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ReachMD

www.reachmd.com

info@reachmd.com

(866) 423-7849

Disparities in Multiple Sclerosis: Optimizing Care of African American and Hispanic Populations

Announcer:

Welcome to CME on ReachMD. This activity, entitled "Disparities in Multiple Sclerosis: Optimizing Care of African American and Hispanic Populations," is provided by Prova Education and is supported by an independent educational grant from Biogen, and Celgene Corporation, a Bristol Myers Squibb company.

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Dr. Saidha:

This is CME on ReachMD, and I am Dr. Shiv Saidha. Joining me to discuss the disparities in MS are Dr. Mitzi Williams and Dr. Megan Weigel. Welcome, Dr. Williams and Dr. Weigel.

Dr. Williams:

Thank you so much for having us.

Dr. Weigel:

Thanks for having us.

Dr. Saidha:

So, to get us started, Dr. Williams, would you mind describing some of the differences in epidemiology including disease characteristics in regard to African Americans, Hispanics, and non-Hispanic white patients with MS?

Dr. Williams:

Absolutely. So there are some key differences, and as you discussed a little bit earlier, traditionally we have thought, particularly here in the US, that MS has been a disease primarily of people of Northern European decent. Over the past 10 years, there's been an increase in literature suggesting that the incidence of multiple sclerosis may be increased in African Americans and, actually, that the risk may be up to 47% higher in African American women. And there are other characteristics that we're finding out about the populations with MS in African American and Hispanics. Even though the incidence in risk is lower in the Hispanic population, some of the disease characteristics are very similar, so there may be a higher incidence of opticospinal disease, meaning more effects on vision and on the spinal cord, which can affect mobility. In the African American population, we're seeing higher disease burdens in terms of MRI lesion load, and with the Hispanic population, we're seeing more of what we call longitudinally extensive lesions in the spinal cord that look very similar to neuromyelitis optica but are typical of MS in this population. In terms of actual disability, we're seeing higher rates of disability in both of these groups, and there are suggestions that African Americans may reach an EDSS of 6 up to 6 to 10 years earlier than their Caucasian counterparts. So there are many differences that we're seeing, but we still need a lot of data to support this, and there, unfortunately, is not a high enrollment of these populations in our clinical trials, so we have to find real-world evidence to help us find the answers to some of these questions.

Dr. Saidha:

I think that's very interesting. Personally, I think that when we talk about deficits in the literature in MS, we are talking about a US-based

population when we refer to African Americans, but really, actually, just ethnicity effects in general on a more global level in the way that they affect this MS disease process are very poorly understood. I will point out that, at least in my opinion, your point about the differences in disability are extremely important and the differences in the way that this condition might behave according to different ethnic groups.

In our center we did a longitudinal study where we tracked 115 African Americans and 115 Caucasian Americans with OCT, or optical coherence tomography, and found, regardless of treatment status, that people with MS who were African American tended to have faster rates of degeneration of tissue in their retinas, and similarly, they also exhibited faster rates of brain and brain substructure atrophy. I think it raises important questions about the way that this disease process plays out according to the different genetic composition and makeup of people as well as potentially the geographic location of where people may be located.

Dr. Saidha:

Those are all excellent points. Keeping that in mind, Dr. Weigel, what do you think is the basis for some of the differences that Dr. Williams mentioned?

Dr. Weigel:

So I think what you and Dr. Williams mentioned is kind of the hard science around what we know about racial and ethnic courses of the disease course in multiple sclerosis, and the challenge really becomes how do we address the soft science, and the soft science, in my opinion, is what prevents people from accessing care and what prevents people from knowing actually where to find it let alone access it, and those are the personal factors, the economic factors, accessibility issues, and cultural issues.

Interestingly, much of our research about racial and ethnic disparities comes from the United States, so what does that mean when we're trying to help our colleagues around the world increase access to care? Well, at least in our country, we know that African Americans are 30% less likely and Hispanics are 40% less likely to see an outpatient neurologist, and this was when the factors like health status difference, insurance, and even demographic factors were taken out of the study. So blacks were also more likely to be cared for in an emergency department than in a longitudinal form of care in a traditional healthcare system. Minority populations are way overly represented in socioeconomically disadvantaged groups. We know this from NARCOMS research. But we also know from Medicaid research, when we have home-based programs to support people of African American and Hispanic American decent, they're not being accessed, so African Americans are less likely to receive case management, equipment, technology, and home modifications compared to whites even though it's available.

So the question is: How and why are these people being missed? And I think that translates back to the cultural aspects that we may be missing in disease care, and some of these include a higher level of distrust of the medical system. And, frankly, if you're really delving into the literature, why wouldn't you be a little bit distrustful of a system, particularly in multiple sclerosis, where less than 10% of the people look like you in research?

Dr. Williams:

Those are really great points, Dr. Weigel, and I think one of the key questions that we as a scientific community are trying to understand is how much of the outcomes that we're seeing is related to underlying biology versus how much is related to social determinants of health, including access to care, implicit bias in medicine, and access to resources, and I think that you beautifully covered many of those points related to social determinants of health.

And now I'll turn to Dr. Saidha and ask: Now that we know more about the health disparities in MS in regard to race and ethnicity, are there any therapeutic approaches that are recommended for the African American and Hispanic communities?

Dr. Saidha:

Thank you, Dr. Williams. I think you raise an excellent point. I think one of the biggest gaps that exists in our treatment knowledge for MS is specific ways to make treatment decisions based on individual ethnicity, and in part, that stems from a lack of clinical trial data. There is some clinical trial data, such as the interim analysis of the real-world ESTEEM study, which showed that dimethyl fumarate was effective and safe for African American and black patients with relapsing-remitting MS. In addition, there's also the PREFERMS study. It was a study in which Hispanic and Latino patients were randomized to fingolimod. In that situation, they had a greater treatment retention and reported numerically higher treatment satisfaction than those who were randomized to injectable disease-modifying therapies.

That being said, there is a general lack of randomized controlled trial data with a limited amount of enrollment or targeted enrollment of specific ethnicities into clinical trials. There has been some analysis based on ethnicity in the CombiRx study, which was a combination of interferon and glatiramer acetate, as well as the phase III randomized controlled trials of ocrelizumab in relapsing-remitting MS, which were the OPERA I and OPERA II studies. These trials didn't show any major differences according to treatment populations, but at the

same time, there was a limited number of participants included in each study. I think moving forward in randomized controlled trials, both in the US and on an international level, we need to make a much more concerted effort to specifically target different ethnic groups for inclusion.

For those just tuning in, you're listening to CME on ReachMD. I'm Dr. Shiv Saidha, and I'm joined today by Dr. Mitzi Williams and Dr. Megan Weigel. We are discussing differences in MS epidemiology among African Americans, Hispanics and non-Hispanic white patients with multiple sclerosis.

So keeping all of this information in mind, Dr. Williams, how can we overcome these disparities?

Dr. Williams:

So that's an excellent question, and you really answered part of it in your last discussion about some of our clinical trial data. Number one, we absolutely need to diversify the participants of our clinical trials. This would definitely help enrich the data and help us to better understand some of the differences that we see in these populations and also, as we discussed, eliminate some of those socioeconomic factors that may be inhibiting or affecting some of our current real-world data. I think that we also need registries to help us better understand these populations that are multi-institutional studies. I know that there is one related to the Hispanic Latino community headed by Dr. Amezcua, and also, there is one that is in the works looking at the African American community as well.

And finally, we need to get more education to the people who are parts of these communities. One initiative called the MS Minority Research Partnership Engagement Network is a group of multiple stakeholders including industry partners, advocacy group representatives, physicians, clinicians, researchers, and people living with MS. And there were several toolkits that were developed to improve cultural competency, including a toolkit for people living with MS who understand clinical research and the importance of involvement as well as one for researchers to better make sure that we are being culturally appropriate when we're addressing these populations. So there's a lot of things that can be done to help ameliorate or solve and close some of these knowledge gaps for these communities.

Dr. Saidha:

Well, this has certainly been a valuable conversation. And before we wrap up, can both of you please share with our audience the one take-home message you want them to remember from our discussion today?

Dr. Williams:

Absolutely. We have come a long way, but we have a long way to go. Our understanding of these populations has improved significantly, but there are many things that we can do to better understand these populations as well as to find better ways to treat multiple sclerosis in those groups.

Dr. Saidha:

That's great. Dr. Weigel?

Dr. Weigel:

So my takeaway message from this conversation uses the term shared decision-making. So it's a buzzword, right, in MS care. We've been reading about it for years. We've been trying to implement it in our practice, but we can't do it if we don't have the right resources for people, so I just would like to encourage clinicians to look for resources for the Hispanic American and African American populations that encourage trust, that encourage adherence, and that encourage them to truly believe that by accessing the healthcare system, they can have a better course of this disease.

Dr. Saidha:

That's excellent and very well summarized. Dr. Williams, Dr. Weigel, I really share very similar sentiments. I would say that from my vantage point, the biggest takeaway from our discussion today is that we really need a lot more information and a lot more research into this disease according to different patient populations as well as how best to make individualized treatment decisions factoring in an individual person's ethnicity. And really, I'd like to see a lot more randomized clinical trial data of therapeutics that really tackles the idea of disparity in response to treatment.

Dr. Saidha:

But unfortunately, that's all the time we have for today, so I want to thank our audience for your participation and thank you, Dr. Williams and Dr. Weigel, for joining me and for sharing all of your valuable insights. It was a pleasure speaking with you today.

Dr. Weigel:

Thanks, Dr. Saidha.

Dr. Williams:

Absolutely. Thank you so much.

Announcer:

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