

WHAT IS ALREADY KNOWN ON THIS TOPIC

Quantitative studies have reported a limited psychological effect of screening for type 2 diabetes

Qualitative work has shown that patients with screen detected type 2 diabetes tend to think their disease is not serious

WHAT THIS STUDY ADDS

Participants' perceptions of type 2 diabetes and their risk of developing the disease changed over the course of a diabetes screening programme

The stepwise nature of the screening programme seemed to facilitate psychological adjustment

Participants were uncertain about the meaning of intermediate screening results, and those with negative results were unaware of remaining at high risk

consequences of the disease to justify lifestyle change, without raising anxiety sufficiently to cause disengagement.¹³ Future research could look at diagnostic consultations between health professionals and people with screen detected type 2 diabetes and impaired fasting glucose or impaired glucose tolerance.

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Self monitoring of blood glucose in type 2 diabetes: longitudinal qualitative study of patients' perspectives

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ABSTRACT

Objective To explore views of patients with type 2 diabetes about self monitoring of blood glucose over time.

Design Longitudinal, qualitative study.

Setting Primary and secondary care settings across Lothian, Scotland.

Participants 18 patients with type 2 diabetes.

Main outcome measures Results from repeat in-depth interviews with patients over four years after clinical diagnosis.

Results Analysis revealed three main themes—the role of health professionals, interpreting readings and managing high values, and the ongoing role of blood glucose self monitoring. Self monitoring decreased over time, and health professionals' behaviour seemed crucial in this: participants interpreted doctors' focus on levels of haemoglobin A_{1c}, and lack of perceived interest in meter readings, as indicating that self

monitoring was not worth continuing. Some participants saw readings as a proxy measure of good and bad behaviour—with women especially, chastising themselves when readings were high. Some participants continued to find readings difficult to interpret, with uncertainty about how to respond to high readings. Reassurance and habit were key reasons for continuing. There was little indication that participants were using self monitoring to effect and maintain behaviour change.

Conclusions Clinical uncertainty about the efficacy and role of blood glucose self monitoring in patients with type 2 diabetes is mirrored in patients' own accounts. Patients tended not to act on their self monitoring results, in part because of a lack of education about the appropriate response to readings. Health professionals should be explicit about whether and when such patients should self monitor and how they should interpret and act upon the results, especially high readings.

Box 1 | The role of health professionals on participants' views of blood glucose self monitoring

M1.4—The doctors would be more concerned about the three monthly reading, because that's what your average is, eh, and that didn't take account of my concerns, which were the big spikes I was getting. Erm, but any chat I have with the doctors nowadays, it tends to be on the, the three monthly reading and not the kind of meter readings that I have.

F33.4—Why did I stop? Because it was sore and I didn't like it. And then I kept thinking, "Well I'm filling out this book, nobody ever looks at it." And you go to the doctors, and they take your blood, and they can decide from what your levels are—so why am I inflicting this pain on myself for nothing?

INTRODUCTION

Despite the lack of conclusive evidence of an association between self monitoring of blood glucose and glycaemic control, guidelines often promote such monitoring by patients with type 2 diabetes. The UK National Institute for Clinical Excellence contended that "Self monitoring can be used in conjunction with appropriate therapy as part of integrated self-care."¹ Thus the recommendation to self monitor appears in guidance to doctors, although its benefit remains uncertain.²

Previously, we assessed the views of patients with newly diagnosed diabetes about self monitoring of blood glucose and found positive and negative views.³ Patients with well controlled diabetes viewed self monitoring positively but patients with poorly controlled diabetes were likely to voice concerns.

Here we explore patients' experiences and views of self monitoring over time, responses to high or low readings, reasons for increasing or decreasing self monitoring, and views of the advice and feedback received from health professionals.

METHODS

In 2002-3 we recruited 40 patients with type 2 diabetes diagnosed within the previous six months and interviewed them three times over the following year. The sample reflected the demographic spread of people with type 2 diabetes in Lothian, Scotland, and included patients receiving care in hospital and in general practice. We interviewed 20 of the 21 members of the original cohort three years later (one had died). We found no obvious differences between this subgroup and the original cohort for demographic characteristics or earlier views on self monitoring (see bmj.com).

We report findings from the 18 participants who had ever self monitored their blood glucose. We coded the data pertaining to self monitoring for these participants across their four interviews and looked at whether, and for what reasons, their

experiences of and views about self monitoring had changed. We undertook a thematic analysis. Data are tagged with participants' sex, number, and interview round.

RESULTS

Seven of the participants were self monitoring blood glucose at the start of data collection, rising to 16 at the end of the first year. At the fourth interview, three years later, 10 were still regularly self monitoring. Of these, three were self monitoring twice a day twice weekly (as recommended), five were checking at least weekly or fortnightly, and one was checking three times every other day.

Three main themes emerged: the role of health professionals; interpreting readings and managing high values; and the ongoing role of, and participants' relation with, self monitoring.

The role of health professionals

Participants emphasised the impact that their relationships with general practitioners, diabetes nurses, and diabetologists had on their self monitoring (box 1). Participants were often provided with glucose meters in primary or secondary care settings and received initial education on their use.

No participants reported having been told by health professionals to stop self monitoring nor receiving additional education about monitoring after the first year following diagnosis. By their fourth interview most voiced concerns about the value that health professionals placed on their readings. Participants who had had contact with diabetologists had "got the feeling" (participant F9.4) "that they didn't really bother too much with the day-to-day results" (M17.4).

Over time participants gained the impression that glycated haemoglobin was the more reliable measure on which health professionals based decisions (see M1.4, box 1). This led to some participants regarding self monitoring as less important or even "pointless" (F8.4).

How participants viewed healthcare professionals sometimes seemed to affect their attitude to self monitoring. Older and less well educated participants articulated being interested in what they perceived to be health professionals' attitudes and had, for example, stopped self monitoring because "nobody ever looks at it" (F33.4). Others in these groups did not engage with their readings but simply collected data in the hope that their doctor would take an interest.

Interpreting readings and managing high values

Interpreting readings remained problematic for some participants (box 2), as did counterintuitive readings (F8.4, box 3).³ Four years after diagnosis, for some, self monitoring "was just a number" (F33.4). In part this was because no participants reported receiving ongoing education. Although

Box 2 | Interpreting readings and managing high values from blood glucose self monitoring

Q: And what do you think when it's higher than normal, y'know, higher than the, sort of, 6s?

F15.4: I always says, "I should be dead" (laughs). That's what I usually say. If it's awfae [awfully] high I says, "Well I shouldnae be here." But I don't—that's what I dinnae understand either. I says, "What do you do when it's high?" She [diabetes specialist nurse] never explained that. I've asked Lyn [neighbour with type 1 diabetes] that, but she disnae ken [know] either—when you can get it up, but how do you get it down again.

low readings presented no problem to participants, as they knew that eating would raise their glucose levels, they reported struggling to know what to do in response to high readings.

If participants did implement a lifestyle change in response to high readings, this tended to be an instant solution rather than a permanent alteration such as long term adjustments to diet. For some participants, the self monitoring technology seemed to promote a focus on the "here and now," which could be detrimental to long term health behaviours and decision making. Only three participants were prompted by higher readings to seek medical advice. These participants were well educated and indicated that they took an active role in consultations.

The ongoing role of self monitoring

Healthcare providers' lack of interest in the readings was the reason for some participants discontinuing self monitoring (box 1). Moreover, the ways in which participants made internal or external attributions for their readings affected their attitudes to self monitoring (box 3). Most who had reduced or stopped self monitoring were those who made internal attributions and blamed themselves for high readings. From a biomedical perspective the readings are used to record fluctuation in levels to help understand overall glycaemic control; however, many participants viewed and interpreted readings as a proxy of short term good or bad behaviour. This focus on individual behaviour often centred around diet and eating practices⁴ rather than other aspects of management, such as exercise. Participants did not tend to attribute high readings to disease progression.

This association between self monitoring and individual behaviour was particularly noticeable for women and was closely aligned with a language of self chastisement. Men were more inclined to use a discourse of curiosity (M37.4), and more sanguinely attribute high readings to external causes such as their medication.

Other reasons for reducing or stopping self monitoring were participants' increased awareness of signs and symptoms and having faith in their subjective knowledge of their blood glucose, and consistency in readings.

Reassurance was a key reason for continuing self monitoring, and for some it seemed to have become integrated into their self image or merely routine behaviour ("Just a habit," F36.4).

DISCUSSION

Participants with type 2 diabetes attenuated self monitoring of blood glucose over time for various

Box 3 | Ongoing role of blood glucose self monitoring**Reasons for discontinuing****Self chastisement**

F14.2—It's telling me I'm being bad maybe or not keeping—not being strict enough—and I think, "Oh oh, I ain't using you today," or whatever. I think that's why I don't use it.

F16.4:

A: Some mornings it would be great, other mornings it would be awful. Sometimes at lunch times it was (sigh); you'd think, "What have I had? Oh I had a digestive biscuit, maybe that was it." But they say you can eat a digestive biscuit, y'know. So you bla—try to think, "What on earth's caused it?" y'know.

Q: Yeah and were you about to say you blame yourself?

A: Yeah, yeah.

Q: Which is never—

A: It's not, no, y'know. You think, "Well I've not done that so it shouldnae be high," y'know. And then if you have eaten something and you are high you thought, "Well hell bloody mend you, you shouldnae have eaten that," y'know.

Bodily awareness

M25.4—I normally, I know how I feel—whether sort of high or low, eh, and if I feel OK and take my medication, eh, I dinnae bother taking my blood.

Consistency in readings

M28.4—I stopped about a year ago because I was getting to the stage I was getting the same sort of levels every day . . . it wasn't sort of fluctuating up and down.

Reasons for continuing**Curiosity**

M37.4—My average when I do my morning and evening checks is around what I need, y'know, 7s. I don't know what it is now, I'll just have a quick check for you.

Reassurance

M1.4—[The meter is] there to kind of reassure me when I do sort of sense that something—I don't feel quite right. It's there to kind of give me the—reassure me it's not a hypo' coming on. That's the main thing.

reasons, including health professionals' perceived disinterest in their results. Consistent, stable readings and increased awareness of physical indicators of hyperglycaemia were also reasons for discontinuing. Participants who attributed their results to external causes were more likely to continue self monitoring than those (typically women) who blamed their own behaviour for high readings. Reassurance and habit were key to continuing self monitoring. Interpreting readings and knowing how to act on high readings remained problematic, and there was little indication that participants used self monitoring to guide or maintain behaviour change.

The clinical uncertainty about the benefit of self monitoring seemed to be reflected in the participants' views about it. Our results support research indicating that patients receiving oral treatment tend not to take action based on their readings,⁵ but our study also suggests reasons for this. The role of health professionals is crucial, particularly as patients seem to need more guidance about interpreting and responding to readings (see bmj.com).⁶ If patients cannot understand their glucose fluctuations they cannot modify their behaviour. How to act on high readings was a consistent problem. Some participants had attenuated self monitoring because their readings were stable⁷; some had stopped self monitoring because they had inferred that health professionals did not consider it important. Others continued without engaging with the results. In all cases, participants' accounts showed a lack of an explicit and unified message from their healthcare team. Some practitioner guidelines advise asking for patients' interpretations of their readings,⁸ and this study has highlighted that patients need explicit education and dialogue about whether to continue self monitoring and how to respond to readings.

WHAT IS ALREADY KNOWN ON THIS TOPIC

There is no conclusive evidence for an association between self monitoring of blood glucose and improved glycaemic control in patients with type 2 diabetes

Patients' perspectives about self monitoring are largely absent from debates about the value of the practice

WHAT THIS STUDY ADDS

Patients' use of self monitoring decreases over time, informed by the perceived disinterest of health professionals towards it

Patients find results difficult to interpret and act on, and few patients use self monitoring to guide and maintain changes to their behaviour or lifestyle

Education about blood glucose self monitoring should be explicit, goal oriented, tailored to individual needs, and on a continuous basis

Although our study lends some support to the relevance of sex, age, and social class, it also signals that other factors may influence patients' attitudes to self monitoring. A complex interplay of demographic and personality characteristics may influence whether patients undertake self monitoring and whether it has a positive impact on glycaemic control. We found that different individuals with similar results continued or stopped self monitoring on the basis of factors such as whether they attributed readings to internal or external factors. Therefore education should be tailored to patients' beliefs and values.

Although we studied patients' perspectives about self monitoring, our results may apply to patient administered health technologies more generally. The strengths of this study are that it includes newly diagnosed and veteran patients' views, provides a longitudinal perspective, and addresses self monitoring holistically within patients' broader views about their diabetes and health service provision. The study's weaknesses are that it relied on patients' accounts and neither objective measures of glycaemic control nor health professionals' views were examined. We selected a sample to reflect the spread of patients with diabetes in Lothian, but our findings may not be generalisable to other settings.

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