



Are patients with type 2 diabetes in the Waikato District provided with adequate education and support in primary care to self-manage their condition? A qualitative study

Rebekah Crosswell^{A,*} , Kimberley Norman^A, Shemana Cassim^{A,B}, Valentina Papa^C, Rawiri Keenan^A , Ryan Paul^D and Lynne Chepulis^A

For full list of author affiliations and declarations see end of paper

*Correspondence to:

Rebekah Crosswell
Waikato Medical Research Centre,
University of Waikato, Te Huataki Waiora,
School of Health, Private Bag 3105,
Hamilton 3240, New Zealand
Email: rebekah.crosswell@waikato.ac.nz

Handling Editor:

Tim Stokes

Received: 1 November 2023

Accepted: 2 February 2024

Published: 4 March 2024

Cite this:

Crosswell R *et al.*
Journal of Primary Health Care 2024;
16(1): 61–69.
doi:[10.1071/HC23141](https://doi.org/10.1071/HC23141)

© 2024 The Author(s) (or their employer(s)).
Published by CSIRO Publishing on behalf of
The Royal New Zealand College of General
Practitioners.

This is an open access article distributed
under the Creative Commons Attribution-
NonCommercial-NoDerivatives 4.0
International License ([CC BY-NC-ND](https://creativecommons.org/licenses/by-nc-nd/4.0/))

OPEN ACCESS

ABSTRACT

Introduction. In Aotearoa New Zealand (NZ), type 2 diabetes (T2D) is predominantly managed in primary care. Despite established guidelines, patients are often suboptimally managed, with inequitable health outcomes. To date, few NZ studies have evaluated the primary care management of T2D at the time of diagnosis. **Aim.** This study aims to explore the provision of education and delivery of care to patients at the time of diagnosis, which is a crucial time in the disease trajectory. **Methods.** Participants were recruited from a Māori health provider in the Waikato District, and diagnosed with T2D after January 2020. Patients were texted a link to opt into a survey (larger study) and then registered interest by providing contact details for an interview (current study). Semi-structured interviews were conducted and were audio recorded, transcribed, and thematically analysed. **Results.** In total, 11 participants aged 19–65 years completed the interviews (female $n = 9$ and male $n = 20$); the comprised Māori ($n = 5$), NZ European ($n = 5$) and Asian ($n = 1$) participants. Three overarching themes were identified, including: (1) ineffective provision of resources and education methods; (2) poor communication from healthcare practitioners; and (3) health system barriers. **Discussion.** Evidently, there are difficulties in primary care diabetes mellitus diagnosis and management. Improvements could include locally relevant resources tailored to patients' experiences and cultural identities. Utilising whānau support and a non-clinical workforce, such as health navigators/kaiāwhina, will drastically address current workforce issues and assist patient self-management. This will allow improved diagnosis experiences and better health outcomes for patients and whānau.

Keywords: communication, diagnosis, healthcare education, primary health care, self-management, type 2 diabetes.

Introduction

Type 2 diabetes mellitus (T2D) is a serious chronic condition, where the economic, physical, and psychological burden is high.¹ In Aotearoa New Zealand (NZ), T2D currently affects approximately 300 000 people, leading to high rates of morbidity and mortality.² Māori and Pasifika populations are disproportionately affected, with Māori being 2.5-fold more likely to receive a diagnosis of T2D than non-Māori,^{3,4} and more likely to be diagnosed at an earlier age.⁵ Māori and Pacific people are also more likely to experience poorer glycaemic control and long-term complications.³ In NZ, the management of T2D is largely delivered by primary healthcare providers.⁶ Adequate education and supportive care to manage diabetes in primary care and patients' daily lives is paramount, particularly at diagnosis.⁷

The diagnosis of T2D can be an emotionally overwhelming experience, where patients are likely to feel a sense of shock, anger, and denial.⁸ Patients are faced with making a multitude of complex decisions and adjustments to their lives regarding medication use, nutrition, physical activity, and lifestyle changes.⁹ To achieve optimal outcomes, patients

WHAT GAP THIS FILLS

What is already known: Diagnosis of type 2 diabetes is a challenging time, where healthcare professionals must consider health literacy, previous medical history, whānau, finances, and psychosocial factors. Current research states the treatment in primary care is suboptimal, compounded by clinical inertia, and that appointment times of 15 min are typically not long enough for sufficient diagnosis and treatment.

What this study adds: The current system of educating and supporting patients in primary care is viewed by patients as unsuitable in terms of appointment times, education, and communication. Graphic, conversational, or imagery-based education methods are preferred to pamphlets, and written sources of information that are tailored to the individual are needed, and must reflect cultural context. More support is required in terms of healthcare practitioners' relationships and culturally safe and compassionate patient care.

should be provided with social, emotional and educational support from as early as possible.

Good communication between healthcare practitioners and patients is required for optimal outcomes,^{10–13} particularly with general practitioners (GPs), who are predominantly the first point of contact at diagnosis. Additionally, practice must be culturally safe (as per the New Zealand Medical Council Guidelines),¹⁴ for shared decision-making and to engage patients and whānau in their own health care, to achieve more equitable health outcomes.¹⁵ At the time of diagnosis, T2D management initially relies on information provision.¹⁶ Education is centred around providing effective coping skills, as well as self-management behaviours, possible complications, and pharmaceutical advice where relevant.¹⁶ However, although the role of education in T2D care has been explored previously, both in NZ^{7,13,17,18} and overseas,^{19–21} patient education and care experiences of being diagnosed with T2D in primary care needs to be further explored. Thus, the current study examines whether primary care in NZ adequately prepares those newly diagnosed with T2D diabetes with education and management advice provision to cope with their condition independently.

Methods

Data collection

This qualitative study was part of a larger T2D management in primary care research project and participants were recruited in one of three ways. First, patients with T2D who completed a survey about their diagnosis experience¹⁸ were invited to participate in an interview. Second,

advertising using electronic posters on 'Diabetes NZ'²² social media platforms and networks were circulated, which invited participants to contact the researcher to volunteer to take part. Third, a snowballing strategy was utilised,²³ whereby participants were invited to tell anyone they knew who might like to participate to contact the researcher, RC. Potential participants were all given an information sheet that outlined the purpose of the study, and any concerns or questions were discussed and answered before consent was given. Once participants had agreed to take part, a suitable interview time and location was organised for interviews, which were held at the participants' convenience (either at the participants' house, or via Zoom). A Māori interviewer was involved in carrying out all interviews (RC). The multi-disciplinary research team included a Māori advisory group (made up of clinicians and academics) to ensure the Māori participant data were collected, analysed, and presented in a culturally safe way.

Procedure

Interviews were conducted using an interview guide consisting of open-ended semi-structured questions (see [Appendix 1](#)). Participants were encouraged to speak about their experience of education and health provision in primary care and expand on their narratives as the conversation naturally evolved. A participant information sheet explaining the purpose of the study was provided before the interview stage, explaining the purpose of the study and further instructions were given to the participant for their own use. At the beginning of each interview, the objective of the study was verbally re-stated, and participants were reminded they could end the interview at any time. Before commencement of the interviews, participants were offered culturally appropriate ways to open the meeting, such as inōi (prayer) or kārakia (Māori incantation). Interviews were conducted face-to-face (kanohi te kanohi) at a location of the participants' choice or via Zoom, and all interviews were audio-recorded. Interviews lasted between 15 and 60 min. All participants were given a NZ\$50 gift card and kai (food) was provided if the meeting was conducted in person, as an appreciation and to recompense participants for their time.

Analysis

All interview data were transcribed using transcription software (otter ai) and checked manually for errors, accents, and colloquial terms. Two researchers (RC, VP) completed the preliminary analysis guided by the thematic analysis by Braun and Clarke.²⁴ For this, each transcript was read, and re-read by the researchers to enable absorption of the data. On each transcript, areas of text were highlighted that were deemed to be significant to the participants' narratives and their experiences with information provision at diagnosis, which formed the codes of this analysis. Each transcript was analysed by each researcher independently through coding

important themes. These highlighted transcripts were shared and reviewed between the original two original coders (RC) and (VP) for consensus and then distributed among the wider team. An analysis day with the broader research team, where these transcripts and themes were comparatively re-analysed for any missing codes, narratives discussed and grouped into five broad themes. These broad themes and findings were discussed in depth with the wider multidisciplinary team to ensure a reflexive and rigorous analysis process. This process involved a comparison of themes, robust discussion and re-analysing until three tangible themes were finalised. Finally, themes were presented to representatives from the Māori Advisory Group (MAG) where they were studied and agreed upon to ensure cultural validity. The Consolidated criteria for REporting Qualitative research²⁵ were used to inform reporting of the study findings.

Ethics

Ethical approval was granted by the University of Waikato Human Research Ethics Committee (reference HREC (Health) 2021#74).

Results

In total, 11 participants aged 19–65 years completed interviews (female $n = 9$ and male $n = 20$ participants); Māori ($n = 5$), NZ European ($n = 5$) and Asian ($n = 1$). Three significant themes were identified from participant narratives: ‘Ineffective provision of resources and education methods’; ‘poor communication with their healthcare professional’; and ‘health system barriers’.

Ineffective provision of resources and education methods

Several participants reported that they were overwhelmed by their T2D diagnosis and not provided with adequate education at the time of their diagnosis to understand the aetiology of diabetes, its physiology, and pharmaceutical advice. For those that were provided education, the methods of resource provision (eg pamphlets, conversations), were ineffective, resulting in a lack of awareness of diabetes physiology, symptomology and mechanisms of action and side effects of medications. However, these same participants did understand T2D impacts their health in negative ways:

‘I still probably don’t grasp the semantics of what diabetes does...it’s just it’s something to do with the pancreas. I know, it’s something to do with blood sugar.... I don’t think I’ve grasped the concept of it...I know that it’s bad’ (Participant 6).

This lack of understanding was further expanded upon:

‘I didn’t grasp an understanding of how I got it [diabetes], that it was never answered, or what if I can get rid of it or anything like that. So I sort of came away thinking I’ll take these tablets, and in six months, everything will be great’ (Participant 7).

Some participants disclosed they were unaware of how to administer medication, such as insulin, and resorted to watching a YouTube video. Monitoring blood glucose on a long-term basis was not effectively explained. Another participant expressed confusion about the best monitoring practices, as this was not part of their diagnosis discussion.

Many participants commented on the suitability of provided resources. Most highlighted their healthcare practitioners provided pamphlets to learn more about diabetes and how to implement sustainable lifestyle modifications. However, although pamphlets were positioned as useful for some, as they could use them for reference later, this was not the case for others. Many emphasised the need for information to be delivered in alternative mediums, such as conversational, or audio-visual formats.

‘I really needed to be talked through it. It’s alright reading pamphlets. But when you take them home, and you put them away, which is exactly what I did! Also, if someone had given me a DVD, or something like that, I would have come home and watched it on the TV so then I would have been able to go from there- because I’m visual, audio you know?’ (Participant 3).

Another expressed:

‘...she [diabetes nurse] started to bring out all of these blinken [sic] pamphlets which end up in the rubbish, sometimes the hands on is better than the book’ (Participant 5).

Participants indicated a need for resources to be relevant and tailored to their specific needs. One patient mentioned she received information on driving and on drinking alcohol, both of which were irrelevant for her. In contrast, other resources were deemed to be effective and well-used by some participants. For example, one participant was given a convenient nutrition information card by his healthcare practitioners. He was able to carry this in his wallet and refer to it when food shopping, allowing him to make more suitable food choices. What made this information distinctive, was its small size, being transportable in his wallet, and its use of numerical and pictorial information.

Although half of the participants were of Māori descent, some had strong feelings towards use of pamphlets designed specifically for Māori patients, whānau and their communities. One participant expressed that he would like to see

more resources in Te Reo Māori, especially those aimed at younger audiences:

“he mate huka ahau” [I have diabetes] ...it would take the stigma away from it, to normalise it. And it would be in very simple language that even an adult who’s starting to learn Te Reo, would be able to absorb and understand’ (Participant 1).

In contrast, one participant said although she liked the use of Māori words (kupu), she did not perceive it was translated in a meaningful way, taking account of cultural context; rather, it was a transliteration of the English version.

‘Even putting in te reo Māori. I gotta spend half the time translating for them [other patients]. That’s like another tick box thing? I think all you have done is just word for word [translated from English to Māori]... so there’s nothing there for us’ (Participant 5).

Poor communication with their healthcare professional

Communication difficulties at the time of diagnosis were reported by most participants, which was demonstrated in a failure to diagnose face-to-face (kanohi te kanohi), participants feeling uncomfortable in bringing up pertinent questions, and a lack of support at a stressful time. For some, discussing diabetes with their healthcare practitioners was not an option at the time of diagnosis; for example, one participant described her diagnosis was delivered via text message, an unexpected and alarming medium:

‘I was diagnosed via a text notification...And it had been as a result of going to the doctor for previous medications, then the message just said, you are now diabetic and just gave the information around the readings’ (Participant 11).

Diagnosis delivery was described in association with concepts of ‘distress’ and a lack of support or time availability from their healthcare practitioners.

‘It is quite shocking to be just to be told that you have diabetes, and then be sent on your way’ (Participant 7).

The manner in which the healthcare practitioners communicated was a further factor in how participants felt about their diagnosis and management (eg some participants felt uncomfortable raising questions). Participants explained the need to feel secure enough to prompt discussions and receive honest, informative answers. Participants also reported a desire to build trusting therapeutic relationships where the healthcare practitioners listened to their concerns.

‘If they [patients] are shy, the GP or health nurse should be welcoming and ask open-ended questions... don’t make them feel uncomfortable’ (Participant 8).

‘It took me ages to find a GP that actually listened...’ (Participant 9).

Many participants reported a desire for explanations about diabetes and medication from their healthcare practitioners in an understandable way. This communication should use simplistic terminology, and minimising the power imbalance can assist with information being effectively received.

‘It’s talking at eye level, not talking up here [indicates a higher level on a hierarchy with their hands]. Because the minute somebody talks up here, well, I’m just going to well....my ears are off...Do away with all the medical jargon, and just dim it down’ (Participant 5).

For some participants, the information they received was insufficient, leaving participants with feelings associated with a lack of support from their healthcare practitioners and having to ‘manage it on their own’. Most patients reported feeling left to their own devices, lost and not equipped to independently manage their disease.

‘I know I’d be able to handle my diabetes if I had the proper support from the beginning, so I’m just winging it’ (Participant 3).

Whereas another participant detailed:

‘It would be great to have somebody who really, really understands and tells me the consequences of what could happen if I don’t do such and such’ (Participant 11).

Patients also highlighted instances where there was a lack of consistency in the communication they received from different healthcare practitioners, leading to confusion, and questioning the continuity of care.

‘I had a tummy bug. Five months into it. And I was like, do I take more medication? Do I take less medication? When I wrote to the doctors, they said, oh, you need to come in and be checked. And then when I rang the Healthline, they gave me different advice’ (Participant 2).

Health system barriers

Health system barriers outlines a theme where participants highlighted they were hindered from receiving the appropriate care required for their T2D management journey, due to a myriad of factors. Participants indicated that the 15-min appointment was not enough to adequately learn about and

understand their diabetes, ask questions, and feel prepared for self-management.

‘You’ve got to bear in mind GP has 15 minutes. It’s not a long period of time to have an in-depth conversation about each medication that they’re going to prescribe’ (Participant 2).

Participants conveyed that seeing different GPs acted as a barrier to some parts of their health care as the therapeutic relationship is weakened. Continuity establishes trust and makes follow-up appointments easier.

‘So I don’t have just one [GP], you know, it’s whoever’s available at the time, which I find annoying... because they don’t read up your notes and so you’ve got to start from scratch every time... They don’t follow up your progress’ (Participant 3).

For participants who identified as Māori, health system barriers such as institutional racism and cultural insensitivity were experienced. This impeded the appropriate, culturally safe care:

‘I know that there’s a lot who don’t really care about it, especially when it comes to people of colour, in general. Pasifika and Māori. They [healthcare practitioners] are just like “you got diabetes, you know, it’s what your people get” like. It’s a whole mind shift. That’s an ingrained type of racism and the thought process that they have...’ (Participant 4).

Although some participants had these negative experiences, there were contrasting positive experiences. One participant found healthcare practitioners of the same culture, or who understood her life experiences.

‘I was dealt with a lot of European older women who were just like, Oh, of course you do [have T2D diabetes]The Māori nurse that I did have she was a lot more [understanding]. She was like, we’re not going to say those things [culturally insensitive comments]’ (Participant 4).

Discussion

The purpose of this study was to examine the education and care received for patients with T2D in primary care at the time of diagnosis. T2D is a complex health issue that requires ongoing management from the time of diagnosis and patients need to be provided with appropriate resources and education to optimise their diabetes management journey.^{7,17,19,26} However, for many patients newly diagnosed with T2D, the provision of resources and education appears to be sub-optimal. Many participants, for example, reported

an over-reliance on pamphlets and written resources. Preferences indicated the need for alternative educational tools, such as conversation, group education sessions and visual imaging (eg video use, pictures, graphs). This aligns with the literature that indicates that educational materials must cater to different learning styles and needs, particularly those with lower health literacy, levels of education and deprivation status.^{27,28} As found by Chepulis *et al.* (2023), when the information was not sufficiently provided, patients would source their own, from the internet, friends and whānau.¹⁸ However, this information was not always reliable and was mainly internationally based and therefore did not always meet their needs. This highlights the genuine need for locally and culturally relevant information, specific to New Zealand’s social and cultural landscape. Health beliefs, current knowledge, medical history, physical challenges, family supports, financial constraints, emotional concerns, health literacy, numeracy and whānau must all be considered when creating educational resources.¹⁶

Healthcare practitioners’ communication with participants was also a significant concern. The method of diagnosis was deemed to be particularly important; although the majority were within a consult, some were via different mediums (eg text, phone). Given the period of time this study was conducted, this may have been a result of COVID-19; however, effective communication and follow-up is still required, regardless of the method of diagnosis delivery. With insufficient communication, participants described feeling as if they had no knowledge of their condition and felt a sense of desertion. It has been identified that the quality of communication and information during this time is directly associated with medication adherence²⁹ and self-management of their disease³⁰ and, therefore, overall diabetes management. Thus, the healthcare practitioner–patient relationship is crucial for optimal diabetes care.³¹

Diabetes is a complex, systemic condition that often requires intensive time spent with the patient. However, the NZ primary care sector is under significant stress at present and Stokes *et al.* (2017) found that when faced with time pressures, healthcare practitioners rely largely on consecutive appointments to try to manage their patient’s condition.³² However, as previous studies state,¹⁸ for some patients, this is not an option, with financial constraints and transportation barriers resulting in missed or fewer appointments, and ultimately in reduced care. This was particularly the case in lower socioeconomic and rural locations.¹⁸ Time pressures directly impact healthcare practitioners’ ability to undertake evidence-based approaches, meaning they are less likely to follow treatment guidelines.^{33,34} Consequently, with this lack of continuity, there is a lack of rapport and unfamiliarity with participants’ medical and social history. Given the nature of short, 15-min appointment times, there is a real opportunity to reduce the workload on GPs through the use of other clinical staff, such as prescribing pharmacists, diabetes nurse specialists and nurse practitioners.

Additionally, there is an excellent opportunity for a non-clinical workforce who are not bound by such rigid and structured appointment times, such as health navigators/kaiāwhina, to assist patients and clinical staff with overall diabetes management. Indeed, evidence has already demonstrated that health navigators/kaiāwhina can improve health outcomes in other areas of health, such as lung cancer,³⁵ disability support³⁶ and mental health,³⁷ by reducing the pressures in primary care and the strain within the overall healthcare system.

Culturally safe care cannot be overlooked at diagnosis, as it was a highly significant and common finding in our current study, interspersed across all themes. With Indigenous Māori populations carrying much of the burden of poorer health outcomes in T2D, it is critical these inequities are addressed. Participants supported the idea of T2D resources being available in Te Reo Māori, but only if it is culturally considered and not direct English translations. Literature suggests there are many Indigenous concepts for which there are no English translations, and philosophical aspects to Te Reo words, which do not correspond to simplistic English translations. In terms of interactions with healthcare practitioners, it was found there is institutional racism and a lack of cultural sensitivity, which has been confirmed by prior literature.^{38–43} For many participants, though particularly Māori, whānau are considered to be proponents of information sharing.^{44,45} Previous studies have stated Māori have less access to health services such as GPs⁴⁶ and a sense of whakamā (shame/feeling of blame) may result from the racism they experience.⁴⁷ Therefore, healthcare practitioners and a health service that is culturally safe is needed, along with a clear understanding of Te Tiriti and its obligations (New Zealand's founding document and partnership with Māori and the Crown).⁴⁸ It is important to note, however, that one patient who experienced such stigma was able to find a healthcare practitioner who was Māori, and was able to develop trust and empathy. This demonstrates having higher representation of Māori healthcare practitioners and those from more marginalised communities, such as Pasifika, rural and low socioeconomic areas, would go some way in reducing this stigma.

Strengths

This paper has included the recruitment of a strong representation of Māori participants for cultural representation. Having a Māori advisory group (MAG), along with Māori researchers, both clinicians and emerging academics, has allowed the analysis and dissemination of this manuscript to be viewed through a culturally safe lens. Participants were recruited from the wider Waikato area, which included smaller rural towns as well as urban centres, to gain a thorough understanding across all geographic locations, with the staff and provision of healthcare structure of primary care clinics sometimes differing. Using the time of

diagnosis allowed data to be captured early in the disease trajectory, so improvements can be made to provision of education at the time of diagnosis.

Limitations

As with any qualitative study, findings cannot be generalised;^{49,50} however, the themes identified were evident across many participant narratives. Although this research did include Indigenous participants, it was not designed as a Kaupapa Māori study, which could yield alternative findings.⁴ Our limited sample size of 11 may have been a cause for potential bias. A larger quantitative study found that 70% of participants were happy with education provided,¹⁸ though this information was all subjectively self-reported. Further, the recruitment strategy could have also played a role in bias, with patients opting in, thus potentially we received patients who wanted to discuss difficult experiences, as opposed to random sampling, which could have captured some more positive experiences.

Conclusion

This study found that, at present, patients with T2D require more information and support at diagnosis, which is a crucial time for patients, and timely engagement can assist with setting patients up for effective self-management in the future. Updated and culturally relevant local resources are required, care should be culturally safe, empathetic, and patient-centred and health system barriers should be minimised, to reduce the already immense burden of T2D on patients and their whānau to improve health outcomes for all.

References

- 1 Susan van D, Beulens JWW, Yvonne TvdS, et al. The global burden of diabetes and its complications: an emerging pandemic. *Eur J Cardiovasc Prev Rehabil* 2010; 17(1_suppl): s3–8. doi:10.1097/01.hjr.0000368191.86614.5a
- 2 Te Whatu Ora. Virtual diabetes and register tool. Wellington, NZ: Te Whatu Ora - Ministry of Health; 2023. Available at <https://www.tewhātuora.govt.nz/our-health-system/data-and-statistics/virtual-diabetes-tool/> [Accessed 9 September 2023].
- 3 Romana J, Law M, Murphy R, et al. Illness perceptions and diabetes self-care behaviours in Māori and New Zealand Europeans with type 2 diabetes mellitus: a cross-sectional study. *N Z Med J* 2022; 135(1561): 31–44.
- 4 Holder-Pearson L, Chase JG. Medical inequity: diabetes in New Zealand. *Front Med* 2022; 1323: 1–5.
- 5 McGrath NM, Parker GN, Dawson P. Early presentation of type 2 diabetes mellitus in young New Zealand Maori. *Diabetes Res Clin Pract* 1999; 43(3): 205–9. doi:10.1016/s0168-8227(99)00003-0
- 6 Dowell A, Stubbe M, Macdonald L, et al. A longitudinal study of interactions between health professionals and people with newly diagnosed diabetes. *Ann Fam Med* 2018; 16(1): 37–44. doi:10.1370/afm.2144
- 7 Chepulis L, Morison B, Cassim S, et al. Barriers to diabetes self-management in a subset of New Zealand adults with type 2 diabetes and poor glycaemic control. *J Diabetes Res* 2021; 2021: 5531146. doi:10.1155/2021/5531146

- 8 Peel E, Parry O, Douglas M, *et al.* Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions and views about information provision. *Patient Educ Couns* 2004; 53(3): 269–75. doi:10.1016/j.pec.2003.07.010
- 9 Powers MA, Bardsley J, Cypress M, *et al.* Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. *Diabetes Care* 2015; 38(7): 1372–82. doi:10.2337/dc15-0730
- 10 Stokes T, Tumilty E, Latu ATF, *et al.* Improving access to health care for people with severe chronic obstructive pulmonary disease (COPD) in Southern New Zealand: qualitative study of the views of health professional stakeholders and patients. *BMJ Open* 2019; 9(11): e033524. doi:10.1136/bmjopen-2019-033524
- 11 Walker RC, Walker S, Morton RL, *et al.* Māori patients' experiences and perspectives of chronic kidney disease: a New Zealand qualitative interview study. *BMJ Open* 2017; 7(1): e013829. doi:10.1136/bmjopen-2016-013829
- 12 Wells S, Rafter N, Kenealy T, *et al.* The impact of a point-of-care testing device on CVD risk assessment completion in New Zealand primary-care practice: a cluster randomised controlled trial and qualitative investigation. *PLoS One* 2017; 12(4): e0174504. doi:10.1371/journal.pone.0174504
- 13 Engelbrecht R, Walker R, Monson K. Understanding experiences of diabetes care among patients with diabetic kidney disease: a qualitative interview study. *Renal Soc Australas J* 2021; 17(1): 10–6. doi:10.33235/rsaj.17.1.10-16
- 14 Te Kaunihera Rata o Aotearoa - Medical Council of New Zealand. Statement on Cultural Safety. Wellington, NZ: Medical Council of New Zealand; 2019. Available at mcnz.org.nz [Accessed 22 September 2023].
- 15 Curtis E, Jones R, Tipene-Leach D, *et al.* Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *Int J Equity Health* 2019; 18(1): 174. doi:10.1186/s12939-019-1082-3
- 16 Powers MA, Bardsley J, Cypress M, *et al.* Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. *Diabetes Educ* 2017; 43(1): 40–53. doi:10.1177/0145721716689694
- 17 Lawrenson R, Joshy G, Eerens Y, *et al.* How do newly diagnosed patients with type 2 diabetes in the Waikato get their diabetes education? *J Prim Health Care* 2010; 2(4): 303–10.
- 18 Chepulis L, Mellsop-Kupe J, Moorhouse S, *et al.* Newly diagnosed type 2 diabetes – does New Zealand General Practice adequately prepare patients to self-manage their Condition? *BMC Prim Care* 2023; 24(1): 162. doi:10.1186/s12875-023-02118-1
- 19 Alamdari AK, Taheri R, Afrasiabifard A, *et al.* Comparison of the impact of face-to-face education and educational booklet methods on health-related quality of life in patient with type 2 diabetes. *J Clin Care Skills* 2020; 1(2): 75–80. doi:10.52547/jccs.1.2.75
- 20 Deccache A, Aujoulat I. A European perspective: common developments, differences and challenges in patient education. *Patient Educ Couns* 2001; 44(1): 7–14. doi:10.1016/s0738-3991(01)00096-9
- 21 Dickinson D, Raynor DK, Duman M. Patient information leaflets for medicines: using consumer testing to determine the most effective design. *Patient Educ Couns* 2001; 43(2): 147–59. doi:10.1016/s0738-3991(00)00156-7
- 22 Diabetes NZ. Research participant opportunities. Wellington, NZ; 2022. Available at <https://www.diabetes.org.nz/research-participant-opportunities> [Accessed 5 November 2021].
- 23 Emmel N. Sampling and choosing cases in qualitative research: a realist approach. Sage; 2013.
- 24 Braun V, Clarke V. Thematic analysis. American Psychological Association; 2012.
- 25 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19(6): 349–57. doi:10.1093/intqhc/mzm042
- 26 Crowe M, Whitehead L, Bugge C, *et al.* Living with sub-optimal glycaemic control: the experiences of Type 2 diabetes diagnosis and education. *J Adv Nurs* 2017; 73(3): 612–21. doi:10.1111/jan.13145
- 27 Torenholt R, Varming A, Englund G, *et al.* Simplicity, flexibility, and respect: preferences related to patient education in hardly reached people with type 2 diabetes. *Patient Prefer Adherence* 2015; 9: 1581–6. doi:10.2147/PPA.S91408
- 28 Negarandeh R, Mahmoodi H, Noktehdan H, *et al.* Teach back and pictorial image educational strategies on knowledge about diabetes and medication/dietary adherence among low health literate patients with type 2 diabetes. *Prim Care Diabetes* 2013; 7(2): 111–8. doi:10.1016/j.pcd.2012.11.001
- 29 Polonsky WH, Henry RR. Poor medication adherence in type 2 diabetes: recognizing the scope of the problem and its key contributors. *Patient Prefer Adherence* 2016; 10: 1299–307. doi:10.2147/PPA.S106821
- 30 Fuertes JN, Mislowack A, Bennett J, *et al.* The physician–patient working alliance. *Patient Educ Couns* 2007; 66(1): 29–36. doi:10.1016/j.pec.2006.09.013
- 31 Marahrens L, Kern R, Ziemssen T, *et al.* Patients' preferences for involvement in the decision-making process for treating diabetic retinopathy. *BMC Ophthalmol* 2017; 17(1): 139. doi:10.1186/s12886-017-0526-z
- 32 Stokes T, Tumilty E, Doolan-Noble F, *et al.* Multimorbidity, clinical decision making and health care delivery in New Zealand Primary care: a qualitative study. *BMC Fam Pract* 2017; 18(1): 51. doi:10.1186/s12875-017-0622-4
- 33 Litchfield IJ, Bentham LM, Lilford RJ, *et al.* Patient perspectives on test result communication in primary care: a qualitative study. *Br J Gen Pract* 2015; 65(632): e133–40. doi:10.3399/bjgp15X683929
- 34 Polster DS. Confronting barriers to improve healthcare literacy and cultural competency in disparate populations. *Nursing* 2018; 48(12): 28–33. doi:10.1097/01.NURSE.0000547717.61986.25
- 35 Kidd J, Cassim S, Rolleston A, *et al.* Hā Ora: reflecting on a Kaupapa Māori community-engaged co-design approach to lung cancer research. *Int J Indig Health* 2021; 16(2): 192–207. doi:10.32799/ijih.v16i2.33106
- 36 Twaddle SK, Khan M. Health and Disability Kaiawhina Worker Workforce 2013 Profile. Christchurch, NZ: Careerforce NZ; 2013. Available at <https://www.careerforce.org.nz/wp-content/uploads/2014/05/2013-Health-and-Disability-Kaiawhina-Worker-Workforce-Profile.pdf> [Accessed 7 August 2023].
- 37 Classen B, Tudor K, Johnson F, *et al.* Embedding lived experience expertise across the mental health tertiary education sector: an integrative review in the context of Aotearoa New Zealand. *J Psychiatr Ment Health Nurs* 2021; 28(6): 1140–52. doi:10.1111/jpm.12756
- 38 Beaton A, Manuel C, Tapsell J, *et al.* He Pikinga Waiora: supporting Māori health organisations to respond to pre-diabetes. *Int J Equity Health* 2019; 18(1): 3. doi:10.1186/s12939-018-0904-z
- 39 Atlantis E, Joshy G, Williams M, *et al.* Diabetes among Māori and other ethnic groups in New Zealand. In: Dagogo-Jack S, editor. Diabetes mellitus in developing countries and underserved communities. Springer; 2017. pp. 165–90.
- 40 Harwood M, Tane T, Broome L, *et al.* Mana Tū: a whānau ora approach to type 2 diabetes. *N Z Med J* 2018; 131(1485): 76–83.
- 41 Hikaka J, Jones R, Hughes C, *et al.* “It is through shared conversation, that I understand”-Māori older adults' experiences of medicines and related services in Aotearoa New Zealand. *N Z Med J* 2020; 133(1516): 33–46.
- 42 Jansen P, Bacal K, Buetow S. A comparison of Māori and non-Māori experiences of general practice. *N Z Med J* 2011; 124(1330): 24–9.
- 43 Walker RC, Abel S, Palmer SC, *et al.* “We need a system that's not designed to fail Māori”: experiences of racism related to Kidney transplantation in Aotearoa New Zealand. *J Racial Ethn Health Disparities* 2023; 10(1): 219–27. doi:10.1007/s40615-021-01212-3
- 44 Rolleston A, McDonald M, Miskelly P. Our story: a Māori perspective of flourishing whānau. *Kōtuitui N Z J Soc Sci Online* 2022; 17(3): 277–97. doi:10.1080/1177083X.2021.1981955
- 45 Rochford T. Whare Tapa Wha: a Māori model of a unified theory of health. *J Prim Prev* 2004; 25(1): 41–57. doi:10.1023/B:JOPP.0000039938.39574.9e
- 46 Barwick H. Improving access to primary care for Māori and Pacific peoples. A literature review commissioned by the Health Funding Authority. Wellington: Ministry of Health; 2000.

- 47 Bourke JA, Owen HE, Derrett S, *et al.* Disrupted mana and systemic abdication: Māori qualitative experiences accessing healthcare in the 12 years post-injury. *BMC Health Serv Res* 2023; 23(1): 130. doi:10.1186/s12913-023-09124-0
- 48 Came H, O'Sullivan D, McCreanor T. Introducing critical Tiriti policy analysis through a retrospective review of the New Zealand Primary Health Care Strategy. *Ethnicities* 2020; 20(3): 434–56. doi:10.1177/1468796819896466
- 49 Parker LD, Northcott D. Qualitative generalising in accounting research: concepts and strategies. *Accounting Auditing Account J* 2016; 29(6): 1100–31.
- 50 Mays N, Pope C. Qualitative research: observational methods in health care settings. *BMJ* 1995; 311(6998): 182–4. doi:10.1136/bmj.311.6998.182

Data availability. Raw data were obtained at the University of Waikato. Derived data supporting the findings of this study are available from the corresponding author upon request (Rebekah.crosswell@waikato.ac.nz).

Conflicts of interests. The authors declare no conflicts of interest.

Declaration of funding. This research was funded by the Health Research Council of New Zealand (HRC21/839).

Author affiliations

^AWaikato Medical Research Centre, University of Waikato, Te Huataki Waiora, School of Health, Private Bag 3105, Hamilton 3240, New Zealand.

^BSchool of Psychology, Massey University, Auckland, New Zealand.

^CDepartment of Nursing, University of Waikato, Hamilton, New Zealand.

^DTe Whatu Ora Waikato, Hamilton, New Zealand.

Appendix 1. Interview guide.

(1st meeting) Introduction – Whanaungatanga

- Thank participant for their time and agreeing to participate
- Ask about karakia/prayer
- Introduce self/background including where you're from
- Respond to participant's own introduction
- Answer questions about yourself
- Ask if it's OK to start the interview
- Explain aims of research and interview
- Verbally go through participant information sheet, and answer any questions/clarify any doubts
- Get the consent form signed and give participant their \$30 voucher and thank participant
- Gain consent for turning the Dictaphone on

Could you please tell me about the time you were diagnosed with type 2 diabetes?

- Who diagnosed them (GP, nurse, Māori health provider, hospital, someone else)?
- When diagnosis was (how long ago)
- Where (location of practice)
- Was diagnosis through a purposeful test or as part of another routine examination? Expected?
- What was their knowledge of diabetes before diagnosis? Had they heard of it before?

Could you please tell me about your experience with managing your diabetes since diagnosis?

- What processes or strategies are used to effectively manage diabetes?
- How do you manage/control/monitor the sugar (blood) levels?
- Are there any barriers/difficulties to managing this?
- Do you feel equipped to manage your diabetes independently? Why/why not?

Had you had any previous experience with diabetes?

- Any knowledge about T2D prior to diagnosis?
- Where did information come from?
- Family/friends with T2D?
- Do you think that your disease is effectively managed by your GPs (primary care)?

Could you please tell me about your experience with accessing information to help you manage your diabetes?

- Has your GP, practice nurse or any other health professional given you, or referred you, to resources that could help you manage your diabetes? Were these provided at the time of being diagnosed?
- If so, what were these? Were they effective in helping?
- Have you accessed other resources to better support the management of your diabetes?
- If yes, what are these and how did you come across them? (Friends, GP, internet etc)
- Do you find the information you have received/independently found to be useful? Why/why not?
- Do you feel that you were appropriately supported by your healthcare providers to be able to manage your diabetes when you were diagnosed... has your views on this changed during the last 12 months?

Can you tell me a little more about your experience since being diagnosed with diabetes? How have you found it?

- Aspects that made the process easier/harder for you and your whānau?
- Who have some of the most helpful people been during this time? Why? (eg support groups, GPs, family/whānau, internet, nurses?)
- What have been the most helpful pieces of information for you? Why?
- Is there anything you would have liked to know earlier on in this journey?
- What has been the hardest part of managing your diabetes?

What advice would you give to someone who has just been diagnosed with T2D?

From your perspective, having been through this diagnosis, how do you think diabetes care/management could be improved?

- What information would you like to have received?
- What additional support could have been useful during this first year?

What do you think is the most important thing for being able to self-manage your diabetes effectively? Have you been appropriately equipped for [this most important thing]?

Is there anything you would like to add or bring up that you think should have been discussed?

Closing of the Interview

Do you have any further questions about this study?

- Check if the participant has any questions about the study
- Check if they wish to close with a karakia or prayer
- Thank them for their time and participation.

Reminders

- Address/contact details to send through summary report of research – *if required*

Thank you so much for your time