



Deniabetes

Jennifer D. Goldman

Every January, for as far back as I can remember, I look forward to the publication of the updated American Diabetes Association (ADA) *Standards of Care in Diabetes*. The first place I look when I open the latest edition is the “Summary of Revisions” section. This year, among many other revisions, there were updates to section 5, “Facilitating Positive Health Behaviors and Well-Being to Improve Health Outcomes” (1). Details provided included approaches to support intervention and psychosocial outcomes for people with diabetes and their families. However, I did not find in this chapter or any other, the guidance I need on managing individuals with signs of the enigma I have called “deniabetes” for the past 3 decades of my career.

How can people sitting in front of us with symptoms, extensive clinical evidence, and laboratory confirmation deny their diagnosis of type 1 or type 2 diabetes or not take it seriously? How can we be standing on our heads and shouting from the rooftops, and yet they still do not seem to hear us? How can we invest so much time and energy trying to convince them to care about themselves as much as we care about them, when, too often, deniabetes still wins? We are all excellent at diagnosing deniabetes, but when it comes to managing it, we are not so great. Perhaps we need a new chapter in the *Standards of Care* on just this topic.

In 2008, a student in the Doctor of Pharmacy (PharmD) program at my institution came to see me after class. She knocked on my office door, looking horrified about asking to speak to me. She could barely get the words out of her mouth.

“Can you please help me?” she asked through her tears. “My sister is going to die.” The student’s 26-year-old sister, Kim, had severely uncontrolled type 1 diabetes, and my student was terrified that her sister would die imminently.

Indeed, Kim was suffering from one of the worst cases of deniabetes I have ever encountered. I called her that night and tried to inspire her with words of wisdom and offer helpful suggestions. She seemed happy to speak to me, but I wondered if that was genuine or if she was just being polite to her sister’s professor. A few weeks later, I got my answer when, despite living an hour away in a neighboring state, Kim transferred her primary care to the family medicine office where I was the clinical pharmacist and diabetes educator.

For Kim, deniabetes began at about 15 years of age, when she was first diagnosed with type 1 diabetes. She admitted talking the good talk throughout the ensuing years, but not walking the walk. She went out of state to college, away from her family, where—not surprisingly—her deniabetes worsened. She decided she didn’t want to have diabetes, so she lived her life as if she didn’t. I remember her telling me that she injected insulin one time in an entire semester. By the time she was forced to leave school because of poor health, her A1C was 19%, and she needed a wheelchair because she was unable to feel her feet and had pain in her legs. Things settled down somewhat, and she continued living her life, never really having good glycemic control, but at least able to walk again. She got married to a wonderfully loving and supportive husband, who I’ve had the privilege to meet.

As expected, deniabetes continued to take a significant toll on her body and mind. By the time we met in 2008, she had peripheral neuropathy, gastroparesis, retinopathy, albuminuria, hypertension, hyperlipidemia, depression, and anxiety, among other complications. We needed to truly recognize how diabetes distress and other psychosocial issues were getting in her way. I tried to give her what she needed, or at least what I thought and hoped she needed: education with a heaping dose of empathy, inspiration, and motivation.

It worked, and before long, she started to both talk the talk and walk the walk. Eventually, she transitioned to an insulin pump, and I remember unveiling her A1C to her at her next appointment. To her absolute joy and delight, it was 7%. She was elated and talked about that day every time I saw her from then on.

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Kim started teaching my clinical students every 6 weeks about type 1 diabetes and insulin pumps and telling her story of deniabetes. She was so inspirational, and her story so moving and powerful, that I wanted to share it to educate more people. We started coteaching diabetes in the PharmD program, where I would present her case to hundreds of students, concluding with the final question, “Do you want to know what happened to her?” After a period of absolute silence as they wondered if she had died, I would bring this beautiful and vibrant woman up to the stage. She would talk about living with type 1 diabetes and about her path of deniabetes leading to her myriad of complications. Then, I would talk about treatment options.

This approach was so well received, and she enjoyed educating others so much, that we went on the road together and did continuing education seminars, where we could teach 500 or more people at a time. We titled our talk “Complications of Deniabetes: The Patient Perspective and Clinical Management.”

Kim started getting involved with the ADA and advocacy groups for type 1 diabetes, but she still came back to campus every year to teach in my class. One year, she asked my students if anyone wanted to donate a kidney for her. I remember in that moment I had a lump in my throat and fear for my patient, who was by now also my

dear friend. Her mother-in-law was a match and donated a kidney for her in 2017.

She then continued her amazing advocacy for people with diabetes and focused on assisting others in coping with deniabetes, until her health started to fail once more. She died in 2019, at the age of 37, after educating and helping thousands of people since the day we had met in 2008.

I think of Kim often when faced with patients dealing with deniabetes. How can I diminish their diabetes distress, improve their outcomes, and help them have a good quality of life? Can I be as inspirational to them as Kim was to so many with deniabetes? Maybe we can add a chapter on the prevention and management of deniabetes to the 2024 Standards of Care.

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This editorial was written with the permission of Kim’s family. Donations can be made to the Kim Hislop Memorial Scholarship for Young Adults online at <https://childrenwithdiabetes.kindful.com/?campaign=1156725>.

REFERENCE

1. ElSayed NA, Aleppo G, Aroda VR, et al.; American Diabetes Association. 5. Facilitating positive health behaviors and well-being to improve health outcomes: *Standards of Care in Diabetes—2023*. *Diabetes Care* 2023; 46(Suppl. 1):S68–S96