

Refereed article

How people with diabetes integrate self-monitoring of blood glucose into their self-management strategies

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ABSTRACT

Background The benefit of self-monitoring of blood glucose by patients has been questioned, and UK policy is generally not to support this, although it is identified that there may be unidentified subgroups of people who would benefit from being supported to self-monitor. The purpose of this paper is to explore the self-management approaches of people with diabetes, and how self-testing of blood glucose contributes to self-management strategies.

Methods This qualitative study of patients' experiences drew data from contributors to online discussion boards for people living with diabetes. The principles of qualitative content analysis were used on posts from a sample of four Internet discussion boards.

Results Contributors described how they were using self-testing within their self-management strategies. Most saw it as a way of actively maintaining control of their condition. The amount of testing carried varied over time; more testing was done in the early days, when people were still learning how to stay in control of their diabetes. Some people had experienced a lack of support for self-testing from healthcare professionals, or had been expected to change their self-management to fit national policy changes. This was seen as unhelpful, demotivating, stressful, and harmful to the doctor–patient relationship.

Conclusions The Internet is a valuable source of information about peoples' self-management behaviours. Patients who are using, or who wish to use, self-testing as part of their self-management strategy are one of the subgroups for whom self-testing is beneficial and who should be supported to do so.

Keywords: Diabetes mellitus, internet, self-management, self-monitoring blood glucose (SMBG), social media

PATIENTS' PERCEPTIONS OF THE ROLE OF SELF-MONITORING OF BLOOD GLUCOSE AS PART OF SELF-MANAGEMENT OF TYPE 2 DIABETES

Background

Type 2 diabetes is a condition that requires people to make significant behavioural changes to achieve personal goals in nutrition, weight, and exercise to effectively self-manage the condition. It is argued that empowerment is an effective approach to diabetes care,¹ one that is characterized by supporting patients' to make informed choices about their self-management goals.

The ongoing health value of maintaining good control of blood glucose levels has been known since the early 1990s when the Diabetes Control and Complications Trial Research Group² reported on the effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus, finding that 'intensive therapy effectively delays the onset and slows the progression of diabetic retinopathy, nephropathy, and neuropathy in patients with IDDM'.

Home blood glucose testing has become the most widely used means of people monitoring their blood glucose levels to support their self-management. It allows people living with diabetes to have 'real time' information and feedback on the complex interaction between lifestyle, diet, and medications. The alternative, the HbA1c measure, provides an indication of average blood glucose levels over the preceding three months. This can offer good guidance on macro control, but not the daily fluctuations that produce that average.

Although there is little argument about people being treated with insulin, especially those on a basal/bolus regime, needing to undertake self-monitoring of blood glucose (SMBG) the benefits of this for people living with type 2 diabetes who are not on insulin are not as clear with studies presenting conflicting results.

A multicenter, controlled prospective trial with 689 patients with an HbA1c range between 7.5% and 11% at the start of the trial found that SMBG was associated with a statistically significant increase in metabolic control compared with people in the control group who received traditional treatment.³ A total of 453 patients with type 2 diabetes were randomly allocated to one of three treatment groups: usual care, usual care plus BGSM, and usual care plus BGSM plus intensive training in interpretation and application of results in the DiGEM trial. The aim of this trial was to 'address the question of whether BGSM was clinically effective and cost effective in terms of the impact on HbA1c, and whether additionally supporting patients to interpret and act on their blood glucose readings increased the effectiveness'.⁴ After 12 months no significant effect on glycaemic control was found, and fewer of those on the intensive arm of the trial were found to have maintained their monitoring.

A longitudinal qualitative study exploring the views of patients with type 2 diabetes about self-monitoring of glucose over time followed 18 patients over four years from diagnosis.⁵

Reporting in 2007, this paper found little to indicate that self-monitoring was being used to support behavioural change, but also found that healthcare professionals (HCPs) showed little interest in the patients' monitoring diaries. This was identified as a factor that influenced some patients to stop monitoring.

Carrying out effective research into SMBG is very difficult. The studies mentioned all have limitations. One trial was limited to people who already had a high HbA1c.³ These people may not therefore have been motivated to take control of their diabetes, whilst people who were motivated and managing their diabetes effectively were quite likely excluded from the study. This was certainly the case in the DiGEM trial⁴ where people already carrying out SMBG more than twice a week were not eligible for inclusion.

Many of the trials included in systematic reviews were carried out with newly diagnosed people, who may have a different attitude to those who already have experience of living with type 2 diabetes. Even if studies do include people further from diagnosis some people no doubt already have their own views on self-management and may exclude themselves from studies because the requirements for inclusion are incompatible with their preferred self-management behaviours.

One final limitation of clinical trials is that they are of limited duration, for example 24 weeks³ or 52 weeks.⁴ Living with type 2 diabetes is, however, something people will have to do for the rest of their lives, and behaviours and attitudes will change over their lifetime.

In the UK, the National Health Service (NHS) sets the standards of care. In 2010, a health technology assessment (HTA) was produced, reviewing self-testing of blood glucose.⁶ A HTA is a review of evidence of the clinical effectiveness of an intervention. The authors concluded that the case for investment in blood glucose monitoring for patients not being treated with insulin is not proven, and that further research is needed to explore the types of patients who may benefit:

'It is difficult to use the evidence base to define those patients with type 2 diabetes who will gain most benefit from SBGM. Extrapolation from the evidence would suggest that specific subgroups of patients may benefit'.

The question of which subgroups are likely to benefit has not yet been answered, a factor that is, as will be discussed later, causing problems for some people living with type 2 diabetes. Some studies have obtained results that help to shed light on factors that may influence patients' motivation to self-monitor, this paper goes further and identifies one subgroup who not only are very likely to benefit if supported, but may also experience a deterioration in condition if they are not.

Methods

The research aim of this paper was to explore the experiences of SMBG by people living with type 2 diabetes. A qualitative approach was adopted, using experiences shared on public Internet communities. The principles of qualitative content analysis were used on posts made on a sample of

internet discussion boards. Content analysis comprises of three stages: preparation, organizing, and reporting.⁷ All the subjects and the threads within these on the discussion boards were examined, and the posts that were deemed by both of the researchers to contain relevant data were copied verbatim from the boards into Word documents. These documents were used for further analysis.

Sampling

In the preparation stage eight online diabetes discussion boards were identified, and the most active four were selected for inclusion. Activity was judged by a combination of the number of people posting on the board, and the frequency of contributions. All the boards included had multiple daily posts. A total of 126 threads, comprising 1584 individual posts, by 561 contributors, were reviewed.

The nature of these online communities is that they are a place for people living with type 2 diabetes to share experiences and advice. Members' experience of 'living with' ranged from the newly diagnosed trying to come to terms with their new status as a person with type 2 diabetes to those with many years' experience. Management regimes varied from diet only to basal/bolus insulin regimes.

Two of the discussion boards were owned by American organisations, and two by UK ones. The site owner was identified either from information posted about the site, or by checking the ownership of the web address in the WHOIS service. Although the ownership of the site may be in one country participants on the boards come from all over the world, the only limitations being the ability to access the Internet, and the need to be reasonably fluent in English, the language of all the boards included.

Data collection and analysis

All posts made within a one-month period in late 2010 were included in the analysis. In the Organisation stage, which includes coding, creating categories, and abstraction⁷ it was decided to analyse the data manually because of the frequency of misspellings, jargon, and 'web speak', e.g. using LOL ('laugh out loud') to indicate where something was said humorously.

Inductive category development⁸ was used, with the researchers immersing themselves in the data allowing codes and names for categories to emerge from the data, rather than looking for pre-existing categories within the data. Sections that had similar codes were then merged into subcategories. Finally, subcategories dealing with related matters were combined to form categories. To improve dependability⁹ of the analysis each researcher initially coded the posts from two of the four boards, and on completion each researcher then also coded one of the other researcher's boards. Codes and codings were then reviewed. This cross-analysis approach was used to increase the depth of analysis, the second coder providing more perspectives, ensuring that nothing was missed, and identifying those sections where more than one meaning might be derived.

Ethics

Because the paper used information posted on open boards, contributions were considered to be in the public domain.^{10,11} Good practice is to anonymise contributions from open message boards when they are used for research purposes to protect the individual's personal or online identity; therefore, the names and online identities of contributors were replaced by pseudonyms.

The only discussion boards included in the research were those freely available for any Internet user to read. Online, people create nicknames to use on discussion boards, some keeping the same nickname across multiple boards. Pseudonyms were therefore created for the online name given.

Qualitative research norms use direct quotes to show precise meanings and nuances of a situation, however using verbatim quotes from Internet discussion boards would make it possible to trace the contributor by searching for the quoted phrase. Therefore, some minor changes were made to the quoted messages.^{12,13}

Results

In the reporting stage, in recognition of the method of data collection the authors have decided to use the term 'contributor' in preference to 'participant' in presenting and discussing the results. The codes identified were grouped into three major themes, with underpinning contributory themes: proactive testing, HCPs, and emotions.

Proactive testing

Where people were self-testing they offered explanations about how and why they did so.

Testing to support decision-making

Petra advised *'Test everything and the effect that on you it has, then eat to your meter'*. Burgundy, who was waiting for a first appointment with a diabetes nurse, explained that she had started to keep a food diary, but wanted to support that with testing, saying, *'how will I know what foods are ok for me unless I'm testing both before and after I've eaten?'*

Contributors felt that newly diagnosed people in particular need to test to support food choices. Susi explained: *'I feel (testing) is necessary as my diabetes is not under control yet, I was only recently diagnosed as Type 2'*. Another recently diagnosed contributor, PinkLady, considered that: *'You need to know how the food that you are eating is effecting you, especially at the beginning while you're trying to get your head around it'*. Grady provided a detailed account of how he uses testing: *'I'm finding that carb [carbohydrate] counting and changing the kind of carbs is a feedback loop.... e.g., I eat something, I count the carbs, then test and see if my BG level goes over my target. If it does I reduce my carbs (cut the portion size or replace it with an alternative) for that meal'*. Jenny explained how knowing the effect it had on her helped her to resist the temptation she experiences walking past the baker's shop: *'I would really love to eat that fresh*

bread, but lots of testing has told me that I just cannot do it safely’.

Being in control

Caligula explained that he found testing to be essential for staying in control of his type 2 diabetes: *‘The only way to find out what works for you is testing. Your GP or Nurse will probably tell you not to test in this way, that is solely down to cost and the mistaken belief that we will get paranoid! We’re adults and we have choices.. which allow us to control our Diabetes’*. When her test strips were withdrawn Flower felt as if her control had also been taken away: *‘it seems like i have had control taken away from how I want to manage which has made me feel quite disheartened’* Penu feels that his consistently good HbA1c readings are attributed to his SMBG: *‘There’s no way that I could keep my control as tight as it is without my testing’*.

Managing testing

Contributors used sophisticated approaches to managing their testing. Wolfie recommends frequent testing in the early days to find out what effect various foods have, and then reducing the testing, acknowledging that it can be stressful to test excessively. Gunnersfan had also reduced the amount of testing over time: *‘I used to test 6–8 times a day, and I’ll go back to doing it if I see my fasting number start to rise, however after getting my levels into a good range I found that I was no longer learning anything’*. Eastender explained: *‘Now I only really test first thing in the morning or if I’ve had something new to eat or my morning bs [blood sugar] level was unusually high’*.

The importance of not testing for the sake of testing was also recognized. Supa shared the view that *‘Spectator testing – just testing to watch the numbers go up and go down is a waste of time, of money, and of a drop of blood’*.

Healthcare professionals

Quite a lot of contributors felt that their HCPs did not support, and even sometimes actively obstructed, their wishes on self-management. Others found their HCPs to be helpful and supportive. Some had encountered a change in availability of test equipment, an experience that they found difficult to cope with.

Testing not supported

Pussycat explained that she was newly diagnosed and *‘I just feel that I’ve been left floundering – there was no mention of testing my blood sugars & I have little ideas about what I can eat’*. KLM has been diagnosed for three years and is not self-testing *‘as advised [not to] quite insistently by the doctor, who I must say is usually very good’*. Virginia felt her HCP was quite aggressive: *‘Well putting it mildly the nurse recently told me off She had a right old go at me asking who told you that you should self-test? I told you, you only test if your on Insulin... you’ll make a mess of your fingers, anyone who tells you to test is WRONG... I usually keep so positive but I feel as if I just can’t be bothered anymore’*.

Support for testing withdrawn

NHS policy was blamed for the stopping of prescribing test strips by some contributors. Angel found that her GP ‘cited NHS advice—no test strips for type 2’s as did Picton: ‘When I first found out I was diabetic last November, my GP allowed me to have test strips. ... Three months later, all of a sudden I was told I was not allowed any more as the government was no longer giving T2 diabetics blood strips as they were not needed’. StokeBloke explained how he found out his prescription for test strips had been changed: *‘I rang today for my repeat and was told that a blanket instruction has been given by the Primary care Trust to stop giving test strips for Typ 2’s. My DN [Nurse] says it’s out of her hands’*.

ForeverT2 describes successfully managing blood glucose when self-testing, but having poorer control when this was stopped: *‘My GP stopped me from testing myself about 2 years back, since then I have never self-tested. When I stopped testing, I had reduced my HbA1c from 9.4 at my initial diagnosis down to between 6.8 and 7.1 using only Metformin and diet. Since I stopped it has ranged from 7.8 to 8.6, and is slowly rising’*. How withdrawal of strips feels was summed up by CR147, saying: *‘You get the diagnosis, take control, do well and they pay you back by taking away the very test strips that helped you to get things under control’*.

Fighting for test strips

Some contributors explained that they felt they had to fight to get their HCPs to prescribe test strips. Peru feels that he is not supported to be proactive: *‘When you try to adopt a pro-active approach to management of (diabetes) you have to fight tooth and nail to get what you want’*. Petra described her success: *‘she did give me the testing strips, though I had to fight for them, having been told we “don’t like giving them to Type 2’s”*. PeterPiper felt that his GP only ‘prescribed them begrudgingly’ after he had shown her the food diary he had kept after buying test strips himself.

Dragon describes struggling with having her test strips reduced: *‘I just can’t bear to fight it yet know I must test a bit more (than once or twice a week), especially when I eat something different and trying to avoid spikes which would be missed. I don’t test every day any more. I test selectively. But the advice (from the GP) still destabilises me – which is why I haven’t been for an HbA1c for 6 months I think’*.

StokeBloke went as far as appealing to his PCT and was invited to a meeting: *‘I explained to her how i manage my food, exercise and medication on a daily basis to keep my BG control really tight. I took all my diaries showing what I eat every day, how I measure all my food, carbs and calories and how this relates to tablets, exercise and my daily BG levels.... Test strips have been reinstated’*.

Buying my own

Some people found their own solution to HCPs not providing test strips on prescription, by buying their own equipment, although as SueM highlights not everyone can afford this solution.

Bowler felt that having to fight to obtain test strips was leaving him very 'stressed out'. He explains that: *'I stopped (fighting) and found a source from Ebay, BG was under control with a lot less stress'*. Not everyone, however, can always afford to fill the gap themselves. SueM feels: *'Our health is at risk if we don't test from the complications that it can bring. They will cost the NHS more than if they prescribed testing strips. The trouble is we take our health seriously so end up buying our own. I'm retired now, so on a pension and it's hard going, particularly at this time of the year as there's also the need to keep warm'*.

In addition to the cost of having to buy test strips, NewKid explains how not having strips provided makes her feel: *'i have always had to buy my strips i asked and asked the drs but they wouldn't give me them, i get mine online and they are about £23 i know its alot but a lot cheaper than from the chemist, i think it is terrible its like saying aww you have only type 2 it doesn't matter about you'*.

Emotions

Contributors expressed a variety of emotions experienced in trying to manage their diabetes. Grady said: *'Using your meter to work out what is actually happening is a good way to stay sane'*. Susie used testing as a way of maintaining willpower: *'outta sight outta mind – if you dont chek it, you eat the wrong foods because you think hey I can cheat today because i don't have to check my sugars'*.

Having test strips withdrawn evoked a range of emotions. Some people expressed anger and frustration, with DMum saying: *'My diabetes has never cost the NHS anything and am extremely angry that i can now only test once or twice a day. i feel like the control of my condition has been snatched away from me'*. Stokebloke discussed how worried it made him feel: *'Since my strips were stopped I have been feeling really down It feels like they are snubbing me for controlling my blood glucose so well. I am totally gutted and worried what to do next'*.

Others described the experience as demotivating. ForeverT2 said: *'I lost heart in controlling my disease when my doctor told me to stop'*, Flower says: *'I'm pretty disheartened'*. Angel described herself as being *'most unhappy since I felt that I was at least trying to be proactive so I ended up paying £25.99 [\$41] for peace of mind'*.

Discussion

An overriding theme that emerged is the one of patient-driven self-management. This is a phenomena that is overlooked in the diabetes self-management literature which focuses rather on HCP-driven self-management, looking at techniques that diabetes educators use,¹⁴ success elements of education programmes,¹⁵ and HCP behaviours.¹⁶

The contributors in this paper, however, were taking the lead in self-managing their diabetes, and were discussing using sophisticated SMBG techniques to support this self-management. Most wanted to maintain a good working relationship with their HCPs, as this was seen as an important element of self-management. The relationships being reported, however, were not always seen as being

helpful, especially when the contributor and their HCP had different views on the need to self-test. Contributors did discuss ways of managing the relationship but the HCP was frequently seen as a gatekeeper who could grant or withhold resources that contributors felt were essential to their effective self-management. In some cases contributors felt so strongly about their preferred self-testing regime that they circumvented their HCP and bought the supplies they needed themselves. This option was only available to people who felt they had enough money to do this, and even then it generated an ongoing negative view of the HCP and damaged relationships.

The DiGEM trial found that after 12 months just over half of the people allocated to the intensive testing arm of the trial had stopped undertaking SMBG.⁴ The trial design allocated people to either the less or more intensive regimes for the entire 12-month duration of the paper. This paper, however, found that self-managing testers changed their testing behaviours over time rather than maintaining the same testing habits. They tested frequently in the early days of living with type 2 diabetes, using testing to understand the effect certain foods have on their blood glucose. Once they gained confidence in this they reduced their testing, making rational decisions about when to, and when not to, test.

People living with type 2 diabetes frequently used terms that showed they felt testing helped them to maintain control of their experience. Having test strips withdrawn was a demotivating experience, which one contributor reported as affecting mental as well as physical health. As it is recognized that people living with type 2 diabetes can have more incidence of depression¹⁷ this should be a matter of concern for HCPs. The emotions expressed by the contributors show that SMBG is a coping mechanism, helping to 'keep me sane' as well as a way of trying to manage the experience of living with type 2 diabetes.

Perhaps the most important result from this research is the insight that social media has afforded in helping to understand self-management strategies of the population who are motivated to take control of their type 2 diabetes. They use SMBG in a proactive way, as a self-education tool, and adapt their testing regimes to meet their changing needs over time. Importantly, they look for their HCP to be a source of help and support in the management of their condition. Diabetes is a condition that people will live with for a long time. The majority of that time they have to manage alone. HCPs, therefore need to be aware of their patient's needs as well as the health service priorities and interpret those policies within a framework of patient empowerment.

CONCLUSIONS

This paper has shown that well motivated people living with type 2 diabetes can make decisions about their self-management, creating sophisticated self-management strategies that integrate SMBG into their daily lives as an essential mechanism to help them manage their condition. People who had adopted such self-management strategies

but then found support withdrawn felt a range of emotions, and even became demotivated in maintaining their previous good self-management. This research has found that people who initiate (or seek to initiate) self-monitoring within a self-management strategy should be considered to be one of

the 'specific subgroups of patients' that will benefit from self-monitoring, and should be supported by their HCPs.

Competing interests

The author(s) declare that they have no competing interests.

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