NHF Insights: The Emotional Toll of Attacks

Dr. Jaclyn Duval:
Welcome to the National Headache Foundation's podcast NHF Insights. The NHF Insights podcast opens discussion with industry partners on the latest research findings and treatments for people living with migraine and recurrent headache attacks. I'm today's host doctor Jaclyn Duval. I'm a board-certified neurologist, UCNS certified headache specialist and own Headache Clinic in Oklahoma. I'm also a board member of the National Headache Foundation.

This edition shares the results from the Harris Poll Migraine report card. This survey was supported by Lundbeck with 550 U.S. adults who currently have high frequency headache and migraine, plus acute medication overuse, versus people who previously had high frequency headache, migraine plus acute medication overuse, but now have currently sustained reduction in attacks. The survey asks about everything from the impact that headache has on people's lives, the effectiveness of treatment options, and even their relationship with their healthcare providers.

With a robust amount of information gathered through this survey, we separated this conversation into a three-part series. Here's a quick breakdown of the insights we will cover. The first section will cover the burden or impact of headache and migraine. The second will focus on treatment and use of over-the-counter medications or caffeine. The third section focuses on the relationships with health care providers and really feeling seen by your provider.

So be sure to stay tuned for all three parts. Today's guest on NHF insights brings a unique perspective on this topic, and we are thrilled to have her here with us today. Doctor Karen Cassiday has a doctorate in Clinical Psychology and is nationally recognized as an expert in anxiety disorders. She has conducted extensive research and is widely published, including in the American Journal of Psychiatry, the Journal of Anxiety Disorders, and she is past president of the Anxiety and Depression Association of America.

Doctor Cassiday also has personal experience of living with chronic pain. Welcome, Doctor Cassiday.

Dr. Karen Cassiday:
Thank you so much, Jaclyn. It is so nice to be here.

Dr. Jaclyn Duval:
Absolutely. We are thrilled again to have your unique perspective. And I want to dig right in. One of the first findings from the Harris Poll that we'd like to talk about is burden, that the burden of living with migraine disease. And what was interesting is that this survey found that

people had significant reduction in headache or migraine attacks, but they're still experiencing substantial burden.

And this really came as a surprise for myself, other health care providers, in that we'd like to think that if you reduce the number of headache or migraine attacks, that burden of migraine would also decrease. But that isn't what the data said. So, Doctor Cassiday, I'd like to know from your experience, why do you think this is happening?

Dr. Karen Cassiday
Well, I think the first thing is that when we look at research and we're looking at outcome researchers, I think have a different perspective than patients do. And so oftentimes in a research study, they'll be including, not just the very good outcome, the very high outcome, whether it's a very low frequency or a decreased, I'm going to call it, intensity of headache.

But also, they'll be looking at sort of that middle group. And you know, in the dilemma is or maybe even slightly below that. And the problem is statistical. That might look good. But if you have hideous headaches and you have them 15 days a month instead of 30. Your point of view is my month is still wrecked.

And that would be because you're dreading the next headache and you're not, unless you have had a lot of training in optimism and focusing on the positive, your brain's natural bias to pay attention to the negative is going to really highlight those 15 days compared to 30 days. So that's one phenomena is what it feels like to have that headache is not the same experience, says looking at data and going, wow, we got a 50% reduction.

So that's one dilemma. And then I think another thing is that, sometimes there aren't, I think, good conversations between doctors and patients about which facets of life are the ones that matter in terms of the patient's sense of quality of life. And so, one thing I've seen and this happens with anxiety disorders, not just headache, is that, if you have had to deal with horrible pain, then it's very likely you're going to fear that pain.

You're going to have dread about it. And when it happens, it's very easy to go down a negative spiral and go, oh my God, not again. I can't take this. I'm throwing up. I can't get out of bed. I'm so dizzy or whatever it might be. And I think, and I know this from patients telling me this when they've talked to their doctors is they feel dismissed and understood unless they can find someone like a doctor Duvall, who's a specialist and who gets it.

And I have actually heard neurologists say things like, oh my God, I hate working with headache. It is so frustrating. Everybody always complains. And so, I think patients sense that. And the dilemma is we know from a psychological perspective, if you feel alone with an experience of suffering, and if you don't feel deeply understood, then it will amplify your pain.

And the best analogy I can give to this is when you have an infant and they're crying, and you've tried everything and they're still crying. We know that just holding them and going there, there, there, and having deep parental empathy for that child helps. They're more likely to soothe and settle. And so, I think there are some gaps there with how we talk to patients about their pain.

Dr. Karen Cassiday:
And that, I know I've had patients say, well, my doctor says, I'm doing really well. I've cut things in half. But my point of view is, my life still is awful. And so I think that's one of our, our issues there is. How do we create more empathy, more understanding, and then also more realistic expectations?

So, I think one thing that's tough as patients is when someone says, “I can help you”, they might be thinking, I have no more pain, no more headache. It'll never happen again. That's everybody's goal, obviously. And the physician is looking at it and going, wow, I can get rid of half or three quarters of your headaches.

And I'm feeling really successful because that's so much better. I'm looking at it like a statistician and I'm feeling successful and it's something that the patient hears or senses and then it creates, I think, distrust or disengagement. And then I think that leads to the phenomena that patients are then less likely to seek newer treatments. Preventive treatments, they give up, they settle.

And then I think sometimes doctors settle where they go, I'll never make them happy. And I'm not going to, strive in this area the way I might in others where I feel like I'm really able to do well because honestly, physicians and nurse practitioners love happy patients. They want to make people feel better.

They want them to have a better quality of life. And it can be, daunting and dismaying to be that physician who feels like I thought I was doing well, and the patient is dissatisfied, right?

Dr. Jaclyn Duval:
Wow. You have me so excited about this entire series. Because I'm so thrilled to delve into that health care provider relationship and, and recommendations you have for us as health care providers, also as patients, to be able to see the success in this relationship because as we tell our patients, this truly is a partnership. And I'll tell patients that it's almost like a dating relationship, that every health care provider you meet may not be the right match.

And so maybe it takes seeking care elsewhere, but making sure that you have those open lines of communication. So I am so excited as we get through this series, I want to circle back to because one thing that we'll see you with our patients is what we call interictal burden. So, for those who may be familiar, we call the interictal time the period between headache or migraine attacks.

So, what we've learned with time is that even in between attacks, these patients may live in a state of fear or worry. And I want to get perspective about is this about lack of control? Tell me your insights into this.

Dr. Karen Cassiday:
Well, I think, if we take it from a research perspective and then my clinical experience, the very worst part of it is the uncertainty. And we know that if you want to make it easy for someone to worry, then you make things uncertain. And what anxiety does is it says, I would like a promise, a 100% guarantee about what the future will hold for me.

And the dilemma is during that interictal phase, even though you might know, okay, it's not going to happen as many times this week or as many times this month or, my premenstrual headaches might not be as bad if you're not sure, because quite frankly, it varies. And, and it's an average of less and less severe.

And so that's one thing. And then what people do when they are worried or anxious is they take a self-protective stance that says it's better to be safe than sorry. So, I'm going to focus on this scary stuff and try and solve that. And the unfortunate dilemma for all of us is whatever we imagine is whatever we experience.

And so when we imagine something frightening or painful, we actually feel it. So, if I'm imagining, my next headache, I'm going to feel scared. I'm going to imagine the pain that I've had. And that is very unpleasant. And then the other thing that we are biologically or hardwired to do is that, to assume that what we feel must be what's really happening in the environment and from a safety perspective, is probably good to be able to respond quickly to pain or imagine fear or imagine awful things.

But it ruins your moment, and it convinces you that better safe than sorry. I better be hyper vigilant. I better start scanning my body for signs and symptoms. And then I see this so often where someone, a patient will tell me, well, I, I'm not sure if I'm having a headache, but I think I'm going into one or I'm maybe having an aura, but I'm not sure.

And if you think about what that's like, it's awfully unpleasant. And so, we see that hypervigilance happening and then that hikes up more anxiety. And then you have someone that doesn't just have a headache disorder, they've got a worry problem and an anxiety disorder about this. And so and we even have a special diagnostic category for this where anxiety related to a medical condition, where it's almost like, a traumatic response.

So that's the dilemma. There is no one who can guarantee or say, okay, the switch is going to stay off so you can go, phew, I'm safe to go, and then I can gear up five days from now. So that that's the dilemma.

Dr. Jaclyn Duval:
You know, I think what some don't realize as well is the same neurochemicals, the same neurotransmitters that are involved in migraine, in the pain process are also involved in anxiety. And just that negative thought process can create a physiologic response in our body.

Why not try. Yes. So we know that worry can play a big role in headache and migraine. And I'm curious what sets people up for worry.

Dr. Karen Cassiday:
Yeah. Well, there's two big factors. And the first one is genetic. And we know that if someone has, the familial genetic background or other people in their family, especially first-degree relatives or the people that you would consider your nuclear family, if they have anxiety disorders, then there's a very high likelihood that you are at risk for that, too.

And I say anxiety disorders because it's not one particular disorder. And we also see the same is true, is if mood disorders run in your family, such as depression, and that these all run together. And we know, the genetic substrate or the genetic the genes that are involved with anxiety disorders are also involved with headache disorders, and there are similar groupings and pairings.

So that's one risk factor that sets you up. And then you have this difficult experience. All this uncertainty. And then that makes it happen. Another thing that we see is hormones okay. And we know particularly for females that, puberty, lactation, pregnancy, menopause are times, when those shifts are happening, then women are at unique risk for having anxiety.

Particularly if they have that genetic substrate. And then another one for all you women who are of childbearing age when you are premenstrual, we know for sure that you are much more likely to experience panic attacks, worry obsessions, compulsions, phobias, and even more likely to think that you should kill yourself. Just with that change. It's, it's a difficult time for women.

And now that we're doing this sophisticated research about the menstrual cycle and looking at changings. So, we see especially changes in progesterone, the big increase and big decrease, really makes women vulnerable. And then the other thing is, if you come from a culture or an environment or a group that considers distress to be a bad thing, especially anxiety, and you're accidentally taught that that's the worst thing that could happen to you and that you need lots of help and that you can't manage it, then it is going to set you up, and it's like lighting a match to, fumes of gasoline.

And let me give an example of that. So now we know, if we look at people age 35 and younger, we see that they believe stress is bad and we see that generations of mid-forties and older just consider stress to be kind of a neutral thing, and it's just something you should cope with. And

they might say stuff like, yeah, life's not fair or you know, okay, everybody has their piece of garbage to deal with in the day.

Dr. Karen Cassiday:
And we see younger generations feel like normal daily stressors. Taking an exam, having a child who is sick, your car breaks down or, we've been experiencing snow right before, this podcast recording, that they regard it as something bad. And then we see the bad thing about stress isn't stress. It's your attitude. And that believing that it's bad then makes it worse and harder to cope with and creates more anxiety because you misperceived that something must be wrong with you, that you are finding this difficult, as opposed to being able to say a self-compassionate thing like, well, yeah, this is frustrating, but I can handle it one step at a

time. This is normal. Everybody has bad days, or some people get headaches and other people have other kinds of chronic problems. They deal with. Very few human beings escape. Some kind of thing they have to cope with during their life. That's really hard. It could be a kid with substance abuse. It could be many other things. And so, your attitude about what it means to have headaches is critical in terms of that quality of life.

And I think what happens during that interictal phase, whether it's, oh, I'm so grateful today, no symptoms. I'm so happy about this, and I'm just going to let go of the future.

Dr. Jaclyn Duval:
I think so many of our listeners, or viewers can relate to this. I know I feel seen in this, I think so many of us have to face this on a day-to-day basis. Well, you gave us so many insights into worry and even practical advice for helping to manage or cope is there anything else that you'd, like to advise that could help decrease worry, manage burden of migraine?

Dr. Karen Cassiday
Yeah. Well, I think, one thing is I think you have to be willing to do an existential shift. And what we see is that people who worry think that difficult experiences are tragic and, or receiving a diagnosis of a severe headache disorder is a tragedy as opposed to a disappointment. And I know when I say this, I'm speaking from personal experience.

Two of my five kids have, pretty severe disabilities. One is non-verbal and in a wheelchair. And I've experienced chronic pain. And I know life is not fair. And yet, I would say I love my life, it is joyful. And one of the things that is helpful that we see from research is to be able to recognize that it helps to focus on the blessings and to try and overcome that negative preference that your brain has to try and notice those bad things, and to realize that it's actually not helpful.

It doesn't keep me safe. It keeps me safe from good mental health and from good coping. And that's not a good thing. And we need instead to take the perspective that says, why not me?

Why not my headache? Why not? Or why not my child? I have two of my sons have, migraines. And we have that in our family.

Dr. Karen Cassiday:
And instead, to realize that we all have suffering, that it may seem from the glamor of social media or just what happens in terms of how people are polished when they're presented publicly that other people escape that. But speaking as a therapist who gets to see the behind the scenes and I know you've experienced this too, is everyone ends up suffering.

And so, if you can look at that and accept that and say, why not me instead of poor me or poor my family member or my beloved friend? That really helps. And then also to realize that every good moment is a blessing and that, one of the more poignant experiences in my life is when one of my kids had terrible cyclic vomiting disorder, horrible migraines, horrible abdominal migraines, had a port, couldn't go to school, was vomiting every day.

We went to a special summer camp, for medically complicated kids. And I get there and it's like Disney World. It was, one of Robert Newman's camps that he had and people had made special blankets, the counselors were there. And here are all these kids that have we all had, like suitcases of medicine and treatment and IVs and stuff.

It was really kind of bizarre, but I just started sobbing, going. I can't believe all these wonderful people. And it was fully staffed with doctors. It had a hospital. Everyone. There was a volunteer. These people didn't know my son or these other kids, but they loved them. And there are people who have funded this, loved people like my son and I.

Instead of feeling sad, like, oh my God, there has to be this camp for these poor children, I, I don't know how to say it, but it just gave me a huge shift. And I felt so blessed that my son got to be the recipient of this kind of selfless compassion. And I want you to think of it that way, is, when I wake up and I don't have a migraine, that's a blessed moment.

I am truly blessed. I get to have a moment with my family. And even if I have a migraine, I'm hugging my grandkid. I have a grandkid, and they're in good health. That's a blessed moment. And so, we see when people can use self-compassion about what it's like to suffer and accept suffering. And when they can recognize the good moments really are our blessings, then that actually is what makes the difference.

It makes it so much easier to not get trapped in that sticky worry and anxiety and depression. Because let's be honest, depression is very common. And if you're a headache sufferer, and that's the trick to put it in a simple little package to make it easier to say I can make it through this day, that's difficult.

And I can have hope knowing this isn't the sum, of my life. These headaches are not all about me and my only perspective. That I am so much more than that.

Dr. Jaclyn Duval:
Wow, doctor Cassiday, thank you so much. I love that focus on the blessings. I feel like we all need to replay you in the morning on the way to, whatever that may be. That, fantastic information, very practical. I want to thank you again, Doctor Cassiday, for your perspective on all of this. And thank you all for your time.

We'd ask that you please join us for part two of the NHF Insights podcast on the Harris Poll Migraine Report Card. Stay tuned for our next episode where we will discuss treatments and use of over-the-counter medications and caffeine. For more information, the National Headache Foundation now has a complete guide to accessing care. Visit headaches.org and click on the Action 4 Access on the main menu to learn more.

Thank you.