Episode 244: Understanding Pain Psychology in Migraine Treatment

Lindsay Weitzel, PhD:
Hello everyone, and welcome to HeadWise™, the videocast and podcast of the National Headache Foundation. I'm Dr. Lindsay Weitzel. I'm the founder of MigraineNation, and I have a history of chronic and daily migraine that began at the age of four. I am here today with two very awesome guests, and I can't wait for you to meet them. I'm here with Dr. Dawn Buse who is a psychologist specializing in headache and migraine and a clinical professor of neurology at the Albert Einstein College of Medicine. Hi, Dawn. How are you today?

Dawn Buse, PhD:
Hi. I'm happy to be here. Thank you.

Lindsay Weitzel, PhD:
Dr. Buse is so popular on HeadWise with our group of people who watch us. And she's honestly popular everywhere in the migraine community, so we're happy to have her. We also have Katy Oakley, the new CEO of the National Headache Foundation. She is a migraine patient, and she has an amazing story, and she has been on her voice before. Hello, Katy. Thank you for being here.

Katy Oakley:
Thanks for having me.

Lindsay Weitzel, PhD:
Today we are going to talk about what it is like when we are told to maybe go talk to a pain psychologist or headache psychologist as part of our treatment plan. And honestly it can feel not great. It can feel perhaps like we failed a little bit or something, or like our doctor is giving up on us and pawning us off to someone else. But in the case of migraine, there are several behavioral therapies for migraine prevention which are supported by data and recommended by scientific societies. So we're going to dig into the nuts and bolts of this a little bit while also talking about that feeling that we have as patients and just going ahead and talking about that elephant in the room, and then having Dr. Buse explain to us why it's good, why it can be important, and how it's helped some of us.

This episode came about because Katy and I were chatting and I heard her say something that resonated with me so much, and I think it's going to resonate with our audience so much. She said that when the idea of pain psychology was first presented to her, the thought that crossed her mind was something along the lines of if the pain would go away, I wouldn't need mental health support. Please just focus on fixing the pain. And I think that all of us have felt that way when someone brought up pain

psychology to us or headache psychology. And so, I brought this up to Dr. Buse, and we had formulated some questions around this idea and this feeling that many of us have probably had. In case people don't know Katy's headache history, I wanted to give her a chance to bring everyone up to speed. Katy, can you please tell everyone how you came to join us all here in the headache space?

Katy Oakley:
Yeah, absolutely. So about ten years ago, I had a head injury. I was biking home from work, and I fell on my head without a helmet. And it was within an instant that my life changed. There was a time in my life where I would wake up with a headache. I would go to bed with one. It impacted every facet of my life. I was diagnosed with post-traumatic headache, chronic intractable headache, and new daily persistent headache. So, as you can imagine my mental health, I really struggled for a long time.

Lindsay Weitzel, PhD:
At what point in your journey did you feel this feeling and have this instance that we're discussing of gosh, will you please just focus on fixing the pain, and then I wouldn't need this support that everyone talks about?

Katy Oakley:
For me, I was living a somewhat normal life, and then overnight I started to have chronic pain. It led to anxiety, depression. I started to have suicidal ideation and suicidal thoughts. And my doctors and my therapist, they were really worried about me. At the time, I was trying to manage work and my social life and trying to be normal. And I say that in air quotes. And it was slowly chipping away at my entire being. And at the point where it started to become unsafe, that my provider said that it was really important that I addressed it. And to be honest, I was really upset at the time. I thought that they didn't believe me, that they were thinking that it was because of anxiety or depression that I was having these severe attacks. And now I realize that it's much more faceted to that. It was an extra level of care. It was adding more tools to my toolbox and taught me a lot of really wonderful skills that I am so glad that I got at the time.

Lindsay Weitzel, PhD:
Thank you so much for sharing that. I love that you're so open about your journey. Dr. Buse, this is such a big topic. There's so much to learn in this field, so we can't do an all-conclusive episode here today. But people can feel defensive when they're referred to pain psychology or headache psychology. Is the assumption that we have failed emotionally or some way and that's why we're in chronic pain? Can you talk about that to us?

Dawn Buse, PhD:
I think there's a lot of feelings that could come. We probably all have different responses, maybe multiple feelings. And this isn't coming out of the blue. Let's go back to the history of migraine from a Dr. Sigmund Freud in mid 1900s in the United States, saying that in fact, migraine was because of unrepressed urges that women had who were histrionic and couldn't handle things. We're not making this up. There's some history here.

We have worked as societies, National Headache Foundation, American Headache Society, International Headache Society, physicians, psychologists, real hard to learn our migraine science and learn that this in fact not a personal shortcoming. This is not that we are not handling pain very well. This is a disease with a genetic predisposition where things happen in the brain, neurochemicals happen that cause extreme pain, disability, and a whole host of other unpleasant symptoms.

So, let's just lay it out on the table. And that is known. That is known across all kinds of providers and healthcare professionals nowadays. But you wouldn't believe how much time I spend talking to my physician colleagues, NPs, PAs, all those healthcare professionals saying, please make the referral carefully. You're not just passing someone off because you're tired of seeing them or you don't have any more that you can help them with. You're not giving up on them, and you don't believe it's all in their head. It is all in your brain, but not all in their head. You don't not believe it's real. Tell them that. Explain, I say this to my health care professional colleagues, please explain what this referral is doing.

And in most cases, it's not passing off only to the behavioral or a psychological provider. It's usually adding a team member. So, if you are fortunate like Katy was to be seen at a truly multidisciplinary center. Katy, I'm guessing you had physicians, nurses. You might have had psychiatry, might have had PT, OT. You might have had biofeedback, psychology. You went to the Diamond Headache center, right, which is an amazing state of the art facility where you're going to get everything. For a lot of listeners, you might be where you have a neurologist, maybe a headache expert, or maybe a general neurologist, or maybe a primary care provider managing your migraine. And they may need to add on a team member from within the center or hospital or even outside the center or hospital.

And so, what we like to think about is that healthcare provider, physician or nurse practitioner or PA is going to be the quarterback still. That person is really organizing the rest of the team. You're just bringing on teammates. But that doesn't always come through in the delivery. And rightfully so, there are people who have felt like they've been fired or let go or let down by their healthcare professional when the healthcare professional didn't know what else to do. That was a shortcoming of the healthcare professional. It wasn't a shortcoming of the person with migraine, but they feel like they didn't know what to do and now they just pass them on.

Lindsay Weitzel, PhD:
And we are also in such a sensitive space sometimes when we are in such severe pain.

Dawn Buse, PhD:
Oh yeah, it's a vulnerable feeling to need help, to be asking for help. Migraine is highly stigmatized in the US, around the world, and it takes a lot of courage to kind of go out and seek healthcare for it and explain your level of disability. And not all health care professionals are going to react to that respectfully or thoughtfully. So, there's some reality behind this feeling. I am not judging this feeling. You absolutely have some real reasons to feel disrespected, unheard, abandoned, passed off as crazy. But the good news I'm going to tell you, we have scientifically proven treatments which are helpful. I think kind of interesting. They're time limited. We're only talking about probably a couple months at most. And often they really carry forward with you. And Katy, I'm curious to hear what you did, the behavioral therapies, were there any that you that you liked, that resonated with you?

Katy Oakley:
Yeah. I did a few different. I did biofeedback, CBT, DBT. Biofeedback I thought was really interesting. I did an inpatient stay at the Diamond Headache Clinic in Chicago. And I was getting treatments, medication treatments, and then it's very holistic. So, there were other approaches as well. And biofeedback, I believe I did it twice a day. And for those of you who don't know what biofeedback is, they hooked me up to monitors. There were sensors, and I had real time feedback and cues on my body's stress levels.

So, as you can imagine, for me, I was in chronic daily pain. I clenched my jaw a lot, and I didn't realize that. And when they put these sensors on in that exercise on my jaw, I learned that if I put my tongue to the roof of my mouth, it would relax those muscles. And even if you're clenching your eyebrows often because you're in distress or pain or whatever symptoms you're experiencing, all of those things they egg each other on. And so, I learned these really interesting techniques that, yeah, it may not have started an attack, but it absolutely helped it from getting worse. Or it could have prevented one from starting because I learned different skills and techniques.

Lindsay Weitzel, PhD:
The American Headache Society Consensus Statement[1] includes certain types of therapies for migraine prevention. Dr. Buse, I do believe biofeedback is one of them. What else is on the list for migraine prevention from the American Headache Society.

Dawn Buse, PhD:
When it comes to behavioral migraine management, biofeedback, as Katy and Lindsay said, has good evidence. Cognitive behavioral therapy, Katy mentioned CBT, you've probably heard of that. As well as mindfulness-based therapies. There's mindfulness-based stress reduction, mindfulness-based cognitive therapy, relaxation therapies, and acceptance and commitment therapy. Those all have data supporting their use for preventing migraine, migraine prevention. And then Katy also mentioned DBT (dialectical behavior therapy), which has some really excellent skills for self-regulation, self-calming, kind of how you interact with the world and how you feel inside, that I really also think can be very interesting and valuable. Katy, what were your thoughts about the DBT experience?

Katy Oakley:
It was really helpful for me for managing really intense emotions and big distress. So, for me, there were some treatments where I was genuinely afraid of. At some points, it sounds silly to talk about, but I would even struggle to get out of a car to go and do it. I wanted to do it. I wanted to feel better so badly, but there was a lot of anxiety. I was incredibly distressed. And so, there were different techniques…

Dawn Buse, PhD:
Katy, that could be like going in to get injections for migraine prevention. Probably someone going in to get an MRI might feel claustrophobic, and you need to kind of do some self-calming, self-pep talks, self kind of management to get through that. And DBT, was some of those skills were helpful for you?

Katy Oakley:
Yeah, absolutely. Especially for an MRI that I had. Listening to some calming music, changing temperatures, there's a lot of really very specific skills that can help you in moments where you're so heightened that you need to be regrounded and reset. And unfortunately, that's a reality for many people in the headache and migraine space.

Another one that I really struggled with was in social situations. A lot of my friends and family were so loving and so concerned, and they would ask me how I was feeling, and I learned a lot of coping skills, of even just planned responses. Or if I was really elevated, going to the bathroom. I always had an essential oil on me where I would take two minutes, and I would stay in the bathroom and I would reground myself. And those things again, I think it could have prevented an attack from getting significantly worse because I was being able to recognize my body and then use coping skills in order to be able to help myself. And I don't think in the very beginning I fully understood that when I got a referral how it could really, in a 360 day-to-day life, impact you. It's the little things and the big things that it can really help you with.

Lindsay Weitzel, PhD:
This leads to a really important question that I think everyone in the audience probably would love to hear about. Dr. Buse, can you tell us more about the actual goals of these therapies? Are they meant to help us cope with our pain, or are they actually shown to prevent migraine attacks and improve other variables related to our pain?

Dawn Buse, PhD:
Well, we have both when it comes to behavioral migraine management. We did mention 5 or 6 different types of therapies. Chances are when you see a therapist, if you came into my office, I would do a little bit of everything. I'd hook you up to biofeedback, and then I'd kind of ask you about a stressful situation. We'd do some CBT, we'd do some mindfulness, some relaxation breathing. And by engaging in these activities, Katy said, sometimes you get so activated.

Well, what we're trying to do is regular, calming of the nervous system. And someone with migraine has a nervous system that activates more easily than maybe someone without migraine. And we want to kind of condition, kind of put that nervous system, like training for a marathon, we are going to condition it to handle these activations, all the little and big stressors. Katy said big things, little things, big stressors that life throws at you, these little daily hassles that activate the nervous system. We want to kind of train it through all of these methods to kind of quickly calm and balance. Balance and moderation are key to living with migraine.

And so, when we look at clinical trials and studies of these therapies, either multiple combined or independently, not only do they have prevention benefits, so reducing number of attacks, as well as reducing severity of associated symptoms, impact disability, quality of life, stigma. And we also tend to see improvements in mood, depression, anxiety. We tend to see improvements in self-efficacy and confidence, as well as improvements in specific areas of life, work life, family life, school life. So it depends on which study we look at it for about exactly which therapy, but the combined therapies show kind of benefits across the board.

Lindsay Weitzel, PhD:
Do we have any data on what types of patients or people are most likely to improve with these behavioral therapies for migraine?

Dawn Buse, PhD:
Yes. We know that youth, kids, teens actually do amazing with these therapies. We've seen that in a major study that these therapies were as effective, well, they were actually much more effective than a medication approach for youth with migraine. For adults, these are great for someone who has a risk factor which might limit medications, maybe someone with heart disease has had a heart attack history, medication interaction, certainly pre-pregnancy planning, pregnancy, postpartum breastfeeding. Nice, safe, healthy alternatives are good to think about. And so really, there's a lot of times when these just seem like really good solutions on their own. But they also play well with others. When we combine gold standard medication treatments or neuromodulation treatments, and we combine them with behavioral therapies, we see better outcomes than either alone. And this has been both in the youth as well as in the adults. We have studies in both youth and adults combining the traditional oral preventives, it's been a while back, with behavioral therapies and seeing really good outcomes.

Lindsay Weitzel, PhD:
Do we have any data on whether medication alone or behavioral therapies alone in certain populations are better? Or is it always better to combine?

Dawn Buse, PhD:
A combined approach is really a wonderful opportunity to, Katy said 360. The 360 kind of manage this disease from all aspects is really nice. Not always possible to get or to do, but when possible, it's really nice. Now they kind of layer in different ways. If someone is taking, for example, acute medication, they're probably taking acute medication throughout their life as attacks happen. And in our large studies that we conduct, we see about 98, 99% of Americans take some acute medication at some point when attacks happen. If they're taking a preventive medication, those usually go on for months or years.

Now, the behavioral migraine management therapies, this is going to be more of a learning, training process, maybe 8 to 10 to 12 weeks. And then you bring those skills forward with you. You may continue your mindfulness or some things Katy talked about, preplanning for those helpful suggestions you hear from your family and coworkers, the breathing, the self-calming before an activating activity. But the actual time of the sessions and seeing a therapist or doing an online or virtual interaction is going to be time limited. So, it's nice to think about learning these skills, and then you're kind of done with the learning in the practice. Just like going to physical therapy, you learn your exercises, you do them as long as you need. They're there for you when you need them.

Lindsay Weitzel, PhD:
I have a very practical question. I think because so few of us have migraine in a vacuum. So many of us have something else along with it. So, for example, with Katy's story, it's perfect. She had more than

one type of headache diagnosis. It wasn't just migraine. It was other continuous head pain along with it. So, let's go beyond migraine and headache and talk about these therapies for all types of chronic pain and painful conditions. Are there differences when these therapies are delivered for someone with migraine versus someone with chronic pain, such as continuous back pain? Or I can even make it personal for me and my family. There's two of us that have really severe neuropathy, burning pain, along with our migraine. So, what do we do in these situations?

Dawn Buse, PhD:
There are specific protocols within these therapies for different disease states. Let's take cognitive behavioral therapy because it's been around for many, many, many decades and it's very well established. Say we're talking about migraine plus insomnia, ideally you would do behavioral migraine management for migraine, and you would learn CBT-I (cognitive behavioral therapy for insomnia).

When we look at something like mindfulness-based therapies, the mindfulness-based therapy actually started with people with chronic low-back pain. That's where it was developed in the 80s and 90s by John Kabat-Zinn at UMass and Amherst. And then what we've done is we've continued to refine it for a migraine population with things that people with migraine experience.

We have different symptoms. We have this cornucopia of pain plus nausea plus light sensitivity, sound sensitivity and maybe some cognitive impairments, maybe we call it brain fog. We got a little different thing going on than someone with low-back pain who might have physical triggers in their life. So you have to kind of be immobile and wear a back brace and watch how much they lift and squat when they lift.

It's a little different story than migraine, where we're talking about raising your healthy threshold, watching those potential triggers, keeping normal regular routine. So there's different specifics within the therapy. So ideally you do want to target your therapy for the disease state or the multiple disease states that you're working with. Now when it comes to something, let's say cluster headache, one of the most painful conditions known to humankind unfortunately, we have not created therapies specific for cluster headache. Not because we don't want to. We're getting there. We work on everything as fast as we can. And so, someone with cluster, might say, okay, well, maybe I would like to try mindfulness, either general mindfulness or the mindfulness for migraine. And maybe it hasn't been tailored exactly for cluster yet. And maybe they actually work on tailoring it themselves for a cluster a little bit and say, here's my symptoms, here's my vulnerability times, and here's what I need to work on. And if you worked with a psychologist or other type of therapist, he or she could do that with you. They could personalize. You wouldn't need to stay within a book or a manual.

Lindsay Weitzel, PhD:
I'm just curious, before we go, if there's anything that either you feel you can say to anyone who might be in our audience who is currently feeling frustrated by the idea of being referred to headache psychology or pain psychology or is hesitant to follow through with this referral. What can you say to that person? I'll start with you, Katy, and then I'll let Dr. Buse close.

Katy Oakley:
Yeah. First, I think it's valid. I think Dr Buse did such a wonderful job speaking to that. But it feels invalidating. So, your whatever you're feeling about that, I think noting that first, but also trying it maybe with some curiosity. It's truly, think about the reason why and what would maybe prevent you from trying something like that. I mean, is it maybe stigma? But really, at the end of the day, at least for me, I really felt like it was adding an extra layer of support. It wasn't about denying my pain. It was about treating my nervous system. It was about I was stuck in this survival mode, and I really needed to take a step back. And it really allowed me to do that in a different way with other options that I truly didn't realize existed. And I love what Dr. Buse said. At least for me, it was so customizable. Like when I had daily pain, it was very different from what I was going in and out of a migraine attack.

Those skills that you learn there, they are different. And I think that that is so important to know that if you find the right professionals, you can find something that can truly fit whatever your experiences. I would strongly encourage trying it, at least for a little bit, if you can. And if it's needed, certainly talk to your provider about it, but it can be really beneficial.

Lindsay Weitzel, PhD:
Dr. Buse, what do you have to say to that person that's frustrated and just wishes someone would focus on fixing their pain instead of sending them to headache psychology?

Dawn Buse, PhD:
I agree with Katy. It's valid. I'm hoping that the person who referred them is also staying on as a provider and adding another teammate. If you do actually just get referred, often abandoned, that's not a good sign, and maybe it is time to break up with that provider. Yeah, I know that break up. But if you're part of a multidisciplinary team or they're sending you out to do this at the same time and it's in line with all of your other therapies also being optimized, you're really adding in an extra layer like Katy said of additional skills, additional resources, things that will take you forward for decades of your life and might even apply in the other aspects of your life as well. And it's kind of interesting. And the good news is, it's not a big-time commitment out of your life. It might be an hour a week with a little homework practice in between for anywhere between 6 and 12 weeks. Or it might be more intense if you're inpatient. It might be every day for a week or two. You can learn some things on your own through podcasts and apps. And try biofeedback, try different skills. But it's not a whole big-time commitment. It also should not be a big financial commitment. Generally, this should be covered by insurance.

And you can always give it a try. And if you aren't interested, you always have the right to stop at any time as well. So it shouldn't be like a big commitment. So as long as it's part of a broader treatment plan that's feeling optimized and feeling good to you, I hope that you explore it and see if there's anything you take from it that you find helpful.

Lindsay Weitzel, PhD:
Well, thank you so much. And I would add, the thing that I always say, I think a lot of people have probably heard me say it is these skills even if they aren't particularly helpful for your pain, let's say the worst-case scenario, they apply to everyday life. And I believe that they are helpful for me in parenting.

They are helpful for just about everything, especially as someone whose pain can be really bad right at the time when my son is not having a great day. So, I think that they're helpful in life no matter what. So, I would encourage people, for that reason, to go ahead and go and get these skills. No matter what, just give it a shot. That's kind of how I feel about it personally.

So, without further ado, we are going to wrap up today and thank everyone for joining us. Thank you, Katy. Thank you, Dr. Buse. This was just awesome and I hope everyone got something out of today's episode. Please join us again on our next episode of HeadWise. Bye bye.

[1] https://pubmed.ncbi.nlm.nih.gov/34160823