

Mā te Whakarongo—a qualitative study exploring the impact of middle ear disease on New Zealand Māori

Lance Buckthought, Jeannine Stairmand, Rebecca Garland

ABSTRACT

WHĀINGA (AIM): The study aimed to explore the impact of middle ear disease on the lives of New Zealand Māori. Ear disease is common, yet there is a paucity of research into the effect it has on people's lives, particularly indigenous populations.

TIKANGA (METHOD): The study used Kaupapa Māori-based qualitative methodology and involved a series of seven semi-structured interviews with Māori adults living with middle ear disease.

ŌTINGA (RESULTS): All participants felt there were delays in recognition and treatment of their ear condition and that there were barriers to accessing healthcare. The ear condition prevented participation in cultural and recreational activities, particularly those involving water. The associated hearing loss affected education and employment opportunities, and together with ear discharge, resulted in social isolation and disconnection from Te Ao Māori (the Māori world). Overall, the condition impacted negatively on mental and spiritual wellbeing. Participants felt that funding for hearing aids, earlier recognition and treatment of the condition and healthcare staff with a better understanding of Te Ao Māori could reduce the morbidity associated with middle ear disease.

WHAKAPAUNGA (CONCLUSION): The study demonstrates that living with middle ear disease presents many challenges and disadvantages for Māori and the importance of early detection and referral to specialist care.

Observational studies suggest that New Zealand Māori have higher rates of otitis media than non-Māori and similar findings have been demonstrated in other indigenous populations around the world.¹⁻⁴ Although causality remains uncertain, healthcare access and socio-economic factors resulting from colonisation are likely to have an important role in the higher rates of middle ear disease in New Zealand Māori.⁴

Previous studies regarding the symptom burden of chronic otitis media (COM) have used questionnaires developed from a physician perspective.⁵⁻⁹ These questionnaires were developed by clinicians experienced in treating middle ear disease, translating experiences (qualitative) into numbers (quantitative). In doing so, judgements are made weighting the symptoms and experiences within the questionnaire. These judgements are informed by their own worldviews and paradigms. There is a paucity of qualitative research related to middle ear disease in any population. Specifically, no studies have considered the effects on quality of life for adult Māori patients living with middle ear disease.

We hypothesise that middle ear disease affects Māori adults in a variety of physical, psycho-social and cultural domains, and affects education and

work opportunities. The study aims to explore this impact.

Method

Reflexive statement

The first author (LB) is a Māori otolaryngology trainee working with RG at the time of the study. During training, LB noted that Māori are disproportionately impacted by middle ear disease and recognised the need for further research in this area.^{1,3,4} The senior author (RG) is a mid-career Pākehā consultant otolaryngologist. A confluence of critical reflection on outcome measures in middle ear disease and cultural safety (RG) led to questioning of paradigms in reporting of otology symptoms. JS is a Māori health and Kaupapa Māori Researcher who specialises in cancer and chronic conditions. Discussions between LB, RG and JS informed study design, analysis and reporting.

Study design

A qualitative study design with thematic analysis¹⁰⁻¹² using a Kaupapa Māori lens¹³ was chosen to gather experiences of Māori adults with middle ear disease using patient interviews. Qualitative research explores in depth the views

of a small number of participants, exploring the lived experience in detail. By analysing the language used and the types of experiences that are common in the group interviewed (thematic analysis), a picture of not only symptoms but the impact of those symptoms can be developed.¹⁰⁻¹² The study was approved by the Health and Disability Ethics Committee (20/NTB/28).

Sampling

To be included in the study participants needed to self-identify as New Zealand Māori, be over 16 years of age and have current clinical follow-up for middle ear disease through the Capital & Coast District Health Board (DHB), Hutt Valley DHB or Wairarapa DHB otolaryngology service.

Potential participants were identified using purposeful sampling¹⁰ by the two otolaryngology clinicians involved in the study. Initial invitation was by a clinical nurse uninvolved in the research, and those interested were provided with an information sheet and invited to be interviewed. Interviews were undertaken at a place and time convenient for the participant. Whānau attendance at interviews was encouraged. A written consent form was completed on the day of the interview.

A semi-structured interview schedule was designed based on the researchers' previous clinical experience with input from Māori. Interviews were conducted between April 2021 and December 2021 by a Māori clinical researcher (otolaryngology registrar). The interview process followed Kaupapa Māori-based principles, acknowledging the importance of te reo Māori (the Māori language) and tikanga (Māori culture) where appropriate, with an emphasis on whakawhanaungatanga (building relationships), and all participants were provided with a koha (gift) of grocery vouchers.¹³⁻¹⁵ Five participants were interviewed face-to-face and two by phone. All interviews were audio recorded.

The audio-recordings were transcribed verbatim,¹⁶ with researcher LB checking for correctness of te reo Māori words. The transcripts were analysed drawing off Braun and Clarke reflexive thematic analysis.¹⁷ Researchers familiarised themselves with the data, generated codes utilising NVivo (version 10 software) and developed and revised themes and sub-themes.¹⁶ Participants were offered their transcripts to review and are referred to below as P1-7. Recruitment stopped when the interview transcripts no longer revealed new themes.¹¹ This was cross-checked with the clinicians' own

extensive experience interviewing patients to clarify if any important themes may be absent.

Results

Participants were seven Māori adults residing in the Wellington region but with whakapapa (genealogy) to iwi (tribes) around Aotearoa New Zealand. Two additional individuals were invited but declined to participate. Six of the participants have experienced middle ear disease since childhood, with one having symptom onset in adulthood. All participants had undergone previous surgical intervention for their ear pathology and have ongoing symptoms requiring otolaryngology input. For participant demographics, see Table 1.

The data analysis revealed living with chronic middle ear disease impacts significantly on Māori patients and their whānau. Participants' quotations are presented in Table 2 and briefly in the text. Themes align with the Te Whare Tapa Whā model described by Sir Mason Durie.¹⁸ These themes are taha tinana (physical wellbeing), taha hinengaro (mental wellbeing), taha wairua (spiritual wellbeing) and taha whānau (family wellbeing). Additionally, there were themes involving interface with the healthcare system and the impact of the symptoms on education and work opportunities which relate to the Te Pae Māhutonga model, also described by Sir Durie.¹⁹

Taha tinana (physical wellbeing)

Participants reported that the physical symptoms left them feeling socially isolated, with particular emphasis on the smell from ear discharge (taringa pirau) and the hearing loss (taringa turi).

Hearing loss impaired communication, particularly in large groups, in the presence of background noise or on the phone, which is very isolating and mentally exhausting.

"I get mentally tired at the end of the day too because my head is trying so hard to listen to people and I just get brain fade." – P3

Participants described their suppositions about how others see them. They were often worried about appearing rude when not answering a question they had not heard or would feel unintelligent when repeating things that had already been said.

Table 1: Participant demographics.

	Age (years)	Sex
Participant 1	52	M
Participant 2	59	M
Participant 3	41	F
Participant 4	50	M
Participant 5	25	F
Participant 6	35	M
Participant 7	64	F

Table 2: Participant quotations.

Category	Quote
Tinana	
Taringa turi	<p><i>“I can’t hear them, and I get anxious about it [phone] ringing, like I can see it ringing there but I don’t want to pick it up just in case it’s something really important.” – P3</i></p> <p><i>“If we’re in a big social gathering and a big conversation is going on and everyone’s talking, I can’t participate. I can’t hear what’s going on properly.” – P4</i></p>
Taringa pirau	<p><i>“My infection was terrible in the sense of the smell. You could smell it. A lot of it was more embarrassing when I was at school.” – P2</i></p> <p><i>“I was that dirty little Māori child. Yeah. I had the cold sores, had the discharging ear. You know, I don’t think anybody really wanted to get close to me.” – P7</i></p> <p><i>“When you see that discharging, everybody goes, oh what’s wrong with your ear? And then it will dry up and leave like a resin on the outside.” – P2</i></p> <p><i>“Definitely had a lot of discharge when I was a kid. I was just, I was ostracised, I think. And I never.... I didn’t make friends.” – P7</i></p>
Hinengaro	<p><i>“And to lose all of those things it was actually, I was right down in my lowest, I bloody broke into tears because we were back where we started.” – P4</i></p> <p><i>“It makes me feel like a bit of an idiot when I know I’m not an idiot, I know what I’m talking about.” – P7</i></p> <p><i>“Personal things at home like the fire, we’ve got a beautiful big fireplace, to hear that wood crackling, the pinecones, you smell them but don’t hear them crackle no more.” – P2</i></p>
Wairua	
Te reo	<p><i>“And learning reo as well kind of gets difficult. Especially when I can’t wrap my hearing around what they’re actually saying; it might be ‘na’ instead of ‘nga’” – P5</i></p>

Table 2 (continued): Participant quotations.

Wai	<p><i>“I’ve always liked providing for the family and stuff, but it’s just the love of the deep. I went two years without going for a snorkel.” – P4</i></p> <p><i>“I always watch the boys go diving, I just hold the rope when they go down. So that’s as much as I get.” – P6</i></p> <p><i>“I love swimming and diving and I can’t go diving because of the hole in my eardrum. I just get middle ear infections all the time.” – P1</i></p> <p><i>“I would just beg to go swimming and of course then I’d end up with earaches crying my eyes out.” – P5</i></p>
Whānau	<p><i>“Being intimate with your partner, you don’t hear certain things. And you’re like oh what’s wrong with her? And she has said something to you, but you didn’t hear her. It can cause an argument.” – P2</i></p> <p><i>“Definitely always felt like I was on the outside. Definitely didn’t feel like I was included in anything. I was really very much on the outside of everything.” – P7</i></p>
Interface with health system	<p><i>“We fell off the radar for a little bit and tried to keep up with all the doctors and stuff and all the records throughout everywhere.” – P6</i></p> <p><i>“Na, you fullas have actually been quite good lately. Just that when I didn’t have any doctors or follow-up from my childhood to now was quite difficult.” – P6</i></p> <p><i>“Yeah, it never, never got picked up. They were in the system and the system just let them down every single time.” – P7</i></p> <p><i>“I spent like maybe eight months going to my GP before they decided to even refer me.” – P3</i></p> <p><i>“I kind of just wish it [surgery] was done earlier.” – P5</i></p> <p><i>“We can come here to as many appointments at the hospital as you want, but, you know, what would really benefit him would be one hearing aid that was decent, you know, it’s crazy.” – P1</i></p> <p><i>“Whakawhanaungatanga [connecting to each other] is really important. And they don’t even realise that it is important, you know what I mean?” – P7</i></p> <p><i>“From the time that I was referred, I feel like the service that I’ve had has been just outstanding ... when it comes to anything hospital related, I found that people know my history. You know, people ... know what questions to ask me.” – P3</i></p>

“People treated me a bit differently because of the fact that they thought I was, you know, dumb.” – P7

“I’d be around people who were like, what’s that smell. And I knew it was my ears.” – P5

One of the most common and distressing manifestations of middle ear disease is the recurrent episodes of taringa pirau. Participants all had a similar experience of being subject to bullying in childhood, reduced attendance at school and avoidance of social situations in later years.

Taha hinengaro (mental wellbeing)

Participants reported avoiding social situations as they are unable to participate in conversation. To counter the embarrassment and isolation, one participant relied heavily on alcohol at social events. Some participants found they became completely dependent on a partner or support

person to communicate on their behalf.

“People think I’m anti-social because I don’t go to the Christmas party and it’s just no good for me. I just sit there, and I get drunk.” – P4

Some participants reported becoming depressed and anxious from the culmination of the associated symptoms, the social and cultural restrictions and the chronic nature of the condition.

“I felt like I was losing myself and that’s why I was so upset, you know.” – P4

Taha wairua (spiritual wellbeing)

Several participants felt that their middle ear pathology and subsequent hearing loss made it difficult to learn or prevented them from learning te reo Māori, which impacted on their sense of cultural identity and ability to access Te Ao Māori.

“Then I was ignorant to the Māori language and ignorant to the Māori people.” – P2

Participants felt their condition prevented them from taking on certain cultural responsibilities such as kaikaranga or kaikōrero (welcoming and speaking on the marae) and dictated what position they held within their iwi, hapū (subtribe) and marae. Furthermore, as noted by one of the participants, kapa haka relies heavily on one’s ability to learn via listening.

“Na I just stay back with the crowd; I don’t get up and talk or anything.” – P6

“Do you think that might have been different?” – I

“Yeah definitely. If I knew how to talk, then I would be able to say something. Cos I’m not someone to sit back. But there’s other ways around it, you just go into the kitchen and just help out there.” – P6

“So, it changes what position you have on the marae?” – I

“Yeah.” – P6

For Māori, wai (water) forms the basis of many traditional cultural practices. Iwi, hapū and marae have intimate connections with certain bodies of water that represent their whakapapa. To be immersed in that water is a connection to their tūpuna (ancestors). Participants felt that one of the most significant consequences of suffering from middle ear disease was the inability to connect with water.

“We literally had a huge connection with the water. It was like everything you know.” – P7

Several participants reported an inability to gather kaimoana (seafood) because of their ear disease. This is often an important social and cultural activity, a way of spending time with friends and providing kai (food) for whānau and events such as tangihanga (funeral). Furthermore, not being able to provide kaimoana results in the added cost of having to purchase kai. Simple daily activities like having a bath or shower were a challenge.

“I mean, you can’t go diving with the boys who go out. Yeah, can’t go get kaimoana and all that sort of stuff. For like the tangi the other week and you can’t go with them.” – P1

“I do my best to keep my ear dry. Cos, I know that’s what causes the infections. So, what I always do when I’m having a shower or washing my hair is I just fold the top half of my ear over my ear.” – P1

The inability to swim is also a barrier to physical activity and can contribute to weight gain and general decline in physical and mental wellbeing.

“I missed out on all the fun of going swimming and all that sort of stuff. And also, the extra exercise I could get from swimming.” – P1

Some participants felt their wairua had been tampered with following surgery on the head or after having hair removed.

“You know, your head has been played with now and that to me blew me away. Having somebody go inside your head when you didn’t really have to.” – P2

“It was just the fact that they cut my hair ... that was my main problem, because I woke up and what was sitting on my chest was my hair.” – P5

Taha whānau (family wellbeing)

The condition and particularly the resulting hearing loss was reported as a cause of strain on relationships.

“And they are the same too, though they can’t hear either. So, we’re all yelling at each other. So, what ends up happening is we don’t, we just don’t because it’s just too much effort. But there’s other ways we interact and it’s like through kapa haka and singing and stuff.” – P3

Some patients have previously said they are unable to sleep in the same bed as their partner when their ear is discharging due to the smell. There was a significant impact on interpersonal relationships, deepening the feelings of isolation. One participant found that her hearing loss and otorrhea made it more difficult living away from her iwi and whānau support networks as it was more challenging to communicate and develop connections with local rōpū (groups), such as kapa haka.

Interface with health system

Consistent with findings in other medical research in Aotearoa New Zealand, all participants felt that there were multiple barriers to accessing treatment for their middle ear condition and several reported experiences of being subject to racism.^{20,21}

“We often got treatment like, well, you know, what do you expect, you are fat and black.” – P1

“It’s because I look Pākehā that I’ve been able to get more or better accessibility.” – P7

Participants recalled challenges navigating the health system due to location changes and an inflexible disconnected system creating challenges for continuity of care with a chronic health condition. Lack of funding for hearing aids was a common complaint.

Participants reported the effects of a lack of connection with individual healthcare providers

(whakawhanaungatanga), which was detrimental to the therapeutic relationship. Some felt they were not listened to or taken seriously, leading to a delay in referral. Conversely, positive relationships in healthcare settings made a big difference.

Education and work opportunities

The chronic nature of the condition combined with symptoms of hearing loss and ear discharge impacted on participants’ ability to benefit from education. Some recalled the embarrassment of the smell made them reluctant to attend school. This also affected work opportunities and work relationships.

Discussion

The results of this study demonstrate that middle ear disease has a profound impact on the quality of life of adult Māori, in addition to far reaching effects for their whānau. The implications are devastating and complex, ranging from physical manifestations that cause social anxiety and withdrawal from culture and community, to impacts on mental health and wairua that result in disconnection from one’s identity.

Of the physical symptoms experienced, hearing loss and otorrhea had the most profound impact on quality of life. The mental exhaustion associated with hearing loss has been previously described.²² Hearing loss and otorrhea frequently resulted in social isolation, embarrassment and discrimination. A study of a Nepalese population suffering from middle ear disease showed that all individuals experienced and feared the stigma associated with their ear condition.⁹ The invisible disability of hearing loss combined with the social stigma of the discharge can mean this suffering is hidden. This potentially limits collective health advocacy of individuals experiencing this condition.

While most research quality of life tools designed for middle ear disease have otorrhea and hearing loss as data points, this study shows the shocking depth and breadth of the symptom impact, often with far reaching consequences from childhood to adulthood. Many physicians might describe ear discharge as a minor annoyance, especially if intermittent, not reflecting the patient’s experience. Therefore, both in clinical practice and in research, more significance needs to be given to this symptom. The sense of isolation, challenges connecting with others and shameful feelings about symptoms influenced the

mental wellbeing of patients. It was common to experience the sense of losing one's identity as a result of the condition, as individuals were often unable to engage in recreational, social and cultural activities that previously defined them.

Several patients felt that their condition had either prevented them from or made it very difficult to learn te reo Māori, and in some situations deterred them from taking on cultural responsibilities and privileges such as gathering kaimoana for tangihanga and speaking on the marae. This can cause a loss of right that may result in abdication of important responsibilities to other family members and subsequent implications for that individual's tamariki.

In Te Ao Māori, water is the essence of life and represents the blood of Papatūānuku (the earth mother).²³ Patients with middle ear disease who expose their ears to water risk infection of the mucosa, resulting in purulent and malodorous discharge. Most participants reported that the inability to enter and connect with water was one of the most significant consequences of middle ear disease.

Certain aspects of middle ear disease and the treatment were noted to have deeper influences on the individual's wairua. Surgery on the head and cutting of hair resulted in a violation of tapu (sacred/prohibited) for some individuals. It is important to consider carefully what to tell Māori patients about upcoming treatment such as surgery and what to expect in the postoperative period. Cultural safety training, including developing local hospital policies, e.g., tikanga guidelines, will be important to foster a safe place for Māori in all wellbeing domains.^{24,25}

The higher rates of middle ear disease in Māori are likely related in part to long reaching effects from colonisation.²¹ The results suggest that middle ear disease can result in further disconnection from Te Ao Māori, poorer educational and work opportunities and subsequently lower socio-economic status and poorer health outcomes. Exclusion from schooling when ears are leaking and isolation from peers due to hearing loss can have far reaching long-term impacts on affected individuals. Furthermore, the ear condition often resulted in strain with personal or work-based relationships.

The inequities that exist in access to healthcare for Māori due to colonisation, marginalisation and institutional racism are widely known. The culturally unsafe environment of our healthcare systems contributes to the significant disparities

in health outcomes for Māori.²¹ Participants reported challenges with the health system interface, providing further evidence of these inequities. While the study participants proved resilient and were able to access care, often through perseverance, there are without doubt many Māori in the community with active middle ear disease that have been unable to navigate the healthcare system to access treatment.

Funding models for hearing aids leave many with out-of-pocket significant expense, or worse still, no access to unaffordable devices. As childhood middle ear disease is not considered permanent, some adults no longer had access to fully funded hearing aids, especially if they were not able to access them as children. These system issues represent an example of institutional racism which is not responsive to the needs of Māori.

Culturally safe practice should inform shared decision-making and advocacy for policy improvements. Clinicians and health systems that understand the significance of symptoms of common ear disorders can be better placed to prioritise these appropriately. This may include earlier referrals, higher triage scores for specialist services/surgeries and types of operations that support the goals of the patient, such as return to water-based activities. Understanding the personal and cultural importance of these goals can inform practice.

A strength of the study is it provides detailed information on the impact of middle ear disease for Māori and the health inequities that exist across multiple domains. The study used a Māori cultural lens to consider wider wellbeing (hauora), enabling the voice of Māori in a common condition. This research is part of an effort to re-imagine the evidence infrastructure used to inform policy and decision making by including patient experiences. Prior to this study there was a paucity of qualitative information available regarding the experiences of Māori with middle ear disease.

Due to the lack of qualitative research in middle ear disease, comparisons with other groups were not possible in this study. We might infer there is likely to be some overlap with other groups; however, the implications on status within hapu and marae, spiritual connection with water and violation of tapu during surgery may well represent true differences. Further research into other ethnic and social groups with middle ear disease would be interesting.

We acknowledge that the researchers have prior clinical and personal experience that has influenced the formation of methodology and thematic analysis.

We interviewed only a small number of Māori, all with different backgrounds, whakapapa and connection to Te Ao Māori, and caution is needed in generalising these findings to all Māori. However, the study provides valuable insights on the impacts of hearing loss on the lives of indigenous and New Zealand adults, populations understudied in this area. We acknowledge those not included in the study, whose experiences may

be different, including those with unmet need and those who have completed treatment.

Qualitative research has an important role in informing quantitative research to measure appropriate variables. By nature, it uses small sample sizes to gather the depth and significance of experiences. This informs quantitative methods such as surveys and disease-specific quality of life tools giving importance to the patient voice.^{10,11,12} This research is particularly relevant with Māori whose experiences may differ from the majority of clinicians, policy makers and researchers.

COMPETING INTERESTS

Nil.

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AUTHOR INFORMATION

Dr Lance Buckthought: Otolaryngology/Head & Neck Surgery Registrar, Department of Otolaryngology/Head & Neck Surgery, Te Whatu Ora – Waitaha Canterbury, Christchurch, Aotearoa New Zealand.

Jeannine Stairmand: Cancer and Chronic Conditions Research Group, Te Rōpū Rangahau Hauora a Eru Pōmare, Department of Public Health, University of Otago, Wellington, Aotearoa New Zealand.

Dr Rebecca Garland: Otolaryngologist, Department of Otolaryngology/Head & Neck Surgery, Te Whatu Ora – Capital, Coast and Hutt Valley, Wellington, Aotearoa New Zealand.

CORRESPONDING AUTHOR

Dr Lance Buckthought: Otolaryngology/Head & Neck Surgery Registrar, Department of Otolaryngology/Head & Neck Surgery, Te Whatu Ora – Waitaha Canterbury, Christchurch, Aotearoa New Zealand.
E: lance.buckthought@gmail.com.

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