

NHF Insights Episode 2 - The Treatment Gap: Awareness vs. Action

Dr. Jaclyn Duvall

Welcome back to the NHF Insights podcast. This is the second of our three-part series on the Harris Poll Migraine Report card supported by Lundbeck. In our first episode, we talked about the burden of living with migraine disease. This time, we'll take a deeper dive into treatment options. I'm your host, Doctor Jaclyn Duvall, and I'm joined again by Doctor Karen Cassiday, a doctor in clinical psychology and a nationally recognized expert in anxiety disorders.

Welcome back, Doctor Cassiday.

Dr. Karen Cassiday

Thank you so much, Jaclyn.

Dr. Jaclyn Duvall

So, in the Harris poll of the 550 people living with migraine, only 15% of them were taking preventive migraine medications, although all would have been eligible for migraine prevention based on their headache frequency. Still, we see that many of them are utilizing over-the-counter medications or caffeine to manage migraine. And furthermore, it's important to note that of the respondents, 33% of them did not identify as having a diagnosis of migraine, migraine disease, or another related diagnosis, despite the fact that they all screen positive on the migraine ID migraine screener.

And so, I really want to dig deeper into this concept of treatment, not necessarily being on preventive medication despite high migraine frequency. Doctor Cassiday, from a psychology perspective, what do you think is preventing people from accessing a diagnosis and better treatment options?

Dr. Karen Cassiday

Well, I think first of all, there's a lot of confusion in the public about what a migraine is or an actual headache disorder versus just getting a headache. And so, I see this in my practice or amongst friends, you know, someone will say, oh, I've got a migraine. And I'm always curious. And I ask them, what's going on?

And I find out, actually, they just have a headache. That's not a migraine. It doesn't have any of the symptoms that we would use to catalog a migraine. Or we'll see people who are having migraines and they're just going, it's a bad headache. And then we also see, if you're male, then you're less likely to seek treatment.

Because I think there is, some culture around men that, you know, says I have to be stoic or, I don't have time to take off from work. You know, that's just not seen as, I don't know,

appropriate, in terms of doing that. So, one is confusion around, like, what? What is it? And then I think another problem is what happens when you seek help for headaches, you know, who do you go to first?

Dr. Karen Cassidy

And so, what we see is there's sort of two routes of entry. One is the emergency room. And so, someone is vomiting or they're just like, I can't take it. I'm screaming in pain or I'm nauseous or I can't move. They go in and then that's their treatment. And they don't get the discussion with a physician about what their symptoms really are, what it means, what they should do.

They're just told on a little discharge summary, consult your general practitioner. And then we know from research that very few people actually follow the directions to seek continuing care. One, they got medication, you know, rescue meds that help them feel better. And they're kind of like, woo, that's over. And two, it's a little bit of a burden to schedule that appointment.

It could be way far away. And then number two who do you go to. I think a lot of patients don't know. Actually, a neurologist is the ideal person to seek treatment from or a headache specialist, someone who has like you gotten board certification and really understands it. I'm going to bet most people don't even know there are such people, or they think of the neurologist as you deal with seizures.

And they have no idea what the scope of practice is. So, they see a general practitioner and most general practitioners are going to not know the full spectrum of treatments, or they may be learned about it, but they aren't going to feel proficient, and they aren't going to have time. And the other thing is, because the way our billing system goes, headache doesn't make it easy to have a long conversation with the patient about what it means.

And so, I think those barriers are the kinds of things that make people feel frustrated or. Well, that was good enough. I had this rescue experience in the emergency room. And so. Okay. That's it. And then I think another problem is the way we get medical information now is we go to the internet. And unless you have a lot of academic or scientific background, it's very hard to know what the good sites are.

And I would bet right now if we went on Google instead of getting the National Headache Foundation first thing, we're going to get a bunch of ads from places that treat headache or from pharmaceuticals. And it's hard to wade through for a prospective patient to figure that. And then we see if you're under the age of 40, then you actually prefer to get information from your peers.

So, you go to the internet. It's like a giant support group. You go, has anyone, you know had this happen before? And you and oh, yes, you know, and then you get all kinds of answers, and you might get an answer is, oh, you know, I use these, essential oils and it really helps me. Or I have a special, you know, barley pillow I put on my head, and I heat it in the microwave or, you know, I heard that caffeine is really helpful.

Dr. Karen Cassidy

That's what my doctor said. And you have no way to know what's good. But you trust them because these are your peers. This is your support group. And so, I think those things are all the obvious explanations there. And then the other thing I think that's happened is every person I've known who suffered with headaches, always after it ends wishes that was the last one.

And the last thing you want to think about is what do I do to help prevent the next one? You just kind of hope it goes away. And I think there's some of that psychologically where we don't want to if we can avoid thinking about it, we don't want to think about what could be done. And then, probably the last thing I want to say is I think what many people do is they settle, and they don't do it deliberately, but they just assume this must be it either, because there's barriers to getting to the right person to help you understand and diagnose your disorder and give you a full explanation of what to expect. All the options, or there's a financial barrier. These things are very expensive.

I remember when some of the latest things came out and people were so excited. The cost was outrageous. If you couldn't get into a trial or persuade your insurance company that you really had failed enough other treatments, and if you're coming for the first time and your company says you've got to fail 2 or 3 other things and they aren't working well for you, how many of you realistically and say, okay, I'm willing to do this for another eight months in the hope that I get this thing that my doctor really believes is the one that's going to help me, that takes incredible persistence and, unreal optimism to keep going.

And so, I think those are the things that make it easy as a human to give up and settle.

Dr. Jaclyn Duvall

Gosh, I there's so much to unpack there. I couldn't agree more. I think back to my clinical experience and patients that I see, and I think one of the big things you brought up was time. And that oftentimes migraine is managed in the primary care setting, but the primary care setting is focused on a lot of metrics, of which migraine is not one of.

And so that lack of time and so many health care providers, because they are so limited, they may not communicate that sometimes there's an order based on what your insurance has dictated as far as prescribing patterns. So, I may have in mind that, okay, we have to start this medication and then another. But what I really think you may need is actually the third in line.

I may not have the time in my clinical practice to explain the entire background and so the patient often left thinking, this is what Doctor Duvall thinks is the perfect medication. If I haven't explained kind of the background. So, with me in my practice, I do try to take the time to show them. We have five major classes of migraine preventive, and this is sort of why we do this.

And this could help with some others. But I see frustration with medications, patients that maybe went to a provider years ago, they were handed a medication that that was found out serendipitously to help migraine. Maybe it was first created for blood pressure management or seizure management or depression. And we figure it out that they can be helpful in migraine as well.

But sometimes they come with baggage other side effects. So, really balancing them, is it really worth the benefit versus the effects. And then oftentimes they may not understand the disease status. And so, as you mentioned they'll have the single attack and then think well the next one's not going to come. Or I can manage that with this medication.

Not understanding the migraine as we believe as a progressive disease. And so not managing this disease can actually result in it snowballing out of control. And I'll explain to patients that just because a medication is over the counter doesn't deem it safe. I know that, Doctor Cassidy, we were having this conversation, so I'd like to get some insight into your thought about these over-the-counter treatments that maybe we've heard from our friend or the internet and, and, and where, where do you think this leads and patients picking treatments?

Dr. Karen Cassidy

Yes. Well, I think one thing that's, unfortunate that's happened in our, modern culture is there's a, I'm going to say, a false war between what we would call traditional medicine or physician mediated medicine and, integrative medicine, things that, maybe are not traditional. And, and so what I see happening and research shows this to be true is people feel that anything that I can do myself must be safer.

And, whether it's, you know, oils, supplements, you know, acupuncture, I mean, something that isn't mediated by a physician, that somehow that must mean it's safe, because we have the concept that the Food and Drug Administration, the AMA, you know, all these things are trying to protect us. And then they falsely perceive the things that might be prescribed are more likely to be dangerous.

Why? Because there's been some big lawsuits and big publicity, and then we don't get the same big publicity when we find out that, ashwagandha can destroy your liver or, kill you or these other, you know, things that you can just get yourself. So that's one problem. And then the other thing is, there's become a divisive political climate where people have lost trust in science and misunderstand the process of scientific research and misunderstand the values of people in medicine and in research.

And they mistake it as, oh, it's just, pharmacy companies wanting to make a profit, and they don't understand the compassion and sincere motivation of people to alleviate suffering. And then that makes them think, okay, the thing I can do, I have more control over, and if you have control then you misperceive it's safe. Because why?

Dr. Karen Cassidy

Because you don't have a list of side effects on this supplement or this oil where the FDA requires this, you know, encyclopedic length thing and black box warnings. And if you are anxiety prone, which many people with migraine are, and you see that, and they have to list everything that ever happened in a study, even if it's something that has nothing to do with the medication.

And so, you read, you know, death, blindness, I mean, all kinds of stuff. Headaches might get worse. And so, people misunderstand that, and then they think, oh, I'm going to trust the other stuff. And then also, you know, you mentioned the issue of if you're in a primary care setting and you don't have time to get the explanations you need, including about why a medication might be better than you feel like, because you can go on the internet and see all this stuff that says Saint John's wort or, you know, lavender oil or bitter, you know, orange or whatever makes you feel happy.

And it helps you, you know, and people wax eloquent, with inflated claims or false claims. And there's no and there's no disclaimer, with that statement, then it can give you a false sense of security. And so, I think that's tough. And then the other thing I have to say about Americans in particular, is our culture is built on the idea that I, as the individual will, am the one who knows best about my life.

I decide if I can bear arms, if I can go to public or private school, and so culturally we create this idea that the individual and their experience and knowledge are more important than other people, including medical experts. And that makes it hard for us to sometimes, develop the trust we need with our health care system and our individual providers.

That makes it easy to get the information that really would be helpful.

Dr. Jaclyn Duvall

Well, I think that that will be so insightful for us to delve into our next part, third part of this series and that really forming this relationship with your health care provider. I'll tell you, as someone who grew up with a parent with chronic disease, multiple sclerosis, my mother would go to doctors appointments with some of the most intelligent people in the country and leave there never wanting to go back.

And so, it's important from our end as providers to understand that fostering this relationship and being a trusted advisor and a teammate and their health care is so important. So, I'm excited to have that conversation. And your insight, the last question I have, in this series is given all of this information, where do you suggest that patients start in their treatment journey?

Dr. Karen Cassidy

Yes. Well, I think the first one is, is that we know it's critically important that you get educated, about your disease, your headache patterns, and what's available in treatment. All the options in this means you need to be willing to find accurate research, such as from the National Headache Foundation. And so that's step one is to try and get the information you need because, I want to tell people, don't settle, that what is exciting at this day and age is we have the best treatments we've ever had in terms of headache disorders compared to when I graduated from graduate school, where literally you had, nose spray and you had

caffeine, and that was pretty much it. Or they'd give people antidepressants. And it wasn't a very good outcome is that it's an exciting time for people. And then the next one would be to realize this is a process because I think, you know, as Americans, we like things to happen fast. We get impatient and we forget that with any kind of disease, it takes time.

It takes time to change the processes that are causing the headaches. It takes time to reregulate your body and that you need to be persistent and patient. And then also, I think it also takes a willingness to say, could there be more? Is there more? And you mentioned your mother going to different people, and I'm guessing the reason she did that is she recognized information can get siloed where it's stuck in one area and another area doesn't know it.

And I would encourage you to realize I can have faith in the medical system. I just need to be persistent to find the people that feel comfortable to me, that I can work with, and I can do experiments and be willing to try different things and to see what that unique combination is. Because one of the things that I'm finding so exciting in mental health and medicine right now is we're realizing there's so many unique individual factors for each person with their body, their brain, their mental, health, that the more we can individualize treatment, the better it is and that it never is a one size fits all situation.

And then lastly, psychologically, we see people want to have a one and done approach to treatment. And probably that experience in the emergency room makes you mistakenly think this is all that can be done is, you know, is I wait till a, a horrible headache. I try to get relief and then it's done. And instead to think of it as, this is going to be a series of experiments with me and my providers and my lifestyle, in finding what is the thing that I need to do each day or things that put me in the position where I can have the fewest and the least severe headaches of all?

And that, just like anything that you practice, it takes time. And if you took up a sport, you wouldn't expect to be the pickleball expert the first time you went out. Well, I want you to think you're not going to be the headache expert on yourself the first time out, that you want to enter into a process.

Dr. Jaclyn Duvall

Absolutely. Well, I do want to remind individuals that because we've talked so much about the emergency room and emergent care, which is so important whenever you're in the midst of a severe attack. But as headache providers, we recommend prevention at just for moderate to severe migraine attacks a month. And so, we can see that the brain in this progressive disease amplifies when we're not controlling it.

So, it's really again partnering finding that right fit of a health care provider. It's okay to ask for second opinions and, and to utilize all of this information together. So, this conversation has been so helpful. Thank you again, Doctor Cassiday, for your invaluable insights to our listeners. Thank you for tuning in to the second part of our three-part series on the Harris Poll Migraine Report Card.

Join us for our final episode where we will discuss the relationship people have with their providers. In the meantime, visit headache.org and click action4access on the main menu to access the National Headache Foundation's comprehensive guide to accessing care. We'll see you next time.