

# Six Impossible Things Before Breakfast: Examining Diabetes Self-Care

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*“I dare say you haven’t much practice,” said the Queen.  
“When I was younger, I always did it for half an hour per day. Why sometimes I’ve believed as many as six impossible things before breakfast.”*

—Lewis Carroll,  
*Through the Looking Glass*

Judging from the quote above, Lewis Carroll’s White Queen from *Through the Looking Glass* is clearly a very smart lady who knows something about diabetes, because the advice she gives to Alice could also apply to diabetes. When it comes to diabetes, though, we not only ask people to believe impossible things, we actually ask them to do impossible things.

We know that diabetes is associated with serious complications. It has complicated treatment prescriptions and demanding lifestyle requirements. Furthermore, daily care for diabetes is done by people with diabetes and their family members. It is not surprising that diabetes self-care can affect family relationships. And, unfortunately, a person’s lifestyle and life priorities may conflict with the treatment prescription, putting that person in a very difficult position.

Our broad goal for diabetes care is to maximize the health and quality of life of people with diabetes, while preventing complications and minimizing costs. Once complications occur, the Diabetes Control and Complications Trial (1) showed us

that their progression can be slowed; thus, we can focus on maximizing our patients’ health while striving to maintain their quality of life.

## Importance of Education

Diabetes education and the people who provide it play an important role by helping people with diabetes and their families find information about diabetes and, importantly, helping them learn how to use that information. The education process also supports people as they learn the skills necessary to understand their treatment, integrate diabetes self-care into their lives, and adapt to the unexpected events and changes that life may bring.

We learned from meta-analyses starting back in the late 1980s, that education that includes a behavioral component is the most effective (2–4). We also know that diabetes treatment requires a health care team; it is not just one individual but many who are contributing to help support people with diabetes (5,6).

People with diabetes typically experience four distinct phases of living with diabetes (7,8). Each phase can influence the type of emotional support and the diabetes education needed at that point in their life.

Phase 1 involves the onset of diabetes and may differ for those with type 1 versus type 2 diabetes. With type 1 diabetes, the onset can be abrupt—a crisis that requires rapid learning of survival skills, sometimes while hospitalized. For those with

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type 2 diabetes, the onset may be slower, more insidious. In fact, some people may consider the development of type 2 diabetes to be a normal part of aging, particularly if some of their family members have diabetes.

Newly diagnosed people with type 1 diabetes and their families must quickly come to terms with living with a chronic disease and the risks for acute complications such as hypoglycemia and diabetic ketoacidosis, as well as long-term micro- and macrovascular complications. Those with type 2 diabetes may be facing the need to change lifelong eating and exercise habits, as well as worrying about future complications. In both cases, individuals and families may need to acquire information rapidly and to adapt to demanding prescriptions and self-care regimens. They are losing their identity as a healthy person and are now becoming a person with a serious chronic illness and very real risks for future complications.

Once people get used to living with diabetes, they enter Phase 2, the health maintenance and complications prevention phase. Most people with diabetes reside in this phase. Our goal is to keep them there for as long as possible, until someone finds a cure. The focus of treatment and education during this phase focuses on prevention of complications, medications, and self-care.

This is the time during which people need to consolidate their lifestyle habits and align them with their health care needs. However, many people during this phase also put diabetes on the “back burner,” as competing demands and priorities take over and diminish self-care efforts.

If individuals are in a stressful work environment, if they are trying to raise a family, or if they are going off to college and meeting new friends and learning new things, diabetes may be assigned a lower priority in their lives. Life is keeping them busy enough.

Unfortunately, this state of affairs can usher in Phase 3, when early complications set in.

This begins a new disease trajectory; suddenly, patients realize they are at serious risk of losing an important ability. Some people respond to the early diagnosis of complications by becoming energized; it is their wake-up call to start managing their diabetes better. Others may respond with a sense of fatalism and increased distress. They may become too incapacitated to adequately manage their diabetes. Each person may need a different type of support and education to cope and to maximize their health and quality of life.

Finally, in Phase 4, complications dominate, and diabetes often again becomes a lower priority, as patients focus more on the comorbidities and complications that require more care or cause more pain. Their efforts may shift away from diabetes, and they may actually have a whole new team of health care providers—physicians, nurses, and dietitians—focusing on their kidney disease, or their heart disease, or some other problem other than their diabetes.

### Progress and Challenges

The diabetes care community has made some major strides in recent decades. For example, we have seen from National Health and Nutrition Examination Survey data that 52.5% of adults with diabetes attained an A1C <7% in the 2007–2010 period, compared to 43.1% in the 1988–1994 period (9,10). Similarly, between 1990 and 2010, the incidence rates of several key diabetes complications decreased. These included acute myocardial infarction (–67.8%), death from hyperglycemic crisis (–64.4%), stroke (–52.7%), amputations (–51.4%), and end-stage renal disease (–28.3%) (11).

This success has resulted from several factors, including new medications, improved access to care, more emphasis on prevention, and particularly improved access to diabe-

tes education. But we still have many people to reach. We need fresh, innovative approaches to help more people with diabetes better manage their self-care and follow their treatment regimens so they, too, can realize the benefits of better glycemic control and prevent complications.

### Collaborating and Understanding

Diabetes requires a collaborative approach involving patients, providers, and patients’ families all working as a team and agreeing on treatment strategies. But this assumes that they are all on the same page. So let’s spend a few minutes talking about diabetes self-care and what a person with diabetes does every day.

The three main areas of diabetes self-care include healthy eating, getting physical activity, and taking medications; these are the activities people with diabetes have to manage every day. To see how they are doing at any given moment, they monitor their progress by checking their glucose levels. The American Association of Diabetes Educators’ AADE7 Self-Care Behaviors (12) identified three important supports needed to accomplish these activities: 1) healthy coping skills, 2) problem-solving skills, and 3) behaviors to reduce risks for complications and comorbidities. At the Joslin Diabetes Center, we thought it important to add one more: that patients must work with their health care team because the relationship with the provider team is the foundation of successful diabetes self-care.

There are two types of goals prevalent in the treatment of diabetes. The first is medical goals, which are often laboratory based and include such measures as A1C, LDL cholesterol, and BMI. Medical goals are typically followed prospectively and are the basis for changes in treatment or adjustments in medications. The second type of goals is self-care goals, which focus on the activities people

with diabetes strive to do each day to better manage their condition.

Although patients do need to know and understand their medical goals, they depend on their self-care goals to direct their day-to-day lives and, ultimately, help them to achieve and maintain long-term health. Thus, people living with diabetes tend to focus on the daily activities that influence their glucose levels. They target their self-care goals, whereas their medical care team may be targeting their medical goals. Thus, patients often have a different focus than the professional members of their team. As providers, we need to understand patients' struggles to meet their self-care goals and respect the emphasis they may place on those, over the medical goals we track in their clinic records. We need to be mindful of what living each day with diabetes feels like for our patients.

### Factors Affecting Self-Care Success

There are three broad categories of factors that affect a people's ability to perform self-care behaviors: internal person factors, external person factors, and external environmental factors.

Internal person factors include such things as cognitive ability, including memory, intellect, organizational ability, ability to plan and problem-solve, and health literacy and numeracy. It also includes motivation, desires, and fears, as well as priorities, attitudes, beliefs, and life experiences. Within this category, we also find their cognitive model, how they approach life, what they think about the meaning of things in their lives, and their coping responses. And we find self-esteem and self-efficacy, education, and also knowledge and understanding of their self-care plan. There are also physiological factors, including their comorbidities, complications, and the existence of depression, anxiety, or other affective issues. These are all personal characteristics that influence people's

behavior and can influence how they behave and how they communicate with their diabetes team.

External person factors include not only how much, but the type of family and social support they have and the intimacy of their family relationships. It includes work-related stress, as well as how physically active their job is, how much privacy they are afforded during working hours, and their work schedule. It also includes their income. And, it includes their relationship with the health care team, as well as whether they have health insurance and what type they may have. These are all external issues that can exert great influence over people's ability to manage their diabetes.

The third category, external environmental factors, includes external factors within the work environment such as the food choices available during the workday and whether the employer provides health insurance. It also includes the availability of and access to appropriate health care. And, it includes community factors such as the culture and mores of their particular community; the availability and costs of healthful foods at neighborhood stores; neighborhood safety and access to safe exercise; and the need to drive versus a walking-friendly locale or the availability of public transportation.

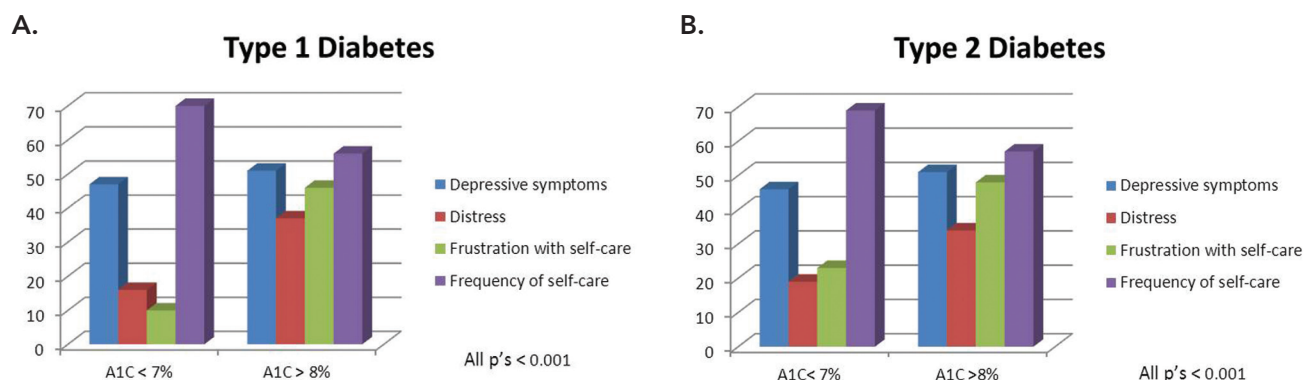
One of the most important internal personal factors related to diabetes self-care is knowledge and understanding of health information. Each person has a lens for filtering information based on his or her experiences, perceptions, and attitudes. The amount of information people retain and how they interpret that information differs from one person to the next (13–15). The perceived importance of information may shift as people become accustomed to living with diabetes. The priority assigned to some aspects of self-care may diminish as other life events and competing priorities become more important (13).

Another crucial set of personal internal factors include the degree to which they feel guilt and self-blame regarding their diabetes. We have done some qualitative studies with patients with diabetes and physicians, in which we asked about their struggles to meet treatment goals. One such study (16) found that many patients used self-deprecating language when asked about their struggles in reaching glycemic targets and discussing self-care. One person said, "That's the reason I think I can't reach glycemic goals. It's because I'm selfish and I'm lazy." Another person said, "Because I think I'm such a bad patient—it's me that's the problem."

In a survey study, we looked at some of the characteristics of >360 patients in good versus poor glycemic control (K.W., unpublished observations). As shown in Figure 1, we found that for both people with type 1 diabetes and those with type 2 diabetes, patients with an A1C <7% had lower depressive symptoms, less diabetes-related emotional distress, less frustration with self-care, and a much higher frequency of self-care than those with an A1C level >8%.

Another particularly important internal person factor is executive function, which encompasses a range of adaptive abilities that enable people to analyze information and carry out plans. Creativity, abstract thought, introspection, attention, memory, reasoning, planning, problem-solving, and organizational abilities all fall under the umbrella of executive function; these are the high-level cognitive skills necessary for adequate diabetes self-care. When someone is attempting to integrate complex self-care behaviors into a busy life, these skills are extremely important, yet difficult to learn and difficult to teach.

As part of the survey study of patients coming into the clinic for medical or education visits, we simply asked patients, "Do you manage time well?"—a yes or no question. We then looked at the frequency of their self-care behaviors as measured by the



■ **FIGURE 1.** Characteristics of patients with (A) type 1 diabetes and (B) type 2 diabetes, in good versus poor control ( $n = 367$ ).

Self-Care Inventory-R (17). We found that those who reported managing time well carried out more self-care behaviors than those who reported that they did not manage time well (65 vs. 53,  $P < 0.001$  for people with type 1 diabetes; 64 vs. 55,  $P < 0.01$  for those with type 2 diabetes).

We found similar results for glycemic control, with those who reported managing time well having better mean A1C results than those who reported not managing time well (7.8 vs. 8.9%,  $P < 0.001$  for those with type 1 diabetes; 8.2 vs. 8.9%,  $P < 0.001$  for those with type 2 diabetes). There were similar findings related to diabetes-related emotional distress and frustration with self-care, as well, with those in better glycemic control having lower levels of distress and frustration.

### Incorporating Cognitive Behavioral Strategies in Diabetes Education

Based on these and other data, we developed an intervention incorporating cognitive behavioral therapy (CBT) strategies for educators to use to help patients manage their diabetes better, with the overall goal of improving glycemia (18). The purpose was not to have the educators become therapists, but rather to evaluate whether educators could use these CBT techniques to support patients in their self-care efforts.

In this study, we randomized 222 adults (50% with type 1 diabetes;

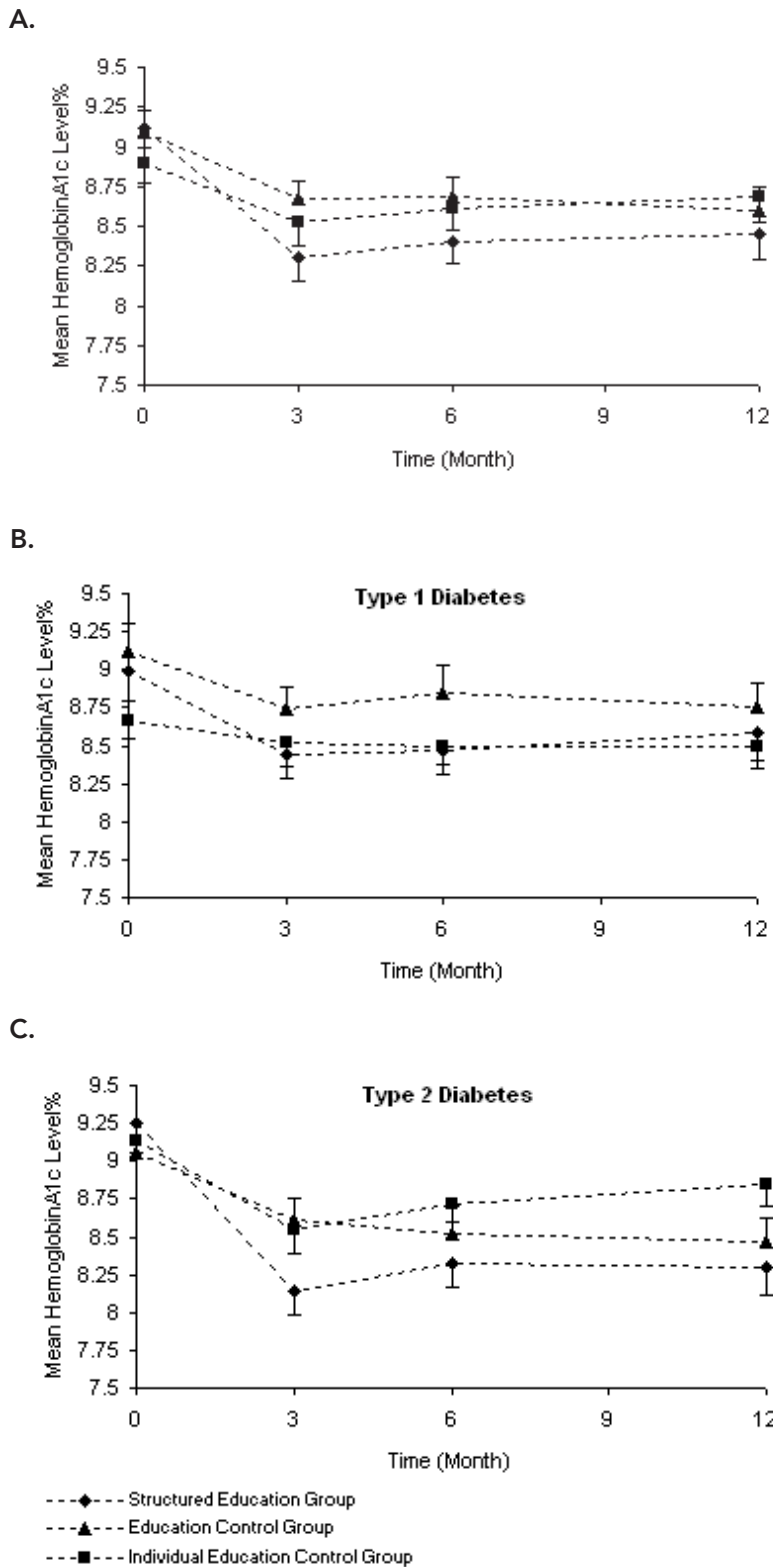
50% with type 2 diabetes) to one of three education arms. The experimental education program, Breaking Down Barriers, was a highly structured group intervention in which the educators were trained to use CBT strategies such as cognitive restructuring any time participants expressed self-blame. The second arm was an attention control group, in which participants received the same educational content using standard group education strategies. Both groups had the same number of sessions (five 2-hour sessions), the same amount of homework, and same amount of exposure to educators, and both received very high-quality education. The third arm received individual education; participants had as many appointments with a nurse educator and a dietitian as they wanted for 6 months. All classes were separated by type of diabetes, based on previous work by Smaldone et al. (19).

All participants had an A1C  $> 7.6\%$ , and nearly all had an A1C  $\geq 8\%$ ; mean A1C was  $9.0 \pm 1.1\%$ . The average age of participants was  $53 \pm 12$  years; the mean duration of diabetes was  $18 \pm 12$  years; and the mean number of years of education was  $15 \pm 2$  years. Assessments were performed at baseline and 3, 6, and 12 months after the intervention.

We found that all arms improved, confirming that diabetes education is effective. The graph on the left side of Figure 2 shows results for all patients,

with each line representing one of the interventions. A1C at 3 months improved in all three groups, with the greatest improvements among participants in the intervention group, and, on average, participants were able to maintain these improvements over time. When we examined the data by type of diabetes, as shown in the graphs on the right side of Figure 2, we found that, again, all of the education strategies worked, and participants with type 2 diabetes responded the best to the CBT-based education, achieving nearly 1 percentage point mean improvement in A1C. Thus, the highly structured CBT-based education group did very well for individuals in poor control.

The type of education provided did not affect BMI, and all arms had similar levels of distress. The number of blood glucose checks and reported frequency of self-care improved for all groups. Interestingly, more participants who answered “no” to the question, “Are you an organized person?” improved their diabetes control in the intervention arm compared to the attention control and individual education arms. However, for participants answering “yes” to the question about being organized, there was no difference in the percentage of people who improved in each of the three arms. We concluded from this that the CBT-based approach worked best for individuals who were less organized and worked as well as the



**FIGURE 2.** Impact of structured education incorporating CBT strategies. Mean A1C levels over time are depicted for the three intervention groups for (A) all participants, (B) those with type 1 diabetes, and (C) those with type 2 diabetes. Error bars represent 1 standard error. Reprinted with permission from Ref. 18.

other approaches for individuals who were more organized.

A 5-year follow-up of this study is now underway. We are finding that, after 5 years and with no reinforcement of the education, participants are maintaining their improvements, although still not reaching target A1C goals.

**Lessons Learned**

The study described above and many others through the years have taught us several lessons. Most importantly, we know that individualizing the educational approach is extremely important. In selecting the most appropriate approach, we must consider such factors as the type of diabetes each person has, the phase of diabetes each person is in, and each person’s personal characteristics, including their organizational and planning abilities and other factors such as whether they also exhibit symptoms of depression, anxiety, or other affective disorders. Other research from our group (20) has suggested that the presence of elevated depressive symptoms diminishes how openly people discuss diabetes self-care with their providers, and strong patient-provider communication is a key component of supporting people in their efforts to manage their diabetes.

**The Importance of Evaluating New Approaches**

Diabetes educators are some of the most creative people in the diabetes care community and often develop new tools and strategies to use with their patients. For example, in a project currently underway at the Joslin Diabetes Center, curriculum developers have created a video to serve as a multi-use educational tool to stimulate discussion and thus facilitate more active, less passive, classroom sessions. Although the video is engaging and fun to watch, we do not know yet whether it will motivate people or affect their behavior. We also do not yet know whether educators will be able to use it effectively to stimulate discussions about

topics such as making changes in dietary habits. Thus, new tools such as this video need to be critically evaluated to ensure that they serve their purpose efficiently and effectively. We may believe it will work, but we will not know until its effectiveness is formally evaluated to assure educators that people with diabetes will interpret it correctly and will be able to use the information it provides to improve their self-care and their health.

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