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More Than a Number

Erin M. Akers



By Erin Akers

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I'll always remember his first, middle, and last name, though I affectionately called him just Dr. M. He was one of the premier pediatric endocrinologists in the area: a gentle old man with salt and pepper hair and a deep, soothing voice I imagined that Santa Claus would have. When he spoke, he was comforting and commanding at the same time. When I was asked who my doctor was, I proclaimed his name proudly.

Dr. M had been my brother's doctor for a mere two weeks when he figured out that I, like my brother, had type 1 diabetes. It was a one in a million catch, diagnosed off of a complaint of blurry vision thrown out at one of my brother's doctor appointments. Dr. M caught my diabetes at least six months before it could progress to the normal diagnosis stage. I was told that most likely I even had a few wandering islet cells left that hadn't been destroyed quite yet. Most children with diabetes grow extremely close to their endocrinologists, seeing them, on average, every three months. I was no exception. I desperately wanted to please him by bringing in "good" numbers and adored the praise he gave me when I did well.

Years later, when my eating disorder started taking control of my life and leaving me adrift in a sea of emotions, thoughts, and fears, I looked to him to pull me back to shore and help me regain control of my diabetes. Instead, I was pressured and pushed further and further until I was drowning in an ocean of numbers and obsession.

By the time I was fourteen I had been living with diabetes for five years, and in those five years I had learned one thing: I was a number. My blood glucose number determined if I got a lecture or praise from the only doctor I had ever truly known. My weight number determined the response I would receive from my nutritionist; her judgement of me as a number coming out as facial expressions of disapproval, making me feel like that number was more important than the journey I had taken to get to it. Five of the most formative years of my life taught me that I was nothing but a number, and in every case, the lower, the better.

When I turned fourteen, I started rebelling, and I turned against the one thing I was the most angry at – those numbers and the system that had made me feel like they were what mattered most about me. I could control those numbers. They wouldn't control me. That thinking, and the anger and emotions that had been building for years since my diagnosis, led me to my eating disorder. I fit the science and research, to a T.

"Patients with diabetes show an increased prevalence of full-fledged as well as sub-threshold clinical eating disorders. Some theories suggest that the cause of this greater incidence might be due to the adolescent diabetic's conscious deprivation of food despite hunger signals, which later triggers binge eating and other dietary anomaly"[1].

Currently, the method used to teach children about diabetes is to make them hyper-aware of their food, and specifically, carbohydrates. For every gram of carbohydrate a human being ingests, their body needs a certain amount of insulin to "cover it," or turn it into usable energy. It seems like such a simple, harmless equation, but it is anything but that. In order to drill it into the heads of children who would rather be playing, sleeping, or doing just about anything besides giving themselves a shot, some doctors have a tendency to talk in extremes: "You must count all your carbohydrates or you'll die. You must take a shot every time you eat a carbohydrate or you'll die!"

As you hit adolescence and your body starts to change, doctors begin to worry about weight, or more accurately, they begin talking to you about your weight. Diabetes comes with an increased chance of heart disease, so doctors stress the importance of weight management. It is absolutely a fair and valid point. But for an overweight child like myself, the extreme became, "You must lose weight or you'll get heart disease and die." Again, I heard the extremes.

By the time I was fourteen I equated food with insulin shots, weight gain with heart disease, and inextricably linked my diabetes with a death sentence. Numbers, whether in the form of blood sugar readings, A1c measurements, or pounds on a scale, became quite literally, life and death. Numbers became how I defined diabetes, and how I defined myself.

I was told by my nutritionist that I was no longer allowed to eat bagels because they were a “too high carb food for a diabetic like me.” It put a genuine fear of food in my gut, no pun intended. At 12 years old I refused to eat a bagel because I was terrified it would make me go blind. I felt so confused around food. Worse were the days when I did everything right and my sugar was still elevated. It made me feel helpless and out of control, around my diabetes and eventually around all food. I couldn’t trust food, I couldn’t trust my diabetes, and the resulting fear pervaded and led to either not eating carbohydrates at all – severe restriction – or eating all the carbohydrates – severe binging. Because of this, I couldn’t simply sit down and just enjoy a bagel until I was well into my twenties.

It’s no wonder that women with type 1 diabetes are 2.4 times more likely to develop an eating disorder than their peers without diabetes [2]. It’s almost more of a wonder that more women with diabetes don’t have an eating disorder.

So what do we do? We can’t stop teaching children with diabetes how to take care of themselves, count carbs, check their blood glucose, get their A1c, step on a scale, or any other measurement of growing up and living with diabetes. At the same time, we also can’t pretend that food and numbers aren’t the most critical aspect of diabetes care. But something has to change! My doctors taught me my broken body was the enemy, and then gave me the tools to abuse it. We have to consider the whole patient with diabetes, not just the numbers that clinically sum it all together.

Dr. Ann E. Goebel-Fabbri, PhD says it best, “Teaching a person how to be a perfect diabetic is akin to teaching them how to have an eating disorder.” It’s a different kind of eating disorder, simply dubbed diabulimia in popular news stories about it. The science of it is pretty simple. As a person with type 1 diabetes, if I didn’t take my insulin, my body couldn’t use the food I had eaten, and I would pee out all the sugar and carbohydrates I had eaten that day. The longer I went without taking insulin, the more starved my body would become, so that it eventually would be forced to feed off of itself. The longer my body went

without insulin, the higher my blood sugar would be, and the more damage was being done to my body. The nerves in my feet were the first to go. Severe peripheral neuropathy, I can say from personal experience, is excruciatingly painful. The complications got worse and worse as my immune system, and eventually my body as a whole, started to deteriorate. It seems so easy to explain, just black and white science. But there is nothing black and white or easily explainable about an eating disorder. Therein lies the biggest challenge in finding a path to healthier living and regaining control from the clutches of diabulimia.

How does one explain to a woman who has had the dangers of out-of-control-diabetes drilled into her, choosing to skip her shots anyway, knowingly speeding up the damage to her body? What’s black and white about a teenager curled up in her bed, sobbing, as a neuropathy flare up makes it feel like someone is stabbing her feet over and over again? Nobody chooses to have an eating disorder any more than they choose to have diabetes. Some mental health professionals say that a person predisposed to an eating

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disorder is like being born with a loaded gun. For many of these patients, traditional diabetes education can be the trigger that sparks their illness. And the bullet of comorbid diabetes and an eating disorder is a deadly one, boasting a mortality rate of 34.6% [3].

Dealing with eating disorders is a delicate and sensitive topic that many doctors tend to shy away from, and understandably so. It's not an easy topic to tackle, and many people even beyond doctors are unaware of how to handle the situation and are hesitant to risk saying the wrong thing and making the problem even worse. But we must not look past the signs that can severely threaten a beautiful life capable of thriving, even with diabetes. By saying nothing, we are silently giving the eating disorder time and room to grow.

There is an epidemic sweeping through the world of people with diabetes. In fact, 30% - 40% of women with type 1 diabetes report intentional insulin restriction for weight loss purposes [4, 5]. But with more research being done every year, and four non-profit organizations now in existence across the globe dedicated to helping people with diabetes and eating disorders, we have to ask ourselves why are so many people with diabetes still suffering and dying from this comorbid disorder?

If my experience is any litmus test for better understanding, for many people living with diabetes, their diabetes education has stopped being the answer and started being the problem. That is not to say that diabetes education isn't needed. Quite the opposite. We need to change our diabetes education, from diagnosis and beyond, to encourage us to think and talk about diabetes control and measurement with a focus on more than just the numbers. We need to actively and aggressively consider quality of life, our personal goals, and the collection of intangibles that makes us a person with diabetes, rather than just diabetes itself. On behalf of all of the people with diabetes who will struggle with some form of an eating disorder in their life, what we really need now is a reimagining of the far too common numerically focused diabetes education. ■■

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