

Understanding barriers to glycaemic control from the patient's perspective

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ABSTRACT

INTRODUCTION: To better understand barriers to glycaemic control from the patient's perspective.

METHODS: An interpretative phenomenological approach was used to study the experiences of 15 adults with Type 2 diabetes. Participants each gave a semi-structured interview of their experiences of living with diabetes. Interviews were transcribed, and themes extracted and organised using a patient-centred framework.

FINDINGS: Participants' stories confirmed many of the barriers in the literature, particularly those related to context, such as family, finances, work. Barriers also related to negative emotional reactions to diabetes: fear of new events (diagnosis, starting pills/insulin); guilt about getting diabetes and not controlling it; and shame about having diabetes. Barriers also related to unscientific beliefs and personal beliefs. There were additional barriers related to poor clinician–patient relationships. Overall, participants had a poor understanding of diabetes, and complained that their clinician simply 'told them what to do'.

CONCLUSION: Using a patient-centred approach, this study identified many barriers to glycaemic control. We suggest that a key barrier is clinician ignorance of their patients' fears, beliefs, expectations, context; of what constitutes a positive therapeutic relationship; and of the limitations of a biomedical approach to patient non-adherence. Faced with both a worsening diabetes epidemic and increasing health care workforce shortages, clinicians urgently need to understand that it is they, not their patients, who must change their approach if diabetes care is to be improved.

KEYWORDS: Communication barriers; diabetes mellitus, type 2; medication adherence; patient-centered care

Introduction

Despite advances in medical management, many people with diabetes have poor glycaemic control, and many barriers to care have been identified.¹ Non-adherence has been identified as a barrier: both the failure of clinicians to adhere to evidenced-based clinical guidelines,^{2,3} and the failure of patients to adhere to medically recommended treatments.⁴ However, biomedical research has been unable to explain why it is that clinicians and patients do not always adhere to expert recommendations.

While previous studies have directly asked patients and clinicians about perceived barriers

to diabetes care,^{5,6} we chose an indirect phenomenological approach to provide new insights into the many factors that impact on how individuals manage their diabetes. To explore and reveal barriers to glycaemic control from the patient perspective, themes were organised within the clinical framework of patient-centred medicine (PCM; see Figure 1).⁷

Methods

An interpretative phenomenological method of inquiry attempts to find meaning in, and learn from, participants' subjective experience. Thus, through their stories (already interpreted experiences), and the interpretative lens of the

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researchers, an attempt is made to get as close as possible to what it means to be a person with diabetes. The research team contained individuals of different genders, countries of origin, ethnicities and educational backgrounds: RJ [male, Canada, Caucasian, medicine], JT [female, USA, Caucasian, medicine], RP [female, New Zealand (NZ), Maori, education], JP [male, NZ, Maori, sociology], and JS (female, NZ, Caucasian, nursing). Each participant was interviewed by two of the authors [excluding JS], and all team members scrutinised the neutrality and defensibility of the analysis.

A purposive sample of 15 adults living in Wairoa, NZ were recruited from patients attending the local diabetes clinic, and selected to vary by ethnicity (NZ Maori or NZ European). Participants needed to be able to put their experiences into words, and give written, informed consent to participation. Participants were offered the opportunity to be interviewed in English or Maori.

Participants' experiences of living with diabetes were audiotaped in semi-structured, face-to-face interviews. The interview guide contained broadly focused questions, permitted probes within areas of inquiry, but also allowed for participants' views of 'what mattered'. The interviews began with an 'icebreaker' question. Succeeding questions focused on revealing, within storytelling mode, participants' actual experiences of living with diabetes for example, *'Think back to when you were first told you had diabetes. Tell us about that experience.'* Probes included: *'Who told you?'* *'How did you feel/react to being told you had diabetes?'* Participants were asked about any experiences of diabetes before they themselves were diagnosed, their personal experience of living with diabetes (diagnosis, treatment, starting insulin, complications) and the effects of all of these on themselves and their families. The interviews were transcribed, with identifying information removed.

Meanings of participants' experiences were derived through all team members independently reading each interview several times, before discussion. The participants' stories were then independently extracted by RJ and JT, using an immersion/crystallisation approach.⁸ Interview

WHAT GAP THIS FILLS

What we already know: Despite advances in diabetes management, many barriers to glycaemic control, including non-adherence, have been identified. However, biomedical research has been unable to explain why both clinicians and patients do not always comply with expert recommendations.

What this study adds: This study identifies and explores barriers to glycaemic control from the patient perspective. The barriers have been organised within the clinical framework of patient-centred medicine, providing insight into why both clinicians and patients may struggle to comply with expert recommendations.

Figure 1. Overview of the six components of patient-centred medicine⁷

1. Disease and illness experience

Understanding the disease requires history, examination, and investigation. Understanding illness experience requires an exploration of four dimensions:

- a. *Feelings/fears:* the emotional/psychological responses to the illness
- b. *Ideas on causation:* the intellectual response to the illness
- c. *Effects on functioning:* the impact of the illness on body and lifestyle
- d. *Expectations:* what the person expects of the provider.

2. Understanding the whole person

The meaning of health and illness to a person varies according to their context. Just as the body is made up of a number of interlocking systems, so too, the individual is a part of a family, a community, a culture, a country and an ecology. Clinical information only becomes useful knowledge when it is placed in the context of a particular patient's world. Ignoring context will lead to errors in both the interpretation and application of findings. Patient contexts include the person (life history, developmental stage), and their place in society (family, employment, leisure, finances, culture, as well as spiritual, social and health care supports).

3. Finding common ground

The process through which the patient and doctor reach a mutual understanding and mutual agreement in three key areas:

- a. defining problems and priorities
- b. establishing goals of treatment and/or management
- c. identifying the roles to be assumed by both the patient and the doctor.

4. Incorporating disease prevention and health promotion

This involves health enhancement, risk avoidance, risk reduction, early identification, and complication reduction.

5. Enhancing the doctor–patient relationship

Each consultation is considered an opportunity to improve the doctor–patient relationship: facilitating communication, growing compassion, and building trust, with the ultimate goal of mutual respect and sharing of decision-making and power.

6. Being realistic

This involves being realistic about time and timing, team-building and teamwork, and wise stewardship of resources.

Table 1. Participant characteristics

Participant number	Gender*	Ethnicity†	Age in years	Years since diagnosis (age at diagnosis in years)	Years on insulin therapy	Years from diagnosis until insulin started
1	F	E	61	11 (50)	6	5
2	F	E	66	14 (52)	11	3
3	F	E	90	30 (60)	30	0
4	F	M-E	33	2‡ (31)	2	0‡
5	F	M-E	72	23 (49)	10	13
6	F	M-E	71	14 (56)	1	13
7	F	E	73	10 (63)	3	7
8	M	M	46	16 (30)	3	13
9	F	M	78	53 (25)	7	46
10	M	M	73	19 (54)	7	12
11	M	M	58	17 (41)	11	6
12	F	Fijian-E	64	18 (46)	2	16
13	F	M	47	9 (38)	1	8
14	M	M	60	20 (40)	1	19
15	M	M	57	28 (29)	8	20
Mean	—	—	63.3	18.9 (44.3)	6.9	12.1

* Gender: F female; M male

† Ethnicity: E New Zealand European; M New Zealand Maori

‡ Gestational diabetes mellitus in first pregnancy at age 20; remained on insulin after last pregnancy at age 31

summaries, capturing the individual meanings of what appeared to matter to participants in their reported experiences, were created. Participants were given the opportunity to read and comment on their interview summary, to ensure they had not been misheard. Barriers to glycaemic control were then identified and organised as themes and subthemes within the PCM clinical framework (see Figure 1).⁷ Agreement that the themes were credible was achieved through discussion within the research team.

This study had ethics approval from the Central Regional Ethics Committee (Ref. CEN/07/22/EXP), which required signed informed consent from all participants.

Findings

Table 1 outlines participants' characteristics. Participant quotes are italicised and followed by their identification number from Table 1. The

headings and subheadings of PCM, as outlined in Figure 1, are used to organise the identified barriers to glycaemic control. Only key barriers pertinent to the discussion are provided below. For content relating to headings and subheadings not included in this section see the Appendix published in the web version of this paper.

Disease and illness experience

Feelings/fears

Fear about the illness

Participants expressed fear when they did not know what was happening, what would happen next, and/or when they perceived a loss of control over their lives—i.e. at specific transition events, such as at diagnosis, at the start of oral medication, and at the start of insulin therapy.

At first, I thought, 'oh here we go, I can't work, I can't do anything'. (#2)

[Having diabetes] was no shock, until I went on to have medications and then it was a bit of shock. (#14)

I thought the end of the world was coming when they said I had to have injections. (#9)

Treatment escalation was interpreted as getting closer to disability and death. Fear of treatment escalation was greatest for the introduction of insulin.

Adding gliclazide—I was not happy because I know that each time you need to add another drug you are moving along that continuum, and for me... I felt like once you hit insulin you are on a slide to ...you know [death]. (#13)

I thought, oh boy, once you are on that [insulin] you have not got far to go. I thought I must be on the way out. (#14)

Hypoglycaemia was a terrifying unknown. Some would take active steps to avoid hypoglycaemia, such as missing insulin doses or overeating.

When I had my first hypo, I hit the ground... I thought, I am going to die here. (#13)

To avoid hypos... I won't have my insulin. (#4)

...eat too much. Because I know that does not give me a low. It might give me a high, but it does not give me a low. The highs ... are easier to deal with than the lows. (#7)

Guilt/self-blame

Participants blamed themselves for both getting the disease and not controlling it.

I have type 2 diabetes, which is self-inflicted. (#1)

A good diabetic is one who controls their diabetes ...I am not a good diabetic. (#7)

Accepting blame for both causing and not controlling the disease, participants expressed feelings of guilt and self-blame. Participants repeatedly talked about 'right' and 'wrong' ways to manage diabetes, 'good' and 'bad' foods, and being 'naughty'.

You are always working on guilt. (#4)

I have not managed to do anything that I should do. (#7)

I am very naughty when it comes to sausages. You can put all the meats in front of me and I will always pick sausages. (#12)

Lack of dietary self-control was policed by family members, by friends and workmates, by health care providers, and even by people who barely know them.

I have a brother-in-law and sister who are doctors... and when they are around, that is when I get in trouble if I am seen to be overindulging, they will remind me. (#13)

Everyone brings the cake... and you know they go, oh, you are the diabetic, don't give her any, she is a diabetic. They treat us like we are lepers. (#4)

If you want someone to tell you you have been naughty, you go to the doctor, or you go to [the nurse]. (#4)

I went to the supermarket... This lady was there and I had some lollies in my trolley... I had lots of nice things in my trolley. She proceeded to take them out, because I am not allowed to have them. (#9)

Shame

There was significant reluctance to self-inject insulin in public. Some expressed shame around exposing their body; others did not want people to know they had diabetes. For some, it was the fear of what others might think.

I do not like lifting up my shirt and stabbing myself in front of people. (#8)

Well, there is so much of me that hangs out, that does not get tucked in, I think I would get a wee bit embarrassed. (#5)

Some people are quite ashamed of being diagnosed as a diabetic. (#1)

There is a bit of a stigma. (#4)

[I am] embarrassed to give needle in public... just like a drug addict. (#12)

Ideas/beliefs about causation

Non-scientific health beliefs

A number of non-scientific health beliefs were identified.

Diabetes is caused by eating sugar

He [husband] does not take sugar in his tea, and then he says, I am not going to start that, having sugar in my coffee and tea. I might get diabetes. (#9)

Proper diet will control/cure diabetes

Despite having had diabetes for many years and taking medications, including insulin, participants were still focused on diet as the key to controlling their disease. There appeared to be no understanding of underlying pathologies (e.g. pancreatic failure) that could not be addressed through diet. Even after years of having diabetes some participants still had the unrealistic hope that the disease would 'go away'.

To me if I could get my diet under control, the diabetes would be controlled. (#7)

I am eating the wrong food... that is why the damn thing is out of order. (#11)

I have followed everything by the book. I would not eat anything that I shouldn't have. They say don't eat this, don't eat that, so I have done it, but I still have diabetes. (#2)

I wanted to get cured... that is what I am looking for, to try to get over it. (#8)

Only people with diabetes need to eat a healthy diet

Despite participants believing that poor diet caused their diabetes, there was the conflicting belief that people without diabetes did not have to eat healthily.

He [husband] will take the tin and he will say to me, you are only supposed to have a couple [of biscuits]. He tells me he is the only one allowed to eat what he likes. (#2)

Diabetes is like 'a cold'

Participants initially believed their diabetes, like previous acute illness experiences, would simply go away, or could be managed simply by taking a pill. This belief led some to just ignore their diabetes, especially if they weren't taking medication.

It is just like having a cold... it will come right. (#5)

It was just diabetes... take a pill and that will fix it. (#10)

They [doctors] just says, you are diabetic and I go, nah, nah, because I was not taking no medication. (#8)

Personal/cultural beliefs

Absence of symptoms equates to health

Participants wanted to feel well but relied on their subjective assessment of how they felt in the present moment to decide if they were healthy or not. If they felt healthy (had no symptoms), then they were healthy.

Well, I just feel if I am feeling good, if I feel my body is feeling good... I see myself as healthy, whether I have got diabetes or not. (#2)

Participants noted that diabetes was different from previous illnesses they had experienced because it caused few, if any, symptoms.

You know when you are sick, you know the sickness is with you, coughing and spluttering and all that kind of thing. (#8)

Lack of symptoms meant some did not take their diabetes seriously.

It is one of those illnesses that you are not aware of it. You are not aware of the dangers of it, until all of a sudden, bang, it [complications] has happened. (#7)

In contrast, feeling unwell was a reason to take action.

It was not until I got sick, I really started to do something about it [diabetes]. (#8)

For many, it was not the disease but its treatment that caused symptoms, including hypoglycaemia.

When I take the diabetes drugs, it makes me feel worse, even though it could be long term making me live longer, but short term, it makes me feel bad. (#13)

I do not feel sick with my diabetes. The only thing that affects me now is [when the] blood [glucose] goes down too quick. I do not get sick, but I feel weak. (#14)

Drugs are chemicals to be avoided

Western drugs were seen by some as 'chemicals' to be avoided: some participants were averse to taking any medication.

I can stand a headache without taking any tablets... I would... try some other alternative things. I would go for a run... or have a feed. (#11)

And with the drugs, I do not drink alcohol... I do not smoke, so having to put Western chemicals or medicines, whatever, into the body is something that I am thinking, why do I need to do this? Why do I want to do this? (#13)

Maori cultural beliefs

Maori cultural beliefs were important to some. For participant #13, her cultural beliefs were in direct conflict with using drugs (see previous quote) and needles. She also relied on traditional Maori beliefs and medicinal plants for healing.

The body is tapu [restricted]... it makes me not like poking holes in it [with needles]. (#13)

I have often wondered whether this has been my struggle with medication, that it is my wairua [spirit], knowing that you can do it without [drugs], because... medication has its place, but for me it has been such a hard struggle to allow it in. (#13)

Finding common ground

Participants' comments suggested that clinicians had assumed problems, priorities, goals of treatment, and their respective roles (clinicians to make recommendations; patients to comply with recommendations) were already mutually agreed.

Mutually defining problems and priorities

Patients' beliefs differ from clinicians' beliefs

Participants held beliefs about health, disease, and acceptability of treatments that were fundamentally different from those of clinicians, and would make reaching mutual agreement difficult (see *Non-scientific health beliefs* section).

Mutually defining the goals

Goals imposed by clinician

Participants reported that clinicians just expected them to 'do what they were told'.

I do not remember that there were really any arguments, it was just that this is what you take when you have got diabetes and just, you know, get on and do it. (#13)

Stick to your medication and take them at the right times and do a bit of exercise, your diet, and that is about all. (#14)

Participants believed that diabetes is caused by eating too much sugar and is primarily controlled through diet, which explains why they felt guilty and ashamed for both causing their disease and not 'properly' controlling it.

Cultural differences with regard to diet were particularly mentioned.

I was sent to a dietitian, and I do not know that being told to have something like a packet of raisins and a yoghurt and a piece of fruit for morning tea... I do not know whether they [Maori] could relate to it, because we have a different style of eating. (#13)

There is some good, healthy [Maori] food... not like some of the food dietitians and nurses say you have

got to eat, does not happen, because Maori do not like those sort of food. (#14)

As clinicians had not negotiated mutually agreed goals, participants simply ignored what they had been told to do, especially if it didn't make sense to them. The patient's main goal of wanting to feel well was seemingly unexplored (see *Disease and illness experience* section).

At the time, what they said, what you eat, ...I ignored that too. It was wrong. It cannot be, because this is what I have been eating all my life. (#15)

Goals not individualised

Not only were goals imposed, but some clinicians appeared to make identical recommendations to all patients, without enquiring what the person was currently doing.

I was walking from where Aunty [name] lives to [town], which is mountainous, every morning, and I was probably as fit as I had ever been, so to be told to beef up your exercise, it is like—where do you go with it? (#13)

Discussion

This is the first research investigating barriers to diabetes care that organises findings within the PCM clinical framework.⁷ By listening to the experiences of people with diabetes, multiple barriers to glycaemic control were identified. Many of these have been previously reported,¹ especially in relation to context (family, finances, work) and fears (insulin, hypoglycaemia). By examining barriers from the patient's perspective, biomedicine's labelling of patients as 'non-adherent' can be challenged, and seen for what it is—clinician ignorance: of their patients, of what constitutes a positive therapeutic relationship in chronic disease management, and of the cognitive bias within the biomedical approach to patient non-adherence. This ignorance is a significant barrier to patients becoming chronic disease 'self-managers'.

Our participants expressed negative emotions (fears, guilt, shame) and unscientific beliefs that indicated a poor understanding of diabetes.

Participants believed that diabetes is caused by eating too much sugar and is primarily controlled through diet, which explains why they felt guilty and ashamed for both causing their disease and not 'properly' controlling it. The belief 'if I feel healthy, then I am healthy', shows that participants used symptoms to determine self-management behaviours. Symptom-motivated self-adjustment of medication has been reported in patients with hypertension,⁹ rheumatoid arthritis,¹⁰ and even cancer.¹¹ The unscientific belief that diabetes was a self-limited illness that would just 'go away' with time, was another reason why participants chose to ignore medical recommendations. These emotions and beliefs may be major barriers to clinicians attempting to escalate management for glycaemic control.

This poor understanding of diabetes was despite participants having lived with their disease for many years (Table 1), and despite having received ongoing 'diabetes education'. So while people are being given diabetes education, it would appear that either the wrong information is being given, or the right information is being given but not in a format that allows the patient to understand it sufficiently to positively influence their emotions, beliefs, and self-management behaviours. As one participant said:

I just could not understand what the hell was that. What is diabetes? She [nurse] was sitting there telling me all about it and I was just going... yeah, yeah. (#11)

The biomedical approach to disease management, where the 'expert' tells the patient what to do, is still a common model in diabetes care, both for treatment and education. Rather than educating the patient by empowering them with knowledge that enables them to understand their disease sufficiently to make their own management decisions, patients are simply given a set of provider-chosen rules to follow ('you should... eat these foods, take these pills'). As so aptly put by Hunt et al.¹²

The problem of promoting self-care behaviours is reduced to simply finding ways to educate and motivate people sufficiently so that they will pursue the obviously [expert chosen] right course of action.

This process of education explains why so many patients with diabetes have such a poor understanding of their disease. Lack of knowledge and poor understanding of specific diet plans, medication (action, side effects, schedules, adjustments), and glucose monitoring (i.e. HbA1c) have all been identified as significant barriers to self-management.^{6,7,13} A Cochrane review of 21 studies of Type 2 diabetes examining various interventions to improve patient adherence concluded that diabetes education ‘showed a small effect on a variety of outcomes including HbA1c’.¹⁴ Thus, while patients may undoubtedly be receiving diabetes education, their resultant knowledge and understanding is insufficient to positively influence their emotional reactions to, beliefs about, and self-management of their diabetes.

Clinician ignorance underpins all of the barriers discussed above—an ignorance of the whole patient (i.e. the person’s illness experience and life context); an ignorance of the critical role of a therapeutic relationship based on mutual trust and respect; and an ignorance of how these two key components positively interact. Without this critical understanding, clinicians are unable to use themselves as positive enablers for change.¹⁵ Within the biomedical paradigm, there is the unstated assumption that the disease expert’s role is to make clinical recommendations and the patient’s role is to comply.

I do not remember that there were really any arguments, it was just that this is what you take when you have got diabetes and just, you know, get on and do it. (#13)

This thinking is ‘blind’ to how it devalues the patient’s expert knowledge of self, interferes with shared decision-making, ‘problematises’ only the patients’ perspective, and effectively prevents patients from making well-informed decisions and actively self-managing their disease in the context of their life. This cognitive blind-spot of the biomedical paradigm has been repeatedly pointed out over a number of decades.^{16,17}

We suggest that the source of this cognitive blind-spot is to be found within positivism’s scientific method of inquiry that relies on quantitative methodologies to uncover the truth.

The method assumes the objective observer does not influence the outcome of the experiment. Clinicians, educated within this paradigm, may see themselves as objective observers to an intervention (treating diabetes with drugs) and recorders of the outcome (HbA1c). When analysing the many potential factors responsible for their patients’ poor outcome, it simply does not then occur to the clinician that the very manner with which they approach an investigation into barriers to care will prevent them from seeing that their relationship and interaction could be a significant barrier to their patients self-managing their diabetes.

Within the biomedical paradigm, there is the unstated assumption that the disease expert's role is to make clinical recommendations and the patient's role is to comply.

This study used interpretive phenomenology to gain a better understanding of the lived experience of people with diabetes. This enabled an interpretation that moves beyond past attempts to identify barriers to glycaemic control. Participants stories speak to themes of potential relevance to people with diabetes in all societies, although the ability to generalise findings externally is not critical.¹⁸ The small sample size is unproblematic for that reason and for three other reasons: transferability depends on logical, rather than statistical inference; rich data do not require large numbers; and the concept of data saturation is not part of interpretive phenomenology.¹⁸ This method aims merely to offer credible interpretations of phenomena in experience, and to generate further questions.

This study identifies many barriers to glycaemic control. However, by organising them within the PCM⁷ framework, the greatest barrier would appear to be clinician ignorance of their patients’ fears, beliefs, expectations, context; of the importance of a trusting respectful therapeutic relationship; and of biomedicine’s blindspot regarding the

assumption that patients should simply comply with the recommendations of clinical experts. Faced with a worsening diabetes epidemic, clinicians need to understand that it is they, not their patients, who must change their behaviour.

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COMPETING INTERESTS

None declared.

APPENDIX: Barriers to diabetes care organised within a patient-centred medicine framework

See Figure 1 in the main article for an outline of the patient-centred medicine framework.

1. Disease and illness experience

A. Feeling/fears (about the illness)

- i. **Fear:** Fear was expressed when participants did not know what was happening, what would happen next, and/or when they perceived a loss of control over their lives. Thus fear was expressed at specific transition events such as at diagnosis ('At first, I thought, 'oh here we go, I can't work, I can't do anything.' #2), at the start of oral medication ('[having diabetes] was no shock, until I went on to have medications and then it was a bit of shock.' #14), and at the start of insulin ('I thought the end of the world was coming when they said I had to have injections.' #9).

Treatment escalation was interpreted as getting closer to disability and death ('Adding gliclazide—I was not happy because I know that each time you need to add another drug you are moving along that continuum, and for me... I felt like once you hit insulin you are on a slide to... you know [death]' #13).

Fear of treatment escalation was most marked for the introduction of insulin ('I thought I was on my last legs. I thought, oh boy, once you are on that [insulin] you have not got far to go. I thought I must be on the way out.' #14).

Hypoglycaemia was a terrifying unknown ('When I had my first hypo, I hit the ground... I thought, I am going to die here.' #13). Some would take active steps to avoid hypoglycaemia, like missing insulin doses ('to avoid hypos... I won't have my insulin' #4), or overeating ('eat too much. Because I know that does not give me a low. It might give me a high, but it does not give me a low. The highs I find are easier to deal with than the lows.' #7).

- ii. **Guilt/self-blame:** Participants blamed themselves for both getting the disease ('I have Type 2 diabetes, which is self-inflicted.' #1), and not controlling it ('A good diabetic is one who controls their diabetes by diet... I am not a good diabetic.' #7). Accepting blame for both causing and not controlling the disease, participants expressed feelings of guilt ('you are always working on guilt.' #4) and self-blame ('I have not managed to do anything that I should do.' #7). Participants repeatedly talked about 'right' and 'wrong' ways to manage diabetes, 'good' and 'bad' foods, and being 'naughty'. ('I am very naughty when it comes to sausages. You can put all the meats in front of me and I will always pick sausages.' #12).

Lack of dietary self-control was policed by family members ('I have a brother-in-law and sister who are doctors... and when they are around, that is when I get in trouble if I am seen to be overindulging, they will remind me.' #13), by friends and workmates ('everyone brings the cake around, ... and you know they go, "oh, you are the diabetic, don't give her any, she is a diabetic." They treat us like we are lepers.' #4), by health care providers ('if you want someone to tell you you have been naughty, you go to the doctor, or you go to [the nurse].' #4), and even by people who barely know them ('I went to the supermarket ... This lady was there and I had some lollies in my trolley, I had sugar, I had lots of nice things in my trolley. She proceeded to take them out, because I am not allowed to have them.' #9).

- iii. **Shame:** There was significant reluctance to self-inject insulin in public ('I do not like lifting up my shirt and stabbing myself in front people.' #8). Some expressed shame around exposing their body ('Well, there is so much of me that hangs out, that does not get tucked in, I think I would get a wee bit embarrassed you know.' #5); others did not want people to know they had diabetes ('some people are quite ashamed of being diagnosed as a diabetic' #1); 'there is a bit of a stigma' (#4); for some it was the fear of what others might think ('embarrassed to give needle in public... just like a drug addict.' #12).
- iv. **Despair:** With the diagnosis of diabetes, participants expressed a despair that seems grounded in a sense of lost freedom regarding the inflexibility of the changes expected/needed to control their diabetes, especially around food. There were now rules and routines to be followed that impacted on multiple aspects of their lives and gave them a sense that they had lost control [autonomy] over their lives.

...this is what my missus says to me, you are not allowed to take this, you are not allowed to have sugar, you are not allowed to have that, you are not allowed to have this and I am going, 'far out', what am I doing here then, you know, if I cannot have all these things. #8

...it was miserable ... things you enjoy and you sort of had to push aside, and wife or families, they were having good things and you more or less could not have tea with them. It changed my life a lot. #15

Participants appeared to see only two mutually exclusive choices—enjoyment of food or proper diabetes management. The dietary changes expected seemed so demanding that the only apparent way of reclaiming some autonomy to enjoy their food was to actively break the rules. To justify the occasional dietary indiscretion, some would even accept an earlier death.

Every so often I am guilty of breaking out. I sometimes crave a bit of chocolate and I think, oh, bust, I am 72, yes, perhaps, perhaps I will break out. It does not worry me ... the thought of death does not worry me. I sort of think, well I am this age now and if the worst comes to the worst, well that is it. That is life and it is over, so I have myself some chocolate. #5

I get growled at by the family when they see I am eating something that I should not be having and my latest catch cry has been, "Oh well, if this is the way I am going to die, I can at least die saying I ate everything I wanted. #7

B. Ideas/beliefs

- i. **Non-scientific health beliefs:**
 - a. **Diabetes is caused by eating sugar:** [and 1A-ii: Guilt/self-blame] ('he [husband] does not take sugar in his tea, and then he says, "I am not going to start that, having sugar in my coffee and tea. I might get diabetes"' #9).
 - b. **Proper diet will control/cure my diabetes:** Despite having had diabetes for many years and taking medications, including insulin, participants were still focused on diet as the key to controlling their disease. ('To me if I could get my diet under control, the diabetes would be controlled.' #7; 'if I am eating the wrong food, you know, that is why the damn thing is out of order.' #11). There appeared to be no understanding of underlying pathologies (e.g. pancreatic failure) that could not be addressed through diet ('I have followed everything by the book. I would not eat anything that I shouldn't have. They say don't eat this, don't eat that, so I have done it, but I still have diabetes.' #2). Even after years of having diabetes some

participants still had the unrealistic hope that the disease would still go away ('I wanted to get cured, yeah, ...that is what I am looking for, to try to get over it.' #8).

- c. **Only people with diabetes need to eat a healthy diet:** Despite participants believing that poor diet caused their diabetes, there was the conflicting belief that people without diabetes did not have to eat healthily ('he [husband] will take the tin and he will say to me, "you are only supposed to have a couple [of biscuits]. Don't have any more." He tells me he is the only one allowed to eat what he likes.' #2).
- d. **Diabetes is like 'a cold':** Participants initially believed their diabetes was like previous acute illness experiences and would simply go away ('it is just like having a cold, you know, in other words it will come right' #5), or could be managed simply by taking a pill ('it was just diabetes, yeah right, take a pill and that will fix it.' #10). This belief led some to just ignore their diabetes, especially if they weren't taking medication ('A lot of doctors knew I had diabetes... they just says, "you are diabetic" and I go, "nah, nah", because I was not taking no medication.' #8).

ii. **Personal/cultural beliefs:**

- a. **If I feel healthy [no symptoms], then I am healthy [no need to take action]:** Participants wanted to feel well ('that is all I want to do, you know, feel good, basically.' #8) but relied on their subjective assessment of how they felt in the present moment, to decide if they were healthy or not, ('Well, I just feel if I am feeling good, if I feel my body is feeling good, and I am feeling good, I see myself as healthy, whether I have got diabetes or not.' #2). Participants noted that diabetes was different to previous illnesses they had experienced because it caused few, if any, symptoms ('I never got sick... you know when you are sick, you know the sickness is with you, coughing and spluttering and all that kind of thing.' #8). Lack of symptoms meant some did not take their diabetes seriously ('It is one of those illnesses that you are not aware of it. You are not aware of the dangers of it, until all of a sudden, bang, it [complications] has happened, and then it is too late anyway.' #7).

In contrast, feeling unwell was a reason to take action ('it was not until I got sick [pneumonia], I really started to do something about it [diabetes].' #8). For many, it was not the disease but its treatment that caused symptoms ('When I take the diabetes drugs, it makes me feel worse, even though it could be long term making me live longer, but short term, it makes me feel bad. The metformin gave me terrible nausea, dry retching and was ... why would you want to do this three times a day when you feel so ghastly' #13), including hypoglycaemia ('I do not feel sick with my diabetes. The only thing that affects me now is [when the] blood [glucose] goes down too quick. I do not get sick, but I feel weak.' #14).

- b. **Western drugs as 'chemicals' to be avoided:** Some participants were adverse to taking any medication ('I can stand a headache without taking any tablets... I would usually try some other alternative things. I would go for a run or something, or have a feed.' #11; 'and with the drugs, I do not drink alcohol... and I do not smoke, so having to put Western chemicals or medicines, whatever, into the body is something that I am thinking, why do I need to do this? Why do I want to do this?' #13).
- c. **Maori cultural beliefs:** For participant #13, her cultural beliefs were in direct conflict with using drugs [see quote above] and needles. ('...the body is tapu [restricted]... it makes me not like poking holes in it.' #13). She also relied on traditional Maori beliefs and medicinal plants for healing ('I have often wondered whether this has been my struggle with medication, that

it is my wairua [spirit], knowing that you can do it without [drugs], because... I know that medication has its place, but for me it has been such a hard struggle to allow it in.' #13).

C. Effects on functioning

- i. **Diabetes controls my life:** Our participants described how the medically recommended diabetes treatments imposed lifestyle changes and routines on them, while the side effects of medications could affect how they functioned at home, at work and socially [see also 2B, 2E and 2F].

Participants self-altered their treatment in an attempt to minimise these impacts. For many, it was the medications, not the disease, that made them feel unwell (see also 1B-i [a] in manuscript).

- a. **Imposed routine [frequently resented]:** Participants with good glycaemic control told how diabetes imposed a routine on their lives, to which they gradually adapted. The daily routine of monitoring, meals and medications (pills, insulin) were resented as a 'damn nuisance' and seemed to represent a loss of the freedom to choose how they lived their life (e.g. to eat what they wanted, when they wanted).

It was a nuisance because I was used to not eating for hours and hours and hours, but I could not do that on these pills, so that was a bit of a trial, and my husband would not want to eat, and I would need to eat, not that I wanted to, I would have to eat, and that would be a nuisance. But we got used to it. #1

...it is just a damn nuisance, and when you go away you have to cart all your damn tablets, ... That's the game. It is part of your ... you know, it is part of your life. #12

Even participants with poor glycaemic control expressed this view ('my whole world revolved around my diabetes' #4; 'I have to take these tablets and I have got to eat the rabbit food' #11; 'it was not a very happy... you know, living the way that you are used to and then you had to do big changes, the smoking and the sugar, that was easy enough to control, but other stuff took a while... even still now it has taken a while.' #15).

- b. **Medication side-effects restrict your life:** Side effects of medications posed a problem for one community worker:

When I was taking metformin, it was difficult to work, because I had to leave the building and go home often to use the toilet, because I would not use it on-site, and because I work in the community and I had to visit homes, I had to juggle when the right time was to take the metformin, so I could get through a workday. #13

- c. **Impacts on the family:** Mealtime is usually an important family gathering, but some participants ended up eating different meals, separately from their families (see also 2B).

...it was miserable... and wife or families, they were having good things and you more or less could not have tea with them. It changed my life a lot. #15

- d. **Imposed dietary change:** Participants regularly mentioned the difficulties in following the recommendations for a healthy diet, but interestingly, few participants commented about exercise.

It is like mentally punishing myself, you know, by mentally saying, you know what that is going to do if you eat it, but the other side is saying, well it is not going to hurt you this once. #7

D. Expectations—see also examples in the article

Patients bring their expectations (as well as their fears [1A] and beliefs [1B]) to every clinical encounter, but may not express them unless the clinician enquires.

i. Poor communication:

- a. **Medical jargon:** Participants had trouble understanding their clinicians ('I know to listen to this kind of thing. It was the cure for me, but when you have got big words...' #8). Participant #4, a health care worker, described how she had to translate medical jargon for her family members ('I went to the doctor and he said this, what does he mean? Like I am starting to have to translate a lot of what the doctors say.' #4).
- b. **Little knowledge transfer to patient:** Despite receiving diabetes education on multiple occasions, many found understanding diabetes difficult ('I do not think I got a good explanation... because it was years later that I understood what diabetes was, and how it kind of went along a continuum.' #13; 'I just could not understand what the hell was that. What is diabetes? She [diabetes nurse] was sitting there telling me all about it and I was just going "yeah, yeah".' #11).

- ii. **Insufficient time:** Patients perceived doctors as too busy to spend time helping them ('I have got a good doctor... but they are busy, real busy, and I suppose you have not got time to talk.' #8).

- iii. **Lack of respect [judgmental clinicians]:** Participants described negative interactions with clinicians ('I know that I probably always get a little lecture and I think anybody would dread that.' #13; 'if you want someone to tell you you have been naughty, you go to the doctor, or you go to [the diabetes nurse]' #4).

2. Understanding the whole person

A. Person

B. Proximal context

i. Family:

- a. **Other family members given priority:** Many of the participants made reference to times in their lives when other family members were a higher priority than their diabetes management.

I had three months, May, June, July, August, I lost a brother and it was sudden, and I had a couple of weeks, terrible time, and I was... what actually happened was, I could not remember if I had taken my insulin, and I could not remember if I had taken my pills, and it worried me. #2

...but at that time, [son] was born in 1995 and critically ill, he was born 480 gm and 18 weeks early, so we had been away with him for six months and so, for probably the first five years my whole focus was about keeping [son] alive and so hearing that I had diabetes really was not, it was not paramount for me, and it was not really a shock. #13

ii. **Finances:**

- a. **Cost of doctor visits and drugs:** Despite general practice being heavily subsidised in NZ, patients still have to pay part-charges when visiting a GP and filling a prescription. To those on a low income, even these co-payments can be significant.

...like you have got to have a job, you have got to pay for all those pills and those visits ... I have to have automatic payment on the doctor's thing and chemist... so many people... they live on the bones of their bum, so they do not want to go to the doctor with, you know, 15 bucks is 15 bucks, I suppose, to some people, compared to 30 dollars for some others. Yeah, I feel that was a factor too was the cost, you know, that [...] a lot of people up, but it almost [...] me up, but I said, 'No'. So, when I see the doctor's account I pay 10 bucks a week on it. #11

Cost is a problem. If I went to the doctor plus medication, that was my week's pay gone. #15

Some participants seemed to see no positive benefit of a visit to the doctor, it was just another cost on top of the medication.

...you know, just to go and get my prescriptions, I got to pay to go there, and just to get it when they know I am a diabetic, and I should be getting that kind of thing, but I have still got to pay, and I really do not like that. #8

- iii. **Cost of 'healthy' foods:** Dietary recommendations may not take account of what people can afford.

I might tell her to buy me brown bread and stuff that I have got to have, and sometimes, my stuff is dearer than beer. I try hard to go without things. That was a big change in my life, changing to the foods. #15

- iv. **Fluctuating financial situation:** For some, what was affordable now, may be unaffordable next month.

I got put off... [GP] put me off work in February on a sickness benefit. That changed my life a lot. I was not on much, because the wife was working, and my medication and doctor bills was not enough, was not enough to make my week. Then I got a community card and then I was accepted for \$200 for my doctor bills, so that helped. It is only when the wife works, my benefit drops, but the wife does give me a bit of spending money. #15

v. **Education:**

- a. **Poor literacy:** Some participants had poor reading levels or were illiterate, and struggled to understand the explanations and pamphlets provided. They felt that health professionals needed to provide simple explanations to help them become better educated about their diabetes.

Some of us cannot read, like me. So, better smaller words and a bit more playing on the simple part, be a lot better for the ones who want to know really what to do about it [diabetes]. #8

vi. **Employment:**

- a. **Shift work:** Diabetes management using insulin added new complexities to work, especially for one participant with changing shifts at the meatworks.

I would come off an '18 hour' and the day shift boss would ring me up, says 'hey, can you come in and do a couple of hours, bro.' It was usually about six, so I would go in. #11

Insulin was not easy to take and you would pop it in, but no, I had to wait between shifts, like smoko or lunchtime. I would do it. I would take it all to work and I just do it. #11

With little flexibility on when he could take breaks, and the avoidance of hypoglycaemia on the job critical, he would usually just eat extra food.

...it was really hard because I could not get off the chain. I used to call out to somebody that was walking around, like a board-walker ... and go, 'Hey, do my job for a minute, eh, I will not be long. I have to go and sit out in the dining room.' Just eat something and get my thing [glucose] back up again. #11

I had to really work to like make myself last, and the only way again was through food. I always had breakfast. It would last until morning tea. Always have morning tea. It would last me until lunchtime. That is how it is supposed to be. Now, that is why the lows came in, because of no breakfast. Get to smoko, oh, I will just have a drink, or nothing at all, and when it gets to lunch-time, before you get to lunch you are starting to get all wobbly. #11

- b. **Lack of privacy to give insulin injections:** There were no facilities at work to allow privacy for giving insulin injections.

The only other place was going in the toilet, which I felt was a no, no, because that is where all the disease, sort of, come from, in the toilets, and that was a no, no for me. Actually, it was a no, no in the dressing rooms, but that was the only place you could go, and we had all our stuff, little stuff in the bags in our locker room, locked up, so not too bad. #15

- c. **Mistaken for IV drug users:** There was always the risk that people might think you were injecting IV drugs.

I used to go to my locker, I wanted to have my insulin... and one young chap walks in and sees me having the insulin with the needle and he, poor chappie, he freaked out. #15

- d. **Drug side-effects on the job:** See examples in the article.

vii. **Leisure:**

Participants reported restricting their social interactions, leisure activities and travel.

- a. **Lifestyle restricted by fear of hypoglycaemia:** The fear of having an hypoglycaemic episode when away from home made some participants reduce their leisure activities (see also examples in the article).

I like tramping and so, before I knew I had diabetes we would just get off in the bush and walk for days and camp out overnight. Now, I would have to take more care if I was walking for more than

an hour at a time. I would have to stop and check my sugars. I could go into hypo, which I have sometimes, if I have walked too far. So, you have to prepare yourself more and what would happen if I was three days into the bush and something went wrong. So, you cannot just do what you used to do as easily. #13

...if I went along, have a few drinks and went hypo, or something like that, and the other guys do not really know what is happening, so better not get in that position, might as well stay home. #15

b. **Nuisance of planning:** (See also examples in the article),

...it is just a damn nuisance and when you go away you have to cart all your damn tablets. #12

c. **Reaction of others:** Participants reduced social interactions as a way of avoiding uncomfortable situations with other people (see below—2B viii. social support).

viii. **Social support:**

Participants were embarrassed to let others know they had diabetes for fear of what they would think or do.

a. **Public stigma of injecting insulin:** (See also examples in the article)

b. **Bullying about food:** Participants hid their diabetes, as they had found that people categorised them and treated them negatively, especially to do with food (see also examples in the article).

...half of them do not know that I am a diabetic, but when they do, they sort of... they change... they start to say 'oh, oh, you cannot...' ...they start to get a bit tippy-toe around here and [I] said, 'No, cut that out... just treat me normally, just like with yourself.' #11

Attempts to control participants' diet came not just from family ('I have got a sister-in-law that does annoy me at times because she will just drag that [food] away and say that "you can't touch that, you're diabetic," and that annoys me.' #2) but even from relative strangers ('I was buying this box of chocolates for my daughter. She never buys herself chocolates, because she says it is a luxury. So, I thought oh, I will buy it for her birthday. This lady came in. I don't know her. She took it out of my trolley. She said, "you are a diabetic", she said "take it out", and then it suddenly clicked, she was at a dinner that I was at, and someone said that I was a diabetic.' #9).

C. Distal context

i. **Culture:**

a. **Cultural beliefs:** See examples in the article

3. Finding common ground

It seemed from the participants' comments that clinicians had assumed problems, priorities, goals of treatment, and their respective roles (clinicians to make recommendations; patients to comply with recommendations) were already mutually agreed.

A. Mutually defining problems and priorities

- i. **Patients' beliefs differ from those of clinicians:** Participants held beliefs about health, disease, and acceptability of treatments that were fundamentally different to those of clinicians, and would make reaching mutual agreement difficult [see 1B above].

B. Mutually defining the goals

- i. **Goals imposed by clinician:** Participants reported that clinicians just expected them to do what they were told ('I do not remember that there were really any arguments, it was just that this is what you take when you have got diabetes and just, you know, get on and do it.' #13; 'stick to your medication and take them at the right times and do a bit of exercise, your diet, and that is about all.' #14).

Cultural differences with regard to diet were particularly mentioned ('I was sent to a dietitian, and I do not know that being told to have something like a packet of raisins and a yoghurt and a piece of fruit for morning tea... our people [Maori] get told to eat these tiny little amounts all day... I do not know whether they could relate to it, because we have a different style of eating.' #13; 'There is some good healthy [Maori] food that you enjoy, not like some of the food dieticians and nurses say you have got to eat, does not happen, because Maori do not like those sort of food.' #14).

As clinicians had not negotiated mutually agreed goals, participants simply ignored what they had been told to do, especially if it didn't make sense to them ('At the time, what they said, what you eat, that was... I ignored that too. It was wrong. It cannot be, because this is what I have been eating all my life.' #15). The patient's main goal of wanting to feel well was seemingly unexplored [see 1B-ii (a) above].

- ii. **Goals not individualised:** Not only were goals imposed, but some clinicians appeared to make identical recommendations to all patients, without enquiring what the person was currently doing ('I was walking from where Auntie [name] lives to [town], which is mountainous, every morning, and I was probably as fit as I had ever been, so to be told to beef up your exercise, it is like—where do you go with it?' #13).

4. Incorporating disease prevention/health promotion

A. Disease prevention

Disease prevention and health promotion recommend evidenced-based actions that healthy asymptomatic people can take to maintain or improve their health before symptoms [diseases or complications] occur.

- i. **Symptoms as motivators [take action when symptoms occur]:** see also examples in the article. As discussed above, participants were more primarily symptom-motivated, whether caused by illness or medication. Conversely, if they subjectively felt well, they saw little point in taking medications that made them feel unwell, just to prevent future potential disease complications.

...if I am in pain and I take Panadol and the pain goes away, I think this is good. When I take the diabetes drugs, it makes me feel worse, even though it could be long term making me live longer, but short term, it makes me feel bad. #13

5. Enhancing the doctor/patient relationship

A. Facilitating communication

Many factors may contribute to poor communication and act as barriers to diabetes care.

- i. **Gender differences:** The gender of the doctor may be a barrier.

...I feel more comfortable with a guy, talking to a guy than a lady doctor. I have got nothing against them, but you just... my shyness or something like that, I don't know. #15

- ii. **Ethnic differences:** One participant only took part in this research study because he was able to choose to have a man of his own ethnicity interview him.

...when [diabetes nurse] asked me, and she read out, '[name]' and I says, 'Oh, yeah, I will have him talk to me' because, not saying nothing about you [name], but he was Maori and I have been brought up with a lot of things about Maori. #10

- iii. **Poor communication:** See examples in the article.
- iv. **Insufficient time:** See examples in the article.
- v. **Lack of respect [judgmental clinicians]:** See examples in the article.

B. Growing compassion, building trust, sharing decision-making and power

- i. **Adherence/compliance thinking:** The adherence/compliance paradigm assumes patients will simply adhere with recommended treatments, and when this doesn't occur tends to blame the patient for non-adherence.

- a. **Paternalistic attitude (adherence assumed, patient autonomy ignored):**

I do not remember that there were really any arguments, it was just that this is what you take when you have got diabetes and just, you know, get on and do it. #13

- b. **Blaming patients for non-adherence [contributing to patient guilt]:** see 1D-iii above.

...if you want someone to tell you you have been naughty, you go to the doctor, or you go to [the diabetes nurse]. #4

6. Being realistic

A. Time and timing

- i. **Workload pressure [limited time in the consultation]:** See examples in the article.