

**Non-insulin treated patients' understandings
and experiences of self-monitoring of blood
glucose: a qualitative perspective**

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Background (1)

- Promoting SMBG in non-insulin treated patients is controversial
- SMBG *may* help to foster empowerment, motivation and self-care
- Limited evidence that SMBG improves glycaemic control
 - SMBG may result in increased anxiety and depression
- Patients' own perspectives and views have been *omitted or assumed*

Background (2)

- 40 patients newly diagnosed with T2DM
- Data collected 2002/2003
- Study aim: to look at whether the devolvment of Scottish diabetes services impacted on disease self-management
- Interviews conducted at baseline, 6 and 12 months

Background (3)

- Recruitment from 17 General Practices & 3 hospitals
- Sample included: 18 women, 22 men; aged 21-77 years (48 yrs mean); all socio-economic groups.
- Emergent study design
 - Issues arising in early interviews informed areas explored in later ones

Background (4) - A confession...

- Patients not originally asked about SMBG
- Patients raised SMBG spontaneously and in emotive terms
- Flexible, emergent design enabled SMBG to be explored more fully in later interviews
 - Whether and why patients undertook SMBG
 - Understandings of, and responses to, high and low readings
 - Changes in SMBG over time, and why

Background (5) - Follow-up study

- Follow-up interviews conducted in 2006 with 20/40 of original cohort
 - Whether, and for what reasons, patients' attitudes towards, and experiences of, SMBG had changed over 4 years

Findings (1)

Peel E, Parry O, Douglas M, Lawton J. (2004) Blood glucose self-monitoring in non-insulin treated type 2 diabetes: qualitative study of patients' perspectives. *British Journal of General Practice*, 54: 183-188.

Peel E, Douglas M, Lawton J. (2007) Self-monitoring of blood glucose in type 2 diabetes: Longitudinal qualitative study of patients' perspectives. *BMJ*, Aug 2007; doi:10.1136/bmj.39302.444572.DE

Findings (2)

Farmer AJ, Wade AN, French DP, Simon J, Yudkin P, Gray A et al. Blood glucose self-monitoring in type 2 diabetes: a randomised controlled trial. Health Technology Assessment 2009; 13 (15)

- Qualitative sub-study (n=40 patients) from DiGEM Trial
- Reinforcement of findings

Findings (3)

- Steady uptake of SMBG in first year
- Use of SMBG had attenuated at year 4
 - Baseline: 20/40 (50%)
 - 6 months: 26/40 (67%)
 - 12 months: 29/40 (76%)
 - 4 years :10/20 (50%)
- Frequency of monitoring also declined at year 4

Findings (4)

- Most patients given meters at hospital; some purchased their own
- Some education/instruction initially received
- Emphasis on the technical aspects of when and how to monitor
 - Patients generally advised to monitor twice a day, two days a week

Findings (5)

- Newly diagnosed patients reported complex and ambivalent views
- Negative views expressed more frankly at/after 6 months
- Psychological issues more prominent than practical considerations

Findings (6) - pros

- Evidence of presence of diabetes

“[Monitoring] lets me have an understanding. Because I do think there is, you know, as I say there's been times when I think, “och 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.” (R4.2)

- *“Finding out what's going on inside me” (R38.1)*

Findings (7) - pros

- Comfort and reassurance

“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.” (R40.1)

Findings (8) - pros

- Motivation

“I’m quite pleased I think if I get a low reading ‘cos I’m obviously doing something right.” (R28.1)

“There was a few times for about a fortnight it was away up in the twenties. Then I thought “right” so I stopped drinking.” (R20.2)

“If I think it is high I can maybe cut back on something.” (R38.1)

Findings (9) - pros

- Heightening personal responsibility
“Keep an eye on it” for “my own peace of mind” (P1.2)
- Promoting independence and autonomy
“If I didn’t have it [meter] I’d be dependent on going 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 regularly to try and get my blood taken” (P25.1)

Findings (10) - cons

- Anger and self-chastisement

“I’m angry at myself for being so weak willed and pathetic.” (R4.1)

“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.” (R17.2.)

Findings (11) - cons

- Inexplicable readings can lead to low morale
“I’ve had a spell of two or three 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.”
(R3.1)

Findings (12) - cons

- Inexplicable readings detrimental to self-management

“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 had nothing, to my knowledge with sugar in it’ and you say ‘I’m going to have a chocolate biscuit, to hell with this.’ (R32.1)

- Uncertainty about appropriate responses

“If it goes high and what is too high? I don’t know. What do you do to counteract it?” (R35.2)

Findings (13) - a summary so far...

- PROS

- Evidence of diabetes
- Low readings = reassurance/comfort
- Encourages lifestyle modifications
- Promotes independence from health professionals

- CONS

- Self-blame
- Inexplicable readings = distress
- Uncertainty about how to manage 'high' readings

Findings: 4 years later... (1)

- Interpreting readings and dealing with counterintuitive readings still problematic
- Uncertainty about what to do in response to 'high' readings
- No further education received

Findings, 4 years later... (2)

“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.” (R15.4)

“When you monitor, it’s supposed to be between 4 and 8. What I don’t understand is when it jumps up. I know if it goes low, you can eat something to bring it up. What if it goes high, what do you do to bring it down?” (R32.4)

Findings, 4 years later... (3)

- High readings promoted 'quick fix' responses (e.g. temporarily stopping eating) rather than long-term behaviour change
- Technology of monitoring fostered a 'here and now' perception
- Few patients presented to health professionals in response to repeated high readings

Findings, 4 years later... (4)

- Monitoring fatigue
- Stable readings; interpreting bodily symptoms
- Indifferent attitudes of HCPs
- Perception/awareness of HbA_{1c} guiding treatment decisions

Findings, 4 years later... (5)

“Why did I stop? ... 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?” (R33.4)

“But I did gather the impression that they didn’t really bother too much with the day-to-day results ... they certainly didn’t ask for these. In fact, when I did – if I told them about it, they were inclined to say, “Oh it varies very much depending on whether you’ve had a cup of tea or a biscuit or whatever”, you know. At least I got that impression, and it seemed to me that it- it maybe wasn’t worth keeping an eye on all of this” (R17.4)

Conclusions (1)

- SMBG does not promote long-term behaviour change
- SMBG can be a 'poison chalice' from an emotional/psychological perspective
 - Readings perceived as proxy measures of good/bad behaviour
- Patients can blame high readings on themselves rather than seeing them as indicating disease progression

Conclusions (2)

- Lack of an explicit and unified message from HCPs
- Patients need more instruction and advice
- Lack of a clear and transparent guidelines for how to respond to readings

To sum up

