ABSTRACT

AIM: In New Zealand, acute rheumatic fever (ARF) remains a significant health problem with persistent ethnic inequities. Māori children 5–15 years of age in Northland have some of the highest ARF rates nationally. This study explored Māori whānau experiences of ARF, including pathways to primary healthcare and barriers and facilitators for diagnosis of ARF.

METHODS: The study applied a qualitative kaupapa Māori approach including eight whānau, two individual interviews and participant observations with 36 participants.

RESULTS: Barriers to accessing primary healthcare included: geographic distance, unavailability of appointments, cost, poor trust and rapport between health providers and whānau. Good rapport, communication and trust with health professionals facilitated utilisation of services. Barriers to diagnosis were lack of throat swabbing and inappropriate prescription of antibiotics. Access to primary care, having health professionals follow sore throat guidelines and trust in health professionals facilitated diagnosis.

CONCLUSION: Health services could better support ARF diagnosis through the development of an effective quality improvement strategy for sore throat management, promoting free rapid response throat swabbing for high-risk populations, and exploring options of self-swabbing. Training and evaluation targeted at rapport building should also be established for health professionals to facilitate primary healthcare utilisation.

Acute rheumatic fever (ARF) is a preventable inflammatory disease that can develop after pharyngitis caused by group A streptococcus (GAS) bacteria.1 The most severe sequela is rheumatic heart disease (RHD) with mitral and/or atrial valve damage, which may require cardiac surgery and valve replacement.1 Prevention of ARF requires early effective treatment of GAS pharyngitis with an appropriate antibiotic.2 Both ARF and RHD remain significant causes of morbidity and mortality in New Zealand.3,4

ARF rates in New Zealand began to increase in the 1980s and have remained high until 2013/14.5 Rates of ARF in New Zealand are highest in Māori and Pasifika children between the ages of 5–14 years.3,4 Incidence rates reported from 1996 to 2005 are 8.0 per 100,000 for Māori, 16.6 for Pasifika and 0.8 for New Zealand Europeans.6 Recent studies show these disparities are widening with increasing incidence of ARF among 5–15 year old Māori and Pasifika children.1,4

Socioeconomic deprivation and household crowding are known to be associated with ARF in New Zealand.1,4 Most ARF cases occur within the most deprived regions of New Zealand, with the highest rates seen in Northland, South Auckland, the Bay of Plenty and Gisborne.4
In 2011, Northland District Health Board (NDHB) reported that 95% of ARF cases within the DHB were Māori children. Rates of ARF among Māori children in Northland, calculated from 2002–2011, were some of the highest in the country with rates of 78/100,000 per year in Māori children between 5–15 years of age compared to 4.6/100,000 per year in non-Māori.

There are few published evaluations to date of primary prevention programmes for ARF in New Zealand. However, international research supports application of targeted primary prevention within high-risk ARF areas such as Northland. Since 2011, the government has funded primary ARF prevention programmes in high-risk areas of New Zealand, but secondary prevention programmes focusing on secondary antibiotic prophylaxis for known ARF cases remain “the backbone of disease control”. Apart from published audits of secondary prevention registers, little research has been undertaken to understand the perspective or experience of the person with ARF/RHD and their whānau (family group).

The project aimed to address these gaps in ARF/RHD research by exploring Māori experiences of ARF/RHD, including their pathways to primary healthcare and key barriers and facilitators for the diagnosis of ARF.

Methods

The study applied a qualitative Kaupapa Māori research design, including participant observations, whānau and individual semi-structured interviews with Māori who resided in Northland at the time of the research. Ethics approval was received from the University of Auckland Human Participants Ethics Committee in 2013.

Kaupapa Māori research

Kaupapa Māori research (KMR) has been described as a critical framework that gives meaning to the life of Māori and analyses unequal relations of power that influence Māori wellbeing. It is a methodology that is controlled by Māori to benefit Māori.

These elements of KMR allow it to operate as an empowering lens that places Māori at the centre of the study and rejects cultural deficit explanations.

Data collection

Participants included people who self-identified as Māori, had ARF and/or RHD and had received ARF/RHD treatment in Northland. Participants also included consenting whānau of people with ARF/RHD. Participants were recruited with the support of NDHB public health nurses (PHNs) and were identified from the NDHB Rheumatic Fever Prophylaxis Register.

KMR approaches to interactions with participants were undertaken, which focused on whakawhanaungatanga (relationship building). Whanaungatanga was established through whakapapa (family) connections and following tikanga and kawa (customs and protocols), including karakia (prayers), kai (food) and koha (acknowledgements).

Participant observation is a method that allows for first-hand accounts of people's lived experiences. Participant observations were undertaken with whānau for up to three days in their homes, workplaces and at community events. Data was collected in a field journal by the researcher, transcribed and analysed as described below.

Eight whānau interviews and two individual interviews were undertaken with participants. Interviews involved open-ended questions based around key research topics allowing for in-depth narratives. Interviews were audio recorded and held in participants’ homes, workplaces and community centres.

Data analysis

Data were transcribed and entered into an NVivo 10 software programme. A general inductive approach was used for data analysis. Independent coding was undertaken by three researchers (two identified as Māori), then triangulated for internal validity.

Results

Participants

There were 36 participants in our study (Table 1).
Table 1: Research participants.

<table>
<thead>
<tr>
<th>Whānau</th>
<th>Pseudonym</th>
<th>Sex</th>
<th>Age*</th>
<th>ARF/RHD status</th>
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<tr>
<td>1</td>
<td>Erena</td>
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<tr>
<td></td>
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<td>ARF/RHD</td>
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<tr>
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<td></td>
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<tr>
<td></td>
<td>Ngaire</td>
<td>Female Child</td>
<td>ARF</td>
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</tbody>
</table>

*Adult (>25 years), Youth (16–24 years), Child (<15 years).
The study identified many barriers and facilitators to accessing primary healthcare services and for the timely diagnosis of RF. These barriers related to direct and indirect costs of healthcare services, and healthcare professionals not establishing positive relationships and communication with whānau.

Good rapport, communication and trust between health professionals and whānau, along with following sore throat guidelines, facilitated utilisation of services and diagnosis.

Accessing primary healthcare

Direct and indirect costs of care

Not all whānau were able to access medical care for their children when needed. Barriers to access included not being able to get appointments with general practice clinics, direct economic costs and indirect costs such as not being able to get time of work, not having access to transport, not being able to afford petrol for vehicles and geographic distance, as explained by Matire:

Yip not very often I could go out so yeah it wasn’t something that my mother could just take me to the doctors, cause my mother was working, my father was working, yeah so not very often I got to go to see a doctor.

Some whānau chose to go directly to a hospital emergency department rather than seek primary care. These decisions were based on direct economic costs, their belief that it was a quicker option, and that they would most likely be referred to hospital anyway. Wikitoria explained why she adopted this strategy:

I know if I go to the doctors [GP] they’re going to send me up there [hospital] anyway so I may as well just go straight up there. So I just went straight up there and, and sat there for six hours waiting for his [son’s] turn.

Healthcare professionals’ relationships with whānau

Healthcare professionals’ attitudes and ability to create whanaungatanga (relationships) with whānau influenced whānau engagement and utilisation of health services. Whānau reported having negative experiences with general practitioners (GPs). Participants described feeling as though they were inferior and were discriminated against. Whānau felt their doctors judged them by where they lived and how they looked, did not listen to them, and were dismissive of their experiences and questions. Erena’s narrative below describes such an interaction:

I think it’s the brushing off like, “you’ve just got the flu” you know? It’s like you’re made to feel you’re a bit bloody second class citizen, like that sort of sort attitude, like we don’t count... I would say to him [GP] questions like “ah doctor X do you think she needs to see a specialist?” [He’ll reply] “who is the qualified doctor here?” that sort of crap.

Utilisation of sore throat guidelines in primary care services

Whānau commonly cited concerns about lack of throat swabbing and under prescription of antibiotics as barriers to trusting GPs. Participants were aware that sore throats could lead to rheumatic fever and should be swabbed by health professionals. However, many participants described situations when they had presented with sore throats, asked for throat swabs and had not been given them. Whānau claimed that unless they had “pushed” they would not have had a throat swab taken, as described by Erena and her son Mikaere:

Mikaere: Yeah [the doctor] just said I had the flu, sent me home on some different drugs.
Erena: Paracetamol sent him home um, [the GP said] “see how it goes over a couple of days”. But he [GP] never took a throat swab.
Mikaere: Nah he just brushed it off...
Erena: And we’re aggressive, we’re really aggressive when we go into the doctor’s.
Mikaere: We have to be aggressive with these fellas.
Erena: But what happens if it’s a whānau that isn’t as experienced or aggressive as us? What happens to them? You know and their kids go undiagnosed because they’re taking what the doctors are saying as law, and it’s terrible care.

Facilitators to accessing primary healthcare services

Factors that facilitated access to primary healthcare and positive experiences of services were whanaungatanga, communication and trust with primary healthcare staff. Huhana stated that the relationship
between her whānau and their GP was critical in their utilisation of primary care services:

*Doctor X is our GP now because he's done really well with our son, when we see him on the street [the GP says] “how's Romana [her son]?” You know? It's become like a personal relationship now, where he asks about him [Romana] and he cares about him.*

**Diagnosis of ARF**

**Delays in diagnosis**

Diagnosis of ARF (from time first taken to a GP) for participants varied between an immediate diagnosis at primary care to a four-month delay and eventual diagnosis in hospital. Two RHD participants explained that their past ARF went undiagnosed until they presented with RHD symptoms. Another two children were only diagnosed with ARF when they presented at hospital with other illnesses. Delays in diagnosis occurred even when whānau suspected their children had ARF and voiced their concerns to GPs. Kahu-rangi had ARF as a child and her eldest son had also been diagnosed with ARF. When her youngest son began exhibiting rheumatic fever symptoms she took him to her GP several times, but as she described, he was misdiagnosed on each occasion:

*A good four years before that [diagnosis of ARF] I had a fair idea that Hohepa [son] had rheumatic fever and I had been into the clinic a couple of times and I had explained to them that I was sure it was rheumatics because of the symptoms he was getting but the doc, the nurses at the clinic were telling me he had rheumatism arthritis and I was adamant that it was rheumatics because I had dealt with the symptoms before with my eldest son but they kept putting it off and kept telling me it was rheumatism arthritis and then yeah, couple years later he's diagnosed with rheumatics... I think about three times I had gone in there with him... they kept telling me it was rheumatism arthritis.*

Two other whānau felt that delays in the diagnosis of their children was due to lack of knowledge and awareness of ARF by healthcare professionals, as Mikaere stated:

*Because they [hospital doctors] had never seen it [ARF] before, there was only one doctor that's what I'm saying, only one doctor who knew his stuff. All the rest they were just practicing on me basically... they didn't know what they were up to.*

**Facilitators of diagnosis of ARF**

Access to primary care, healthcare providers’ knowledge and appropriate action of sore throat management were the key three factors that facilitated the diagnosis of rheumatic fever for participants. Trusting GPs to have an understanding of ARF and provide expected sore throat management influenced participants’ health-seeking behaviours. Anahe’a’s narrative illustrates positive interactions between whānau and GPs:

*They [GPs] always take swabs, every time, like even with my moko [grandchild], he's two in March, even when I hear him cough, poor Dr X (laughs). I'm pretty sure he's [grandchild] too young to get rheumatics but oh he's off to the doctor to get swabbed, my poor moko you know? He, [the] doctor goes “I'm pretty sure it's not [rheumatic fever]” and I go “I don’t care, I want it swabbed”.*

**Discussion**

KMR has been described by Linda Smith as a decolonising tool to understand, analyse and address structural inequities experienced by Māori in New Zealand. Applying this critical framework enabled a non-deficit, whānau-centred approach to be undertaken through a Māori lens and worldviews. This approach highlighted how systemic structural failures of New Zealand's health system perpetuate inequitable outcomes in ARF experiences for Māori. Barriers whānau faced accessing primary health services in Northland included geographic distance, unavailability of appointments, lack of access to transport and childcare, direct and indirect costs of services, and lack of trust in health professionals due to poor management and whakawhanaungatanga by GPs. These barriers are consistent with health literature in New Zealand, indicating these are persistent issues not yet addressed through health policy or systematic change.

Direct and indirect costs of health services are recognised access barriers for Māori, and can influence delays in diagnosis of ARF/RHD. From October 2014, doctor visits and prescription medicines were free for patients under 13 years of age in Northland. From July 2015, this government initiative was extended nationally. Despite this initiative, there are still notable inequities...
in access between Māori and non-Māori due to direct and indirect costs. The Ministry of Health 2015/16 update of the New Zealand health survey reported that almost one quarter (24%) of children had experienced unmet need for primary healthcare during the past 12 months due to direct costs, lack of childcare, lack of transport and unavailability of health appointments. There were also significant ethnic differences reported after adjusting for age and sex differences, with Māori children 1.3 times more likely not to have accessed primary healthcare when they needed it than non-Māori children. A sub analysis of the Northland data of the New Zealand Health Survey 2011–14 revealed similar trends with 24% of Northland children reporting unmet need for GP services over the last 12 months and citing similar barriers to seeking GP care. These inequities demonstrate the complexity of issues influencing access to healthcare. Rather than relying on a single intervention to target direct cost, a multi-pronged approach that can address multiple barriers could be a more effective strategy.

Not being able to obtain timely GP appointments is an increasingly common barrier to accessing healthcare in New Zealand. Initiatives such as walk-in clinic appointment systems and flexible operational hours have been proposed to counter this issue. However, there are structural barriers in implementing such innovative services, mostly due to funding mechanisms of general practice and the private business model that predominates in New Zealand. Given the health impact and complexity of this issue, further research is needed to explore the influence of existing primary care models on health, and to investigate alternative models.

Barriers to ARF diagnosis identified in the study were the lack of throat swabbing and inappropriate prescription of antibiotics. Many whānau were not given throat swabs or prescriptions for antibiotics even when presenting to GPs with sore throats, requesting throat swabs and disclosing histories of rheumatic fever. These experiences indicate negative perceptions by whānau of GPs within Northland and influenced whānau decisions to bypass primary care services in favour of secondary care. Best practice guidelines for sore throat management in New Zealand recommend that throat swabs are undertaken and patients are started on appropriate antibiotic treatment if the patient is deemed at ‘high risk’ of developing rheumatic fever. All whānau members who presented to GPs with sore throats in this study would have met at least two of these high-risk criteria, demonstrating that sore throat guidelines are not consistently followed in general practice within Northland. These findings are supported by a recent study undertaken assessing adherence of school-based sore throat programmes and GPs in Northland to national guidelines for the management of laboratory-proven GAS. The study found that one in five children presenting to general practices with positive throat swabs did not receive treatment regimens recommended by the guidelines.

A number of reviews show that guidelines often only have moderate effectiveness in improving clinical outcomes or changing process of care. However, evidence suggests that an effective quality improvement strategy including: audit and feedback, computerised advice, point of care reminders, practice facilitation, educational outreach and processes for patient review and follow-up can overcome health provider barriers. Given the experiences of whānau in this study, we recommended that such a strategy be developed.

Our findings support other ways of increasing access for whānau to high-quality sore throat management, including the ‘rapid response’ free at point of care access currently being implemented for children at high risk in Northland in pharmacies and schools, and potentially other community venues. Recent research suggests that self-swabbing or swabbing by parents/caregivers is non-inferior to swabbing by health professionals for GAS detection. Self-swabbing may overcome some barriers whānau experience in accessing primary care. The feasibility of implementing self-swabbing requires further research.

One of the greatest facilitators of positive experiences for whānau within Northland’s primary healthcare system was health providers’ ability to establish trust and whanaungatanga with whānau. The impact
of good rapport, communication and trust with health professionals has been well established in New Zealand, with greater rapport promoting increased patient satisfaction.\textsuperscript{24,25,40} Declining confidence and trust in GPs was reported in the 2015/16 New Zealand Health Survey with adults who reported no confidence and trust at all in their GP increasing from 2.1\% in the 2011/12 Health Survey to 3.4\% in 2015/16 Health survey.\textsuperscript{26} Training and evaluation targeted at rapport building should be established for health professionals to facilitate healthcare utilisation and merits further research.

This study provided a whānau-centred context to ARF/RHD research in New Zealand, demonstrating how experiences and narratives of those who suffer from disease are important. Presenting patient\textsuperscript{21,25,30,32} and whānau voices\textsuperscript{41} within health contexts is an approach not yet utilised within ARF/RHD literature.

The study included a relatively small sample size, and therefore may not represent the diversity of whānau experiences. Selection bias may have also occurred during recruitment.

Despite these potential weaknesses, the research provides a beginning point to inform ARF/RHD prevention approaches in Northland from a qualitative, KMR methodology. This framework can be applied to future research looking at experiences of ARF/RHD in New Zealand to provide a fuller understanding of these challenging issues.

**Competing interests:**
Nil.

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