

Blood glucose self-monitoring in non-insulin-treated type 2 diabetes: a qualitative study of patients' perspectives

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SUMMARY

Background: Self-monitoring of blood glucose is controversial in the management of type 2 diabetes. Some research suggests that self-monitoring improves glycaemic control, whereas other research is sceptical about its value for people with type 2 diabetes who are not on insulin. Although blood glucose meters are widely available and used by this group, patients' own views are absent from the debate.

Aim: To explore the pros and cons of glucose monitoring from the patients' perspectives.

Design of study: Qualitative repeat-interview study.

Setting: Patients were recruited from 16 general practices and three hospital clinics within four local healthcare cooperatives in Lothian, Scotland.

Method: Interview data from 40 patients diagnosed with type 2 diabetes within the previous 6 months were analysed using thematic analysis informed by grounded theory. We report findings from round 1 and round 2 interviews.

Results: Glucose monitoring can heighten patients' awareness of the impact of lifestyle; for example, dietary choices, on blood glucose levels. Glucose monitoring amplifies a sense of 'success' or 'failure' about self-management, often resulting in anxiety and self-blame if glucose readings remain consistently high. Moreover, monitoring can negatively effect patients' self-management when readings are counter-intuitive.

Conclusion: Our analysis highlights the importance of understanding the meanings that newly diagnosed patients attach to glucose self-monitoring. To maximise the positive effects of self-monitoring, health professionals should ensure that patients understand the purpose of monitoring and should clarify with patients how readings should be interpreted.

Keywords: blood glucose; blood glucose self-monitoring; glucose testing; patient education; qualitative study; type 2 diabetes mellitus.

Introduction

SELF-MONITORING of blood glucose is a contested issue in diabetes management.¹ To date, research on self-monitoring has overwhelmingly relied upon glycosylated haemoglobin (as measured by HbA_{1c}) as the sole outcome measure to evaluate the success or failure of blood glucose self-monitoring.²⁻⁴ Very little research has addressed broader issues, such as quality of life.^{5,6}

Although self-monitoring is considered the 'cornerstone' of diabetes care,⁷ and may improve glycaemic control in patients with type 1 diabetes,⁸ it is of questionable value in type 2 diabetes management.⁹⁻¹¹ Concern has been articulated about the wholesale provision of monitoring equipment without either a clear rationale for use or education to ensure effectiveness, especially given the cost implications to the NHS.^{2,8,10,12,13} Nevertheless, self-monitoring is often recommended for people with type 2 diabetes, particularly those who are newly diagnosed. The meters, which are often provided free of charge from hospital clinics, are widely available from pharmacies and advertised in the media.¹⁴ The use of blood glucose meters is assumed to give more power to patients by encouraging greater involvement in self-care and, in so doing, generate more equal partnerships between patients and health professionals.^{14,15}

However, patients' views about self-monitoring are almost entirely absent from current debates.¹⁶ This paper adds the dimension of patients' perspectives by drawing on the findings of a qualitative study of newly diagnosed type 2 diabetes patients' experiences of services in Lothian, Scotland. We have reported other findings from this study elsewhere.^{17,18,19} The component of the study reported here addresses patients' opinions about blood glucose self-monitoring, using qualitative methods that allow for the exploration of cultural attitudes²⁰ and the meanings that patients attach to this aspect of their disease management.²¹

Method

Recruitment and sample

Following approval from the Lothian Research Ethics Committee, health professionals recruited 40 patients clinically diagnosed with type 2 diabetes in the previous 6 months, either face-to-face or by letter (with an 'opt-in' procedure). Recruitment took place in 16 practices (in four local healthcare cooperatives) and three hospitals in Lothian. This ensured that the sample had diverse experiences of primary and secondary diabetes services. The local healthcare cooperatives spanned poor to affluent and urban to rural areas, enabling the recruitment of participants from different social classes. Purposive selection ensured that the

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HOW THIS FITS IN

What do we know?

Much of the medical literature is sceptical about the value of blood glucose self-monitoring for people with type 2 diabetes who are not taking insulin. Blood glucose meters are widely used by these patients, yet little is known about their own experiences and views of self-monitoring.

What does this paper add?

This study gives an in-depth understanding of patients' perspectives regarding self-monitoring their blood glucose — both positive and negative. Clinical practice could be improved by stressing the purpose of monitoring to patients, and explaining how meter readings should be interpreted.



sample's demographic characteristics were broadly representative of all newly diagnosed type 2 diabetes patients in Lothian/Scotland (Table 1).²² All participants were white, except for one Pakistani woman, and all were treated by diet alone or by diet and metformin and/or gliclazide. Following the first interview, one participant commenced treatment with insulin. His round 2 data has been excluded from this analysis as our emphasis is on non-insulin-treated diabetic patients, although we recognise that people with type 2 diabetes may progress onto insulin treatment.

Qualitative interviews

Forty round 1 interviews were carried out from April 2002–July 2002 and 38 round 2 interviews were carried out from October 2002–January 2003. The total number of interviews was 78, as two participants were not available for interview at round 2. Interviews were held at 6-monthly intervals to maximise the development of rapport, thereby improving the quality of the data, and to assess whether patients' attitudes and interpretations about their diabetes management remained consistent or changed over time. Interviews averaging 1 hour were conducted by the first author. All participants gave informed consent to be interviewed and an interview topic guide was used to elicit discussion of the same issues across the interviews. Interviews were tape recorded with participants' written consent, and transcribed verbatim in full. In round 1 interviews, half of the participants discussed monitoring spontaneously. This led to the inclusion of specific questions on this topic in round 2 interviews. These were: 'Tell me about monitoring your blood sugar', 'Have there been changes in the amount of monitoring you do?' and 'What do you think and do when you get high and low readings?' Participants are referred to by number and interview round; that is, P1.2 refers to participant 1 interviewed at round 2.

Data analysis

Qualitative data analysis is invaluable in explicating interpretations and meanings ascribed to health behaviours.^{23,24} Our analysis was informed by grounded theory, which involves concurrent data collection and analysis.²⁵ This design enabled patients to raise the issues that they perceived as most salient, and allowed themes to be identified and tested during the study that may not have been initially anticipated.

Table 1. Demographic characteristics of sample (n = 40).

Characteristic	n
Sex	
Female	19
Male	21
Age at first interview (years) ^a	
21–40	7
41–50	12
51–60	9
61–70	10
71+	2
Socioeconomic group ²⁶	
I–II	10
IIIN	12
IIIM	13
IV–V	5
Site of recruitment	
General practice	23
Hospital	17

^aMean age = 53.5 years, median = 50 years, range 21–77 years.

As qualitative data analysis involves generating hypotheses and systematically examining the meanings participants attach to phenomena,^{24,27} emergent hypotheses were incorporated into, and examined in, later interviews. We repeatedly examined and cross-compared transcripts, and held regular team meetings to identify recurrent themes within the data and discuss deviant cases.²⁹ In undertaking thematic analysis, we extracted data across interviews and organised it into initial and higher codes once we had achieved consensus regarding salient themes. NUD*IST, a qualitative data indexing package, facilitated data coding and retrieval.

Results

In the round 1 interviews, half of the patients in the study used blood glucose meters and seven did not self-monitor. By round 2, the number of those using meters had increased (Table 2). Most patients reported having been provided with meters from hospital diabetic clinics and had experienced (usually three) structured group-based education sessions, which included instructions on meter use. Some, who had purchased their own meter, reported receiving instructions from a practice nurse. Modes of obtaining meters and amounts of education did not appear to differentially impact on patients' views of glucose monitoring. Psychological issues took precedence in patients' accounts. While patients' accounts remained largely consistent over time, negative views appeared more frankly expressed in round 2 interviews.

Overall, patients provided complex and multifaceted accounts about monitoring. The practical ease or difficulty of the procedure itself appeared less prominent for patients than the psychological impact of monitoring. Some (particularly men) said that they liked the technical sophistication of glucose monitoring, and one described the meter as:

'A great machine.' (P20.2.)

Others found testing:

'No trouble at all.' (P19.2.)

Table 2. Monitoring across interviews.

Mode of monitoring	Round 1 n (%)	Round 2 n (%)
Glucose meter (hospital provided)	15 (37.5)	21 (52.5)
Glucose meter (patient purchased)	5 (12.5)	5 (13.0)
Total glucose monitoring	20 (50.0)	26 (68.4)
Urine testing	13 (32.5)	7 (18.4)
No testing	7 (17.5)	5 (13.0)
Total	40 (100)	38 (100)

and characterised the procedure as:

'Simplicity itself.' (P17.2.)

Generally, patients played down practical problems, but some reported that using the meter was an 'inconvenience' or that:

{It is a} ... *pain in the neck.*' (P22.1.)

Some patients complained that testing did not fit into their lifestyle or work patterns, that the lancets resulted in 'sore' fingers, or that they encountered problems in using the monitor:

{I struggle to} ... *work that darned thing, that machine.*' (P22.2.)

Pros of self-monitoring

For the majority of patients who were asymptomatic, the numerical display of blood glucose figures appeared to render their otherwise invisible and imperceptible illness visible. Heightened 'aware[ness]' and 'evidence' of their condition were, they felt, unambiguously delivered by the meter 'in black and white'. Objective indications of changes in blood glucose were perceived as useful because some patients lacked an understanding of diabetes:

{I am} ... *still not really sure what being diabetic is ... It's not as though one wakes up in the morning and says "Oh this is a seven point nine day."* (P17.2.)

Glucose monitoring was seen as important because, in the absence of diabetic symptoms, it was viewed as a tool for:

'... find[ing] out what's going on inside.' (P1.2.)

In providing a uniform assessment measure, self-monitoring appeared to foster congruence between professionals' evaluations of the disease based on 'laboratory values'²⁹ and patients' own understandings. Importantly, for some patients monitoring affirmed the continued presence of their diabetes post-diagnosis:

'It lets me have an understanding. Because I do think there is, you know, as I say there's been times when I

think, "oh they've made a mistake", you know. It can't be this. But then when you do get a higher reading, you realise, well if your sugar levels can go to that then there is something wrong. So it keeps it in perspective.' (P4.2.)

'I think I was a bit [in denial] in the beginning but it soon sort of hit home that I wasn't but I kind of thought "Oh well now are you sure he's [the doctor] got this blood test right", y'know, but when I started, especially when I got the monitor I thought "well, y'know, it is right because it would be lower than that if it wasn't y'know."' (P40.1.)

Moreover, monitoring provided 'reassurance' and comfort to patients who felt it was:

'... a good aid to control.' (P37.1.)

When patients' glucose readings were within the advised guidelines (4–8 mmol/l) and fluctuations in readings were easily interpretable, they emphasised the positive role that monitoring had in their diabetes management:

'Well it's useful in that it confirmed how I felt about myself, about my health. It confirmed that everything was going along the right road.' (P22.2.)

'It's just sort of comforting to know that it's not going high and it's at the level where it won't cause any complications that's the biggest thing I think ... I find it reassuring.' (P40.1.)

'It's specific, it's there, and again it's motivational as well. You think "I'm still succeeding", y'know, so yes I do find it useful.' (P23.1.)

Many patients described low readings as a high point in their diabetes management. Furthermore, patients often reported personal gratification on obtaining low readings:

{I feel} ... *proud of myself.*' (P32.1.)

{I am} ... *quite pleased I think if I get a low reading 'cos I'm obviously doing something right.'* (P28.1.)

Monitoring appeared to bolster a perception that diabetes management is the patient's responsibility. This was manifest in remarks about the importance of 'keep[ing] an eye on it', often 'for my own peace of mind'. Some patients felt that self-monitoring cultivated independence from health services, and enhanced self-regulation:

{It is} ... *a real help in sticking ... [to a diabetic regimen].*' (P37.1.)

'If I didn't have it [blood glucose meter] I'd be dependent on going up to the doctors or up to the nurse to get my blood taken and sending it away and really making a nuisance of myself like going up there regularly to try and get my blood taken. Whereas if I do it in the house

then there isn't any problem, I mean I'm not inconveniencing anybody.' (P25.1.)

'I feel now that I can sort of regulate it myself, really y'know sort of, I think I know now that, erm sort of, if I start, y'know, if I've eaten something with sugar in it I know the following day then it's going to be, y'know, high ... I know from the day before that, y'know, what I've eaten, y'know, it's sent it up.' (P28.2.)

Additionally, some conveyed the direct impact glucose monitoring had on their diet by encouraging appropriate modifications in the light of higher readings:

'If I think it is high I can maybe cut back on something.' (P38.1.)

'There was a few times for about a fortnight it was away up in the twenties. Then I thought "Right" so I stopped drinking.' (P20.2.)

Cons of self-monitoring

Following the receipt of glucose meters, some patients felt that they became 'obsessed' and others 'paranoid' about their readings:

{I was] ... *letting it rule me.*' (P14.2.)

Excessive monitoring, however, was often temporary and far less evident at round 2. Patients realised that testing could cause some discomfort:

'I have only five fingers and they're all sort of pricked useless.' (P17.2.)

And they tended to reinstate the (often) recommended twice a day, twice weekly monitoring routine. Blood glucose parameters were described as problematic by patients where they felt they were receiving either contradictory information about upper thresholds, or no guidance about ideal parameters:

{I don't know] ... *what you're supposed to [be] in between.*' (P7.1.)

They felt '... hot under the collar' about being left 'in the dark'. Although most patients were clear as to how to counteract hypoglycaemia, many appeared to lack awareness of how to manage hyperglycaemia. One patient commented that:

'If it goes high, and what is too high? I don't know. What do you do to counteract it?' (P35.2.)

Others were uncertain about whether or not health behaviours; for example, taking exercise, would have a positive impact on their glucose levels.

Increased self-responsibility was often accompanied by increased self-blame and negative emotional reactions to high glucose readings:

'The overeating and, er "Oh I had that Kit Kat", y'know, [I'm] angry at myself for being so weak and pathetic.' (P9.2.)

'I'm inclined to worry that, erm, I'm failing to do something as a sense of responsibility and that just hangs round me like an albatross really. I feel "Oh dear I must do something more about it" and, erm, the monitoring has emphasised that, if I may say so. I wasn't so bothered about it before I started monitoring.' (P17.2.)

Experiencing 'scary peaks', as one participant described higher readings, prompted a search for explanations:

'What did I do different from the day before?' (P38.1.)

Overall, participants offered 26 different reasons for high figures. In 22 of these explanations, participants' own behaviour was implicated. Self-blaming accounts mostly focused on eating 'bad' foods, and being lax with diet ($n = 14$). The remaining explanations identified disruptive work patterns and/or stress ($n = 3$), drinking alcohol ($n = 3$), and lack of exercise ($n = 2$). In only four instances did patients not see themselves as culpable; for example, because of equipment failure.

Counter-intuitive glucose readings, inability to 'fathom it out' and not 'know[ing] a reason for' high blood glucose readings all were reported as sources of distress and anxiety:

'If my blood sugars are high and I think they shouldn't be I really get fed up, y'know erm, because unlike with type 1 where you can take insulin and correct it down a bit with this I just take the pills and eat healthily and what I found really [laugh] annoying at times is when I've had a spell of 2 or 3 days as I had recently when I know I've been really hot on the diet, y'know really, really good, erm, and perhaps done a bit of exercise and I find that the readings are high. Y'know, for goodness sake — and then other times when, at a weekend for example, eating something which I probably shouldn't have done ... I find out that the readings are rather better. I find that kinda dispiriting sometimes.' (P3.1.)

'What was getting to me as well was checking my sugar level after having a good day, not going [for] a walk but having had a good day and then checking it later on and it was quite high.' (P7.1.)

'Sometimes if you get, not depressed, but when you're saying "I've not had a bit of sugar today or yesterday and it's so high. I've not had a bit [of] fruit. I've had nothing, to my knowledge with sugar in it and it still reads so high" and you say "I'm going to have a chocolate biscuit, to hell with this ... and suffer the consequences in the morning". In the morning you think this is going to be fifteen or something and you do it and it comes out five [point] two and you go "Eh this just doesn't seem to tally".' (P32.1.)

In some cases (as illustrated by P32.1 above), inexplicable readings adversely effected adherence to diabetic regimens by promoting nihilistic attitudes.

Finally, some patients felt monitoring was 'a waste of time' if health professionals were not interested in their readings. Patients who reported diligently logging their readings were disappointed when doctors were disinterested:

[The doctors were] ... *not the least bit interested in it, and I feel like asking them why the hang did they give me it in the first place.*' (P22.2.)

These comments imply that, contrary to the principles of empowerment, some patients are self-monitoring for its perceived benefit to doctors.

Discussion

Summary of main findings

Our analysis highlights that these patients see both pros and cons in self-monitoring. Positive aspects are that glucose monitoring provides evidence of the continuing presence of their diabetes, low readings can offer reassurance and comfort, and it can encourage self-regulation and regimen modifications. Disadvantages are that patients can become distressed by inexplicable readings, and regularly checking blood glucose can amplify a sense of personal 'failure' when the meter does not provide the message patients are hoping for. This can lead to self-blame and, in some cases, to the abandonment of the diabetic regimen. The findings suggest that, whereas patients with well controlled diabetes view glucose monitoring positively, patients with poorly controlled diabetes are more likely to voice concerns and have problems with self-monitoring.

Strengths and limitations of this study

Exploring patients' views in an in-depth and unstructured format adds an important, and hitherto missing, dimension to monitoring diabetes. Our results highlight the importance of including lay knowledge and social contexts in determining whether glucose monitoring should be encouraged among patients with type 2 diabetes who do not take insulin. Although this was a small qualitative study, a diverse range of patient perspectives were represented. One limitation of the study was that patients' medical records were not available to us, and therefore we could not compare patients' perceptions with glycaemic control measured by HbA_{1c}. It is implicit in our data, however, that some patients' reported disillusionment when doctors did not take an active interest in their self-monitored glucose levels, may stem from the weight placed on HbA_{1c} in shaping the clinical management of the illness. Our repeat-interview study goes some way towards providing a longitudinal perspective, but focused only on those who were newly diagnosed. These patients may provide responses to the technology perhaps less striking in habituated patients. Indeed, getting patients accustomed to using blood glucose meters — because they may later be prescribed insulin — is sometimes a reason for providing meters early on, yet our findings do not wholly substantiate this view. Frequency of self-monitoring seems to decrease when patients' glucose levels are stabilised and/or they feel little new information is gained through monitoring.¹⁴ Issues of monitoring 'fatigue', and/or continued

or renewed interest in self-monitoring, could be explored in future research.

Implications for clinical practice

Self-monitoring equipment is now widely, and often freely, available to patients with type 2 diabetes, and is marketed in our consumerist society as a desirable health-related product. It is likely that the use of this equipment will increase, despite the clinical efficacy remaining inconclusive. For newly diagnosed type 2 diabetic patients who use blood glucose meters, it is clear that what the meter can tell them about their condition and how they are managing it is important to them. We can only speculate why patients often place a great deal of prominence on their meter readings — perhaps it is the meter's technological sophistication or the influence of health professionals — but clinicians should be mindful of this. That participants in this study voiced a range of — often contradictory — views about self-monitoring has important ramifications for the advice and education that health professionals offer patients. Clinicians should discuss monitoring with patients *before* equipment is offered, because health benefits derived from it should not be automatically anticipated. Ascertaining the patient's own position on self-monitoring; why it might be useful for them, and their views about the role of technology in health care, may be helpful in this respect. Health professionals could outline the positives and negatives of monitoring, as highlighted in this paper, to new patients in order to facilitate informed choice.

For these participants, it appears that education sessions were more successful in conveying the practical aspects of how to carry out monitoring than the purpose of monitoring or the interpretation of results. A narrow focus on the procedural elements of glucose monitoring at the expense of contextualising its role in diabetes management, can lead patients to assume that they are monitoring for their doctor's benefit, rather than their own. This suggests that the purpose of monitoring and interpretation of results should be reinforced in education sessions and in future clinical appointments. Checking that patients understand why they are monitoring, and exploring what makes monitoring useful from their perspectives may aid monitoring efficacy. Discussing patients' understandings of their readings and clarifying how readings should be interpreted may also circumvent problems associated with 'high', counter-intuitive, and inexplicable figures.

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