

Perceived Treatment Efficacy: An Overlooked Opportunity in Diabetes Care

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In seeking to understand and address the self-management obstacles our patients with diabetes face, clinical and research efforts during the past decade have typically focused on such crucial factors as depressive disorders,¹ perceived severity of diabetes,² impaired social support,³ diabetes self-efficacy,^{4,5} and environmental costs.⁶ However, we suggest that a core obstacle has been overlooked: the issue of perceived treatment efficacy (PTE). Simply put, when patients do not believe that a recommended treatment action is accomplishing anything, when no tangible positive outcome is apparent, they are likely to lose interest in continuing to perform the action.⁷

Perceived Treatment Efficacy

There are a number of other terms that overlap with the PTE concept; these include “outcome expectancies,” “medication beliefs,” and “perceived benefits.” Outcome expectancies refers to patients’ beliefs about the positive and negative outcomes of following through on a specific behavior;⁸ as a subset of that concept, medication beliefs refer to patients’ outcome expectancies regarding the specific use of their medications. The medication beliefs literature originates from the work of Horne and Weinman,⁹ who have drawn the distinction between patients’ perceptions of the necessity of taking a specific medication and their concern about the medication’s potential adverse effects. Finally,

both PTE and the concept of perceived benefits relate directly to the potentially positive consequences that are believed to accrue in response to effective self-management behavior.⁷

No matter the name, the research literature shows, not surprisingly, that the more individuals believe that a self-management action will produce a positive outcome and that negative consequences will be absent or minimal, the more likely they are to continue that behavior.⁷ We strongly suspect that it is the specific belief in promoting tangible, positive, *short-term* outcomes that motivates ongoing self-management more effectively than a belief in influencing *long-term* outcomes. In support of this hypothesis, one study evaluated adults and adolescents with type 1 diabetes and found that self-management was predicted by patients’ beliefs that their actions positively influenced their ability to control their blood glucose levels but not by their beliefs about whether those actions could prevent long-term complications.

Effects of PTE on Self-Management

We suspect that PTE is a singularly problematic and not uncommon issue in diabetes, especially in type 2 diabetes. Patients are asked to regularly engage in a series of complex self-management tasks over the course of years where the chief incentive for those efforts is, essentially, that nothing terrible will happen (i.e., a marked drop in the risk of developing

long-term complications). From this perspective, there may be little tangible sense that patients’ own efforts are making a positive difference from one day to the next.

Consider, for example, the case of Mr. Park:

At the age of 45 years, Mr. Park is shocked to learn that he has type 2 diabetes. With a BMI of 36 kg/m² and an A1C of 8.5%, he understands that his weight is a crucial issue, and so he decides to take action. He begins walking 3–4 days/week and cuts his consumption of sweets and sugar-sweetened soda. When he returns to his physician several months later, he is pleased to learn that he has lost 10 lb. Still, his A1C remains elevated at 8.1%, and his physician instructs Mr. Park to begin metformin and attend a local diabetes education program.

Mr. Park fills his prescription, but he never takes his new medication. He does not attend the diabetes education program and does not return to see his physician for several years. When he does return, his A1C is 8.8%, and he reports severe numbness in both feet.

When asked about what he thought when his physician first prescribed metformin, Mr. Park said, “I was pissed at him, myself, everybody. I had lost weight, I had been behaving, and for what?” Why did he think that his hard work had not paid off? “I don’t know. Probably because the game is rigged. When it comes to diabetes, I bet hard work never pays off.” How could he really tell if he was

succeeding with diabetes? "I would know; it would be obvious. The numbers wouldn't be so out of whack, and I wouldn't have to take these pills."

And Mr. Park is not alone. Our clinical experience suggests that a sizeable number of patients with diabetes become discouraged by the perceived lack of tangible positive outcomes. This is often the result of their focus on personally determined markers for success that can only lead to disappointment. Like Mr. Park, many patients decide that the chief indicator of treatment efficacy is the number of medications they must continue to take. In this view, fewer medications means better health; more medications (or higher dosages) indicates that the individual must be sicker. However, in a disease such as type 2 diabetes, where effective metabolic control is likely to require more and more medications over time, the actual number of medications that a patient has been prescribed is likely to be a very poor indicator of true treatment efficacy.

In diabetes, actual treatment efficacy is typically assessed as a function of long-term risk. When patients achieve adequate control of lipids, blood pressure, and blood glucose, the risk for long-term complications is dramatically reduced. However, many patients are not aware of the crucial importance of their own metabolic data and how to interpret it. For example, several studies have shown patients' knowledge regarding their own A1C values is limited.^{10,11} Also, many patients rarely check their blood glucose, and, of those who do, many do not know how to interpret the data to accurately assess what is and is not working.¹² Even worse, we see that blood glucose monitoring often serves, inadvertently, as a demotivational agent.¹³ Patients often view individual blood glucose results

as evidence of personal success or failure, which, given the common variability and often unpredictability of blood glucose levels, can lead to significant discouragement and a sense that their own actions do not matter.

The Power of PTE

We suggest that this presents the diabetes community with a tremendous opportunity. A crucial reason why some patients are able to stay motivated to manage the disease day after day, year after year, is their conviction that their actions are making a positive difference. And they and their health care team have found ways to highlight this impact in a tangible way over time.

For those who are struggling, we believe that self-management can be promoted in a proactive manner by harnessing the power of PTE. For interested health care providers, here are three suggested strategies for how this might be achieved:

1. Assess PTE.

Identify how patients identify diabetes-related treatment efficacy. This could be done with a direct question similar to what was asked of Mr. Park above: "How could you really tell if you were doing well with your diabetes?" The crucial issue is to determine whether patients believe that efficacy is based on feelings (e.g., "I don't feel any better, so I guess these pills aren't working"), medications (e.g., "I don't take as much insulin as my brother, so I am probably doing OK"), actions alone (e.g., "I know I have been eating poorly, so I must be doing poorly"), or—more accurately—actual numerical outcomes based on metabolic data (e.g., A1C).

In group programs here at the Behavioral Diabetes Institute, we introduce common scenarios to stimulate discussion among participants and identify erroneous beliefs.

One of our typical presentations is as follows: "Roy takes two different diabetes pills and insulin, and his last A1C was 6.8%. Sam hasn't been prescribed any diabetes pills, and his last A1C was 9.1%. Both patients are the same age and have had type 2 diabetes for the same length of time. Who is doing better with his diabetes?" Remarkably, most of our patients do not find this an easy question to answer.

2. Redirect to the right outcomes.

Help patients see that their current diabetes health and their risk of developing long-term complications are not determined by how they feel, the type of treatment they use, or the number of pills they take. It is their metabolic results that matter. Be sure to emphasize and re-emphasize that the need to increase medication or start insulin is not a sign of failure and is not a true indicator of treatment efficacy. No matter what medication they may or may not be taking, if they have chronically elevated blood glucose, blood pressure, or lipids, future problems are more likely.

As a second step, provide patients with personalized feedback illustrating how these metabolic indicators may be influenced by self-management actions. Make use of online risk calculators (for example, the Diabetes PHD risk assessment tool at www.diabetes.org, or "My Diabetes Health Assessment" at www.heart.org) to help patients see how behavior changes such as smoking cessation, weight loss, and proper medication-taking can potentially influence metabolic parameters and thereby decrease complications risks. This can also help patients recognize the benefits of the efforts they have already made and where any new efforts might be best expended for maximum gain. Once patients realize which outcomes are most important for them to focus on and

know how best to achieve those outcomes, the power of PTE becomes more obvious.

To illustrate, consider once again Mr. Park. Once the facts were laid out for him, Mr. Park became convinced that his A1C was the crucial outcome to focus on. He could see that his A1C drop in the first few months resulted from his own positive actions. As he learned that an A1C of 8.1% was still dangerously high, he could better understand why metformin had been prescribed. The subsequent A1C rise occurred because, to a large degree, Mr. Park had failed to make use of his potent tool for battling hyperglycemia—his prescription for metformin. This led to a complete reframing of how Mr. Park understood his diabetes; for the first time, he could believe that his own actions might have a positive impact on his health, and he knew what next steps to take.

3. Devise meaningful home experiments.

Enhance PTE directly by collaborating with patients to develop personalized self-management experiments that can demonstrate how their own healthy actions influence outcomes. One approach is to regularly present and discuss easy-to-read graphic feedback that highlights metabolic change over time. For example, when Mr. Park returned for his next clinic visit, his A1C had dropped to 7.8%. When shown a simple line graph that highlighted the dramatic change since his previous visit (8.8%), he could see that taking his prescribed medication and returning to his previous lifestyle change efforts had been efficacious and, therefore, worth continuing.

A second approach is to introduce simple, structured self-monitoring of blood glucose (SMBG) experiments that focus on identifying more immediate out-

comes.¹⁴ For example, one patient wondered how breakfast was affecting her blood glucose levels. Was she eating too much? Was she taking the correct insulin dose? She agreed to check her blood glucose for 7 days, each morning before breakfast and then 2 hours later. She recorded her results and, with her health care provider, calculated her average post-breakfast blood glucose rise during that week. Although significant inter-day variability was apparent, her mean blood glucose rise during the week was 30 mg/dl, reassuring her that her current breakfast-specific actions were—on the whole—effective. Encouraged by these results, she was anxious to devise further home experiments, beginning with determining the effects of regular exercise on her blood glucose levels.

As a means to spread this concept of personally meaningful, structured SMBG experiments, one of us (WHP) has collaborated with Roche Diagnostics to develop a simple paper tool called the “Testing in Pairs” tool, which is available for use with patients at no cost. Details are available online at <https://www.accucheck.com/us/data-management/testing-in-pairs.html>.

In conclusion, there has been limited recognition of the potential importance of PTE in diabetes care. A considerable portion of what we typically refer to as “patient noncompliance” in diabetes may be the result of impaired PTE. If patients do not believe that a recommended action—be it exercise, dietary change, SMBG, or taking medications—is contributing to an observable, positive short-term impact on their diabetes health, it is perfectly understandable that they might lose their motivation to continue to perform that action. Even worse, if they become convinced that prescribed treatments are directly

contributing to poorer outcomes (e.g., “If I start insulin, my health is likely to worsen”), they will be very reluctant to cooperate. By assessing PTE and addressing it directly, health care providers can help their patients feel more interested and engaged in ongoing diabetes self-management.

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