NHF InSights Episode 3:

Jaclyn Duvall, MD:
Welcome back for our final episode of our three-part series on the Harris Poll Migraine Report Card, supported by Lundbeck. I'm your host, Dr. Jaclyn Duvall. In the past two episodes of this podcast, we've discussed migraine and headache burden, along with treatment options. This episode of our discussion is one that's focused on the relationship that people have with their healthcare provider, and one that I'm really excited to talk about as a provider myself. I'm joined again by Dr. Karen Cassiday, a doctor in clinical psychology, and is nationally recognized as an expert and anxiety disorders. Welcome Karen.

Karen Cassiday, PhD:
Hi Jaclyn, I'm so glad to be here.

Jaclyn Duvall, MD:
I'm excited to talk about this relationship with healthcare providers in particular. And of course, we've discussed that the Harris Poll really focused on a number of different aspects living with migraine disease burden, treatment options. But now we're going to talk about what responders wish their healthcare providers knew. So, in the Harris Poll Migraine Report Card, many responders wish their healthcare provider who was managing their headaches understood more about migraine.

And there were three main points specifically they wish they knew. Number one, how much headaches affect their mental well-being. Number two, how much pain their headache attacks caused. And number three, why do they get headache attacks. More than a third of both groups wish their healthcare provider better understood the mental and emotional health. And in fact, the survey identified that 47 to 54% of responders worried about asking their healthcare provider too many questions.

Gosh, this really sets the stage for a bad relationship if we can't feel comfortable asking questions. So today we're going to explore why do you think people are feeling misunderstood by their providers. And Dr. Cassiday, I'd like to talk about the relationships that patients have with their provider and really gain your insight on this.

Karen Cassiday, PhD:
I think this is such an interesting question, because we know on the part of providers that they're the kind of people that like to get things right. In order to get through nursing school or medical school, you have to be an excellent student, and you have to be very persistent. And typically, you're the kind of person that likes getting things right and you like succeeding and you're willing to put yourself to the task.

And the dilemma with that is that your mindset is there must be a way I can make this right and let me do my job. And then if you're also that provider that is in a healthcare system where you don't have the luxury of time, then you can get into a bind. And the bind is you may not be able to do what you want to do, or the thing you're trying to get right is the billing and to make sure that you are going to get paid. And then you have hospital administrators or clinic administrators who are saying, hurry up.

And so I think a lot of times if you aren't at a specialist clinic and you're in the general practice area, then if you're a provider it's frustrating for you because you are just trying to figure out what medication can I do to help this person. And you don't have the time to go into some of those concerns that feel like, wow, this might take up too much time to talk all about their mental health. I'm trying to find which medication I need to use. So that's one problem.

And I think on the part of the patient, I think one thing that's very difficult is that I do believe in our culture, people feel embarrassed and ashamed about pain and headache pain. And I think that's because for so many years, pain has been misunderstood as a psychological problem. And I remember when I was in graduate school in the 80s, they were still thinking so many of these pain disorders were a result of depression or anxiety the person couldn't expect.

And now we know that is absolutely false. These are disorders with physiologic processes, with genetic predispositions, with real causes, that it's more misfortune of the gene pool as opposed to what kind of coping you do. And we see that actually the psychological distress comes after you get the disorder rather than because of psychological distress. And so, I think that makes patients feel hesitant because they realize there is stigma about this.

And then I think the other thing that's tough is, if you're a patient, you don't know what to tell the doctor beyond my head really hurts. I'm vomiting, I can't see. You get focused on the physical thing. But in all truth, if you have the misfortune of having chronic migraines or cluster headaches or other severe headache disorders, then the worst part is actually what the experience of pain is like. It's not just that it's a physical phenomena and the dread or the aftermath of just going, oh my God, that was so bad. I missed my child's bar mitzvah because I was vomiting and sick in the emergency room.

And the other thing I have to say is, if you're a provider and you're not a psychiatrist, then chances are you got three months of a required psychiatric residency. And it would have been usually in an inpatient unit, and it wasn't with chronic pain patients. And so, by happenstance, you haven't had training in what's a good way to talk to people like that. You had training over and over and over, how do I quickly go through a decision tree or a matrix and arrive at a diagnosis and then a treatment. And I think all of those things mixed together make it a difficult dance for everyone.

The other thing that I see is if you do have anxiety, then one of the things it makes you do is reassurance seeking. And reassurance seeking is where you're trying to verify what you just heard or to get more information, or to compare it with stuff that you read. And so, you ask way more questions. And what do most medical providers do is they go, oh my goodness, this person won't be quiet. And instead of going, they're anxious. They actually need reassurance. They need time. They start, thinking, oh dear, I'm looking at my clock. This was supposed to be a 20-minute appointment and they accidentally cut the patient off too soon.

And there was a very interesting study done about this because, they found that physicians in general and nurses are afraid that the patient is going to talk too much, so they cut them off too soon. And they found that if you do nothing and let them talk, on average, you only add 90 seconds to three minutes to the appointment. Okay, that's actually not very much. That's not enough to change the billing category. And so, we see these competing forces happening.

And then the other thing I think too, is patients get intimidated by the medical setting. They're aware of the fact this person knows so much more. And if the doctor does not have user friendly language, and so they use the phrase interictal phase and they don't explain it, then that can make people start to get quiet and not share as much because they're feeling like I'm just feeling a little uneasy. I'm feeling kind of ignorant. I don't want to interrupt this expert. And then that can lead to the phenomena that you saw in your study. It's so very understandable.

Jaclyn Duvall, MD:
This is such invaluable insight that you provided. I like to remind everyone, our staff, our providers and our clinic, our patients that that we're all human. And within the healthcare setting, a lot of times from the patient standpoint, as you've mentioned, they may not be aware of everything that goes into the backside of medicine, as I call it.

And so, you're right, as providers, we're keeping the space of this is the appointment and my engagement here, but there is a whole list of rumination of what about the back side of all the other things that go into this one encounter. So, a reminder that we're human, that we make errors and that sometimes coming to the table with that sort of exception or experience and understanding can really help facilitate the conversation.

I've had patients come into my office that carry baggage from healthcare providers and stigma that has been placed on them. And they come in assuming that we're just like them. And that can be hard. As a human, my first inclination is to clam up and to be upset that they're already upset with me and I haven't met them yet.

And so, I think it takes a two-way street for us to interact with one another. And so sometimes I'll take a step back and I'll say, gosh, I can really sense that you've had a hard time with the healthcare community and I'm sorry for that. I want you to know that I'm here today, and I hope we can move forward together. And sometimes this simple language can really open the door and bring down walls in facilitating these conversations.

Karen Cassiday, PhD:
Just that simple statement you were saying, you're doing something powerful. You're communicating empathy for the patient’s experience. And I think one thing that happens, if you've grown up in an academic system that praises you for being right and correct, and the way you impress others is with all your accomplishments, you forget that the most powerful thing you can do is to show compassion, not your credentials.

And I think sometimes if physicians would remember that what really reassures the patient is to know there's someone here who grasps my human experience in this situation. That can be so incredibly helpful. And one thing I'm always trying to train my staff to do is to say there's no point in taking anything personal from the patient. People are just anxious or depressed, and that makes them irritable. It makes them freeze. It makes them want to run. And our job is to remember we want to restore hope. We want to develop trust. And have a good thick skin for the fact that sometimes this is a bumpy ride.

The other thing I wanted to say is, we know also, if you're black, or Native American, then you're very likely to feel very suspicious about healthcare encounters, because we know for sure that our medical system has let you down, and in terms of cultural bias and microaggressions. And so, if you're one of those people, then I would encourage you to say, okay, the average person really does want to work with you, and they need your help. They need your willingness to say, that didn't feel so good. I know you didn't intend to dismiss me or to not take me seriously. But let's try over, and to be brave that way.

Jaclyn Duvall, MD:
I love that, taking a step back to actually voice that. I want to take time just to speak to healthcare providers in general, because I have seen so many primary care physicians do a fantastic job in the headache for migraine management world. And one thing that I'll encourage my colleagues to do is that they should not be expected to manage every aspect of someone's health within one visit.

And I think it's okay, as healthcare providers to take a step back and say, gosh, I really want to focus on migraine and the concerns you have and the burden pertaining. I can tell that this is very important to you. Today's visit was pertaining to your diabetic management or your high blood pressure and so we didn't set aside enough time for that. Why don't I see you back and we focus on just this disease. And it's okay to say that and to schedule separate time so that we aren't rushing through this conversation and we're getting it the time that it deserves.

So, I'd like to break down some things people can do with this relationship. What would you recommend to the patients practically, to help facilitate this?

Karen Cassiday, PhD:
The first thing that I would suggest is to go in with the assumption that this person really wants to help you, instead of an assumption that says, what if they don't understand me. And to think ahead of time, what are your priorities. Because your doctor or your nurse practitioner needs to know that you are concerned about your stress level, your mental health, your depression, your ability to cope. And to realize that you're not just looking for a medicine. You're looking for a way to make your life better.

And that can be helpful. And to realize that mental health is part of the conversation. And the thing that I think is exciting about medical training now is that we see that there's way more emphasis on the physician patient relationship, on the psychology of what it means to be someone who has a health problem. And we know that the profession really wants to address this.

So, one would be to think of your priorities that it's not just I want to get rid of my headache, I want to worry less. And that can help your doctor provide referrals if necessary or to have reassuring conversations. And then the other thing I would say is you need to decide what are my expectations. And you need to voice those clearly, because I think sometimes if your doctor doesn't understand that actually the thing in your mind, the only thing that matters is to never have another headache, then you get to have a different kind of conversation than if they just mistake you as you just want some medication.

And the reason I'm bringing that up is, I think sometimes the reason this relationship gets difficult is because the patient's expectations are different than the physician's. And that the conversation that I'm always having with my patients is to gently and over time, help them understand that we have no way

to cure their condition, but we can make their life a lot better. We can help them learn to manage it, and we can have them not dread, and to really live a good life. But we can't ever get rid of the potential to have another anxiety attack. And in this case, it would be we aren't yet able to cure headache. But we can make your life a lot better. And that is a conversation that usually needs to happen over multiple visits.

And then the other thing that I would suggest on the part of someone who's suffering from migraines is to also recognize that, how this person feels to you is important. And if you have a couple of interactions and you realize I just don't feel comfortable or I feel like their style is too abrupt or I feel dismissed, it really is okay to find someone else. Because we found, regardless of someone's specialty or training, that when they feel trust in their medical provider, their care goes better and their health is better. And that's not a placebo effect. I think it really means there's better communication. There's more openness and vulnerability between both the patient and their provider, and things go better. And so, I want to empower you to realize some people just might not fit me. And that's okay.

Jaclyn Duvall, MD:
What excellent advice. Excellent discussion that we've had Dr. Cassiday. Before wrapping up, I am curious about your thoughts on future research. Like many surveys, sometimes the results we receive present more questions than they do answer. So, I'm curious if you have any thoughts on future surveys that could be created to dig deeper into this topic, gaps that we've identified, or what future research might be warranted?

Karen Cassiday, PhD:
Well, I think from the psychological perspective, I think we really need to work more on quality of life and to really look at what are ways we can improve people's ability to cope. And not just in, I think, simple ways that we borrow from other things, but really looking at what are the unique barriers for people who suffer from chronic headache disorders, to acquiring that resilient, mentally well mindset that we know helps people who experience chronic pain.

And another thing that I think would be really helpful is to figure out what can we do on a medication side to better figure out how do we manage anxiety and depression. Because the thing I see is many people are like, well, let's just give you an antidepressant or an anti-anxiety. And sadly, we know that only about 40% of the people that don't have headache get an initial response from those medications, that's what a patient would consider is a good outcome. And there really hasn't been good research looking at are there unique factors in this population where we need some more nuanced medication strategies.

And then the really exciting area that I am so intrigued by, two exciting areas, would be genetics and inflammation. And if there's anything I'm seeing now across the scientific world, is inflammation is outrageously important, and it's a root factor in many things. And we're seeing, for example, that we know that diet is important in inflammation, exercise. And we need to look at what are more nuanced ways we can help people with migraines to look at inflammation. And then also, I'm hoping in my lifetime we're going to find ways to manipulate the gene code and to come up with genetic cures, like actual cures, that we could do for these disorders. And I'm terribly excited about that avenue for all of health.

Jaclyn Duvall, MD:
Oh, absolutely. I couldn't agree more. It's so exciting the strides that we're making in medicine and science. So, I couldn't agree more. I want to thank you again for joining me in this discussion, Dr. Cassiday, and thank you to all of our listeners for tuning in to our three-part series on the Harris Poll Migraine Report Card.

Coming out of this discussion, we encourage each of you to think about the impact that your mindset has on living with chronic disease, reflect on your current treatments, and try to understand if they're really working for you. And build a stronger relationship with your healthcare provider. Set goals and expectations together and don't shy away from talking about mental health.

If you haven't already, check out the National Headache Foundation's new comprehensive guide to accessing care. Visit headaches.org and click Action4Access™ on the main menu. Thanks again and we'll see you next time.