

Episode 216: The Impact of Migraine Stigma & Why It Matters

Lindsay Weitzel, PhD:

Hello and welcome to HeadWise, the videocast and podcast of the National Headache Foundation. I'm Dr Lindsay Weitzel. I'm the founder of Migraine Nation, and I have a history of chronic and daily migraine that began at the age of four. I am super excited to be here today with someone who is a repeat guest. I am here with Dr. Susan Hutchinson. Hello, Dr. Hutchinson, how are you?

Susan Hutchinson, MD:

Hello Lindsay. Great to be here with you.

Lindsay Weitzel, PhD:

Thanks for being here again. Dr. Hutchinson is an esteemed guest for this topic. She is a headache specialist and the founder of Orange County Migraine and Headache Center in Irvine, California. She is sought after for her knowledge related to women and headache medicine. She is the author on a recent publication that is related to migraine and stigma that we're going to discuss today.

Our topic is migraine stigma and some other things related to that that I can't wait to delve into. The manuscript that we are discussing that Dr. Hutchinson is one of the authors on, it is called *Factors and Reasons Associated with Hesitating to Seek Care for Migraine: Results of the OVERCOME (US) Study*. We're going to discuss this today because I'm pretty sure that just about everyone in our audience is going to find these results interesting. They pertain to pretty much all of us with migraine or chronic headache. And so I'm going to start out by asking Dr. Hutchinson to just explain to us what medical stigma is and why it is so important.

Susan Hutchinson, MD:

This is such a good topic, Lindsay. It's so important and I know we both are individuals with migraine so we can be certainly extra empathetic with this. But I actually looked it up. Because when I thought of medical stigma, I thought how is it really defined? And what I came across is it's when someone is defined by their medical illness rather than as an individual. And so that can be very consequential, I think, to someone's quality of life when they feel like that's who they are as their disease rather than an individual.

Lindsay Weitzel, PhD:

Why do you think now this is super important? Because it's not just migraine. It's all of the other headache conditions and somewhat even the other pain conditions. Why do you think migraine is so stigmatized?

Susan Hutchinson, MD:

I think there's several reasons. But I think the first thing that really comes to my mind is that it's an invisible disease. I mean, sure, you might see someone holding their head if they're in pain, but when we have a migraine, we're not in a walker or a wheelchair. We don't have a big cast on our leg. And I

think when it's invisible and maybe we put on makeup that day and look pretty nice, I think you can think, well, how can that person be suffering. They look pretty good. And so I think the main reason is because it's an invisible disease that you don't see. But I also think it's because over the years a lot of us have been told it's just a headache. I think there's still a lack of education on those that don't have migraine, and they don't realize it's so much more than just the headache. It's the nausea, the sensitivity to light, sometimes just that mental fog. But again, those are often invisible, so others think, well, is migraine really real.

Lindsay Weitzel, PhD:

I also wonder, as someone who has experienced migraine and chronic head pain pretty much my whole life, I do feel that there is in our culture such an association with stress and migraine that it may or may not be valid in the way people think of it. And I think that they almost like to look at people as well, if you just manage your stress better. Clearly you're doing something wrong and they like to blame you. And sometimes I wonder if that attributes to the stigma to a little bit. And also, because pretty much everyone has experienced some type of headache, it's easy for them to sort of think that they've experienced something like a migraine before. And sometimes I wonder if all those things put together, what you said and what I just said, make it a disease that's very easily stigmatized.

Susan Hutchinson, MD:

Yes. And it'd be interesting, wouldn't it, if everyone that only ever had a tension headache, I almost wish that everyone could have a migraine one time to really appreciate it. Because you're right, almost everyone that was ever born has probably had a tension headache at some point in their life, and we both know that's mild to moderate disability. You typically don't have the nausea, the sensitivity to light, and that can be brought on by stress. We didn't choose who our parents are. Most of us, we were genetically predisposed to get migraine. And it is very, very legitimate. And it's just so unfair for when those that have never experienced migraines, they judge us. And that could certainly lead to, I think, a lot of depression and even maybe some self-doubt.

Lindsay Weitzel, PhD:

I think this is important because so many of us, I think even myself at a certain phase of life, would have just pooh-poohed stigma and said, big deal, you're judging me because of my pain or my disease. But with the data and with what is really known medically now, how does stigma affect us mentally, emotionally, physically? Can it make us sicker?

Susan Hutchinson, MD:

Oh, absolutely. Lindsay. I think with stigma, and just part of that is hesitating to get good care, often with stigma you feel like others are minimizing your disease burden. Or they think you're using migraine as a secondary gain. For example, in the workplace that can really eat away at someone. And I think it certainly can lead to depression. If someone already has depression, it could make the depression worse. It can also increase anxiety. And then there's that thing called interictal burden, where even in between migraine attacks, sometimes the person, they're not even happy. Their quality of life isn't good because they're wondering when is the next attack. So yes, I think there's a big relationship between those that feel the stigma of migraine and all these emotional and quality of life issues.

Lindsay Weitzel, PhD:

One thing I did want to bring up is referring to some previous recordings we've done. Dr. Buse has been on discussing how sometimes the outcomes in people with migraine who experience stigma are worse than people who have not experienced as much stigma. So, we shouldn't just pretend like stigma is not a big deal. It's something we should pay attention to. Thank you for addressing that with us here. In the most recent study that you were one of the authors on, how was stigma found to affect people with migraine?

Susan Hutchinson, MD:

The main thing it did was it showed that in this very large study, and I've got the numbers here, it was amazing. This was again from the OVERCOME trial. And this involved a very large number of those with migraine, over 58,000. And here's what's a sad state of affairs, is that 45.1% or roughly 26,000, at some point had hesitated to seek medical care.

And part of that ties back with this stigma. And a comment on that too, is when you hesitate to seek medical care because of perceived or real stigma, what's that going to do? You're not going to get better, are you? It's probably going to make things worse. Because we know that if you don't have optimal treatment over time, you can sometimes, the term is transform or chronification, where you can go from let's say someone had infrequent headache attacks, maybe episodic migraine, over time unfortunately, let's say they hesitated care due to stigma, they could then transform into a much more refractory chronic migraine condition.

Lindsay Weitzel, PhD:

Exactly. And I think a lot of our audience is aware of that. But for people who may be thinking that they can put off seeking care and not have repercussions, unfortunately we are more likely to chronify if we don't get care. We get worse and so doing that is just not a good thing. It's not good for us. What are some of the other reasons that people with migraine may avoid seeking care or delay seeking care?

Susan Hutchinson, MD:

I have some of these. I'm going to look at my notes. One that is pretty obvious would be lack of insurance. And just the other day, Lindsay, I had a virtual visit with a patient who decided not to renew his insurance. And please, I just encourage everyone out there, have medical insurance. Certainly, lack of insurance was one factor.

And I think also if a person, let's say with migraine, had in the past has been minimized by a health care provider, their family, their coworkers, that could cause them to hesitate to get medical care, again ultimately leading to that disease chronification. And as I mentioned before, it's so sad what family members or coworkers think that you are using migraine as a secondary gain as a way to not go to work. And the incredible individuals like in my practice, they're very hard workers, most of them. And they tend to feel very guilty when coworkers think of them using their migraine. So, there's many reasons, but those are the key reasons why I think patients often don't seek medical care.

Lindsay Weitzel, PhD:

I think that that is really important to bring up. I think because of the nature of what I do, most of the people that come talk to me are people who had an experience where it was not a positive experience with a health care provider related to their migraine or their chronic pain. And so this is so important that we, to me, that we address that. Just keep trying change health care providers. Do what you need to do until you are taken seriously. So I love that you brought that up.

Susan Hutchinson, MD:

I was just mentioning where I see a lot of stigma and patients not being heard is when women go in for their well woman exam and they see their gynecologist. And I'm not here to put down all gynecologists. There are some incredible ones out there. I've had gynecologists tell patients when they talk about, let's say, a menstrual migraine, honey, it's just a headache or it's just part of PMS. And you can imagine if someone's been told that, it makes you hesitate to probably seek care again. But as you mentioned, if your health care provider is not listening to you and not validating that you have a migraine, I certainly think it's time to seek another health care provider.

Lindsay Weitzel, PhD:

We've already gone over the consequences of delaying care. You're very likely to chronify, become worse, etc. What advice do you have for people who feel they need to hide their migraine disease, or who might feel ashamed of their pain?

Susan Hutchinson, MD:

I think if you are listening and you're someone that is hiding your disease burden, please know that you're not alone. The population of migraine in the United States in any given year is about 13%. If you're a female, depending on your age bracket, it could be as high as 25%. So, see if you can join a support group or go online. And there's many different online chat forums. There's National Headache Foundation. You can go to headaches.org. I just think that you need to have what I call a community. And that can help you realize that you're not alone and to really learn to speak up for yourself. And please understand that migraine is a very legitimate neurological disease.

Lindsay Weitzel, PhD:

You did mention that women were one of the groups that were more likely to delay seeking care. Can you comment on that?

Susan Hutchinson, MD:

Yeah, I would comment that I think a lot of women, especially when you're they're younger, let's say under the age of 40, their only health care provider often is an OB-GYN. And OB-GYNs, some are very good at migraine, but some are just focused on the kind of gynecological issues. So, I would also encourage, if you're hesitating to talk to your OB-GYN about it, and you probably need to have a primary care provider, someone like a family medicine physician, internal medicine.

And if you don't, please make an appointment to see them. And I would also encourage anyone listening to schedule a visit just to talk about your headaches. Because another problem Lindsay is

when patients put headache as one of ten things on their list. Or if you try to talk to your OB-GYN about it, but they're focused more on contraception and doing your breast exam and your pap smear. They may have run out of time. So I think to get better care, schedule an appointment with a primary care provider and say that is just to talk about your headache and don't try to cram other things in. Because that's going to give you a very good way to judge, is that provider legitimizing by condition? Does he or she believe in migraine? Are they up to date with treatment? But again, so I guess I'm saying to those listening, think of headache, particularly migraine, as important enough to schedule a visit just to review that.

Lindsay Weitzel, PhD:

And something else that I always like to bring up is I think a lot of women, especially younger women, will be from families where they're used to it. Well, my mom had migraine and my sisters and my grandma and some of them, it got better after they got pregnant or such and such and so they try to ignore it early in their careers or while they're in college, etc.. And I always just try to encourage people, well, we have better medicines now than we had when your mother was in college, etc.. And to try and go ahead and seek out treatment. Because I was from one of those families where because my dad was so sick with headaches so often that I thought everyone was. So don't just assume that this is the norm because your family was like that.

Susan Hutchinson, MD:

I agree, I'm an example. What was interesting in my family, my mother said we get sinus headaches. Well, Lindsay, she would be sensitive to light and her head would be throbbing. And I tried to tell my mother, here I am, her daughter, a headache provider. I said, mom, I think they're migraine with sinus symptoms. Oh, no no, no, they're sinus headache.

So that's an example where I think my mother, even years ago, didn't want to call it migraine because again, it could have been she felt it was stigma and it was more comfortable to call it sinus headache. But I also wanted to comment and follow up in what you're talking about. Just because it runs in your family doesn't mean that your pattern or presentation is going to be the same as someone else's.

So you're right. Sometimes migraines do get better during pregnancy. Sometimes they get better with things like continuous birth control. But your experience may not be the same as other people in your family. And please don't delay seeking care there. You're right, there are so many wonderful migraine specific medications now that are targeted for migraine that are very well tolerated. And the goal for that would be to get treatment in which you take at the early onset of a headache attack and hopefully in 1 to 2 hours, you're headache free, back to full function, and you have relief of the other associated symptoms like nausea and light sensitivity.

Lindsay Weitzel, PhD:

Thank you so much. I think that's so helpful to our audience. Is there anything else you'd like to add on this topic before we go today?

Susan Hutchinson, MD:

Just in closing it, I've said this several times, I think it's worth repeating that please know that migraine is a legitimate neurological disease. And you need to be treated as an individual with a condition that is important to treat. And please, you need to have a health care provider that respects that, understands that migraine is legitimate, and is going to do everything they can to help you.

Lindsay Weitzel, PhD:

Thank you so much, Dr. Hutchinson, and thank you, everyone for tuning in today. Please join us again for our next episode of HeadWise. Bye bye.

Susan Hutchinson, MD:

Thank you.