

Māori and Pacific peoples' experiences of a Māori-led diabetes programme

Taria Tane, Vanessa Selak, Kimiora Hawkins, Vanita Lata, Jonathan Murray, DeAnn Nicholls, Amelia Peihopa, Ngaraiti Rice, Matire Harwood

ABSTRACT

AIM: Type 2 diabetes mellitus (T2DM) disproportionately affects Māori and Pacific peoples in Aotearoa (New Zealand). Despite this, the lived experiences of T2DM and its management by Māori and Pacific peoples are scarcely acknowledged in health literature. The present study examines the lived experiences of T2DM by Māori and Pacific participants in the Mana Tū diabetes programme. Mana Tū is a Māori-led diabetes support programme co-designed by the National Hauora Coalition (NHC) alongside patients with diabetes, clinicians, health service planners and whānau ora providers.

METHOD: The study used qualitative methods underpinned by Kaupapa Māori (Māori approaches) approaches. Twenty-two semi-structured interviews were conducted with participants of the Mana Tū diabetes programme and their whānau (thirteen Māori, 9 Pacific) from Tāmaki Makaurau (Auckland) and Te Tai Tokerau (Northland).

RESULTS: The study identified barriers, facilitators and motivators for participants to live well with T2DM. Four key themes were constituted: (1) whānau experience of T2DM, (2) cultural safety in healthcare interactions, (3) whānau ora (collective family wellbeing) and (4) Kaupapa Māori approaches to health interventions. Themes were consistent across Māori and Pacific participants.

CONCLUSION: Findings suggest that Māori-led health interventions can better support Māori and Pacific people living with T2DM and are needed to ensure these communities receive appropriate, responsive and equitable healthcare.

Type 2 diabetes mellitus (T2DM) disproportionately affects Māori and Pacific peoples in Aotearoa.^{1,2} Māori, Pacific and people living in high socioeconomic deprivation experience significant inequities in the incidence of this condition and the associated complications, hospitalisations and mortality.^{2,3} Māori and Pacific peoples are also diagnosed at a younger age, which leads to an earlier onset of diabetes-related complications, and diabetes contributes to the shorter life expectancy of Māori and Pacific peoples compared with non-Māori, non-Pacific.⁴ Current health service approaches to reduce these inequities focus on early detection and the medical management of diabetes.⁵ These approaches largely take place within primary healthcare settings, with the intention of reducing the burden on secondary care services.⁶ Despite these attempts, there is a lack of evidence that healthcare

interventions within primary care settings are effective at enhancing equity for Māori and Pacific peoples living with T2DM.⁵

Internationally, culturally responsive health interventions have shown promising results in the prevention and management of T2DM.⁷⁻⁹ In Aotearoa, culturally responsive health interventions for Māori with diabetes and their treatment need to acknowledge a complex set of factors, including the social determinants of health, the cultural incompetence of many health practitioners and institutional racism in health (and other) service settings.^{10,11} For Māori, as for other Indigenous peoples, these factors are all by-products of colonisation and intergenerational/historical trauma.^{10,11} Effective interventions purposefully deploy decolonising Kaupapa Māori attributes such as tikanga Māori (traditional Māori customs), mātauranga Māori (traditional Māori

knowledge), kaupapa Māori (Māori values of traditional knowledge), whānau ora (whānau wellbeing in relation to individual wellbeing) and traditional methods of healing based on interconnected relationships, spirituality and psychological, physical and social factors.^{10,12,13} Similarly, health interventions that centre holistic wellbeing, collective responsibilities, identity and cultural values have been shown to be responsive in Pacific communities too.³⁵

Mana Tū, a whānau ora approach to long-term conditions, is a Māori-led, Kaupapa Māori approach to supporting people living with poorly controlled T2DM and their wider whānau (family members).¹⁴ Mana Tū (which means “to stand with authority”) uses a decolonised approach that positions whānau to stand with authority while living with a long-term condition. Kai Manaaki (skilled case managers who are embedded within primary care) are a core feature of Mana Tū. Kai Manaaki provide a “walk alongside” approach to case management to support diabetes self-management in Māori and Pacific peoples living with poorly controlled T2DM (defined as HbA1c>64mmol/mol).¹⁵

Little is understood about the experiences of Māori and Pacific peoples living with T2DM or their experience of health interventions.⁶ This gap in knowledge situates a qualitative exploration of their lived experiences nicely. This study aims to explore how participants in the Mana Tū programme construct and give meaning to their experiences navigating health and social services in Aotearoa, as well as their experiences living with T2DM and their journey in the Mana Tū programme.

Methods

This study used a qualitative Kaupapa Māori approach to undertake and analyse data from semi-structured interviews with participants of the Mana Tū diabetes programme in Auckland and Northland and their wider whānau.

Methodology

This study applied Kaupapa Māori approaches, foregrounding Māori ways of being and understanding, recognising the impact of colonisation on hauora Māori (Māori wellbeing), legitimising mātau-

ranga Māori and situating participants as experts of their own past, present and future hauora.^{16,18,19} Utilising Kaupapa Māori approaches was fundamental to the direction of this study, as it appropriately aligned with the wider conduct of the Mana Tū programme (Kaupapa Māori, Māori-led and whānau-ora-based). Steps were taken to ensure that the Kaupapa Māori research approach taken here was “safe” for both Māori and Pacific participants. First, the inclusion of Pacific expertise occurred at each step of research, including consultation, data collection and analysis.³⁷ Second, we created a “negotiated space” where the relationships between distinctive worldviews were expanded.³⁶ Finally, the “give way rule”¹⁹ was established at the outset for any cultural interpretations needed that involved our Pacific participants, although it was not required. Deploying the give way rule from the outset allowed for a pathway by which the research team could call upon a Pacific research advisor to appropriately decide on the cultural interpretation of an event, incident or story.¹⁹

Participants

Actively enrolled participants of the Mana Tū programme and their wider whānau members were invited to participate in semi-structured qualitative interviews with the author (TT). Fluency in English was required for participants to take part in the interviews, but a language interpreter option was offered to participants whose first language was not English. Interviews were conducted and transcribed in English and te reo Māori (where used). Participants were recruited through Mana Tū Kai Manaaki caseloads, and interviews took place across the Northland and Auckland regions. Participants were offered to invite their Kai Manaaki to attend the research interview as an additional support person, if desired.

Data collection

Semi-structured, qualitative interviews were carried out by the author (TT) and focussed on three areas in the construction of lived experience:

- experiences of navigating health and social services in Aotearoa
- experiences of disease burden
- experiences of the Mana Tū programme.

Interviews were conducted at a location chosen by participants, predominantly their homes or in a private room at their local general practice clinic. Kaupapa Māori approaches, which emphasised whakawhanaungatanga (building connections and relationships), whanaungatanga (strengthening relationships and connections), karakia (prayer) and koha (acknowledgments), were utilised during engagement with participants. Interviews lasted an average of 30 minutes (ranging from 20 minutes to 90 minutes) and were conducted until data saturation was reached.

Data analysis

Interviews were audio recorded by the author with the permission of the participant and any whānau members present. Recordings were first transcribed by TT in an orthographic style. Transcripts were regularly reviewed by members of the research team at the time and discussed with TT in research hui (meetings). During these hui, initial coding, themes and positionality of TT were explored from the perspectives of the wider research team and were used to guide subsequent interviews and analysis. Transcripts were sent to participants, who were invited to contact the research team to discuss or request any changes to their interview transcripts.

Thematic analyses were used to explore participants' lived experiences of T2DM and taking part in Mana Tū. Initial coding was generated by TT using both inductive and deductive approaches.²⁰ Following the initial coding, broader themes were then produced and discussed with the wider research team. NVivo12 software was used to assist with coding and storage of the transcripts.

All identifying information, such as names and locations, were removed to maintain anonymity. Only generic demographics, such as gender, ethnicity and rurality of their location within their district health board (DHB), are included in Table 1 to provide context to responses.

Research team

The immediate research team at the time of data collection and analysis was comprised of the lead investigator (MH), research manager and programme manager (TT) of the wider Mana Tū study. The lead

investigator identifies as a wāhine (female) Māori (Ngāpuhi) and is a prominent Māori health researcher in Aotearoa. The lead investigator provided overall guidance and oversight to the study and data analysis. TT, also a wāhine Māori (Te Roroa, Ngāpuhi) was responsible for conducting the qualitative interviews and led the interpretation of findings. TT took part in reflexive journaling throughout the research process, which assisted her in contextualising how she situated herself within the research and interpreted the lived experience of participants.

Ethics approval and registration

Ethics approval was obtained from the New Zealand Health & Disability Committee (reference: 17/NTB/249/AM02). The wider Mana Tū study was registered with the Australian and New Zealand Clinical Trials Register (reference: ACTRN12617001276347).

Results

Participants

A total of 32 participants were interviewed, including twenty-two actively enrolled participants of the Mana Tū programme and 10 of their whānau members.

Demographics were collected on actively enrolled Mana Tū programme participants only. All Mana Tū participants who were interviewed self-identified as Māori and/or Pacific, and 13 out of the 22 Mana Tū participants identified as female (see Table 1 for participant demographics). The mean age of participants was 58 years. The whānau members described themselves as carers, siblings, children, grandchildren, or spouses to the Mana Tū programme participants.

Themes

Narratives were largely centred around their lived experience of T2DM within the Aotearoa healthcare system, the importance of cultural safety in healthcare interactions, whānau ora (collective family wellbeing) and Kaupapa Māori approaches. These narratives were grouped into the following key themes:

- Whānau experience of T2DM
- Feeling culturally safe
- Whānau ora
- A Kaupapa Māori approach

Table 1: Mana Tū participant demographics.

ID	Participant gender	Participant DHB	Ethnicity
1	F	Semi-urban	NZ Māori
2	F	Semi-urban	Cook Island Māori
3	F	Rural	NZ Māori
4	F	Rural	NZ Māori
5	M	Rural	NZ Māori
6	F	Rural	NZ Māori
7	M	Urban	Samoan
8	F	Urban	Samoan
9	F	Urban	Samoan
10	F	Semi-urban	NZ Māori
11	F	Urban	NZ Māori
12	M	Semi-urban	Samoan
13	F	Semi-urban	Niuean
14	F	Urban	NZ Māori
15	M	Semi-urban	Tongan
16	M	Urban	NZ Māori
17	M	Urban	NZ Māori
18	M	Urban	NZ Māori
19	F	Semi-urban	NZ Māori
20	F	Semi-urban	NZ Māori
21	M	Urban	Fijian
22	M	Urban	Tongan

M: Male. F: Female. NZ: New Zealand. DHB: District health board.

Key elements of each of these themes are described below.

Whānau experience of T2DM

The presence and impact of T2DM in conjunction with other illnesses was significant and experienced across multiple generations. Participants described the intergenerational burden of T2DM and felt overwhelmed by the enormity of disease in their whānau, to the point where T2DM was somewhat normalised. Participants also acknowledged the presence of T2DM within their whānau as a key motivator for them to participate in Mana Tū. Mana Tū Kai Manaaki were viewed as facilitators who supported participants through grief and challenges associated with T2DM.

“We lost four of our young ones. Not through suicide but being obese. Uncontrolled diabetes. Yeah, so I had a bit of a sad patch, which I suppose this programme Mana Tū came in handy, you know? [Kai Manaaki] was here for the first couple of weeks going, ‘oh, come on. You can do this!’”
– Female, urban New Zealand Māori

The presence of T2DM in whānau often motivated participants to learn about the condition, engage in condition-related knowledge sharing with their wider whānau and become role models for good self-management. Motivators were spoken about as both positive (seeking life longevity) and negative (fearing complications of T2DM and death).

“They’re still well and kicking you know, driving around, walking around in their mid-80s, turning 90s. So, they must be doing something right. I just sort of use them as examples. If they can live a long life by doing all the right things, you know, then I’m sure I can.” – Male, urban Samoan

Feeling culturally safe

Participants experienced both positive and negative interactions with healthcare professionals when seeking healthcare support related to T2DM. Negative interactions were often experienced when engaging with health professionals who had different cultural backgrounds, particularly Pākehā (New Zealander of European descent) doctors. Negative experiences often

made participants and their wider whānau members feel judged, misunderstood and inferior, which led to distrust and disconnection from healthcare services. Culturally safe engagement within healthcare settings was highly valued by participants and their wider whānau members because it provided a pathway for meaningful connection and mutual understanding of their native language, cultural worldview and sociocultural lived experience.

“The only thing different they [health professionals] can do is more like this lady here [Kai Manaaki]. Get the right approach. Get someone who can connect. They [whānau] want to speak with someone who speaks their [the patient’s] language for starters, who knows their [the patient’s] culture. And I think that if they want to start getting a bit more targeted in their [the health services] treatment of diabetes, that’s what they need to look at.” – Male, urban New Zealand Māori

Kai Manaaki were often described as drivers of culturally safe engagement in Mana Tū visits and during consultations between participants and their healthcare providers. Kai Manaaki attending healthcare appointments alongside participants meant that cultural needs and aspirations could be communicated more effectively. Kai Manaaki could advocate for participants entitlements and disrupt any unequal power relations that would normally exist in these environments.

“I respond a lot to Māori because they know how Māori people, especially old, and the ways that we sit.”
– Female, rural New Zealand Māori

The intersections between health, culture and social contexts were noted by some participants who spoke about feeling that the wider social contexts influencing health events were not considered by some Pākehā health professionals. Participants valued the understanding of these contexts and support offered by Kai Manaaki, which extended to the wider whānau.

“She [Kai Manaaki] helped me without being pushy or you know. Because some people, Pākehā get pushy. Sorry for saying that. But you

know, they get pushy and then they just dump you when they can't make you do something. They just dump you. Whereas [Kai Manaaki 1] and [Kai Manaaki 2] don't. Even with my sister. [Kai Manaaki 2] will say, 'oh, next time we will come out and visit her.' And she's always better after [Kai Manaaki 2] calls in." – Female, urban New Zealand Māori

Whānau ora

Whānau ora (collective family wellbeing) was viewed by most participants as a critical success factor of the Mana Tū programme, as it allowed participants and their wider whānau to navigate health and wellbeing goals as a collective group. This collective navigation strengthened participant support systems, allowed for small and achievable changes over time and improved holistic wellbeing for the collective whānau.

"I think it was perfect timing because when [Kai Manaaki] came on my aunty was staying with me during that time and I think it was the way in which [Kai Manaaki] approached it. Instead of excluding my aunty, she actually included her. So that, and my aunty found it really beneficial for herself. So, it has had that rippling effect for her as well because she even appreciated those visits." – Female, urban New Zealand Māori

Participants also spoke of the collective responsibility their whānau members had in supporting and caring for them. This responsibility was seen as an unconditional and natural obligation in the collective whānau journey to live well and often meant that younger whānau members would step into carer roles for their elders.

"I don't know if there was some kind of way that whānau like ours, like our whānau, who have had to at the end of the day come together and take responsibility and put all these things in place to help support mum's health, you know, to support her health from here on. I don't quite know what that might look like because I've had to give up full-time work to move back home you know, to come home." – Whānau member of female rural New Zealand Māori

A Kaupapa Māori approach

Many Māori and Pacific participants valued the ability to explore and focus on domains of wellbeing beyond physical health in the Mana Tū programme through its Kaupapa Māori approach. This often included a focus on taha wairua (spiritual health), taha hinengaro (mental health) and taha whānau (family health).

"Also having a Māori is important for me. Coz' they kind of understand the cultural element of things as well, and also the spiritual aspect of health. Both cultural and religious has been good. So, she understands me with that. So, you know, having those common beliefs, those common things definitely helps. It's very supportive." – Male, urban New Zealand Māori

This extension beyond the physical health domain applied to goal-setting activities carried out during Mana Tū visits, where participants and their wider whānau often focussed on goals associated with social connection and spiritual and mental wellbeing.

"Nah, it's been great, the goals I've been setting. I've achieved most of them. Not only health but socially and personally." – Female, semi-urban New Zealand Māori

Both health and social outcomes were viewed by participants as interwoven into their holistic wellbeing. For some participants, seeing their Kai Manaaki actively address social outcomes was important to maintaining their wellbeing. Additionally, participants and wider whānau members commented on the various barriers that impede navigation of the social care system.

"[Kai Manaaki] would go and do things for him at social welfare that was a lot lifted off his shoulders you know. He didn't have to go but [Kai Manaaki] did it for him and it was so helpful. We couldn't believe it when she went to social welfare, and she'd come back straight away. We'd be like, 'how did she do it so fast?' If I was to go there I'd be sitting in the queue and waiting for hours and hours, which I have experienced." – Whānau member of male semi-urban Tongan

Discussion

These findings highlight the challenges still faced by Māori and Pacific peoples living with T2DM in Aotearoa and provide a lens for system-reflection on how Māori-led approaches can tackle inequities and better support Māori and Pacific peoples to live well with long-term conditions.

T2DM had a significant impact, was widespread and had an intergenerational presence in whānau of the participants, to the point where the experience of T2DM was inevitable and normalised. The presence of T2DM often motivated participants to learn about the condition and model good self-management behaviours. The challenges faced by participants and their whānau in relation to disease burden was clearly evident across interviews and replicate the challenges experienced by Māori and Pacific peoples in other long-term conditions.²¹ The mana-enhancing support provided by Kai Manaaki was highly valued by participants in their journey to live well. This finding is consistent with similar models of care delivered in primary and community care levels.³⁴

Low levels of cultural safety in interactions with health professionals were a deterrent from the healthcare system. Mana Tū was seen as a model example of a culturally responsive programme that enhanced connections between Māori and Pacific peoples and the healthcare system. The cultural responsiveness of Kai Manaaki in their practice was seen as critical to establishing a trusted connection with participants. These findings are consistent with evidence that reinforces the importance of language and cultural identity in the healthcare setting.^{22–23} Participants also acknowledged cultural barriers with Pākehā health professionals, which may allude to segmentation of biomedical models and socially insular Western medical paradigms.²⁴

The concept of “whānau ora” in this analysis is seen as an approach that focusses on improving the wellbeing of whānau as a collective group, rather than solely working with an individual alone.²⁵ The focus on whānau ora in Mana Tū enhanced social support structures and drove positive ripple effects in wider whānau outcomes. Mana

Tū provided a pathway for participants to navigate their journey towards living well, as a collective. Wider whānau care and support in managing T2DM was seen as an unconditional responsibility of the collective whānau group and fundamental to participants living well. Children often stepped into informal carer roles when supporting their elders living with T2DM, reinforcing traditional Māori care customs and values.²⁶ The intergenerational duty of care between younger whānau members and their elders was seen as natural. It revitalised pre-colonial Māori social support structures that help the collective thrive.^{27–28}

Kaupapa Māori approaches are designed to address social injustices and achieve equity, revitalise Māori cultural values and practices and transform peoples' lives in positive ways.^{29–30} Kaupapa Māori approaches require Māori leadership not only to deconstruct colonising systems and processes, but also to reconstruct these systems in a decolonising manner. Kaupapa Māori approaches used in Mana Tū supported participants and their whānau to explore aspects of their wellbeing external to physical health. This holistic approach saw taha wairua (spiritual wellbeing) as a prominent narrative and central to whānau healing. The Kaupapa Māori approaches used also appeared to have benefits for both Māori and Pacific participants, which demonstrates the multi-cultural responsiveness of the programme.

For both Māori and Pacific participants, actively addressing social issues in Mana Tū helped to reduce social stressor barriers that may have impeded their health while simultaneously highlighting discrimination faced by some who navigate health and social services in Aotearoa. This recognition of wider social contexts allowed a better understanding of the impact wider social contexts have on physical health.³¹ Understanding sociocultural contexts that can impact health is particularly important for Māori, who have been significantly marred by the impacts of colonisation and are still suffering from social injury.³²

The concepts revealed in this research highlight the benefits of a Kaupapa Māori approach for both Māori and Pacific people living with T2DM and reinforce the need for more culturally tailored and targeted

health interventions in Aotearoa. To adequately address these inequities, interventions need to respond to the complex needs and issues experienced by Māori and Pacific peoples. Achieving equitable outcomes in Aotearoa is critical to ensuring that the future is one where all Māori and Pacific whānau thrive, live well and live long. Lastly, the perspectives of Māori and Pacific communities where health interventions are delivered should be actively and consistently incorporated in all service

delivery designs and analyses in Aotearoa, to ensure programmes are culturally safe and fit for purpose.

This analysis is timely, given the lack of prior research privileging the qualitative accounts of Māori and Pacific participants' experiences within a Māori-led diabetes programme and the recent announcements regarding the initiation of the New Zealand Māori Health Authority and Iwi-Māori Partnerships Boards as health service commissioners.³³

Competing interests:

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Author information:

Taria Tane: Independent Researcher, Ora Project Solutions: Te Tai Tokerau Northland.

Vanessa Selak: Senior Lecturer, Section of Epidemiology & Biostatistics, University of Auckland: Tāmaki Makaurau.

Kimiora Hawkins: Mana Tū Kai Manaaki,

Whangaroa Health Services: Te Tai Tokerau Northland.

Vanita Lata: Mana Tū Kai Manaaki,

Tāmaki Family Health Centre: Tāmaki Makaurau Auckland.

Jonathan Murray: Leader, Primary Health Network,

National Hauora Coalition: Tāmaki Makaurau Auckland.

DeAnn Nicholls: Mana Tū Kai Manaaki,

Papakura Marae Health Clinic: Tāmaki Makaurau Auckland.

Amelia Peihopa: Mana Tū Kai Manaaki,

The Drs New Lynn: Tāmaki Makaurau Auckland.

Ngaraiti Rice: Kaiwhakamana, Here Toitū,

National Hauora Coalition: Tāmaki Makaurau Auckland.

Mature Harwood: Associate Professor, School of Population Health,

University of Auckland: Tāmaki Makaurau.

Corresponding author:

Taria Tane, Independent Researcher, 148A Awakino Road, Dargaville, +64210600025

Taria@oraprojectsolutions.co.nz

URL:

www.nzma.org.nz/journal-articles/maori-and-pacific-peoples-experiences-of-a-maori-led-diabetes-programme

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