

# Race and MS: Confronting inequities



## **Uncovering the gaps in MS research, diagnosis and treatment.**

**by Brandie Jefferson**

Diagnosing multiple sclerosis can be a lengthy, circuitous, sometimes frustrating process no matter what the person's background is. Although some research on race and MS suggests Black and brown people get diagnosed sooner — perhaps because they have more severe symptoms earlier — some of the stories Dr. Mitzi Williams, MD, has heard in her clinic paint a very different picture.

“In my clinical experience, a fair amount of my Black patients have had delays in diagnoses,” says Williams, a neurologist and MS specialist at the Joi Life Wellness Group in the Atlanta metro area. “They said, ‘The doctor told me Black people don’t get MS.’”

## **Getting personal**

Get to know [Jovany Hernandez](#), [Billie Walker](#) and [Jenelle Montgomery](#) by reading about their experiences with MS.

There is no blood test or single genetic marker to tell a doctor that someone does or does not have the disease. Instead, a diagnosis is pieced together by ruling out other things (such as Lyme disease) and using MRI scans to look for lesions in the brain, spinal cord or optic nerve. Doctors also question patients about their history, teasing out stories that might indicate a

prior flare-up or perhaps suggest a different diagnosis altogether.

In short, MS doesn't always present itself. You have to go looking for it.

"MS symptoms can be common to other conditions, so if a patient is not a classic phenotype, a doctor may not go looking for it," Williams says.

## **Awareness often lacking**

In particular, the expected phenotype of MS is a person of European descent. Recent research, however, indicates a higher incidence of MS in Black people than previously thought — consistent with the rate in white people.

Many times, people with MS can be their own best advocates, but only if they know what they're advocating for. Knowledge about MS is spreading, but in his experience, Dr. Ariel Antezana, MD, director of the NeuroMedical Clinic of Central Louisiana MS Center, says for many people of color — particularly Black people and Hispanic people, including those with Latin American backgrounds — there simply isn't enough awareness of MS. "For a lot of people of color, their understanding of the disease is much less than in the white population," he says.

That was true of 30-year-old Jovany Hernandez, who lives in Florida. In 2016, he went to the emergency room with pain radiating from his testes into his legs. He was told he might need surgery if he wanted to have children in the future. In his late 20s and recently married, Hernandez was planning a family, so he decided to have the surgery. The pain went away, and so did his concerns, until he experienced severe vertigo, which morphed into double vision.



**Jovany Hernandez (center), was diagnosed with MS in 2017. Photo:**

He went back to the ER. “They did an MRI, and they found lesions, the whole shebang,” Hernandez says. “They called them ‘abnormalities.’” This was the first time he heard “multiple sclerosis,” but that wasn’t his diagnosis. Doctors told Hernandez that he probably did not have MS, but an MS mimic, specifically, acute disseminated encephalomyelitis.

Then, as is common with relapsing-remitting MS, Hernandez’s symptoms simply went away. “I forgot about MS, to be honest,” he says.

Just before Christmas of 2017, his face went numb. Hernandez waited it out through the holidays and returned to the hospital on December 26 for another MRI. “Within two hours, they diagnosed me with MS.” No one told Hernandez, “Latinos don’t get MS,” and he says bias or any preconceived ideas on the part of the medical system wasn’t something he even considered. “I just wanted to get better.”

But Hernandez, the son of two Cubans, had a symptom that is relatively common among some in the broad demographic under the umbrella of “Latin American” — vision issues. After his bout with vertigo and double vision, he could have pressed the MS issue, but he didn’t know enough about the disease to do so.

By the time it came to talk about treatment options, Hernandez was prepared and had immersed himself in MS research. He was able to be his own advocate.

## **Gaps in knowledge, lack of trust**

For others, crossing the bridge from diagnosis to treatment can be difficult.

When that time comes, a person might meet with a clinical pharmacist like Jenelle Montgomery, who works for the Duke University Hospital. She helps people understand their medication options and works with them to navigate questions about insurance and other logistics. Montgomery answers a lot of questions. Many factors affect how much people understand therapies, their efficacy and their importance. “Knowledge gaps in education for Black and brown people do exist as an extension of the socioeconomic and health disparities we see in the U.S. as a whole,” Montgomery says.

“I think these disparities can have greater consequences with Black and brown patients,” Montgomery adds. Because even with a similar knowledge gap, Black and brown people face a higher disadvantage than their white counterparts. “Research shows Black people with MS might have more aggressive disease and greater disability,” she says. “And in Hispanic and Latin American populations, people are diagnosed at a younger age.”

Therefore, it’s crucial that newly diagnosed people and their doctors move as quickly as possible to knock down any potential barriers to care and put together a treatment plan,

Montgomery notes.

On its own, though, being better educated about therapies won't persuade everyone to consider taking a disease-modifying therapy (DMT) or unfamiliar medication. "Particularly with African Americans, you sometimes see a mistrust of the healthcare industry, that it's going to exploit them or treat them unfairly," says Dr. Nuha Abou-Zied, MD, an MS specialist at Wake Forest Baptist Health in North Carolina.

The mistrust is warranted. From the "Father of Modern Gynecology" James Marion Sims, who experimented on enslaved women, to the Tuskegee Study, which for 40 years observed Black men with syphilis, not treating them even after the discovery of penicillin, history is rife with mistreatment of Black and brown men, women and children.

This history is not ancient — the last living participant in the Tuskegee Study died in 2004 — and many communities have not forgotten.

Trust must be earned. Having more Black and brown neurologists, more doctors who implicitly understand this history, would help, Montgomery says. "I do think that giving knowledge and education to patients can be more effectively delivered, and more effectively received if they build trust," she says. "That could be done by seeing people who look like you."

In 2019, the American Academy of Neurology counted 2.7% of its members as Black and 8.5% as Hispanic or Latinx. Even without a shared cultural perspective, Abou-Zied says, respecting another person's beliefs and culture can go a long way toward earning trust. When people do not want to start on MS therapies, there are a few things she might do: If they are stable, she might agree to observe for a while.

If a patient wants to lean on their religion, or a safe, non-medical treatment, she agrees. "Most of the time, once I follow up, I say, 'Why not do both? Yes, pray or use CBD lotion, but also start on a DMT.'"

"Doctors will sometimes dismiss people if they don't want to be on medication," she says, "But most people are quite reasonable. I'll just explain the options."

However, there are cases where it's clear patients do not understand the potential repercussions of not starting a DMT.

"I never use scare tactics," Abou-Zied says. "I try to be mindful and have a positive outlook, but I do sometimes tell people, 'Look, we have to stop this.'"

A mindful approach is particularly crucial in Black and brown populations because of the course the disease takes. "Most of the damage happens in the first few years," Abou-Zied says. "And by the time there is disability, there is little I can do."



**Billie Walker, here with her daughter, was determined to remain strong after her MS diagnosis.**

Even if someone decides to use a DMT, they still face decisions. They may hear conflicting information when it comes time to choose one of the now 19 available options. It's not infrequent to hear, for instance, that some drugs work better in Black patients than others. There is some data to support this, but not much. When it comes to any question about the biological relationships between race and MS, there just isn't enough evidence to say, one way or another.

## **Race and MS**

To better understand how race may affect the way people experience MS, one first has to understand what "race" means in the context of medicine and if the categories we use — which are predominantly based on how people look — suggest any underlying biological similarity.

In a paper published earlier this year in the Multiple Sclerosis Journal, authors J.L. McCauley of University of Miami's Miller School of Medicine and Lilyana Amezcua of the University of Southern California's Keck School of Medicine looked at this question in service of MS research. The National Multiple Sclerosis Society funded the study.

From a genetic standpoint, most Black Americans have genes with a mixture of European origins and African origins. People who fall under the category of Hispanic have in their genes differing amounts of DNA originating in America, shared with Native American people, in addition to Europe and Africa. And of course, any individual can have genetic material with

origins from anywhere in the world — whether or not they know it.

The categories used in everyday language are insufficient when it comes to studying the disease.

For example, the authors write:

“The use of a single Hispanic ethnic category is insufficient to distinguish genetic variability between Mexican and Puerto Rican populations, which could be important when examining why a certain disease that has a genetic basis is more common among individuals with Puerto Rican ancestry versus those individuals of Mexican ancestry.”

Or, as Abou-Zied says: “It’s more about genetics and not about appearance or color of skin.”

Race is not a substitution for genetic markers, but race can function as a starting point.

“MS is far behind in genetic research,” compared to certain cancers, for instance, Williams says. “We see worse outcomes in Black and Hispanic populations, and we’re working our way backward to see if there is some underlying biology to it, or is it socially determined, or some combination of both. We just don’t have the data.” There aren’t a lot of biomarkers to help determine disease severity, she says.

## **MS symptoms and disease progression**

“We have to be very careful about generalizing, but the trends we see are that Black people with multiple sclerosis tend to have more disability earlier in the disease,” Williams says.

Black people with MS also tend to have more lesions on the optic nerve and spinal cord, correlating with disability, according to Amezcua and McCauley’s research. “Black people have to use a cane up to six years earlier than their white counterparts. They are admitted to nursing homes earlier. They have more MRI lesions, as well as faster atrophy or shrinkage of the brain.

“In just about every domain,” Williams says, “they do worse.” But she points out that the research is limited and that more studies are necessary to understand why. She adds many Black people with MS do well.

Among the populations that make up Hispanic and Latin Americans, MS tends to present itself earlier, according to a study published this year by Amezcua in the Journal Practical Neurology. Although the rate of disease is lower than in white Americans, outcomes are poorer, Williams says. “We see optical disease, long spinal lesions and poorer outcomes in terms of disability.” To narrow the gap, researchers and healthcare professionals need

reliable data. In its absence, however, there are steps that clinicians and people with MS can take to help ensure the best possible outcomes.



**Jenelle Montgomery draws solutions from experience on race and MS.**

Abou-Zied trained for 14 years to specialize in MS. In general, she says doctors training in neurology do not have a lot of exposure to many of the varied illnesses under that umbrella, including MS.

“In my four years, I only saw a few MS patients,” Abou-Zied says of her residency. “MS was kind of tucked away, aside from a few inpatients,” who would not necessarily present in the same way a new patient with suspected MS would. Many non-specialist neurologists do take a particular interest in MS, keeping up to date with the latest developments and research, she says. Still, she says, the field could benefit from more exposure to different MS populations during residency.

Williams, also an MS specialist, agrees. “I would love to broaden access to MS-specific care,” she says. Although, she says, merely having access to a general neurologist would be an improvement in many communities.

Presenting a clearer picture of what’s at stake is also something the doctors all agreed could go a long way to improve outcomes. “I’ve seen a number of people who were diagnosed but did not take a DMT because they weren’t informed of the consequences of the disease,” Williams says. “They’ve said, ‘Oh, I didn’t realize what was at stake.’”

Antezana has seen the same at his clinic in Louisiana. “Lots of patients know the disease, but they don’t know how bad it can be,” he says. “It can be debilitating if not treated, but it can

also be a chronic, manageable condition if it's diagnosed in time and, critically, if it's treated appropriately."

## **Cultural considerations**

The culture of medicine isn't the only external factor affecting outcomes; in some Black and brown communities, traditions, perceptions and expectations can be an influence for better or worse.

Antezana says it's not unusual in immigrant communities, where people shun the hospital for fear of being looked on with suspicion or, if they don't have documentation, fear of being deported. He tries to reach people where they are, hosting community events and speaking at seminars and webinars.

Being an immigrant from Bolivia, Antezana also can speak to a wide range of people in their first language. He recently spoke in Spanish at a National Multiple Sclerosis Society webinar, discussing the relationship between COVID-19 and DMTs.

"I enjoy it," he says. "When I see patients in a busy clinic, there's not a lot of time to discuss everything. You have to focus on the patient him/herself." Webinars give him a chance to discuss a broader range of topics.

Williams notes that people may not recognize that in marginalized communities, they can seek other opinions, even if their needs are not being addressed. "If you don't get what you need, it's OK to get a second opinion," she says. She is quick to add, "That doesn't mean you get up and leave a doctor that doesn't say what you want to hear."

Some communities may perceive chronic illness as a sign of weakness, Montgomery says, or fear it means losing independence. Those perceptions can lead to delaying treatment or even impact a decision to go see a neurologist in the first place — all of which can lead to poorer outcomes, according to Montgomery.

It's unclear whether societal factors are the only ones at play. It's not clear what biological mechanisms might underlie poorer outcomes for Black and brown people with MS. There isn't much data either way.

## **A lack of data**

"One of the biggest limitations we have is that most of the data we have is not clinical trial data," Williams says of data specific to Black and brown people with MS. "Clinical trial data is key." It eliminates the gaps that may be caused by socioeconomic factors. Medication is most likely free. Access to a doctor is guaranteed. If a trial participant has any changes in condition — such as a relapse — a doctor will see them quickly.

"With everybody getting essentially the same care, we will be better able to see trends and



actual outcomes,” Williams says. What is clear from the limited clinical trial data that is available is both promising and disheartening: “People do very similarly.”

But she cautions that research with larger numbers of people is needed.

“If you look at most of our trials, probably the largest number of Black people enrolled in any clinical trial program is about 60 out of several thousand people,” Williams says. Most trials average 10–20 Black participants. “You cannot make a generalization about a whole population based on 15 people.”

There is even less data for Hispanic, Latin American and Native American people with MS. There are a few possible reasons for the lack of Black and brown people involved in clinical trials: a history of being experimented on as opposed to being willing participants in experiments, difficulty traveling to and from a medical institution, the potential to need to miss work. All of these factors are potential barriers to anyone, but they hit Black and brown communities harder.

Still, information coming directly from Black and brown people with MS suggests they face additional roadblocks when studying participation. A survey of 2,600 people, including about 400 Black and brown people, conducted by the MS Minority Partner Engagement Network, asked for people’s attitudes toward research. “Most of the responses about research were very positive,” Williams says. When asked, a majority of participants of all backgrounds said they would participate in research. Looking at the reasons Black respondents said they didn’t participate, “Many said they weren’t asked and didn’t know where to find info about being involved in clinical research.”

And on the clinical side, enrollment criteria can often rule out people with certain conditions that are more likely to be found in Black and brown communities, Williams says, such as diabetes or high BMI (body mass index).

## **Diversity in research**

Williams is hopeful, however, that change is coming. “COVID has brought attention to the disparities of healthcare in our country,” she says. “I hope that this will have a ripple effect in terms of increased funding about the differences we see.”

“I’m hopeful we’ll get some answers,” Williams says, “because now tools are more readily available and there is more of a focus on this work.”

**Brandie Jefferson is a writer in St. Louis, Missouri. She was diagnosed with MS in 2005.**

Learn more about how MS affects the Black community: [Black women with MS speak up](#) and [Obstacles to access](#).

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