, especially in a way that benefits Māori.

Secondly, there is a distinct absence of a Māori voice within rheumatic fever literature. In order to address issues for Māori, interventions need to reflect Māori realities, and therefore we need to gather the Māori voice (B. Jones, Ingham, Davies, & Cram, 2010; L. Smith, 1996, 2012). Māori are experts of their lived experiences and hold the knowledge of stories, issues and lives (Eruera, 2010). A Kaupapa Māori research approach enables Māori voices to be gathered in a way that is relevant to Māori in order to better inform healthcare delivery (L. Smith, 2012).

Further, it is said that to gather Māori perspectives, whānau should be targeted, given that whānau are the core unit of Māori society (B. Jones et al., 2010). Importantly, the significant role of whānau to provide support during disease treatment and management is recognised in Māori experiences of healthcare in Aotearoa (Cram, 2014a; Dew et al., 2015; Kerr et al., 2010; Walker, Signal, Russell, Smiler, & Tuhikai-Ruru, 2008; D. Wilson & Barton, 2012). Therefore, if Māori perspectives of disease management are to be gathered, the whānau (as opposed to the individual only) may present a more appropriate focus for research activity (B. Jones et al., 2010).
Understanding Māori healthcare experiences specific to the context of rheumatic fever is therefore warranted and necessary. Furthermore, undertaking research inclusive of the Māori whānau perspective is expected to help ‘fill gaps’ within current understandings of why rheumatic fever inequities persist between Māori and non-Māori.

### 2.7 Summary of background

This chapter has provided background information relevant to understanding the policy context for rheumatic fever in Aotearoa, rheumatic fever epidemiology, rheumatic fever inequities, and explanations for rheumatic fever inequities for Māori. These inequities are of major concern given the observation of a global reduction in rheumatic fever rates and suggest that this disease represents significant and persisting inequity for Māori and Pacific peoples in Aotearoa.

Section 2.5 explored available literature to identify the explanations for Māori rheumatic fever inequities via three key pathways: access to social determinants of health, access to healthcare, and access to quality of care. Quantitative research exists that describes rheumatic fever inequities and its association between deprivation and housing. Although socio-economic disparities are likely to contribute to rheumatic fever inequities, socio-economic factors including deprivation and household crowding (and other related variables) do not fully explain the inequities observed given that inequities exist when data is stratified for ethnicity. Broader literature pertaining to Māori access to healthcare and quality of care generally can help to understand the persistence of inequities. However, rheumatic fever is distinctive in that it is preventable, almost non-existent in non-Māori non-Pacific people, and requires prolonged contact with the health system (monthly for a minimum of ten years).

There are significant gaps in the literature and Māori appropriate research is needed. The following chapter, the methodology, outlines the Kaupapa Māori approach used to gather whānau experiences, perceptions and their lived realities of rheumatic fever. The following chapter presents the Kaupapa Māori Research methodology used to inform the research approach undertaken in this thesis.
3 Methodology and Methods

3.1 Introduction

This chapter introduces the methodological approach to the research, and the research methods used to collect data. The methodology of the research is first outlined, beginning with the positioning of the researcher. Kaupapa Māori Theory, which is a dynamic and evolving theory, formed the Kaupapa Māori research methodology. Whānau interviews, informed by the Kaupapa Māori research methodology were chosen as the method to collect data. Data was then analysed using thematic analysis.

3.2 Methodology

This section introduces the theoretical approach used in the research, and begins by outlining the positioning of the researcher. Kaupapa Māori Theory is described through an explanation of its developmental origins and evolving nature. The Kaupapa Māori research methodology used in this research, informed by Kaupapa Māori Theory, is then explained through the presentation of statements outlining key tenets of the methodology relevant to this research.

3.2.1 The positioning of the researcher

Walter and Andersen (2013, p. 42) state that methodology is “a theoretical lens or worldview through which research is understood, designed, and conducted”. They argue that a predominant aspect of a research methodology is the researcher’s own social, economic, and cultural positioning as it shapes their worldview. Social positioning is the filter through which we make sense of the world. One’s social positioning inherently informs the research questions we ask, the interpretations we make, and the theoretical paradigms that make sense to us (Walter & Andersen, 2013).

Given the importance of our own theoretical positioning as researchers, it is important to recognise how this might relate to the research. I approached this research as a young Māori female. I was born in Tāmaki Makaurau to a Māori mother and Pākehā father. I have an educational background in public health. I whakapapa to Te Ātihaunui-a-Pāpārangi and Ngāti Tūwharetoa. I approached this research from a Kaupapa Māori perspective. Kaupapa
Māori ‘makes sense’ to me. When I was first exposed to this theoretical space in my last year of undergraduate study, it was as if my aspirations for my whānau and the reasons why I studied public health were being articulated in a body of existing literature. As a public health student I am motivated to address health inequities, confront racism, and counter rhetoric that ignores the structural drivers of health outcomes for Māori. Kaupapa Māori provides me with a space to critically analyse racist systems and structures that continue to oppress Māori. Being a junior researcher also influenced this study. I am at the early stages of my journey as a Kaupapa Māori researcher and I am developing the theoretical and practical skills to allow me to navigate the social and political environment in which I operate.

### 3.2.2 Kaupapa Māori Theory

Kaupapa Māori Theory is a dynamic and evolving theory that provided the theoretical foundation of this research. Kaupapa Māori theorists have described Kaupapa Māori Theory as “the conceptualisation of Māori knowledge” (Nepe, 1991, p. 15) and a space where “Māori language, knowledge, culture and values are validated and legitimated” (G. Smith, 1997, p. 467). Kaupapa Māori Theory is inherently intertwined with Māori culture and involves theorising about the world through a Māori worldview. Kaupapa Māori Theory provides a space for thoughts, theories, and values that are Māori (Pihama, 2001; G. Smith, 1997).

### The development of Kaupapa Māori Theory

Kaupapa Māori Theory is a theoretical stance that was developed from both Māori worldviews underpinned by mātauranga Māori (Māori knowledge) and through contemporary Māori movements for change – as a part of wider resistance against colonisation and support for the revitalisation of te reo Māori (the Māori language) (G. Smith, 1997; L. Smith, 1997). In order to ground this research in Kaupapa Māori Theory, it is first necessary to outline Kaupapa Māori origins. Despite its relatively contemporary presence in academia, the foundations of Kaupapa Māori Theory are grounded within a long-standing theoretical base (Nepe, 1991; Pihama, 2001).

### Mātauranga Māori

Kaupapa Māori Theory has its origins in a Māori worldview grounded in mātauranga Māori (Pihama, 2001; G. Smith, 1997). Māori have always been theorists and continue to theorise about the world according to a distinct body of knowledge (Pihama, 2005). This knowledge
has been handed down through generations and has been formed over time by Māori expertise and experiences. As such, the epistemological foundations of Kaupapa Māori Theory were in existence long before Pākehā arrived in Aotearoa (Pihama, 2005, 2010). Kaupapa Māori Theory cannot be comprehended without an understanding of mātauranga Māori (Māori knowledge) and tikanga Māori (Māori cultural customs and practices). This is a fundamental premise of Kaupapa Māori Theory given that in order to genuinely explore issues for Māori (such as rheumatic fever) there must be a theoretical foundation that is from a Māori worldview (Pihama, 2010).

Contemporary Māori movements for change

Kaupapa Māori Theory as a theoretical assertion in academia arose out of wider Māori struggles for tino rangatiratanga (self-determination) and mana motuhake (authority / self-governance) (G. Smith, 1997; S. Walker, 1996). Māori continue to resist Western hegemony in multiple spaces that have been formed from the legacies of our tipuna (ancestors) (Pihama, 2001). In particular, the revitalisation of te reo Māori in the Kura Kaupapa Māori (schools based on Kaupapa Māori philosophies) movement (G. Smith, 1997; L. Smith, 2012). Kaupapa Māori Theory is a part of this broader resistance against colonisation (G. Smith, Hoskins, & Jones, 2012).

The majority of prevailing academic research traditions are founded on the culture, history and philosophies of Western thought (L. Smith, 2012); influencing the way research questions are framed and understood, which data collecting instruments are used, and how data are analysed and interpreted (Chilisa, 2011; Cram, 2001a; L. Smith, 2012). Research remains an important tool driving colonisation processes as it is associated with defining legitimate and illegitimate knowledge systems and ways of knowing (L. Smith, 2012). As a result, Māori language, knowledge and culture have been systematically silenced, misrepresented, and condemned in academia (L. Smith, 2012; S. Walker, 1996).

In the late 1980s, there was an increasing desire by Māori to preserve Māori culture and knowledge from further subjugation (S. Walker, 1996). During this time of Māori revitalisation (sometimes referred to as the Māori renaissance), putting a halt to harmful research on Māori was seen as crucial in order to stop the exploitation of Māori knowledge (L. Smith, 2012). From this social movement, there was a desire for Māori to have 'space' in academia, to take control over knowledge creation for the betterment of Māori, and to affirm tino rangatiratanga as tangata whenua (G. Smith et al., 2012; L. Smith, 2012). The original principles of Kaupapa Māori laid out by Graham Smith (1997) were:
• Tino rangatiratanga (self-determination)
• Taonga tuku iho (cultural aspirations)
• Ako Māori (culturally preferred pedagogy)
• Kia piki ake i ngā raruraru o te kainga (socio-economic mediation)
• Whānau (extended family structure)
• Kaupapa (collective philosophy).

Smith (2011), Pihama (2010) and Smith et al. (2012) continue to emphasise that Kaupapa Māori must be a fluid and dynamic theoretical space that adapts and responds to changing contexts. As such, it is important to discuss the dynamic nature of this theoretical space.

The dynamic and evolving nature of Kaupapa Māori Theory

A fundamental premise of Kaupapa Māori Theory is that it is (and must remain) dynamic and evolving (Pihama, 2010; L. Smith, 2011). This is a crucial aspect of Kaupapa Māori Theory as its nature reflects the diverse Māori population and the ever changing contexts of Māori in an age where we continue to face and resist colonisation (L. Smith, 2011).

There is not one concise definition or explanation of what Kaupapa Māori Theory is (L. Smith, 2011). This stems from the need to steer clear from creating boundaries for Kaupapa Māori research. A concise definition of what Kaupapa Māori Theory is, risks signifying that it is static and unchanging, which would limit the widespread utility of Kaupapa Māori Theory. As such, Kaupapa Māori Theory has several interpretations (Mahuika, 2008; L. Smith, 2011; S. Walker, 1996). Kaupapa Māori Theory involves living and engaging with the world as Māori. This is a strength of Kaupapa Māori Theory as it has the ability to adapt to the diversities and complexities of whānau, hapū (sub-tribe) and iwi (tribe) in contemporary Aotearoa in a way that is relevant to us as a people, and to the space in which it is being used (Mahuika, 2008; L. Smith, 2011). The way in which Kaupapa Māori Theory was used in this research is explained in the following section.

3.2.3 Kaupapa Māori research methodology

Kaupapa Māori Theory provided the theoretical foundations through which this Kaupapa Māori research methodology was informed. The Kaupapa Māori research methodology used in this research is one that has drawn from multiple perspectives, namely Graham Smith (1997), Linda Smith (1996, 2012), Leonie Pihama (2001, 2010) and Sheilagh Walker (1996). The Kaupapa Māori research methodology used in this research is outlined in this section.
through the presentation of statements. Each statement is described and then placed into the broader context of this research. This methodology informed the whānau interview method outlined in the following section of this chapter.

**Kaupapa Māori is situated within a Māori worldview**

Kaupapa Māori privileges a Māori worldview, which is implicit in its origins in mātauranga Māori (Nepe, 1991). This validates ways of Māori knowing, doing, and understanding (Pihama, 2001). As a result, a Māori worldview is considered the norm in Kaupapa Māori as opposed to the prevailing notion of Māori as the ‘the other’ in Western research (L. Smith, 2012). This research examines Māori experiences of rheumatic fever from a Māori perspective in a way that reflects Māori realities. Māori cultural practices are not measured (or othered) against the perspectives of Pākehā and are considered valid in their own right (G. Smith, 1997). The research gathered the views of Māori in a way that was concordant with tikanga Māori. For instance, cultural practices such as karakia (prayer) and whakawhanaungatanga (forming relationships) were present in the research. Research analysis and writing was also undertaken from a Māori worldview.

**Kaupapa Māori is Māori owned and controlled**

Kaupapa Māori is about power and control resting within Māori understandings and practices (Bishop, 2005). From the conception of this research, through to research dissemination, control has rested with Māori. In this research, Māori control has been exhibited in two realms. Firstly, Māori researchers control the overall research process, and secondly, Māori whānau controlled the whānau interview processes. Māori participated in this research at multiple levels. Detailed in Section 3.3.2, the project was located within Tōmaiora, the Māori health research unit within Te Kupenga Hauora Māori (the Department of Māori Health) at the University of Auckland.

Māori control ensured that tino rangatiratanga was maintained throughout the research process. The concept of tino rangatiratanga is associated with Māori sovereignty and self-determination. Walker (1996, p. 131) distinguishes that “rangatiratanga denotes mana [authority / power] not only to possess what is ours, but to control and manage it in accordance with your own preferences”. This ensured a Māori centred agenda (where the issues and needs of Māori whānau with rheumatic fever) remained the focus. This also ensure that the outcomes of research were relevant to Māori (L. Smith, 2012).
Kaupapa Māori recognises Māori as a diverse people

Kaupapa Māori takes into account whānau, hapū and iwi complexities. This aligns with the aforementioned dynamic nature of Kaupapa Māori Theory (Pihama, 2010). In contemporary society, Māori live in a high degree of cultural, social, linguistic and physical differences. What makes one Māori is not definite, it is dynamic, contextual and situational (McIntosh, 2005; Webber, 2009). Smith (2011, p. 11) states that “Kaupapa Māori privileges aspects of who we are as a people now, rather than the idealised view of who and what we are. It privileges the complexity of who and what we are”. In turn, this research recognised that Māori whānau have diverse realities. This was reflected in the recruitment process and in the broad inclusion of patients and their whānau. This was also reflected in whānau control where whānau determined all the processes undertaken during the interviews (outlined in the research design below).

Whānau sit at the core of Kaupapa Māori

Kaupapa Māori recognises the centrality of whānau to te ao Māori (the Māori worldview). Whānau translates to family, but importantly also includes extended family and the idea of whakawhanaungatanga (Bishop, 1995). Kaupapa Māori recognises the customs that emphasise the cultural and collective values of Māori. For instance, whānau and the process of whakawhanaungatanga are key elements that this study embodied (B. Jones et al., 2010). Whakawhanaungatanga acknowledges not only the relationships Māori have with each other but also the relationships we have with the world through whakapapa (genealogy) (Mead, 2003). The importance of whānau in this research upholds the responsibility and obligations that research has to nurture and care for relationships (B. Jones et al., 2010).

The importance of whānau was reflected in this research by gathering the whānau experience rather than the experience of the individual patient with rheumatic fever. The research recognised that Māori exist not only as individuals but also as a part of a wider whānau (Mead, 2003). In recognising diversity, patients were able to determine what whānau means to them and include whomever they deem as whānau in their interviews. They were also given the opportunity to conduct interviews alone if that was their preference. As outlined in the following chapter, the research was informed by the ‘Community up’ approach to researching whānau (Cram & Kennedy, 2010), a research method that recognises and emphasises the diversity of Māori and whānau in Aotearoa.
Kaupapa Māori rejects a deficit analysis of Māori

Kaupapa Māori opposes negative theories and theoretical paradigms that marginalise Māori (G. Smith, 1997). Western academic traditions are rampant with deficit theories (Valencia, 1997). Deficit theories are theories that position Māori as deficient, inadequate and problematic (L. Smith, 2012). For instance, when unequal health outcomes for Māori are apparent (such as the rates of rheumatic fever in Aotearoa) the problem is said to lie with Māori (Reid & Robson, 2007). This kind of colonial thinking is often referred to as victim-blaming (Ryan, 1971). This research opposed deficit theories and maintained a structural perspective during data collection and analysis.

Kaupapa Māori is transformative

Linda Smith (2011, p. 14) states that "Kaupapa Māori is not about describing the status quo, or altering a few aspects. It is about transforming and changing the kaupapa [purpose / issue] for all of us. Kaupapa Māori is about making a difference and change in people's lives". Drawing on critical theory, Graham Smith (1997) emphasises the notion of praxis in Kaupapa Māori. Praxis is described by critical theorist Paulo Friere (1970) as the notion of action that is informed. Therefore, acquiring knowledge is ineffective to produce change, rather, explicit and informed action is necessary (G. Smith et al., 2012). Graham Smith (2003) emphasises the need to centralise the issue of transformation in Kaupapa Māori as it continues to grow and evolve. Kaupapa Māori is both a tool for critical analysis and a pathway for meaningful change (L. Smith, 2011).

This research used Kaupapa Māori to provide positive strategies and changes as it aligns with Graham Smith's (1997) original principle of kia pīki āke i ngā raruraru o te kainga (the principle of socio-economic mediation). Smith (1997) argues that there is a need to mediate and assist in alleviating disadvantages that Māori communities experience; therefore highlighting that the importance of research as being positive and beneficial to Māori communities.

Kaupapa Māori brings a critical analysis of structural power imbalances to the forefront of enquiry

Kaupapa Māori as a theoretical space in academia was borne from the need to oppose colonisation and support the revitalisation of our culture and language (G. Smith, 1997). It provides us with a theoretical process that ensures the struggles and inherent power relationships within those struggles are a conscious part of analysis (Pihama, 2001).
Structural analysis is a key aspect of Kaupapa Māori that aligns with critical theory (G. Smith, 1997). Graham Smith (2012) asserts that if power structures in society are not critically examined, then as Māori we are remaining content with being oppressed. Therefore, Kaupapa Māori has a clearly articulated political agenda that sits alongside cultural aspirations (G. Smith, 1997).

Bishop (1995, p. 13) states that Kaupapa Māori is committed to a "deconstruction of those hegemonies which have disempowered Māori from controlling and defining their own knowledge within the context of unequal power relations in New Zealand". This means that this research understands that Māori health inequities, specifically rheumatic fever inequities, are the result of societal structures that systematically oppress Māori.

3.2.4 Summary of methodology

Kaupapa Māori Theory provided the theoretical foundations of this research, and informed the Kaupapa Māori research methodology. As a theoretical perspective, Kaupapa Māori is not new, and it is continually evolving. The Kaupapa Māori research methodology used in this research was outlined through the presentation of statements that signified the key tenets of the methodological approach to the research.

3.3 Methods

This section describes the whānau interview method used in this research to obtain data. The whānau interview method used in this research was influenced by previous work with whānau (A. Anderson et al., 2015; B. Jones et al., 2010; Kennedy & Cram, 2010).

3.3.1 Research design

The whānau interview method was chosen to investigate the research question and obtain a comprehensive understanding of whānau experiences of rheumatic fever. Jones, Ingham, Cram, Dean, and Davies (2013) argue that successful health interventions require development with whānau, and that the delivery of health interventions requires culturally relevant approaches, which reflect the realities of those concerned.

This study aimed to privilege the role, view and experiences of whānau. Eruera (2010, p. 1) asserts that “whānau are experts of their everyday lived experiences and hold the
knowledge of their stories (past and present), aspirations, issues and complex dynamics that exist”. Use of a whānau interview approach allows this perspective to be actioned.

The research method was informed by the ‘community up’ approach to researching whānau and was developed by Kennedy and Cram (2010). Outlined in Table 5, this research method was initially developed by Cram (2001b) and was informed by Smith (2012). The ‘community up’ approach provides a useful framework for formulating research methods and guided the researcher in the undertaking of the interview process for this study. Table 5 firstly outlines cultural values, which are statements asserted by Smith (2012), developed to recognise the accountabilities researchers have to indigenous communities. The second column is a translation of how these values can be applied to research methods (Cram, 2001a). The third column is an extension of those guidelines with a focus on whānau (Kennedy & Cram, 2010). Guided by this framework, the following sections will outline the research methods used in this research.

Table 5. A ‘community up’ approach to researching whānau (Kennedy & Cram, 2010, p. 6)

<table>
<thead>
<tr>
<th>Cultural values (L. Smith, 2012)</th>
<th>Researcher guidelines (Cram, 2001b)</th>
<th>Te kaupapa ā te whānau – whānau researcher guidelines</th>
</tr>
</thead>
</table>
| Aroha ki te tangata              | A respect for people – allow people to define their own space and meet on their own terms | • Engage in cultural ‘rituals of encounter’, guided by whānau  
• Allow whānau to define their space and meet on their own terms  
• Whakawhanaungatanga – it is important for whānau to make linkages and connections with each other and with the researcher(s)  
• Respect the fluidity and diversity of whānau |
| He kanohi kitea                 | It is important to meet people face-to-face, and to also be a face that is known to and seen within a community | • It is important for the researcher to be known and be seen by whānau |
| Titiro, whakarongo... kōrero | Looking and listening and then maybe speaking. Develop understanding in order to find a place from which to speak | Allow whānau to set the agenda for the research, including the pace at which it proceeds and decisions about:  
• What is the whānau's story?  
• What do whānau want to speak to?  
• What is the role of researchers within the space that whānau claim? |
| **Manaaki ki te tangata** | Sharing, hosting, being generous | • Enable whānau to participate in the research (e.g. budget for whānau travel)  
• Provide food and refreshments during research encounters  
• Allow for appropriate koha for whānau  
• Enable whānau to move in and out of their [research] space |
| **Kia tūpato** | Be cautious – be politically astute, culturally safe, and reflective about insider/outsider status | • Be cautious that our whānau are kept safe – that whānau are left in the same, or a better, space than before they engaged in the research  
• Allow whānau the time and space to practice their own tikanga (e.g. karakia)  
• It may be important for the whānau to know of support services that can offer them ongoing support for any issues and concerns raised during the research |
| **Kaua e takahia te mana o te tangata** | Do not trample on the 'mana' or dignity of a person | Ensure that the research journey is enjoyable and enlightening for whānau, including:  
• Communicate with whānau about the research, including sharing the findings and publications  
• Acknowledge whānau ideas about the current and future research |
| **Kia māhaki** | Be humble – do not flaunt your knowledge; find ways of sharing it | • Be humble – do not flaunt your knowledge, but find ways to create a context for whānau to access it  
• Answer whānau questions (or seek out the knowledge) and share your knowledge  
• Support whānau in their understanding and use of research findings |

Sourced from: Kennedy and Cram (2010, p. 6)

### 3.3.2 Setting

As previously mentioned this research was located within the Tōmaiora Māori health research unit, Te Kupenga Hauora Māori (Department of Māori Health), University of Auckland. The location of the research within Tōmaiora allowed the researcher to access ongoing support from Māori health researchers as appropriate (in particular around Kaupapa Māori). This was particularly important to the research method given the researchers’ aforementioned positioning as a junior researcher.

The study was undertaken in the CMDHB region, South Auckland, New Zealand. CMDHB is a large DHB and is made up of four regions (known as localities): Franklin, Manukau, Otara / Mangere and East Auckland (Counties Manukau District Health Board, 2015). Participants were recruited from all four areas of CMDHB and the whānau interviews were conducted...
where participants resided. Whānau interviews were held in locations that participants chose, which included their home, homes of extended whānau or in their community.

### 3.3.3 Participants

This study involved rheumatic fever patients and their whānau. The inclusion criteria for patients participating in this study were:

1. Self-identified as being of Māori ethnicity
2. Resided in Counties Manukau region during the study period
3. Had recurrent rheumatic fever from 2010 until 2014 or had recurrent hospitalisations due to rheumatic fever from 2010 until 2014

No age restrictions were placed on the inclusion criteria in order to include a wide range of experiences of rheumatic fever. The patient with rheumatic fever was the primary participant, and contributed to coordinating the whānau interview time, location, and attendees.

### Whānau

Whānau of participants were explicitly invited to join the study. Their engagement and inclusion with whānau was important as they occupy a central role in Māori culture (B. Jones et al., 2010). In recognition of the diversity of whānau, no restrictions were placed on the age of participants, number of whānau members invited, or who constituted whānau membership. The diverse understanding of whānau was undertaken to recognise the diverse realities of Māori. Outlined in Table 5, Jones et al. (2010) emphasise the need for researchers to recognise the diversity of whānau and respect tikanga practices in each and every home so that each family is treated without assumptions or expectations in regard to others.

### 3.3.4 Consultation

Consultation played an important role in this research, from the inception of the idea, through to research dissemination. Consultation involved both Māori and non-Māori. Clinicians who specialise in rheumatic fever were consulted with to inform clinical aspects of the project, and were also involved in decisions surrounding the scope and setting of the project. District nurses were also involved in project formation, and primarily played a role in recruitment strategies and processes. Kaumātua played a role in informing tikanga
throughout all aspects of the project. As mentioned, ongoing research support through formal consultation also occurred within Tōmaiora. Alongside guiding the research processes, consultation also guided dissemination planning to ensure this research remains transformative for rheumatic fever patients. The networking that occurred from consultation with clinicians and nurses within CMDHB was important and allowed for communication and information exchanges.

3.3.5 Participant recruitment

Purposive sampling was used to recruit study participants. Purposive sampling is selecting patients based on their relevance to the study, aligning with its particular purpose (Lewis & Ritchie, 2003). Potential participants were recruited by their respective district nurses based on the inclusion criteria previously outlined. The nurse leaders from each locality within CMDHB were consulted with kanohi ki te kanohi (face to face) about this research, and had agreed to take part in the recruitment process.

Following consultation, district nurses were asked to screen their patients for those who met the study criteria. District nurses identified patients as Māori using the ethnicity data gathered by the DHB. The district nurse would then describe the study to eligible patients using an information sheet (Appendix A) when giving patients their monthly bicillin injections. Once given the information, the patient was asked if they would like to be contacted with more information about the study. If patients agreed to be contacted with more information about the study their contact details were taken down by the district nurse, and passed on to the researcher.

The researcher then contacted the potential participant. Upon contact, participants were asked to self-identify their ethnicity. The researcher then provided the potential participant with the participant information sheets (see Appendices B and C) and consent forms (see Appendices D - F). At this stage, an opportunity was given to potential participants to ask any questions. Once participants confirmed that they would like to take part in the research, interview appointments were set, including the date, time and location – which varied depending on what suited the participants.

During the time period of recruitment, six Māori patients who met the inclusion criteria agreed to be contacted. One potential participant could not be contacted (post agreement for contact), and another potential participant was unable to schedule an interview within
the timeframe of the study. Four patients with rheumatic fever were included in the study, alongside six additional whānau members. This resulted in a total of 10 study participants.

3.3.6 Data collection

Data were collected through audio-recorded whānau interviews. The whānau interviews were designed to ensure the participants comfort and safety were upheld. This included starting with mihi whakatau (a short welcome), provision of kai (food), and finishing with the gifting of koha (acknowledgement) to the participants. The focus groups were opened and closed with karakia if the whānau wished. The protocol of the ‘community up’ approach to researching whānau (Table 5) was employed by the researcher during this process (Kennedy & Cram, 2010). During the data collection phase, the researcher was constantly mindful of the diversity of whānau, and did not make assumptions as to how the interview would be carried out. This meant being open to different tikanga. For instance, before the researcher offered to do karakia, the whānau were asked if they had any preferences as to how the meeting would open, close, and generally proceed.

The beginning of each interview was an important phase as there was limited time to build rapport. Building rapport established a safe and comfortable environment for the participants to open up and share personal experiences. The whānau interviews were guided (but not controlled) by a semi-structured interview schedule. This was created to organise the discussion topics in order for the facilitator to channel group interaction and ensure a range of broad topics were covered. The interview schedule was informed from previous related research and a review of relevant literature (A. Anderson et al., 2015).

The format of the interview schedule comprised of a set of discussion topics that were loosely framed as questions. The discussion topics in the interview schedule (provided in Appendix G) were: introductions; history of rheumatic fever; initial diagnosis; treatment; secondary prophylaxis; experiences of healthcare settings; impacts on wellbeing; recurrences of rheumatic fever; and, re-hospitalisations for rheumatic fever. During the introductions, information about the participant with rheumatic fever, including their basic demographic details and diagnoses, was ascertained. Whānau members were also asked to introduce themselves and state their relationship to the participant with rheumatic fever.

The discussion topics in the interview were intentionally broad in order to allow for flexibility. This allowed for the exploration of individual / whānau experiences, while retaining the ability of the data to be collated for analysis to answer the research questions.
The flexible nature of the interview schedule further coincides with the assertion in this research that Māori are not one homogenous group, therefore could have (and did have) different experiences of rheumatic fever (B. Jones et al., 2010). Further, flexibility also allowed for the whānau members to participate, contribute and engage with the questions asked. This meant that different perspectives within the whānau were heard, which helped to gain a more comprehensive understanding of the experience of rheumatic fever. In effect, the participants guided the discussion, allowing the researcher to probe for more depth where necessary, to skip over areas that had already been covered, or to follow completely novel topics if they arose.

The duration of interviews ranged from one to 2.5 hours. Four of the five interviews were undertaken in whānau homes, with one taking place in a local park. Kai was shared with everyone who was present in the home regardless of whether or not they participated in the interviews. In some cases, kai was shared during the interview at the request of the whānau rather than following the interview.

### 3.3.7 Data analysis and interpretation

**Transcription**

The researcher transcribed the whānau interviews verbatim. Verbal characteristics of the discussion were noted such as half-finished thoughts, laughter, emphasis on certain words and incomplete sentences. Once transcribed, data was entered into qualitative analysis software NVivo10.

**Thematic analysis**

Grounded in a Kaupapa Māori perspective, data was analysed using the thematic analysis approach articulated by Braun and Clarke (2006). Thematic analysis is a research method that enables the identification, analysis, interpretation and reporting of themes within data. A theme “captures something important about the data in relation to the research question” (Braun & Clarke, 2006, p. 81). This method of thematic analysis is useful for health research (Braun & Clarke, 2014). The process of thematic analysis involved six steps:

1. Familiarising yourself with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

Themes were categorised into metatemes and subthemes. During analysis, themes that related to each other were grouped into metatemes. The themes within each metateme were then called subthemes. Importantly, Braun and Clarke (2006, p. 84) state that "data are not coded in an epistemological vacuum", and this approach draws heavily on theory and interpretation, the standpoint of which must be made clear. In this sense, the themes were not formed from the data alone, the themes were grounded in a Kaupapa Māori theoretical approach, a part of which is entwined with the researcher's social positioning. This process was undertaken with oversight from the project supervisors who have senior experience in the application of Kaupapa Māori methodology to qualitative research. Triangulation of the generation of initial themes was undertaken by project supervisors to ensure the process was robust and adequately aligned with Kaupapa Māori research practice.

3.3.8 Ethical considerations

Ethical approval for this project was obtained from the University of Auckland Human Participant Ethics Committee prior to commencing this study (Reference No. 014652) (Appendix H). Approval was also obtained from CMDHB (Research Registration No. 2067) (Appendix I). There are some ethical issues that need to be acknowledged for this research project and these include: anonymity and potential coercion.

There was a risk of potentially identifying participants from information surfacing from the whānau interviews. To ensure anonymity of participants, any potentially identifying characteristics (e.g. name of town, medical clinics, schools) was changed or omitted in the transcripts and any later research documents / writing. Pseudonyms were also allocated to participants and used on transcribed documents and all later documents.

Using district nurses to recruit participants could have potentially been seen as a subtle form of coercion from participants given the trust involved in these relationships and the potential power imbalance. This is because patients may have felt obliged to participate in the study when asked, out of fear of disappointing them. To ensure that participants' choice to participate or not would have no effect on their relationship with their district nurse / GP, the participants were given information both verbally (through recruitment and at the start of interviews) and written, in the information sheets to ensure them that their participation
would not influence these relationships. These issues were further emphasised and discussed at consultation meetings with district nurses.

3.4 Summary of Methodology and methods

This chapter began by introducing Kaupapa Māori Theory, its dynamic nature, and the Kaupapa Māori approach taken in the context of this research. The chapter then presented the methods used to carry out the research. Informed by Kaupapa Māori Theory, data were collected through whānau interviews, which were guided by the ‘community up’ approach to working with whānau. The whānau interview method was chosen in order to gather the collective experiences of Māori whānau experiencing rheumatic fever in CMDHB region. The subsequent chapter presents the results of the whānau interviews.
4 Results

4.1 Introduction

This chapter presents the results from the thematic analysis and interpretation of the whānau interviews using the methods outlined in the preceding chapter. Firstly, the chapter provides a brief description of the participants with rheumatic fever and their whānau. The chapter will then outline the whānau experiences of rheumatic fever, organised into four metathemes: (1) whānau living contexts, (2) whānau experiences in the health system, (3) impacts of rheumatic fever, and (4) the importance of whānau.

4.2 Participant summary

This study involved five interviews with four whānau. As outlined in the methodology, participants with rheumatic fever were recruited through their respective district nurses and were asked to nominate members of their whānau to participate with them in the interviews. This section provides an outline of each participant with rheumatic fever and their whānau, including the details of rheumatic fever diagnoses as shared by participants. This information is summarised in Table 6. The whānau members interviewed will be referred to by their relation to the participant with rheumatic fever.

Table 6. A summary of the participants with rheumatic fever and their whānau

<table>
<thead>
<tr>
<th>Whānau</th>
<th>Participant with rheumatic fever*</th>
<th>Gender</th>
<th>Age</th>
<th>Age first diagnosed</th>
<th>Age of recurrence(s)</th>
<th>Whānau members interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Rachel</td>
<td>F</td>
<td>30</td>
<td>14</td>
<td>25</td>
<td>- Mother</td>
</tr>
<tr>
<td>2</td>
<td>Brandon</td>
<td>M</td>
<td>23</td>
<td>14</td>
<td>No recurrence**</td>
<td>- Mother, - Step-father</td>
</tr>
<tr>
<td>3</td>
<td>Tamati</td>
<td>M</td>
<td>18</td>
<td>14</td>
<td>16, 17</td>
<td>No whānau present</td>
</tr>
<tr>
<td>4</td>
<td>Rawiri</td>
<td>M</td>
<td>21</td>
<td>14</td>
<td>17</td>
<td>- Mother, - Partner, - Younger brother</td>
</tr>
</tbody>
</table>

* Pseudonym used for participants with rheumatic fever
** Brandon had not been diagnosed with a recurrence of rheumatic fever
Rachel was a 30-year-old female at the time of the research. Two interviews were undertaken with Rachel and her whānau, one individual interview, and one with Rachel and her mother. At the time Rachel was residing in Tāmaki Makaurau with her husband, her three children, who she raises full time, and her father. Her first episode of rheumatic fever occurred when she was living in Te Tai Tokerau in 2001, aged 14 years. She had a recurrence in Tāmaki Makaurau in 2010, 11 years later, at the age of 25. Rachel’s mother lived in the Waikato region at the time of the first interview with Rachel, and was in Auckland during the time of the second interview.

Brandon was 23-year-old male who participated in this study, who resided in Tāmaki Makaurau. Brandon was interviewed with his mother and his step-father. He had two children with a third on the way. He was diagnosed with rheumatic fever when he was 14 years of age. He has not since had a recurrence; however, he had been re-hospitalised numerous times due to heart complications caused by rheumatic fever.

Tamati was an 18-year-old male participant who was from Te Tai Tokerau but was raised in Tāmaki Makaurau. Tamati requested to be interviewed alone. He had his first episode of rheumatic fever when he was 14 years old, living in Te Tai Tokerau. Since his first episode, he had two recurrences of rheumatic fever, one at age of 16 and then again at the age of 17. During both of these recurrences he was residing in Tāmaki Makaurau.

Rawiri was a 21-year-old male respondent who was living in Tāmaki Makaurau. He was interviewed with his mother, his partner, and his younger brother. Rawiri was first diagnosed with rheumatic fever when he was 14 years of age and suffered a recurrence when he was 17. He was living in Tāmaki Makaurau in both instances.

4.3 Results

This section presents the analysis and interpretation of the whānau interviews. Participants described a range of experiences of rheumatic fever. Four key areas, which formed metathemes, were pertinent from the whānau interviews: (1) whānau living contexts, (2) whānau experiences in the health system, (3) impacts of rheumatic fever and (4) the overarching importance whānau. Each of the four metathemes is comprised of subthemes that denote narratives emerging within metathemes.

The four metathemes represent content relevant to each of the whānau interviewed, with some whānau experiences varying within the subthemes. Subthemes that comprised a
particularly broad range of whānau experiences are further separated by subheadings. A summary of the metathemes and subthemes arising from thematic analysis is provided in Figure 3.

**Results**

1) Whānau living contexts
- Unstable housing
- Deprivation
  - Transport
  - Financial difficulty
  - Poor housing conditions

2) Whānau experiences in the health system
- Whānau experiences of racism
  - Provider bias
  - Mistreatment
  - Dehumanisation
  - Victim blaming
- Communication and rapport
  - Communication and language
  - Lack of information given
  - Building rapport
  - Ethnic concordance

3) The impacts of rheumatic fever on whānau
- Emotional and social wellbeing
- Access to education and employment

4) The overarching importance of whānau
- Whānau as patient advocates
- Informal carers
- Whanaungatanga and manaakitanga
- Absence of whānau felt

**Figure 3.** A diagram to summarise the four metathemes and subthemes arising from thematic analysis of the whānau interviews.
4.3.1 Whānau living contexts

In talking about their experiences of rheumatic fever all participants placed the phenomenon within broader living contexts. Whānau living contexts had a significant influence on their overall experience of rheumatic fever, as these were the contexts in which the participants fell unwell, and subsequently engaged with the health system. Two subthemes emerged from data analysis: unstable housing and deprivation.

Unstable housing

Unstable housing was a common feature of whānau rheumatic fever experiences. Unstable housing refers to the absence of a fixed residence, and includes the phenomenon of irregularly moving between family members, friends, foster homes and being on the street (Mental Health Council of Australia, 2009). Arising from various circumstances, all participants spoke of moving between whānau members’ homes during their rheumatic fever experience. These circumstances included family issues, parents being incarcerated, being under the care of Child Youth and Family (CYF)\(^ {10} \), and drawing on whānau support. These contexts were important at the time they were first diagnosed, and especially important leading up to the recurrence of rheumatic fever.

When recollecting the time when he was first diagnosed with rheumatic fever, Brandon recalled living “back and forth from Nan’s to [Aunty]’s”, Rachel was similarly living “back and forwards, Northland, to Auckland, Northland, to Auckland”. Moving between cities played a key part in the onset of rheumatic fever for Rachel, as this affected her adherence to antibiotics:

I got sick one school holidays when I came down to Auckland, and um, the doctor put me on antibiotics for two weeks, so anyways, the school holidays were over and I went back up north and I left my antibiotics here in Auckland. So two weeks later, I woke up with the sorest joints.

Unstable housing also played an important part in the recurrence of rheumatic fever for participants. Due to the nature of rheumatic fever treatment provided by the health system (outlined in Section 2.3), a stable home address is necessary for district nurses to visit

\(^ {10} \) Child, Youth and Family is a government agency in New Zealand that has a broad range of services dealing with the legal protection of abused children, youth offenders and youth justice, adoption and foster care (Child Youth and Family, 2016).
patients diagnosed with and provide secondary prophylaxis every 28 days. Thus, frequently moving residence was a key barrier to participants with rheumatic fever receiving regular injections. Tamati highlighted the significance that an unstable home played on his treatment. When asked about his experience of getting injections he replied:

   It’s not the injections! It’s just, when I move [homes], I just, when I move, I don’t know, I’m not bothered with trying to get [district nurses] to come give my injections.

Rawiri's journey being under the care of CYF particularly highlighted the salience of unstable housing on receiving injections. Rawiri grew up in multiple foster homes, under the care of CYF, from a young age. He was released from CYF care when he was 16 years old, then was homeless until he was adopted. Rawiri's mother described:

   Once he was out of the foster system he was homeless basically. So you sort of drifted around a bit didn’t you? Stayed with different sort of friends, and extended family and stuff like that... Until he came here.

In this particular case, Rawiri suffered from a recurrence of rheumatic fever when he was homeless. He explained:

   I wasn't taking [the injections], because I was like in and out, I was in foster homes and stuff. So I wasn’t really stable, and I didn’t want anything to do with stuff like that. And then, once I got back into a stable place, then I went back onto it.

Deprivation

When sharing their experiences of rheumatic fever diagnosis and management, it became apparent that whānau were living in contexts of severe deprivation. Areas of deprivation that emerged in the whānau interviews included transport, financial difficulties, and poor housing conditions.

Transport

Lack of adequate transport was an issue for the participants as it impeded their access to health services. In some cases this lack of transport meant whānau did not access healthcare or delayed accessing healthcare until their symptoms significantly worsened. For Rachel,
having no transport resulted in her having to crawl to hospital with her grandmother and her two-year-old cousin:

I had to crawl. Because we had no car, and this is up North, so we had to walk on the railway tracks and my nan, she felt so sorry for me, but I said “nah I can do it”, I crawled all the way to the [hospital]… on my hands and knees… like on the railways tracks like, it took a good hour to get there but normally it’s like 5 minutes away...

...oh I was just so bad, so I put shoes on my hands just to get through. So people were like, we made it across the tracks, and the tracks took us all the way into town so once we got into town, I’d hold nans hand, take a few steps, sit down, like and I would take another few steps.

Access to transport not only hindered patients’ access to healthcare, but also limited the opportunity of whānau members to visit, and support them. This had an emotional effect for Brandon’s mother, who was unable to visit and support her son due to a lack of transport:

I have no car half the time, so I have to wait for somebody to come along and drop me off at the hospital, and the buses, there’s a bus station over here, but on certain days when he [Brandon] called out to me, I had no money to get over there. So other than that, while he’s crying inside the hospital, I would be crying coming out.

Financial difficulty
Throughout some of the interviews it became evident that at various points of participants’ journeys they were experiencing financial difficulty; lacking the financial resources required to access the health system. As previously noted, Brandon’s mother had no money to get to the hospital to visit her son. Rachel’s mother commented that the “financial worry” of healthcare was what she believed to be the "bottom line" or an overall issue of having children with rheumatic fever:

That’s the only downside, is the financial wise of the parents with their children who have rheumatic fever, especially when they have to take them to the doctors, and get the medicine and that.
Ambulance costs were reported to be an issue for some participants with Tamati calling an ambulance the first time he suffered from rheumatic fever but "because of the bill" for that episode he decided not to ring for an ambulance when he experienced a recurrence of rheumatic fever the following year.

Similarly, financial issues negatively affected whānau support as well as disease management. Rachel’s mother stayed with her for six weeks in the hospital. During her stay, the hospital did not provide her with any food and she was unable to afford the food in the hospital café. This situation led to Rachel giving up her own hospital food to give to her mother. Rachel said "it was expensive" and it made her feel bad:

...the only thing they'd give [my mother] was like, a sandwich. Like oh, sometimes I wouldn't eat. That's because I wasn't hungry. I would say, you have it mum, because I felt sorry for her.

**Poor housing conditions**

Two whānau discussed experiences of living in poor quality housing that was cold and too small for the needs of their whānau. Rachel stated:

My house was so cold, I hated it, we would just stay in the room and watch TV, oh it was so cold. We had no carpet, I couldn't believe that housing...

Rachel provided a detailed account of her experience with AWHI and Housing New Zealand. She had a positive experience with AWHI as they were able to help with modifying her home. Importantly, a larger home was needed and so AWHI transferred her whānau to Housing New Zealand. Rachel had a bad experience with Housing New Zealand:

Rachel: Oh so this [room] had no carpet, AWHI came and my [district nurse] once again, she referred me to [Housing New Zealand] and she was like “is your house cold” and I said “yes it's freezing here man, it's so freezing!”. So AWHI got on to getting me a heater, some carpet, insulation.

Researcher: So did AWHI come around?

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11 Housing New Zealand is a government agency that provides housing services for those in need of assistance (Ministry of Social Development, 2016b).
Rachel: Yeah they gave me a talk, what they could do for me, how they could help me, yeah, so that was good. So I um, basically, they assessed my house at first, and then they said they were putting me in for a transfer with Housing NZ [New Zealand], so I went to Housing NZ and I got declined. So AWHI took me there and then yeah, and Housing NZ’s argument was why didn’t I go here when I got, when I had the second relapse.

Researcher: Really?

Rachel: Yep, I could have applied then.

Researcher: So... with Housing NZ, you were declined.

Rachel: Yeah because I didn’t come when I had a relapse at the time... they said like “you survived through it, you know, all this time, so you can survive another...” ... and I should have brought doctors notes or... when I got it at the time, which was like 5 years ago.

Rachel further went on to explain that she felt like “it was a no straight away” and that her whānau were not given a chance. It was emphasised ”I think they already made their mind up from the start – nope, no”.

4.3.2 Whānau experiences in the health system

This metatheme comprises whānau experiences within primary and secondary healthcare settings including interactions with health professionals. Experiences within the health system were significant in the whānau interviews, as participants spent extended periods of time in hospital upon their diagnosis of rheumatic fever (or recurrence). Time spent in hospital ranged from one month to one year for participants. Furthermore, given the duration of secondary prophylaxis, participants were required to remain in contact with the health system for an extended period of time after discharge from hospital. In turn, whānau experiences in the healthcare system were vast, with two broad areas standing out: whānau experiences of racism, and communication and rapport. The two subthemes are relevant across the diagnosis, treatment and management phases of rheumatic fever episodes.
Whānau experiences of racism

In participant narratives within healthcare settings, it was evident that they were subject to personally mediated racism. This theme was linked to negative experiences of healthcare given that participants believed that being Māori affected the way that health professionals perceived, and subsequently treated them. An important aspect of participant experiences was that the vast majority of the participant’s healthcare providers were non-Māori. This subtheme is divided into four areas: provider bias; mistreatment; dehumanisation; and, victim blaming. Although these areas are presented separately, it is acknowledged that there is overlap between these concepts and that they each represent aspects of personally mediated racism (C. Jones, 2000; van Ryn et al., 2011).

Provider bias

It was evident in some whānau narratives that participants experienced healthcare informed by prejudice (i.e. negative feelings and evaluations of individuals because of their group membership) from health professionals because they were Māori. When talking about his experience in the hospital, Brandon reported that his nurse just “didn’t like brown people” and said that he felt judged based on the colour of his skin and was treated badly. He described:

...because I was brown, and she was like white, from day one when I just went in there and met her, I could just feel that she had problems with me, just from looking at me.

Brandon and his mother further explained:

Brandon: I just think they don’t care about us, that’s all I think, just, they don’t care about Māoris, because when I see them with Pākehā they’re alright.

Researcher: They’re alright?

Brandon’s mother: Have a giggle.

Brandon: [Health professionals would] have a laugh [with the Pākehā patients], but as soon as they come back to me, but as soon as they come back to me, their faces change and everything, so I just put it down to racism, they don’t like Māoris, they don’t like brown people.
Furthermore, Rachel had a negative experience in the hospital when she suffered a recurrence of rheumatic fever; her whānau were asked to leave and were ‘told off’ by a nurse because they were allegedly “too loud”.

Rachel: Because I was, you know, Islander and Māori you know, you have more family that come and visit you, and like [the nurse said angrily] “oh, can yous keep it down”.

Researcher: Oh did you get asked to be quiet?

Rachel: Yeah, “keep it down!” and when my [whānau] would leave [the nurses would] be like “oh you know, you need to tell your visitors that you’re not the only patient in the hospital” and stuff like that... It's like, my own kids that are coming to visit me.

This excerpt was important to Rachel’s whānau, as it caused her whānau to stop visiting her because they were made to feel ashamed by the staff. This negative experience also increased Rachel's desire to be discharged early because she felt that she could not be with her whānau in the hospital. Rachel’s mother also shared her thoughts on this experience:

They don't like loud, loud people you know, [a Nurse said] "consider the other patients", and yet the other patients were happy, they were laughing as well, they were happy, they didn’t care they were happy. But [the nurse said in an irritated tone] "oh but you need to have consideration, you shouldn’t have so many people in the room".

This narrative raised another issue for this whānau. A nurse responded negatively to Rachel for having “so many people” visiting; however, this was the reality for her whānau. This narrative an example of the hospital staff sending negative messages to Māori that their whānau reality (i.e. size) was not appropriate for the hospital context.

Rawiri’s mother explained how she felt stereotyped as a bad parent. This was evident in the way that she was asked about her whānau living situation by a healthcare provider who assumed that she was a bad parent who was living in poverty:

Rawiri’s mother: We had contact from, I’m not too sure if it was a social worker, or someone from the hospital, wanting to see about getting insulation for the house, and heating, and how many children did I have
sleeping per room. And I was like "Ummm, one child per room, and no thank you my house is fine" do you know what I mean, that assumption that like, a Māori Polynesian problem, and poor people get it, you know. And almost sort or poor parenting, poor care of kids.

Researcher: Did you feel that by the way they asked you?

Rawiri’s mother: Yeah, it was definitely, yeah. It definitely came across that there was the assumption that we had sort of, substandard housing and substandard care for the kids and stuff like that. And I think that’s kind of dangerous, because strep throat is strep throat, you know.

_Mistreatment_

Whānau reported that the attitudes held by health professionals against Māori manifested as mistreatment, a form of discrimination (van Ryn et al., 2011). These experiences, illustrated in this section, caused both physical and emotional harm and negatively affected the overall whānau experience.

The participants described being subject to negative attitudes of health professionals, that they felt resulted in mistreatment. Rachel reported that “you get nurses that can’t be bothered with you” and Rachel’s mother said that “you’re just annoying, that’s the way the nurses treat you”. Rachel shared:

Yeah so it was hard for me to pull my pants down, pull my pants up, and I couldn’t buzz the nurse like come and pull my pants down, you know, because they were getting shitty like “oh, this girl again”.

This resulted in her “[feeling] a bit funny to ring the buzzer if [she] needed something”, so she chose not to.

Mistreatment was a particular area of concern for mothers who found it hard to see their children being treated poorly and noted that this caused significant distress for whānau. Rachel’s mother was concerned that her daughter was treated “like a sack of potatoes” by the nurses.

In the shower, oh my goodness. If you know the child is sore, and in pain, you don’t be rough with them.
Rachel’s mother was also concerned at the way that her daughter’s head was being treated by healthcare professionals during their personal interactions. For instance, it is a common Māori cultural belief that the head of a person is considered tapu (sacred) and should be treated respectfully (i.e. not touched directly without permission).

When it came to her hair, her head. The way they were washing her was like wash up and wipe [motions of rough, fast, quick, hair washing]. You know, just wash up. And I said “No, you shampoo her hair [gently], you condition her hair, and then you wash it and wipe it”. They were half-pie12 there’s a lot of things they were doing half-pie.

Participants all spoke of health professionals being rough with them, which caused them physical pain and distress. Tamati described “they’re rough”, causing pain because “they just grab you”, “they just weren’t even watching what they were doing” and that needles were being “shoved in”. Brandon described:

Instead of asking where it’s sore, you know they just poke around and squeeze things, and obviously if they see it’s swollen, why would you go and squeeze and ask “does it hurt?”... it hurts!

Brandon emotionally shared his story of severe mistreatment. Detailed in the following excerpts, the mistreatment started when he reacted with anger towards a nurse who was rough with him, and the nurse then developed “a problem” with him. Brandon described his experience of neglect that followed, which resulted in him letting his anger out on his wheelchair:

I would push the button, nobody would come for ages then I would go to the front desk and ask “how come nobody is coming?” And everybody would just ignore me, so I went back down the hallway and smashed my wheelchair against the wall, started kicking the walls in and then that’s when I was noticed.

After this incident, the nurse who had “a problem” with Brandon, took his wheelchair away:

12 ‘Half-pie’ is a colloquial term in Aotearoa meaning something is done to a poor standard or without effort
Like I need a wheelchair to go from my room to the playroom or anywhere, and she would be like, "I'm taking the wheelchair", "What for, I need it to go-" "No, you're not going anywhere today" [said the nurse] and would take my wheelchair away.

This taking away of Brandon's wheelchair was an extreme breach of Brandon's rights. Additionally, Brandon felt that he was seen to be the problem. The situation started with Brandon getting angry at his rough treatment, and resulted in abusive behaviour from his nurse. Furthermore, as a result of this experience, Brandon subsequently discharged himself early from hospital and did not complete his required rheumatic fever treatment.

Dehumanisation
Participants also shared experiences of feeling dehumanised when receiving healthcare. Dehumanisation refers to the denial of human qualities, personality or humanity, to a group of people, and permits mistreatment (L. Smith, 2012). Dehumanisation is a key manifestation of personally mediated racism (C. Jones, 2000).

Tamati expressed that he would have preferred health professionals to "talk to me like I'm a human, not just something to poke at". Furthermore, a way in which whānau expressed feeling dehumanised was in feeling like numbers (as opposed to individuals with needs). When discussing her negative experiences while caring for her child in hospital, Rachel's mother stated:

Rachel's mother: I think sometimes they think people are just numbers.

Researcher: People are just numbers?

Rachel's mother: Yeah, when they're in hospital, "Oh yeah okay" [the nurse would say in a hasty standoffish tone] "Oh yeah I've seen this patient" tick, tick, tick, you know.

When asked if any improvements could be made to her experience in the hospital, Rachel's mother commented:

With the nurses I would tell them, treat them like they were your own children, with love and care. Don't treat them like they're just a number.
Victim blaming

During the whānau interviews it became apparent that messages received from health professionals, and health promotion information, perpetuated notions of victim blaming. Such discourse locates Māori and Māori characteristics as the problem as opposed to the broader factors that drive poor health outcomes (Reid & Robson, 2007). Victim blaming had an impact on whānau and was evident in excerpts where whānau internalised these victim blaming notions; blaming themselves for their illness and their limited access to treatment.

Whānau spoke of some examples whereby health professionals perpetuated victim blaming explanations for the situations they were in. The following situation occurred after Rachel’s partner confided in her district nurse about how he was struggling to look after their young children on his own:

[The nurse] could see that [my partner] was worn out, so she gave me a good telling off, and I cried. She was telling me like “You can do things for yourself. You know, don’t just lie on that bed, try and help yourself”. So she gave me that kind of talking to.

This made Rachel feel like the problem / issue when she was bedridden after her recurrence of rheumatic fever because there was an assumption that Rachel did not want to help herself.

Additionally, there were notions voiced by healthcare professionals to participants that parents of children with rheumatic fever did not care about their childrens’ health. One nurse commended Rachel’s mother for staying with her daughter for an extended time in hospital because she “cared” about her daughter. This insinuated to Rachel’s mother that mothers who were not able to be with their children in hospital were perceived not care about them.

Some of the nurses were happy that I was there, because some of them would come in, and they would talk to me about it. You know “it’s nice to have a mother here, with her child, because some parents don’t come in, and they don’t care about their children, whereas we know you care about your child, and it’s good that you’re here, so you know exactly what’s going on with your daughter”.

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In this instance, the nurses failed to recognise the myriad of reasons why parents may not be able to stay in hospital with their children. The nurses instead made the potentially incorrect assumption that parents do not care about their children’s health.

Furthermore, Rawiri’s mother commented on the rheumatic fever health promotion advertisements on television and believed that the information sources perpetuated stereotypes of Māori as being the "problem" to the public.

I think it’s better that recently there is a lot more public awareness, but even, yeah, even then I think it’s sort of almost... personally to me I feel like it’s aimed at a... and I know that Māori and Pacific Island kids are more likely statistically, more likely, but yeah, I think that it portrays it as really being a Māori and Pacific Island problem.

Rawiri’s partner, who worked as a primary school teacher, agreed with this statement and said that she noticed that these messages were also received by her students:

Oh I definitely agree. Like I work in a decile 1\textsuperscript{13} school, and we have got a district nurse on site that swabs every day, kids with sore throats, but yeah, all the ads are brown kids, it’s kind of just... you know. And that’s, the kids at school sort of have that mind set too. So like, the kids of lighter skin colour, they’ve got a sore throat but they won’t go and see the nurse, because, I don’t know, they’ve got that view that “I can only go see the nurse if I am brown”, or, you know.

It was also evident that victim blaming notions were internalised by whānau. In the context of discussing receiving secondary prophylaxis, Rachel stated "Yeah, because I’m hopeless, like I keep forgetting" and when asked about accessing the doctors clinic she said “I had transport, I just slacked it”. Furthermore, while describing his experience of not accessing secondary prophylaxis, Rawiri said "when I move, I don’t know, I am not bothered with trying to get them to come give me my injections”. Rawiri’s reality was that he was homeless and floating between whānau members houses from a young age, yet he blamed himself.

\textsuperscript{13} Deciles are a measure of the socio-economic position of a school’s community relative to other schools in Aotearoa. Decile 1 schools are the 10\% of schools with the highest proportion of students from low socio-economic communities (Ministry of Education, 2016).
**Communication and rapport**

Narratives around communication and rapport were a significant aspect of whānau interviews and were especially pertinent to experiencing recurrent episodes of rheumatic fever. Participants spoke repeatedly about the nature of healthcare provider communication as being a significant driver of their healthcare experience. Communication was also tied into rapport by the whānau who noted that good communication established rapport and that establishing rapport with health professionals was critically important to good care for whānau. Components of this subtheme include communication and language, a lack of information, building rapport, and ethnic concordance.

**Communication and language**

Communication and language use was an area that parents reported frequently as influencing their experiences in the hospital. Participants largely talked to the way health professionals did not engage with whānau, did not make attempts to help them to understand what was happening, did not facilitate two-way communication, and used language that was difficult for whānau to comprehend. When asked what would have made his journey through rheumatic fever easier, Rawiri shared this story about poor communication from health professionals, which resonated with stories from the other participants with rheumatic fever:

Rawiri: I remember sitting in the hospital and they would always say oh, the doctors going to come and see you soon, and then he [the doctor] would come and he would say this stuff but like I would nod my head, but I don’t know what he’s talking about.

Researcher: What do you think would make it easier there?

Rawiri: Probably the way they um, the doctors actually explain things, because that's, it's pretty confusing when they just use like big words, and I don’t know what they're talking about.

Researcher: Did you feel like you could ask?

Rawiri: I did ask sometimes, but their response was the same so I just left it....

Researcher: Oh, okay.
Rawiri: Yeah... because... if they just, like if someone tells me something I don’t really know about, and I ask, and I still don’t get it, I just leave it, like I just let it go, but then I will still be wanting to know, but I don’t know.

Rawiri’s mother: He’s shy

Rawiri: Yeah I guess I, and confused, because I actually don't know what they're talking about, like they're actually just saying big words, it’s confusing.

Initial poor communication contributed to Rawiri’s recurrence of rheumatic fever given that he was discharged from the hospital the first time with little information about his condition and necessary ongoing care.

Rachel’s mother felt that the reason for these communication issues was the power imbalance between doctors and patients and how this manifested in poor communication. She discussed:

When it comes to the doctors and that, I would ask them to explain themselves clearly to the parents, to their level, not to their way of speaking at a doctor’s level. Because people don’t understand a doctors’ level.

She further discussed the power imbalance that exists between doctors and patients, which results in parents finding it difficult to ask questions, when asked about this she said:

It’s like umm... Dominate? You know, the doctors are up here, and you’re down here “what I say goes”. You know?

Rachel’s mother was trying to articulate the power differential felt in these conversations, which made it difficult for whānau to obtain information about care. This resulted in whānau coming away from the hospital with an insufficient understanding of what their child was going through and a lack of in-depth understanding about their rheumatic fever management.

Whānau did discuss some examples of good communication. These instances were important to whānau, and improved their healthcare experience. However, these experiences were not as commonly discussed as the negative experiences. Participants liked it when the doctors “[put] it straight to layman terms, for us as our slang”, as opposed to using confusing language as described above. Moreover, a few of the participants liked
doctors communicating “through pictures”. Rachel recalled “when I was looking at the pictures I was like oh wow, oh it’s attacking my throat like, oh it’s attacking this and that”.

Visual aids were especially helpful for Brandon’s mother who did not “do too well with reading, especially when they have those big ass words”. It is important to note here that visual aids such as diagrams and pamphlets were helpful alongside verbal communication, but did not suffice on their own, nor should they be used as a replacement for verbal communication. Brandon’s mother reported a negative experience when she was given something “from the internet” and told “you read up on this” by the doctor and then left alone with little verbal communication.

Furthermore, participants appreciated being given the time and space for two-way communication, and being asked if they had any questions in a way that made them feel comfortable doing so. Brandon’s mother emphasised that doctors should “let the patient say something”. Rawiri highlighted this also:

Some of [the nurses] actually talk to me about it, or ask me if I want to know anything, sometimes if I do I would let them know, and they would tell me, or try and explain it to me basically. Yeah, that’s pretty cool.

*Lack of information*

In relation to poor communication and language, a lack of information provision overall was another key issue for whānau. In some cases, no effort was made to provide the necessary information needed. This issue was especially pertinent to receiving secondary prophylaxis. Participants reported being left with “big blanks” in the hospital even after asking for more information, this resulted in participants not fully comprehending rheumatic fever treatment and management. For some, it was this lack of information (and therefore understanding) about rheumatic fever that contributed to their eventual rheumatic fever recurrences.

Firstly, lack of information as an issue for whānau because they did not understand their diagnoses, evident in the paucity of details provided about their own cases of rheumatic fever during the whānau interviews. When asked about their rheumatic fever journey, and details around their diagnosis and treatment during the interviews (such as the severity of their symptoms, in particular carditis) some participants were unable to give detailed information because they did not know. The inability of participants to provide the researcher with details surrounding their diagnoses is indicative of a lack of information
given to them from health professionals. This left important gaps in their stories, and this research. For instance, Tamati spent an entire year in hospital and yet had no idea why his stay was that long.

Lack of information was pertinent to the utilisation sore throat antibiotics. Rachel stated that she was given no information about the importance of finishing the course of antibiotics to treat strep throat when she was moving between Tāmaki Makaurau and Te Tai Tokerau. When asked what would be the best way to prevent rheumatic fever, she said:

I think more info [information]. Yeah, more communication from a doctor to a patient. The doctor could like, say, maybe, "This is what could happen if you don't take your antibiotics". Like they need to let the patient know that it is very, very important to take antibiotics... If I had have known I would have definitely gone back to the doctors like "oh, I left my antibiotics in Auckland, I need some more" you know, stuff like that. I wouldn't be having these problems.

A lack of information from health professionals was also present in narratives around secondary prophylaxis. Rawiri’s mother stated:

I thought that was, that was really bad, the way they give information and even when Rawiri did first start having the penicillin injections, he knew he had to have them, but didn't sort of really understand what, how it worked, or why it worked and why it was supposed to you know affect his heart.

Importantly, not only were interview participants not given sufficient information, even after specifically asking doctors to provide additional information, they were still left with gaps in understandings of their situation. This was related to poor communication, but also due to health professionals not attempting to provide information from the patient’s perspective. Brandon stated "[the doctors] never explained anything to me... they just told me if I don't do it I'll die. That's the only explanation I got". Rachel's mother reported a similar experience when asking doctors about Rachel’s illness in the hospital. She stated "they didn't even try, they just didn't try". This was also emphasised by Rawiri’s mother, who said "I tried talking to doctors about it, but some doctors, they didn't, they just didn’t really give you much information".
Building rapport

From the whānau perspective, building rapport with health professionals was critically important to good care both in the hospital during initial rheumatic fever and during ongoing disease management. Building rapport for whānau meant forming relationships with their health professionals that were based on mutual understanding and relied heavily on good communication. Building rapport also required health professionals to make an effort to “get to know” the whānau. Whānau spoke of building rapport in a similar sense to whakawhanaungatanga (the Māori process of establishing relationships). Whānau discussions around rapport stemmed from emphasis on building rapport with health professionals, continuity of care. Rapport extended beyond doctors and nurses, to other hospital staff.

Alongside the examples of good communication presented in the preceding subtheme, whānau emphasised that building rapport was about engaging in conversation with their nurses. For Tamati, building rapport was as simple as the nurses asking how his day was and having “little conversations” instead of “just doing their job and walking away” (which is what tended to happen to the participants). Tamati further noted that the “good nurses” were “the ones that talked to you... because they want to know something about you”.

Building rapport with health professionals was particularly important in secondary prophylaxis, given the invasive nature of the monthly injections. Knowing the district nurses coming into their homes was important for whānau because it made the experience more comfortable. This was discussed by Rachel. She said that “they made me feel comfortable, and they reassured me” and Rachel said that she got used to injections and liked the nurses coming to their homes “because I ended up building good relationships with them”. Rapport with nurses equated to less pain given experienced because it enabled that the nurses to become were aware of their patients’ preferred technique for their injections. Rachel further described:

It’s good when you, when you know your nurse and you’re used to [the nurse], it makes you feel comfortable, you know their jabbing your butt. You know, you have to pull your pants down and yeah. I built a really good relationship with one of my nurses... And they know me too, so they always bring the buzzy bee and the ice pack.

From the whānau perspective, building rapport with nurses required continuity of care, which refers to the patient's experience of a continuous relationship with a health
professional (Gulliford, Naithani, & Morgan, 2006). Having changes in staff members meant that the whānau had to re-build rapport from scratch, or did not have the chance to build rapport at all. When asking about receiving monthly injections, Brandon and his mother discussed:

Brandon: Different nurses, that’s what [I didn’t like], the different nurses.

Researcher: Did they change every month?

Brandon: Yeah basically I had a new person.

Brandon’s Mother: Every visitor that came [to my home] was a different lady
I’m like, where’s the last lady?

When asked if they could make any changes to their experience in the hospital, Brandon said he wanted “bonding” and the “same crew” to be working. This was because he felt that during his hospital stay, the nurses would just “come out of random”, and that they did not know or care about him.

Rawiri’s whānau talked about the good rapport they had built with their GP over time and how this resulted in better care:

She’s really approachable, and very, the good thing about, we go to appointments and she obviously read up her notes before and you know, she’s totally up with the play when you go in there, so, she asks relevant questions and it’s not like, starting from scratch like it has been with some other doctors.

Rapport with non-clinical staff members in the hospital (such as social workers), and hospital cleaners, were important positive experiences of the whānau. Rachel said the social workers were like her “best friends” during their stay in the hospital and were helpful not only to the patient but also to her mother. Rachel also noted that “social workers were such a huge help, huge comfort to my mum”.

Further, Brandon formed bonds with the hospital cleaners during his stay. Brandon said the hospital cleaners stayed the same while the nurses changed, which meant he was able to build rapport with them. The cleaners “smiling faces” in the morning made his experience better and they would be “joking around” with the children; making their experience in the hospital more positive. Brandon described “I always woke up to see somebody smiling at
me”, thus, the cleaners were important to care. The basis of this was that the cleaners communicated with him and they were familiar faces.

Researcher: Did [the cleaner] help with your journey of rheumatic fever?

Brandon: Yeah! “Hello, how are you today” walking past with her cleaning trolley, parked it, came up to have a talk with me, see how my day is.

For Brandon, the cleaner helped him to navigate through his experiences of mistreatment from the doctors. After describing the emotional effects of mistreatment, Brandon explained that afterwards when he was angry and felt hostility from health professionals, that:

It would be the cleaner, or somebody that I know, like that’s always been good to me. They would come “oh what’s the matter”.

Ethnic concordance
Ethnic concordance (i.e. being of the same ethnic background) with health professionals was associated with improved communication and rapport building by participants. This was important to participants who felt less judged and were able to connect with health professionals who shared their ethnic or cultural background. In these contexts, being Māori was not a factor that evoked a negative reaction. Therefore, ethnic concordance was overall associated with better quality care. When speaking about communicating with health professionals, Rachel’s mother stated "Māoris do get treated different, and if you get a Māori nurse, you’re lucky".

Rapport was built easily with Māori nurses and participants felt that they were able to communicate more effectively with them. Brandon reported that: “every brown nurse I had there was all good... they just ask me if I’m alright. That kind of simple stuff”. Whānau were able to easily build rapport with Māori nurses as opposed to Pākehā nurses for some participants. Brandon’s mother described:

...maybe the best thing that I came to was the islander [Pacific] nurses. I always got along with Islanders. Māoris, Islanders, always. But I had trouble trying to get along with the Pākehā nurses. I would try! But, they didn't really want to know me or anything.

Revealed in this transcript is that the benefit of ethnic concordance for Māori extended to include Pacific nurses as well.
4.3.3 The impacts of rheumatic fever

Rheumatic fever changed the lives of the whānau involved in this study, significantly disrupting the lives of the participants with rheumatic fever and their whānau who cared for them. While the impacts of rheumatic fever were quite extensive, two key subthemes emerged from the data: emotional and social wellbeing and access to education and employment.

Emotional and social wellbeing

Rheumatic fever negatively affected the social and emotional wellbeing of participants. The emotional and social impacts of rheumatic fever stemmed from having to emotionally cope with being unwell and bedridden, missing out on school for extended periods of time, being unable to play sport, and gaining body weight. Importantly, these issues affected participant's identities and affected their social lives. As such, the emotional and social impacts of rheumatic fever emerged as a subtheme.

Rheumatic fever had a severe emotional effect on participants at the time they were diagnosed, which was an experience that participants had difficulty coping with. Rachel described how she “went so sour” after being diagnosed and putting on weight as a result of rheumatic fever, which lead her to suffering from depression:

Yeah, [I had to quit] netball... I put on a lot of weight, which made me depressed too. That was another thing... being on bed rest, and not being able to be physical, and I put on a lot of weight, and so when I went back to school here, I just had a hard time settling in again, and repeating all over again...

Rachel's depression caused her to become emotionally “closed”. She said: "I went through a buzz where I was just, you didn’t want to be around me. I just shut, up, like a closed book”.

Brandon gave a detailed account of how rheumatic fever affected his life. He said it "ruined everything I used to do, sports and all that”. To Brandon, rugby was more than just a form of physical activity, it was a central tenet of his social life and important part of his identity. Brandon explained:

[The Doctors] just, basically just told me that I have a heart disease, and that I need to drop basically everything I am doing in my life, and start fresh. Because everything I was doing was all physical, and sports and all of that...
...I was doing good as [at school]. I was doing well with [rugby] league, getting up there with my sports, everything, school. I was alright in intermediate. I was naughty but I always you know, got through, what I was asked to do and all that. And once I found out I had rheumatic fever and it would affect my life, and I just didn't want to know anybody, didn't want to do anything. Just didn't wanna listen, anything like that. It just changed my whole, my whole life around really.

Revealed in this excerpt is the experience of social isolation, which was driven by shame and embarrassment. Brandon further described:

I didn't want anybody to see me like that. Because they all knew me as a strong kid, they always, I didn't want anything, not weak like how I was, I felt weak, and just little.

As a result, Brandon became “naughty” and started to take out his emotional pain on his whānau; eventually turning to consuming substances to help him cope. He remorsefully recalled “I didn’t know what was happening, I was scared, taking all my shit out on everybody”.

[After being diagnosed with rheumatic fever] I just got worse and worse to [my nan]. I started not listening, running away, yeah. Sort of um, started smoking drugs... all that kind of shit. Yeah, just the whole different me really, started drinking, yeah.

As evident in the transcript above transcript, seemed to bear the brunt of their children’s emotional pain. Whānau members reported their children becoming angry and ‘taking it out’ on their whānau, which also exacerbated the child's emotional pain and guilt in hindsight. This was evident in the tone and mood change of the conversations in the interviews.

The emotional pain of their children was a struggle for mothers. Brandon’s mother said “I didn’t know how to cope with it”. She recalled both her and her son crying and her looking to her mother for support:

He was a little asshole, he wouldn’t tell me what was going on, but he would cry about it. Um, my mother, every time she would try and explain the things to me, I would be crying.
Rawiri’s mother said that the emotional and social impacts of rheumatic fever on the wellbeing of children required a health service response, especially for youth. She believed that treating rheumatic fever was more about managing sore throats and preventing a recurrence.

...Certainly the whole time [my son] has been here, there has never been any support of that sort you know, with the, coping with it mentally, yeah there’s been none of that, which I think there should be.

...I think that they should, well it’s more than just, I mean it is a medical condition, but coping with having a condition that is life threatening and you know, for, a young person, you know that’s pretty scary... And um, there’s just nothing there, it’s just basically you need to come at this time, have your injection every 4 weeks and we’ll take your blood pressure every second time, and we will weigh you every second time, and you know, you have the scheduled [clinic] appointments and that’s it. You know there’s nothing to sort of, deal with his feelings oh what it’s like to have, you know, have a potentially life threatening condition. And I think there should be. Like, adults as well would need it, but particularly for kids and young adults, yeah.

**Access to Education and Employment**

Rheumatic fever impeded access to education and employment for both the participants with rheumatic fever and their whānau. Participants with rheumatic fever were absent from school and work for extended periods of time on bedrest as they recovered from the rheumatic fever. Whānau also took time off work to care for their ill whānau members. Facing barriers to accessing education and employment had emotional and social effects that were discussed in the previous subtheme.

As previously mentioned, participants with rheumatic fever all reported long periods of time in the hospital at each diagnosis or re-hospitalisation (from a month up to one year). Given that the age of the initial diagnosis of the disease was 14-years for all participants (coincidentally), rheumatic fever had a significant impact on the education of the participants. Not only did participants miss school, but struggled going back to school, especially as they felt they had “changed” due to the aforementioned social and emotional effects of rheumatic fever. The difficulty coping with returning to school was highlighted by Brandon. When Brandon went back to school after rheumatic fever he recalled:
Time after [getting rheumatic fever], going to school was ratshit, [the teachers] would just baby me, treat me like a little kid, and didn't want all that, I just wanted to be treated normally, I just wanted to do normal things, everybody in my school gets to do sports, [physical education] and all that, and I had to sit on the side, and watch. I wasn't allowed to do nothing so I'd just walk home, and truancy officers would pull me up, I'd swear at them "get fucked", cops would come around "you need to be at school".

The above excerpt also reveals the emotional effects of missing school, emphasising the linkages within this metatheme. Emotional effects were linked to participant engagement in school and extended to overall educational achievement. This was further foregrounded by Rachel's experience:

I felt a bit depressed for the next few years, I felt a bit depressed because I had to repeat fifth form. Moved back to Auckland and then I had to repeat. And I felt like I missed out a lot.

Rheumatic fever also affected employment for participants. This was because participants were unable to work during periods of illness and hospitalisation. Moreover, some participants worked in labour intensive jobs that required heavy lifting and physical exertion, which is advised against for those with lasting heart damage (Heart Foundation of New Zealand, 2006). Rawiri was a labourer and had concerns with going back to work; concerns that also related to him not wanting people to know about his illness because he was ashamed / embarrassed of his condition. Rawiri’s mother said:

[He was] worried that it would affect how [his co-workers] looked at him and whether they thought he was capable, and you know, whether [he] kept [his] job.

Brandon lied on his job application when asked if he had any existing medical conditions that may affect his job out of fear that he would not get employed.

Even today I'm not allowed to do [physical activity], I'm not allowed to lift heavy, and that's basically my job, what I do at work... I am a [labourer], just

14 In Aotearoa the term 'ratshit' is slang used to describe something that is bad or awful.
lifting heavy objects, but like, just lifting bails by myself, I’m not allowed to do that.

Brandon’s skills were in manual labour, but he was unable to work and did not qualify for the disability allowance. He explained that because he did not qualify for an allowance while he was unwell he had to continue to lie on his job applications so that he could remain employed; despite knowing the potential risk to his heart that his job causes. He said bluntly, “I gotta get paid”.

Some whānau members also stopped working for a period of time in order to spend time in hospital with their sick partner / parent. Rachel’s mother took time to move from Tāmaki Makaurau, to Te Tai Tokerau to stay with Rachel for six weeks; she then stayed with her while she was on bed rest. Furthermore, Rachel was married with children when she experienced a recurrence of rheumatic fever. Her partner quit work in order to care for her and her children.

Researcher: So [your partner] looked after the kids?

Rachel: Yeah, he would look after the kids, he stopped work then.

Researcher: Oh did he stop work?

Rachel: Yes

Researcher: How did that impact you guys?

Rachel: Financially it was a bit hard, emotionally it was ok, and then he started to feel, he just wanted to make sure the kids were taken care of properly, and I was looked after. So he just thought oh nah ill stop working.

When asked if it was a hard decision to make for her partner to stop working, Rachel said “No, not really” because “it was easy for him he just said nope, not going to work. And it was good though. Things worked out really good then, with the support at home”.

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15 Disability Allowance is a weekly payment for people who have regular, ongoing costs because of a disability, such as visits to the doctor or hospital, medicines, extra clothing or travel (Ministry of Social Development, 2016c).
4.3.4 The overarching importance of whānau

The importance of whānau was a significant element of whānau narratives. This is unsurprising given the significance of whānau in te ao Māori (Māori society). However, the role that whānau played was one that was largely in response to negative experiences. As demonstrated in the data presented, Māori face a number of negative experiences in healthcare settings that are indicative of Māori needs not being met. Whānau thus were required to step in to respond to these situations, to mitigate negative outcomes, and to ensure adequate treatment for rheumatic fever was received. The overarching importance of whānau falls under four subthemes: whānau as patient advocates; whānau as informal carers; whanaungatanga and manaaki; and, the absence of whānau felt.

Whānau as patient advocates

Whānau were required to act as patient advocates. This was largely in response to experiences of personally mediated racism and poor communication. In response to a lack of information provided by health professionals, whānau actively sought information about rheumatic fever and pressed health professionals for more information via asking questions. Rawiri’s mother explained:

I have done lots of googling. I have read any information I can get my hands on about it, and I also question the doctors and the specialists and we go as well, I would always ask questions. Sometimes I could see like the, they would talk to [Rawiri] and I can see that he’s, you know, he will look over at me and I can see that he’s not really understanding, so I will ask some more questions to try and get um, what we want, or the information that we want out of it.

Advocating for her son extended to Rawiri’s mother following-up with doctors and nurses:

I will start phoning the doctor or the nurses you know, they said this at [the clinic] and they said this at [the clinic], and I don’t think that should have to happen you know, they should do what they say they are going to do and they should follow through with it, which they haven't.

Rachel’s mother believed that “speaking up” to health professionals when whānau needs were not being met was critical to receiving good healthcare.
Yeah, gosh, that's your child, stick up for your child. I think [other parents] were scared they would get kicked out, I didn't care. If you're going to kick me out, you're going to know all about it.

Rachel's mother was able to ‘stand up to’ doctors and voice her concerns; however, she did recognise that it is not easy for all parents to do the same given the power dynamics that exist between doctors and whānau. She described:

Rachel's mother: That's what I get annoyed about aye. The way the treat Māoris. You know, the way they treat um, Māoris. Not only Māori’s, and Islanders!! You know, oh man. And our parents, they don't even speak up, they're too scared.

Researcher: Do you think they're scared because –

Rachel's mother: Superior. The way [the doctors] talk, the way they speak, the way they speak.

...I can see that [the parents of children with rheumatic fever] are hurting and they can't say anything. Just tell the doctors, tell the doctors. I think that's why my girl was so grateful that I was there, because I didn't care. To help me to understand I want them to speak English, speak my language. Come down to my level, don't speak medical side, come down to my level, I can’t handle that.

**Informal carers**

Some whānau reported mothers taking on roles as informal carers during their children's stay in hospital; taking on roles that were normally fulfilled by nurses and cleaners. This was in response to poor care provided and mistreatment. There was also a sense of mistrust in health professionals as evident in the tone of the interviews. Rachel’s mother's story of her time caring for Rachel was told in detail. She stayed in hospital with her for six weeks; sleeping on a lazy boy chair or sometimes a mattress if there was one available. She said:

If my daughter is in hospital I want to know exactly what's going on, and I will look after my daughter properly. I will look after her the way she deserves to be looked after.
...The nurses told me what needed to be done, what she needed and what they want to do to her. And I said “oh okay, just tell me what needs to be done, and can you show me”.

Rachel’s mother proceeded to take over her daughter’s care by making her bed, monitoring her, bathing and feeding her. This had an important effect on Rachel’s hospital experience; where she considered herself lucky in comparison to other children in hospital who did not have their whānau there with them.

Whānau also spoke of support networks between mothers and grandmothers of the participants with rheumatic fever and how these networks allowed for informal care. Whānau support was strong; whānau held close bonds. Brandon’s mother was incarcerated when he was diagnosed with rheumatic fever and his nanny took over his care. Brandon’s mother described:

Because I wasn’t there. And my mother said “I’ll help him” and I’m thinking, why should you mum, you’re getting too old, I done my time just so I can come out, take my children away so my mum can grow old, she’s 72 now. You know, and I’m 42.

Another important role played by whānau was mitigating the emotional effects of rheumatic fever; providing strong emotional support for their whānau members. For Rachel, it was the experience of meeting her husband that helped her to heal her emotional wellbeing:

I said, “oh my life is effed”, nah I had a hard time. But then umm, I met my partner, and yeah, he picked me up and, I’m beautiful the way I am. I had to learn to love myself all over again. So yeah, now I do, I love myself.

**Whanaungatanga and manaakitanga**

Whanaungatanga and manaakitanga (support) were evident in the whānau interviews. Whanaungatanga refers to building relationships, and manaakitanga refers to “nurturing relationships, looking after people, and being very careful about how others are treated” (Mead, 2003, p. 29). These concepts are of high significance in te ao Māori and underpin tikanga Māori. In this sense, whānau support (or whānau responses to the health system) extended beyond family members as whānau often formed relationships with, and looked after, other whānau in hospital.
Because Rachel's mother stayed in hospital for a long period of time, she began to form relationships with children who had no whānau present. She recalled: “because I knew my girl was alright. You know, I made sure she was alright first, and then I went round, and “miss!””. Rachel’s mother explained that the children would call out “miss!” when they needed her and that she would ensure they had what they needed and advocated for them too. She formed motherly bonds with them. Rachel’s mother also looked after other mothers who came in to the hospital; mitigating issues of stress caused by communication and lack of information:

Some of the other parents, oh my gosh, I felt so sorry for them. One mother just broke down in tears and I said “what's the matter” [she said] “well I don’t know what to do, they haven’t told me”. So more or less, I told her “this is what you do” and she goes “they didn’t tell me that”...

...because I was there so long with my girl, every time I saw a new [Māori parent] I said “this is what you do”.

Brandon was 'taken in' by a Pacific whānau (who were there supporting their son who also had rheumatic fever) during his stay in hospital. He explained how they cared for him:

Brandon: The only reason I got past everything really was having the right roommate.

Researcher: Oh your roommate, tell me about that!

Brandon: He was an Islander. He was in there for the same thing as well, he just had his operation, he wasn't allowed to do everything, just like me. His family used to come up every day, and pretty much sit up there from the morning to the night. And like, the day after him moving in, his family used to always come in the morning, open our curtains, wake us up and tell us “shower boys”, get us both in the shower.

Researcher: They showered you?

Brandon: Just got us up and ready for the day. “Hey boys, breakfast is here”. I used to deny it "nah yous have it... it's alright I'm not hungry". [They would say] “Nah nah, come on bro, come and eat”. They used to offer it to me, I had my own food and snacks there, but they always used to say "nah here".
... [The Pacific whānau] put the table between our beds, and said “here bro, come have a feed” and I'd deny “nah, nah, it’s all good” and the Mum would go “No, eat, eat”. I was like “Nah, it’s ok” “No! Eat!”. Okay then. And I got to know everybody really, right down to the cleaners, basically all the nurses, all his family that came up. Yeah, they would come and say “hi” to me, morning, ask me if I wanted anything like a change of clothes or something. [The Pacific whānau] were offering me clothes, heaps of things just like... Coming up and gifting me things. Yeah...“bro, what do you got today?” “Nothing I’ll just kick back in bed all day” “Nah nah, come on, we’ll go for a walk”. Then I would have his brother pushing me, the Mum would be pushing him.

**Absence of whānau felt**

The critical importance of whānau to rheumatic fever experiences was also evident in narratives where whānau were not present. Essentially, this meant participants with rheumatic fever had no additional whānau support to respond to or mitigate the negatives experiences and poor care.

When Rawiri was first diagnosed with rheumatic fever, he was in foster care with no support. This situation led to him discharging himself because he was scared and did not understand what was happening to him due to poor communication from health professionals. Rawiri recalled that he was never followed up with after he discharged himself and therefore did not know about injections; eventually leading to the recurrence of his condition. His mother told this part of the story for him because he was shy and asked her to:

> Because there was no one there apparently, when the doctors did come to talk to him, he didn't have anybody with him, he was by himself, and it freaked him out. And so, you just left didn't you.

Rawiri’s mother noted that the health system needs to be more responsive and provide support; particularly because in Rawiri’s case, he did not have any. It is important to note here that she did not adopt Rawiri until he was 17; a few months after his recurrence of rheumatic fever:
I think that, um, bearing in mind I was only told what happened, because I wasn't there, that having doctors come and talk to a kid, and there being NO support person with them, no one to, I mean there should have been someone there I think, even if like, he didn't obviously have family or anybody else there, to support him, even if there was like a social worker, or someone that could, that he could you know, ask and who could support him, and explain to him what was going on. Um, the follow up, which obviously non-existent. Yeah, I think those, yeah, I think, when Rawiri told me that he was by himself when he was told "you've got this" and you know "it could kill you" and so on, who wouldn't freak out when they were told that, even as an adult. You know, let alone a 15-year-old boy. I think that was shocking.

For Brandon, being left alone for periods of time with no whānau elicited fear, which significantly worsened his hospital experience:

Researcher: So tell me, what being in hospital for [a month] was like.

Brandon: At first, it was dumb... It was ratshit because I didn't have anybody, my Nan kept coming up, her and Aunty would come up maybe, once a week or twice a week. And I wouldn't see them after that, I would just buzz out, like f*** It was me by myself what else am I gonna do.

Researcher: What do you mean buzz out?

Brandon: Just f***, I used to be scared of the hospital, bad things happen at the hospital. Well, from what I could remember. Just, losing people at the hospital. So I just thought, f*** I'm gonna lose myself and nobody's going to be here.

Whānau absence was also reported by Rachel's mother who noticed how much having no whānau affected children. This is what elicited her response to caring for other children in the wards along with her own daughter:

I felt sorry for some of the other [children], ohhh my God, the other children needed their mum [Rachel would say] "I'm so lucky to have you" she would cry and I would go "ohh my gosh".
4.4 Summary of results

This chapter has presented the results of the whānau interviews. Whānau began their stories by providing the contexts in which they were living at the time of first diagnosis. Narratives then emerged about experiences within the health system, being in healthcare settings, and interacting with health professionals. These narratives were grounded in experiences of racism, and poor communication and rapport were important elements of the overall experience. Rheumatic fever caused important ongoing impacts on participant lives; impacting on emotional and social wellbeing and inhibiting access to education and employment. This chapter outlined the overarching importance of whānau as a key theme that was evident in the participants’ narratives. The following chapter will discuss these results by relating the findings of this study to existing literature.
5 Discussion

5.1 Introduction

This chapter will discuss the findings of the research. Important points presented in the results chapter will be discussed in relation to available literature relevant to whānau living contexts, whānau experiences in the health system, the impacts of rheumatic fever and the overarching importance of whānau. Following this, the strengths and limitations of the research will be presented.

5.2 Summary of Findings

This research sought to understand the lived experiences, knowledge and perspectives of Māori and their whānau who have experienced recurrent rheumatic fever or re-hospitalisations for rheumatic fever. More specifically, this research aimed to understand whānau perceptions of rheumatic fever, their interactions with the health system and health professionals, and to identify where health services can be improved in order to reduce inequities. Four metathemes were elicited from the research and are discussed respectively in this chapter. The metathemes are whānau living contexts, whānau experiences in the health system, impacts of rheumatic fever and overarching importance of whānau. Whānau experiences were complex, multifaceted, and influenced by broad historical, social and political contexts.

The living conditions of whānau in this research were generally poor. Whānau members experienced socio-economic deprivation and faced financial difficulties, lacking access to basic necessities such as transport and stable housing. These contexts played a significant role in determining whānau experiences as these were the contexts in which participants became unwell with rheumatic fever. Poor whānau living conditions affected access to healthcare. Whānau experiences in the health system were predominantly negative with some whānau experiencing multiple types of racism including personally-mediated racism from health professionals and institutionalised racism associated with healthcare delivery (C. Jones, 2000). Another critical element of whānau experiences was health professional communication and rapport with whānau describing both positive and negative interactions. Rheumatic fever diagnosis, treatment and ongoing management significantly
impacted the lives of participants and their whānau who cared for them. Overall, rheumatic fever negatively affected the social and emotional wellbeing of whānau. Rheumatic fever also impeded access to education and employment for participants in this study. Participant narratives highlighted the strong importance of whānau acting as advocates and carers in response to negative healthcare experiences. The importance of whānau was also signified in negative experiences occurring when whānau members could not be present during healthcare experiences.

5.3 Discussion points

This section is structured in terms of the metathemes arising from thematic analysis and will discuss the results of this study in the context of available national and international literature.

5.3.1 Whānau living contexts – the impact of significant socio-economic deprivation

Whānau in this study lived within contexts of socio-economic deprivation. Resources required to access healthcare such as finances, appropriate housing and transport were lacking for whānau. Not surprisingly, the whānau interviewed within this study faced difficulties accessing healthcare as a result. In some cases, these difficulties were extreme. One participant had no access to transport and was forced to crawl to the hospital in pain on her hands and knees. Other participants mentioned that they had missed appointments and treatment due to changing living arrangements associated with shared care amongst extended family members (e.g. grandmothers, aunties) or whilst under state care through CYF. The socio-economic conditions experienced by whānau created several barriers to healthcare access. This delayed help-seeking for symptoms of rheumatic fever and made it difficult for whānau to receive regular secondary prophylaxis.

The association between rheumatic fever and socio-economic deprivation has been recognised for many years (Al-Sekait et al., 1990; Bhave et al., 1991; Gordis et al., 1969; Jaine et al., 2011; Longo-Mbenza et al., 1998; Zaman et al., 1997). Jaine et al. (2011) found that from 1996 to 2005 higher rates of rheumatic fever in Aotearoa were associated with decreasing household income and higher levels of deprivation. Based on research with indigenous children in central and northern Australia, Parnaby and Carapetis (2010) similarly associated rheumatic fever with poverty and poor living conditions. The findings
are also consistent for what is known about the CMDHB region. Robson et al. (2015) note that 58 per cent of Counties Manukau Māori live in the two most deprived deciles (i.e. NZDep deciles 9 and 10) signifying significant deprivation associated with indicators of socio-economic positioning such as reduced access to transport, household crowding, no home ownership, low income and unemployment (Robson et al., 2015). It is documented in rheumatic fever literature that deprivation can influence other factors that further affect rheumatic fever such as household crowding, housing quality, and access to healthcare (Heart Foundation of New Zealand, 2009; Jaine et al., 2011).

Housing is a dominant theme and area of discussion within rheumatic fever research. Substandard housing conditions including overcrowding and the association with the spread of GAS is widely documented (Adanja et al., 1987; Gordis et al., 1969; F. Gray et al., 1952; Grover et al., 1993; Jaine et al., 2011; Longo-Mbenza et al., 1998; Zaman et al., 1997). Housing is also a key area of focus in the rheumatic fever prevention plan, with initiatives such as AWHI to improve housing conditions through carpeting, heating and insulation (Counties Manukau District Health Board, 2013). In this study, all whānau emphasised unstable housing has an important aspect of their experiences of rheumatic fever with some whānau having difficulty accessing a stable home. Whānau reported that frequently moving between homes was a barrier to accessing primary healthcare and secondary prophylaxis, which can lead to the recurrence of rheumatic fever.

Housing issues are known to disproportionately affect Māori living in Tāmaki Makaurau (Goodyear & Fabian, 2014). The Māori housing strategy (2014) recognises that stable housing is critical for wellbeing and yet Māori encounter many barriers to accessing stable housing (Flynn et al., 2010). Housing New Zealand report that Māori have high rates of residential mobility compared to European and Pacific populations in Aotearoa (Flynn et al., 2010). The reasons for this are largely related to social and economic factors (Flynn et al., 2010; Statistics New Zealand, 2007). For example, moving house can be a normal part of family formation and support, but it can also largely reflect deprivation (Howden-Chapman, 2004). In the CMDHB region, two-thirds of Māori children live in rented accommodation (Robson et al., 2015). The cost of rental accommodation in Tāmaki Makaurau has increased significantly in recent years and plays a significant role in housing issues (Goodyear & Fabian, 2014). Housing costs can represent a large portion of whānau income meaning that there is a reduced amount of income left over for other necessities such as transport and healthcare. This situation can lead to crowded housing in order to save money (Goodyear & Fabian, 2014; Howden-Chapman, 2004). Māori face many barriers to accessing stable
housing and are more likely to experience difficulty accessing rental accommodation due to housing discrimination\(^{16}\) (Harris et al., 2012a; Harris et al., 2006a). Further, Māori make up a large portion of those living in social housing\(^{17}\) and also have significantly low rates of home ownership (Flynn et al., 2010; Goodyear & Fabian, 2014). The findings from this study align with the evidence of significant deprivation for Māori whānau living within the Counties Manukau region, which in turn resulted in reduced access to stable housing.

'Residential mobility' is a term used to describe unstable housing, or situations of moving frequently (Howden-Chapman, 2004; Jatrana, Richardson, & Crampton, 2013). The issue of residential mobility has been eluded to in previous rheumatic fever research. Spinetto et al. (2011, p. 232) stated that "transient living patterns, or shifting and leaving no forwarding address creates follow-up difficulties" for nurses to deliver secondary prophylaxis, or make an inter-register referral to another area for continued treatment. From the analysis of whānau narratives in this study, it is evident that such contexts were complicated, and that the circumstances of moving (such as being under care of CYF until the age of 16 of age and then being homeless) meant that the rheumatic fever patients interviewed in this study were unable to leave a forwarding address for the district nurses. Unstable housing as a barrier to healthcare receipt is important for rheumatic fever patients, as rheumatic fever requires ongoing monthly follow up healthcare for a minimum of 10 years. For this mode of delivery to be effective at preventing recurrences of rheumatic fever, patients are effectively expected to have a stable residence for the delivery of secondary prophylaxis via district nurses within the communities. The findings from this study suggest that this requirement for effective delivery did not reflect the lived reality of study participants and may be a significant issue for other Māori whānau with rheumatic fever.

At the time of writing this thesis, the 'housing crisis' in South Auckland (the prominent region that CMDHB covers) is being foregrounded as one of the most urgent and pressing issues facing Aotearoa (Clarke, 2016). In recent years, the availability of affordable, safe, warm and dry housing within Auckland has become relatively non-existent, particularly for middle to low income families. Māori in particular have been affected severely and large increases in homelessness (e.g. families sleeping in cars) have been seen in South Auckland.

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\(^{16}\) Housing discrimination refers to “the racism that some groups such as indigenous people, migrants, and ethnic minorities are more likely to suffer personally from private landlords if they are renting, and from institutional lenders if they are seeking a mortgage” (Howden-Chapman, 2004, p. 164).

\(^{17}\) Social housing is defined as "subsidised public sector housing that is provided to tenants by local, state, or national governments or not for profit trusts." (Howden-Chapman, 2004, p. 164).
The situation is so serious that Te Puea Marae (a marae in South Auckland) have opened their doors to provide shelter and food to families in urgent need (Clarke, 2016). This example demonstrates a massive government failure in providing for the housing needs of whānau and requires urgent and immediate attention.

Residential mobility is also associated with reduced access to primary healthcare (Jatrana et al., 2013). Jatrana et al. (2013) explored the association of residential mobility with affiliation\(^ {18}\) to primary care providers in Aotearoa. It was found that residential mobility has a strong independent effect on affiliation with a primary healthcare provider. This means that people who move their place of residence more frequently are less likely to be affiliated to a primary healthcare provider. This effect persisted when controlling for deprivation. Jatrana et al. (2013) explain that finding a new primary care provider when moving can be difficult due to daily living / routines being disrupted, adjustment to new neighbourhoods, and depending on the motivation for moving (such as personal crisis), these issues can take priority over finding a new healthcare provider (Jatrana et al., 2013). Moreover, primary care systems in Aotearoa require you to formally register with a Primary Healthcare Organisation (PHO) in order to receive subsidised pricing. Individuals can only be registered with one PHO at any given time. If you are not registered with a particular PHO you can still access primary healthcare as a ‘casual patient’ at an unsubsidised price, which can be up to NZ$75 for an adult. Thus, housing mobility can increase financial barriers to accessing affordable primary healthcare (Cumming et al., 2014; Jatrana et al., 2013).

A lack of access to transport was a barrier for whānau accessing healthcare. Access to a vehicle and the cost of public transport restricted access to hospital for support, follow up appointments and seeking medical help in a timely manner. Not having access to transport therefore exacerbated participants' symptoms of rheumatic fever. Anderson et al. (2015) also noted transport difficulties faced by Māori in the Te Tai Tokerau region; reporting that whānau often did not own a vehicle or could not afford petrol for their vehicles to attend rheumatic fever treatment for their children. Transport is a recognised barrier for disease management for Māori (A. Anderson et al., 2015; Cormack et al., 2005; Cram, 2014b; Lee & North, 2013; Slater et al., 2013).

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\(^ {18}\) Affiliation refers to “having a usual source of care (doctor, nurses or medical centre), or primary care provider” (Jatrana et al., 2013, p. 101)
5.3.2 Whānau experiences in the health system – the impact of differential treatment, marginalisation and racism.

Whānau in this study experienced substandard healthcare treatment. Participants believed they were treated differently by health professionals because they were Māori. For instance, some whānau reported being treated with disrespect, feeling inferior by the way health professionals spoke to them, and felt blamed for their health problems. Although whānau had some experiences of good communication from health professionals, the majority of health treatment experiences shared within this research described difficulties in communication and building rapport. These narratives highlight the overall importance of health professionals in shaping the Māori healthcare experience.

Experiences of personally mediated racism were characterised by whānau reports of health professionals having negative assumptions and attitudes towards whānau (i.e. prejudice) that resulted in differential treatment (i.e. discrimination) (C. Jones, 2000; van Ryn et al., 2011). Participants commented that some health professionals “didn’t like brown people” and that this was evident from the tone of their voice, their facial expressions, and lack of communication. These descriptions are known characteristics of implicit bias demonstrated in non-verbal language and behaviour resulting from negatively held assumptions and stereotypes about patients associated to a particular social grouping (van Ryn et al., 2011; van Ryn & Fu, 2003).

The findings of this research align with national qualitative research showing that Māori experience poor health due to negatively held attitudes and beliefs among health professionals (A. Anderson et al., 2015; Cormack et al., 2005; Jansen et al., 2009; McCreanor & Nairn, 2002a; D. Wilson & Barton, 2012). D. Wilson and Barton (2012) reported Māori having negative experiences in hospitals as some health professionals were intolerant of whānau needs and Māori were treated poorly when compared to Pākehā. While it is often noted that behaviours informed by implicit biases can be subtle and difficult to recognise (Dovidio et al., 2002), in this research some participants shared alarming stories of explicit discrimination. For example, one participant recalled a nurse confiscating their wheelchair based on what they believed was their skin colour. Other participants reported having their hospital call / alarm buzzers ignored or turned off when they were in need.

A manifestation of racism and provider bias is the ‘deficit’ or ‘victim blaming’ discourse commonly used to explain Māori health outcomes. This discourse locates the problem and responsibility with the individual and discards the structures in place that create, maintain
and exacerbate health inequities (Reid et al., 2000). During interviews whānau shared that they felt health provider’s blamed them for not complying with treatment and that some health professionals ignored the difficulties they faced accessing care. Health professionals located Māori as the problem. This is consistent with research in Aotearoa concerning negatively held beliefs about Māori by clinicians (McCreanor & Nairn, 2002a, 2002b; Penney et al., 2011). Penney et al. (2011) found that when health interventions were not working for Māori, many clinicians placed blame on Māori and did not see themselves or the health system as being at fault. Anderson et al. (2015) reported that whānau in Te Tai Tokerau felt that some health professionals attributed rheumatic fever to poor parenting.

Communication and rapport building with health professionals played a significant role in whānau experiences of rheumatic fever. Participants perceived good communication and rapport to be positive and beneficial; however, poor communication was a much more common occurrence for whānau in this study. Poorly communicated information by health professionals was characterised by language that was difficult to understand, little opportunity for two-way communication, and no space created for questions. Poor communication was related to an inability to build rapport between whānau and health professionals. This left whānau feeling misunderstood and dissatisfied with the quality of care received. Whānau reported feeling ill-informed about rheumatic fever causation and management, especially around secondary prophylaxis. Lack of understanding in whānau was a source of stress and confusion.

The importance of communication and rapport to the health of Māori is consistent with other health research in Aotearoa (Cram et al., 2003; Jansen & Smith, 2006; Kerr et al., 2010; Penney et al., 2006; Slater et al., 2013; D. Wilson & Barton, 2012). When good communication exists within a hospital setting, a strong relationship can develop. Greater rapport is conducive to Māori patient satisfaction, as patients feel like they are being heard and their needs are being met (Kerr et al., 2010; Slater et al., 2013). This research found that building rapport is of particular importance to the secondary prevention of rheumatic fever, given the importance whānau placed on feeling comfortable when they receive secondary prophylaxis. However, some patients in this study reported their district nurses frequently changing, therefore rapport was difficult to develop. Some participants in this study talked about poor communication and a lack of information sharing from health professionals as a discriminatory experience. This is a finding that is consistent with previously investigated Māori experiences of healthcare (Penney et al.,
This research is consistent with previous international analysis of patient interactions with health professionals which confirms that in multiple different settings patients of ethnic minorities are less likely to receive sufficient information from health professionals, establish rapport, and be encouraged to participate in discussion (Ferguson & Candib, 2002).

This research found evidence that poor communication and rapport contributed to poor health literacy of whānau as some whānau possessed very little knowledge about their symptoms and treatment. The lack of knowledge participants with rheumatic fever and their whānau had about their condition was particularly concerning, one participant was hospitalised for an entire year, but could not tell the researcher why because they did not know. Moreover, for some it was not until their recurrence that they understood the importance of secondary prophylaxis. Health literacy has been defined by the Ministry of Health (2010, p. 1) as “a person’s ability to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions”. Health literacy is a key issue in relation to rheumatic fever policy (previously outlined in section 2.2). The research confirms that health literacy is an important issue regarding rheumatic fever disparities. However, this research challenges the prevailing framing of health literacy as being about “a person’s ability”, as this places the onus on Māori patients and whānau and subsequently ignores the role of health professionals in delivering health information. Cram (2014b, p. 4) states that health literacy is “about providers’ ability to provide culturally responsive information and services to Māori”. The findings of this research reinforce the need to focus on the “providers’ ability” as having a major impact on the health literacy of whānau.

Critical to these experiences of personally mediated racism and poor communication was the predominance of Pākehā health professionals within healthcare settings. Whānau preferred health professionals who were Māori because they felt like they received better quality care, communication was improved, and were not discriminated against. However, Māori health professionals were uncommon. Māori preference for doctors who are Māori has also been identified by Ratima, Brown, Garrett, and Wikaire (2007). Preference for ethnic concordance supported by international evidence that ethnic concordance (increases patient satisfaction and improves healthcare (Cooper et al., 2003; Smedley et al., 2003).

Overall, whānau narratives about healthcare highlight the overarching influences that health professionals have on perpetuating poor health outcomes by providing differential
care to Māori. This research contributes to literature that shows Māori are marginalised in healthcare settings (Curtis et al., 2010; Elers, 2014; Jansen & Smith, 2006; Reid & Robson, 2007; Reid et al., 2000). The marginalisation of Māori is systematically produced. Beliefs, practices and policies deeply embedded in health sector organisations serve those of the Pākehā population and disadvantage Māori, regardless of intent (C. Jones, 2000; Reid et al., 2000; van Ryn et al., 2011). Curtis et al. (2010) acknowledge the need to explore the role of the clinician with respect to Māori disparities in Aotearoa. This study attests to this in the context of rheumatic fever, as it is evident that the interactions at the clinician level had important influences on the whānau experience.

5.3.3 Impacts of rheumatic fever

Rheumatic fever significantly affected the lives of whānau in this research. The emotional and social impacts of rheumatic fever were severe and not addressed (and in some cases made worse) by their healthcare provision. Whānau also left paid employment in order to care for those with rheumatic fever. In turn, the experience of rheumatic fever contributed to socio-economic deprivation for whānau.

Rheumatic fever treatment was not conducive to mental and emotional healing, leaving whānau feeling unwell. Participants with rheumatic fever described that it was detrimental to their mental health and reported experiencing feelings of depression, anger and stress, with one participant using illicit substances to cope. Rheumatic fever also severely affected the social lives of participants. Most participants with rheumatic fever reported that being unable to play sport was troubling. Rheumatic fever impacted on their identity and self-worth. Importantly, these issues were not addressed by health professionals or health systems and it was recognised by whānau that addressing this in healthcare was necessary.

From a Māori perspective, hauora (which translates to health and wellbeing) is holistic and encompasses physical, mental / emotional, spiritual and whānau health (Durie, 1998). Thus, the western biomedical views of health generally reflected within the health system often exclude Māori interpretations of health and wellbeing (Durie, 1998).

Previous research concerning Māori experiences of healthcare has found that holistic interpretations of health were not in line with those held by health services (Jansen et al., 2009; T. Walker, Signal, Russell, Smiler, & Tuhīwai-Ruru, 2008; Williams, Neighbors, & Jackson, 2003; D. Wilson, 2003; D. Wilson & Barton, 2012). A. Anderson et al. (2015, p. 19) found that rheumatic fever caused significant stress for whānau, eliciting emotions of
“worry, stress, sadness, anger, guilt and confusion”. It has been previously reported that healthcare provision is not aligned with whānau perceptions of health and wellbeing given that their emotional and spiritual needs are not met in hospitals, causing distress (D. Wilson & Barton, 2012). This is consistent with research by Walker et al. (2008, p. 31), which identified that “the hospital deals with your physical problems but they do not deal with your mental and spiritual problems”. The exclusion of Māori perspectives on health and wellbeing further marginalises Māori in healthcare settings (Jansen & Smith, 2006; D. Wilson & Barton, 2012). One mother in this study recommended that rheumatic fever treatment should extend beyond the management of sore throats and GAS reinfection to provide emotional support for youth (and their whānau) dealing with the condition and its associated stressors demonstrating the need for more holistic healthcare services and policies.

The educational effects of rheumatic fever were also documented for whānau in Te Tai Tokerau by Anderson et al. (2015). It was found that children returning to school post rheumatic fever hospitalisation found it difficult to concentrate and engage in their studies. Rheumatic fever additionally affected employment for whānau. Again, Anderson et al. (2015) found that whānau members, particularly mothers, had to leave paid employment to accommodate treatment and care of their children for periods of up to one year. Education and employment are critical social determinants of health (Marmot, Friel, Bell, Houweling, & Taylor, 2008). In Aotearoa, Māori have lower rates of educational attainment and employment than non-Māori (Marriott & Sim, 2015; Robson et al., 2007). This study has shown that rheumatic fever experiences can contribute to, and impact on, employment inequalities. In this research participant experiences of recurrent rheumatic fever and re-hospitalisations were directly influenced by deprivation. Therefore, by impeding access to education and employment, rheumatic fever also compounded pre-existing socio-economic problems for whānau.

5.3.4 The overarching importance of whānau

The participants of this study emphasised the value and importance of whānau support. Whānau were vital in providing support and assisting with the treatment and management of rheumatic fever. Whānau fulfilled many roles; acting as advocates and ensuring their loved one was adequately cared for and received the information they needed. Much of the support whānau provided was in relation to adverse situations where health systems were not meeting needs of whānau.
The important role of whānau support in disease treatment and management has been documented in Māori experiences of healthcare in Aotearoa (Cram, 2014a; Dew et al., 2015; Kerr et al., 2010; Penney et al., 2006; T. Walker et al., 2008; D. Wilson & Barton, 2012). The importance of whānau support is also evident in research from the indigenous perspective in Canada (C. Baker, Daigle, Biro, & Joe, 2000). Walker et al. (2008) illustrated that whānau acted as advocates with health professionals in a similar manner to whānau in this study; gathering information for their ill whānau member and taking responsibility for care. Māori participants in a study by Penney et al. (2006) placed emphasis on the need to involve whānau in consultations; however, also felt that health services did not understand nor support the role of whānau in healthcare; particularly with respect to giving and receiving information.

Whānau support also extended beyond the kin of the whānau involved in this study. For one participant, whānau support came from the extended whānau of a fellow patient when their own whānau members could not be in attendance at the hospital. Moreover, a mother in this research cared for other Māori children and their respective parents. Consistent with these findings, D. Wilson and Barton (2012) noted whānau reports of Māori caring for Māori patients from other whānau, in the same way that whānau in this study did. Participants found it necessary to advocate for other Māori on the ward who did not have whānau with them at the time. Support of this nature was also found in other indigenous communities. Baker et al. (2000) found that first nation’s people came together and supported each other in hospital settings that were not in alignment with their culture values, to meet each other’s cultural needs.

Whānau play a crucial role in Māori society (Mead, 2003) and are said to be a cornerstone of Māori health (Durie, 1998), which is reflected in our actions and beliefs (Mead, 2003). Whānau support in this study was positive for participants as it provided support and care not otherwise met by health professionals. Such notions are consistent in literature previously mentioned (Cram, 2014a; Dew et al., 2015; Kerr et al., 2010; Penney et al., 2006; T. Walker et al., 2008; D. Wilson & Barton, 2012). However, whānau support arose largely out of a necessity to respond to adverse situations (such as poor communication and discrimination) with whānau acting in response to a health system that was not meeting their needs. These findings align with Māori hospital experiences reported by D. Wilson and Barton (2012). D. Wilson and Barton (2012) found that whānau undertook care of their whānau during hospital stays out of necessity. This necessity arose in response to negative
experiences with health professionals, as care from nurses was substandard or ignored, which evoked mistrust.

From these findings, one might infer that whānau should be encouraged to provide basic healthcare within healthcare settings and that whānau should be empowered to do so. This inference is made in health policy in Aotearoa (Ministry of Health, 2002). However, it is important to recognise that whānau are largely mitigating the failures of the healthcare system; failures that should not be occurring. Endorsing whānau support and empowerment in the context of substandard healthcare delivery, risks devolving responsibility for overcoming health inequities from the health system onto Māori (Boulton & Gifford, 2011; Penehira, Green, Smith, & Aspin, 2014). Penehira et al. (2014) discuss the need to contextualise discussions of this nature (which they term ‘whānau resilience’) bringing the systems and structures, that require Māori to be so supportive of each other to the fore. Such an assertion is also made in indigenous literature internationally (Lavallee & Clearsky, 2006). This research urges that whānau support should be conceptualised and approached as an adjunct to healthcare (rather than a substitution for inappropriate healthcare) that meets the needs of Māori. We must first and foremost focus our attention on the systems and structures that cause inequitable healthcare provision and avoid accepting Māori whānau caregiving as a replacement for poor quality healthcare delivery.

A key strategy that aims to improve healthcare delivery for Māori is Whānau Ora. Whānau Ora is a relatively new strategy that aims to improve the overall health and wellbeing of whānau by adopting an approach to healthcare that takes into account broader determinants of health (Taskforce on Whānau-Centred Initiatives, 2010). Specifically, Whānau Ora encourages health, social services and education providers to work efficiently and effectively together in order to meet the needs of whānau in a comprehensive way. Importantly, Whānau Ora places whānau at the centre of service delivery and seeks to support whānau to self-determine their own objectives and priorities in order to achieve optimum wellbeing (Boulton & Gifford, 2014). The findings of this research reinforce the need for Whānau Ora to not only be available, but also effectively integrated within CMDHB given that the participants in this research experienced unmet needs across multiple service dimensions (i.e. primary, secondary and tertiary healthcare, education and social service needs). Despite Whānau Ora being currently funded within CMDHB, the participants in this study are likely to have been diagnosed with rheumatic fever prior to the establishment of Whānau Ora. Hence, the potential benefits that this service may provide for Māori with rheumatic fever are yet to be seen.
5.4 Strengths

This research was grounded in Kaupapa Māori Theory. Kaupapa Māori Theory provided the research with a number of strengths. The research was Māori led, with control resting with Māori at all stages of the research process. Rheumatic fever was explored in a way that placed Māori at the centre; privileging Māori worldviews in a way that is relevant to Māori whānau.

A non-deficit approach to understanding rheumatic fever was taken. This research shifted the gaze away from Māori, towards the health system and health professionals, identifying inequities that are amenable to change. This meant moving beyond describing inequities, to questioning the underlying factors that might maintain current rheumatic fever inequities for Māori. In turn the research adds to the necessary literature base driven by Kaupapa Māori, that speaks back to common framings of Māori as ‘the problem’ (L. Smith, 2012).

The research gathered the Māori voice. The data collected in this study was rich, with diverse experiences emerging from within each whānau. In turn, this research provided a qualitative context to existing rheumatic fever literature in Aotearoa that is predominantly quantitative.

The study was overseen within Te Kupenga Hauora Māori with guidance from experienced Kaupapa Māori researchers from both clinical and non-clinical backgrounds, which strengthened the research and provided a culturally safe space for the research to be undertaken.

5.5 Limitations

The findings of this research have limited generalisability. This was a qualitative study that explored the experiences of four whānau. Thus, the narratives from this study may not be representative of the whole population of whānau experiencing recurrent rheumatic fever and re-hospitalisations in Tāmaki Makaurau. It is acknowledged that the project initially intended to interview up to ten whānau. However, due to difficulties in recruiting more than four whānau and time restrictions associated with the project timeframes (including in the context of a Masters of Public Health postgraduate study deadlines), the total of four whānau was considered adequate for the purposes of this study. While the number of participants may be considered less representative of broader experience than a larger study might have been, the data obtained was in-depth and varied whānau experiences
Regardless, care must be taken when considering how the results can be generalised to other contexts.

As with any research, researcher bias associated with personal worldviews and positioning may have influenced the interpretation and the findings for this research. It is acknowledged that another researcher is likely to have constructed different categories and themes. However, Kaupapa Māori makes explicit that the researcher is not separate from the research but is a part of it (Webber, 2009) and the worldview of the researcher undertaking this work has been described and discussed within section 3.2.1 of the methodology chapter to make such influences transparent.

Despite these limitations, this research provides important insight into the knowledge and experiences of whānau that have been affected by rheumatic fever, thus can help to inform understandings of the rheumatic fever inequities in Tāmaki Makaurau from a whānau perspective.

5.6 Summary of discussion

This chapter discussed the results of this research in the context of available literature. Strengths and limitations of the research were also considered. The following chapter will provide conclusions and recommendations arising from the results of this research.


6 Recommendations and conclusion

This chapter concludes the thesis. Recommendations arising from the research findings are provided in the areas of healthcare delivery, further research and policy. The thesis then ends with a concluding comment.

6.1 Recommendations

This research has revealed a number of areas that need to be addressed in order to address the persistence of rheumatic fever for Māori. In order to address the issues identified in this research as discussed in the previous chapter, recommendations are made in the area of healthcare provision, further research needed to be undertaken, and for health related policy. Whilst some of the drivers of rheumatic fever inequities do lie beyond jurisdiction of the health system, the health sector has a central role in developing interventions that can deliver to the needs of the population it serves, regardless of ethnicity or living context.

6.1.1 Healthcare provision

In order to meet Māori health needs and reduce inequities, mainstream health services within CMDHB need to better reflect Māori needs, values and priorities. This involves reorienting the current way healthcare is delivered to ensure practices are more conducive to good health for whānau. Some ways this can be achieved are listed below:

Support and resource cultural safety training for health professionals working within CMDHB

- Cultural safety training should be implemented as mandatory training for health professionals working within CMDHB in order to address the inequities arising from racism from health professionals (Came & da Silva, 2011). Cultural safety is a process of critical self-reflection with a focus on the perceptions, behaviour and biases of the healthcare providers themselves as opposed to learning about the culture of the patients (De Souza, 2008).

- Cultural competency (which focuses on health providers understanding cultures different from their own) is currently espoused by the Royal New Zealand College of General Practitioners (RNZCGP) for Maintenance of Professional Standards (Royal New Zealand College of General Practitioners, 2013). Cultural competency is
criticised for its role in perpetuating racism and discrimination, as it fails to recognise historical and structural causes of health inequities, and subsequent power imbalances. In turn this can perpetuate perceptions of Māori as different (Came & da Silva, 2011). Therefore, CMDHB should ensure that health professional training avoids a focus on cultural competency alone and moves to integrate a cultural safety focus as outlined above.

**Strengthen and encourage whakawhanaungatanga in consultations with Māori patients**

- Alongside cultural safety training, training specifically targeted to whakawhanaungatanga should be established and promoted for health professionals throughout primary and secondary healthcare settings within CMDHB. The ‘hui process’ is a health education framework that could be implemented to support this (Lacey, Huria, Beckert, Gilles, & Pitama, 2011). This framework was developed to improve doctor-patient relationships and communication within a culturally safe process and is currently used in training of medical students. A central tenet of the hui process is for health providers to expect to ‘reciprocate’ via the sharing of personal information to Māori patients (associated with the whakawhanaungatanga process) (Lacey et al., 2011). This culturally appropriate approach to clinical encounters has been reported to improve both patient and provider satisfaction with the clinical encounter (Lacey et al., 2011) and may help to address the lack of rapport, trust and poor communication experienced by patients (and their whānau) in this study.

**Provide counselling and cultural support for patients with rheumatic fever and their whānau**

- Support that addresses the holistic nature of hauora Māori should be provided for patients with rheumatic fever. Support should be provided based on patient and whānau preferences and should encompass both emotional and cultural support. While these services do exist within CMDHB, they need to be made an explicit part of rheumatic fever treatment and whānau should be given sufficient and timely access to information about these services when their child is diagnosed with rheumatic fever. Whānau should also be given the option to undertake counselling together or separately. The duration / amount of counselling should be established on a case by
case basis, dependant on the individual patient and whānau needs. This service should be free of charge.

**Provide ongoing support for rheumatic fever patients to reintegrate back into school post hospital discharge**

- Support should be provided to children in order to assist their reintegration back into school. Support could be emotional (such as counselling), educational (such as tutoring or additional help for National Certificate of Educational Achievement).

**Adapt the provision of ongoing secondary prophylaxis to facilitate uptake when housing is not stable**

- The provision of secondary prophylaxis needs to be adapted to respond to rheumatic fever patients who may not have stable housing conditions.
- For instance, Māori rheumatic fever patients should be provided with a number of options through which they can contact district nursing services or local community health services, regardless of location. For example, a 24 / 7 free call number that is easy to remember could provide a way for Māori who move around or find their circumstances changing to organise secondary prophylaxis appointments.
- Secondary prophylaxis services should also be accessible within health organisations that are in close proximity to Māori rheumatic fever patients and their whānau (e.g. local marae, local Māori health provider, local GP clinic), regardless of that patient's living situation or the ability to provide a forwarding address.

**Increase focus on the integration of Whānau Ora as routine recommended practice for rheumatic fever patients and their whānau**

- Whānau Ora has potential to remedy a number of issues whānau have raised, particularly in addressing the issues associated with complex living situations that required help to extended beyond what the doctors and nurses were providing them. Whānau Ora is currently present within CMDHB. However, there needs to be an explicit focus on the integration of Whānau Ora within rheumatic fever care. This will require Whānau Ora to be appropriately resourced, and will also require the support of mainstream healthcare providers.
6.1.2 Further research

There are several areas that have arisen from this study that require further research. The evidence base for Māori and rheumatic fever is limited; both quantitative and qualitative research pertaining to rheumatic fever care for Māori is necessary in order to improve Māori rates of rheumatic fever, and eliminate recurrences.

Investigate how to best address provider bias

- Research is needed to identify the most effective strategies to reduce negative stereotypes, racial prejudice, and discrimination within healthcare. Cultural safety has been identified as a promising option. However, the practical application of culturally safe practice for whānau in health settings, given the current resources and capacities, needs to be investigated. For efforts to be effective, organisational change may be required that addresses the cultural values and norms that underpin healthcare services.

Prioritise research that gathers the Māori voice

- Given the propensity to devise interventions for (rather than with) Māori (L. Smith, 2012), it is critical that Māori voices are privileged in future research. Effort should be made to ascertain whether current and recommended actions align with, or are conducive to, realisation of whānau needs and aspirations. This should be done from a Kaupapa Māori perspective.

Explore what culturally appropriate services look like from the whānau perspective

- Mainstream health services need to reorient their practice to better cater to Māori. Māori are diverse, and so too are whānau experiences. What culturally appropriate services would entail for Māori in the CMDHB region needs to be explored from the whānau perspective. Importantly, this would include an exploration of the role of the whānau in healthcare delivery. The healthcare provision and further research recommendations outlined above are an attempt to offer some solutions. It is acknowledged that any suggestions should be further examined, and include research with Māori whānau to ensure that the recommendations made within this thesis are relevant and appropriate.
6.1.3 Policy

There is currently a policy imperative to reduce rates of rheumatic fever (Counties Manukau District Health Board, 2013). Policy needs to take into account the differential access Māori have to the health system due to the overrepresentation of Māori living in deprivation, and barriers to governmental support need to be reduced.

**Prioritise and resource emergency and social housing for Māori with rheumatic fever and their whānau**

- Whānau with rheumatic fever should be given priority access to emergency housing, which is urgent housing provided to those who are at risk of homelessness, urgently need a place to stay, and have no other way of getting accommodation. Furthermore, whānau with rheumatic fever should be eligible for stable social housing that suits their needs (Ministry of Social Development, 2016a). This will require the Ministry of Social Development to reduce barriers to whānau receiving housing. Housing is a particularly important issue in Tāmaki Makaurau, with significant need faced by Māori for stable, adequate housing (Goodyear & Fabian, 2014).

**Eliminate the over-representation of Māori living in socio-economic deprivation through inter-sectorial collaboration**

- Inter-sectorial collaboration is urgently required to systematically address the over-representation of Māori living in socio-economic deprivation. In recognition that rheumatic fever is associated with social determinants of health, the health system cannot act alone. Collaboration between other sectors, such as the Ministry of Social Development, Ministry of Education, and Housing New Zealand, is required.

- Explicit recognition of the need to overcome the significant levels of socio-economic deprivation faced by Māori in Aotearoa, and having this reflected in policy and resource allocation, is critical.
6.2 Concluding comment

This research aimed to explore the lived experiences, knowledge and perspectives of Māori patients and their whānau who have experienced recurrent rheumatic fever or re-hospitalisations for rheumatic fever in the CMDHB region of Tāmaki Makaurau. The rationale for this focus was to gather the whānau voice in order fill gaps in current knowledge around the persistence of rheumatic fever in Māori populations. The findings of this research indicate that current health services are not meeting the needs of whānau, and that whānau receive substandard care from health providers. In turn, the health system plays an important role in contributing to ongoing rheumatic fever inequities in Māori. The implications of these findings require action to be taken that frames the health system itself as a locus for change. Furthermore, this research highlights that in order to overcome inequities, rheumatic fever needs to be contextualised and addressed as a part of the ongoing racism that is present in Aotearoa, manifesting at both the institutional and interpersonal level.

The narratives presented in this thesis are that of four whānau. As the researcher, I have made every attempt to present these narratives with the same energy and emotion through which they were told to me. Within the scope of a Master’s thesis, this has been a challenge as I navigate two worlds - te ao Māori me te ao Pākehā. Throughout this research I grappled with the reality that every whānau who represent the data in the graphs presented in section 2.4, holds a powerful story. Whānau in Aotearoa experiencing rheumatic fever, the children like Brandon whose opportunities for education are severely hindered, and the mothers like Rachel's who give up their jobs to care for their children, they all deserve better. It is essential that the insights provided by these four whānau impel action. The persistence of rheumatic fever in Māori communities is unnecessary, unjust and unacceptable. Māori are not (and should not be framed as) ‘the problem’. The problem lies in the societal structures that permit the persistence of rheumatic fever inequities, and it is in these structures that we must locate change.
References


Appendices

Appendix A: Information sheet for district nurses

Whānau experiences of recurrent rheumatic fever in Tāmaki Makaurau

This project has been approved by the Counties Manukau Health Research Committee and Director of Hospital Services (Research registration number: 2067) and the University of Auckland Human Participants Ethics Committee (Reference number: 014652).

Information for nurses

Tenâ koe, my name is Hannah Burgess (Tāwharetoa/Te Atihaunui-a-Pāpārangi) and I am undertaking research towards a Masters of Public Health. This research aims to explore whānau experiences of recurrent rheumatic fever and recurrent hospitalisations due to rheumatic fever in Tāmaki Makaurau (Auckland). This includes the impacts of the illness on whānau, and their relationships with health services. The project aims to gather in-depth stories and experiences from the whānau perspective. The results of this study will be used to feedback to CMDHB, and presented to other relevant stakeholders.

Who is involved in this study?

- Hannah Burgess (MPH Candidate) and Dr Annika Anderson, Dr Elana Curtis (My supervisors) – Te Kupenga Hauora Māori, The University of Auckland.
- Dr Briar Peat (advisor) – Physician, CMDHB/The University of Auckland, and Dr Alison Leversha (advisor) – Physician, AHB/The University of Auckland.
- We also have support from Belinda Paku – Rheumatic Fever Liaison Nurse/AWHI Coordinator CMDHB.

What are we asking of nurses?

We are asking district nurses to help us recruit people to be in our study. The people we want in our study are:

- Māori who have (or have had) recurrent rheumatic fever from 2010 until 2014
- Māori who have (or have had) recurrent hospitalisations due to rheumatic fever from 2010 until 2014

Their whānau will also be included if that is their wish. We are asking that you provide your patients with information about our study (provided below) and to ask them if they are interested in being involved. Please follow the steps below:

1. Before the end of the patient’s visit to receive their monthly bicillin injection, please read/provide them information about this study (attached).
2. If they are interested we ask that you fill out the contact detail form (attached).
   - This is so we can then provide the potential participant with more information about the study and ask if they would like to participate. Please note that they are not obliged to participate and their choice to participate or not will have no influence on their relationship with you or any health services. This just means that we can send them more information (a participant information sheet).
   - If the patient is not interested, ignore step three.
3. Once the form has been filled out, please fax this to Michelle Gilbert:
   - Michelle Gilbert – Community Support Worker BhF, Home Health Care
   - Fax: 64 9 270 4733

The above three steps are the extent to which we are asking you to be involved. Your help is greatly appreciated.
Information for nurses to give to their Māori rheumatic fever patients

What is the research about? This research aims to explore whānau experiences of recurrent rheumatic fever and recurrent hospitalisations due to rheumatic fever in Tāmaki Makaurau (Auckland). This includes the impacts of the illness on you and your whānau, and your relationships and contact with health services. Overall, the project aims to gather in depth stories and experiences from the whānau perspective. The results will be used to provide recommendations on how health services can be improved for you and those in the future.

People who will be involved in the study are... those who self-identify as Māori who have (or have had) recurrent rheumatic fever or a recurrent hospitalisation of rheumatic fever and their whānau.

If you want to be in the study... the researcher (Hannah) will visit you and your whānau (or on your own if you wish) for an interview at a date, time and venue that suits you best. During this visit, a kai will be shared, and we will discuss your experiences with recurrent rheumatic fever.

If you want to know more about this study or potentially want to be a participant in it... I, your District Nurse will give your contact details to Hannah and she will contact you and give you more information about the study and then invite you to participate in it.

Please note... if you do decide to participate in this study it will be entirely your choice (voluntary) and will not affect your access to treatment or relationship with your District Nurse. Also, if you decide to take part in the study you can withdraw from it at any time without having to give a reason.

For any clarifications or queries, please do not hesitate to contact Hannah Burgess (student researcher) at any time.

Hannah Burgess
Te Kupenga Hauora Māori, The University of Auckland
Ph: 021 444 358
Email: hbur042@aucklanduni.ac.nz
Patient information

Please fill this out if the patient expresses interest in participating in this study

Name: ________________________________

Date of Birth: ___/___/____

Phone Number: ______________________

Caregiver name (if patient is under 16): ______________________

Email: ______________________________

Preferred method of contact (please circle): Phone Email Don’t mind

Preferred time/day to contact (please circle): Day Evening between........&........

Once this has been filled out please fax to:
Michelle Gilbert – Community Support Worker RhF, Home Health Care
Fax: 649 270 4733
Appendix B: Participant information sheet

Whānau experiences of recurrent rheumatic fever in Tāmaki Makaurau, Aotearoa.

Student researcher
Hannah Burgess (Tōwhareto/Tē Ati Haunui-a-Pāpārangi)
Email: hburg042@aucklanduni.ac.nz
Ph: 373 7599 Ext 82219

Principle investigator
Dr Anneka Anderson (Kāti Tōhu/Kāti Māmoe)
Email: a.anderson@auckland.ac.nz
Ph: Tel: 373 7599 Ext 82373

Participant Information Sheet

Kia ora, my name is Hannah Burgess (Tōwhareto/Tē Ati Haunui-a-Pāpārangi). I am a masters student in Te Kupenga Haunora Māori, The University of Auckland. I would like to invite you and your whānau to participate in a study about the experiences of whānau who have family members (adults and children) with recurrent rheumatic fever or recurrent hospitalisations due to rheumatic fever in Counties Manukau, Tāmaki Makaurau/Auckland. This project will be used towards a Masters of Public Health thesis supervised by Dr Anneka Anderson. Your participation in the study is entirely your choice (voluntary) and will not affect your access to treatment or relationship with your District Health Nurse (treatment provider). If you agree to take part in the study you are free to withdraw from the study at any time without having to give a reason, and this will not affect your health care. If you are willing to take part in the research, we will contact you in approximately one week.

About the study
The aim of the study is to find out about your whānau/family’s experience of having recurrent rheumatic fever/hospitalisations so we can improve the experience for others in the future.

If you decide to participate we would like to interview you and your whānau (whānau interviews). We will interview you by yourself if for any reason your whānau can’t be included or if this is what you prefer.

You have been identified by your District Health Nurse (or treatment provider) associated with Counties Manukau District Health Board to take part in the research. If you agree to be in the research, or would like to know more about the research, then the nurses will pass your contact details onto us so we can get in touch with you and organise a time to meet. If a child in your care is under 16 years old, then you as their legal caregiver will be asked to decide whether or not they may also be included in the study.

Approximately 50 people will take part in this study. The study will take place in various venues in Counties Manukau, depending on what suits you and your whānau should you choose to take part.

The study will take place over 18 months, finishing in December 2016.
Who is invited to participate in the study?
Whanau with members (children and adults) who have recurrent Acute Rheumatic Fever, who identify as Māori, and who live in Tamaki Makaurau are invited to participate in this study.

What is involved?
The whanau interviews will take between 1 to 2 hours. Whanau do not have to answer all of the questions and can leave the interview at any time without having to give a reason. However, if you do decide to leave the interview, we will not be able to withdraw/delete the information you have given us before you leave. These interviews will be held at local community centres or in whanau homes if this is what your whanau want. The interviews will be digitally audio recorded. The audio recording will then be kept as an electronic document until it is transcribed (typed out) by a researcher or a research assistant and then it will be deleted. The typed copy will be kept by the researcher for 6 years. You may request a typed copy of interviews if you would like one.

Confidentiality & privacy
No material that could personally identify you (let other people know who you are) will be used in any reports on this study. Identity of individual interview participants will be kept confidential. In whanau interviews, because your whanau will know each other, we will not be able to guarantee that your identity will be kept confidential (secret). However, we will ask that you each keep one another's identity and what was talked about in the interviews confidential (by not telling people outside of the whanau who has been involved and what has been said in the interviews). Information collected from the study will be stored in a locked cabinet on University of Auckland premises, separate from participant consent forms, for a total of 6 years. After this time, all data will be destroyed by a disposal company that provides security for confidential documents.

Results and dissemination
The study will finish in December 2016. Information from the study will be used to improve health services, especially for rheumatic fever. The findings from the study will be used to inform or be combined with future research on rheumatic fever, presented in academic publications (journals and books), to health care service providers, at academic conferences, and reported back to you as a whanau, and your local community through oral presentations and through summary documents. The results of this study will also be written up by the student researcher, Hannah Burgess, as a part of a thesis towards Masters of Public Health.

Risks and benefits
There are no direct risks or benefits to you or your whanau as participants in this study. If the researcher does become privy to any incidental findings that would pose danger for participants they will immediately alert the District Nurse involved with the whanau. There is also no cash payment for your participation in the study. You will be provided with koha ($30 voucher) in appreciation of giving up your time for the study (even if you decide to withdraw from the study after the information is collected).
Any questions?
If you have any queries or wish to know more please contact the principal investigator (my supervisor), Dr Amelia Anderson (Kai Tahu/Kati Māmoe), a.anderson@auckland.ac.nz, Te Kupenga Hauora Māori, University of Auckland, Tel 373 7599 Ext 83373.

You may also contact the Head of Department/ Tumuaki, Associate Professor Paparangi Reid (Te Rarawa), p.reid@auckland.ac.nz, Te Kupenga Hauora Māori, University of Auckland, Tel +64 9 923 1922.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide): 0800 555 050
Free Fax (NZ wide): 0800 2787 7679 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdc.org.nz

If you have any medical questions or health concerns please contact Healthline (a free service with trained nurses to give you advice): 0800 611 116

For any queries regarding ethical concerns you may contact:
The Chair,
The University of Auckland Human Ethics Committee
Office of the Vice Chancellor
Private Bag 92019
Auckland 1141
Telephone 09 373 7599 extn. 83711.
Email: ro-ethics@auckland.ac.nz

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 01/07/2015 for 3 years, Reference number 014652
Appendix C: Participant information sheet for children

Whānau experiences of recurrent rheumatic fever in Tāmaki Makaurau, Aotearoa.

Participant Information Sheet (tamariki/children)

Kia ora, my name is Hannah Burgess (my he i are Tawharetoa and Te Ati Haunui-a-Paparangi). I work at a big school called a University and my job is to find ways to make sick people better. I would like to invite you and your whānau/family to be a part of a study I am doing about a bug that makes you sick called rheumatic fever.

It is up to you whether you want to be in this study or not. If you don’t want to be in it that is okay, you won’t get in trouble with anybody. If you do choose to be in the study then change your mind later that is also okay, you can leave it whenever you want, and you don’t have to say why. If you do want to leave the study just tell your mum, dad, another family/whānau member or me.

What is the study about?
Rheumatic fever is a bug some children/young people get that gives them a sore throat. We want to find out about what happened to your whānau/family when someone in it got sick from this bug so we can make things better for other kids who might get sick in the future.

What will happen if you are in the study?
If you decide to be in this study I will come and have a kōrero (conversation) with you and your whānau/family about the bug, and hear your whānau/family’s stories. If you don’t want me to spend time with you or talk with you, just tell your mum, dad or me and I will stop straight away.

When we are having a kōrero/conversation, I will be recording what we say so I can listen to it again later and make notes.

Keeping who you are private
Your whānau/family may not want people to know you have been in the study and might want to keep this a secret so we will not put your name in our notes. We will keep information about what we find in the study and all the bits of paper you (and your whānau) have signed for 6 years then we will destroy it.

What will happen when the study is finished?
The study will finish in December 2016. We will use this information in other studies, write about what we found from the study in books and tell people like doctors, nurses, teachers and your whānau what we found out.
Any questions?
If you have questions about the study please ask your mum/dad/whānau member to contact me or one of the numbers below.

Hannah Burgess, hburg042@aucklanduni.ac.nz, Te Kupenga Hauora Māori, University of Auckland,
Tel 373 7599 Ext 83373.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.
Telephone: (NZ wide): 0800 555 050
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdc.org.nz

If you have any medical questions or health concerns please contact Healthline (a free service with trained nurses to give you advice): 0800 611 116

For any queries regarding ethical concerns you may contact:
The Chair,
The University of Auckland Human Ethics Committee
The University of Auckland
Office of the Vice Chancellor
Private Bag 92019
Auckland 1141
Telephone 09 373 7599 extn. 83711.
Email: ro-ethics@auckland.ac.nz

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 01/07/2015 for 3 years, Reference number 014652
Appendix D: Individual consent form

Whanau experiences of recurrent rheumatic fever
Tamaki Makaurau, Aotearoa.

Individual consent form
This form will be kept securely for a period of 6 years.

I have read and understood the information sheet for this study. I understand how and why I have been invited to participate in the study and I have been able to ask questions and have them answered in a way I understand.

I understand that my participation in this study is my choice (voluntary) and I may withdraw myself from it at any time without having to give a reason.

I understand that my participation in this study will not affect health care for myself or my whānau or our relationship with our District Health Nurses.

I understand that I do not have to answer all of the interview questions and that I can leave the interview at any time.

I understand that if I choose to leave the interview I will be able to withdraw the information I have given you before I leave if I wish to do so.

I understand that no information which could identify me (let other people know who I am) will be used in any reports on this study.

I understand that the interview will be digitally audio recorded.

I understand that the audio recording of this interview will be deleted after it has been transcribed and that all information collected will be stored in a locked cabinet on University of Auckland premises, separate from participant consent forms, for a total of 6 years. After this time, all information will be destroyed by a disposal company that provides security for confidential documents.

I understand that information from the study will be used to improve health services, inform or combine with future research, presented in academic publications, at academic conferences, to health care providers and reported back to the community through oral presentations and through summary documents.

I agree to take part in this research.

Participant’s name

Participant’s signature: ________________________________

Date: / / ____________________________

Researcher's name: ________________________________

Researcher's signature: ________________________________

If you wish to receive a typed copy of this interview please provide your mail address below and we will mail a copy to you:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 01/07/2015 for 3 years, Reference number 014652

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Appendix E: Whānau consent form

Whānau experiences of recurrent rheumatic fever in Tamaki Makaurau, Aotearoa.

Whānau Interview Consent Form
This form will be kept securely for a period of 6 years

I have read and understood the information sheet for this study. I understand how and why my child/children and I have been invited to participate in the study and I and my children (if old enough) have been able to ask questions and have them answered to our satisfaction.

I understand that the participation of my child/children in this study is my choice (voluntary) and I may withdraw my child/children from this study at any time without having to give a reason.

I understand that my and child/children’s participation in this study will not affect health care for myself, my children or other whānau members or our relationship with our District Health Nurses.

I understand that if I, my child/children or any other whānau member tells the researcher that my child/children do not feel comfortable being interviewed the interview will stop immediately.

I understand that no information which could identify myself or my child/children (let other people know who they are) will be used in any reports on this study.

I understand that because whānau members in the interview know each other, confidentiality of my child/children cannot be guaranteed (people might know who they are).

I understand that the audio recording of the interview that includes my child/children will be deleted after it has been typed out and that all information collected will be stored in a locked cabinet on University of Auckland premises, separate from participant consent forms, for a total of 6 years. After this time, all information will be destroyed by a disposal company that provides security for confidential documents.

I understand that information from the study will be used to improve health services, inform or combine with future research, presented in academic publications, at academic conferences, to health care providers and reported back to the community through oral presentations and through summary documents.

I agree to take part in the research, and let my child/children take part in the research.

Participant’s name_____________________________________________________

Child/children’s name/s and age/s_________________________________________

_____________________________________________________

_____________________________________________________

_____________________________________________________
Participant's signature

Participant's contact details

Date: / /

Researcher's name

Researcher's signature

If you wish to receive a typed copy of this interview please provide your mail address below and we will mail a copy to you:

Approved by the University of Auckland Human Participants Ethics Committee on 01/07/2015 for 3 years, Reference number 014052
Appendix F: Consent form for children

Whānau experiences of recurrent rheumatic fever in Tāmaki Makaurau, Aotearoa.

Consent form (tamariki/children)

We will keep this form for 6 years.

I have read the information paper and someone has explained to me about the study and I know what it is all about.

I know why you asked me to be in this study.

I could ask questions about the study.

If I did ask questions I understood the answers to them.

I understand that it is up to me if I want to be in this study (my choice) and I can leave the study whenever I want to and I don’t have to say why.

I understand that I won’t get into trouble with anyone if I don’t want to be in the study.

I understand that if I tell my mum, dad or Hannah (the researcher) that I don’t want her to talk to me and my whānau/family then she will stop right away.

I understand that no one will know I have been in the study, my name will not be written down in any notes.

I understand that Hannah will record the conversation we have using a voice recorder.

I understand that Hannah and her study team will use this study to find out how to make things better for children with rheumatic fever.

I understand that Hannah will keep this piece of paper and other information for 6 years then she will destroy them.

I understand that Hannah and her study team will write a book about what they find in the study and tell people like doctors, nurses, teachers and my whānau about it too and use it for other studies on rheumatic fever.

I do want to be in the research.
Child's name

Child's age:

Parent/Caregiver's contact details

Parent/Caregiver's signature

Date: / / 

Researcher's name

Researcher's signature

If you have any queries or wish to know more please contact the principal investigator (my supervisor), Dr Anaeke Anderson (Kōtahi/Kōtahi Māori), a.anderson@auckland.ac.nz, Te Rupenga Hauora Māori, University of Auckland, Tel 373 7599 Ext 03373.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 01/07/2015 for 3 years, Reference number 01-5652
Interview schedule

This semi-structured interview schedule guided, but did not control, whānau interviews. The bulleted questions below served as prompts to encourage the participants to share their story and were only asked when appropriate.

Background context/introductions:
Can you please tell me a little bit about yourselves?
- Time spent living in area
- Whānau/home context

History of rheumatic fever:
- I understand that you or a whānau member may have had rheumatic fever a few times is this right?
- How many times have you been hospitalised?
- Can you tell me about the first time you or your whānau member got rheumatic fever?
- How did you know you or your whānau member was sick (sore joints, fever, etc...)?
- What did you do when you or your whānau member first noticed you/they were sick?
- Where did you or your whānau member go for health care?
- When did you or your whānau member go?
- Has anyone else in your whānau had rheumatic fever?

First time:

Diagnosis of rheumatic fever
- Where was it diagnosed?
- When was it diagnosed?
- How was it diagnosed?
- Did your doctor explain what rheumatic fever was to you or your whānau member (if yes, what did they say, how well did you and you whānau understand this)?
- Was there anything that made the experience difficult?
- Was there anything that made this experience easier?
- How do you and your whānau think that the diagnosis of rheumatic fever could be improved?

Treatment of rheumatic fever
- Did you/they receive treatment?
- What kind of treatment did you/they receive?
- Where did you/they receive the treatment?
- Was there anything that made this difficult?
- Was there anything that made this easier?
Secondary prophylaxis

- How do you or your whānau member feel about having the injections?
- Do you understand why you need them?
- Was/is there anything that made the treatment experience difficult?
- Was/is there anything that made the treatment experience easier?

Experiences in healthcare settings

- When you think back to how you or your whānau member was looked after when they first got rheumatic fever is there anything that you think worked well? (what and why)
- When you think back to how you or your whānau member was looked after when they first got rheumatic fever is there anything that you think didn’t work well? (what and why)?
- How did you/your whānau feel about the nurses and/or doctors you encountered?
- Was there anything that made the experience difficult for you/your whānau?
- Was there anything that made this experience easier for you/your whānau?
- How do you and your whānau think healthcare for rheumatic fever be improved?

Recurrence:

- Tell me about the second time you were diagnosed with rheumatic fever
- How was it different?
- How was it the same?

Same questions as above for the first time – experiences with diagnosis, treatment, experiences of healthcare services.

Rehospitalisations:

- Have you been rehospitalised because of rheumatic fever?
- If so, why?
- How many times?

Impacts:

- Has having rheumatic fever changed any aspect of life for you or your whānau?
- If so, how?

Wrap up:

- Are there any questions or comments you or your whānau would like to make?
Appendix H: UAHPEC ethics approval

Office of the Vice-Chancellor
Finance, Ethics and Compliance

UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

01-Jul-2015

MEMORANDUM TO:
Dr Anneka Anderson
Te Kupenga Kauora Maori

Re: Application for Ethics Approval (Our Ref. 014652): Approved with comment

The Committee considered your application for ethics approval for your project entitled An exploration of whānau experiences of recurrent acute rheumatic fever in Tāmaki Makaurau.

Ethics approval was given for a period of three years with the following comment(s):

Thank you for attending to the amendments.
1. Please amend the title of the Consent Form for Tamariki/Children to Assent Form.
2. Please add an email address to the UAHPEC Chair contact details on the PI/PIs (ro-ethics@auckland.ac.nz).
3. Please ensure that all application reference numbers on the PI/PIs and CFs are for the current application, and the approval date is 1 July 2015.

The expiry date for this approval is 01-Jul-2018.

If the project changes significantly you are required to resubmit a new application to UAHPEC for further consideration.

In order that an up-to-date record can be maintained, you are requested to notify UAHPEC once your project is completed.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals if you wish to do so. Contact should be made through the UAHPEC Ethics Administrators at ro-ethics@auckland.ac.nz in the first instance.

All communication with the UAHPEC regarding this application should include this reference number: 014652.

(This is a computer generated letter. No signature required.)
Secretary
University of Auckland Human Participants Ethics Committee

cc. Head of Department / School, Te Kupenga Hauora Māori
   Dr Elana Curtis
   Miss Hannah Burgess
   Assoc Prof Mary-Jane Reid
   Elizabeth Peat

Additional information:
1. Should you need to make any changes to the project, write to the Committee giving full details including revised documentation.

2. Should you require an extension, write to the Committee before the expiry date giving full details along with revised documentation. An extension can be granted for up to three years, after which time you must make a new application.

3. At the end of three years, or if the project is completed before the expiry, you are requested to advise the Committee of its completion.

4. Do not forget to fill in the 'approval wording' on the Participant Information Sheets and Consent Forms, giving the dates of approval and the reference number, before you send them out to your participants.

5. Send a copy of this approval letter to the Awards Team at the, Research Office if you have obtained funding other than from UniServices. For UniServices contract, send a copy of the approval letter to: Contract Manager, UniServices.

6. Please note that the Committee may from time to time conduct audits of approved projects to ensure that the research has been carried out according to the approval that was given.