

# Barriers to Diabetes Self-Management in New Zealand Patients with Type 2 Diabetes and Poor Glycaemic Control

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## Research article

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# Abstract

**Background:** Despite the fact that there is an increasingly effective armoury of medications to treat diabetes many patients continue to have substantially elevated blood glucose levels. The purpose of this study was to explore what the barriers to diabetes management are in a cohort of people with diabetes and poor glycaemic control.

**Methods:** Qualitative semi-structured interviews were carried out with 10 people with diabetes who had known diabetes and a recent HbA1c of > 11.3% (100 mmol/mol) to explore their experiences of barriers to diabetes self-management and glycaemic control.

**Results:** Barriers to diabetes management were based around two key themes: biopsychosocial factors and disease awareness / information delivery. Specifically, financial concerns, social stigma, medication side effects and cognitive impairment due to hyperglycaemia were commonly reported as barriers to medication use. Other barriers included a lack of knowledge about their own disease, poor relationships with health care professionals and a lack of relevant resources to support diet and weight loss.

**Conclusion:** people with diabetes with poor glycaemic control experience many of the same barriers as those reported elsewhere, but also experience issues specifically related to their severe hyperglycaemia. Management of diabetes could be improved via the increased use of patient education and availability of locally relevant resources.

## Background

Type 2 diabetes mellitus (T2DM) is a chronic condition that currently affects approximately 7% of New Zealand's population, including a disproportionate number of Māori.<sup>1,2</sup> Importantly, the prevalence of T2DM is increasing year on year due the close association with obesity,<sup>3</sup> with a greater number of younger people also now being affected.<sup>4</sup>

Medically, the goals of T2DM management are to control glucose levels (as reflected by glycated haemoglobin (HbA1c) measurements) and other cardiovascular risk factors such as hypertension and dyslipidaemia, with the aim to prevent, delay or slow the progression of microvascular and macrovascular complications.<sup>5,6</sup> However, despite the fact that there have been significant improvements in the availability of medications to treat diabetes, many people with T2DM continue to have poor glycaemic control. Indeed, in a recent review of more than 3500 people with T2DM in the Waikato region, more than half had a most recent HbA1c of > 55 mol/mol (7.2%),<sup>7</sup> and this has not improved from that reported earlier in 2006.<sup>8</sup>

The management of T2DM is multifaceted, including patient education, medication and lifestyle changes.<sup>9 10</sup> In primary care in New Zealand, management of T2DM should include promotion of a healthy lifestyle, regular monitoring of clinical measures, use of medication and specialist referral as

required.<sup>9</sup> General practitioners (GPs) are expected to offer all people with diabetes an annual review of their risk of diabetes-related complications, though recent data from New Zealand suggests that only 50–60% of all people with diabetes complete this annually.<sup>7</sup>

However, despite the implementation of these health system strategies, many studies have identified that patient-level barriers can significantly impact on glycaemic control and diabetes management.<sup>11–15</sup> To date, these issues have not been investigated in detail in New Zealand though in 1998, a multi-ethnic qualitative study in South Auckland looked to identify barriers to diabetes care from both the patient and the health care provider (HCP) perspective. This study identified that barriers spanned many different themes, including the need for translated educational material, psychological barriers, and physical and social barriers to care.<sup>16</sup> Similarly, in 2007, in a cohort of people with T2DM, psychological factors (strictness of medication regimen and motivation) were ranked as being important barriers to care by both patients and HCPs.<sup>17</sup> Further, in 2013 a small study with rural patients reiterated the fact that barriers to glycaemic control are varied and many, but also reported that these can include a lack of medication adherence and a lack of understanding by the clinician of the patient fears, beliefs and expectations around their diagnosis and disease management.<sup>18</sup> Importantly, however, none of these three studies report on the HbA1c measurements at the time of the interview and it is impossible to determine how barriers may differ between those who have good versus bad glycaemic control. Indeed, despite the fact that structured diabetes education is becoming more recognised as a critical component of diabetes management<sup>19–21</sup> international studies continue to report that people with very poor glycaemic control may present with unique barriers and challenges.<sup>22</sup> These include becoming easily frustrated in situations such as delayed or inappropriate use of insulin therapy<sup>23,24</sup> and significant deficits in diabetes knowledge,<sup>22</sup> indicating that many could benefit from more individualised management.

To date, no study has reported on the barriers to glycaemic control as they pertain to New Zealand people with diabetes with excessively high HbA1c levels. Thus, this study was designed to provide a recent evaluation of the barriers to diabetes care and glycaemic control specifically in those with T2DM who have very poor glycaemic control.

## **Methods**

### **Setting**

This study was conducted in the Waikato region of New Zealand, as part of a larger Waikato-based 'Diabetes in Primary Health Care Study'. Participants for this qualitative study were recruited from two general practices: one based in an urban locality and the other in a rural locality. These two practices were chosen because they have previously agreed to participate as a research practice.

### **Participants and recruitment**

A sub-set of 100 people with T2DM with poor glycaemic control (HbA1c > 11.3%; 100 mmol/mol) were selected at random from the two general practices (50 from each) and invited via a letter to participate in this qualitative study. Participants had no prior knowledge of the researchers or the project prior to being contacted, though all were provided with a participant information sheet describing the research team and the nature of the project. Ten participants responded to our invitation, and all were therefore interviewed for this study. Overall, participants comprised five Māori, four New Zealand European (NZE) and one Asian patient. Six of the participants were female and all were aged ranged between 26 and 75 years. Three participants were enrolled with the rural practice, and seven were enrolled with the urban practice.

The study took place between July and August 2019. Participants were asked to discuss their experiences as a patient with T2DM, and their experiences of barriers to quality diabetes care. Semi-structured interviews were carried out with each participant by BM, a trained female researcher using an interview guide prepared specifically for this study. Each interview was approximately 30–60 minutes in duration, and took place at either the participants' homes or a local café. Family were allowed to be present during the interview.

## **Analysis**

Participant interviews were recorded as field notes and via an audio recorder. Audio recordings were transcribed and anonymized. Pseudonyms have also been used to ensure the anonymity of participants. Transcripts and field notes were thematically analysed.<sup>25</sup> Analysis was carried out by two experienced researchers (BM and KM) independently first, and then together to ensure a rigorous analysis process. Final analysis was overseen by a third researcher (SC), where general themes and subthemes were discussed, constructed, reviewed and refined. Participants were given the option to see their interview transcripts but all declined this opportunity.

## **Results**

Data analysis identified two overarching themes contributing to poor glycaemic control: 'biopsychosocial barriers' and 'disease awareness and information delivery'.

### **Biopsychosocial barriers**

Participants indicated that having T2DM, and the resulting continued need to control their glycaemic levels had a significant impact on various other areas of their lives (financial, social, physical and cognitive). Such affects tended to occur in a negative feedback loop: while the disease affected these various aspects of patients' lives, the financial, social, physical and cognitive factors also then acted as barriers to achieving and maintaining optimal glycaemic control.

### **Financial**

Participants highlighted significant financial costs associated with living with T2DM. For instance, many participants pointed out that the mounting costs of medication (particularly Insulin), mandatory health care provider (HCP) visits, alongside the need to take time off work and transport costs were a day-to-day reality of living with T2DM. Such accumulating costs then made it difficult to continue maintaining/achieving optimal glycaemic control:

***"It starts hitting your pocket ...that's how bad it got, I was spending about 65-100 bucks just on medication every three weeks." (Simon, male, 42, urban)***

***"It kind of added up, and I didn't have enough money to pay for it and I remember standing there thinking should I ask the girl to put it on sort of an account for me, but you know my pride got the better of me and I just said can you just put it to the side and I'll return. I returned like two weeks later because I was being paid fortnightly and so I had to suffer 'cause I wasn't getting any medication at that time." (Sean, male, 37, urban)***

## **Social**

Many participants also reported that social judgements received from others in public, or from family members when taking their medication, became a barrier to self-management of T2DM. Insulin injections were particularly disliked, primarily because of the impact that this had on other family members. Debbie reported how her daughter had made negative comments about her injecting insulin:

***"I would be getting the [insulin] pen out, and my daughter walks in 'ewww don't mum, not in my bloody kitchen you don't'" (Debbie, female, 58, , urban).***

Consequently, participants tended to avoid taking their medication in order to shield their family members from the entire seemingly gruesome process. For instance, Simon reported that he didn't think it was socially acceptable to be injecting himself with insulin in front of his young son in case his son copied him and hurt himself with the needles:

***"I don't want to do injections, and that's one of the reasons I stopped for quite a while -because of my son being so young. [I] didn't want him to see me doing that and think [that] it was normal.....so I stopped taking it for like six months."(Simon, male, 42, urban)***

## **Physical**

Many participants also indicated that the side effects of T2DM medication served as a barrier to glycaemic control. As a result, many participants refused to take their medication, actively changed their medication, or found alternate remedies that fit with their individual lifestyle. Phil admitted that he stopped his medication because it affected his work:

***"The medication [metformin] yes, I did change it, I think it's effecting me now.... I get diarrhoea, so I try not to take it while I'm working cause I'm on mobile patrol so it's not ideal" (Phil, male, 42, rural)***

Sean, on the other hand convinced his HCP to change his medication due to its adverse side effects:

***"I didn't like the Metformin because I just felt like it was honestly wrecking my insides and the doctor understood ... and so I pressured the doctor to push me onto the insulin".(Sean, male, 37, urban)***

Given the negative side-effects of the medication, participants actively sought out alternative methods for controlling their blood glucose levels, including experimenting with the effects on their body after prolonged periods of not taking their diabetic medication and using cinnamon, or a particular diet plan (e.g. Keto) to help control their diabetes. However, the side effects of these alternatives seemed to be worse than the medication itself, resulting in substantial increases in HbA1c levels and reduced quality of life. Therefore, both participants later returned to medication, upon advice from their general practitioner.

***"I've looked at other methods of dealing with it [T2DM] like having cinnamon and stuff, because cinnamon is apparently meant to be really good for diabetes. So I was just trying to take it [cinnamon], instead of having all these pills" (Simon, male, 42, urban)***

## **Cognitive and psychological**

Additionally, participants reported concerns about their diabetes having a negative effect on their cognitive health, which impacted on their ability to effectively manage their disease. For instance, some participants thought that their diabetes influenced their mental health, indicating that the disease prevented them ***"from being able to think straight"***(Laura, female, 49, urban). Importantly, this lack of mental clarity was observed to be worse during periods of poorer glycaemic control, which then further impacted on a number of factors that made patient management of T2DM difficult. For instance, participants commonly reported the inability to remember to take their medication:

***"It's not very nice when you can't think because your brain fog". (Laura, female, 49, urban)***

***"Cause man, half the time I don't remember to take my pills." (Simon, male, 42, urban)***

Consequently, several participants devised strategies to help them remember. However, even this was impacted by memory loss due to poor glycaemic control:

***"Sometimes I have forgotten, like today. Normally I am in a habit of putting the [insulin] pen on the table which I forgot to do this morning" (Debbie, female, 58, urban)***

Some participants also recognised that they were not consciously aware of the 'brain fog' while their HbA1c levels were excessively high, though they often reported the ability to 'think clearer' when their HbA1c levels were lower. In contrast, others did recognise symptoms of poor mental health functioning during the time when their diabetes wasn't being managed well. These participants all indicated that it wasn't until they made significant lifestyle and medical changes which resulted in good glycaemic control that they understood the severity of their cognitive impairment.

Overall, participants reported that they perceived their diabetes as unfixable, feeling powerless in their management, and that they are being 'punished' and forced to live with the disease indefinitely. Commonly the disease was described as being a burden, overwhelming and a liability. Two participants also wished that the disease had been better explained to them by their HCP, or that they had received more appropriate resources about T2DM while they were in the earlier pre-diabetic state as this would have played a significant role in their health management. Accordingly, the ability to appropriately manage T2DM was also affected by a patient's level of knowledge and understanding about the disease, alongside the information provided to them by their HCP and other publicly accessible resources.

## **Disease awareness and information delivery**

An awareness and understanding of T2DM in terms of disease biology, its implications for ongoing health and how to manage the disease are vital for understanding the need to maintain good glycaemic control. However, based on the participant accounts from this study, it is clear that many people with diabetes do not have a clear understanding on what T2DM is and how it should be effectively managed. Additionally, barriers to gaining a better understanding of the disease also exist, due to inadequate information being delivered by both HCPs and other publicly available resources.

### **Patient Factors**

Many participants reported not having a full understanding of their T2DM and this was identified as a significant barrier to glycaemic control. Weight management is considered to be an important factor that affects T2DM control, though many participants reported being unequipped to know how to lose weight with diabetes. Laura, for example, alluded to feeling trapped with her diabetes because when she tried to do something to reduce her weight she would often experience a hypoglycaemic episode:

***"Every time I would go on a weight loss programme my sugars would crash and I'd end up in hospital because they were at 1.0 [mol/mol]. Then they'd shove sugar down my throat". (Laura, female, 49, urban)***

Participants also reported experiencing hypo- and hyperglycaemic episodes which influenced their diabetes control behaviour of trying to cut down on their sugar in order to lower their blood glucose levels:

***"I have had one slip up where I had took my insulin and stuff, went for a walk and I collapsed on the side of the road" (Simon, male, 42, urban)***

As a result, Simon lost his trust in his dietary plan and was reluctant to cut down on his sugar intake and alluded to his body being different to others and needing sugar to feel normal. Two other participants reported similar stories where there was a lack of knowledge about how to manipulate their insulin dose when working longer shift hours and not being able to consume food at normal times.

The majority of people with diabetes also had a very limited understanding of HbA1c (despite all having a recent measurement of >100mmol), how T2DM affects the body, and how their diabetic medication

works. One participant acknowledged this misunderstanding, yet simultaneously indicates that she still does not have clear knowledge about her medication:

***“I always thought that metformin was supposed to bring my sugar level down. I only just found out that it’s not...they’re to keep your valves or your arteries open or something like that” (Laura, female, 49, urban)***

Other participants reported that their diabetes was poorly controlled because they did not understand the extent of severity of their disease and several preferred to ignore the direct impact that T2DM was having on their body. Penny for instance, only accepted years later that she had sustained physical damage to both her feet and eyes that was caused by diabetes:

***“The bottom of my leg is discoloured and [it] has been for a number of years. It was kind of like the first warning that I had diabetes, it was the first sign and I knew that, and I just chose to ignore it... I went to have my eyes checked this year for the first time, and they showed me the damage that was done to my eyes that won’t be healed again” (Penny, female, 64, urban)***

The importance of consuming food with medication, and Insulin levels needing to be adjusted in response to the quantity of carbohydrate eaten were both factors that several participants reported that they were unaware of and did not understand. Accordingly, this lack understanding had negative impacts on these participants’ ability to effectively manage their diabetes and therefore acted as a key barrier.

## **Healthcare Professional Factors**

Participants reported negative experiences with HCPs when dealing with their T2DM and this was also identified as a barrier to glycaemic control. Many reported issues that included a lack of cultural awareness, lack of appropriate communication, mistrust in the HCP and perceived insufficient information being provided by the HCP. Many found that their HCP was not overly helpful:

***“There wasn’t much help from the health professionals [nurses]..... their answers when I did talk to them were..... yes they were kind of, quite snarky.” (Phil, male, 42, NZE, rural)***

***“I’ve learnt to favour the GPs that will support you now and ignore the ones who don’t” (Simon, male, 42, urban)***

Some people with diabetes did receive support in the form of pamphlets or were directed to online resources on diabetes from some GPs and other practice staff such as nurses. Others sought these resources themselves. However, all found that the resources available for people with diabetes in New Zealand were not directly relevant and thus were unhelpful to them.

## **Other resources**

A lack of availability and access to relevant resources was a major theme that participants reported as impacting on their diabetes management experience. Participants reported that the information they received from their HCPs was out dated and not culturally appropriate:

***“They gave me a diet book ... [there’s] a non-cultural perspective, but I think they were also outdated which makes them not that relevant.” (Penny, female, 64, urban)***

Some participants attempted to seek out their own health education through online educational tools. However, these were also not relevant to the New Zealand context, given they were mostly tailored to the American market:

***“There is a YouTube channel, I’ve been watching then for a while, but she’s American so it’s hard to follow, they’ve got different stuff over there” (Rose, female, 25, urban)***

Others resorted to seeking out secondary specialists in an effort to gain more advice. However, this option was not available for those living in rural localities:

***“I went, tried to suss out a nutritionist or something like that, to get ideas and things, but there’s no one around here” (Phil, male, 42, rural)***

Finally, participants expressed an interest in having access to ideas and resources on how they could make diabetic dietary changes through cooking and food that suited their lifestyle in the New Zealand context. Such resources could serve as another tool to boosting patient confidence and motivation to actively control and maintain their glycaemic levels.

## **Discussion**

As this study shows, people with T2DM with very poor glycaemic control may have a range of barriers that lead to reduced self-management of their disease. Many of these barriers are similar to those reported in other studies in New Zealand,<sup>16–18</sup> despite the fact that these earlier studies likely included patients with varying degrees of glycaemic control. Participants in our study, for example, also reported shame associated with insulin injections, significant fear and altered behaviour to prevent hypoglycaemia, and lack of disease awareness, suggesting that these factors may be relatively common in people with diabetes (particularly insulin users), irrespective of a person’s HbA1c levels. However, our study also demonstrates that poorly controlled diabetes left participants feeling cognitively impaired or with a state of ‘brain fog’ that made it difficult to remember and complete even simple tasks (including taking medication). Indeed, diabetes is known to associate with a greater cognitive decline compared with no diabetes, and impairment has been shown to be worse in those with poorly controlled disease.<sup>26, 27</sup> Further, the findings of our study supports previous research demonstrating that cognitive impairment can lead to worse diabetes care management<sup>28</sup>. Several participants indicated that they forgot to take their medication because they were unable to think clearly, likely as a result of the severe hyperglycaemia. However, this appears to create a destructive, negative feedback loop in which reduced medication adherence can then lead to even worse glycaemia, such that the self-management of the disease is even further impacted.<sup>29</sup> This lack of mental clarity needs to be recognised and understood in people with very poor glycaemic control, ideally with support provided to counter the depression, emotional distress and

forgetfulness that can result.<sup>30</sup> Further, in those who have significantly elevated HbA1c levels, strategies for improving medication adherence should be emphasized, as improved diabetes control has conversely been shown to create a positive feedback loop and improve cognitive performance.<sup>31</sup>

Our study also highlighted two additional significant barriers that were specific to glycaemic control in New Zealand: the mounting patient-level costs associated with diabetes management, and the limited resources available to patients and whānau (family) about their disease. Focusing on the first point, despite New Zealand's public health system being at a relatively high standard in terms of access to healthcare and medication, compared to other countries in the OECD, many participants (urban and rural) highlighted that financial cost was a significant barrier to diabetes management. Patients in New Zealand do have access to high user healthcare cards, which entitles them to reduced costs for doctors visits and prescriptions if they meet certain criteria; however, the use of these cards has not been evaluated, and it is unknown whether these cards, and therefore lower healthcare costs, are passed onto patients with diabetes as often as they could be. Further, high user cards reset annually, and the healthcare costs could again become a significant burden before a patient again meets the criteria within the new calendar year. We suggest, therefore, that it would be beneficial to understand how well high user cards and other subsidies are being used by patients with financial difficulties, possibly educating doctors and patients alike about their availability to support ongoing healthcare.

Secondly, the limited resources provided and available to people with T2DM in New Zealand is also a direct barrier to glycaemic control and self-management of the disease. Participants stated that while their HCPs often failed to provide adequate or up-to-date and thus relevant information, those who were pro-active with trying to improve their health and diet also struggled to find information that was relevant to them. Several participants indicated, for example, that they actively sought resources on the internet to learn more about diabetes and the foods that they should and should not eat. However, in a New Zealand context, the information available on the internet appears to be lacking, particularly around culturally appropriate and responsive resources that are applicable to Māori. For instance, while many patients looked to Youtube for videos on healthy eating with diabetes, these were primarily American, and entirely out of context for New Zealand patients. This is concerning, particularly as research from the last 25 years consistently showed that there are local ethnic and geographical differences in diabetes knowledge, education and disease predisposition.<sup>20, 32-34</sup> As highlighted by Lambrinou and colleagues,<sup>35</sup> patient education and support for self-management are fundamental to diabetes care. As such, steps need to be taken to provide better, culturally appropriate information on diabetes and its treatment for patients in New Zealand, which can help them manage their disease well, and also prevent barriers such as misconception and stigma.

The strength of this study lies in the fact that it included a reasonably representative view of Māori patient experiences. This is important given that the prevalence of T2DM is higher in Māori than in non-Māori<sup>1,2</sup> and given that there is increasing awareness of the importance of providing culturally responsive health care in New Zealand (including for diabetes).<sup>36</sup> A possible limitation of this study was that our

participant population was derived from two primary care practices in a single region. Therefore, given that diabetes management and care in primary care is highly dependent on and varied based on the provider and the regional District Health Board (DHB), barriers may vary across these practices / DHBs. Accordingly, an avenue for future research could be to explore barriers to T2DM management at a national level, with participants from a broad array of GP practices from across New Zealand.

## Conclusions

In conclusion, this study shows that whilst the participants in this study experienced many of the same psychosocial barriers as those reported elsewhere, they can also experience barriers directly associated with their hyperglycaemia (e.g. cognitive impairment) which may impact on their ability to remember to take medication etc. We also identified that financial concerns and a lack of locally relevant resources for patients with T2DM were key barriers to New Zealand patients in particular. Accordingly, financial support for people with diabetes (possibly improved use of high user cards) and creating more appropriate education resources for disease management may be areas that the Government and District Health Boards should focus on.

## Abbreviations

T2DM Type 2 diabetes mellitus

HbA1c Glycated Haemoglobin

GPs General practitioners

HCP Health care professional

NZE New Zealand European

## Declarations

### Ethics approval and consent to participate

Approval was granted by the University of Waikato Health Research Ethics Committee. All study participants provided signed, written consent.

### Consent for publication

all authors have read and approved the manuscript.

### Availability of data and materials

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

## Competing interests

Nil

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## Authors' contributions

LC, RK, RP and RL conceived and designed the study, BM completed all patient interviews and undertook initial thematic analysis with KN. SC provided qualitative research expertise and oversaw the analysis process. LC, BM, RK and SC prepared the manuscript for publication.

## Acknowledgements

Nil

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