



National
Multiple Sclerosis
Society

**MS Learn Online
Feature Presentation
MS and the African American Community: Diagnosis and Clinical Course
Featuring Mary Hughes, MD and Walter Royal, MD**

>>Dr. Hughes: Welcome to MS Learn Online. I am Dr. Mary Hughes, Chair of the Division of Neurology for the University Medical Group of the Greenville Hospital System in South Carolina, and am also a member of the National Board of Directors for the National Multiple Sclerosis Society, and the Chair of the Society's African-American Advisory Council.

I'm delighted to be here with Dr. Walter Royal, who is a Research Associate Director for the VA Multiple Sclerosis Center of Excellence East, and for the Maryland Center for Multiple Sclerosis. He is also an Associate Professor of Neurology at the University of Maryland Medical School, and a member of the National MS Society's Clinical Care Committee and National African-American advisory council. Walter, it's good to talk to you.

>>Dr. Royal: It's good to be here, Mary.

>> Dr. Hughes: I'll start out with asking you the first question. When you're talking to your patients, is there something unique about how African-Americans experience MS?

>> Dr. Royal: You know, Mary, that's a very good question. My patients tell me that, as an African-American, they often wonder where their experience as a patient is the same as someone else. Certainly multiple sclerosis is not very well understood in the African-American community, so they have a much more difficult time talking about their illness and feeling confident that others will understand them and accept them, so it can be very difficult, as an African-American, to experience the disease.

>>**Dr. Royal:** So, Mary, have any of your patients ever discussed any frustrating diagnostic experiences with you?

>> **Dr. Hughes:** You know, I think we need to address that whether they raise it or not. Getting a diagnosis of MS is difficult in the best of circumstances, and not uncommonly, many of our African-American patients have not had the best circumstances. The misdiagnosis, the frustration with being told that what they were experiencing was quote-unquote “all in their head”. How do you address that with your patients?

>> **Dr. Royal:** Well, one thing we talked about is the issue of trust. Very often, patients, especially if their physician is not African-American as well, there can be an issue of trust. Patients may have a difficult time being open with their physician, and actually, I hear patients say to me that very often, they are not sure that their non-African American physician appropriately interprets what they say, and there seems to be issues with communication.

>> **Dr. Hughes:** You know, the analogy I use with my patients is that if I take my car to a mechanic, and it keeps squeaking, I may go back once, but I’m not going two or three years back to that same mechanic, and I think one of the things that we really need to encourage our patients is to feel proactive, and that they’re much more important than their car, and that if they don’t have that good relationship, that they need to establish that with a physician, and that’s not only a primary care physician, but their neurologist.

>> **Dr. Royal:** So, what do you think that physicians can do so that the experience is better for patients, for their African-American patients?

>> **Dr. Hughes:** Well, it’s changing. Even in medical school, we’re starting to teach medical students about the cultural differences. I don't know about you, but I certainly know I didn’t get that when I was in medical school. But even when we talked about communication, eye-to-eye contact. One of my best examples was that I’ve heard was that you can only bring one person in the room, but as you know, we tend to come with our families, so until Grandma has signed off on the decision, a lot of times we’re really not going to get through the conversation, and that we really need to be open to having multiple family members in the room, and extended family is so important to us when we’re talking about understanding disease process and how we approach it.

>> **Dr. Hughes:** When patients ask you how are they going to do, is there anything unique to the conversations you have with your African-American patients?

>> **Dr. Royal:** That's a very good question. As you know, Mary, the information that we have so far strongly suggests that the clinical course for an African-American patient with MS is likely to be more progressive than what it would be for their white counterpart, and that over a given period of time, that they're more likely to develop more severe disability.

>> **Dr. Hughes:** So, there is something unique to experiencing MS, everything from the literature that suggests that MS may be more aggressive in people who are African-American, that they may have more frequent relapses, that they may not recover from relapses as well as their Caucasian counterparts. There's the literature that suggests that their response to treatment may not be the same. Do you take any of that information into account when you're choosing an initial treatment for someone?

>> **Dr. Royal:** In general, with initiating treatment in a patient, it doesn't really affect my choice very much. However, there are reports that some disease modifying therapies may be better than others for an African-American patient, and I certainly keep that in mind. What I discuss with the patient is, are those types of concerns, however, and try to make the patient understand that it's important for them to be vigilant in being aware of their symptoms and discussing them with me.

>> **Dr. Hughes:** I certainly agree with you. I think that's important. We're talking about the role they have to play in making sure they stay very active with learning about the disease process. They be very practical in their conversations with physicians, and, as you well know, there is a lot of literature suggesting that African-Americans aren't as comfortable with talking to their physicians, and don't always feel that their physicians understand them, and it is that in a disease as complex as MS, we really need to work towards encouraging people to feel that they have the right, and the need to be able to express themselves and make sure they can get their questions answered.

>> **Dr. Royal:** That's right. So, that can be reflected in the fact that patients may be even more uncomfortable with revealing their diagnosis than, let's say, someone from another racial group, or just the idea of illness in the black community is--

>> **Dr. Hughes:** Do you think there's a stigma to MS in the African-American community?

>> **Dr. Royal:** I would certainly expect that to be the case. I think that sickness, in general, is something that is- - may not be as accepted in the same way, as in other

communities. Granted, that's not that there are not the support mechanisms available to patients with illness, but it's handled in a different way. African-American patients tend to be less willing to discuss their problems with others who are not close to them, and I think that that reflects a tendency for there to be less acceptance of certain manifestations of illness within the African-American community.

>> **Dr. Hughes:** When you said that, it brought to mind that-- I've sure you've seen that when we go to different patient education programs, that we're less likely to see African-Americans in the audience, although I would argue that the information is just as important if not more important for us to learn, and we're just-- it's not part of our culture to go out into public on these-- to support groups or to patient information, and I certainly encouraged my patients to consider that, and to go with their families, so that everyone can understand what's going on.

>> **Dr. Royal:** And I would certainly agree with that. That being the case, I'm sure you've also noticed that there is a tendency for there to appear African-American support groups, which raises the issue that there are different approaches that one can see taken with those support groups that you may not see in others.

>> **Dr. Hughes:** There better be food served. And we're more comfortable having support groups meeting in church settings and-- those are generalizations, but there are differences in how many of the African-American support groups have developed themselves.

>> **Dr. Royal:** And, of course, the African-American patient feels more open about discussing their experience and sharing information that they may feel is more relevant to their situation in those sorts of environments.

>> **Dr. Hughes:** I think one of the challenges is that, we're less likely to know somebody else who has MS, and so then you're dealing with, "What on earth are you talking about, is it contagious?" A lot of the myths of, well, what is MS, are you one of Jerry's kids now, and so the people around you, not that they don't mean to help, but if they don't understand the disease and are not really aware of it, but I think that's changing with the-- Montel Williams and Walter Williams coming forward and really talking about their diagnosis. That's been very helpful.

>> **Dr. Royal:** Yes. It is important to get the information out to make people aware that they're not alone in this, in their struggle with their disease, and that there is support and help and there's hope.

>> **Dr. Hughes:** And great examples of people who have done well.

>>**Dr. Hughes:** I was taken by surprise when Michelle Obama revealed that her father had multiple sclerosis, and I think that's been really helpful when she's talked about what it's like to live as a family member with someone who had multiple sclerosis, and certainly, hopefully, that that has helped to destigmatize the diagnosis of multiple sclerosis. Have you discussed that with any of your patients?

>>**Dr. Royal:** Well we have discussed that, and I would agree that her example really drives home the point that MS can affect anyone, that as someone growing up in a household with a parent with multiple sclerosis, to know that one can accomplish things such as she has.

>>**Dr. Hughes:** Well, even to be the parent, and to say, "My child can succeed." I think that's one of the burdens that people live with, "Is my diagnosis of MS going to have a negative impact on my child?" And in fact, the literature actually suggests that children growing up in a home with someone with MS are more empathetic, maybe more successful, and I certainly think that Michelle Obama has been an incredible example of that.

Last summer, my son and I had the opportunity to see Walter Williams and the OJs perform, and I think that was a wonderful experience, it was a great opportunity to say, "And he has MS," rather than the other way around. Mr. Williams, OJ, incredible musician. My ten-year-old sings all his songs, and knows him better than I do, but to look at how much he's succeeded and what an impact he's had on our community, and oh yes, by the way, he has MS.