

A fresh perspective



Our understanding of how MS affects the black community is evolving.

by Vicky Uhland

A decade ago, Marques Jones was cruising in the fast lane.

He'd wake up in his Richmond, Virginia, home at 6 a.m., visit the gym, put in a full day's work as a process engineer, socialize with his wife and friends, and rarely get to bed before 2 a.m.

But then the headaches and fatigue began. "I was 25 years old, and I couldn't stay up past 9 p.m.," he says.

Jones, who remembers missing only four days of school due to illness as an adolescent, wasn't sure what to do—especially when the doctor said he looked "healthy as a horse" and there wasn't anything wrong with him.

But the fatigue and headaches persisted, so Jones turned to his father-in-law, who is a doctor. He referred Jones to an internist, which set off a two-year cycle of visits to six different neurologists, a cardiologist and even an ear, nose and throat specialist. Finally, in 2008 at age 27, Jones was diagnosed with multiple sclerosis.

Jones' odyssey of doctors' appointments and false diagnoses is not uncommon in people with MS. But what is different is that Jones is African-American. And that difference, he and others believe, influences every step in his MS journey—from diagnosis to treatment to the very course of the disease itself.

"African-Americans with MS face a medical jungle," Jones says. The reasons for that are varied and complex, but thanks to recent research and doctor and patient initiatives, there is growing awareness about the unique challenges that MS presents for African-Americans.

Debunking the MS myths

As recently as 15 years ago, many people in the medical community viewed MS as a disease that predominantly affected those of European descent. The idea that African-Americans don't get MS was based mainly on two pieces of data, says Dr. Annette Langer-Gould, a neurologist at the Kaiser Permanente Department of Research & Evaluation in Pasadena, California. The first is a 1979 study of 5,300 World War II and Korean War veterans that found that white males were approximately twice as likely to get MS as black males, and the second is the overall lack of MS diagnoses among black people in Africa.

But Dr. Langer-Gould says MS diagnosis is difficult throughout Africa because there are very few MRI scanners or neurologists. She also believes the military study was flawed because it only included a small number of African-Americans. In fact, a 2015 article written by six noted MS researchers and published in **Neurology Clinical Practice**, reported that out of nearly 60,000 published articles about MS, only 113, or about 0.2 percent, focus on African-Americans.

"There can still be a fear of being experimented on, a fear of being a guinea pig," says Dr. Mitzi Joi Williams, an African-American neurologist at the Multiple Sclerosis Center of Atlanta and one of the authors of the 2015 article. Some of this fear, particularly among older adults, is a result of the Tuskegee Syphilis Study. From 1932-72, rural, impoverished African-American men were recruited for this study under the guise of receiving free healthcare from the government. They weren't informed of the true purpose of the research—to study the progression of untreated syphilis—and were prevented from accessing treatment. The outrage and sense of betrayal that caused reverberated for decades.

Now, fewer adults are aware of the Tuskegee trials and there is a greater focus on medical ethics today, so the trust in medical research has improved. And over the last decade, more African-Americans have participated in MS studies. Dr. Williams says those studies have thoroughly busted the "African-Americans don't get MS" myth. In fact, some studies show that African-Americans, particularly females, are actually diagnosed with MS much more frequently than people of European descent.

Recent findings

A 2012 study of military personnel published in **Military Medicine** reported 46 percent more cases of MS in blacks than in non-Hispanic whites. And a 2013 study of 496 newly diagnosed people conducted by Dr. Langer-Gould and her colleagues found that blacks had a 47 percent increased risk of MS compared with whites. The study, which was published in **Neurology**, also found that among blacks, women had triple the risk of MS compared with men. This mirrors the increased risk of MS among women of northern European ancestry.

A follow-up study Dr. Langer-Gould and her team conducted found that about 26 percent of blacks have a family history of MS, a rate similar to that of whites. "So it could be that it's not a new disease in African-Americans, but just underrecognized," she says. There's also the theory that people with darker skin tones don't transform sunshine into vitamin D as easily as

people with lighter skin and thus may have an increased risk of MS. “But that doesn’t explain why our study showed that Hispanics and Asians have a lower risk of MS than Caucasians,” Dr. Langer-Gould says.

An earlier diagnosis?

With such pervasive evidence of MS in African-Americans, doctors consider it as a potential diagnosis much more readily now. What’s more, there’s some evidence that MS, a disease that is suspected to be caused by a combination of genes and environment, can manifest differently in African-Americans.



Judy Boone felt like one of the only black people living with MS when she was diagnosed a decade ago. Photo courtesy of Judy Boone

On a Friday morning in January 2007, Judy Boone woke up in her home in Knightdale, North Carolina, and discovered she was completely blind in her right eye. She was also so numb on her right side that she couldn’t stand. She rushed to the hospital and underwent a series of tests. “The doctors said, ‘We think you have MS,’ and I said, ‘I don’t have MS because African-Americans don’t get MS.’ ”

Boone, who was 40 years old at the time, was indeed diagnosed with the disease. What’s more, she presented with both of the MS symptoms that are more common in African-Americans than other ethnicities: optic neuritis, which leads to vision problems; and transverse myelitis, an inflammation of the spinal cord that causes mobility issues.

A 2004 study published in **Neurology** reported that MS that’s restricted to the optic nerves and spinal cord occurs in 17 percent of African-American patients compared with 8 percent of

Caucasian patients. And transverse myelitis affects 28 percent of African-Americans with MS compared with 18 percent of Caucasians.

Unlike subtler MS symptoms, mobility and vision issues can spur a person to visit a doctor more quickly. And that may be why the study found that once they get medical attention for their symptoms, African-Americans tend to be diagnosed with MS faster than white people (one year after symptom onset for blacks compared with two years for whites).

Dr. Langer-Gould's study did not show this difference—and neither did Jones' personal experience. While Dr. Langer-Gould's paper revealed interesting results, it has not yet been duplicated in other research.

Dr. Williams says little data exists on the prevalence of other MS symptoms in African-Americans.

The disability dialogue

The researchers on the 2004 study also noted that African-Americans were more likely to eventually need canes or wheelchairs than their white peers. Other studies since then have reported similar results, making it a commonly held belief that African-Americans have a more aggressive MS disease course than people of European descent.

African-Americans do tend to have more spinal cord lesions than people of other ethnicities, say Drs. Williams and Langer-Gould, and spinal cord lesions can cause more mobility issues earlier in the disease and lead to greater disability.

Dr. Aljoeson Walker, associate professor of neurology and ophthalmology at the Medical University of South Carolina, says lesions in the spinal cord can result in more debilitating symptoms than those in the brain. "Like in real estate, MS is all about location, location, location," he says. "Every area of real estate in the spinal cord has a different purpose that tends to be more clinically apparent, so any lesion can produce a symptom that will bring you to the doctor. But in the brain, it may take five to seven lesions for a clinical symptom to occur."

Nevertheless, it's still unclear whether the greater degree of disability occurs in most African-Americans with MS or in just a subset of them, says Dr. Williams.

While previous research suggests that MS also has a later onset in African-Americans, Dr. Langer-Gould's study didn't find that to be the case. Another study, published in 2003 in **Multiple Sclerosis**, reported that African-American women and white women have a similar age of disease onset, but African-American men have a younger age of onset. Given the lack of consensus, more research needs to be done in this area.

Cultural concerns

Some African-Americans may be diagnosed at a later age simply because they may visit the doctor later. This could be due to their distrust of doctors—partly because of the Tuskegee

trials and partly because of cultural mores.

“In the African-American culture, people often want to be seen as strong, not vulnerable, making it difficult to talk to others, including family members, about their illness,” says Dr. Annette Okai, medical director at the Multiple Sclerosis Treatment Center of Dallas.

When Angela Lott of Hazel Park, Michigan, was diagnosed with MS in 1992 at age 32, she felt like she couldn’t discuss her disease with many of her friends and family.



Angela Lott, diagnosed with MS more than 20 years ago, encountered negative attitudes about the disease from people in her community. People at her church did not want to talk to her about it.

Photo by Riku Foto

“People in my church didn’t want to hear I have MS—they felt like it meant I had a lack of faith. One sister with MS at my church wouldn’t take medication because she felt like if she didn’t claim her disease, it would go away,” Lott says. “And I felt like my family was afraid and ashamed, that somehow I brought the disease on myself. Because I don’t look like I have a chronic disease, I think they figured it would go away if we didn’t talk about it.”

This attitude may be particularly true for people who have “silent” MS symptoms like fatigue, heat sensitivity, cognitive difficulties or depression.

Anqunette Jamison, a former Fox 2 Detroit morning news anchor who was diagnosed with MS in 2013, says many African-Americans don’t realize that depression is an MS symptom. “In my family, the mentality is, ‘You’re not marching for civil rights [like your forebears]—what do you have to be depressed about?’”

Some African-Americans feel that a social bias extends into healthcare as well. In 2012,

Richard Wright, a 43-year-old living in Harrisburg, Pennsylvania, started feeling numbness in his groin. He thought he had pulled a muscle during a workout, but when the numbness spread into his legs, he became concerned. And when he developed urination problems, he decided to visit a doctor. Like many people who don't have their own doctor, he went to the local hospital's emergency department. "The doctor was so cold, with no empathy. The nurse treated me like I was a robot," says Wright, who wonders if his race was a factor.

Even though he did eventually get an MS diagnosis after a second visit to another hospital and was prescribed medications that improved his symptoms, Wright doesn't feel good about the experience. "For me, going to the doctor was traumatizing rather than enlightening. It was almost like they didn't want to care for me," he says.

Jones agrees that concerns like this can complicate both diagnosis and treatment options. "If we're sick enough that we finally go to a doctor and then we hear there's nothing wrong with us, we'll believe that because we don't want to see the doctor anymore," Jones says. "This can be a real problem with MS, which can present as so many things and is difficult to diagnose."

Are certain drugs less effective?

Like many people with MS, Lott has tried different medications. She started with interferon injections every other day but didn't like the flu-like side effects. So she switched to a weekly interferon drug. Eventually it stopped working as well, so she says her doctor has recommended different medications. Lott is now on an interferon that she takes three days per week, which is working for her.

It's been suggested that interferon is not as effective in African-Americans, but that's based on very little evidence. Because it's difficult to do studies on the effect of different MS medications solely in black people, Dr. Okai says researchers have relied on sub-analyses of existing clinical trials.

That includes one trial on Rebif[®], an interferon medication, which involved over 600 people. But Dr. Williams says only 36 of them were African-American, and "it's hard to generalize with 36 people."

Other drug data is scarce, but Dr. Okai says a five-year trial showed that African-Americans did as well as people of northern European descent on alemtuzumab (Lemtrada[®]). And Dr. Walker, along with Dr. Okai, says one study suggests that natalizumab (Tysabri[®]) has been shown in clinical practice to be equally effective in African-Americans and Caucasians, "particularly in those with dramatic and significant lesion loads, but without the [risk of] PML." (PML, short for progressive multifocal leukoencephalopathy, is a rare infection of the brain, usually fatal, that can develop in people who take Tysabri and also test positive for antibodies to the JC, or John Cunningham, virus.)

The high cost of MS medications can also be a problem, which is why Dr. Walker encourages

all of his patients to fill out enrollment forms for financial assistance from the DMT manufacturers. That way, patients may be eligible for reduced prices without having to reveal their financial status to the doctor.

Changing lifestyles

The importance of a healthy diet and exercise can hardly be understated. But for people with MS, it's especially critical, says Dr. Walter Royal III, director of the Maryland Center for Multiple Sclerosis Treatment and Research. That's because lifestyle-linked health conditions like obesity, diabetes, high blood pressure, high cholesterol and heart disease can hasten the progression of MS, and addressing these problems can slow disease progression.

And, according to the American Heart Association, these conditions disproportionately affect African-Americans. In fact, 63 percent of black men and 77 percent of black women are overweight or obese.

Knowing that weight gain and unhealthy eating patterns may play a role in MS, Jones recently changed his diet and lost 24 pounds. But it wasn't easy. "When I go to family functions, I get encouraged to eat food that doesn't exactly promote the best health. Because everyone might be more heavysset, they think I'm skinny even though I now fall into the normal range," he says. "People look at me like I've got five heads because I'm eating Greek yogurt with strawberries, and organic oatmeal, rather than bacon and fried potatoes."

Lack of exercise can also be an issue. A 2016 survey of people with MS published in **Archives of Physical Medicine and Rehabilitation** found that, on, average, African-Americans exercise less than people of northern European ancestry. And exercise has been shown repeatedly to have positive effects on physical mobility, cognition and mood. While the reasons for African-Americans' lower exercise rates aren't clear, researchers hope to drill deeper into this issue and address it with new strategies.

Family has a big influence in many African-Americans' lives, which is why Dr. Williams says it's important to include family members in treatment discussions and decisions. "Bring them with you to your doctor's visits, because hearing about your disease from healthcare providers face-to-face can have a bigger impact than hearing it from you," she says. "Take them to education programs offered by the National MS Society. When they see 50 to 60 other people with MS talking about the same symptoms you have, they can see you're not just making things up."

No longer the silent disease

After he was diagnosed with MS, Jones says his grandmother, a nurse's aide, advised him to keep his disease private. "She was afraid of people's preconceived notions about MS and how it would affect me in society and the workplace," he says.

Boone, however, believes her community has come a long way since her diagnosis in 2007, and opening up about MS is the right thing to do. "Back then I felt like I was the only African-

American who had MS, but now I feel like there's just as much support for us as anyone else."

Much of this is due to concerted efforts to educate physicians and members of the African-American community about the disease. But it's important that African-Americans be involved in those educational efforts, says Dr. Royal.

While new advances and attitudes help ensure that MS is no longer a hidden disease in African-Americans, there are still obstacles to proper diagnosis and treatment. The bottom line, Lott says, is to "never be ashamed to advocate for yourself, even if others aren't advocating for you."

As for Jones, he decided not to remain silent. He speaks frequently in his community about MS and is chair of the government relations committee in his area. "I've tried to be as much of a champion for MS awareness as I can, because only when we demystify the disease can we make progress," he says.

Vicky Uhland is a freelance writer and editor in Lafayette, Colorado.

Want to contribute to our understanding of MS in African-Americans? Join a research project at [iConquerMS](#) or the [North American Research Committee on Multiple Sclerosis](#).