Multiple Sclerosis Association of America

MSAA Podcast:

The Many Faces of MS: Exploring Diversity Within Multiple Sclerosis – Episode 3

Host: Peter Damiri

With special guest: Dr. EJ Gettings, DO

Peter Damiri:
Hello, and welcome to the Multiple Sclerosis Association of America's podcast, "The Many Faces of MS, Exploring Diversity within Multiple Sclerosis." I am Peter Damiri, Vice President of Programs and Services for MSAA, and your host for today's program. I am honored to welcome our guest presenter, Dr. E.J. Gettings, to the program, who will be sharing with us his insights on multiple sclerosis and its impact on various patient populations. Dr. Gettings is an assistant professor of neurology at Temple University in Philadelphia. Dr. Gettings, thank you so much for being here and giving us your time today.

Dr. EJ Gettings:
Great. Good morning, Peter, and thank you for the opportunity to come and talk to you about what I think is a very important and at times underrepresented topic, looking at diverse populations with this disease.

Peter Damiri:
Absolutely. Appreciate that. So, before we begin our specific topic today, could you just give us a brief overview of multiple sclerosis?

Dr. EJ Gettings:
Sure. As many of you know, multiple sclerosis is an immune-mediated disease of the central nervous system, which is the brain and spine. Your immune system is what is normally responsible for doing things like fighting off infections. In the case of many diseases, your immune system loses the ability to tell self from those infections. It's supposed to be fighting off. And in the case of multiple sclerosis, the immune system causes damage to something called myelin, which is the coating of part of your nerve cells. When this happens, it can cause multiple different types of symptoms. If it happens acutely, it's something called a relapse, and it can be seen in the more common type of the disease, something called relapsing-remitting multiple sclerosis, which affects about 85 to 90% of people initially diagnosed with this disease.

It is relatively common. It affects roughly a million Americans. We see it more in women than in men; it's about three times more likely to be seen in women than men. It's more frequently seen in younger adults and as such, it's the second most common cause of disability in working-age adults. But we do see it in older adults as well, but certainly more commonly in the young. In the past, there's been this thought that it affects Caucasian populations more frequently. But we think now that that's really a biased assessment. Some of the more recent data that's come out suggest that actually African-American women are specifically at very high risk for this condition. And certainly, we see it in a wide range of people of all races and kind of all geographies within our country. There has been noticed to be an increased risk at higher latitudes. So, for example, if, you know, you grew up in Maine, your risk is higher than if you grew up in Miami. And that's for a number of different reasons as well.

Peter Damiri:
Great. Thank you for that overview. And, you know, our topic today is exploring diversity. And you mentioned Caucasians, African-Americans, I believe maybe the Hispanic-American MS communities are affected as well. Could you tell us some of the differences, and how MS affects some of these patient populations?

Dr. EJ Gettings:
We believe that multiple sclerosis may act differently in different populations of patients. So, for example, in general, African-Americans and Hispanics may experience the disease differently than Caucasian populations. Now, as I mentioned before, the prevalence of multiple sclerosis is just as high and may even be higher in African-Americans and Hispanics. And our goal with the treatment of this disease, in general, is to in addition to helping quality of life, affect disability, and prevent disability. And unfortunately, African-Americans living with multiple sclerosis may be at higher risk for disability. We know that from a number of different studies, we believe that African-Americans have a higher risk for disability even at onset. So, in other words, the first time someone sees a neurologist, they're at a higher risk for already having a preexisting disability at that time. So, we’re not completely sure why that’s the case. Certainly, there are a lot of reasons why we think it may be occurring.

So, on average, African-Americans tend to have an older age of onset when they're diagnosed. We know that the risk for vascular co-morbidities, so those are things like: high blood pressure, diabetes, and high cholesterol are seen more frequently in African-American and Hispanic populations. And we do think that that may increase the risk for disability. But then there are also data to suggest that African-Americans are less likely to be referred to specialty services and there are concerns with access to care, specifically access to neurologists. They're less likely to recover from their initial relapse or initial attack in those people living with relapsing-remitting multiple sclerosis.

Later on in the disease, we've seen that there are higher rates for admission to nursing homes, and when people are admitted to nursing homes, typically the disability level is higher. Once there, people living with multiple sclerosis in the African-American and Hispanic populations are more likely to need a cane, more likely to need a walker. And the disease tends to be more aggressive earlier on. So, the length of time between the first and the second relapse tends to be shorter in these populations.

So, in addition to some of these clinical findings, there are some data regarding objective evidence to suggest that African-Americans living with the disease have a more severe disease. We look at things like MRI as a metric, or as a tool, for monitoring the disease. And there is some data out there to suggest that African-Americans living with multiple sclerosis have a larger lesion load, meaning they have more lesions seen on their MRI at the same point in the disease.

There are other things that we use on MRI as tools for identifying progressive disease and as tools for identifying someone's risk for disability. That includes things like black holes, which is a specific finding that we see on MRI, and then also atrophy. And in African-Americans and Hispanics living with this disease, these tend to be seen more frequently than in Caucasian populations.

There's also been a suggestion that progressive disease may be seen more frequently in these populations. And one of the things we can look at regarding brain volume loss and loss of nerve cells is something called OCT, which is a specific test that can be done to look at the back of the eye and can be used as a tool to identify progressive MS and identify areas of damage and something called a retinal nerve fiber layer thinning. And that's seen more frequently in African-American populations. So, in short, we think that people in the African-American population, Hispanic populations, are seen with a more severe disease, and there are a number of ways in which we think that that's actually occurring.

Peter Damiri:
Wow. You've provided a lot of helpful insights, and there certainly are a lot of significant differences, especially with the course of the disease and the progression. Are there any specific causes that could relate to that or factors or genetics or anything to really point to?

Dr. EJ Gettings:
So, the short answer for that is that at the moment we don't know why there is that difference. Certainly, more research needs to be done to identify these differences, to establish truly that there are differences, and to see what is driving the difference in outcomes for people living with this disease. There has been a suggestion that maybe genetics may be contributing to this. There's been some research looking into different immune system abnormalities that may be different in African-American populations. For example, one specific line of cells, something called B cells, may be more related to the disease burden in African-Americans. Now, that's important because some of our more recent therapies that have been FDA-approved for this condition target B cells more effectively than some of the older, more traditional therapies for the disease. So, we certainly need more research to identify why there is this difference.

And in addition, to just the genetic and the immune changes with the disease, there may be social factors that are contributing to this. I mentioned earlier that access to care can be an issue in these populations in addition to access to effective management of vascular comorbidity, again, high blood pressure, diabetes hyperlipidemia, which is high cholesterol, which we do believe contributes to risk.

Peter Damiri:
Right. So, if you're not able to get the care that you need or be seen by an MS specialist or get the MRIs you need to track progression, you know, that could certainly allow the disease to progress further, correct?

Dr. EJ Gettings:
Exactly. Access to comprehensive specialized MS care is not seen as much in the African-American and Hispanic populations. And that's something that we as healthcare providers need to do a better job.

Peter Damiri:

Sure. Sure. And certainly, you know, that's been a big area of service that we're looking to provide as well and get into a lot of those underserved MS populations, not only with the African-American and Hispanic communities but really the rural communities, too, where they just don't have the special MS centers to go to.

Dr. EJ Gettings:
Another significant area of concern and need is with rural populations that have their own barriers and have their own difficulty in getting to specialized care. And that's an area where the MSAA has worked quite a bit, and certainly, in healthcare in general, we need to do a better job at accessing those populations, especially as it relates to some people living with MS that have a disability, that it's even more difficult. And that's an area where something like telemedicine or telehealth can really be important.

Peter Damiri:
Absolutely. Well, let's talk about treatments. We know that it's critically important for a person diagnosed with MS to be on an FDA-approved disease-modifying therapy. In your practice, do you see any differences among the patient populations in how they respond to the therapy?

Dr. EJ Gettings:
There are a number of different FDA-approved medicines that have come out for the treatment of multiple sclerosis. Most of them received approval for relapsing-remitting multiple sclerosis, but more recently, the FDA has approved therapies for primary progressive and secondary progressive. One of the real challenges with this disease is that there's so much variability.

Peter Damiri:
Sure.

Dr. EJ Gettings:
And that many people with MS do very well, they are on treatment and are able to continue to work and continue to do all of the things they want to do with family, and have a high quality of life. Unfortunately, there are people that, even despite the best therapies that we have, may not do as well.

So, with that variability in mind, one of the things that we do see is that in general, in practice, we do feel that African-Americans living with this disease tend to be more refractory to treatment, meaning that even with some of the more effective treatments for managing multiple sclerosis, they may continue to get worse. Now, that may mean they may continue to have relapses despite the right therapy, effective therapy. It may also mean that they're more likely to develop progressive disease, whether that's primary progressive or secondary progressive MS. And when I say that I mean that despite not having relapses, they may slowly be worsening over time. Now, we do have therapies available for the treatment of those conditions, but unfortunately, despite those therapies, people may continue to get worse. Now, we do need more data to identify that and see why it is that people in the African-American and Hispanic populations may continue to worsen despite being on effective therapy.

Peter Damiri:
Excellent information. Great points. Yeah. It's something that now hopefully with the more progressive medications available, you know, that would be a better treatment option for a lot of folks. We talked about treatments, and certainly, these medications come about through clinical

trials, and I know that's a big topic in the MS community. Can you talk a little bit more about the diversity in clinical trials?

Dr. EJ Gettings:

Well, in general, we rely on clinical trials to demonstrate that our therapies work. OK, so the goal of clinical trials is to identify that the medications that we use for multiple sclerosis are effective and that they're effective at preventing relapses and slowing disability. The FDA uses the data from these clinical trials to make a decision regarding the approval of therapy. So, the FDA-approved medications that are available now are only available because people living with the disease have participated in these clinical trials to provide data for us to show that these medicines actually work. Now, this is not by any means unique to multiple sclerosis, however, the studies and the clinical trials that have been performed have not adequately included minorities in this population, and that's certainly for a number of reasons.

But if you look back at some of the initial clinical trials that were done in the 1990s, looking at what's generally considered to be platform therapies, so glatiramer acetate and interferon, the population was less than 10%, typically between 5 to 10% African-American. And we know that in general, the population of people living with multiple sclerosis that are African-American is much higher than that. Unfortunately, those numbers have not improved consistently with clinical trials and there are a number of reasons for that. So, some of the more recent clinical trials have had numbers as low as 2% of the population in a clinical trial being represented by African-Americans.

Peter Damiri:

Yeah, that’s much lower, right?

Dr. EJ Gettings:

So, you know, there are a number of reasons why this is the case. Certainly, as we mentioned before, access to specialized care and comprehensive care centers, which is where most of these clinical trials are performed, there is skepticism in certain populations regarding clinical trials for different historical reasons, understandably, but it is important. So more recently, it is becoming increasingly difficult to perform placebo-controlled trials in the United States. We recognize that many of these therapies work. So, for people living with multiple sclerosis, the idea of being enrolled in a trial where potentially they’re being randomized to not get medicine is something that is... it's difficult to enroll people into these trials for good reason.

For that reason, many of the more recent clinical trials have included populations from other countries, so Europe, Eastern Europe. And we have to question how well those populations generalize to our population here in the United States, specifically regarding minority populations. So, the inclusion of African-Americans and Hispanics is important. Again, it's not something that we see only in multiple sclerosis but given the differences that we talked about earlier and how the disease progresses, and the differences that we see on MRI and clinically in people living with this disease that are African-American and Hispanic, it's really important for us to do a better job with getting a better-generalized population.

Now, many pharmaceutical companies have identified that this is an issue, and many of them are investing in different ways to look at these populations. So, we'll see. So hopefully within the next few years, we will have more data to report and a better understanding of how these therapies work in different populations. But in general, what I would say is that you know, participating in clinical trials is really important. And for those people who are interested in participating in clinical trials, but maybe it hasn't been brought up to them before, it's important to talk to your neurologist or talk to the person who's managing your disease. Advocacy organizations such as the MSAA are also very valuable in putting you in touch with the people that can get you involved in these clinical trials.

There are clinical trial registries out there, such as clinicaltrials.gov, that can help you identify where you can go to participate in these. And it's important to remember that clinical trials are needed not just regarding MS therapies. We use clinical trials to look at a number of different ways in which MS affects people's lives and quality of life.

So, one big area that really has been underrepresented is symptomatic management. So, in other words, the management of things like fatigue and depression, and walking and walking speed, is an area that we really need to concentrate on going forward. And it's important to consider that those are areas for clinical trials for improvement as well. So, wellness is certainly another area that there are a lot of clinical trials that are ongoing. Diet, control of the vascular changes that we talked about before, high blood pressure, diabetes, and certainly physical therapy, and cognitive therapy. There are a lot of different ways to get involved and moving the field forward so that you and future generations can really, really benefit from this good research.

Peter Damiri:
Absolutely. That's a great point because a lot of people do think maybe clinical trials are just for the medications for treating the disease. But you mentioned the wellness aspects and the symptom management aspects. That's a big part of getting more information and more therapies, correct?

Dr. EJ Gettings:
Definitely. And reach out to your neurologist, reach out to the MSAA, and other advocacy organizations. There is a lot of really good work that's being done out there and not just with medicines. So, there is a benefit in participating in these for yourself and for future generations of people living with this disease. So, it can be very worthwhile for people.

Peter Damiri:
Absolutely. And kind of on that note, of wellness and taking care of yourself, you mentioned the risk of disability being much higher in the African-American and Hispanic populations. So certainly, we encourage everyone to be on an FDA-approved medication. But in addition to that, and hopefully, people are, is there anything else that people with MS can do to decrease this higher risk?

Dr. EJ Gettings:
In general, with multiple sclerosis, there are a number of things that we feel can also decrease your risk for disability in the future, other than the FDA-approved medicines that you talked about. One of those things is, as I mentioned before, this idea of vascular co-morbidity. So, these are other conditions that people live with in addition to multiple sclerosis. So, it means high blood pressure, diabetes, high cholesterol, and smoking, certainly. Now, there is a higher risk for those conditions, or for many of those conditions, in people in the African-American community and the Hispanic community.

Now we're not 100% sure as to why these conditions increase the risk for disability with multiple sclerosis. So, in other words, is this a disease-specific mechanism, meaning does it actually make your MS worse, or does it happen for other reasons? We're not sure, but it is recommended that people make good, healthy living decisions to try and decrease their risk of developing these conditions. And then so for people also who are living with MS and may have these conditions already, it's important to make sure that you're following up regularly with not just your neurologist, but your primary care physician to make sure that if you're a diabetic, that your blood sugar is well controlled, your hemoglobin A1C is well controlled, that your blood pressure is well controlled as well, because, you know, in addition to just the MS specific therapies, these other conditions may decrease your risk going forward.

Peter Damiri:
Sure. And people may focus so much on MS, that they're not paying attention to other health issues that they should be seeing their general physician, correct?

Dr. EJ Gettings:
Exactly. Exactly. And another big piece here is smoking. We do believe that smoking increases the risk of disability with the disease. Again, we don't know 100% why that's the case, if it actually worsens the MS itself, or if it's because of other changes within the brain that tobacco products have. There are a lot of resources available to try and help you quit smoking. Many of those are available through the state that you live in. Your primary care physician can provide resources. Your neurologist can provide resources to help you quit. For those people who can't quit on their own, there are medicines, patches, and lots of different alternatives to try and help you, at best, quit, but also cut back on smoking if you can't quit, with the goal of eventually stopping completely.

Vitamin D is also an interesting question and it's kind of an incomplete story at this point. For many years there's been this thought that low vitamin D increases your risk for the development of multiple sclerosis. And then a thought as well that in people already living with the disease, low vitamin D levels increase your risk for worsening with MS, and this came out of some of the initial epidemiologic studies and geographical studies that said that, as I mentioned before, that your risk for developing MS is lower if you live closer to the equator. Now, we know that most of the vitamin D we get, we get through sunlight. So, the thought was that vitamin D may be related to this decreased risk in people who are exposed to more sunlight as they live closer to the equator.

Now, interestingly, many of the initial studies that were done showed that this risk was seen in Caucasian populations, but yet African-Americans and Hispanics living with the disease may not be at a higher risk for the development of MS with low vitamin D levels. And in addition to that, they may not see that higher risk for disability with low vitamin D levels when they already have the disease. Now, it's been identified more recently that this is a little bit more complicated, that the 25 hydroxy vitamin D level that we use to measure vitamin D levels may not be as accurate in African-Americans because of a difference in the protein that vitamin D actually binds to in the blood. So, it's a bit of an incomplete story. However, vitamin D in general is well tolerated. It's certainly safe and it is not expensive. It's affordable. So, in general, we do recommend it. Now, it's something to talk to your neurologist about as the dose of your vitamin D doesn't matter as much as the level that's in your bloodstream. So having that checked is something that you should talk to your neurologist or your provider about.

In addition to this, you know, diet certainly we think can influence the disease. We in general recommend a heart-healthy diet. So, if you're going to eat meat, leaner meats, certainly more fresh vegetables, less preserved foods, and exercise is a very good thing for a lot of reasons. Even short amounts of exercise can have impacts on walking, impacts on spasms. And tightness in your legs can also really improve and impact your thinking and your cognition in addition to your mood. So, exercise is certainly something that can be an important part of wellness with this disease. And it's something that even for people who have difficulty getting what we traditionally consider to be exercise short bursts of physical activity, walking, getting on an exercise bike, stretching, those are all very important things for the control of this disease.

Peter Damiri:
Absolutely great points. And even for people who have some disability and difficulty walking, seated exercises, seated yoga, I heard, was a fantastic way to still keep limber a range of motion.

Dr. EJ Gettings:
Very true. So, yoga is a great way to maintain some exercise for people who are having more difficulty, and even for people who aren't. So, it can really help with spasticity and with stretching, muscle strengthening, and balance. Yoga can really be a fantastic addition for many people living with this disease.

Peter Damiri:
As we wrap up our program, we want to make sure that we provide some helpful resources for our listeners. What suggestions do you have in terms of resources and tips?

Dr. EJ Gettings:
For many people with this disease, multiple sclerosis can be very isolating. It does not have to be. There are a lot of resources out there. The MSAA is an excellent example of an organization that provides a lot of support for people with this disease. Reach out to them, reach out to other advocacy organizations, and to your neurologist. There is a very vibrant community of people who take care of this disease. And that does not just include neurologists, it includes physical therapists, occupational therapists, people who do cognitive rehab, and nutritionists. So, certainly nursing as well. So, there's a very vibrant community of people who are there who want to help, and it's about finding those people to help you go forward. And we very often can make the mistake of spending too much time talking about medicine. And certainly, MS therapies are effective and they're important, but there's a lot more to controlling this disease than just medicine. And that's where things like diet and controlling some of these other conditions really become important, exercise as well. So, there are a lot of resources out there. So, you know, reach out to the people we mentioned; it can really make a difference in terms of your quality of life and going forward.

Peter Damiri:
Well, that is great advice. And we really appreciate all that you've shared with us today. Dr. Gettings, thank you again, so much. So, this concludes our podcast, “The Many Faces of MS, Exploring Diversity within Multiple Sclerosis.” On behalf of the Multiple Sclerosis Association of America, I would like to thank Dr. E.J. Gettings for sharing his insights on this very important topic.

I would also like to thank Gradwell House Recording for hosting us today and producing the program, and our funding partners, Celgene and Novartis, for supporting this podcast, as well as additional programs spotlighting MS and the family. This podcast, along with additional information on multiple sclerosis, can be found on MSAA's website at mymsaa.org. Once again, thank you so much for joining us.