Use of Self Glucose Monitors Among Type 2 PWDs: Patient Perspectives

by Amy Tenderich, MA

Abstract

In Brief

This article reviews the controversial topic of self-monitoring of blood glucose (SMBG), often referred to as "home glucose monitoring," in persons with type 2 diabetes. It presents a brief overview of the medical differences of opinion on this topic, and then provides results of an online survey in which 732 patients were queried about the extent of training they received on using a glucose meter, their satisfaction with this training, how they employ their meters, and their general thoughts and feelings about SMBG.

Purpose

To explore the self-reported experiences of type 2 diabetes patients around the country with regards to use of a self glucose meter.

Introduction

The clinical value of regular SMBG (self-monitoring of blood glucose), or "home glucose testing" in type 2 diabetes is quite controversial. A number of studies have found either no significant differences in A1C outcomes in groups that were testing versus not testing, or "no evidence that SMBG confers benefits for outcomes other than A1C such as mortality, long-term complications of diabetes, body weight, patient satisfaction, or quality of life."¹

Other studies indicate there is "little indication that (patients are) using self monitoring to affect and maintain behavior change."²

A summary of observational studies by the International Diabetes Federation (IDF)³ illustrates the difficulty of comparing SMBG outcomes in various groups of type 2 patients, including a wide variety of treatment regimens, from diet alone to oral or injectable glucose-lowering meds that may cause risk of hypoglycemia, to varying timing/frequency of SMBG.

IDF's ambiguous recommendation: “SMBG should be used only when individuals with diabetes (and/or their care-givers) and/or their healthcare providers have the knowledge, skills and willingness to incorporate SMBG monitoring and therapy adjustment into their diabetes care plan in order to attain agreed treatment goals.”

Meanwhile, the American Association of Diabetes Educators (AADE)⁴ and American Association of Clinical Endocrinologists (AACE)⁵ both indicate that SMBG may be beneficial for patients not requiring insulin therapy, to provide feedback about the effects of their lifestyle and pharmacologic therapy, and that “testing frequency must be personalized.”
In a 2012 Standards of Medical Care\(^6\) assessment, the American Diabetes Association (ADA) states that “the optimal frequency and timing of SMBG for patients with type 2 diabetes on non-insulin therapy is unclear.” And they further note: “Several randomized trials have called into question the clinical utility and cost-effectiveness of routine SMBG in non–insulin-treated patients.”

A typical reason cited for this inefficacy of testing is that patients simply aren’t adequately following recommendations from health care professionals.\(^7\)

To date, very few studies have explored the patient perspective on home glucose testing beyond including standardized scales of “well-being” in more mechanized studies. The current survey was designed to explore patients’ experiences with home glucose meters, including: the degree to which they believe they received adequate training and by whom, how often they use their meters and to what end, and their feelings about meter results and costs. Strong emphasis was placed on open comments for qualitative analysis.

**Context: Three Schools of Thought**

To provide context for the current study, we interviewed two leading endocrinologists, a diabetes and psychology expert, and a veteran patient advocate who’s been working as a journalist serving the type 2 patient community for nearly 20 years.

Three schools of thought about the value of home glucose testing among type 2s emerge:

1. “They shouldn’t test much at all.”

   “If there’s no immediate action the patient can take, testing regularly might not help them,” says Dr. Richard Jackson, senior endocrinologist and researcher at Joslin Diabetes Center in Boston. The thinking is that for many patients, an A1C value every three months can provide sufficiently useful information, without the frustration of having to draw blood for daily numbers that serve little purpose. The push for increased testing may be driven by the device companies wishing to sell more product.

2. “They’re just not getting the right education / motivation.”

   Dr. Anne Peters, director of the Clinical Diabetes Programs at the University of Southern California (USC), who has a new study being published this October indicating that it’s positive for patients to test more, notes that proper education and motivation are intrinsically tied together. She says that patients need good training on how to employ the meter, but also need to feel empowered; they must be able to “see the impact” of their testing efforts, otherwise testing is just an unnecessary burden.

   Dr. William Polonsky, founder of the Behavioral Diabetes Institute in San Diego, who is also studying patients’ thoughts and feelings about SMBG, agrees. He says many patients stop testing because they feel it is pointless, as long as the data they gather is not actionable. He says the focus of SMBG should be shifted from “data collection” to “helping patients use the meter as a way to learn about their own body and how things affect them.”

3. “They’re not focusing on the right thing (food).”

   Finally, David Mendosa, veteran type 2 diabetic, book author, journalist and blogger, believes the whole medical establishment may be missing the point. He says glucose meters are really all about measuring the role of carbohydrates in diabetes management. A meter makes the results of a patient’s diet choices
immediately apparent. Mendosa believes meters could be best used as a tool to help many Americans curb their high-carb diets.

Nora Saul, certified diabetes educator and 20-year licensed dietitian at Joslin Diabetes Center in Boston, agrees that SMBG is under-utilized for gathering information about how patient’s blood glucose responds to different types and amounts of food – especially for judging the effects of high-carb food choices/diets.

But what are patients’ current experiences with regards to obtaining a glucose meter, being taught about its purpose, and daily use? Our survey explored these questions.

Survey Methods

A total of 732 patients filled out an online survey residing on the patient community site DiabeticConnect.com in early September 2012. The survey contained 16 multiple-choice questions with ample area for adding additional answers and personal comments. The questions pertained to how respondents obtained a meter, who trained them to use it and to what extent, how often and in what ways they (and their healthcare team) currently use their meter, and various queries as to how they feel about the testing experience and the meter results. Patients were also asked what the perceived value of testing is for them, and what they would most like to learn about home glucose monitoring if further training were available.

Demographics: Respondents were asked to self-identify only in terms of their diabetes: 93% (698) indicated they were diagnosed with type 2 diabetes. Of those, 19% were diagnosed within one year or less; 23% within 1-3 years; 28% within 3-5 years; and 30% had type 2 for more than 8 years.

Results

In addition to the numerical data, a total of 4,633 reader comments were gathered in response to 12 open-ended questions, following the multiple choice questions described above.

As a baseline: 87% (583) said they were prescribed a meter by a doctor or other healthcare provider. Only 78 respondents said they purchased a glucose meter on their own, and just 4 people said they were provided a free glucose meter.

96% said they use their meter regularly. Of those indicating they do not use their meter, choices of reasons for non-use were:

- I can't afford the test strips
- I don't understand what the numbers mean
- I don't know how
- Testing doesn't help me control my diabetes
- It's too painful
- The meter doesn't work properly
- Other

The no. 1 reason indicated was "other" with a variety of comments, the most common being: ”I can't remember to do it,” and “It's a hassle to carry around.”
Of the preset choices for non-meter use, the top reasons selected were "testing doesn’t help me control my diabetes" (41%) and "I can’t afford the test strips" (30%).

When asked, "Who showed you how to use your meter?" The No. 1 answer among all respondents was "no one, I learned myself" (41%), the No. 2 answer was "a nurse or CDE" (38%), and just 5% said they were instructed by a doctor or endocrinologist. (see Figure 1)

Figure 1: Who Showed You How to Use Your Glucose Meter? (All Respondents)

Among those who were prescribed a meter by their doctor, a full 36% still said they learned to use it themselves. 41% were showed by a nurse or CDE, and just 12% were trained by an endocrinologist or other physician. (see Figure 1-A)
The next survey question asked, “Were you given a good explanation of glucose targets by your healthcare professional?” to which 61% (400) said yes, 25% (165) said no, and 15% said they don’t recall or don’t know what a glucose target is.

There were 50 participant comments garnered on this question, skewed almost exclusively towards patients dissatisfied with the instruction they were given by their care providers, for example:

"I'm thinking no... My doctor at the time was not the best! And after nearly 7 years I still don't know."

"My first doctor was too busy to explain anything. I've changed doctors several times. I may again.”

"Given a pamphlet and the meter and told to come back in a month.”

"I don't understand what A1C is. I don't understand food exchanges.”

"Different providers have wildly different ideas about what my glucose targets should be.”

"My doctor handed me a set of ADA papers. No teaching, no explanation. I learned nearly everything (online) and from my diabetes education classes.”

"Somewhat, but I got better information at the Diabetes Forum online. That is where I learned how to use my meter to 'test' my foods and figure out a consistent diet that works for ME.”

Interestingly, there was heavy mention of the internet as a source of information and training (online communities, blogs and videos) in the comments section throughout the survey – despite the fact that none of the questions or preset answer choices mentioned this option.

To the question: “Were you given a good explanation of the best times of day to test your blood glucose by your healthcare professional?,” 60% (393) said yes, 30% said no, and 10% said they don't recall.
comments were gathered; a common theme was that patients were "basically told to test before meals without too much elaboration" or told "nothing other than morning fasting testing."

When asked "Were you given good guidance on how to treat high and low glucose results by your healthcare professional?," the results were about half and half: 48% said yes, 46% said no, and 6% said they don't recall. 61 comments were entered; a common theme was that patients were told how to treat lows only, not highs. An interesting side note on this question was numerous patients complaining that their doctors show little concern or empathy, for example:

“My endocrinologist’s office staff doesn’t care about me. They’re cold. They’re all young new grads that are more concerned about me being impressed with the fact that they have a degree. I'm not. There is a saying in healthcare, 'People won’t care how much you know until they know how much you care."

When asked, "Do you use your meter results to guide you in making lifestyle changes?,” 29% (187) said always, 41% (265) said most of the time, 20% (133) said sometimes, and the rest said rarely or never. 38 comments were gathered, many noting that they do not know what the numbers mean, and were not even aware they were supposed to make changes based on meter results.

To the question, "How often do you check your blood glucose when you're away from home?,” 46% (296) said frequently, 29% (189) said sometimes, 19% (122) said rarely, and 7% (43) said never. 48 comments were input. Most indicated that they test more often when not at home because they are out of their usual routine. This seems to indicate a level of sophistication that contradicts other results in the survey.

We also asked respondents: "Is there an emotional component to using your meter? (For example, do you get upset if the results are not ideal?)” To this, 42% (275) said sometimes, 18% (115) said most of the time, and 9% (60) said always. The remaining 31% said rarely or never. So a full 69% indicated an emotional component. 51 people commented, many noting that they were often “afraid to know the results”; would get upset if they “have been 'consciously good’ and the numbers are still high”; or they are uncomfortable about loved ones seeing their numbers – as this makes them feel guilty, or they may be reprimanded for their "bad numbers."

Asked whether their healthcare team downloads and/or looks at the data on their meter during appointments, 43% (280) said never, 25% (163) said always, 11% (72) said most of the time, and the remaining 20% said sometimes or rarely. 79 people commented. It was particularly interesting to note that almost all commenters said they either email meter results or print them out and bring them in to the doctor’s office proactively – all self-initiated by the patients. No one remarked on their doctor’s proactive efforts to download or otherwise obtain meter results. A number of respondents commented that they don’t have a “healthcare team” at all.

Asked “Does the cost of test strips limit you from using your meter as much as you’d like?,“ 47% (309) said yes, and 53% (342) said no. While the numerical results were split, there were 94 comments input on this question, indicating it is a “hot button” issue for patients. Even those who said they were thankful to have insurance coverage lamented that test strips are far too expensive and that most insurance plans only cover two test strips per day – “not enough to test at odd times for highs or lows.” Those who wish to test more aggressively had plenty to say about what is wrong with the current coverage model, for example:

“My insurance has encouraged me to use a different meter (I suppose they get a deal from that company), but I prefer my FreeStyle Lite. Shouldn’t be that way!”
"I test 5-7 times a day to keep in tight control, and I have to fight with insurance to get it covered. I was even asked by a health care provider if I was really using them or if I was selling them on the black market!! Sheesh!!”

In conclusion we asked patients: “If you were able to get additional education on how best to use your meter, what would you most like to learn?” They were asked to check “all that apply” from a set of six choices. (see Figure 1-B)

Results were, in order of priority:

- 56% (335) chose how to best react to too-high or too-low results
- 50% (296) chose how to use your meter results as a guide to lifestyle changes
- 35% (208) chose best time(s) of day to test
- 28% (169) chose how to make sense of data downloaded from the meter
- 27% (160) chose how to view and/or download the test results
- 26% (157) chose what to do with the control solution

Figure 1-B: What Would You Most Like to Learn?

82 reader comments were input. The issues clustered around four core topics:
Comments on What Patients Would Most Like to Learn

“What would you most like to learn about Glucose Testing?”

Four core topics emerged:

1) Effects of Food

“How much each meal raises my blood sugar, how long it takes to come back to a reasonable rate.”

“How to use the meter to make changes in my diet.”

2) Understanding Bodily Variables

“Hormones, stress and other ‘triggers’ that affect glucose levels ...”

“Why I sometimes go up with exercise instead of down.”

3) Understanding Meter Variables and Use

“How to minimize meter inaccuracy.”

“Inconsistencies - different fingers have different readings?”

“How to scroll through memory on the meter... navigation of past data can be confusing.”

4) How to Take Appropriate Action

“I know what to do with lows but what do you do with highs?”

“How to recognize patterns when lifestyle has many variables and time schedules for meals / exercise.”

“How to get my fasting results lower.”

“How to get your doctor to prescribe more strips. Once a day testing tells me nothing.”

“Ways to make testing more appealing. I know it’s something we all have to do ... but after a while ... it just gets ... boring causing myself and possibly others to test less than we should.”

In a final, open-ended section, we asked respondents “What else would you like to share about glucose meters and testing?” 274 people input comments. The most consistent theme was the lack of adequate
support for testing among type 2s. This included insurance coverage and affordability of testing supplies. For example:

"Doctors don't seem to stress testing for type 2 diabetes, but I've found it essential. My grandfather is told to test only once a day. I find the lack of support for us using meters and CGM devices disappointing. I think like type 1s, we could really benefit from such technology."

"Told my doctor that sometimes I test 12 times a day. Instead of congratulating me, I was told that my testing was excessive. I told them that I test when I need to and I don't let the cost of the strips limit my testing decisions. I think the doctors need training. I think diabetics need low cost testing supplies. Hurrah for Wal-Mart!"

Numerous responses also posed questions about meter accuracy and called for improved product design, i.e. the meters are too "bulky and inconvenient to carry around," and "too big to take along running or hiking." Several noted that the screens must be backlit to see in low-light situations, especially at night, and they should have a built-in USB port or other tool for easy data downloading, along with weather-proof casing.

The final, unprompted theme that emerged in the comments section was emotions about the testing experience. It was called "a necessary evil" and "a pain in the ass." Many people felt "left alone" with their meter, i.e.:

"I feel there should be more education. I had to ask the pharmacy how to use my meter. I was lucky to get someone who was interested in diabetes aids."

"I am angry that I have been suffering for years when it was all so simple any doctor should have been able to help me."

Cross-Tabulations:

Of those who received a meter from a doctor or healthcare provider, 36% reported having to learn how to use the meter by themselves. 41% said they received training from a nurse or diabetes educator. Only 3-8% were taught by a doctor or someone else in the doctor's office, and 4% by a pharmacist.

Of those who purchased a glucose meter on their own, 79% also learned to use it on their own.

In terms of using the meter to guide them in lifestyle changes, the numbers were fairly even: 69% of those given the meter by a professional chose "always" or "most of the time," while 72% of those who purchased their meter independently reported the same.

The emotional component also seems to be the same regardless of where the meter came from: 68% who received a meter from the doctor reported negative emotions about testing sometimes to often, while 71% who got the meter on their own reported the same.

Of those reporting that they were given a good explanation of the best times of day to test and good guidance on how to treat highs and lows, 97% in both groups said they use their glucose meter regularly. (see Figure 2)
Of those who do not use their meter regularly, 43% said they were either not given a good explanation of the best times to test, or they don’t recall being told this information (13%). (see Figure 3)

Figure 3: Patients Who Do Not Use Their Glucose Meter
Of those who say they do employ their meter to guide them in making lifestyle changes “always” or “most of the time,” 64% reported being given good explanations of when to test and 54% got good advice on how to treat highs and lows. (see Figure 4)

Figure 4: Patients Who Use Meter to Guide Lifestyle Choices

Of those who reported a negative emotional reaction to testing “always” or “most of the time,” 49% said they were either not given good guidance on treating highs or lows, while 8% don’t remember a healthcare professional ever mentioning this. (see Figure 5)
Conversely, of those who reported only “sometimes,” “rarely” or “never” experiencing negative emotions associated with testing: 62% were given a good explanation of glucose targets, 61% said they did get good guidance on best times of day to test, and 51% received good guidance on how to treat highs and lows. (see Figure 6)

Figure 6: Patients Who Sometimes, Rarely or Never Experience Negative Emotions
Core Findings

Regardless of how they obtained it, over 40% of patients said they learned to use their glucose meter on their own. While more than half of respondents report being told the best times of day to test, only about half were given good guidance on how to treat too-high and too-low results.

Over 40% said their healthcare providers never download or even look at their meter results.

Receiving education on glucose monitoring was highly correlated with meter use: 97% of those receiving good training on times of day to test and reactive treatment said they use their meters regularly. Over 60% of those currently using their meters to guide lifestyle changes were given good training. Of those not using their meter regularly, nearly 60% said they were not even told the best times of day to test.

Negative emotions associated with testing are common: nearly 70% of respondents indicated frequent negative reactions. This was also correlated with lack of training: 57% of those reporting frequent negative emotions said they were not given good guidance. Of those who report less frequent negative emotions, 50-60% said they did receive good guidance on various aspects of meter use.

Over 50% of respondents report wanting to learn more about making meter data actionable: how to react to high and low results, and how to use the results to guide lifestyle changes.

Discussion
Our data indicates significant motivation among patients to learn to use their meters in a productive way – to identify and treat highs and lows, and to make meaningful lifestyle changes. However, there is a great deal of frustration over lack of useful meter training.

Comments indicate that this frustration extends to a more general sense of inattention and lack of empathy from healthcare providers, and to a common lack of the financial means to make the most of using these tools.

While earlier studies have shown that more frequent SMBG use was linked to more frequent congratulations and helpful feedback from healthcare providers, our survey appears to indicate that positive feedback from healthcare providers is sorely lacking.

Earlier studies have also concluded that “there was no significant evidence available that SMBG had an effect on patient satisfaction, general well-being or general health-related quality of life.” While our study did not tap into the larger picture of quality of life, it does indicate that glucose testing itself is often a negative experience for patients no matter how well-trained they feel.

Comments gathered here indicate that patients would appreciate more emphasis on using glucose meters as proactive tools, rather than being viewed as a means to “discovering mistakes.”

A lack of satisfactory patient education appears to be contributing to a self-fulfilling prophecy: the notion that SMBG is not useful among persons with type 2 diabetes, or is useful only among patients taking insulin or other glucose-lowering medications that increase the risk of hypoglycemia.

Amy Tenderich, MA, is a journalist, blogger, book author and nationally known diabetes/patient advocate. She is founder and editor-in-chief of the leading blog DiabetesMine.com, and also serves as Vice President and Chief Patient Advocate for Alliance Health Networks, the health social media company behind DiabeticConnect.com, the fastest-growing social networking site for people with diabetes, with 750,000 registered members to date.
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