



Can Do MS Podcast

Navigating the Complexities of Health Literacy and MS

Episode 38

Can Do MS Host: Welcome back to the Can Do MS podcast. We are bringing to you episode 38 entitled "Navigating the Complexities of Health Literacy and MS." Today's episode is brought to you by our sponsors Biogen, Genentech, and Novartis Pharmaceuticals. Today, we're featuring a Psychologist Roz Kalb, Neurologist Liliana Amezcua, and Shawn Feliciano. We'll discuss how ethnicity and health literacy has shaped Shawn's MS journey and what self-advocacy tools she employs to live her best life. We'll also hear from Liliana about what makes MS and Hispanic and Latino communities unique, and the research being conducted to better understand MS in this space. Thanks for tuning in. Please welcome, Roz, Liliana, and Shawn.

Roz: Hello everyone! I'm Roz Kalb, the clinical psychologist with Can Do MS and I'm very, very excited to be here today with two wonderful people to share their perspectives. And so I'm going to first ask, Dr. Liliana Amezcua to introduce herself.

Liliana: Hi, everyone! I am Dr. Liliana Amezcua. I'm an associate professor of Neurology at the University of Southern California, and I'm very excited to be here today, to talk about multiple sclerosis and the Hispanic Latino Community.

Roz: Wonderful. Thank you and Shawn Feliciano.

Shawn: Good morning, everybody! I am a person living with MS. I've had relapsing-remitting multiple sclerosis since 2009. I currently live in Arizona and I'm very excited to be here as well.

Roz: Again. Thank you both. So I'm going to go back to Dr. Amezcua right now and ask you what the research tells us about MS in the Hispanic Latino Community?

Liliana: Well, thank you very much for asking that and I do want to first say that what we know about this population is probably less than 1% of what we know of multiple sclerosis. Nevertheless, there are very interesting findings or information that we're learning, not just about this population and community, but about multiple sclerosis itself. So one of the things that we understand, historically, is that this population is usually at a lower risk of getting multiple sclerosis. This comes from, you know data from all over Latin America where it shows that overall the prevalence meaning, how many people are affected with multiple sclerosis is considered low.

However, there were two studies in the United States recently that came from two big managed care settings and are finding certainly that the incidence rates, meaning the number of new cases of them as - is rising. For example, African Americans. But the Latino Community or population still continues to be at a 50% lower risk of getting MS. Nevertheless, when you look at those rates and you compare them to what has been published in Latin America, they're much higher. And so that's sort of telling us it's like well we have Latino Hispanics here in the US that soon will become part of the majority. We're seeing a lot more cases, not yet as many as what we see in whites and African Americans, but the rates are climbing. And so, we're likely to see more MS in this community.

One of our earlier studies, and this came because we wanted to better understand how does disease affect them when nothing has been published. And so we wanted to compare them to whites of European background, which is classically the common population affected with them MS and what we found were two very important differences. One is that when they do get MS, they are at a younger age compared to two white individuals and this lower age of onset appears to be also driven by place of birth. So those that are born in the United States are actually even younger when they do get an MS. So those, certainly are speaking to likely environmental factors and genetics because we know genetics is important in MS that are driving sort of the age of onset. So yes, the Latino community may not get as much MS as other populations, but when they do, they're younger. So that's certainly something to consider as we're looking at disease progression.

And when they get - if they do get ambulatory problems, they're likely to be at a younger age. The other factor that we observed and when comparing this population to white individuals is that it appears that the most common presentation involves the optic nerve. So known as optic neuritis. So this is very different to, for example, African Americans are more likely to present with spinal cord syndromes and in white individuals, are more likely to present with sensory problems. So again, this happens to be the most common presentation and the fact that they're a younger age and coming in with visual problems is telling us that it's likely a

true presentation or the issue of the age of onset, that it is a younger age of onset. And certainly, other studies which are certainly of concern and we want to make sure that this population knows what MS is and knows the importance of treatment because we do see a faster rate of progression. So again, not only are they younger and they have the propensity to get more progression at a faster rate so to shorter time.

So we really want to make sure that we have resources for this population with multiple sclerosis.

Roz: Well, thank you and it's so interesting to think about this one disease, presenting so differently, and at such different lifetime points in different populations. So thank you. So Shawn, health literacy is a hot topic these days, but many people don't know what that term means. So what did it mean to you as you look for a healthcare team that met your needs as a Hispanic woman?

Shawn: That's a really great question. And I think a little bit ironic because I think I fit into that population at the time that didn't really know what health literacy meant. And I think it was just in talking with my neurologist several times and really asking a lot of questions because here we are for me, especially I have this disease that I know nothing about. There are all these medications out there that are varied and so where I'm supposed to make a decision, but if I don't know what the disease is all about, then I'm certainly not going to know what disease-modifying medication might be good for me. So I was in that category with definitely with just being really naive. Also, I had a lot of other questions as far as being a Latina with MS and all of the different cognitive testing, so there was a lot of uncertainty as far as what is this disease? What are the medications? And what is this testing about? How is the testing going to affect me? Who is bilingual - trilingual actually? And is there a difference between how that testing affects me and how it might affect somebody who's white? So there's definitely a lot of illiteracy out there as far as being a person who has an MS, who has just been diagnosed.

Roz: And I appreciate your bringing up the issue of cultural sensitivity of testing that is used and that is something we want people to bring up with their Healthcare Providers, whether they're having mood testing or cognitive testing or any other kind of testing. That's just a really important issue. So, Dr. Amezcua, you are a provider for many Hispanic Latino MS patients. So why is health literacy so important to you as a provider?

Liliana: Well, I mean it's definitely very important - and it should be for every provider. I mean, we know historically from multiple different diseases that low health literacy is consistently associated with poor health outcomes. This includes sort of leading to a poor health status, increased mortality poor compliance, and adherence with medications. Also, it has been associated with a sort of increased utilization of services. For example, more visits to the, ER, and we know, I mean, what is MS? It is a complex disease, right? Even regular Physicians have a trouble defining it. So it does require a higher understanding of medicine because, again, diagnosis is complex or medications are complex and they don't necessarily go to make you feel better. And so those are definitely issues that we need to tackle to provide better a sort of better health literacy.

So in order to achieve it, of course, that patient needs to be able to read, write, comprehend, have access to really sort of effective material resources either on the web, written, or for example, a podcast like this. They also have to have some develop - what is their interaction? Like what it should be with their Healthcare professionals? And if we don't have that then the potential of having lower health literacy, and having poor outcomes is higher. So it's tremendously important for me and instantly what we tried to do is with every patient. But certainly, with the Latino Community, it's important to be culturally sensitive because one is this is a disease that like we said, probably less resources for this population. For some, it's important to have it in Spanish or have it as bilingual because maybe the patient itself, may be more inclined to read it in English, but their family members want to have it in Spanish, and certainly certain cultural practices for this population is that the family may be very involved in those decision-making. So you add a little complexity there where the health literacy needs to be present for the patient, but probably also for those that are surrounding them and making those decisions. In many cases, I find sometimes the patient went ahead and did exactly what that family member told them to, and certainly if there was poor health literacy, then you see the effects of that.

Roz: So, Dr. Amezcua, let's just get really specific since we're talking about health literacy. What is your message? Your flashing light to your patients about the COVID vaccine?

Liliana: One, it's safe. So if you have not gotten vaccinated, please get vaccinated. Two, if you are on immunosuppressive medications to treat your multiple sclerosis, you now should be getting your booster. And so these are really important that the benefits outweigh the risk, so, please get back to vaccinated.

Roz: Thank you for that. So, as a Psychologist, I focused a lot on how people managing invisible symptoms which are so common in MS, like pain, fatigue, with cognitive challenges. So I'm going to get to Shawn in a minute and ask her how she has talked about these symptoms with others. But I'm curious, Dr. Amezcua, how you raised these conversations with your patients. Do you approach the mood and cognitive symptoms, pain, differently with your Hispanic Latino patients than you do with other patients or is it the same?

Liliana: So very interesting concept. One is we definitely know and this is I guess the most common sort of invisible symptom is pain, right? And there's a lot of studies sort of talking about the relationship between pain and ethnicity and that's because these experiences are how you experience it. As I understand it is based on those experiences. There's some historical connotations, learning, how we learn, how we respond to it. And so it has a strong cultural background to it. And so it is going to influence how we go about it, how we perceive it, and our emotions. And so certainly what we're talking about and this has been certainly now having been around as population for many, many years is that it's really important to listen and connect the different words they're trying to use to express a symptom. So, for example, I learned about how they describe a sort of fatigue. So in Spanish, or just the way that there is fatigue has almost being described as depression which then sometimes depression is being described as being tired like how the fatigue that describing or the body aches all over is actually depression.

Roz: So Shawn invisible symptoms, like pain, or fatigue, or mood and cognitive issues. Have you had challenges communicating with your health care team or your loved ones about any of those invisible symptoms?

Shawn: I think I've had more challenges, not so much with my health care provider, would probably be family-wise. I think this is something that resonates with others with MS and the MS community. And that's it has something to do with our past lives. So what we did in our past lives and so others. It kind of reminds me of the stages of grief because part of it is denial. And so it's not only us as people or persons living with MS but it's also our family members who knew that person before the MS. So they have this concept- this romantic concept of this person who still exists but is not the same. And so for me, it was more of when I'm tired just having to explain to somebody why I'm tired because they've never seen that side of me, and because I don't always act like I'm tired. It's even that much harder for them to really cope with those invisible symptoms and know that, yes, I'm still Shawn, but I'm really not the same person. I've not had problems with health care providers.

Roz: I'm very relieved to hear that. We don't always hear that. So that's good news. So Dr. Amezcua, if you had one nugget. One key message that you wanted listeners to take away from today's fabulous conversation. What would that message be?

Liliana: Well to note that you having MS, you're not alone. We are here for you. We are trying to better understand how MS affects you and doing our best to be able to provide you the resources to live your best life. And because we are in the pandemic, if you have not gotten vaccinated, please go get vaccinated. Please go, answer your fears and concerns with your provider.

Roz: Thank you, and Shawn, how about you? What's the most important you want people to get?

Shawn: I think, for me, it's the fact that one has to ask questions. We have to be able to be strong enough to do so because if you don't, we're not advocating for ourselves or for anybody else. And we're certainly not helping ourselves. We're not helping others. We're not helping our Healthcare Providers and we're not advocating for change. And the only way that we're going to do that is by really taking that leap of faith, a lot of times and being a little bit transparent, a little bit vulnerable.

Roz: Thank you both so much for sharing your wisdom. And your good advice and just your personal experiences with everybody. It's been a pleasure talking to you. Thanks very much.

Shawn: Thank you, Roz.

Liliana: Thank you.

Shawn: Thank you for having us.

Can Do MS Host: Wow, thank you so much, Roz, Liliana, and Shawn for sharing your perspectives with us, and to our sponsors, Biogen, Genentech, and Novartis Pharmaceuticals. Ethnicity and health literacy can be difficult conversations to start. So we really appreciate your openness. Big thanks to Roz for facilitating such a thoughtful discussion. Finally, our

biggest thank you goes out to our listeners for tuning in to another episode of the Can Do MS podcast. If you enjoyed today's episode and you'd like to help support the podcast, please, share it with others. Post about it on social media or leave a rating in review. You can also follow us on Instagram, @candomultiplesclerosis. Thank you so much, and we'll see you again soon.

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