# Find Empathy

Multiple Sclerosis: Not Just a White Woman's Disease

EPISODE 3

Meghan Beier, PhD

Tyler Campbell

Jackie Bhattarai, PhD

Mitzi Williams, MD

## Course Highlights

Upon completion of this course, participants will be able to: Discuss racial disparities as they pertain to diagnosis, treatment, and outcomes of African Americans and racial minorities with multiple sclerosis.

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Identify at least one strategy for promoting equity and eliminating disparities in ethnic minorities with MS.

**Meghan Beier, PhD:** [00:00:00] Welcome to the Find Empathy Podcast, where we discuss the interaction between health and emotions.

My name is Dr. Meghan Beier, and I'm a clinical psychologist with training in Health Psychology, Rehabilitation Psychology, and Neuropsychology. In this first series, we're going to focus on a population that I work with very closely, individuals and families living with multiple sclerosis.

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Today's episode focuses on an important topic, not only in multiple sclerosis, but many chronic medical conditions. And that topic is racial disparities. When I first learned about multiple sclerosis, I was taught that it was a disease that primarily affected white women. We know now that this understanding was wrong and in the following conversations, you're going to hear from a neurologist, a clinical and research psychologist, and the story of one man's lived experience.

Our experts include Tyler Campbell, a patient advocate, living with multiple sclerosis.

**Tyler Campbell:** I had a diagnosis of multiple sclerosis and had no idea what that was. As an African American male, very cultured on things to look for very cultured on sickle cell, um, high blood pressure, high cholesterol, diabetes, and cancer. This MS thing?

**Meghan Beier, PhD:** Next, we hear from Dr. Jackie Bhattarai, a clinical psychologist that specializes in multiple sclerosis and a health disparities researcher.

**Jagriti 'Jackie' Bhattarai, PhD:** I see patients with MS, uh, at Johns Hopkins in our outpatient rehabilitation neuropsychology clinic. Most of the rest of my

time is spent doing research on, um, a couple of different projects that focus on racial health disparities between Black and white individuals with MS.

**Meghan Beier, PhD:** And finally, we hear from Dr. Mitzi Williams an MS neurologist and researcher.

**Mitzi Joi Williams, MD:** I'm a board-certified neurologist and a fellowship trained multiple sclerosis specialist. Um, the work that I do is primarily focused on, um, multiple sclerosis clinically. I also see some general neurology and in terms of my research and advocacy work, I've really focused on, um, understanding MS in ethnic minority populations, as well as emphasizing the importance of increasing diversity in clinical research.

# Tyler Campbell

**Meghan Beier, PhD:** This podcast is going to start with an interview with Tyler Campbell. Tyler received a football scholarship to San Diego State University. In 2005, while attending San Diego State during his junior year, Tyler was diagnosed with multiple sclerosis and became one of the first individuals to play division one college football with this disease.

After graduating in 2009, Tyler moved back to Austin and was awarded the honor of becoming an ambassador for the National MS Society. He's an entrepreneur and he specializes in delivering empowering, inspiring, and motivational messages of confidence and self-worth. He coined the phrase, "TC Speaks" and travels the country, sharing his testimony with youth, colleges, and businesses.

This episode has a lot of really important topics and very important themes that you're going to hear discussed in a more academic way by Dr. Bhattarai and Dr. Williams, later on. Some of the things that I want you to pay attention to are how he got diagnosed. What others' reactions were when he got diagnosed and the support that was helpful to him, as well as the support that he was looking for, but found missing. Finally, he also talks about some really vulnerable topics like mental health and sexual dysfunction, which are very common in multiple sclerosis, but often unasked, unspoken about, and overlooked in the medical community.

This is a really great topic and such a great interview. And I hope you enjoy this conversation with Tyler Campbell.

Thank you so much for being here. I'd love to just hear a little bit about, who you are and your journey with MS.

**Tyler Campbell:** Yes, ma'am. My name is Tyler Campbell born on an amazing day, October 26, 1986. A fantastic day in history. Might I add? Um, but yes, uh, I am, um, I'm a native Texan, a diehard Texan born and, and, uh, in Houston, Texas raised in Austin, Texas, and, um, born into somewhat of a family, uh, with a football background, my father [00:05:00] and mother great people.

My father's name is Earl. My mother's name is Renee and, um, just great dynamic parents. My dad just happened to be an NFL Hall of Famer and a Heisman trophy winner, Earl Campbell. Right. And so, um, I fell in love with football, Meghan. That was like my first, everything sports, everything, it wasn't pushed. I didn't come from a family that pushed.

If it were up to my parents, my father did not want us to even play football, wanted us to find, uh, another avenue. But I think the greatest thing that my parents showed me, my father showed me, um, was male love. I had a father who was very open about giving us kisses on the cheeks. I had an older brother, um, wrapping his arm around us and telling us that he loved us, um, very much kind of going against the grain a lot of times for at least an African American household.

But I was shown that and I thought that's kind of how everything operated. So, I come from a family that had love in the home. Very much love in the home. During my middle school years though, um, I, I went through a school system that's predominantly white. And as I was getting older and in my teenage years, I started, um, actually isolating myself more.

I did not know how to handle the emotions of being different. And, um, that kind of started that little aspect of mental health for me because although I came from a home of a love. Parents, very open about their door being open and coming to them for anything. Um, I went through a phase. Feeling like nobody could understand me, um, which I'm sure is what so many others in adolescents go through.

And it's an interesting dynamic because with males, um, we are often, uh, just as much, if not more emotional. As women are. So yeah, you're talking about a young man and his adolescents who really should have spoken more up about what he was dealing with.

But I was diagnosed with multiple sclerosis when I was 21 years old at San Diego State University. I went through the ranks and had learned to internalize a lot of my emotions. Starting at middle school level. Um, I played football. My parents did not want me to do that. I just, I said that because I didn't want people to think that it was forced. You came from a home of love of football, provided a free avenue of education, which if I didn't want anything else, I felt it was my duty to pay my family back by making it to where they didn't have to pay for my education. That was important to me.

I woke up one day, a month after my 21st birthday. After playing Brigham Young, BYU, uh, University in a football game last game of the season in May. And I flat out, woke up and I could not walk. I could not talk. And I had paralysis down the right side of my body.

And yeah. After going through a phase of doctors, not understanding at the school what was going on. And I was sent to a neurologist in LA Jolla, California spinal tap, MRI, uh, within about two weeks' time, I had a diagnosis of multiple sclerosis and had no idea what that was as an African American male, very cultured on things to look for very cultured on sickle cell, um, high blood pressure, high cholesterol, diabetes, and cancer.

This MS. Thing. Nobody knew, but I was fortunate to have a mom who was a former registered nurse. And so she had heard, didn't know all about it, but had heard of the neuro term or this, this autoimmune disease. MS gave me a voice that went against the grain of that young kid who had internalized a lot of emotions, had withheld a lot of what I was feeling and for whatever reason, my voice is what has allowed me to not be succumb to this disease. It is something that has been therapeutic for me. When handling this disease and I don't know how it happened, Meghan. It goes against the grain of that 12-year-old, a teenage boy, a young man growing up into adulthood in college that goes against the grain.

But what I found is the ability to utilize my voice, totally reshaped my life and totally reshaped my outlook of multiple sclerosis. It gave me something that I never had at any point in my life. And I grew up with stage fright.

**Meghan Beier, PhD:** Very different than what you're doing now, because you're putting your voice out there every day.

**Tyler Campbell:** You, I tell people all the time, if you knew the 12-year-old, if you knew the 21-year-old, uh, Tyler Campbell, that's not, that's not it. It's totally different, honey. Very different.

**Meghan Beier, PhD:** So it's interesting to me that you said you got, um, diagnosed relatively [00:10:00] quickly for most people, especially Black men, because many people that I talk to or that I've worked with, especially individuals in the African-American community, um, they go years before getting diagnosed.

I know I was in grad school. I've only been working in the MS field, you know, a little over 10 years now. And I was taught even only 10 years ago that this was a white woman's disease. And I think many times what I hear from people is that they automatically, especially if they're older, they assume that they're having a stroke; those symptoms are put on other things. I wonder, have you heard that from others?

**Tyler Campbell:** Yeah. I think my first awakening to it was when I finally got to Scripps LA Jolla Memorial hospital and the way in California, very beautiful place. I just went there for the wrong reason. You're supposed to go see the seals. I went to go see a neuro.

Um, as soon as I walked in my first ever appointment, I walk in, I'm dragging my foot. I'm dragging my right arm. There's MS written all over me, or at least there's something wrong with this guy. If you're walking down the hall and I take my seat. And an elderly white woman looks to me and she says, son, what are you doing here? And I said, ma'am, I have no idea. She said, you're too young to be here.

And I think that was the first like moment where I was like, when I got diagnosed. Started looking it up. And then I reverted back to what this lady had told me. I was like, that's why she was saying it because I did not fit. And so for me, the first thing I wanted was to find someone who looked like me, Meghan, the first name that I found was Montel Williams, but I was in California.

I'm a college student. I have no parents around I'm on my own. Montel Williams is doing talk shows on daytime TV. I've got class. I'm not going to what I'm saying is I knew I'm not going to meet Montel Williams.

And. I couldn't find another Black male just to tell me that it was going to be okay. I just needed someone that didn't look like the elderly white woman, no offense, she was kind. For me and my own psyche. I just needed like how my father would tell me yo, it's going to be okay Tyler, things are going to be, that fatherly figure. That's kind of what I was looking for. I didn't have it in my own father. He didn't have multiple sclerosis. I didn't have an uncle. I didn't have it.

And so I tried to find it. I never did. And I think. In the wakenings of those moments. That's when I understood that I have to do something because I didn't want anybody else to have to figure out MS. Alone, through hardship, through bumping your head through all this trial and error. And I felt there was a need automatically.

And I'm 21. I am, I felt the need automatically to at least lift a voice to make it easier for somebody else. I was raised, like you, always try to help somebody. You always try to be a blessing to someone else. You always try to open another door. Those are just the way the things I was raised. And so this fit that mold because when I went through that sadness and I did, I had hard times, tough times crying tears, why me? Um, erectile dysfunction at 21. Um, all these other things from a male's perspective that I was dealt and I just needed a shoulder to lean on and crying. And I never found that person that looked like me.

And so I said, okay, I'm not going to find that at least right now, in this time in my life, but why should somebody else, i.e., Black male or white male or anybody else, why should they have to go through. Or not be able to find someone that they can identify with?

**Meghan Beier, PhD:** Absolutely. And I think you are that person. I mean, I'm, at least I'm seeing you out there, sending this message to many people and, and being a voice that other people can look to. And, you know, it's interesting, you said that you had some mental health symptoms or some sadness that you started to experience in high school, and then, you know, once you were diagnosed, And I think I heard you say that you are working with, a psychologist or therapist. Can you tell me a little bit about that?

**Tyler Campbell:** Yeah. Uh, it goes totally against the grain. Um, I come from a culture, um, not only to be a male cause we are very machismo. We don't need help. Right. We're good. Right. Um, and then, uh, from, from our cultures, like we have a saying, what goes on in this house stays in this house and it is one of the most things that somehow was brought to a level of, yes, that's awesome saying, but in all actuality, it's one of the worst things that you could say. Because then you're, you're eliminating yourself from seeking help and attention. That is much needed from a different perspective. A lot of times people hear this, they don't understand that, my wife is a social worker. My [00:15:00] wife comes from a background of seeing a therapist. She started seeing one, I believe when we were in college together, she's a, she's a former track athlete. Um, I met her in college and so, um, I've seen my wife go through the therapy process. From the time we were dating until all the way through.

And when I started seeing that there was an added need. Um, that my wife couldn't fulfill. There's some things in my past that, that 12 year old stuff that has taken like about six or seven months now of therapy to finally kind of catch up and I'm learning the process, why there's a lot of things that I had to get through, um, to ultimately be able to help my disease and the way that I carry it.

And so, um, MS. You know, there are some things that, yes, you're going to dig into physically for and mentally for your MS. But what you're going to find out is okay. There are triggers for you. There are stress there's way to stress that we are carrying. And we all know that stress is one of those big underlying things that trigger relapses.

We know that. Um, so why not dive into a lot of where that stress comes from? Because all the MS did was add on to the added stress. So what if we can alleviate, those unaddressed stress points, those unaddressed triggering points that have never been dealt with for years and years and years before MS even came to the building.

So that's kind of where I encourage people to try to get a grip on those things, because that's the way to stress that you can leave and, and close doors on certain things that have been left, open and unaddressed. You know, and it's, it's not easy. Meghan, it's painful. I don't want people to be under the facade.

It's, I've cried many tears about it. There have been, uh, tough conversations I've had to have with in my marriage. I still go through counseling for erectile dysfunction through this day. Um, but through that process, it's made me more open. I've learned how to eliminate certain aspects and people out of my life that quite frankly don't need to be there.

And it's made me, and my wife have greater levels of communication, especially about the sexual dysfunction stuff that I've been battling for, uh, 13 years now. So it's, it's an ongoing process. I've never made it, but there's a lot less stress in my life. When it comes to the disease, just because of things I've had to eliminate from 12 year old, 13 year old Tyler.

**Meghan Beier, PhD:** I have a few follow-up questions. Let's start with this one, which is, you know, I. I'm really impressed and blown away that you're willing to talk about the erectile dysfunction. I think that's fantastic because we know that 90% of men with MS experienced some sort of changes in their sexual health and up to 85% of women, maybe even more.

And. Many people don't even talk about it, right. That doctors sometimes are afraid to talk about it and bring it up. I've even worked with some of my own patients who it took several months for them to bring it up to me. So I, I just think it's great that you're putting that message out there.

What do you think is important for doctors, mental health providers, people who work with the MS community? How can they make this topic more open and accessible and something that we can be open and vulnerable about?

**Tyler Campbell:** Yeah. Uh, so again, uh, trial and error, right? Um, it happened to me at 21. No disrespect to neurologist at that given time at all.

But the one thing that I say is make it a forefront conversation for males and females, because we're, we have those conversations about optic neuritis possibilities. We have those brain fog, type of conversations. We have the fatigue, uh, you know, a lot of the big things. The big agenda is the, the drop foots, the paralysis, the equilibrium's, the, the pain, um, the tremors, we have those types of things.

This thing is just as much important I feel as all of the others. So, so go ahead and mention that. The figures that you're talking about, I had never known any of those figures, but they are prevalent for male and female. And if it's happening to females, yes, it's happening to males too. And you you've pointed that out and vice versa.

So I was experiencing all of my stuff at 21 and where I went wrong is thinking that it's only me with my MS and where my lesions are. I guess that's what's. But it's actually more prevalent in a lot of male and females, but I never heard that Meghan. And so my advice would be to add the dysfunction, add the, um, the, the loss of feeling the numbness, add, add all of those things, because we know they're taking place in other parts of the body.

Please address those things. I remember I cried tears, Meghan, to my mother, I was, I had a really bad relapse, um, that, that took football away from me. And I cried on my mother's. My mother laid at the foot of my bed. I was, I was, I couldn't move and I was crying and I told her mama, like, I, I can't feel nothing.

And it's worse this [00:20:00] time than it was before I said, things are like spasming out, down below my belt. I don't like how in the world do I explain this to a woman? If I ever want to get married, it's like, I'm already, so I'm already just off of dysfunction. I'm already downplaying what my future could be.

So there goes, there goes added stress. Right. And so, um, but I w I would've maybe been a little bit more prepared. Had I known that this happens to everybody. Number one. So if it happens to everybody, at that age, you know, you think you're young, you forget that as a male, you're going to get to that point anyway, with all the, with all the erectile dysfunction commercials, we've seen them, all, all those things, things it's going to happen to you.

Okay. It happens to everybody, but, um, it's just happening to you a little bit earlier. So, so you get a hold of it on it now and address it now. Um, you're on, in your late forties, early, like trying to regress back. Um, so get a, hold on it now, like those are the types of things, the types of learnings, uh, the type of psychology help.

I never knew about any of that stuff. Yeah. That's why I said, I figured it out the hard way on my own, and I got there, but, but it's, it needs to be a discussion. I feel like in all the other symptoms and all the other things that may not work as well as they used to before.

**Meghan Beier, PhD:** Right, right. Yeah. So it's almost like knowing that that's potentially coming from MS.

And that there are things that can be done about it. Right. Cause I think there's a fear there from many people that I talked to, that this is, this can't be addressed or we don't know how to address this. And that's just not true. Right, right. Um, so how did you find the therapist that you're working with?

**Tyler Campbell:** I love it. Okay. So again, the beautiful thing about it, having open communication, no matter where you are, if you're dating. Um, if you're trying, if you're just a single, um, your communication outlet is key, um, about what you're going through, whoever that person is that you can trust. Confide right.

Confide. And so for me, again, my wife, I'd always seen her go through the therapy process. So, um, it was one of the psychology websites. Meghan, it's like, you can pop out a psychologist anywhere. I don't know if it was psychology today. I don't know if it's it's it's psychology something. Um, and I found, long story short. I found a list of psychologists. But then as a Black male, I opened up and started asking some of my Black male friends who I knew were married that were in my circle, never bought up therapy a day before in their lives. Right. And then I had one friend who his, he had just lost his sister. So he'd gone through grieving counseling and I say, wow, how's that being? And he said, you know, obviously being great. I said, who's your therapist. And he

recommended his. And his eyes were opening up. Like, wow, you want to go see one? He had never seen one until the grief was too much. So that was, and so we, so it actually deepened our friendship, which was dope. And then my wife simultaneously, we researched on the psychology website that she gave me and, uh, narrowed it down, researched the one, my friend gave me, seeing what his ratings were. You know, you do your homework, just like you would have doctor your homework and watch this. I knew what I wanted. I wanted someone who wasn't a too old. Um, and, and, and Meghan, I wanted a minority. I not necessarily Black, not necessarily, uh, had to be Black, he's not Black.

Um, but I wanted somebody who was a minority, um, because then they, they, they could offer their own advice as well. From that perspective on shaping my world, they understood my world and what I was playing in. And it, wasn't hard. It was not hard. There are more people seeing therapists around us, but for some reason you never talk about it. Cause I guess people think you're, you're cuckoo for cocoa puffs or something's wrong with you. Right. And so that's how I found it within my own, within my own friends. And in my own wife.

**Meghan Beier, PhD:** I love that. I love that. Did, did your therapist know anything about MS before you met him? Is it a him?

**Tyler Campbell:** Yes, it's a him. So he had heard of the disease. Didn't have an MS patient, but he had heard of the disease and, but he learned more about what it can do to the body through me. Right. He knew it was auto immune disease dealing with brain and spine. Okay. So that's the base level of where he was now from there.

Obviously he's done more homework about since acquiring me to make our sessions more.

**Meghan Beier, PhD:** So finding somebody to, that's willing to do a little bit of that legwork to figure out, you know, what you're going through for any of the things. I mean, it doesn't even just have to be MS, but anything that they're not experienced with, you want somebody that's open to that and

**Tyler Campbell:** And do your, do your homework. If the first one doesn't work, it's okay to try another and another, it is just like our MS stuff. Um, if the first neuro doesn't work for [00:25:00] you, please go get another. And what you're encouraged to do, um, long story short. You, you, you will find what you were looking for, Meghan, you will find what you're looking for.

**Meghan Beier, PhD:** I actually tell every single person that I meet with for the first time that if we're not connecting by session two, you need to find somebody else tell me, and I will give you a list of people that are nearby, but the goal is for you to meet your goals, not for you to sit in my office. So I think it's really important. Exactly. If it's, if they're not working for you, try somebody else, because there will be somebody that you connect with.

**Tyler Campbell:** I love that. That's powerful. Thank you for being so open.

**Meghan Beier, PhD:** Truly my, my goal for people is that they get better. And if you are the reason, we know that the research shows that if you are not connecting or vibing with that person, then you're not going to get better. A large percentage of what makes therapy work is that you feel connected and able to open up to that other person.

I know that you're doing a lot of advocacy work as well. And can you talk about that?

**Tyler Campbell:** Yes, absolutely. Therapy has been so awesome for me because it's gotten me to a place where it actually enhanced my gift. MS. Like I told you, I thought football was all that I had. The world of MS showed me that my gift is actually through speaking. And so what I tell everybody is please don't, don't wish to be like somebody else walk with what you are gifted with, and it will make more and more room for you in this world.

Um, so my gifts started out as being a support groups, uh, just being open and talking and having dialogue. And with that philanthropy came when I was in college. I had already started. I always had a heart to help other people. I had started with helping other, uh, elementary schools that were underfunded, um, with fundraisers when I was in college.

And when MS came into my life, I said, okay, I have a heart for kids, but my shift needs to be something that's heartfelt and more personable. Um, and that's when. I said, why don't we start with MS. Uh, so I started working with the Pro Player Foundation, a foundation that was helping me in California. They normally help professional athletes. I didn't make that, but I had a heart and I had, um, a willingness to serve. I have a voice, uh, not like most professional athletes. You don't have to, I don't have fear of a microphone. And I had a dad and a mother who were very supportive. Again, they didn't know all about, we learned about MS together, but my family jumped behind me and I said, Hey, I want to, I want this my path of giving.

This is what I want to do, uh, to help other people. And so we start doing, uh, events and fundraisers, uh, to raise money and funds for research and MS. Um, some had been scholarship recipients within that for MS for multiple sclerosis. And I've been doing it for over 10 years. And it's just evolved. It's been a true blessing.

You find a cause near and dear to your heart. And, um, now I have a greater in depth, uh, evolvement because it had initiatives in place. As you say, educate, elevate, and collaborate, which is where we're trying to raise more awareness, more education for the underserved in the minority communities. Um, the Latin X communities, the African-American communities, but everybody has a hole because there's so much more learning that must be done.

You know, and so, um, yeah, it's, I've taken what I have and I'm walking in it, not trying to be something different. I have MS. I love to speak. It's nothing crazy. And you just take those things and work on them every day. Um, it that's, that's what my heart is. I just have a, I have a gift to speak, but a heart to serve.

And that's all that we have.

**Meghan Beier, PhD:** So one final question. If people want to follow the work that you're doing, kind of hear more about what you're doing, where can they find you?

**Tyler Campbell:** I have a website: https://iamtylercampbell.com. And on social media, I am @tcspeaks32. Um, I also, Oh, I forgot about this, Meghan. Holy smokes. I also have a radio show. I don't have a background in radio, Meghan. So I have a radio show, um, that's every Saturday at 12:00 PM on a sports network, but I don't talk anything about sports and I'm the number one radio show on Saturdays for the network. But it's on 104.9, the horn FM. You can download an app called The Horn app on every device that you have, and you can listen and I just speak. About encouraging words. Of course, a highlight multiple sclerosis is cause it's a part of my life, but my whole thing is, um, getting people to understand their self-worth.

Helping men to understand that it's okay to be vulnerable and just diving into conversations in life experiences that I've had with the hope that it can bless somebody else. And, uh, that's it.

**Meghan Beier, PhD:** Wonderful. Well, thank you so much. I really, again, truly appreciate your time and energy being here and talking with me.

**Tyler Campbell:** Thank you for what you [00:30:00] do, because we need more people like you, um, because you got to open up to somebody.

# Jackie Bhattarai, PhD - Clinical Psychologist and Researcher

**Meghan Beier, PhD:** In this next interview, you're going to hear from Dr. Jackie Bhattarai, a clinical psychologist at Johns Hopkins and a health disparities researcher. She discusses the disparities she has personally observed in her own clinical work, as well as ways that she tries to address these types of disparities.

She also discusses the research as she is doing to address disparities and to better understand MS related mood disorders, and how those mood disorders are different between white and Black individuals with MS.

As you listen to some of the differences in depression symptoms, I want you to think back to Tyler's description of his own depression and how it started when he felt isolated in a mostly white social environment. Finally, Dr. Bhattarai discusses foundational principles for promoting equity.

Thank you again for joining today.

**Jagriti 'Jackie' Bhattarai, PhD:** Thank you. I'm excited to be here.

**Meghan Beier, PhD:** I wanted you to first tell us a little bit about your research and clinical work.

**Jagriti 'Jackie' Bhattarai, PhD:** I see patients with MS, uh, at Johns Hopkins in our outpatient rehabilitation, neuropsychology clinic. And most of the rest of my time is spent doing research on, um, a couple of different projects that focus on racial health disparities between Black and white individuals with MS.

My initial idea for this really came about because I had, um, an interest in disparities work back from my dissertation. And after I, uh, had the opportunity to complete an MS fellowship at Johns Hopkins, I came to realize from the clinical work, the disparities that were really just blatant in my clinical work between, the patients with different backgrounds.

And so then I decided I want to look at what causes these differences or maybe what leads to these differences. And so now, um, the research that I'm doing

focuses on like differences in healthcare that patients receive, differences in patient's adherence to maybe some of those healthcare recommendations and then just in general experiences that patients have with MS related health care and other outside of the healthcare route, like other related experiences. So it takes a big like qualitative approach because we don't really have that many established instruments to capture all of those things that I just mentioned.

**Meghan Beier, PhD:** Can you talk a little bit about some of those disparities that you were seeing in the clinic?

**Jagriti 'Jackie' Bhattarai, PhD:** So the, the, the disparities I was noticing in clinic were, one, related to what I was reading in the literature. So those neurologic disparities, where my Black or African American patients, um, would have more advanced like disability or disease progression or have, you know, the progressive MS type, versus some of the relapsing remitting. And I noticed that they were also much, later in life, diagnosed with MS. Um, and thus, like their disease was much more advanced and progressed and, the other differences I noticed kind of touched on in the literature, but not, not comprehensively as I think that they deserve to be covered.

And those are like the personal experiences and how they cope with MS and like the related difficulties and like who they go to for, you know, maybe the first symptoms they found and what they attributed them to. You know, I had a patient who was having some severe exacerbations at the time, but she refused, an African American patient, she refused to get on any DMT, like despite what her neurologist was recommending. And not that she was argumentative by that means she was very willing to listen and, you know, weigh out the pros and cons, but she was into the complimentary and like alternative techniques. That worked better for her, because the medication DMTs just cause so many side effects, it wasn't even worth it to her to try others anymore.

**Meghan Beier, PhD:** I've come across numerous patients, especially Black and African American patients who, when they show up to the emergency room with neurologic symptoms, I've heard multiple times that people immediately assume they're having a stroke instead of looking at something like MS.

Even people who've made statements that, that their community neurologist basically assumed that they couldn't have MS, and maybe that led to them taking longer to get diagnosed. Is that what you meant by the interaction between healthcare or how healthcare might be different for people who are, Black, African-American, Latin X community?

**Jagriti 'Jackie' Bhattarai, PhD:** Yeah, exactly. Exactly. And thank you for mentioning the Latin X community. My, my research so far does not, [00:35:00] involve that involve that population though. I would like to in the future. So when I talk today, I'm just talking about the populations included in my study. That's not to, um, under-recognized the other groups.

But when I'm talking about the differences in healthcare, they're they're kind of two-fold. One the differences that we're seeing between underserved and underrepresented groups and then white patients in our healthcare system. And that's general things that apply across the board, across conditions, and that's how they are treated in the waiting room or how their provider might communicate with them, or maybe the assumptions that people in that space make about what they know, what they might be interested in, and what they might be experiencing.

And so then that goes specifically to MS where like MS has always been historically thought to be a white person's disease. It's just more recent that we learned about the increased risk that Black or African American people, especially women have for MS.

So if a Black person walks into a clinic with MS like symptoms, this is probably not the first thing that's going to come up in their mind because of a perception about what MS is and who it affects.

You have to be pretty well-resourced to be able to be diagnosed with MS. The symptoms are so vague. They, um, they range, they range and they're so various from person to person. And so to rule out other conditions takes quite a bit of resources, time, appointments, and connections, you know, with the right specialists and whatnot. We know there's disparities in access to those things too.

**Meghan Beier, PhD:** Absolutely. Yeah. So it's so, so true. Can you tell me a little bit about the differences in terms of research? My understanding is that many individuals, because MS was considered a white person's disease, and even more specifically a white woman's disease, and we know, like you mentioned that that's not actually accurate, that many Black and African American individuals have not been included in research studies. I wonder if you can speak to that a little bit.

**Jagriti 'Jackie' Bhattarai, PhD:** Yeah. So less than 1%, right, as of 2015 focused on Black and African Americans. And so this is a challenge in the MS research. We just, we don't have enough representation of Black and African

American, or other historically underrepresented groups and MS research. So if, if we're not studying these groups in research, how can we get the word out that these groups are also affected. Um, and this goes into, you know, that patient I was telling you about who was really just hesitant to get on any medication because of the side effects.

Well, if these medications are studied primarily on a certain group of people, we don't know if the side effects are going to impact other groups differently. And so the, and that's a scary thing. It's like you start a medication and you don't know how it'll impact you. And you're not finding anything online that might give you any guidance. Right? So of course, then you're kind of scared to try anything, right. Anything else. And, um, one, you know, one thing I, I, I think, and I think that I will be right down the road. We don't know for sure yet, but I think that the prevalence of MS is much higher in the Black or African American or Latin X communities than we even currently know.

So we recently learned that Black women specifically have a higher risk than other groups for MS. But, um, I think like the prevalence is much higher. We just haven't been able to recognize it. Or there it's not diagnosed or due to some of the mistrust and access issues that certain communities have, I think like people haven't been diagnosed who may actually have the condition.

And I say this because something that is really important that I think like the research community overlooks is that a lot of Black and African American people have European ancestry in them. You know, you look at like the history of, uh, in the, at least in the United States and individuals who are born out of like interracial or biracial families, that's a lot of people. So. It's not very surprising that that rate is high, but yet I, I think like in MS, because of the traditional perception, maybe it's a surprise to people, but when you think about it, it shouldn't be.

**Meghan Beier, PhD:** Right. Absolutely. I know you've been talking a little bit about disease modifying medications and diagnosis. But I know that you did at least one study, and probably more looking at mental health differences between white individuals with MS and Black or African American individuals with MS. Mental health studies [00:40:00] looking at underrepresented groups or traditionally underrepresented groups, in MS are even fewer than probably the medically related things. I wonder if you can talk a little bit about what some of your findings have been there?

**Jagriti 'Jackie' Bhattarai, PhD:** Those findings were quite interesting. We looked at Black and African American individuals and white individuals with

MS at the top of the income quartile and the bottom of the income quartile. And we looked specifically at depression and anxiety symptoms. And so we wanted to see, are there differences in depression and anxiety symptoms based on, which income quartile these individuals are? So maybe being at that top of the income quartile maybe protects you from some of these symptoms.

What we found was that in general, Black and African-American individuals had higher rates of depression and anxiety across the board. But then when we kind of dug deeper and looked at differences in income, we found that for anxiety, being at the top of the income quartile did kind of protect for anxiety. So anxiety kind of like evened out between the two groups. Why that's the case? We don't know exactly, but we can very much make educational assumptions, right? Based on what the existing research tells us. If you have more financial resources, maybe you you have transportation, so you don't have to worry about dangerous from walking from your workplace to home, or just other things that make you feel more secure in the place you work, live, and resources that you need access to. So that would certainly ease anxiety. So that makes sense.

For depression though, depression, despite being in the upper quartile of people with MS. Uh, Black and African American still had a higher depression symptoms compared to their white counterparts. So, so what that tells us is that being in the higher income quartile, doesn't protect you from these symptoms. Why that is, again, we don't know exactly, but the existing research can maybe inform some of this.

And my big hypothesis there is that as an underrepresented group, Black or African American, in that upper quartile you then end up finding yourself in spaces that are mostly white. And so then comes feelings of maybe isolation or not not having that community as you're used to having in that space.

Just the lack of social support or the lack of belonging is one theory about why that may be the case. And, um, also other, other things like, you know, having to prove yourself or feeling like you represent your entire group instead of yourself as a person. So I think all of these factors could be leading to it. It's just it's complex and we need so many more research studies before we can verbally say what's going on.

**Meghan Beier, PhD:** Absolutely. I'm glad to see that there's more and more research that's being funded in this area, because as you've mentioned, it's incredibly underrepresented and has not really been looked at in great detail up to this point.

I'm interested to know about, how either your own research or the literature that you've looked into, how that informs your clinical care in terms of either neuropsychological assessments or, psychotherapy with Black or African American individuals with MS.

**Jagriti 'Jackie' Bhattarai, PhD:** Yeah. That's that's a really good question. I think it, it informs a lot of what I do in the clinic context. The mistrust that's kind of there, especially where I work in Baltimore, between the medical system, here at Hopkins as, and then with the Black or African American community here in Baltimore. There's a lot of mistrust, uh, rightfully so the Black and African American community has not been treated the best, you know, by medical and research institutions in the past. And so, although we are working hard to kind of justify and like make that partnership, right. It continues to have significant barriers for patients.

What I really focused on is establishing rapport, establishing that relationship with patients because that, that trust is so critical for them to, you know, come back and then for us to like actually gain benefit from obtaining any sort of psychological care.

And sometimes I think we like to sweep this like kind of adverse or negative history under the rug. Cause you know, nobody wants to talk about it. But, sometimes I find that just outwardly saying that I, I want to acknowledge that this is a thing and this is a factor. And if this impacts you, then I'd like to talk about, if, if you're willing how we can work to address that barrier. And, and so people have been very receptive to that. It's a [00:45:00] delicate balance. And with respect to the neuropsych testing. So I do neuropsych evaluations in clinic to assess for different areas of cognition, including memory and processing speed, other things.

And so what we find is like a lot of the tests that we administered that are available to us in my field, um, are not normed on many like of these underserved groups yet, including African-Americans. And so like, sometimes we're faced with this challenge of even though we don't have norms, do we administer this test and provide this service, especially in a case where the person may not be able to access this type of service in another nearby location. And so looking at those norms and, you know, deciding like what does this really mean for the person based on their score? So I'm very just upfront with patients when it comes to that and just be very outright.

**Meghan Beier, PhD:** That's really helpful. So you sort of just tell them, you know, what limitations there are in terms of your interpretation of this data,

because you know, it hasn't necessarily been normed on certain with certain communities and even when it has, sometimes that information is out of date and doesn't necessarily represent the communities that we are working with.

**Jagriti 'Jackie' Bhattarai, PhD:** Some of the, uh, neuropsych tests that we work with in our field, they are normed on Black and African Americans, but the norms pretty much show a lower level of functioning. And while that may reflect the data at the time they were developed, or even now there's such a big controversy in the field about like, should we still use that because, is it ethical to hold a whole group of people to a lower standard for something.

**Meghan Beier, PhD:** Yeah, absolutely. I know we had an entire meeting recently, just sort of talking through what data we have available on this specific topic and it is complex, but it's also something that we need to keep having conversations around. So we figure out how best to serve the people that we're working with.

**Jagriti 'Jackie' Bhattarai, PhD:** Right. Yeah. Yeah. And I think those conversations are increasingly happening now. Uh, sadly I think COVID is forcing us all to look at uncomfortable and difficult things, but I think it is about time. So I'm glad that these conversations are happening.

**Meghan Beier, PhD:** Absolutely. Should have been happening a long time ago. But right. It's good. It's good. That it's, I, you know, it's good that they're increasingly yeah happening.

I wanted to ask one more thing about, you know, you had recently, um, published a paper and also presented at one of our rehabilitation psychology conferences on the idea of promoting equity. And I think that that paper was more focused on the disability community, but I wonder if there's any themes from that paper that could be applied in, in this context.

**Jagriti 'Jackie' Bhattarai, PhD:** Oh, certainly. I love that, that you asked that question. Thank you. So it did focus largely on the disability community and it, the, the paper focuses on, uh, general themes. The, the underlying, like foundational principles of our field, rehabilitation psychology, that really can help promote health equity on a larger scale, then kind of the individual clinical one-on-one scale. And even though it focused on people with disabilities, I think that people from underrepresented backgrounds and racial backgrounds, you know, Black or African American are also quite represented in the disability community, you know, so there's overlap there.

I think one of the main takeaway messages from those foundational principles, all of which are great. I think the one main takeaway message is this idea of nothing about us without us. And so that quote really exemplifies, I think, what PCORI also loves. That research is the most effective when the people that it's studying or the people that it's focusing on guide that research, because then it's the most useful, because they decide what's problematic and what's most useful in their lives. Not the researchers.

And so historically, and traditionally, research has been formulated and developed by researchers at these institutions. With good intentions, I guess, to like help certain patient populations or certain groups. But at the end of the day, who knows best about what's going to be most helpful? It's these groups themselves.

And so this term of stakeholder engagement, which has become kind of like cliche at this point, but it's, it's very important, the true meaning of it. And that is that I think that individuals who the research is focusing on should, should be incorporated in all phases of the research and, um, If you look at the disability community, all the legislation that has been made in the United States, and historically, that has really put the disability community at a disadvantage, was made without [00:50:00] any input from that community.

**Meghan Beier, PhD:** Without representation.

**Jagriti 'Jackie' Bhattarai, PhD:** Yeah. Yep, exactly. So of course, yeah. It's, it's led to some really negative, significant disadvantages that impact the community to this day.

So now, if we can include more of the people that we are studying in our research or, in legislation, even then, I think that those legislative actions, those research studies and findings are going to be that much more effective. And so in the studies I have going on while, you know, one, one piece of it might be taking this traditional quantitative method of looking at the data that's out there or using standardized instruments. The second piece, I try to always like incorporate a qualitative piece. So then it becomes like a mixed methods study where I want to get the participant's experience. What they report, what they have experienced in the healthcare system, through interviews or focus groups.

And in the future, I think I really would like to, and I hope other researchers too, could involve these individuals throughout the research process, including, uh, studies, inception, like developing the idea of what are you going to study.

So one last thing I'll say about that. Last night, I was actually contacted by a close colleague of mine who works for iConquerMS. And she told me about this survey and the survey pretty much just asks MS patients about what they would like future research on MS and COVID to be about. What do you think would be important? So I've already started sharing that with a couple of my patients. I think future research efforts should very much follow that type of model.

**Meghan Beier, PhD:** I have two final questions for you. Thank you. This has been really great. My understanding is that you do some of this community participatory research where you are working with communities, or you are sitting down with community members to talk about what research is important to them. Is that true?

**Jagriti 'Jackie' Bhattarai, PhD:** Yes. Yeah, yeah, yeah, yeah. I'll elaborate a little bit on that. And so that involves being a part of a CAB, a community advisory board, the CAB is from the Johns Hopkins Center for Health Equity. And so this, this CAB involves researchers at Johns Hopkins as well as community leaders in the Baltimore community, and then also patient representatives who have participated in many studies and are volunteers essentially to kind of be a spokesperson for other people in their community. So we have patient participants who join and so they have great input on anything from new studies that can develop. To what areas to focus on in these studies and also very importantly, how to disseminate this information. And so this has been really, really a great experience. There's also, government people who work in the government and are involved in the legislation process who also attend. And then, so now we're seeing many members are both researchers and by community members, which is great to see that level of collaboration and integration.

One of my other studies that is looking at place and race-based disparities in MS. That study, I'm working with their community engagement core in the Hopkins Center for Health Disparity Solutions. They have been really instrumental in providing suggestions for how I I can incorporate the community and have stakeholder engagement throughout my research process.

So some of the things that I am starting to engage in is with neighborhood associations and then presidents of those neighborhood associations who can disseminate information about my study and try to get people to participate.

**Meghan Beier, PhD:** And I imagine that these kinds of research methods also, don't eliminate bias in research, but potentially reduce it because you're not just getting a, are certain swath of the population. You are really trying to reach into

different communities and let everyone, or as many people as you can know about this research so that it does have a greater representation.

**Jagriti 'Jackie' Bhattarai, PhD:** I agree. Yeah. It's not eliminating all the problems, right, that we have in research, but it's definitely just such a, such a wonderful, great, potentially a big step towards that.

**Meghan Beier, PhD:** I'm just going to end with this question. Is there anything else that you think would be important or helpful for community mental health providers to know about about your research?

**Jagriti 'Jackie' Bhattarai, PhD:** Yeah. Yeah. That's a good question. I think of two things. The first thing is a little bit more basic and it's just to keep an open mind when patients present with symptoms and what that could [00:55:00] be.

Keeping an open mind and keeping up with the literature. That's so hard to do because we're all so busy. Right? But, um, maybe finding certain newsletters or finding certain avenues where you can routinely revisit the literature to see what's what's out there.

**Meghan Beier, PhD:** Absolutely. Well, thank you again so much for providing your time and expertise on this topic. It's a really important one. And I just really appreciate that you're not only doing this research, but you are advocating for others to be looking at this research as well, which is just as important.

**Jagriti 'Jackie' Bhattarai, PhD:** Thank you. And I also want to say, thank you so much. Thank you for giving me a platform to be able to talk about these issues that I find to be incredibly important too. And I have very much enjoyed getting to speak with you today. I appreciate you focusing on this topic as well in your podcast.

# Mitzi Joi Williams, MD - MS Neurologist and Researcher

**Meghan Beier, PhD:** In this last interview you're going to hear from Dr. Mitzi Joi Williams. She's a board-certified neurologist and fellowship trained multiple sclerosis specialist who serves as the founder and CEO of Joi Life Wellness Group Multiple Sclerosis Center in Newnan, Georgia. She is considered a subject matter expert in neurology, multiple sclerosis and health disparities.

Dr. Williams has over 15 years of experience in the field of MS. She received her undergraduate degree in neuroscience and behavioral biology from Emory University in Atlanta, Georgia, and received her Doctor of Medicine degree from Morehouse School of Medicine also in Atlanta, Georgia. She completed her internal medicine internship, neurology residency, and MS

fellowship at Georgia Health Sciences University. Dr. Williams has spearheaded and participated in multiple steering committees and work groups to further research in underserved populations with MS with a focus on the African American population. She has recently joined forces to increase diversity in clinical trials and educate the community about the importance of research participation.

Through collaborations with national and international committees she advocates for people living with MS to share in the decision-making process with their healthcare teams to combat this illness. Dr. Williams is an author of, "MS Made Simple: The Essential Guide to Understanding Your MS Diagnosis." She continues to live out her mission to provide personalized MS care delivered with expertise, compassion, and joy.

In this interview, I want you to look for several different topics and themes, truly important to this topic. Dr. Williams discusses the incidence of MS in Black and African Americans, and why that incidence may be even higher than what we already know.

She also discusses multiple reasons for racial disparities in diagnosis, outcomes, and prognosis, as well as mental health changes in Black individuals with MS. Dr. Williams discusses her efforts to build a registry in which researchers can better understand and ultimately address racial disparities.

Please enjoy this interview with Dr. Williams.

**Jagriti 'Jackie' Bhattarai, PhD:** Thank you so much for joining me today. Can you tell me a little bit about your clinical work, advocacy, and research?

**Mitzi Joi Williams, MD:** Absolutely. Thank you so much for having me. I'm a board-certified neurologist and a fellowship trained multiple sclerosis specialist. Um, the work that I do is primarily focused on, um, multiple sclerosis clinically. I also see some general neurology and in terms of my research and advocacy work, I've really focused on, um, understanding MS in ethnic minority populations, as well as emphasizing the importance of increasing diversity in clinical research.

**Meghan Beier, PhD:** You know, it's, this is such an important topic. I'm, I'm remembering even from my own graduate training, which was not that long ago I was taught that MS was more of a white woman's disease. And I think that we are recognizing that that's not true, that there's more to that story. Can you tell me a little bit about prevalence and incidents of MS in different communities?

**Mitzi Joi Williams, MD:** Absolutely. So, I was taught the same thing in my training that MS was primarily a disease of young white women. And if you look at the worldwide prevalence, that still primarily is true, right? The highest incidence of MS is still in, you know, places like Europe, um, the UK. Uh, but we do have a significant number of folks here in the U S who have MS.

There was a prevalence study done by the National MS society in 2019 that suggested that there were nearly a million people in the U S who have multiple sclerosis. , which when you talk about 2 million people worldwide, that's almost half of the folks, um, with multiple sclerosis that we know of, one of the things that's been very interesting is in the past 10 years or so , we're noticing that there may be a higher risk and a higher incidence of MS actually in the [01:00:00] African-American community, which is quite surprising. Now I live in the South in Atlanta, Georgia. And what I would notice is that even though we were taught that MS was a white woman's disease, when I would go out to my waiting room, whether it was when I lived in Augusta, , and was working at the medical college or here in Atlanta, a huge MS center with eight providers, half of my waiting room, if not more, would be Black patients with MS.

And so, I early on began to see this disconnect between what we were taught and what I was actually seeing in the real world.

And in the past 10 years, we have data to help support that, that actually the incidence of MS. Maybe highest in African Americans. There was a study that was performed by the Kaiser group in Southern California, as well as a study published by the VA, suggesting that incidence is higher in Black people here in the United States, and also that the risk for MS may actually be up to 47% higher in Black women. Now, if we look worldwide, the numbers are still highest in people of Northern European descent. If we look at the incidents in Scandinavia, if we look at it in Europe, uh, in the UK, um, those are still the highest rates of incidents, but here in the U S actually we do see a significant number of MS, and we see a significant number of cases in the Black community.

**Meghan Beier, PhD:** Can you tell me a little bit about, what might be driving some of those differences?

**Mitzi Joi Williams, MD:** Right. So, the honest answer is there's a lot that we don't know, and this is really what has driven my work to focus on increasing diversity in clinical research.

Because when we look at these numbers, uh, you know, we have different pockets of information from different parts of the country. Unfortunately, in the us, unlike many other countries, we don't have a national MS registry. So if you go to places like the UK. Some of our other, uh, countries, you know, uh, are their colleagues across the pond actually have everyone in their country who has MS in a registry can kind of monitor, uh, what types of treatment people are getting the demographics and things of that nature. But we don't really have that here, so there are a lot of things that I think could be driving it. Number one, I think that MS has definitely been under-recognized and underdiagnosed in minority populations because you have to almost have a suspicion to look for MS. So if a person doesn't fit the profile, they may come to diagnosis very late or be misdiagnosed with other conditions. You know, I think that one of the drivers for recognizing these increased incidents and occurrence is that we have more availability of MRIs, which are really our main diagnostic tool for multiple sclerosis.

When I was in training, I remember it to get an MRI on someone you had to have a really, really darn good reason. I mean, even if you thought you had a good reason, the radiologist still might call you and say, this is a really expensive test. Do you really need to order this, you know? And so now that MRIs are much more widely available, we can get an MRI if somebody has a headache, if their eye is twitching, any reason we can get an MRI now. And so we're, we're picking up a lot of people because there's more accessibility of the testing. And I think that also as the knowledge of the increased incidents is kind of filtering out into the general community. Um, people are more suspicious of MS and these populations.

Um, so I think that that certainly is a big driver in terms of if there was a biologic or environmental factor that's leading to it. I think we haven't gotten there yet. There are certainly a lot of questions about lifestyle choices and how these may affect risk for MS. So, they may be involved. Things like smoking, um, things like obesity, which may be, you know, higher in some populations may be driving some of it.

But I think we're just at the tip of the iceberg and try to understand why we're seeing these differences.

Yeah, absolutely. I've heard that story so many times with many of the individuals that I'm working with, many of the Black patients that I've worked with have said that when they first showed up to the emergency room or their primary care doctor, um, that it was automatically assumed that they were having a stroke or they were having something else, that MS was not the first thing on the list.

**Meghan Beier, PhD:** So really, um, getting that information out there, as you said, um, to not only neurologists, but community providers may have a big impact. Um, not only on diagnosis, but maybe outcomes. Um, can you talk to me about that? I've always heard from neurologists that, um, Black individuals with MS have worse outcomes or may progress more quickly, you know, how much of that is true? How much of that do we still need to figure out through research? And if there are differences again, also, do you have any sense of what might be, driving those differences?

**Mitzi Joi Williams, MD:** Yeah. So that's a, that's an excellent question. So in terms of the differences that we see, what we have from the literature that's available is that the studies suggest that African Americans have a higher level of disability earlier on in their MS.

That they also have potentially more aggressive disease, so higher burden, more lesions or white matter changes in their [01:05:00] brains, more atrophy or shrinkage of the brain, which can lead to problems like cognitive dysfunction can also lead to other, uh, you know, generalized symptoms. They tend to have more spinal cord lesions or spinal cord damage, which can lead to mobility issues.

So some of the studies suggest that Black patients, um, or Black people living with MS. May have to use a cane or walker up to six years earlier than their white counterparts, there are also studies that suggest that they're admitted to nursing homes earlier. And I think one of the studies that I've been using in all of my presentations, that is a very, shocking is that there was a study, uh, performed by, Dr. Lilyana Amezcua was a lead author on that she's at, at USC and they looked at mortality. And so they looked at mortality rates in MS patients who, where MS was listed as the primary cause of death over about a 10 year time span, I believe. And what they found was that Black patients died at higher rates at younger ages.

Right. Which suggest that there may be more disability. And so that to me is a very startling and shocking, statistic or problem that, that even increases the urgency of us kind of focusing on these issues in terms of drivers of that, or why

we see that, you know, we really don't have a good understanding of what part the biology plays, right?

There are some studies that suggest that there may be more B-cell involvement for instance, um, and that certain treatments that target B cells may be more effective in African Americans. Um, and we also know that certainly, uh, social determinants of health play a large issue or a large part in some of the outcomes that we see. Do people have access to care?

There are studies that suggest that, you know, Black people with any neurologic condition are 30% less likely to see a neurologist, right? Living and they have a neurologic condition. Right. So, we're not even talking about getting to an MS specialist. We're talking about seeing a general neurologist.

And so there are huge issues with access to care, insurance coverage, access to medications. Also, we have to think about bias within the healthcare system. You know, are people being provided equal treatment? Is there any type of discrimination in the way that, people's care is given and the time that's spent, et cetera.

And so there are a lot of these issues. And again, it underscores the fact that we need more diversity in our clinical research. Most of our clinical trials, our major clinical trials for MS. Have less than 5% enrollment of Black people. And so we can't really get to the bottom of these issues until we begin to study them in a controlled way.

So if we remove the barriers to access to care, is there a biologic basis left there, um, that is causing or driving these changes? Or is it really all that people have difficulty accessing the system appropriately and continuously, and that's, what's leading to the poor outcomes. So the honest answer is we don't know, but there are certainly many of us who are working on in trying to get some of these answers.

**Meghan Beier, PhD:** My understanding is not only just, there hasn't been the enrollment in clinical trials, but even that, I think you were an author on this that less than 1% of research, in the MS community has focused on, ethnic minorities. I know you've touched on this a little bit, but are, is there other research that you think is really important that we should be focusing on in the next, five, 10 years?

**Mitzi Joi Williams, MD:** Absolutely. So I think that, first we have to make sure that we are reaching out to communities appropriately.

You know, I think there is a lot of work that needs to be done on both sides, right. In terms of the way that we designed the studies that we do, as well as making sure that we're out making a appropriate outreach to communities that we want to be involved in the research. I think the real-world data is going to help us a lot in the coming years.

You know, certainly we have clinical trials. We already have upwards of 20 medications or therapies for multiple sclerosis. And so, moving forward, um, although there are many treatments that are on the horizon, making sure that we're recruiting appropriately is going to be important. I think that the use of real-world data, registries, other types of cohorts is going to be extremely important. I've been very fortunate to be involved in a couple of projects that I think will help advance this work. One of which is the CHIMES trial, which is the first, clinical trial focused on, African American and Hispanic, Latino American patients with MS.

And so, uh, we started enrolling for that last year. I'm the lead investigator for that trial. And we're hoping to find some of these answers, although with a small number of patients, we're hoping to kind of find some of these answers in a controlled setting, to be able to look at how people do on a therapy, that's already improved their MRIs, and see what happens when we, remove some of [01:10:00] those barriers. And we were very intentional about the way that the trial was designed. We had input from people living with MS in the trial design, um, and try to remove some of those barriers that are common, to keep or exclude people from being involved in clinical research, which I think was very impactful.

The other thing that I think is extremely important is that I'm one of the founders of the National African American MS Registry, which I'm very excited about. Yes. So, this is something that's been in the works. For about 10 years, uh, but practically in the work for three years, myself and some of my colleagues, Dr. Stan Cohan, who's at Providence healthcare system in Portland, Dr. Annette Okai, who's in Dallas, and Dr. Annette Howard who's in Houston. We've been working very diligently to get this up and running, to try to understand some of the demographics, if there are issues with access to care, are there questions in the registry about research participation? We've really been trying to move the needle, so to speak, um, and to try to not only just get people involved in research, understand, but to try to improve the outcomes.

One of the things that really encouraged me, or kind of spearheaded me really diving into this work is that I was giving a talk about 10 years ago, about MS in the African American community. And I realized after giving that talk that, I

had been doing this work for some time, but nothing changed appreciatively. I just had more and more studies that were saying same thing. And so I think that we're moving in the right direction toward finding some of these answers, um, and hopefully improving the care, not just for Black people, with MS, for everyone, with MS.

**Meghan Beier, PhD:** You mentioned, that there are certain clinical, or clinical and research barriers that are getting in the way, um, just sort of switching gears to the clinical side. What are some of the barriers that you think are getting in the way of care of African American, Latin-X, and other ethnic minorities with MS?

**Mitzi Joi Williams, MD:** So I think that, you know, there is, in our community, one of the difficulties or one of the amazing things about MS, I won't call it a difficulty. One of the challenges about MS is that there is so much information that's coming out about MS. Which is great. When I first started practicing, we only had a couple of treatments, I would go to a conference like our Academy of Neurology.

And in order to attend an MS class, there'll be one on Saturday and there might be one, the following Wednesday, it was very, very spread. But now MS does everywhere. Right? We have all of these treatments every year, almost we have a new therapy that comes to market or even two or sometimes three. And so with this volume of information, it's very easy to miss certain things if you're not looking for them. So I'm very focused on MS in minority populations. But it, but I'm an MS specialist. And so if you're talking about the general neurology community, trying to keep up with the treatments that are available, also keeping up with data, like this is very difficult. And so I think one of the barriers is that there's not a widespread knowledge of this data about, the higher incidents in the African-American community, as well as the more aggressive disease course in the African-American and Hispanic, Latino communities.

And so. I think that people tend to treat it as very traditional MS. I think that also there is a culture shift in the way that we treat MS. Where many MS specialists are focused more on treating aggressively or with high efficacy therapies early, whereas more traditional. Um, some of our generalists may be more focused on what we call escalation therapy, where we wait for something to happen before we switch.

And so I think that kind of these philosophies are coming to a point where it's really making a difference, unfortunately in the outcomes for our patients, because if we don't switch therapies appropriately, it leads to more disability,

sometimes if we start people on lower efficacy therapy and wait for something to happen, they tend to have worse outcomes. And so I think that the barrier, the biggest barrier is kind of disseminating this knowledge that not only does MS occur in these populations, but that it can be more aggressive and we need to be very vigilant about how we treat it. Um, because. It could lead to very severe outcomes, a significant disability.

**Meghan Beier, PhD:** One final question for you here. Any sense of differences in terms of mental health outcomes, mental health treatment, and what advice would you have, in talking to mental health providers in academic medical centers, as well as the community?

**Mitzi Joi Williams, MD:** Yeah. So I am a huge advocate, of mental health accessing mental health services. Right? I think it is extremely important and key to successful treatment of multiple sclerosis. Because in treating the whole person, we have to recognize that with all of the regular life stressors, you add a chronic disease on top of that, that's unpredictable. We don't know what's going to happen. In some cases, people have symptoms that they don't know if they're going to get better. Or they may [01:15:00] have loss of their dream job or ability to do, um, you know, things that they had gone to school for years to do or care for their families, et cetera. So mental health is hugely important to successful treatment of MS.

And so I think, you know, the advice that I would have is to look at and treat the whole person, uh, particularly for minority communities there often can be a stigma about accessing mental health services. People don't want to be viewed as crazy or take crazy pills, so to speak, but I certainly, am very, clear with my patients about the importance of mental health and how mental health affects physical health.

So I think that we certainly try to approach everyone as an individual. We try to make sure that we recognize that there are lots of, stressors for these patients. I think in addition, for minorities to the stressors of, you know, systemic racism in their everyday lives as an additional stressor, in addition to life stressors, like taking care of kids, family, plus the chronic disease, you know, I think all of these things are coming to the forefront.

So we have to look at people as individuals, we have to acknowledge, um, the things that have occurred discrimination or other experiences they face. And try to move forward and establish a trusting relationship. And I think that that's something that has been a godsend for many, many, many of my patients is,

accessing mental health services appropriately, and helping to remove that stigma so that they can live their best lives with MS.

**Meghan Beier, PhD:** Thank you so much for the time that you took to talk with me about this today. If people want to follow you, see the work that you're doing, where can they find you?

**Mitzi Joi Williams, MD:** They can find me everywhere! So I am, uh, The Nerdy Neurologist, trademark. I am The Nerdy Neurologist.

If people want to follow me on social media, I'm on Facebook and I'm on Instagram as The Nerdy Neurologist. I'm on LinkedIn by my formal name, Dr. Mitzi Joi Williams. And then I'm also on Twitter @NerdyNeuroMD. And so I post a lot about the different work that I'm doing, about the different lectures, and I also have a new podcast that I started a couple of months ago called Brain Chat with The Nerdy Neurologist, it's on all of the podcast platforms, Apple podcasts. Google podcast, Spotify, et cetera. And so we address different topics such as the African American registry. We just did an episode last night about that as well as things, general education MS, and COVID vaccines. Um, and I also have patients or people living with MS come on and talk about some of their experiences and how they overcame some of their challenges to live well with MS. So, that's how you can find me.

**Meghan Beier, PhD:** Fantastic. Thank you so much again, I really appreciate the time you took and, I look forward to keeping in touch with you.

**Mitzi Joi Williams, MD:** Absolutely. Thank you so much for having me.

**Meghan Beier, PhD:** Thank you for listening to the Find Empathy Podcast!

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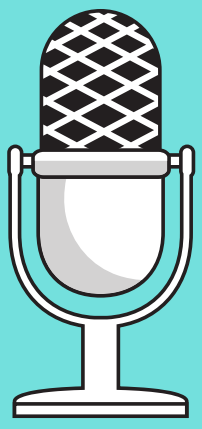

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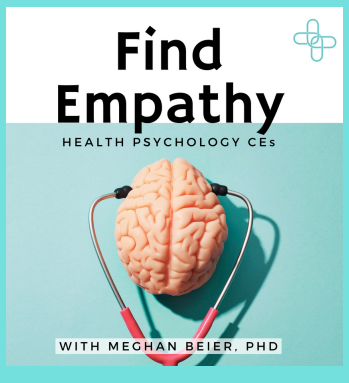


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