Episode 215: Understanding the Phases of a Migraine Attack

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. Everyone get excited because I am here today with Dr. Dawn Buse. Hi Dr. Buse, how are you?

Dawn Buse, PhD:
Hi, Dr. Weitzel, and hi to everybody joining us.

Lindsay Weitzel, PhD:
Dr. Buse is a Clinical Professor of Neurology and a psychologist who specializes in headache. She is very well known and respected in our community, and everyone seems to love when we have her on our podcast. We have an exciting topic today. We are going to talk about some new data from the MiCOAS study that Dr. Buse is involved in that has to do with different symptoms that we have in the phases of migraine. So many people with migraine notice that there are different symptoms that come with various stages of their migraine attacks. For example, I notice, especially as I got older, I started to notice that I got brain fog before the extreme part of the pain would show up.

I'm sure a lot of us have different stories we could tell related to that. Dr. Buse is part of this group of researchers who ran the MiCOAS study, and she's looked into this phenomenon. And she has brought the data with her today to talk to us, and I can't wait to hear what she has to say. So, Dr. Buse, when you study these phases of a migraine attack, what are the names of the phases? What exactly are these phases that you look at?

Dawn Buse, PhD:
We went with a kind of very straightforward naming strategy: pre-headache, headache, post-headache, and then we have kind of fancy word between migraine attacks. So those three are the migraine attack. And then between attacks we borrowed this word from epilepsy. When people have seizures, they call it the ictus and when they're between seizures they call it interictal. So, we call it interictal, but basically between migraine attacks.

Lindsay Weitzel, PhD:
This is a curious question because I think depending on how long you've had migraine and how many times it's changed, because it really does, if you've had it many years it changes. It doesn't stay the same forever. Does everyone experience symptoms in the non-headache phases?

Dawn Buse, PhD:
No. Symptoms in the non-headache phase seem to be experienced more by people with more frequent migraine, especially chronic migraine, especially near daily migraine. But it can also just be a sign of activation of that trigeminal vascular system in the brain may be not completely calming down between

attacks. So, some of the symptoms that people might have lingering between attacks might be sensitivities, photophobia, phonophobia, osmophobia. That is sensitivity to light, photo, extreme sensitivity to sounds, phonophobia, and extreme sensitivity to smells, osmophobia.

And someone may say I can never walk by a candle store at the mall or the smell of, enter whatever word you want here, gasoline or chlorine or perfumes, fragrances, colognes. Even between attacks someone with migraine might say it makes me nauseous. It makes my head hurt. I worry it might start an attack. So those are common interictal symptoms, symptoms that just are with you all the time, the sensitivities.

You might notice that people with migraine, even more frequent migraine especially, might always wear baseball hats and sunglasses and might like to have their eyes covered. Or maybe they don't wear hats because they might have allodynia. And allodynia is when something hurts, dynia, that doesn't normally hurt. So, something on your skin, something in your hair, wearing a ponytail, a headband, a tight hat. And someone may say, I can never wear a headband. In fact, I love headbands. They're so cute. I really can't wear a headband. That pressure kind of gets to me. So those are some of the interictal symptoms.

But let me back up and tell you a little bit more about MiCOAS, if that's okay. MiCOAS is the measuring what matters in migraine project. It's sponsored by the FDA because the FDA really wanted to know what, truly, people who live with migraine consider important in their treatments. As we know, the FDA approves therapies, be they drug or device or other. And they approve therapies in these long processes of clinical trials that some listeners maybe have even participated in. And we have these endpoints. So how do we say it works. Well in prevention it may be a 50% reduction in migraine days or a 50% reduction in headache days. Or in an acute therapy, in a therapy taken at the time of an attack, it may be at two hours you're pain free or two hours you have pain relief or 30 minutes you have pain relief.

Well, those endpoints, how we say yes this drug works or no it doesn't, were actually chosen a little bit arbitrarily by researchers, not by people living with migraine. The FDA said we really must have people living with the disease tell us what they consider effective. And so, they sponsored several grants where we would really work with people living with the disease to find out what are the symptoms, what are the burdens and disabilities and impacts, and what endpoints are important to people living with the disease.

So, in MiCOAS project, this FDA sponsored project, where we have our co-PIs, Dr. R J Wirth, Dr. Richard Lipton. And then we have a fabulous team of psychometricians, which is like statisticians, as well as qualitative researchers. And that's one reason why these data are really special. In qualitative research, you don't fill out a checklist of items that are already pre-populated and thought up by someone else. It is that a researcher asked a question to someone like what do you experience during a migraine attack. And then they listened and recorded exactly. So, these are qualitative data. In MiCOAS, we had qualitative interviews with people living with migraine. And we said what do you experience during a migraine attack. And to organize it clearly, we made the headache phase kind of the central pillar.

Now we all know not every migraine attack needs to have headache. In fact, there’s kind of a nickname for the silent migraine without headache, maybe aura without headache. But that's more rare. For this purpose, headache we kind of made the middle phase. We have the pre-headache which for many people might include a prodromal phase which we'll talk about in a minute. And for some percentage

of people, might be followed between the prodrome and the headache with an aura. About 20% of people with migraine may have aura and they may not have it every attack. Aura of course is those sensory unusual symptoms: visual symptoms, tingling, difficulty forming words. There's quite a few aura symptoms. So, both of those can be in the pre-headache phase, headache phase, post-headache phase, and then that interictal or between time.

Lindsay Weitzel, PhD:
Let's start with the pre-headache phase which I think some people know it as the prodrome or the phase before the headache begins. How long does that usually last?

Dawn Buse, PhD:
A prodrome phase can last 24 or even more hours. And it sneaks up so gradually. You have migraine. I have migraine. Do we always know when it started. For me, my neck kind of hurts. I'm sitting in my desk chair. I'm not sure. I probably stretch my neck. I move it a little bit, I rub it. At what point do I say, ah, that's a symptom. That's a prodrome symptom. They kind of sneak up gradually. But a good 24 hours and what has happened is our nervous system has initiated an attack. Things have happened in certain parts of our brain. The hypothalamus and some other parts with the trigeminal kind of nucleus have gotten activated and certain symptoms will start. And the hypothalamus is one that is quite involved in this prodrome phase. Hypothalamus is kind of our calendar. It's our Google calendar, keeps us on track. It does our cycles, all sorts of things related to cycles, sleeping and waking and all sorts of cycles, all sorts of calendaring in our body. And that's one of our things that gets started. And that's why we have what you might think of as a really kind of strange group of symptoms that I'm sure you'll ask about in just a minute. So that's our prodrome phase.

And then some people will have that aura which can be anywhere between 5 to 60 minutes-ish. It's all “ish” because our brains are so special and unique, and each person is special. So let's say 5 to 60 minutes that aura. And then it resolves right around the time that that headache is started. But of course, we probably have headache building up and we probably have those prodrome and aura phases kind of coming down. So they're probably really overlapping a bit. One's kind of waning and one's kind of waxing.

Lindsay Weitzel, PhD:
So, it's slightly different for people with and without aura, but what types of symptoms are people most likely to experience in this pre-headache or prodrome phase before the headache begins?

Dawn Buse, PhD:
Exactly. In the MiCOAS where we did these qualitative interviews, people came up with about 70 symptoms that happened at some point during their attacks or between attacks. And people started to say the same things as each other, and we looked for themes. And then we took these 70 symptoms, and we tried to organize them. So, we thought of what's kind of in the ICHD-3 criteria. What are our hallmark migraine symptoms. And those are things that are in criteria like head pain, nausea and vomiting, light and sound sensitivity, aura. Those are our real hallmark symptoms. And then we thought about physical symptoms that weren't in the criteria symptoms: neck tension, the allodynia, the changes in appetite. We also have a group where we're calling them psychological, emotional. We'll talk

about those. And then we have cognitive or mental function. We took everything that people told us. We said how do these kind of fall into groups. These are the groups that we made. You can make different groups, but they kind of made sense to us. And then what we did was we did organize by when people reported.

In this kind of pre-headache phase, which could be prodrome and aura, interestingly, even though we said before you get your headache what are your symptoms, about a third of people said head pain. And that might be somehow noted as different. We all know our bodies. It might be that somehow that's a different kind of pain than my migraine headache. About a third of people said aura. Two thirds of people said nausea. Three quarters of people, 75%, said light sensitivity, that photophobia. 60% said sound sensitivity. Now those are our cardinal symptoms.

Now let's jump into more physical symptoms. About a third had decreased appetite. 40% talked about fatigue or exhaustion. About a third said they can't sleep if they wanted to. About a quarter, 25%, said neck tension. 40% said sensitivity smells. About a quarter said allodynia or things hurt: hat, ponytail, skin. 30% said blurred vision. 30% said numbness, and another 30% said tingling and weakness, which is part of aura for some people who have a specific type of aura. Those are the physical.

Now we're still in the pre-headache. Let's talk about emotions. About a third said anxiety. Oh no, that attack is coming. Even if they didn't cognitively say an attack is coming, something feels off. People started getting anxious. 60% said irritability and impatience which either they would notice or their family, friends and coworkers might notice. And a lot of cognitive symptoms. We have two thirds talking about difficulty with concentration, 42% said avoid making decisions like, don't even ask me what I want for lunch. I can't make any decisions, 45% said fogginess, 60% said trouble speaking, remembering words, putting their thoughts together clearly. A third said memory, 22% said it's hard to learn things, study, that sort of thing. And another third said difficulty processing information.

So, you could see a wide range. And I'm guessing for those people who are watching this podcast, some of these may make sense to you. You might say, yes, that's me during the pre-headache either all the time or some of the time. And then you being the beautiful, unique individual you are may have a symptom or two that's a pre-headache symptom for you that other people didn't mention. And that is one of the amazing aspects of migraine.

Lindsay Weitzel, PhD:
What I think some people might be curious about at this point is, were most of these people chronic or episodic?

Dawn Buse, PhD:
We did a perfect half and half, 50 percent, 50 percent. Really good question. A perfect half and half. We tried to get folks who had about four headache days per month or more, up to about 26 days. And with a perfect half and half, we had a beautiful split along racial lines, ethnic lines, gender, income and geographic area. We tried to be really careful to be really inclusive. And our researchers did an amazing job at that. And a lot of it was thanks to our physicians around the country who helped us in different parts of the country recruit. When we said, we need more men. We need more people of color. We need more people from the South. They were like, okay, we're good at helping. We're going to do this.

Lindsay Weitzel, PhD:
I was asking because I think for the people who are chronic or really get a lot of headache days a month that are listening, it's a very difficult thing for people whose symptoms and headache days run together. And I bet they're they were wondering, as I was wondering as you were talking about that.

Dawn Buse, PhD:
Exactly. Do you have interictal times when you have near daily migraine or headache. It might really be at a kind of a headache with some prodrome, some postdrome. It may all be kind of even mushed together a bit as you kind of live at this high kind of place of headache activity that may just bounce up and down a tiny bit instead of no activity. Yes migraine attack, no migraine attack.

Lindsay Weitzel, PhD:
Let's move into the headache phase when the pain is there during the headache phase. What sort of symptoms do people experience other than head pain? Are they noticing other things or does their head hurt too much?

Dawn Buse, PhD:
Oh, that's a good question. Yes, people said exactly that. That some of those things in the prodrome may still be there or the pre-headache may still be there. But because now their head hurts so much, they may not be paying attention to some of those other things. So, in fact, people did say that. We had a 100% headache during the headache phase because that's how we defined it. But we had two thirds with nausea. We had 27% of people talk about vomiting. We had 80% who were still super sensitive to light, 60% who are still super sensitive to sounds. And a third talking about still being very sensitive to odors, smells. Now we had a new one come on. A third of people talked about vertigo and dizziness now in this phase.

Now our emotions switched here. If you remember pre-headache, we talked about anxiety and irritability, impatient, kind of activated states. Now we're going into depression. We're seeing depression increase a little bit more with a little more people answering feelings of depression. Kind of think depression as kind of quieting and calming, kind of a more calm quiet down state, with anxiety being kind of a more up activated state. But the irritability and impatience has gone up even a little bit with 65% talking about irritability in patients. And then in our cognitive symptoms, everything that was hard before is still hard. People struggle with concentration and focus, two thirds of people. 45% said I avoid making decisions. We still see that memory struggles in a third of people, losing words or speech in a third of people retrieval and recall and difficulty processing information. But this isn't surprising. You're going through just a really bad kind of pain and nausea and sensitivity to light experience. You really don't want to be balancing your checkbook.

Lindsay Weitzel, PhD:
As you say, none of us want to do calculus in the headache phase.

Dawn Buse, PhD:
Rightfully so. Yet, the cognitive symptoms were really predominant in that pre-headache phase. Now maybe without the headache being there, people could still focus. Or maybe they were still at work and school. Or maybe they were still doing things where maybe by the time the headache is started, they've gotten themselves out of that and to home or a relaxed place or they stopped what they were doing, turned off the movie, turned off the computer. So maybe it also wasn't something they were as aware of once the headache is started because, as you said, the headache is kind of all present, all encompassing.

Lindsay Weitzel, PhD:
Dr. Buse, how long is the headache phase usually just by definition? How long is it and in this data?

Dawn Buse, PhD:
The headache phase is defined in criteria by the ICHD-3, the International Classification of Headache Disorders third edition that we use for all of our criteria, as lasting between 4 to 72 hours untreated. A migraine headache is one that lasts between 4 to 72 hours if untreated. Hopefully it might go faster and shorter. Treatment can help. Sleep can help. It can be shorter in youth. So children, teens, they don't have to have that four hour limit to call it a migraine headache if untreated. But up to 72 hours, this is no short thing. We're talking multiple days of headache if untreated.

Lindsay Weitzel, PhD:
Let's move on to the post-headache phase. When I read this study, there is something that I found so surprising just based on my own experience and people I was talking to. And I can't wait because it's kind of fun. Let's talk about the post-headache phase, how long it lasts, and the symptoms that people were experiencing.

Dawn Buse, PhD:
The post-headache phase is really characterized by fatigue, tired, feeling wiped out. Some people will even refer to it as a migraine hangover. The headaches gone but you are not back to yourself yet. So, what was reported in the MiCOAS study? A third of people still reported light sensitivity, sound sensitivity. Two thirds talk about fatigue and exhaustion. One third are hungry again. They're ready to eat, so increased appetite. I wonder if this is what you're talking about. So about a quarter are still feeling irritable and impatient. But 27% talk about feeling euphoric. Was that what surprised you?

Lindsay Weitzel, PhD:
Well, not necessarily. I think I've seen people experience euphoria. Maybe I've experienced that every once in a while. I think the fact that it wasn't that many people that reported feeling depressed. Some did but it wasn't above 25%, correct?

Dawn Buse, PhD:
Yeah, we have about 22% still reporting depression. If we talk about depression across the phases, we've got 20% reported it. So, one in five people pre-headache mentioned depression, 1 in 4, 25%, during headache, 22% post-headache, and 15% interictal. So, depression stays pretty consistent across all phases including interictal. It's not a symptom that seems to come and go with an attack like nausea. It's not there and then it's there. Depression seems to be something that if someone's experiencing it, it stays with them.

Anxiety as well. Anxiety is higher pre-headache at 30%. And then we've got about 20% in headache, about 17% post-headache. So a little bit of relief. And still 27% interictally, which may be about anything in general but could include worries about the next attack. So both of those stay kind of stable. Whereas something like irritability in patients, 60% pre-headache, 65% headache, and then down to 25% post-headache and zero people reported it interictally. So, we've got some different patterns for different symptoms.

Lindsay Weitzel, PhD:
And I found that interesting. I think I expected depression to be higher in the post-headache phase for some reason, just based on my anecdotal observations. But I found it interesting that it wasn't quite that high. It was still there though.

Dawn Buse, PhD:
And everyone's unique. So for people who are watching, whatever your experience is, your experience is and is entirely valid. And it may change for you, as Lindsay said, from attack to attack, from season to season. It could be different when someone's pregnant or not pregnant. Different from when they're a teenager versus in perimenopause. Attacks change. And they also may be different depending on what treatments you're using. Some of the treatments will affect and positively dampen down or eliminate some of these symptoms even during attacks. There's some of our preventive treatments that people say, I'm still getting my migraine attacks, but they're not as severe. I don't have this symptom or that symptom. These symptoms are a funny thing.

A couple more things about post-headache, kind of this wiped out, tired. But we do have two thirds of people say that they feel relief. A third of people talking about euphoria, which may be related to some of the neurochemicals that are involved in a migraine attack, like serotonin and dopamine. And then we still have some kind of cognitive symptoms hanging in there, difficulty with concentration and focus, fogginess. We have 42% of people saying they still feel foggy, feel slow. And still have 27% of people talking about memory impairment.

Lindsay Weitzel, PhD:
I think a lot of us directly after a migraine feel like if we think too hard, jump in and study for that calculus test or for example whatever, that the migraines going to come flying back. That’s a feeling that I've always had even since childhood.

Dawn Buse, PhD:
There's validity in that. It's a totally rational, intelligent thing to think. And of course we had to come up with a term for it. We call it cephalalgiaphobia. Cephalalgia being the headache, so fear of the next headache. And we talk about specifically cogniphobia. Fear that overexerting yourself with thinking will bring on head pain or a migraine attack. And again, just because I'm using the word phobia, I don't mean it's irrational. I know we talk about phobias like fear of heights or fear of clowns, that you'll think, oh, an irrational fear or fear of dentists. Although that's probably a separate topic. But none of those may be irrational. But in this case, be afraid of heights. Be afraid of snakes. I say be afraid of clowns. I don't like clowns. Nonetheless, I have digressed. I am going to come back to us and say that having fear, cogniphobia, that over exerting yourself mentally, may increase head pain is not unfounded and sets what phobia fear of what havoc the next attack is going to cause in your life is completely founded and rational. We just had to give them fancy names because we like to put parts of Latin words together.

Lindsay Weitzel, PhD:
I think that most people will find some comfort in the fact that there is a name for this experience that they probably have been having.

Dawn Buse, PhD:
It’s so common that we in the headache research and headache clinical world, we have terms, we have publications. Go to PubMed [https://pubmed.ncbi.nlm.nih.gov] which is free. PubMed is a free website by the National Institute of Health where you can look at any research study done in the world and look up cogniphobia and cephalalgiaphobia and look at some of our research. It's really common. You're not alone. I would say almost anything you've experienced with migraine, you're not alone. And I once had a support group one time that I just called the TMI support group. I said, let's talk about flatulence and gas. Let's talk about diahharea. Let’s talk about constipation. These are all related to migraine. Who knew? I mean, migraine is head to practically toe. It's amazing how many symptoms can be involved in a migraine attack.

Lindsay Weitzel, PhD:
Last but not least, let's go to the interictal phase or the phase between migraine attacks. For everyone out there who's lucky enough to have days like that, I think most of us would like to think that we don't experience symptoms related to migraine during this time. But that might not be the case. What were people reporting during this interictal phase?

Dawn Buse, PhD:
They reported the things that we've always found in our interictal research that stay high some people, the sensitivity to the senses, light, sounds, smells. You're still not going to want to have your coworker wearing perfume or walk by the candle store at the mall even between attacks. And partially, we could call this osmophobia. Fear that those strong odors either they are making you nauseous or that they will make you nauseous. So they might increase your head pain.

The allodynia stays with some people. That skin hurts. Hats, ponytails are painful. And then that the cognitive impacts stay with some people. Some people say I kind of feel foggy or I don't feel like I'm at

my best self. I don't feel sharp enough. Now, this is a tricky one. We know some medications cause cognitive impact. Like topiramate is one that has a side effect of cognitive impacts. We know that it can be part of a migraine attack. We know it also can be part of other things going on, like it's part of depression. It's part of perimenopause and menopause. It's part of a hormonal life event. It's part of pregnancy, which are all comorbid with migraine.

And it's funny I say pregnancy is comorbid with migraine. Migraine is common in young to midlife women. Pregnancy is common in young midlife women. So technically, that is our definition of comorbidity. And then the biggest, biggest stand out interictally is anxiety. Two thirds of people still have anxiety interictally. They worry about what they've missed, what they need to make up, and what's coming ahead with future attacks. Can they plan. Do they need to make changes to their plans, make changes to their life. What's going to happen. Anxiety a very common part of life for people with migraine.

Lindsay Weitzel, PhD:
This is all very interesting. And I love this study, and I want to thank you and all your colleagues who did it. From my perspective of when I read this study, I hope that people will be kind to themselves before and after the pain phase and be reassured that they aren't the only people experiencing symptoms before the pain comes and after it's gone. That's easy to say and then when you're in your work environment and you can't think, but it's hard to even say you have a migraine because your head doesn't hurt yet. It's all very hard and it causes anxiety to be worse. But now that we know this is normal, you're not the only person experiencing this. It can be very helpful. And I just hope everyone can be kind to themselves. What is it that you hope people will take away from this?

Dawn Buse, PhD:
I agree. I would love to destigmatize. Head to toe friends, anywhere can be affected with some interesting, unusual constellations. Don't be afraid to share with your doctor. You can learn from podcasts like this and other great sources of information like the National Headache Foundation and the American Migraine Foundation. You can go online and see, oh my gosh, these are not uncommon symptoms. Your doctor may have treatments or advice, or they may be able to tweak your treatments based on what symptoms you're having or what side effects you're having. There may be some treatments that are better for X or Y or Z. So that's something to think about.

So I want people think about be your own detective. Figure out what your attacks are like so that you can really start to figure out when one is coming on. Couple things you can do. One, it means you can plan a little bit more. Maybe you wrap up wherever you are, whatever you're doing. Are you driving? Are you at work? Do you need to get your kids home? What do you need to do to get yourself to a safe, comfy, cozy place with your treatments? And two, we are looking at data that some of our treatments can start working and be effective in the prodrome. And we used to say take those acute treatments as early as possible once you feel the head pain. But in fact, if you are a pretty accurate predictor, we are starting to say that some of these treatments, some of the acute treatments, treatments taken at the time of an attack, we'd like to see you take them in the prodrome. So, you might talk to your doctor about when she or he actually wants you to take the acute medication. It may be earlier than you think, and you may be able to cut short that 4 to 72 hours of headache pain. I know you can cut that shorter with all sorts of things: medication, neurostimulation, mindfulness, sleep, get into a comfy spot, all of the above. Do all the things. And it lets you know. okay, now is my time, I need to do this. It also let you

tell your family, friends, and coworkers, those who are on board your support system, okay, I feel one starting. Let's all get to our battle stations here. I'm going to do this, honey. You're going to help with kids, best friend. You're going to pick up kids from school. Boom, boom, boom, get your plans in place. So that's really helpful as well. And third, think about a great prevention plan. If you don't have a prevention plan, we have medication prevention. We have behavioral therapy prevention CBT, relaxation therapy, mindfulness. We have neurostimulation prevention. We have nutraceuticals herbs and vitamins. And we have the healthy lifestyle habits that matter. We have a short list of what matters that regular sleep, the staying hydrated, the regular nutrition and managing stress and exercise.

Five things that matter. Because why do they matter? They keep that hypothalamus on a good circadian cycle that makes it happy, nervous system happy. So, if you are having no interictal time, you're always activated, there's a chance that getting more optimized prevention on board may help calm and quiet that nervous system. I fully realize that many people watching this maybe optimized on all of the treatments and may see headaches expert providers and may be doing everything and still have very frequent migraine and still not have interictal kind of rest time for their nervous system. I'm sorry. I know that not everyone has the luxury of quieting your nervous system.

Lindsay Weitzel, PhD:
We always try to send love to that group on this group.

Dawn Buse, PhD:
Yes, yes, we're here for you. We feel you. It's not your fault. Hang in there. Science is growing. More treatments are being developed. Hang in there. Those are my takeaways. Be your own detective. Know yourself. Tell your doctor all of your symptoms. Use it to plan your life and plan your treatment.

Lindsay Weitzel, PhD:
And be kind to yourself if you're not feeling well even though the pain phase isn't there. So anyways, thank you so much.

Dawn Buse, PhD:
It's all real. Migraine is more than a headache. It is all yucky.

Lindsay Weitzel, PhD:
Thank you so much Dr Buse for talking us through all of this. Thank you, everyone for listening. Join us again for our next episode of HeadWise and sending love. Here's wishing all of you some pain free time, and we hope that some of you or all of you got something from this episode.

Dawn Buse, PhD:
Pain free and associated symptom free time.

Lindsay Weitzel, PhD:
Everyone have a great day. Bye-bye.

Dawn Buse, PhD:
Bye