

## Patients had to lobby for correct diabetes diagnoses: Was their race a reason?

January 16 2024, by Bram Sable-Smith, KFF Health News

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Credit: Christina Morillo from Pexels

When Phyllisa Deroze was told she had diabetes in a Fayetteville, North Carolina, emergency department years ago, she was handed pamphlets with information on two types of the disease. One had pictures of

children on it, she recalled, while the other had pictures of seniors.

Deroze, a 31-year-old English professor at the time, was confused about which images were meant to depict her. Initially, she was diagnosed with type 2 [diabetes](#), as shown on the pamphlet with [older adults](#). It would be eight years before she learned she had a different form of diabetes—one that didn't fit neatly on either pamphlet.

The condition is often called latent autoimmune diabetes of adults, or LADA for short. Patients with it can be misdiagnosed with type 2 diabetes and spend months or years trying to manage the wrong condition. As many as 10% of patients diagnosed with type 2 diabetes might actually have LADA, said Jason Gaglia, an endocrinologist at the Joslin Diabetes Center in Boston.

Deroze and three other LADA patients who spoke with KFF Health News, all Black women, are among those who were initially misdiagnosed. Without the correct diagnosis—which can be confirmed through blood tests—they described being denied the medicines, technology, and tests to properly treat their diabetes. Three of them wonder if their race played a role.

"That does seem to happen more frequently for African American patients and for other minoritized groups," said Rochelle Naylor, a pediatric endocrinologist at the University of Chicago who researches atypical forms of diabetes. "Doctors, like any other person walking this planet, we all have implicit biases that impact our patient experiences and our patient care delivery."

Black patients have long struggled with bias across the U.S. health care system. In a recent KFF survey, for example, 55% of Black adults said they believed they needed to be careful at least some of the time about their appearances to be treated fairly during medical visits. Hospital

software used to treat patients has been investigated for discrimination.

Even a common test used to manage diabetes can underestimate [blood sugar levels](#) for patients who have [sickle cell trait](#), which is present in nearly one in 10 African Americans.

LADA ostensibly has nothing to do with race, but misconceptions about race, weight, and age can all lead doctors to misdiagnose LADA patients with type 2 diabetes, said Kathleen Wyne, an endocrinologist who leads the adult type 1 diabetes program at Ohio State University.

Type 2 diabetes develops in people, often over age 45, whose bodies cannot properly regulate their blood sugar levels. Type 2 accounts for at least 90% of diabetes cases in the U.S. and has a high prevalence among African Americans, Native Americans, and Hispanic populations. It can often be managed with lifestyle changes and oral medications.

LADA is more akin to, or even thought to be another form of, type 1 diabetes, an autoimmune condition once dubbed "juvenile diabetes" because it was most often diagnosed in children. Type 1 occurs when the body attacks its cells that produce insulin—the naturally occurring hormone that regulates blood sugar by helping turn food into energy. Without insulin, humans can't survive.

LADA is difficult to diagnose because it progresses slowly, Gaglia said. Typical LADA patients are over 30 and don't require injectable insulin for at least six months after diagnosis. But, like type 1 patients, most will eventually depend on injections of pharmaceutical insulin for the rest of their lives. That delay can lead physicians to believe their patients have type 2 diabetes even as treatment becomes less effective.

"If you have someone who comes into your office who is obese and/or overweight and may have a family history of type 2 diabetes—if you're a

betting person, you bet on them having type 2 diabetes," Gaglia said. "But that's the thing with LADA: It unmask itself over time."

Mila Clarke, who lives in Houston, finally saw an endocrinologist in November 2020, more than four years after being diagnosed with type 2 diabetes. During that visit, she recounted her struggles to manage her blood sugar despite taking oral medications and making significant changes to her diet and exercise regimens.

"What you just explained to me, I believe, is a classic case of LADA," Clarke recalled being told. "Has anybody ever tested you for type 1 antibodies?"

Because both type 1 diabetes and LADA are autoimmune conditions, patients will have antibodies that type 2 patients typically don't. But, as Clarke recounted, getting tested for those various antibodies isn't always easy.

Clarke, now 34, had leaned into her type 2 diagnosis when she received it in 2016 at age 26. She started a blog with nutrition and lifestyle tips for people with diabetes called "Hangry Woman," and garnered tens of thousands of followers on Instagram. Clarke said she wanted to fight the stigma around type 2 diabetes, which stereotypes often associate with being overweight.

"Some of the harshest comments that I had gotten were from people with type 1 who were like, 'We're not the same. I didn't cause this. I didn't do this to myself,'" Clarke said. "Well, neither did I."

Clarke also felt her initial doctor thought she just wasn't working hard enough.

When she learned about continuous glucose monitors, wearable

electronic devices that allow patients to track their blood sugar around the clock, she asked her primary care doctor to prescribe one. The monitors are recommended for [patients](#) with type 1 and, more recently, some with type 2. "He flat-out told me, 'No. It's going to be too much information, too much data for you,'" she recalled.

Clarke switched to a different primary care doctor who she felt listened better and who prescribed a continuous glucose monitor. (Clarke later became a paid ambassador for the company that manufactures her device.) The new doctor eventually referred Clarke to the endocrinologist who asked if she'd been tested for antibodies. The test came back positive. Clarke had LADA.

"In the health care system, it's really hard to vocalize your needs when you are a woman of color because you come off as aggressive, or you come off as a know-it-all, or you come off as disrespectful," Clarke said. "My intuition was right this whole time, but nobody believed me."

Immediately, Clarke noticed an "eye-opening" difference in how she was treated. She started insulin injections and was referred to a dietitian and a diabetes educator. She wondered: Why wasn't it easier to get tested for antibodies?

Those tests are imperfect and can have false positives, said Gaglia of the Joslin center. Still, Ohio State's Wyne argued that every diabetes patient should be tested for at least the most common antibody associated with type 1.

"Aren't you saving lives if you're identifying the type 1 before they come in with DKA and die?" Wyne asked, referring to [diabetic ketoacidosis](#), a serious complication of diabetes most commonly associated with type 1.

Deroze started asking her doctor for antibodies tests in 2017 after

reading about a type 2 blogger's experience being newly diagnosed with LADA.

Her endocrinologist denied her requests. She thinks the doctor thought it was impossible for her to have an autoimmune form of diabetes because of her race and weight. She sought a second opinion from a different endocrinologist, who also refused to test her.

"I just felt unseen," Deroze said.

After a bout with diabetic ketoacidosis in 2019, Deroze finally persuaded her gynecologist to test her for antibodies. The results came back positive. One of the endocrinologists apologetically prescribed insulin and, later, an insulin pump, another ubiquitous piece of technology for people with type 1.

And for the first time, she encountered the words "diabetes is not your fault" while reading about type 1 diabetes. It felt like society was caring for her in a way it hadn't when she was misdiagnosed with type 2. That's troubling, she said, and so is how long it took to get what she needed.

"My Ph.D. didn't save me," said Deroze, who now lives in the Miami area. "You just see the color of my skin, the size of my body, and it negates all of that."

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Citation: Patients had to lobby for correct diabetes diagnoses: Was their race a reason? (2024, January 16) retrieved 28 April 2024 from <https://medicalxpress.com/news/2024-01-patients-lobby-diabetes.html>

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