Making a Meaningful Difference: Learning From People, Practice, and Research

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I am truly honored to receive this award and to represent the work of diabetes education. I would like to use this time to share with you what I have learned from people, practice, and research about what it takes to make a meaningful difference for people with diabetes.

Everybody has a story, and every story has a lesson. At the beginning of every story, there is excitement and anticipation about how each chapter will unfold. We look forward to a meaningful experience along the way, and sometimes the story takes twists and turns that we do not expect. But, in the end, it all comes together, and it all makes sense.

When Diabetes Hits Home: The Power of Love

The first chapter in my story as a diabetes educator begins with my family. Everybody knows the love of family. It is where life begins, and it never ends. In this story, there once were two sisters who were happy and healthy and enjoying life together (Figure 1). These two sisters always looked out for each other. After all, they had so many shared memories from growing up together. As teenagers, we had so much to look forward to. But then, all of a sudden, my sister was losing

weight unexpectedly, and her weight was close to 90 lb. She was drinking constantly and running to the bathroom a lot. I remember my mother looking up her symptoms in her medical books and saying, "I think you might have diabetes." I remember my sister saying, "No, I don't."

But it turned out she did. That was in 1975. There was no self-mon-

FIGURE 1. The author (left) and her sister as children (A), and the author (right) and her sister today (B).

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itoring of blood glucose (SMBG) at that time, and diets were strict. My sister was taught to weigh and measure her food and to follow the ADA Exchange diet—the gold standard at the time. I remember being so impressed with how well she followed her diet in the beginning, and I felt so relieved. I thought to myself, “She will be okay; she knows what to do, and she can take care of herself.” But I quickly learned that this was easier said than done.

I noticed that, after the first 6 months of amazing diligence, my sister seemed weary of the process and was having challenges with high blood glucose. She kindly told me that it was *her* diabetes and that she just wanted me to be her sister and not get involved. For many years, I watched from the sidelines, hoping and looking for an opportunity to help. It is no surprise that I delved into the area of nutrition and diabetes and became very passionate about helping people with diabetes.

As I counseled patients with diabetes, it was so very clear to me that the diet was the hardest part of the diabetes self-care regimen. That gave me an idea. One day, knowing that my sister still might not be open to discussing her own challenges with me, I asked her for help in my practice. I said that I wanted to know how I could help my patients more, and I thought that she could give me some guidance. I wanted to understand why it was that she did so well in the beginning with following the diabetes care plan, but then seemed to drop it all together. I remember her response like it was yesterday: “I clearly remember that first meal plan,” she said. “I was given a list of all the things I couldn’t eat and was told to weigh and measure all my foods. After 6 months of carefully weighing all my food portions, I decided that I could not live the rest of my life eating two-thirds of an apple for lunch. I decided I would

just do the best I could to try to eat healthy and exercise regularly.”

As her sister, my heart sank. As a dietitian, I thought to myself, “It was not doable, and she gave up!” Clearly, she felt that, if having diabetes meant doing all of these things to perfection, she would have to risk living with the consequences of high blood glucose and hope for the best. I remember thinking, “It was the diet that was the problem. This is my area, and I need to do whatever I can so that this does not happen to one more person with diabetes, at least not on my watch!”

I became passionate about making sure that my messages about diet were realistic and doable and tailored for each patient. I wanted to be sure that I focused on realistic, patient-selected goals that instilled the hope that managing diabetes can be doable.

Diabetes Control and Complications Trial: “Need to Know” Versus “Nice to Know”

Everybody wants the opportunity to make a meaningful contribution. In 1983, I had the amazing opportunity to get involved in research with the Diabetes Control and Complications Trial (DCCT), a study designed to compare the effects of conventional diabetes treatment to intensive therapy on the development of long-term complications in people with type 1 diabetes. The goals of intensive therapy were to maintain near-normal blood glucose levels and aim for an A1C $\leq 6.5\%$ (1). In 1983, we had the advantages of SMBG technology, multiple daily injection regimens, insulin pumps, and A1C testing to help tailor our treatment approaches, allowing us to focus on what really worked. Here was my opportunity to contribute to making a difference in the lives of people with type 1 diabetes, particularly in the area of diet.

We had an education checklist for DCCT participants that outlined all of the diet-related topics we would review so that they could better manage their diabetes. I remember sitting at a meeting with my colleague,

Beverly Halford, discussing how many different topics there were and how much information these patients needed to learn and process and how that could be overwhelming. At the same time, as a study group, we soon realized that the goal of intensifying insulin therapy to achieve A1C targets without hypoglycemia and weight gain could not be accomplished without attention to diet (1,2). If only we knew which aspects of diet were most important in achieving better blood glucose control, then we could help patients prioritize which diet behaviors were most important to focus on. That is, maybe we could make the diet component more doable by focusing on the “need to know” versus the “nice to know.”

We decided to conduct an ancillary study (3) to try to determine which diet behaviors were associated with better A1C outcomes. To do so, we asked 623 intensively treated patients to complete a survey about the methods they used in implementing dietary advice, adhering to meal plans, managing changes in food intake, treating hypoglycemia, limiting consumption of concentrated sweets, and timing insulin in relation to meals and snacking habits.

We learned that, in the context of intensive therapy, there were six diet behaviors that were associated with lower A1C values (Table 1) (3). Each of these diet behaviors was associated with a 0.25- to 1-point lower A1C.

TABLE 1. Dietary Behaviors Associated With Lower A1C in the DCCT (3)

1. Adherence to diet
2. Adjusting insulin for variations in food intake
3. Treating hyperglycemia promptly by reducing food or increasing insulin
4. Avoiding overtreatment of hypoglycemia
5. Avoiding extra snacks
6. Being consistent in nighttime snacking habits

The information learned through this study was used from that point forward by DCCT dietitians to help study participants get closer to their A1C targets so that, as a research group, we could achieve the clinically meaningful separations in glycemic control that we needed to study the course of diabetes control and complications.

We now know, based on the DCCT results, that every 10% reduction in A1C results in a 43% risk reduction in retinopathy and that the legacy of the DCCT's intensive diabetes therapy regimen continues its imprint on diabetes-related health outcomes 30 years later (4,5). I now know as a dietitian and diabetes educator how to help patients with type 1 diabetes separate the wheat from the chaff by focusing on the "need to know" instead of the "nice to know." "Make it doable" is still the lesson.

Diabetes Prevention Program: The Power of Lifestyle Change

Everybody wants to prevent diabetes. In 1996, our research team became involved in the Diabetes Prevention Program (DPP). This randomized, controlled trial was exciting because it was designed to compare a lifestyle intervention aimed at 7% weight loss and increased activity to a diabetes medication (metformin) and to placebo with regard to effects on diabetes incidence in individuals with impaired glucose tolerance (6).

As a DPP co-investigator and lifestyle coach, I was involved nationally in helping design the lifestyle intervention. As we screened study participants, I remember wondering whether people who did not yet have a disease would be motivated to engage in a treatment to prevent it. We soon found out that, when people learned that they were at risk to develop diabetes, they were highly motivated to prevent it.

The story of Tim, one of my DPP participants, tells all. At 47 years of age, Tim found out he had prediabetes. His identical twin brother had

had type 2 diabetes for 3 years. Tim's doctor told him he was highly likely to develop diabetes within 5 years of his twin brother because they had the same genes. He decided to join the DPP because he wanted to do everything he could to prevent diabetes.

When Tim joined the DPP, he was 5'10" tall and weighed 200 lb; his BMI was 27 kg/m². He was excited to learn that he was randomly assigned to the lifestyle intervention program. He learned that his lifestyle intervention goals would be to lose 7% of his body weight to a target weight of ≤186 lb and to increase his activity level to ≥150 min/week. He rated his motivation to change his lifestyle at a "9" on a 10-point scale, and his self-confidence to do so as "5" out of 10 because he had never been on a weight loss program before.

Tim's wife attended almost all of his individual coaching sessions to learn how she could support his efforts. Based on Tim's initial weight, he was assigned a fat intake goal of 42 g/day based on his calorie goal of 1,500 kcal/day. At first, Tim and his wife found keeping food records and learning about the sources of extra fat and calories in their diet to be time-consuming. They also found it difficult to adjust the traditional Italian recipes their family enjoyed. However, with practice, feedback, and support, Tim found that he could change his eating habits and lose weight while still enjoying his favorite foods. Over time, he found that the process became easier, and the lifestyle changes became his new eating routine.

After 6 months in the DPP, Tim had lost 16 lb, to a weight of 184 lb, and he was exercising for 200–400 min/week. Through his participation in the DPP, Tim now weighed 50 lb less than his twin brother (Figure 2). For the remainder of the program, he continued to have individual follow-up visits every 4–6 weeks, and at the end of the DPP, he had maintained his weight of 184 lb. When he was debriefed on his results at the end

■ **FIGURE 2.** DPP participant Tim (right) and his identical twin brother.

of the DPP, he learned that, after 4 years of lifestyle intervention, he had reverted to normal glucose tolerance by both fasting and 2-hour postprandial blood glucose criteria at that time (7).

Tim and the other DPP participants learned that, compared to placebo, metformin can reduce the risk of developing diabetes by 31%, and lifestyle intervention aimed at 7% weight loss and 150 min/week of activity can reduce that risk by 58% (6). The effectiveness of a modest lifestyle change was approximately double that of the medication intervention.

Tim recently converted to diabetes based on an oral glucose tolerance test. However, his A1C remains steady between 5.3 and 5.6%. Tim, at age 64, had delayed diabetes for 17 years beyond his identical twin brother. His most recent weight was 192 lb (4% weight loss from his DPP baseline), and he is exercising ~300 min/week, doubling the original DPP exercise goal of 150 min/week.

Tim's story tells us that *modest* lifestyle change seems to trump the expression of high-risk genes. In fact, evidence from the DPP has proven this to be true. Lifestyle intervention participants who had the transcription factor gene *TCF7L2*, which is

associated with susceptibility to type 2 diabetes due to impaired β -cell function, did not develop diabetes at the same rates as participants in the metformin or placebo groups with the same high-risk gene (8). The same findings were replicated when those with the highest genetic risk score who received lifestyle intervention were found to have significantly lower diabetes incidence rates than their counterparts in the placebo group (9).

Tim's story and these research results inspire me to continue to help patients with lifestyle change. I can provide a message of hope based on the evidence that preventing or delaying diabetes is doable with modest lifestyle change. I can encourage them by telling them that they are not doomed to develop diabetes if they have high-risk genes in their family history; losing 8–10 lb could make a big difference, and every pound they lose matters.

Psychological and Behavioral Predictors of Weight Outcomes: The Importance of Balancing Structure and Flexibility

Everybody needs the flexibility to find our own way. That is why one size does not fit all and no one diet is right for everyone. Early in the DPP, I was excited about the potential of weight loss and increased activity to prevent diabetes. In my clinical practice, I had already witnessed the power of small weight losses and modest changes in activity to dramatically improve blood glucose control in my patients who already had type 2 diabetes. So, I asked myself, "What if the lifestyle program works to prevent diabetes? What will we need to know?" Knowing that there are so many nutrition, activity, and behavioral topics to review with patients to help them lose weight, I asked myself, "Is there a way to make this more doable? Can we help patients prioritize their focus on the behaviors that are most important in predicting sustainable weight loss? How can we discern the 'need to know' from the 'nice to

know?'" I decided to conduct another ancillary study to try to identify the most important modifiable predictors of achieving the activity and weight loss goals in both the short term and long term.

At the end of the DPP, we learned that weight loss was the dominant predictor of diabetes prevention and that, for every kilogram of weight loss, there was a 16% reduction in risk for developing diabetes. We also know that lifestyle participants who did not meet the weight loss goal at year 1, but who achieved the physical activity goal of 150 min/week of brisk activity, had a 44% lower incidence of diabetes (10). Although the lifestyle intervention was successful, not everyone was able to achieve the weight loss targets. It turned out that 49% of lifestyle participants achieved the 7% weight loss goal at 6 months, and 37% maintained the 7% weight loss at study end (11).

In our ancillary study, 274 lifestyle participants (~25% of the cohort) completed questionnaires to assess their weight loss history and a variety of psychological and behavioral factors. The questionnaires were administered at baseline and at 6 months after completion of the 16-session core lifestyle curriculum. We learned that the most important psychological predictor of weight loss was low-fat diet self-efficacy—self-confidence in their ability to follow a low-fat diet. For each unit improvement in low-fat diet self-efficacy score during the core curriculum, there was an almost threefold greater likelihood of achieving the 7% weight loss goal at study end (12). In the DPP, we promoted self-efficacy by teaching participants skills related to setting small achievable goals, self-monitoring and balancing fat intake, stimulus control, managing stress and high-risk situations, and problem solving, which could explain these self-efficacy improvements.

We additionally learned that the most important behavioral predictor of weight outcomes was flexible dietary restraint. For each

unit increase in dietary restraint skills during the core curriculum, there was a 4.3-fold greater likelihood of achieving the 7% weight loss goal at study end (12). Teaching patients flexible dietary restraint skills appears to be key. Rather than trying to adhere to a specific diet plan, DPP participants had the flexibility to find their own way. Participants self-monitored their weight and their eating and could compensate by eating less in response to any small increases in weight or any overeating episodes. They experienced this as a successful balancing of eating behavior rather than as a setback or failure to follow their diet and eat perfectly.

As health care providers and diabetes educators, we can focus our energies on teaching dietary restraint skills and on other strategies that promote self-efficacy for both diet and activity behaviors. This evidence reminds me that people with diabetes need to be repeatedly reassured that they do not have to eat and exercise perfectly; they need some structure, but they also need to learn to balance that structure with some flexibility with themselves by aiming to eat better on more days than not and by fitting activity into their lifestyle in ways that work for them. Having the flexibility to find their own way to achieve clinical goals makes lifestyle change more doable and more sustainable.

Look AHEAD Trial: The Importance of Looking Beyond the Headlines

Everybody wants to make a difference. I was fortunate to be involved as a co-investigator and lead interventionist in the Look AHEAD trial, helping to design the lifestyle intervention that was based on the DPP (13). Look AHEAD randomly assigned 5,145 patients with type 2 diabetes who were overweight to receive either a lifestyle intervention with goals of 7% weight loss and 175 min/week of activity or a program of diabetes support and education to

see whether the lifestyle intervention would reduce cardiovascular morbidity and mortality over the long term (14). After a median follow-up of 9.6 years, the lifestyle intervention did not reduce cardiovascular events defined as heart attack, stroke, hospitalization for angina, or death compared with a program of diabetes support and education (14).

For me as a diabetes educator, however, the clinical implications of the Look AHEAD trial go way beyond the headlines. As we debriefed our lifestyle intervention group participants on the results of the trial, we heard a common refrain that was best articulated by Bob, one of our trial participants. He said “I hope that people outside of Look AHEAD that are interpreting these results . . . don’t lose sight of the impact that this lifestyle program has made on our quality of life.”

TABLE 2. Benefits of Lifestyle Intervention Versus Diabetes Support and Education in the Look AHEAD Trial (15)

Improved outcomes for:

- A1C
- Blood pressure
- Triglycerides
- C-reactive protein
- Retinopathy
- Nephropathy
- Diabetes remission rate
- Sleep apnea
- Fatty liver disease
- Sexual dysfunction
- Urinary incontinence
- Physical function
- Knee pain
- Quality of life
- Depression
- Body image dissatisfaction

Reductions in:

- Number of medications
- Medication costs
- Hospitalizations

A multitude of published articles speak to the positive impact of the lifestyle intervention, not only on cardiovascular disease risk factors (i.e., improvements in A1C, blood pressure, and lipid levels with less medication use and associated costs), but also on numerous other conditions (Table 2) (15). When we examine the list of benefits, it is so clear why the lifestyle participants felt so adamant about how much better they felt, both physically and psychologically. The initial weight losses with this lifestyle intervention are among the best achieved through lifestyle modification.

The Look AHEAD lifestyle program, modeled on that of the DPP and including the proactive use of meal replacements, clearly needs to be translated into the clinical practice setting for patients with type 2 diabetes. This goal is particularly important in light of the findings from the SHIELD study (Study to Help Improve Early Evaluation and Management of Risk Factors Leading to Diabetes). The SHIELD study, a 5-year, prospective survey of >22,000 adults with or at risk for type 2 diabetes, had two key findings. First, people know what to do but do not know how to do it; that is, they know they are supposed to lose weight and increase their activity, but they just don’t have the skills or “know how” to do it in a sustainable way. Second, more effective interventions

are needed to help patients improve health-related behaviors (16).

In 2012, I received funding to conduct a pilot study adapting the Look AHEAD lifestyle intervention for clinical practice in a program called Improving Diabetes Outcomes Through Lifestyle Change (IDOLc). IDOLc compared an adapted Look AHEAD lifestyle intervention to usual care. In this study, we randomly assigned 57 primary care patients with type 2 diabetes to receive either a 19-week group lifestyle program adapted from Look AHEAD or usual care, defined as individual medical nutrition therapy sessions with a dietitian. Compared to the Look AHEAD participants, IDOLc participants were more likely to be male (60% in IDOLc vs. 40% in Look AHEAD), slightly older (62 vs. 59 years of age), and had comparable ethnic representation. At baseline, the IDOLc intervention cohort was more medically complex and had a higher rate of insulin use (70% vs. 15% in Look AHEAD) and a higher mean A1C (8.2% vs. 7.3% in Look AHEAD), with comparable initial BMIs.

Our results show that, despite prevalent use of insulin and sulfonylureas, more than twice as many lifestyle group participants met the 5% weight loss target, with one-third losing $\geq 10\%$ (Table 3). This was achieved with simultaneous improvements in glycemic control and significant reductions in medication use (17). Patients reported greater improvements in dietary

TABLE 3. Weight and Diabetes Outcomes at 6 Months in the IDOLc Trial (17)

	Medical Nutrition Therapy	Lifestyle Intervention	P
Weight loss (kg, mean [SD])	2.1 (3.5)	6.6 (7.0)	0.004
$\geq 5\%$ weight loss (n [%])	6 (20)	13 (46)	0.04
$\geq 10\%$ weight loss (n [%])	1 (3)	9 (32)	0.005
A1C change (%; mean [SD])	−0.39 (1.51)	−0.70 (1.13)	0.4
Medication discontinuation or dose reduction (n [%])	11 (38)	23 (82)	0.0007

restraint skills, low-fat diet behaviors, and self-efficacy for following a low-fat diet.

The IDOLc lifestyle intervention program has been well received, and Kevin's experience in the program is just one of many positive, heart-warming stories that we have witnessed. Kevin was one of the people assigned to receive the lifestyle intervention in IDOLc. He was 61 years old, weighed 276 lb, and participated in no regular physical activity. Kevin was on 60 units of glargine insulin and metformin and had an A1C of 7.9%. His blood pressure and lipids were well controlled with medications. After participating in the 19-week program, he lost 47 lb. His A1C, blood pressure, and lipids were in target range. He was able to discontinue insulin and lisinopril at the end of the intervention and had an A1C of 6.3%.

Kevin still reports in with his progress. Eighteen months later—1 year after completion of the intervention—he had lost a total of 62 lb. He is walking 6 miles/day on 5 days/week. Kevin's story emphasizes an important message from the SHIELD study: people know what to do; they just need to learn how to do it. It's not about willpower, it's about lifestyle skill power, and we can teach skills to help people make sustainable lifestyle changes. Twenty-two months after starting the program, Kevin is 68 lb lighter, with the ABCs of diabetes control (A1C, blood pressure, and cholesterol) all still in the target range. His A1C is 5.9%, and he is on a trial off of metformin treatment.

Based on the success of our pilot study, we have now received 5 years of National Institutes of Health funding to conduct a larger-scale translation study called REAL HEALTH–Diabetes (Figure 3). In the REAL HEALTH–Diabetes study, we will randomly assign 210 community health center patients who have type 2 diabetes to receive one of three treatments: 1) dietitian referral for individual medical nutrition therapy,

■ **FIGURE 3.** The author with her Real-Health Diabetes team.

2) a lifestyle intervention delivered via in-person group, or 3) a lifestyle intervention delivered via a new approach using a telephone conference call group to find out whether this could be a way to extend the reach of the program. Each intervention will be delivered for 2 years. Our primary study outcome will be the mean percentage of weight loss at 6 months, 1 year, 2 years (end of the intervention), and finally at 3 years (after 1 year of no intervention) to assess sustainability. We will also assess a variety of medical, psychological, and behavioral outcomes and quality of life.

After 20 years of work designing and implementing these lifestyle programs, there is one thing I know for sure. Lifestyle programs can provide patients with diabetes more of what they truly want and need: better health outcomes, less medication use, better quality of life, the continued ability to enjoy eating, and, most importantly, the know-how to achieve their weight loss and activity goals. So, what does it mean to make a meaningful difference? For me, as a diabetes educator and dietitian, it is not just about contributing to landmark research studies in the area of diabetes and obesity. It is about creating a “can-do” feeling and improving the well-being of the patients who

are struggling to manage these lifestyle-related conditions.

We all know that the twin epidemics of diabetes and obesity are growing exponentially and that there is much more work to do. But each of us can commit to brightening the corner where we are. For me, it is not about what I do, but rather how I do it. Patients come to me feeling discouraged about managing their diabetes or their weight, and we talk about the steps that they can take to improve their health. When I see their eyes brighten and their hopes rising, and I hear them say “That’s doable,” my heart skips a beat because I know I have had a meaningful conversation, and that means it has been a successful day.

For me, the final lesson and the moral of this story for diabetes educators is that it’s not just about *what you do*, but also *how you do it* that can make living with diabetes more doable for your patients. Our collective story on making a meaningful difference for people with diabetes is still being written.

Duality of Interest

Ms. Delahanty is a consultant for JanaCare and has stock options in Omada Health and JanaCare. Both companies are adapting lifestyle interventions using online technology. No other potential conflicts of interest relevant to this article were reported.

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