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Making sense of change: patients' views of diabetes and GP-led integrated diabetes care

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Abstract

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Background Health system reform is directed towards better management of diabetes. However, change can be difficult, and patients' perspectives are a key aspect of implementing change.

Objective This study investigated patients' perceptions and experiences of type 2 diabetes (T2DM), self-care and engagement with GP-led integrated diabetes care.

Design Qualitative interviews were conducted with purposively selected patients with T2DM following their initial medical appointment in the new model of care. Normalization process theory was used to orientate the thematic analysis, to explain the work of implementing change.

Setting Two specialist GP-based complex diabetes services in primary care in Brisbane, Australia.

Participants Intervention group patients ($n = 30$) in a randomized controlled trial to evaluate a model of GP-led integrated care for complex T2DM.

Main outcome measures Participants' experiences and perceptions of diabetes management and a GP-led model of care.

Results Three themes were identified: sensibility of change, 'diabetic life' and diabetes care alliance. The imperative of change made sense, but some participants experienced dissonance between this rational view and their lived reality. Diabetes invaded life, revealing incongruities between participants' values and living with diabetes. They appreciated a flexible and personalized approach to care.

Discussion Participants responded to advice in ways that seemed rational within the complexities of their life context. Their diabetes

partnerships with health professionals coupled providers' biomedical expertise with patients' contextual expertise.

Conclusions Learning to manage relationships with various health professionals adds to patients' diabetes-related work. Providers need to adopt a flexible, interactive approach and foster trust, to enable better diabetes care.

Background

Chronic diseases, including diabetes, are placing substantial and increasing demands on health systems worldwide. The global prevalence of diabetes is greater than 8% and is continuing to rise.¹ Of the million Australians living with this condition, 85% have type 2 diabetes.² Between 2001 and 2009, hospital-related diabetes expenditure more than doubled, from \$300 to \$647 million,³ while diabetes presentations in primary care increased 32% in the decade to 2009/10.⁴

Management in the primary care setting by general practitioners (GPs) is common for most people with type 2 diabetes in Australia.⁵ Further, it is widely acknowledged that primary care is critical to the diagnosis and quality improvement in diabetes care.⁶ To that end, this sector is undergoing substantial reform in Australia to ensure access to the most appropriate care for people at the right time and in the right place, both now and in the future.⁷ The goals for diabetes patients are to improve care coordination, self-care support and quality of care at the primary–secondary care interface. Strategies include enhancing primary care capacity via up-skilled GPs and multidisciplinary team care.^{7,8} Early evidence about a GP-led model of care for complex diabetes in the primary care setting is encouraging, with better linkages between primary and secondary care and uptake of preventive screening practices.⁹

Still, the progression of systemwide changes to practice is often unpredictable as change in clinical practice can be difficult to achieve, as past examples indicate.^{10,11} Providers differ in response to systemwide reforms such as multi-

disciplinary team care for the management of chronic disease,^{12,13} or in the case of diabetes, may resist the introduction of clinical practice guidelines.⁷ Reluctance to engage in best practice prevention guidelines for diabetes has been linked to providers' lack of confidence and time pressures.¹⁴ Others have also highlighted the administrative, organizational and professional complexities involved in achieving change in practice.^{11,15–17} This has led to a greater interest in understanding how change is implemented and embedded in everyday practices and the elements that might make a difference.^{18–20}

From the patient perspective, a diabetes diagnosis is confronting not the least because of the expectations associated with necessary treatment regimens. More significantly, it is seen to disrupt self-identity, forcing critical self-examination²¹ and typically a protracted process of reconciling the requirements of diabetes management with leading a full life.²² Arguably, much of the empirical focus has been on understanding individual experiences of diabetes, related self-care behaviours and compliance issues. Notably, patients are unlikely to view treatment processes and regimens as health professionals do, as what they value is linked to personal preferences.²³ A study on diabetes services, for example, found that patients preferred primary care providers to be expert in diabetes care,²⁴ although patients with chronic disease also value the combined expertise of different professionals.^{25,26} Patients' engagement in preventive diabetes practices has also been found to be influenced by their relationships and interactions with their GPs.²⁴ In a study by Lu and Harris,²⁷ patients responded positively to GPs who were proactive in managing their health and

who they perceived were professional, knowledgeable and willing to address their concerns. Patients also react differently from health professionals to information about diabetes management, which in turn impacts their self-care.²⁸ This has been linked to communication differences and providers' lack of understanding of patients' lived realities.²⁸ These studies contribute to our understanding of how patients are likely to engage with GP-led integrated diabetes care and possible barriers. However, further empirical work is necessary to uncover patients' perceptions and experiences of engaging with professionally led treatment regimens alongside their own self-management.

The qualitative study reported here examined patient views on their diabetes and self-care and experiences of engagement with a GP-led model of diabetes care in the primary care setting. The aim of this model was to provide diabetes care to patients who would otherwise visit a hospital-based outpatient clinic and consultant for their diabetes management. In the GP-led model, complex diabetes care is provided by a colocated multidisciplinary team comprising an endocrinologist, advanced-skilled GPs (clinical fellows), a credentialed diabetes educator and a podiatrist; with access to other allied health staff on referral depending on patient need.²⁹ Normalization process theory (NPT)^{30,31} was used as a guiding framework to understand not only how patients made sense of their diabetes, but also the work they engaged in for self-management purposes and were expected to do in relation to their interactions with health professionals in a GP-led model of care.³¹ Notably, NPT focuses on the ensemble of tasks and routines both individually enacted and enacted in partnership with health professionals to manage chronic disease.³² For example, NPT has been used in the area of chronic heart failure and is particularly valuable in capturing individuals' experiences of 'health-care work' they undertake themselves and in relationship with health professionals.³² This orientation is particularly relevant to the current research as it provides a framework for eliciting what might be important in engaging patients in improvements in diabetes care.

Methods

Study design

A qualitative study, utilizing in-depth interviews with patients diagnosed with type 2 diabetes receiving a GP-led diabetes service in the primary care setting, was conducted to explore patients' views and experiences of a new model of diabetes care, in comparison with usual care and in relation to the personal meaning and experience of living with diabetes. The qualitative study is part of a multisite mixed methods project incorporating a randomized control trial (RCT) to determine the effectiveness of a GP-led intervention for specialist diabetes care, delivered in a primary care setting.³³ The qualitative study provides an opportunity to expose factors that can facilitate or impede change and ways to enhance adoption and acceptability of the model of care. Patients were interviewed within three months of an initial appointment at a GP-led diabetes service and will be re-interviewed at twelve months to enable a more in-depth analysis of comparison to usual care. This study focuses on the first interview with patients and specifically, the sense they make of diabetes, their self-care and their interactions with health professionals.

Participants

Ethics approval was obtained from Metro South Hospital and Health Service Human Research Ethics Committee, and the Medical Research Ethics Committee at The University of Queensland. Patients randomized to receive the GP-led diabetes care were then purposively sampled. Recruitment occurred in two of the primary care intervention sites to ensure the sample had diverse experiences of the new model of diabetes care. Purposive selection ensured diversity also in terms of age, gender, years with type 2 diabetes and baseline glycated haemoglobin. A sample of 30 interviewees was proposed to reach saturation of themes,³⁴ but the final target number was left open until saturation was confirmed.

The sample was identified from existing participants in the RCT who had consented to a potential interview within three months of their baseline clinic appointment and twelve months later. Patients were contacted by phone by one of the researchers (LB) with information about the study and invited to participate in an interview. For those who agreed, a suitable date and time was negotiated for a home visit to conduct the interview and was confirmed by letter. Of those invited, 23% ($n = 9$) declined to be interviewed, with the most common reason being that they were too busy ($n = 4$).

Data collection

An interview guide, incorporating key topics and open-ended questions linked to the research aims and conceptual ideas of NPT, was used to enhance consistency of inquiry across the data collection process.³⁵ In seeking to understand how participants perceived and experienced their diabetes and its management in the context of receiving GP-led diabetes care, they were asked to talk about their diabetes diagnosis and how they perceived their health currently; their views and experiences of their usual diabetes health care; diabetes self-care experiences; and expectations of their health care over the next twelve months. Interviewees were also given an opportunity at the end of the interview to comment about other issues of importance to them.

All interviews were conducted face-to-face by one of the researchers (LB) and audio-recorded for transcription in a de-identified form. Participants were reassured that their interview content would be treated as confidential and anonymous

and that they were free to discontinue the interview if they so wished, with no adverse effect on their health care.

Data analysis

The approach to analysis commenced with a more deductive process using specified theoretical concepts drawn from NPT. Four key concepts^{31,36} from NPT were used initially as sensitizing concepts to categorize and code the data, then used to guide the interpretative processes in a more inductive way. This enabled us to explore how patients make sense of their diabetes (coherence), how they engage with self-management tasks as well as with health professionals (cognitive participation) and clinic routines (collective action).

To ensure clarity in relation to the aim of the qualitative study, these four conceptual components were contextualized with definitions and questions to guide the analytical process (Table 1). Although the fourth NPT component of 'reflexive monitoring' is mentioned for consistency, we anticipate it will be more fully explored in follow-up interviews. During the inductive process, there were constant comparisons within and across the four conceptual categories to add another layer of analysis and integrate interpretation of the data. This approach to analysis reflects an abductive approach in that 'observations are strategic in the sense that they depend on a theoretically sensitized observer who recognizes their potential relevance. Rather than engaging with the scholarly literature at the end of the research project, as inductivist approaches have often advised, abduction assumes extensive

Table 1 Normalization process theory deductive concepts applied to the change process in diabetes self-care

1 Coherence: (Sense-making work)	2 Cognitive Participation: (Relational work)	3 Collective Action: (Enacting work)	4 Reflexive Monitoring: (Appraisal work)
What sense do patients make of diabetes in their life, and how it can be managed?	How do patients engage personally and interpersonally with diabetes care activities and how do they view this self-care and relational work?	What clinic routines are patients expected to follow, and what resources do they have for this?	What do patients deem to be of value in their clinic-related diabetes care, and what makes these things seem beneficial?

familiarity with existing theories at the outset and throughout every research step' (p. 173).³⁷

The data were hand-coded, because this approach enabled better immersion in the data, and it was a manageable task for the amount of data to be analysed.³⁵ This process was assisted by managing data through a data matrix in an Excel spreadsheet.

The practicality of this modified framework was tested on five transcripts; then, the terminology was refined for greater clarity during the on-going data analysis. This contextualized approach provided a foundation for the subsequent inductive thematic analysis during which themes were derived, compared and interpreted to address the aims of the qualitative component of the research.³⁸ This involved interrogating the data with the guiding questions in Table 1 to identify themes and interpret their meanings.

The thematic analysis involved several steps.³⁹ Firstly, each transcript was read and openly coded into categories defined by the NPT components; next, patterns and exceptions between and within transcripts were noted and reflected on; interesting portions of text were noted; then dimensions were developed to categorize the descriptive concepts; and finally, axial coding was used to construct relationships between dimensions and concepts. Quotations were selected to illustrate the themes and show overall patterns in the findings.³⁵ During this process, the possibility that some portions of text might not fit within the NPT framework was considered. Data to support alternative explanations were sought while seeking a best-fit explanation, and exceptions to patterns were noted.³⁵ Two members of the team (LB and MF) conducted the analysis independently and resolved any disparities through discussion. An audit trail of the analytic process was kept to maximize inter-rater reliability.³⁵

Results

The information in Table 2 was drawn from interviewees' baseline clinical and survey data. Slightly more males (17) than females were recruited and the mean age of participants

was 60.2 years, although most were at least 50 years. Most were retired or reported home duties as the main employment status and most self-reported health as good/very good.

In parallel with the three NPT components, the inductive thematic analysis produced three main themes characterizing the views and experiences of participants with diabetes in this study: (i) sensibility of change; (ii) 'diabetic life'; and (iii) diabetes care alliance (Table 3). Participants generally expressed self-awareness about the need and imperative for change, but the lived reality of diabetes challenged this rationality for some, due to the pervasiveness of diabetes and the difficulty sustaining the burden of self-care and expectations. Nevertheless, participants' experiences overall highlighted the personal change process involved in diabetes self-care. The more personalized approach offered

Table 2 Characteristics of baseline patient interviewees (*n* = 30)

Characteristic	<i>n</i>
Mean age: 60.2 years	
Age groups	
<50 years	6
50–64 years	13
≥65 years	11
Gender	
Females	14
Males	16
Employment status ¹	
Full-time work or self-employed	7
Part-time or casual work	5
Unemployed or unable to work	3
Home duties or retired	14
Mean duration diabetes: 12 years	
Mean age diabetes onset: 49 years	
Mean baseline HbA1c: 8.8%	
HbA1c > 10%	10
HbA1c ≤ 10%	20
Self-rated health ²	
Good or very good	13
Fair	11
Poor	4
Preferred health-care setting ¹	
Primary health care	20
Hospital	7
Both	1

¹1 missing.

²2 missing.

Table 3 Main themes

Themes	Sensibility of change (Coherence)	'Diabetic life' (Cognitive Participation)	Diabetes care alliance (Collective Action)
Definitions	Self-awareness that change is necessary and sensible due to the health risks but experiencing dissonance between the rational view and the lived reality	Personal challenges of managing what is viewed as an invasion of diabetes into all aspects of life and the incongruities between personal values and expectations and living with diabetes	The routines and partnerships in care have to be flexible and individualized to take account of personal contexts and expectations

by the GP-led diabetes service was valued by participants because they perceived their individual needs being of central interest in the helping relationship. Each main theme is discussed in more detail below with representative extracts provided by the participants. Participants were identified by unique codes from P1 to P30, with the site indicated in brackets.

Sensibility of change

The first theme focuses on participants' capacity to appreciate and respond to the implications of their diabetes status. Although facing health risks, participants needed to make sense of change as a priority in their diabetes care before being able to commit to such change. Once committed, however, they often found that implementing recommended changes in their everyday routines was a complicated and difficult process. The imperative of change made rational sense to most participants. They realized and accepted that glycaemic control hinged upon accommodating change now, to minimize the long-term future effects of diabetes on their physical health and quality of life:

Now you can't be, what shall I say, pig-headed about this. You can meet people who say, oh, to hell with this, I'm going to eat what I like. Well, you have to be reasonable, because you do have a longer life if you can measure and manage [P20(1), male, 71 years].

I want to make these changes, and they're telling me 'Yes, these are the right things to do – keep up with them' [P12(1), male, 41 years].

However, for a minority of participants, the prospect of serious diabetes complications seemed to sit outside the limits of rationality, temporarily at least, as these participants could see little logical connection between their current diabetes status and future diabetes complications. This mindset triggered disbelief and disregard for the need to change:

[W]hen I first got sugar diabetes, I didn't realise how bad it was and what it could do to you and all the rest of it. I just thought it was something like the flu or something like this [laughs]. So I just went and shrugged it off and, of course, when you shrug something off, you know yourself, when you've got sugar diabetes you can't shrug it off [P30(2), male, 66 years].

[T]he doom and gloom merchants, they say you've got diabetes, you're going to – your legs are going to fall off your body, your eyes are going to fall out, and all that sort of stuff [laughs]...the continuous, repetitive, negative reinforcement to me is not helpful. It might be to some people, but to me it is definitely not helpful...I saw three doctors down at the local practice and two of them pretty much did that. They gave me a lecture as if I'd never heard it before and blah, blah, blah, and as if that would change my behaviour. Well my behaviour doesn't change by telling me not to do something [P16(2), male, 68 years].

As these extracts suggest, for patients with diabetes who feel relatively well, implementing change entails convincing themselves to agree to make major changes now to minimize complications that seem too remote to be taken as serious risks. Patients may accept or resist the imperative of change, as others⁴⁰ have found.

Resistance may indicate that making sense of the need for change is not a simple process. It is possible that resistant patients are equivocating over the relative value of a disciplined lifestyle when they know their diabetes will progress anyway.⁴¹ These scenarios highlight the significance of the patient–provider interactions and in a GP-led model of care, more likely the central role of the doctor in effectively adapting and framing information to resonate with individual patient realities.⁴²

Even when change did make sense in the interests of glycaemic control, some participants were hampered by dissonance in their struggle with newly imposed disciplines as the first extract below indicates. Moreover, as indicated in the second extract, the pervasive nature of the diabetes struggle could often deplete motivation for self-care.

By the time I get home, I'm tired, I've become really lazy and we'll go and get takeaway, and I know that's not the best thing but sometimes it's the easiest way out for us [P01(1), female, 40 years].

Initially, I was very – very on the ball with looking after it, and then probably after about five years, maybe a bit more, I got – well, now, I basically got jack of it. This is just too much. It's invading every part of my life. So I got quite slack with it, and then probably about – it's actually almost a year ago now, but I thought no, I've got to get serious about this again, so I started doing things to improve myself [P12(1), male, 41 years].

It was not enough for participants to accept diligent on-going self-care as a priority, because strategies to achieve and sustain the recommended changes could be elusive. This inner tension between knowing and doing stood in the way of their progress towards glycaemic control. By ignoring advice or responding to it with contradictory behaviour, participants were perhaps revealing an underlying belief that the tasks were too difficult.⁴³ Participants' dissonance may also have hinted at a shortfall between health professionals' 'checklist' approach to clinical encounters and patients' unmet challenges of implementing advice in the contextual complexity of patients' real world.⁴⁴

In their efforts to make sense of the imperative of change and implement it, patients may experience cycles of pressure, reasoning and attempted adjustment. The daunting and recurring work of establishing and sustaining change corresponds to the coherence and cognitive participation aspects of NPT. This work is largely internal, and its recurring labour is thus easily underestimated. Previous research on patient experiences of chronic heart failure has similarly highlighted a 'treatment burden' linked to day-to-day self-care work, treatment routines and lifestyle changes.³² Moreover, as the theme implies, the relational aspects of living with diabetes, including interactions with health professionals, are likely to be significant to adjustment and change. This is examined in the next theme, 'diabetic life'.

'Diabetic life'

A diabetes diagnosis drafted participants into an experience in which managing the disease seemed to infiltrate all aspects of life, confronting participants with the need to take personal action to manage their diabetes. They were constantly reminded of the reality of a 'diabetic life' and the sustained effort of self-care that was required, although this generated conflicts for some participants who perceived the self-care regimen as a difficult and sometimes unfair burden.

If you don't put the hard yards in, like going to the Biggest Loser, it's really difficult. It goes on really, really easily, but to get it off again, virtually impossible [P11(2), female, 55 years].

'I'll take it for a while, and then go, nah, this is too difficult. You've turned it into a burden and a chore, and it's my health...there are things I've got to do that non-diabetics don't have to, but they don't have to be to the extent where your life becomes completely secondary to it' [P12(1), male, 41 years].

As the above extracts indicate, although over time participants wrestled with keeping control over their diabetes, some perceived control as being subject to an oppressive schedule rather

than a simple matter of compliance. By contrast, breakthroughs occurred that enabled participants to gradually become more actively committed to their diabetes care. These breakthroughs seemed to take place independently of *what* participants had been informed about their diabetes and instead seemed more contingent upon *how* individuals incorporated diabetes knowledge into their personal contexts. In some cases, as these next two extracts illustrate, the breakthrough was the realization of how their actions, or non-actions, were affecting their health.

I was naïve to believe that if I take insulin, everything is okay so I can eat whatever I want. At least for me, it's not working. It has to be all of it together [P03(1), female, 58 years].

I went through [the initial phase] for a little while – nobody is going to dictate to me what I am going to eat...[Later,] I just came to the realisation that I was just harming myself, really. And then I was pretty – I was very, very good for a long time. And then I ate my way out of a depression after the floods, which in turn caused my heart attack, because I was stressed to the max...I thought I was fine, a little bit angry but I was coping. Obviously I wasn't! [P28(1), female, 56 years].

Notably, awareness did not dissuade some participants from experimenting with their regimens. Rather, it was evident that with insights gained over time about their personal diabetes indicators and 'diabetic life'; some participants were willing to push the limits of what was recommended.

I love to eat ice-cream, so if I want to have ice-cream I check my blood sugar at night and if my blood sugar is down to 5.8 or 6, I know I can have two scoops of ice-cream and it won't hurt me. Because it won't – it will only bring my blood sugar up 6.8 or 7.4 or 7.8, it won't put it through the sky [P30(2), male, 66 years].

Everything has to be value calls. It can't be absolute. So for me, [it's] the muffin in the morning. I've tried to cut them down until it's just the ones that I really, really want; because I know my body doesn't like them. I also have very high insulin resistance in the morning, so it's just

doubly bad, but when I'm doing other things elsewhere that are good, it's something I've got to make the call on [P12(1), male, 41 years].

These findings resonate with previous research on the needs of people with type 1 diabetes, which showed how diabetes knowledge and experience helped people adapt in highly personal ways and self-manage the lifestyle restrictions.²¹ In other examples, it was evident that participants over time constructed the 'diabetic life' in such a way that it was a motivator for personal action. In the first example below, the participant was activated by thinking about her 'diabetic life' as a job to be done, while the second participant below integrated the activities of a 'diabetic life' into his sense of self.

I've really had to think this is just another job in the list of jobs that I have to do, but if I want to live a long, healthy life, I need to take control of [the diabetes] [P21(2), female, 52 years].

Taking your medication, taking your diet and once you get into that, it then becomes part of you and then you don't think too much on it. That's how I'm feeling at the moment. Initially I felt, 'Ooh, this is going to be really disrupting my life, this, that and the other'. But, as I said, you have to accept that you've got [this condition] [P20(1), male, 71 years].

As this theme exemplifies, a diabetic life comprises multiple steps of discovery for the individual and about the tasks and routines that make up good self-care. However, the diabetes pathway can be fraught with risk. In addition to the inertia of diabetes-related fatigue, diabetes care regimens can be readily compromised by personal and social factors. Self-care is regarded as a core element of effective diabetes management,⁴⁵ yet implementing it can be complex and confusing in patients' real-world context,⁴⁶ resulting in variable adherence.⁴⁷ If patients discover that effective diabetes management hinges on effective self-care but are unable to achieve it, there is a further risk that they may regard their efforts as futile and the purpose of their care regimen may fail. Klein and Lippa⁴⁸ found that the

crucial element in self-management was not rules and procedures but problem-solving skills for the dynamic scenarios of patients' life context. This hints at both potential inadequacies in training for self-care and the tenacity of patients who persevere with the work of adjusting to the diabetic life.

Diabetes care alliance

Interactions with health professionals and the established routines of clinic attendance were important to the participants. They perceived the clinic routine as more personalized and valued the routine work of physical checks and reviews.

'I feel like they're all looking after me as an individual. I don't feel like I'm a number, I don't feel like I'm a guinea pig or someone that's just going to go through [as] the grist of the mill. I really do feel like they're interested in me' [P13(2), male, 45 years].

As long as someone's keeping an eye on [me]... having my blood test and having the results reviewed is important for me [P19(1), female, 63 years].

Moreover, the routines and personalization of the GP-led model of care appeared to create a positive environment and sense of an alliance with health-care professionals which was conducive to diabetes management.

I think [the community clinic] will help, because I'm now taking an interest in it. If I only went to the GP, I don't think I would have got that interested, because the GP wasn't that interested [P16(2), male, 68 years].

To go along with what the doctors and nurses are saying...I think that is very important. I'm quite happy with [the new care]. Hospitals worry me so I don't particularly want to go to hospitals...[Previously, a private consultant] wouldn't tell me anything on diet. He'd say, 'You need to see a dietician about that.' He was quite abrupt...[whereas now,] I could ring [the diabetes educator] if I wanted to know anything [P18(1), female, 76 years].

However, it is also of note that the alliance was perceived and used differently by participants depending on how they viewed their

role in relation to health-care professionals and in the management of diabetes. For example, some participants perceived their role as following the rules set out by the health professionals and learning to adapt accordingly.

[You] have to stick whatever the doctors tell you to do, and especially the food that you eat, because if you eat the wrong food, that's where the problem is...I want you to know that I am a different person now...because I know if I stick to the rules, I'm happy. And I'm strong. I'm – it's – for me, I'm very happy at the moment because I'm normal now [P05(1), female, 62 years].

You've got to learn to live with it...you do your best, you try and follow all their rules and the things they've taught you and things like that [P23(1), male, 62 years].

Although accepting of health professionals' advice, others were sceptical about merely following rules. This was not an expression of defiance; rather, these participants considered it too simplistic an approach to the complexities of managing diabetes in their life context.

[GPs] just follow a set procedure. This happens, therefore we do that, I'm sure...doctors follow...guidelines that they read and say if we hit this thing we do that. You know, I've solved problems all my life in the computer area, but we don't follow guidelines, we actually go back to the first principles and solve the problem, but it's a different type of problem-solving [P16(2), male, 68 years].

In some cases, participants adopted a surprisingly active role. This was apparent in the extent to which they were prepared to negotiate with a doctor where they felt this was warranted to either hasten or pace specific aspects of their diabetes management:

My GP introduced insulin to me, but it didn't work because I didn't add the tablets that are [now] actually making insulin work in my body. But because it didn't work, I asked to see the specialist [P03(1), female, 58 years].

My GP hasn't pushed me because she knows me, and she knows if she pushes me too hard I'll go

the other way. Knowing your problems and knowing your mental blocks, she can work around it [P02(2), male, 66 years].

In these examples, it is evident that an active patient–health professional alliance is important for engaging patients in the work of diabetes management but likely also a critical factor in sustaining the long-term collective work that diabetes management requires. Patients are already well-informed by their experience-based insights into the dynamics and nuances of managing their care, as others have found in the context of type 1 diabetes.⁴⁹ A less traditional consultation style which gives weight to patients' own goals and preferences alongside clinical goals is key to success in diabetes care,⁴² although no guarantee. However, van Dam *et al.*⁵⁰ reported that GPs using a traditional approach find such change difficult to achieve and sustain, which hints at an under-addressed aspect of medical education. Wanting an active alliance with health professionals is thus not a wish for dependence, as patients need and want a supportive partnership with their diabetes health professionals.

Discussion

This study presents important insights into the work of normalizing type 2 diabetes management from the perspective of patients, but with noteworthy implications for the health professionals who support them. Our findings provide insights into how people begin and undertake the work of change that their diabetes requires of them. These insights enhance our understanding of patients' highly personal self-management work and their engagement with treatment routines and health professionals, thus enabling clinicians to fine-tune their support of individual patients.

The first theme highlighted the paradox of participants knowing how to care for their diabetes yet not necessarily doing so effectively. The imperative of change confronted patients with personal and emotional hurdles that complicated the change process, adding substan-

tially to the work to be carried out. Their approach and commitment to change reflected different risk rationalities, a finding that concurs with Whitehead and Russell,⁵¹ who suggest that many health professionals still use older models of health education that simply provide information and expect patients to change as a result, with little acknowledgement of the challenge-ridden gulf between knowing and changing, and indeed between change and sustained change. Patients live in realities that differ from what health professionals understand and expect of them, and which are constrained by influences beyond patients' control.^{51,52} Our participants *did* respond to the imperative of change, but in ways that seemed rational and consonant with their own circumstances at the time, even though these ways may have differed from the conventional advice of clinicians.

Our second theme focused on the ways in which participants pushed their boundaries as they worked with what diabetes now required of them, in order to adapt it to their life context. Living within different realities, the participants adapted and experienced their diabetes in different ways. This finding supports to some extent the findings of Lawton *et al.*⁵³ who reported that, for some, the perception of diabetes controllability diminishes over time as the disease progresses regardless of compliance with recommended self-care activities, which excuses non-compliance. Some of our participants showed ingenuity and adaptability in their experimental approach to make the diabetes regimen flexible enough to work within their personal and social realities. Whitehead and Russell⁵¹ describe patients' efforts to manage the competition between health-enhancing and health-damaging forces as a balancing act. In our study, participants' risk-taking behaviour conditioned them to understand that apparently minor infringements had little impact on their blood sugar levels while simultaneously providing rations of highly valued quality of life. Although participants listened to health professionals' advice, adopting it was unavoidably influenced by patients' own complex and interacting life context.

In the final theme, the participants' partnership with health professionals highlights the relational milieu likely to be valued by patients. This milieu accommodates health professionals' expert biomedical knowledge *as well as* patients' expert contextual knowledge of daily managing a complicated disease. Working together should make it easier for patients to gain and maintain control of their diabetes by coupling both types of knowledge, as others^{28,54} have suggested, although some health professionals may not welcome an active partnership with their patients.⁵⁵ How this alliance 'plays out' is important in the process of change to achieve effective self-care and improved quality of life. While a previous pilot study⁵ found that patients appreciated being treated as co-members of their diabetes care team, the finding of participants' satisfaction with a compliant role,⁵ is only partially supported in the present research. In the complexities of managing diabetes in their life context, some participants found that rule-keeping did not work as well as their own experimental fine-tuning of health professionals' advice. Compliance neither guarantees glycaemic control nor halts disease progression,⁵⁶ yet rule-keeping for some participants seemed to help stabilize their diabetes and gain acceptable quality of life. Those who were comfortable to *not* comply with prescribed rules of care and instead fine-tuned their own care through experience, also reported acceptable consequences. The implication is for health professionals to adopt a flexible, interactive approach with each patient. While preserving mutual trust within the alliance, patients may or may not adopt providers' advice and routines. The implication for patients is that they must learn to manage not only their diabetes but also their relationships with various health professionals, which adds to their diabetes-related work.

Study limitations

Our findings are based on a small sample drawn from two practice settings in a limited geographical area. However, the novel aspect of this research is our use of NPT to understand the perceptions and experiences of patients in managing diabetes in the context of GP-led diabetes care.

It is possible that contextual differences related to individual practice settings have contributed to participants' views and experiences. We anticipate that the follow-up participant interviews after twelve months will provide opportunity to expand our understanding of patient experiences but more so, to examine in more detail how they are engaging with a GP-led model of diabetes care.

Conclusions

In this study, we have explored patients' experiences of managing their diabetes within a model of GP-led integrated diabetes care, identifying three themes: sensibility of change, 'diabetic life' and diabetes care alliance. Participants lived with the paradox of knowing about diabetes care but with no guarantee of success. For some, this led them to push the boundaries of their regimen to accommodate it in their life context, as well as to seek trust-based relationships with their health professionals to achieve the best clinical outcomes while preserving quality of life. There is potential benefit to patients in the flexible and more contextualized guidance of a GP-led model of care, and we will be interested to explore participants' perceptions of the model at follow-up.

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Conflict of interests

The authors declare that they have no competing interests.

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