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<https://reachmd.com/programs/cme/special-patient-populations-in-ms-utilizing-shared-decision-making/10579/>

Released: 12/14/2018

Valid until: 01/14/2020

Time needed to complete: 15 minutes

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## Special Patient Populations in MS: Utilizing Shared Decision-Making

Announcer:

This is CME on ReachMD! The following activity, titled *Special Patient Populations in MS: Utilizing Shared Decision-Making* is provided in partnership with Prova Education and supported by educational grants from Biogen and Genentech.

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Your host is Vanessa Zimmerman, MS Certified Nurse.

Vanessa Zimmerman:

Even though multiple sclerosis is the most common cause of non-traumatic disability in young adults, access to care still varies greatly among ethnic and racial groups. Further complicating this issue is the fact that these patient populations, in addition to those with late-onset MS, haven't been significantly

represented in clinical trials. So how can we ensure that we're providing our patients with the best possible care despite this disparity?

I'm Vanessa Zimmerman, an MS Certified Nurse in our Comprehensive MS Center. Today, I have the pleasure of speaking with Dr. Clyde Markowitz, Director of the MS Center, and Associate Professor of Neurology here at the University of Pennsylvania. Today we'll be discussing how we can improve access to care for all patient populations, including atypical presentations and possible implications for treatments. Dr. Markowitz, welcome to the program.

Dr. Markowitz:

Thank you.

Vanessa Zimmerman:

So the first question that I have for you is, now that we have just mentioned racial disparities; unfortunately, they do exist and are most commonly seen among African-American, Asian, and Hispanic MS patient groups. So to start us off, Dr. Markowitz, can you expand on what these challenges are?

Dr. Markowitz:

Yeah. It's a big challenge for us. So, some of the concerns that we have are access to care. There may be problems with under-insured; maybe patients do not have adequate insurance, they may not be able to afford coming to doctor's visits for MRI follow-ups, or even some of the testing we do, such as spinal fluid analysis. So, cost can be one important piece.

Cultural – so a lot of times people don't really have a great trust in the medical profession, for one, and it may be just in their whole world maybe you don't go to the doctor, you know, it's a cultural thing. So it's not necessarily that they don't want to get the care, but how they are brought up in the world that they live in may not include medicines and include the understanding of the disease. Education is a big piece to this; they may not have a good sense about what is MS and how it can affect them and what the long-term implications for disability might look like. A lot of times, it can be frustrating for us as physicians because they may not trust us. They may not believe what we tell them, then you know, they go out on the internet and talk to other friends, things like that, and it can be a little bit problematic to try to get across what is MS and how that is ultimately going to cause a problem for them.

So, some of the things we deal with – somebody may come to the doctor because they had an optic neuritis and they couldn't see for some period of time; they get better and are feeling fine. So they view that as, 'well, I'm fine now, why do I need to be on the treatment?' and that is an education piece. We have to be able to tell people what the course of this disease looks like. So, these are all barriers that we face to be able to get people to understand what the disease is, to tackle some of the issues related to insurance questions, insurance costs, costs of the medications, and be able to really try to get them

on treatment so that we can, you know, prevent disability.

Vanessa Zimmerman:

With that being said, can you discuss its presentation in African-American patients and how that impacts management decisions?

Dr. Markowitz:

Yeah. So, we've done evaluations of different populations of patients over the years, and the African-American population, even though they are a much smaller percentage of the U.S. population, they do seem to have a higher rate incidence of developing MS than the Caucasians. With that being said, it's not just the incidence that is of concern there, it's actually they seem to have a much more aggressive course. What that looks like is, you know – and some of that may have to do with education. By the time we see them, sometimes, you know, you see them after their first attack and, you know, maybe they come to the medical profession, we get them worked up, get an MRI scan, you may see an extensive amount of lesions in their brain and spinal cord, which seems to be much more prominent than when you look at the Caucasian population.

We also know that, if you delay that treatment, the likelihood of you having a very positive impact is going to be reduced. So it may be that they come to us later for a variety of reasons; might be access, education, etc., but even if you take them at whatever point and you start to treat them with whatever therapy, they do not respond as well as the Caucasian population overall. We had injectable therapies with interferon or glatiramer acetate; we've learned that looking at that population of African-Americans, they did not seem to be particularly responsive to interferon therapies and, in fact, may even, to some degree, make it worse for them. But we've learned over the years that some of the more aggressive therapies like natalizumab may be more effective in this population of patients. So, we kind of have to take a much different approach for this population of patients when they present to us because we know their prognosis and their outcome will not be as good. We tend to be much more aggressive about treating them up front.

Vanessa Zimmerman:

That's wonderful information, and now I'd like to turn to Hispanic and Asian-American patients. Can you expand on MS presentation, disease course, and their potential impacts on management for these groups?

Dr. Markowitz:

Sure. So, Hispanics as a group seem to have maybe a lower rate of development of MS compared to the African-American population. And the Asians seem to have an even lower rate, as well. Now, what's interesting about it is that the Asian population may have more of what we can an opticospinal

form where they have more involvement of the optic nerves in the spinal cord; where the Hispanics were a little bit more like the African-Americans in that regard.

So, we know there are genetic drivers to the disease course and they seem to be more responsive to one whole group of medications, where the African-Americans don't. The Asians are maybe slightly different in that regard, as well; there is much more involvement in the optic nerves and spinal cord. There's a different set of drugs that might be more effective in that population; maybe looking at B cell-depleting therapies, things like that.

You have to start thinking about tailoring treatments that may be more beneficial for a population that we, in our clinical trials sometimes, don't take that into consideration. Some of the more recent studies, we've started to break those groups out and see whether or not one drug is going to be more effective in one group or another.

Vanessa Zimmerman:

Now earlier we talked about how the presentation and course of MS vary among different ethnicities, but now I'd like to turn to another group of patients that are poorly represented in clinical trials; those with late onset MS. What are the most common characteristics of this patient population?

Dr. Markowitz:

Again, interesting, when we do our clinical trials, we have usual cutoff dates in the relapsing clinical trials of, let's say, 50, sometimes 55. But we know that MS can show up later; it can show up into their 40s, 50s, 60s, and I even last week diagnosed somebody in their 70s for the first time. And when you look at that group of patients, they tend to be a little bit more likely to be male, they tend to have more of a progressive course, they may be more even of the primary progressive phenotype, not necessarily secondary progressive, but more primary progressive from onset. And we know that the disease course later in life is more of a progressive course with increasing neurologic dysfunction. It looks more like a myelopathy with spinal cord involvement quite heavily.

These patients are not particularly responsive at the ages of 50 or 60 years old with a progressive course, and they're not going to be as likely to respond to slow the progression of disability on some of the injectable therapies. In reality, we have only one compound currently approved for primary progressive MS, and we have no therapies right now for secondary progressive MS, at least not in the progressive phase without. There are some in development, and we hope they get approved in the near future. But, you know, we get concerned that this population is the unmet group.

The best we have right now is one of the anti-CD20 molecules, ocrelizumab, which has been shown to be effective in primary progressive disease.

Vanessa Zimmerman:

And just to circle back around to our discussion earlier when you described some of the barriers that

affect access to care for different ethnicities, I think it's important to note that interprofessional collaboration can really help overcome these barriers. Based on our experience in working together, I'd like to talk a little bit about what we've done to help patients from urban and suburban Philadelphia areas access specialty care for MS. As you have said here today, MS is a complex disease.

And a multidisciplinary approach to assure minority patients have access to specialized care for disease management is essential. We are very fortunate to have that multidisciplinary approach here. It does start with the PCP. Many of these populations, minority and the older population, the PCP is their primary connection. And we definitely have a relationship with them and keep them in the loop constantly in their plan of care. The physician and the nurse practitioners certainly provide the diagnosis and the disease management. The MS nurse helps to meet the information needs for the patient and the family or caregiver; this is very important in some of these populations. And they act as the first-line contact in symptom management and coordination of care. We have our own MS-dedicated social worker, and he can assist patients with needs such as employment, whether to disclose to their employer, FMLA issues, finances, etc. So we are very fortunate in that regard.

We also have – are fortunate to have pharmacy. We have two dedicated MS pharmacists that can sit down with these patients and talk to them about what medication they're going to be on, why they would be taking that medication, and to help educate them on the disease-modifying therapy and what it is going to be doing for the disease. This education process is important for the minorities, including older populations, because the drug itself is very costly, how is it working, why do they need to take it, insurance/Medicare population have this huge donut hole gap that they have to pay a lot of money for their medication, so the pharmacist can definitely be helpful in getting the funding if they need it. So advocacy groups can also provide minority-specific knowledge and strategies and assistance that are not available maybe elsewhere. So communication between all of these disciplines is very important in providing comprehensive MS care, especially with minority populations.

The fact that they have access to all of our various providers increases our chance of getting them information that they need. So, and once the patient is in the system, the challenge is to continue the follow-up of their care. This is how we use shared decision-making strategies to achieve this goal. So some patients can and do fall through the cracks, and we try to do our best to prevent that. This minority and this older population have the potential to become part of this group. So again we can use this multidisciplinary approach to keep them in the system and continue to adhere to treatment and disease management. It's crucial for the physicians and the nurse practitioners to see the patient at regular intervals, and maintain close follow-up.

It's also important for the physician to include the patient in decision-making. They want a big role in why they're doing – what they're going to take and why they're going to take it because there are some differences with the therapy, and we're going to try and meet their lifestyle. The MS nurse is in an ideal

position to frequently look at that whole big picture, to make sure the patient stays on track. A lower education level may hinder the patient's understanding of the need to adhere to MS treatment and, as you had said earlier, they may say, 'I feel fine, why should I continue taking this treatment?' and will often stop. The minority population, as you mentioned, their disease may be more severe and they are younger and are saying, 'I'm not going to take this therapy' and sometimes they disappear, and it's up to us to keep track of them, try and hound them to get them here to explain to them why they need to be here. The social worker again can be of assistance to them for all – to help them meet these needs, if it be financial. And our pharmacy can – the specialty pharmacy and the pharmacist can keep track and identify a non-adherence issue fairly early, and that can help to keep people on track.

So communication with the patient is a crucial point, and some patients in some cases, we may need a translator, or we may need education materials that are written in a different language, and we can get that if we need it. So, shared decision-making respects the patient's autonomy, respects the patient's goals and values, and the ultimate goal will be improved quality of life for that patient. So, Dr. Markowitz, is there anything you would like to add on to those pieces?

Dr. Markowitz:

Yeah, I mean, you brought up great points. I think shared decision-making in today's world is a requirement for how we manage patients; both from the standpoint of patient understanding what the benefits of the treatment are, what the risks of these treatments are. And, in a conversation with the patient, discuss what are these benefits, what are the expectations of the medications, what are the side effects, how we monitor them, so that when they buy into whatever decision we make, they feel like they've been included in that conversation. And at the end of the day, they're going to adhere to the treatment because they feel like they're responsible for it.

Vanessa Zimmerman:

And it's definitely true that they won't tell you, the physician, what's going on, and might tell it to somebody else; either the social worker or the nurse or pharmacist.

Well this has been a great discussion on how we can better care for those MS patients who are unfortunately often overlooked, and I'd like to thank you, Dr. Markowitz, for joining me on this important topic.

Dr. Markowitz:

Thank you.

Announcer:

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