



The Most Important Thing We Give to People Is Hope: Overcoming Stigma in Diabetes and Obesity

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Editor's Note: This article is adapted from the address Ms. Valentine delivered as the recipient of the American Diabetes Association's (ADA's) Outstanding Educator in Diabetes Award for 2019. She delivered the address in June 2019 at the Association's 79th Scientific Sessions in San Francisco, CA. A webcast of this speech is available for viewing at the ADA website (professional.diabetes.org/webcast/outstanding-educator-diabetes-award-lecture%E2%80%94most-important-thing-we-give-people-hope).

I was blessed with wonderful parents, good skin, and a lovely family, in which everyone—and I mean everyone on both sides—had diabetes. I was diagnosed with type 2 diabetes myself 39 years ago, at the age of 31.

My diabetes journey started with insulin. Over the next 6 months, I lost 30 lb and got off of insulin, and I stayed off for the next 8 or 9 years. Eventually, though, my glucose levels started going up again, and I started back on insulin and eventually was even using U-500 human regular insulin to get my blood glucose levels in a near-normal range.

Why would I do that? I did it because my first diabetes training as a health professional was with the late Dr. Lois Jovanovic in New York City. She convinced me way back then that controlling glucose was essential to living long and living healthy with diabetes, and she was right.

Since being diagnosed, I have been running my own one-rat study, and I have tried everything—every class of diabetes medication. I have tried them all. It is one thing to read the studies and the labels, but it's another thing to know how it feels to take a certain medication.

A 6-Year Personal Journey

In 2002, when I was really overweight, I had an epiphany at Dallas–Fort Worth airport. I was running to catch a flight, and the gate agent was getting ready to shut the door. Another woman about my age and size was coming from the other direction in a motorized wheelchair. As I settled in for my flight, with the seatbelt feeling too tight around me, I realized that I needed to lose weight.

Now you'd think as a diabetes educator for more than 20 years, I would have already known that. But for whatever reason, it was at that moment that I finally got it.

I started working really hard, eating smaller portions and exercising more, and after a year I had lost . . . 10 lb. Losing weight is *hard*. Then, I got into a pramlintide open-label clinical trial, and over the next 18 months, I lost about 20 lb. The day exenatide came on the market, I started on it, and then I *really* started losing weight. At the end of 6 years, I had lost 100 lb (Figure 1). I did it the old-fashioned way: with good drugs and a determination to stay focused.

A Decades-Long Professional Journey

So how did I get here? In 1981, after I earned a master's degree in nursing from the University of Oklahoma, I went to work in the Diabetes and Hypertension Division of the Oklahoma State Health Department in Oklahoma City, where I helped to set up diabetes education programs in county health departments around the state. As it turns out, county health departments are ideal locations for diabetes education. In communities with several hospitals, local health departments are neutral territory. Some of the "I'm in Control" programs we started back then are still going today.

I was named Diabetes Educator of the Year by the American Association of Diabetes Educators (AADE) in 1984. The next year, I moved to Albuquerque, NM. Dr. Neil Kaminsky and Dr. Dorothy Gohdes convinced me I needed to come and help set up a diabetes center for Presbyterian

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FIGURE 1 The author before (A) and after (B) losing 100 lb.

Hospital, and it was great fun. We established a dedicated inpatient diabetes unit plus an outpatient education program. At that time, we were doing a much better job of managing diabetes outside of the hospital, so the inpatient unit eventually became unnecessary, but we continued with the outpatient center for quite a while.

In 1993, I went to work for the University of New Mexico, with Drs. Patrick Boyle and David Schade. We did some interesting work with a team approach to managing diabetes and started gaining experience with then-new medications such as metformin and insulin lispro.

My diabetes educator friend Cathy Gray and I set up a freestanding diabetes education center in 1998. We had educators in a network all over Albuquerque in different primary care offices. This was a successful model to support primary care practices and made diabetes education more accessible for patients as well.

In 2010, I took a position providing diabetes education and management in a primary care group, and in 2014, I became medical director of Health Scripts, supporting its speakers bureaus of nurse practitioners and physician assistants

traveling all over the country. In 2015, I was still doing that and also working for a specialty group in Albuquerque.

I am also a volunteer clinician with the University of New Mexico's ENDO ECHO. Project ECHO is a collaborative model of medical education and care management that empowers clinicians to provide better care to more people, right where they live. It is an excellent program helping rural providers who do not have access to specialists with specialty endocrinology care.

By 2017, I thought I might retire, but then I was asked to see patients 2 days per week as the diabetes specialist for a primary care group serving an underserved population, and that's what I am still doing today. I work with a group owned and staffed by nurse practitioners, and I am their in-house diabetes specialist. The patients are great and really interesting. My biggest challenge is that we don't always have access to the medications I know would really help them.

In 2019, I was named the American Diabetes Association's Outstanding Educator in Diabetes, bringing me full circle from the similar award I received from AADE 35 years ago.

Facing Stigma, Personally and Professionally

One of the things I discovered when I lost a lot of weight was that, although I now looked thin, on the inside I was still a 250-lb woman. One day, I was at a national meeting, chatting with a few women I have known for a long time. I heard them talking about a woman across the room in a derogatory manner because she was overweight.

I thought, “*What? You can’t mean that!*” But then I realized they had been doing it all along; I just had never been in on those conversations. In that moment, I discovered stigma and bias in a way I had never known before.

“Stigma” has been defined as labeling and identifying human differences via stereotyping, in which the labeled person is linked to undesirable characteristics (1). It describes physical characteristics or character traits that mark the bearer as having lower social value (2).

When clinicians hold such attitudes, the results for their patients can include avoidance of care, stress, mistrust of the provider, poor participation in the therapeutic regimen, and poor communication between patient and provider (3).

Addressing Diabetes Stigma

The term “diabetes stigma” refers to experiences of people with diabetes of negative feelings such as exclusion, rejection, or blame resulting from the perceived stigmatization of having diabetes.

Blame (e.g., “You brought this on yourself”) and shame (e.g., “I should have done better”) are key aspects of diabetes stigma.

Brené Brown, who developed Shame Resilience Theory, defines shame as “the intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance or belonging” (4).

In an online survey sent to 12,000 people with diabetes (5,6), Adam Brown and his colleagues at the diaTribe Foundation discovered some interesting things about diabetes stigma. Notably, 76% of survey respondents with type 1 diabetes and 52% of those with type 2 diabetes reported having felt stigma. Although one might think those percentages would be reversed, we must remember that stigma is related to visibility; the more intensive a respondent’s therapy was, the more stigma was reported. Stigma also increases feelings of depression and is linked to poor participation in the therapeutic regimen and an increase in complications (7). Overall, the most commonly reported experience of stigma in the diaTribe survey was

the perception that diabetes is a character flaw—in other words, that having diabetes represents a failure in personal responsibility.

Glycemic Control and Diabetes Stigma

Does diabetes control affect perceptions of stigma? In the diaTribe survey, Brown and his colleagues found that, among people with type 2 diabetes who reported having excellent diabetes control, 19% reported experiencing stigma, whereas among those who reported having poor glycemic control, 61% reported experiencing stigma. Similar results were found for respondents with type 1 diabetes (34 and 56% of those with excellent and poor glycemic control, respectively, reported experiencing stigma). And, as we all know, greater perceptions of stigma lead to more guilt, blame, shame, embarrassment, and isolation for people with diabetes.

Obesity Stigma and Diabetes Stigma

For many people with type 2 diabetes, the stigma they experience may stem from having diabetes or from having obesity. Either way, they are often treated as if they have a character flaw rather than a metabolic disorder based, perhaps in large part, on genetics. Analyses of genome-wide association studies have shown that the genetic risks for complex diseases such as type 2 diabetes involve cumulative, small effects of many genes and only some genes with a moderate effect (8).

Recognizing and Confronting Implicit Bias

The concept of “implicit bias” has to do with the subconscious judgments we make that are often based on stereotypes. The following is an example.

Did you know that more than half of Asian Americans with type 2 diabetes don’t know they have it? That compares to about one-fourth of Americans overall who are unaware that they have diabetes. This difference might be caused by an implicit bias—in other words, a stereotype—that all people of Asian descent are thin and healthy. Asian Americans are 34% less likely than white Americans to be screened for diabetes, even though they are twice as likely to have undetected diabetes.

Is it possible that we all operate with unconscious biases? Yes, it is. Although you may think, “I am not biased; I’m completely impartial,” we all have little stereotypes, implicit biases, floating around in our brains, and those biases are affecting the care we provide to patients.

Watch Your Language

One of the things we need to do to overcome such biases is to clean up our language, and by that, I mean our language referring to people with diabetes. The words we choose can express negative and disparaging attitudes and contribute to our patients’ already stressful experience of living with this disease.

Jane K. Dickinson and her colleagues published a terrific article on this topic in 2017 (9). The following are some guiding principles they laid out for communicating with and about people with diabetes.

- Diabetes is a complex and challenging disease involving many factors and variables.
- Stigma that has historically been attached to a diagnosis of diabetes can contribute to stress and feelings of shame and judgment.
- Every member of the health care team can serve people with diabetes more effectively through a respectful, inclusive, and person-centered approach.
- Person-first, strengths-based, empowering language can improve communication and enhance the motivation, health, and well-being of people with diabetes.

Attributes of the recommended style of language are shown in Table 1; Table 2 provides examples of how to replace words that carry negative connotations with more positive language.

Why Language Matters: Expectancy Theory

Does language really matter? In a word, yes.

Let me tell you about Expectancy Theory, which was developed by Robert Rosenthal and Kermit L. Fode in 1963 (10). These researchers had an idea that expectations can change behavior outcomes. To test this theory, they gathered some college students and told them they would be training rats to run a maze and that one group of students would work with rats that were specially bred to have better maze-running abilities, whereas the other group would work with more average rats. In truth, however, all the rats had been bred the same ordinary

way, and they were randomly assigned to the student groups.

Maybe you can see where this is going. The students worked with their rats, and guess what happened? The supposedly average rats were slower and had a harder time getting through the maze, and the supposedly specially bred rats did much better at maze-running.

One might think, “How could having higher expectations affect a rat?” Well, it was probably that the students spent more time, took more care, and paid more attention to the rats they thought were special during the training.

Just to be sure, Rosenthal and Lenore Jacobson, a California school principal, did the same study with children instead of rats (11). Teachers in 18 elementary school classrooms were told the names of about 20% of their students who had supposedly been found through testing to have “unusual potential for intellectual gains.” After 8 months, the “unusual” children, who were actually just selected at random from the class rolls, showed significantly greater gains in IQ than the other children in their classrooms.

The moral of this story is this: if we believe that our patients are going to do better, if we believe that everybody has the capacity for achieving their glycemic targets, we can make a huge difference. We must approach our patients with intention and with the expectation that they will be able to achieve optimal health.

It’s Time to Eliminate Stigma

The good news is that stigma is 100% curable. Here are some steps we can all take to reduce or even eliminate stigma.

- Recognize it. Hear your self-talk. Hear that little conversation that goes on in your head, because if you can hear it, your patients can, too—loud and clear!
- Resist the urge to blame and shame. Diabetes is *not our patients’ fault*, and blaming and shaming has absolutely

TABLE 1 Preferred Forms of Language for Communicating With and About People With Diabetes

Attribute	Definition
Person-first language	Words that indicate awareness, a sense of dignity, and positive attitudes toward people with a disability/disease. Places emphasis on the person, rather than the disability/disease
Strengths-based language	Opposite of a deficit approach; emphasizing what people know and what they can do. Focuses on strengths that can empower people to take more control over their own health and healing

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TABLE 2 Suggested Language to Replace Common Diabetes-Related Terms That Have Negative Connotations

Common Negative Terms	Suggested Replacement Language
Compliance, compliant/noncompliant, adherent/nonadherent	<ul style="list-style-type: none"> • Use terms such as engagement, participation, involvement, and medication-taking • Just state the facts (e.g., “He takes his medication about half of the time” or “She takes insulin whenever she can afford it.”)
Control (as a verb or adjective), controlled/uncontrolled, well controlled/poorly controlled	<ul style="list-style-type: none"> • Use “manage” • Again, focus on the facts (e.g., “She is checking blood glucose levels a few times per week” or “He is taking sulfonylureas, and they are not bringing his blood glucose levels down enough.”)
Control (as a noun): glycemic control, poor control, good control, bad control	<ul style="list-style-type: none"> • Discuss A1C results, blood glucose levels, blood glucose targets, and time in range
Diabetic (as an adjective): diabetic foot, diabetic education, diabetic person	<ul style="list-style-type: none"> • Use terms such as foot ulcer, infection of the foot, diabetes education, and person with diabetes
Diabetic (as a noun): “Are you a diabetic?”	<ul style="list-style-type: none"> • Person with diabetes • “Do you have diabetes?”

Adapted from ref. 9.

no value and in fact impairs their ability to achieve the targets that you want to help them achieve.

- When you hear others blaming and shaming, call it out. They need to hear it.
- Reframe your perceptions. When you look at people with diabetes, see them as individuals and try to understand their feelings and their life circumstances.
- Be respectful. Listen and learn about your patients and their culture. Show interest.
- Acknowledge the hard work involved in everyday diabetes management. It’s not easy. It requires a lot of activity and a lot of brain power.
- Make eye contact. Consciously work at making more eye contact. It will make a big difference in your relationships with patients.
- Help people cope with stigma through your diabetes education programs. Explore their level of diabetes distress and help them understand that they are not alone.
- Encourage the media to challenge and defy common stereotypes of diabetes.
- Look at the costs of and reimbursements for diabetes products and services to identify and call out ways in which people with diabetes are treated unfairly. Advocate for equity in access, treatment, and costs.

Finally, we need to take the lead. The health care professionals, the researchers, and the people with diabetes who lead this community need to be the ones to say, “Let’s stop diabetes stigma *now*.”

One way we can take the lead is to come out of the diabetes closet ourselves. I am always surprised when I find out about a colleague who has diabetes and does not share that

fact with patients. By staying in the closet, health care professionals with diabetes miss an opportunity to embrace openness and transparency in a way that could have a huge positive effect on their relationships with patients. Having diabetes has been a real professional advantage for me, and it can be for you, too. You don’t need to feel ashamed—*it’s not your fault!*

Above all, remember that the most important thing we give to people with diabetes is hope. To all of our patients who feel invisible because of their weight, ethnicity, sex, age, or infirmity, we must say, “I see you. I SEE YOU!”

DUALITY OF INTEREST

V.V. serves on advisory boards for Abbott Diabetes Care, Adocia, AstraZeneca, Capillary Bio, CeQur, Janssen, Lexicon, Lilly, Merck, Novo Nordisk, Sanofi, and Xeris. She is a speaker for AstraZeneca, Janssen, and Lilly. No other potential conflicts of interest relevant to this article were reported.

REFERENCES

1. Link BG, Phelan JC. Stigma and its public health implications. *Lancet* 2006;367:528–529
2. Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. New York, Simon & Schuster, 1963
3. Phelan SM, Burgess DJ, Yeazel MW, Hellerstedt WL, Griffin JM, van Ryn M. Impact of weight bias and stigma on quality of care and outcomes for patients with obesity. *Obes Rev* 2015;16:319–326
4. Brown B. Listening to shame. Presented at a TED: Ideas Worth Sharing conference in March 2012. Available from www.ted.com/talks/brene_brown_listening_to_shame. Accessed 18 September 2019
5. Liu NF, Brown AS, Folias AE, et al. Stigma in people with type 1 or type 2 diabetes. *Clin Diabetes* 2017;35:27–34
6. Brown A. Diabetes stigma: who feels it, what’s the impact, and what can we do about it? Presentation at the American Association of Diabetes Educators 2016 Annual Meeting in San Diego, CA, 14 August 2016

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7. Goldney RD, Phillips PJ, Fisher LJ, Wilson DH. Diabetes, depression, and quality of life: a population study. *Diabetes Care* 2004;27:1066–1070
 8. Cirillo E, Kutmon M, Gonzalez Hernandez M, et al. From SNPs to pathways: biological interpretation of type 2 diabetes (T2DM) genome wide association study (GWAS) results. *PLoS One* 2018;13: e0193515
 9. Dickinson JK, Guzman SJ, Maryniuk MD, et al. The use of language in diabetes care and education. *Diabetes Care* 2017;40: 1790–1799
 10. Rosenthal R, Fode KL. The effect of experimenter bias on performance of the albino rat. *Behav Sci* 1963;8:183–189
 11. Rosenthal R, Jacobson L. Teachers' expectancies: determinants of pupils' IQ gains. *Psychol Rep* 1966;19:115–118
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