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Te Maatai Manawa a Whaanau: Maaori and Pacific People's Experiences of Echocardiography in Rheumatic Fever Health Care in Auckland, New Zealand

Anneka Anderson[1,2] | Monleigh Muliaumasealii[1,2] | Tira Phillipson-Puna[2,3] | Rachel Webb[1,4] | Nigel Wilson[1,5] | Shannon Leilua[2] | Kim Arrowsmith[1,2] | Rachel Brown[2] | Florina Chan-Mow[4] | Adam Dennison[4]

[1]The University of Auckland, Auckland, New Zealand | [2]The National Hauora Coalition, Auckland, New Zealand | [3]Auckland University of Technology, Auckland, New Zealand | [4]KidzFirst, Middlemore Hospital, Auckland, New Zealand | [5]Te Toka Tumai Auckland/Auckland City Hospital, Auckland, New Zealand

Correspondence: Anneka Anderson (a.anderson@auckland.ac.nz)

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ABSTRACT

Aims: This research aimed to gain an understanding of rheumatic fever related echocardiography experiences from Indigenous Maaori and Pacific children, adolescents and their whaanau (family members) in the Counties Manukau region of Aotearoa New Zealand to improve these services.

Method: The study used qualitative Indigenous Kaupapa Maaori consistent and Kakala methodologies. The research was based in the Counties Manukau region of Auckland, New Zealand. Data was collected through interviews with Maaori and Pacific children and adolescents with rheumatic fever or rheumatic heart disease who had recently had echocardiograms and their whaanau. Data was analysed using a general inductive thematic analysis.

Results: Seventeen Participants Were Included in the Study. Four Themes Were Identified in the General Inductive Analysis: (1) Communication; (2) Engagement; (3) Access; (4) Kaiaawhina.

Conclusion: By identifying barriers and facilitators of echocardiography services for rheumatic fever, this research provided knowledge and insights that can assist in developing child, adolescent and whaanau-focused models of care that have the potential to improve patient experience and echocardiography services in Aotearoa New Zealand.

1 | Introduction

Acute rheumatic fever (ARF) is an autoimmune response to group A Streptococcus pharyngeal infection [1]. ARF can lead to rheumatic heart disease (RHD) and chronic heart valve damage, from one or more episodes of ARF [1]. ARF and RHD are significant health issues in Aotearoa New Zealand (NZ) that inequitably affect Maaori and Pacific children and adolescents [2–4]. The Counties Manukau (CM) region of NZ has the highest rates of ARF and RHD nationally, where approximately 60 children are diagnosed with ARF annually [5, 6].

Echocardiography is essential to diagnose and grade valve disease in ARF and RHD [7]. Evidence demonstrates an increased risk of developing ARF when there is a whaanau (family) history of ARF, and that siblings of children with ARF are at increased risk of RHD [8, 9]. Familial echocardiographic screening is an important part of holistic care for whaanau diagnosed with ARF, and is recommended in the New Zealand Guidelines for the prevention, diagnosis and management of rheumatic fever and rheumatic heart disease [7].

Gaining insights and understandings of lived experiences of echocardiography for children and adolescents with ARF or

Brief Points

- What is already known
  - Echocardiography is essential for the diagnosis and management of Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD) along with other childhood heart conditions in Aotearoa New Zealand and globally.
- What this paper adds
  - This paper provides a comprehensive understanding of barriers and facilitators of ARF and RHD echocardiography services for Maaori and Pacific children, adolescents and their whaanau in Aotearoa New Zealand. Findings can improve patient experience and ongoing management of ARF and RHD in Aotearoa New Zealand, with relevance to other global settings where ARF and RHD are endemic.

RHD could offer valuable information to improve paediatric echocardiography services. Despite a growing number of NZ studies exploring peoples' experiences of ARF and RHD health services [10–12] and broader health system experiences [13] there is no specific research on echocardiography experiences.

This research—Te Maatai Manawa a Whaanau—which translates to investigating family heart health, aimed to seek an understanding of echocardiography experiences from Maaori and Pacific children, adolescents and their whaanau to improve these services in the CM region of NZ.

2 | Materials and Methods

2.1 | Methodology

The study applied qualitative Kaupapa Maaori consistent and Pacific Kakala methodologies. Kaupapa Maaori consistent methodologies maintain the core principles of Kaupapa Maaori research but can include non-Maaori researchers or participants [14]. Kakala is a Tongan participatory-centred methodology that uses a symbolic representation of garland making [15].

The project received ethics approval from the Northern A Health and Disability Ethics Committee in 2022 (ref 12 190).

2.2 | Recruitment

- Participants were recruited through purposive sampling and identified through the CM secondary penicillin prophylaxis ARF/RHD register. Eligible participants were contacted by a researcher, invited to participate and provided with information and consent forms. Participants were included if they were on the CM ARF/RHD secondary prophylaxis register.
- Self-identified as Maaori and/or a Pacific ethnicity.
- Received an echocardiogram 3 months prior to recruitment.
- Or were a caregiver, sibling, or relative of a child/adolescent who had an echocardiogram.

2.3 | Data Collection

Data collection used semi-structured whaanau interviews and applied a whaanau tuatahi approach that included Maaori cultural practices [16]. Interviews were facilitated by ethnically concordant researchers including three Maaori, one Niuean and one Samoan/Cook Island/Maaori researcher.

Interviews were undertaken by phone, in person at mutually agreed venues or online via Zoom. The interviews explored experiences of echocardiography services, including facilitators, barriers and recommendations for service improvement.

Data were audio recorded, transcribed verbatim and translated into English where appropriate at the time of analysis by the ethnic concordant researcher/s who facilitated the interview.

2.4 | Analysis

A general inductive thematic analysis [17] was applied to the data. A coding framework was developed through collaborative discussions with the Indigenous researchers based on patterns identified from individual coding of the key words, phrases, ideas and concepts expressed in the transcripts.

The same researchers independently analysed narratives within the coding framework. The analysis sought to identify patterns that informed the research questions. The raw themes were developed collaboratively and shared with the broader research team and a researcher with lived experience of RHD to ensure they reflected Maaori and Pacific worldviews.

3 | Results

Ten whaanau including eight children and adolescents with ARF/RHD ($n = 17$) participated (Table 1).

Four key themes were identified from the analysis: (1) communication; (2) engagement; (3) access; (4) kaiaawhina. Each is described below.

3.1 | Communication

Communication was one of the most common themes that emerged from whaanau narratives. Whaanau described communication from health care professionals as a barrier to their care. Whaanau explained that communication with health professionals was unclear, confusing, jargon-heavy and '*overwhelming*'. These approaches may not have fully supported inclusive, shared understanding among whaanau who spoke languages other than English, as well as English-speaking whaanau. Whaanau found the medical terms used to discuss their health,

TABLE 1 | Summary of participants.

Whaanau	Pseudonym	Participant type	Ethnicity	Age	Gender
1	Rimu	ARF/RHD	Rarotongan	Adolescent	Male
	Kalei	Mother	Rarotongan	Adult	Female
2	Mapa	Grandmother	Maaori	Adult	Female
3	Pua	ARF/RHD	Maaori	Child	Female
	Totara	Father	Maaori	Adult	Male
4	Kauri	ARF/RHD	Maaori	Child	Male
	Leilani	Mother	Maaori	Adult	Female
5	Lose	Mother	Maaori	Adult	Female
6	Raataa	ARF/RHD	Maaori	Adolescent	Male
	Siale	Mother	Maaori	Adult	Female
7	Malia	ARF/RHD	Maaori/Niuean	Adolescent	Female
	Tiare	Mother	Maaori/Niuean	Adult	Female
8	Maanuka	ARF/RHD	Maaori/Niuean/Tongan	Adolescent	Male
	Fiti	Mother	Maaori/Niuean/Tongan	Adult	Female
9	Sei	ARF/RHD	Samoan	Adolescent	Female
	Heilala	Mother	Samoan	Adult	Female
10	Awa	ARF/RHD	Tongan	Adolescent	Male

including echocardiograms, were unfamiliar. Many whaanau felt overwhelmed with the communication, as Totara stated:

> The information they did give us (about the echocardiogram) was a lot to take in and in some instances, it was overload.

Whaanau described not being provided with sufficient information and limited opportunities to ask questions as barriers to understanding what was happening during echocardiograms. For young people such as Maanuka, this led to confusion and anxiety:

> It (echocardiogram) made me feel like I can't really ask any questions about anything relating to it because it's the process, and pretty much we had to wait (for the results). It just made me feel it was a little bit off because they didn't tell us anything.

Whaanau recommended that time should be allocated during echocardiography processes to ask questions of the sonographer. Furthermore, whaanau stressed that communication needs to be undertaken in language that is understandable, meaningful and available in their respective languages. They felt it was important for their echocardiogram results to be provided in a smaller timeframe; some waited for several weeks before receiving their results.

Participants found visual forms of communication (such as video clips, #D heart models, diagrams) helpful to overcome English barriers and medical jargon, As Tiare explained:

> Everything was pretty much explained to us after her operation with all the pictures and just explaining a lot beforehand, before going into the scans [echocardiogram] and stuff. Yeah, I got quite a bit of info [rmation], which was good.

These examples highlight how using timely communication in simple language, supported with visual aids, can increase understanding of echocardiography and promote positive health engagement experiences of whaanau.

3.2 | Engagement

Engagement and interactions between whaanau, health professionals and the hospital environment itself affected whaanau experiences of echocardiography. When whaanau experienced engagement from health professionals that was '*unwelcoming*' dismissive or rushed they often left feeling undervalued, a burden and uncomfortable. As Fiti described:

> She (sonographer) was very closed, like [her] back [was] to us while she was scanning... I even said to her 'Can you tell us anything?' She was like 'You need to talk to your GP' ... Things were kind of awkward... it was hard for us to go in there knowing he's vulnerable... It was just very clinical and low communication; I would say little to none pretty much.

If whaanau are engaged in overly professional and an uncompassionate way then they are unlikely to actively re-engage with future echocardiograms, ARF, RHD or clinical health services.

The physical environments of clinics and hospitals created further barriers to engagement with echocardiography services. Whaanau noted how echocardiographic scans were designed for individual patients not whaanau. They felt that health professionals' attention was often more focused on scans and notes and less on them and their children. Some children described the clinic spaces as '*cold*', '*dark*' and '*lonely*'. Children recalled feeling '*sore*' and '*cold*' due to their bare skin being exposed in cold rooms and use of cold gel. Children described feeling '*sore*' when transducers were pressed too firmly onto their bodies. Commonly whaanau felt they could not express this discomfort to sonographers, as Kalei and Rimu explained:

> When they do all the echo[cardiogram] scans that he's had it's not until we come out of the room that he says, 'That was sore Mum (pain from the transducer).' I'd say, 'Why didn't [you] say anything?'
>
> —Kalei

> Yeah, I am pretty shy... Some were alright but some were kind of sore because like Mum said, the pressure.
>
> —Rimu

These examples demonstrate that if whaanau are not engaged in a welcoming way and not provided an explanation of what they are likely to feel during the scan, then they are unlikely to communicate if something is uncomfortable and are less likely to be motivated to return for reoccurring echocardiography appointments.

Many whaanau felt '*rushed*' through their echocardiogram within '*busy*' hospital environments, this affected their engagement experiences with sonographers. Whaanau attributed these experiences to high workloads of hospitals, limited staff and discrimination, as Heilala described:

> We went for an echo[cardiogram]. Probably the person that was doing the echo[cardiogram] had a really busy day, so they were kind of just, 'Get on the table. Do this, do that.' We felt like the person just wanted to get the echo[cardiogram] over and done with. It wasn't a nice experience.

Positive engagement with health professionals facilitated experiences of echocardiography. Whaanau described positive engagement as feeling welcomed, acts of kindness, reassurance and sensitivity, as noted by Leilani:

> The lady (sonographer) made him feel comfortable. She put a blanket on him... she would make him feel a little bit, well, to me, it looked like she was making him feel comfortable. I had been to another one, his last one... That time he was very uncomfortable and was cold... It was pretty much rushed to me.

The inclusion of incentives and distractions during echocardiograms was a memorable facilitator for children. Whaanau noted that when health professionals or play (Child Life) specialists played movies, included toys, provided blankets and took the time to talk to children in a kind and reassuring manner, they were less anxious and more comfortable having an echocardiogram. As described by Rimu and Kalei:

> I think it went fine. They (health professionals) checked if I'm alright, I was doing pretty good.
>
> —Rimu

> Almost an hour we'd be in there. They had movies playing for him while they're doing the scan... he'd just fall asleep.
>
> —Kalei

These examples show that empathy by the sonographer can enable children to feel respected at the start of the scan and can lead to positive health service experiences.

3.3 | Access

Access made a notable difference to whaanau experiences with echocardiography. A barrier with access was the inflexibility and timing of appointments. Whaanau often found it difficult to accommodate appointments with other commitments such as work, whaanau and school. As a result, some participants like Mapa had to rely on other whaanau members to take children to echocardiograms:

> Yes, it was the last one. But my daughter had to take him that day because I had a house inspection the same day. So, I had to stay behind. I made her go.

The location of echocardiography clinics in large, busy hospitals was difficult for some whaanau to navigate and for most, even getting to the hospitals was challenging. Negotiating public transport, having enough petrol for private transport and the availability and cost of parking were other barriers experienced by whaanau, including Totara, who explained that '*being on a benefit doesn't help, especially the price of petrol*.' Lack of parking at hospitals and the cost of parking were the most common access barriers noted by whaanau, as Mapa described:

> Challenges, yeah, the drive and park and pay [is] a lot of money for the parking. Yeah, cos sometimes the parking's not even open, we have to park right up the road, around the corner.

Whaanau found that having flexibility with echocardiography appointment scheduling helped mitigate access barriers. Receiving text reminders for appointments was also found useful, as well as being provided with parking tickets as Pua recounted:

> They give you a little pass that you put on your windscreen. You don't have to display a ticket and you can be there all day, all night and they won't tow you.

The examples demonstrate that interventions such as parking tickets and text reminders can help reduce access barriers and improve echocardiography experiences for whaanau.

3.4 | The Role of Kaiaawhina

A common facilitator of echocardiography for whaanau was having a whaanau member or kaiaawhina (people who support whaanau with their health management, often as health employees) to assist them in scheduling appointments, organising support and helping them locate clinics. Some whaanau such as Tiare relied on other whaanau members to assist them:

> [Malia's] nana came with us so she would watch the kids while me and [Malia] is in the waiting room. … I just pick[ed] her up, took her with us because she wanted to be there for [Malia] as well.

Play (Child Life) specialists were noted as helpful for whaanau, not just due to the distractions and incentives described above, but also because they were able to build a rapport with whaanau, answer questions they had and liaise them with appropriate hospital staff. Maaori support services and kaiaawhina (health employees) were also noted in interviews and remembered for their kindness, helpfulness and support, as Totara described:

> She (play specialist) answered any question that I had and if she couldn't when the doc[tor] was there, she asked the questions for us so that we'd get the answers that we were looking for. It was a really good supportive system in there.

Having roles like these embedded in echocardiography services was a common recommendation from whaanau.

4 | Discussion

The primary aim of the study was to gain insights and recommendations from Maaori and Pacific whaanau with ARF/RHD who had experienced recent echocardiograms to improve echocardiography services. The study recognised that whaanau experienced poor communication where they did not understand the procedure or feel confident enough to ask questions, they experienced difficult engagements with health professionals that were sometimes rushed and unwelcoming and encountered access barriers to services. These findings are consistent with literature around broader ARF, RHD and other health service experiences of Maaori and Pacific people [10–13], indicating the systemic challenges in NZ health services, including echocardiography.

The research identified facilitators of health experiences including receiving jargon-free and visual information, use of developmentally appropriate incentives and distractions during echocardiograms, having flexible appointment scheduling and parking vouchers, and access to play specialists and kaiaawhina. If implemented consistently, these aspects of care could improve engagement with echocardiography services and therefore improve the diagnosis and management of ARF and RHD in NZ, helping to mitigate the inequitable impacts of these diseases on Indigenous children and young people, including Indigenous Pacific people living in NZ.

Echocardiograms are usually performed by an echocardiographer and reported later by a heart specialist. Explaining this process gently at the start and end of the echocardiogram test should be mandatory for the echocardiography staff. It should not be assumed that whaanau will recall this when children or adolescents are known to have had a prior echocardiogram.

This study demonstrated that undertaking research using Indigenous methodologies can improve echocardiography services by delivering a culturally responsive approach to health care in NZ. This approach could be applied to other Indigenous populations and health services in local and international contexts.

The study did have limitations. It included a relatively small number of participants and was undertaken in a large urban area, focusing on children with ARF/RHD; therefore, it may not be generalisable to other regions of NZ or global settings. Despite these limitations, the research provided knowledge and insights into echocardiography experiences for whaanau with ARF/RHD in NZ, an area previously not explored and has the potential to improve future services by developing more child and whaanau focused models of echocardiography care in ARF and RHD contexts.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Due to ethical requirements and Indigenous data sovereignty management we are unable to share the data.

References

1. J. Bennett, J. Zhang, W. Leung, et al., "Rising Ethnic Inequalities in Acute Rheumatic Fever and Rheumatic Heart Disease, New Zealand, 2000-2018," *Emerging Infectious Diseases* 27, no. 1 (2021): 36–46.

2. E. Tilton, B. Mitchelson, A. Anderson, et al., "Cohort Profile: Methodology and Cohort Characteristics of the Aotearoa New Zealand Rheumatic Heart Disease Registry," *BMJ Open* 12 (2022): e066232.

3. S. J. Jack, D. A. Williamson, Y. Galloway, et al., "Primary Prevention of Rheumatic Fever in the 21st Century: Evaluation of a National Programme," *International Journal of Epidemiology* 47, no. 5 (2018): 1585–1593.

4. J. Gurney, J. Stanley, M. Baker, N. Wilson, and D. Sarfati, "Estimating the Risk of Acute Rheumatic Fever in New Zealand by Age, Ethnicity and Deprivation," *Epidemiology and Infection* 144, no. 14 (2016): 3058–3067.

5. The Institute of Environmental Science and Research (ESR), *Rheumatic Fever Bi-Annual Report July 2017 to June 2018* (ESR, 2018).

6. R. Webb, N. Culliford-Semmens, A. ChanMow, et al., "High Burden of Rheumatic Heart Disease Confirmed by Echocardiography Among Pacific Adults Living in New Zealand," *Open Heart* 10, no. 1 (2023): e002253.

7. A. Anderson, C. Mills, N. Rentta, et al., *Aotearoa New Zealand Guidelines for the Prevention, Diagnosis, and Management of Acute Rheumatic Fever and Rheumatic Heart Disease: 2024 Update* (Health New Zealand/Te Whatu Ora, 2025).

8. N. Culliford-Semmens, E. Tilton, N. Wilson, et al., "Echocardiology for Latent Rheumatic Heart Disease in First Degree Relatives of Children With Acute Rheumatic Fever: Implications for Active Case Finding in Family Members," *EClinicalMedicine* 37 (2021): 100935.

9. M. G. Baker, J. Gurney, J. Oliver, et al., "Risk Factors for Acute Rheumatic Fever: Literature Review and Protocol for a Case-Control Study in New Zealand," *International Journal of Environmental Research and Public Health* 16, no. 4515 (2019): 39.

10. A. Anderson, C. Mills, and K. Eggleton, "Whānau Perceptions and Experiences of Acute Rheumatic Fever Diagnosis for Māori in Northland, New Zealand," *New Zealand Medical Journal* 130, no. 1465 (2017): 80–88.

11. A. Anderson, B. Peat, J. Ryland, et al., "Mismatches Between Health Service Delivery and Community Expectations in the Provision of Secondary Prophylaxis for Rheumatic Fever in New Zealand," *Australian and New Zealand Journal of Public Health* 43, no. 3 (2019): 294–299.

12. S. Tu'akoi, M. 'Ofanoa, S. 'Ofanoa, et al., "It Can Hurt Your Heart: A co-Designed Cross-Sectional Survey Exploring Pacific People's Understanding of Rheumatic Fever in Auckland, New Zealand," *Healthcare* 13, no. 22 (2025): 2924.

13. R. Graham and B. Masters-Awatere, "Experiences of Māori of Aotearoa New Zealand's Public Health System: A Systematic Review of Two Decades of Published Qualitative Research," *Australian and New Zealand Journal of Public Health* 44 (2020): 193–200.

14. P. Malpas, A. Anderson, J. Wade, et al., "A Critical Exploration of Collaborative Kaupapa Māori Consistent Research Project on Physician-Assisted Dying," *NMJ* 130, no. 1454 (2017): 47–54.

15. K. H. Thaman, "Towards Cultural-Sensitive Curriculum Development," *Pacific Curriculum Network* 1, no. 1 (1992): 3–5.

16. B. Jones, T. Ingham, C. Davies, and F. Cram, "Whānau Tuatahi: Māori Community Partnership Research Using a Kaupapa Māori Methodology," *MAI Review* 3, no. 1 (2010): 1–14.

17. D. R. A. Thomas, "General Inductive Approach for Analyzing Qualitative Evaluation Data," *American Journal of Evaluation* 27, no. 2 (2006): 237–246.