

Patients' experiences of screening for type 2 diabetes: prospective qualitative study embedded in the ADDITION (Cambridge) randomised controlled trial

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ABSTRACT

Objectives To provide insight into factors that contribute to the anxiety reported in a quantitative study of the psychological effect of screening for type 2 diabetes. To explore expectations of and reactions to the screening experience of patients with positive, negative, and intermediate results.

Design Prospective qualitative interview study of patients attending a screening programme for type 2 diabetes.

Setting Seven general practices in the ADDITION (Cambridge) trial in the east of England.

Participants 23 participants (aged 50-69) attending different stages in the screening process.

Results Participants' perceptions changed as they progressed through the screening programme; the stepwise process seemed to help them adjust psychologically. The first screening test was typically considered unimportant and was attended with no thought about its implications. By the final diagnostic test, type 2 diabetes was considered a strong possibility, albeit a "mild" form. After diagnosis, people with screen detected type 2 diabetes tended to downplay its importance and talked confidently about their plans to control it. Participants with intermediate results seemed uncertain about their diagnosis, and those who screened negative were largely unaware of their remaining high risk.

Conclusions This study helps in understanding the limited psychological impact of screening for type 2 diabetes quantified previously, in particular by the quantitative substudy of ADDITION (Cambridge). The findings have implications for implementing such a screening programme in terms of timing and content.

INTRODUCTION

Type 2 diabetes mellitus is a progressive disease, which can lead to considerable morbidity and mortality as a result of cardiovascular, renal, and retinal complications. Disease onset may occur up to 12 years before clinical diagnosis so many patients are asymptomatic.¹ Screening by measuring blood glucose concentrations can diagnose type 2 diabetes and identify people with impaired fasting glucose or impaired glucose tolerance who are at risk of developing the condition.² Evidence suggests that earlier detection and treatment may lead to improved health outcomes.³ However, it is not clear whether the potential population benefits outweigh the possible costs, which include adverse psychological effects of screening and subsequent treatment.

The Anglo-Danish-Dutch study of intensive treatment in people with screen detected diabetes in primary care⁴ (the ADDITION trial) is evaluating the cost

effectiveness of screening and intensive treatment of screen detected cases. A substudy⁵ of the ADDITION (Cambridge) trial investigating the psychological impact of screening reported minimal adverse effect overall.

We devised a prospective qualitative study to provide insight into the factors that contribute to anxiety during screening, as noted in the quantitative psychological impact substudy of ADDITION (Cambridge), and to explore expectations and reactions to the screening experience of patients with positive, negative, and intermediate results.

METHOD

Participants

We were keen to capture the experience of patients through the entire stepwise screening process. Because only 7% of people in ADDITION (Cambridge) who took the first test (random blood glucose) went on to take the final test (oral glucose tolerance) we sampled at three stages in the screening process. Thirteen participants were interviewed before their final test and after receiving these results, five more were interviewed once after their final results, and five were interviewed after the first test only.

All participants were patients at seven ADDITION (Cambridge) study practices; recruitment was by invitation letter with an opt-in reply slip. The table on bmj.com provides a breakdown of participants' sex and diagnosis.

Data collection

HE conducted all interviews in participants' homes or workplaces; these were audio recorded and transcribed verbatim. All patients gave written consent. Interviews covered the different stages of the screening process (box 1 on bmj.com). The initial question, "Thinking back to when you received the invitation to screening what were your initial feelings?" encouraged participants to tell their story of the screening experience from the beginning.

Analysis

The analysis was informed by grounded theory, involving concurrent data collection and analysis, together with systematic efforts to check and refine emerging categories of data.^{6,7} Themes were not predetermined; rather, those that emerged in early interviews were discussed in team meetings (HE, RD, JL) and were used to inform subsequent interviews and analysis. Throughout the interview and analysis phases, team meetings focused on exploring patients' underlying reasoning, discussing deviant cases, and reaching agreement on recurrent themes and findings. HE and RD

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independently read through and cross compared all transcripts. We used NVivo7 (QSR International), a qualitative data indexing package, to help in data coding and retrieval.

RESULTS

Participants' accounts of their screening experience showed how their perceptions of type 2 diabetes and their own personal risk changed over the course of the stepwise screening programme (box 2 on bmj.com). Participants seemed to undergo a process of psychological adjustment, typically from attending the first screening test without considering its implications, to the final test where they confronted the possibility of having diabetes, as demonstrated by these contrasting quotes:

Patient 5 (male, impaired glucose tolerance, age 69) "I wasn't concerned at all, you know I thought, well I'll just go along and if I can help well okay all well and good, go and see what happens."

Patient 18 (female, impaired glucose tolerance, age 64) "So I go for number one, I go for number two and then I have to go to number three. So it's a build up all the time, making me think, well OK there's a possibility you know . . . there's a strong possibility you know' in that sense [. . .] you've gone through the three, so your brain's adjusted anyway."

Initial stages of the screening process

Participants' reflections on the initial ADDITION invitation letter highlighted an unquestioning perception of screening being "good" (box). Most participants seemed to consider the initial test "routine" and thought little about the implications of the possible results, an attitude typified by one patient's comment that "it can only be a good thing." Attenders rarely expected to test positive, except for one woman who had a family history of diabetes. At this point in the screening process, some participants drew attention to their perceived lack of risk factors such as not having a sweet tooth, whereas others downplayed risk factors such as being overweight. Some participants did not know why they had been invited.

Most participants who tested positive on the first occasion reported being "not unduly worried." A high random blood glucose concentration was often attributed to the food consumed for breakfast or the previous evening. Participants typically reported expecting the next (fasting) test to be negative. Indeed the participants interviewed after the first test all said they were not worried. Accounts of the health professionals' reassuring manner in giving results, particularly their use of the term borderline, seemed to contribute to this lack of concern in some cases.

Prediagnostic test expectations

After testing positive at the second (fasting) test some participants still expected to test negative at the oral glucose tolerance test, one hypothesising that the large number of patients referred for this test meant that only a few would be diabetic. Others now thought if they did

have diabetes it would be a "mild" type because of the lack of symptoms.

All but one participant interviewed before their oral glucose tolerance test had taken in information about type 2 diabetes from the media and from health professionals, friends, and family at this stage. Some reported how diabetes did not seem to affect their friends' lives, furthering positive perceptions of it being a controllable condition.

Reactions after diagnosis (box 4 on bmj.com)

Newly diagnosed type 2 diabetes

The most common reaction to being diagnosed with type 2 diabetes was to downplay its importance; only one participant reported shock. Testing positive at the first two tests seemed to lead participants to adjust their expectations from testing negative to an increased likelihood of having diabetes. A few participants reported symptoms, previously not considered relevant (such as tiredness and thirst), that they now linked to the disease.

The one participant to describe shock was also afraid about the severe consequences of type 2 diabetes. In contrast, the rest emphasised the lack of severity they associated with the disease. All newly diagnosed patients talked confidently about their plans to control the disease; in some cases a diet-only regimen fuelled the perception that their diabetes was mild. Furthermore, most of this group reported being grateful that the screening programme had identified their diabetes at a treatable stage; indeed, one patient described it as "a wake up call" to change his lifestyle.

Intermediate and negative results

Participants with intermediate (impaired fasting glucose or impaired glucose tolerance) or negative oral glucose tolerance test results suggested that they had known they did not have diabetes despite their earlier high readings. Some stated that they would have been surprised if they had been diagnosed, which contrasts with the lack of surprise reported by those who were. Often this belief was reinforced by lack of symptoms, despite being apparently aware of the disease's early asymptomatic period.

Participants diagnosed with an intermediate condition seemed confused. They appeared to be unaware of this diagnostic label, or struggled to explain its meaning, or had received seemingly confused messages from their general practitioner. Most patients seemed unconcerned by their result, often normalising the condition, and reported feeling reassured by their general practitioner or nurse who had recommended simply annual checks. This diagnosis had not triggered lifestyle change even in those who had expressed intentions to change if diagnosed with type 2 diabetes in the pretest interview.

Only one participant, unhappy with his general practitioner's explanation, wanted further information about impaired glucose tolerance. Participants diagnosed with intermediate conditions had mixed views about their likelihood of getting type 2 diabetes in the future. Some patients accepted that lifestyle change would affect their risk of developing diabetes, but none appeared to be aware of the risk of cardiovascular disease associated

with impaired fasting glucose or impaired glucose tolerance.

DISCUSSION

This prospective qualitative study highlights the fluid and changing nature of participants' perceptions at different stages of a stepwise screening programme for type 2 diabetes. The data indicate that participants underwent a process of psychological adjustment as they progressed through the programme. The findings help to explain the low levels of anxiety seen among participants in the ADDITION (Cambridge) screening programme, including those eventually diagnosed with the disease.⁵

Although participants talked about diabetes screening being a good thing—enabling the disease to be detected at an early, supposedly treatable stage—on a personal level most tended to downplay or not engage with their individual risk. Many participants, for instance, talked about attending the first test without considering the possibility of testing positive. Upon receipt of a positive test, there was a tendency to use an explanation other than diabetes and expect the next test to be negative.

By the time of the final diagnostic (oral glucose tolerance) test, participants had had time (nine to 10 weeks) to take in diabetes related information from the media or through conversations with friends, family, or health professionals. They had typically moved to accepting

the increased possibility of being diagnosed with type 2 diabetes, but of a mild and controllable type. Minimising the threat of type 2 diabetes in this way may have helped participants prepare themselves mentally for a positive diagnosis, and helps account for the lack of anxiety seen in these participants.⁵

The confidence that patients diagnosed with type 2 diabetes expressed in their plans to control their disease seemed to be related to several perceptions and factors: the disease having been discovered “at an early stage,” a lack of severe complications,⁸ and being on a diet-only regimen.⁹ Our findings suggest that the duration and stepwise nature of the screening process is also salient, enabling gradual psychological adjustment. However many stages there are in a screening programme, people go through a process of readjusting their expectations of personal risk. In the absence of a stepwise screening process, psychological reactions might be different. Hence, future research should compare the effect of a stepwise screening programme with a one-off diagnostic oral glucose tolerance test.

Patients with intermediate and negative results

Participants with impaired fasting glucose or impaired glucose tolerance tended to lack awareness of this diagnosis or struggled to explain the meaning and its implications. These participants, and those with a negative final test result, also expressed no intentions to change their lifestyles, despite having high blood glucose concentrations in the first few tests and the increased cardiovascular risk associated with impaired glucose tolerance or impaired fasting glucose. Given that many participants had not realised about these risks earlier in the screening process, this finding is unsurprising. It may also indicate a lack of accepted professional understanding and management protocols for treating patients at increased metabolic and cardiovascular risk, a problem previously raised by a qualitative study with general practitioners.¹⁰

Implications

Even patients who tested negative at the first two tests remain at high risk of developing type 2 diabetes (as the risk score identified them in the top quarter for risk).¹¹ Hence, the minimal importance attached to the first test, and relief arising from a negative random or fasting blood glucose test, could undermine the population benefit of a screening programme if these people do not realise that their risk remains high.¹² Thus, patients should be made aware of the risk factors that led to their screening invitation. Furthermore, the lack of intentions to change lifestyle in participants who did not test positive at the final diagnosis raises questions of when and how “risk of diabetes” might be effectively conveyed to patients to motivate changes in lifestyle.

The lack of anxiety associated with the screening programme may suggest a low psychological cost to implementing screening nationally. However, the tendency not to perceive type 2 diabetes as a serious condition is a potential concern. A challenge for health professionals is to convey enough information about the potential

Typical perceptions at initial stages of the screening process

Screening is good

Patient 8 (male, impaired glucose tolerance, age 64) “I didn't really think too much about it 'cause I'm a great believer in preventive medicine if you like. It's like preventive maintenance on the car 'cause if you do it beforehand it saves you a lot of problems later down the line”

Expectations of initial test results

Patient 17 (female, normal, age 58) “I thought I'll just go along and I'd no reason to think there might be anything [diabetes] . . . I've never had a particularly sweet tooth”
 Patient 4 (female, type 2 diabetes, age 58) “I had been given these tests before from my doctor, because of my family. My grandmother and grandfather both had diabetes and nine out of their 11 children had it, including my mother. And my cousins have got it so I would not be surprised if—it wouldn't be a shock anyway”

Reflections on reason for being invited

Patient 11 (male, type 2 diabetes, age 55) “I suppose the criteria they put forward was over 40 and overweight . . . I certainly unfortunately fit into that”
 Patient 3 (male, normal, age 69) “No. No. I don't know why I was invited, I think maybe it's because I've had hypertension 'cause they say that it can lead to diabetes, I don't know”

Unimportant event

Patient 3 (male, normal, age 69) “I know it [random blood glucose] was quite high. But I'd had rather a big meal the night before [. . .] a great big plate of ice cream and two bananas and which I imagine put the blood sugar up quite a lot”
 Patient 5 (male, impaired glucose tolerance, age 69) “I was surprised at that initial test, that it was higher than the ones I've been doing here, but I thought, well these things happen. And I know with my wife at times her readings do fluctuate”

Prediagnostic test expectations

Patient 1 (male, type 2 diabetes, age 61) “If I have got diabetes or any form of diabetes, it's very light anyway, you can control it quite easily. It's not—I don't think for one minute I've got it life threatening. I would be dead by now wouldn't I?”
 Patient 6 (male, impaired fasting glucose, age 50) “Obviously I hope I'm not diabetic and have to inject myself. I've got a couple of friends who are diabetic that do that. But it doesn't seem to have slowed them up too much or worry them”

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.