

Episode 188: What is Complex Migraine?

Lindsay Weitzel: Hello everyone, and welcome to Head Wise, the videocast and podcast of the National Headache Foundation.

I'm Doctor Lindsay Weitzel. I'm the founder of Migraine Nation, and I have a history, excuse me, of chronic and daily migraine that began at the age of four. I am excited to be here today with a repeat guest headache medicine specialist, Doctor Fred Cohen.

Hello, Doctor Cohen, how are you today?

Fred Cohen: I thank you for having me back.

Lindsay Weitzel: Doctor Cohen is an assistant professor at the Icahn School of Medicine at Mount Sinai. He always has just awesome things to tell us, and I'm really excited to have him here today. We have a bit of an unusual topic. Our topic is complex migraine. Some people might be thinking, what on earth is that?

I've been wanting to cover this topic for some time now because a number of people are being diagnosed with complex migraine, and believe it or not, it's not even a diagnosis.

Listen. Listed in the PhD three. This means this is not a classification of headache that has been formally recognized by the International Headache Society and also the information online. If you are to Google complex migraine can be a little bit confusing. So, I'm hoping that Doctor Cohen can sort of elucidate for us what this is and why, many people are being diagnosed with this term.

So, Doctor Cohen, for people that have not, been on and watch before, when you have, you have been our guest. Can you just tell us really quickly why you love working in headache medicine so much?

Fred Cohen: Sure. So, my short background is when I was an intern, internal medicine, I so I mean, I suffered migraine my whole life. Just dealt with it. Never knew what it was. In residency. It all got much worse because you know, you're working on hours in a hospital. And it was there. I got referred to a headache medicine specialist.

Never knew it was a thing, you know, and I got treated in my mind growing up way better. And then that's all, like, I knew what I wanted to do, you know? So that's why I. So, I get into this and, you know, a lot of people are thinking like, oh, what's headache? What's migraine? You know, because I just thought my whole life I had, I had it.

That's all I did. But, you know, I had this severe, you know, throbbing pain. I got a once a week and it's. No, it's more than just a headache. There's something we could do about it.

Lindsay Weitzel: Okay. All right. Well, I think it helps, for us to know your motivation for working in the field. So, I always like to ask you that question. so my first question might seem a little bit obvious, for some of the people listening in, but, you know, in case people, haven't heard our, our episodes before or just don't know, I don't want to talk about complex migraine without first defining exactly what a regular migraine is.

So can you just tell us what a regular migraine, not a complex migraine. A regular migraine is really quick.

Fred Cohen: Sure. So, a migraine is, a condition that has a there's a couple of features to it that, you know, it's a headache you're having. You're having pain that's usually moderate to severe. A lot of you think it has to be unilateral one sided. It could be both. A lot of people think it has to be behind your eyes or in front of your head, which is the common presentation.

But it could be on the side in the back of the head. What's important is really the severity. It's moderate to severe and that it lasts at least four hours. You know that kind of pain is what we classify migraine. You know, it's not like oh I get a headache for like, you know, ten minutes. And still, it's usually enough to be interfering with one's life.

You know, most people the common thing we hear is, oh, I have to go to a dark, quiet room. It's typically it's associated with features such as, you know, a light sensitivity, sensitivity, you know, sensitive to smells that can be knowledge. They can be vomiting. And again, it's not it has to be all those things. There are people who have none of those sensitive features.

but again, it's just more than just having this pain. Other areas are affected.

Lindsay Weitzel: Okay. so, let's move on then. Now that we know what a, you know, normal typical migraine is, let's move on to talk about what our topic today is, which is complex migraine, which as I said, is maybe not a true listed diagnosis.

According to most headache specialists. Yet as someone who is in the migraine community and watches and listens to what people are saying, many people are coming home, sometimes even after a hospitalization, and have been diagnosed with something called complex migraine.

And they're posting in support groups and asking, what is this? I don't really understand it. So, let's talk about why this is happening and why people are being categorized as having complex migraine.

Fred Cohen: You know, so complex migraine is term. I hear a lot and I'm very happy you're bringing this up because I think it's important to clarify what that really means, because I see it time and time again. Patients get referred to me. They come from another physician or provider. They said, oh, I've been told I have a complex migraine because you hit it on the head

before, whereas, oh, this, you know, headache side doesn't really have this diagnosis because we don't, we don't use that term.

you know, there are different classifications of migraine we were bringing about, and you were saying what's typical? Not typical. First, I always tell my patients every migraine, every headache is unique. You know, you were humans with pain. We don't always follow the textbook.

and we sort of breaks down migraine into what we call typical aura, and what not would be a typical or typical aura one, you know, most people sort of think of in a stereotypical migraine presentation, the or something being like skin dilating lights, meaning like sort of zigzag flashing around, maybe a blind spot, tunnel vision tingling.

It's in the hands or face, you know, maybe, difficulty understanding or sort of, feeling it hot, hard to speak. And that's what most or symptoms are. And that I want to add only about 30% of people with migraine get. Or that means majority don't have any of these symptoms I'm talking about. Right. But those, is what most or symptoms have.

But then we get into the not typical per se. And this is what most providers not had exposures most other providers were sort of label as complex.

but again, it's sort of this bigger family. And that breaks down to what we call migraine with brain brainstem or that is also hemiplegia. Migraine, retinal migraine is also a migraine with unilateral motor symptoms.

Mums you know, and that sort of encompasses all what is termed complex migraine.

Lindsay Weitzel: So, I find that so interesting that you said that because I think when I opened up this conversation with you and said that I think we should do an episode on this to elucidate some of this confusion and elucidate this topic for people.

people that were talking to me about what their symptoms were when they had been diagnosed with complex migraine, I was wondering, gosh, how do they know that wasn't hemiplegia migraine, for example, because many of the symptoms they were describing were,

I would almost just call it may be a more severe aura than your average aura. And it was all being stuck in this box of complex migraine. So, so what are some of the things like, just I, I would like to just bring up like someone just recently I do know had, some paralysis issues, for example, numbness, and some paralysis on one side of the body. So, is that something that people are throwing in with complex migraine, and what else could it be?

Fred Cohen: So that comes up sounds it could be either hemiplegia, migraine or moms and hemiplegia sort of is when you have in addition to having sensory, you know, numbness, you

have a motor weakness. It could be very scary because it can mimic a stroke. And then you have moms as well. And I always get asked what sensory mums and I have a migraine.

You know how migraine generally occurs in youth. It's not common for it to present when we're older. You know, typically the classical presentation is one. There's a strong genetic component. There are genes we know confirmed to be associated with it. And it typically presents, in someone's teens, whereas moms can present later. And also, in an individual with moms, typically the weakness will last longer, whereas the hemiplegia is just during the or episode.

And one of the key features of moms is there's something called giveaway weakness, where someone who has true hemiplegia, migraine. If I was to say, oh, grab my hand, or if I was to push against their hand, they wouldn't be able to do it. Whereas in mom's giveaway, weakness is when it first there's resistance, then it gives out.

You know, that's sort of a way we differentiate it. And that matters because it goes with treatment in these sort of complex migraine, hemiplegia, brain stem or retinal migraine we typically don't treat with triptans. Whereas in mums triptans are treated with but what you're describing sounds like it could be hemiplegia or months.

Lindsay Weitzel: Okay. So, one of my questions, one of my next questions was going to be if someone is diagnosed with complex migraine is it treated the same as typical migraine? But it almost seems like it could be a number of different types of migraine, and you might not know.

so, I was wondering if you could comment on that.

Fred Cohen: Yeah. So really the big treatments that make it different is, diodes, ergot amine and triptans, which are common rescue medications,

and retinol, migraine and heavy drug migraine is typically not prescribed as concern and might provoke or lead to a kind of stroke brainstem aura. The current consensus is to avoid it. You know, there is a theoretical concern that it could provoke a stroke or cause some kind of vessel dilemma, some kind of, issue with that, because those treatments do cause a constriction when it comes to preventive, the only one would be beta blockers.

You might have heard of people on like for panel all tomorrow Natal all these are first line treatments for migraine. But in those cases, hemiplegia retinal and brainstem. Or they might avoid that class. But other common treatments like topiramate you know try to enter the presence like Ellisville. You have your seizure monoclonal antibodies like Camavinga and Galatea Jovi, the G pens and those are all fine.

And those conditions, you know, so it's only a certain class of the medications that are,

of that are avoided. So, it does make but it does make a bit of a difference, you know. But it doesn't mean it's only a certain amount of the job, you know, fully, you know, root of all our other common drugs.

Lindsay Weitzel: Okay. Do you feel that if this is something that that people are having trouble with or are experiencing or have been diagnosed with, that they should see a headache specialist.

Fred Cohen: Yes. You know, well, first, I will preface that with, you know, if you're someone who is suffering with headaches that are interfering with their lives and speak to your doctor, you know, there's so many people when they come to see me, they're like, oh, I had no idea this was, you know, migraine or other kinds of headaches.

no idea that, there was, you know, doctors like your treatments. So, I always say bring it with your doctor, and then someone who's suffering from a kind of migraine, like these, like. Let me also highlight. We haven't talked much about brain stem or just real quickly brain stem. Or is if you have vertigo tonight is which is ringing in the ears. if you have, dysarthria, dysarthria is that you have problems speech like

there's aphasia, dysarthria which are very easily confused. Aphasia is you have trouble understanding or in your mind you're like, oh, I know what I want to say, but I just can't say it. Whereas the sad thing is you're slurring your speech. One is sort of a motor issue, you know, that's, not and having difficulty understanding and difficulty speaking not on from a motor standpoint is actually typical aura.

There's a famous video I forgot it was very recent, actually, of a reporter in LA where on the air she just started saying random words. but she but she doesn't slow her speech, just says random things and stops talking like she becomes unresponsive, just staring at the camera. I remember they sent it to the hospital. I thought they were.

She was having a stroke and then ended up, it being just migraine with or whereas dysarthria. What I'm talking about is that you're speaking but and again this sort of mimics a stroke. You're slurring your speech. but that's sort of what encompasses brain stem or, but all of these are really sort of concerning things. And that's why it is important.

You know, the answer to go back to your question to see a headache specialist, because a lot of these we need to assess for other neurological conditions. We have to make sure there's not something else after one of the, you know, primary objectives of an evaluation with so many offices, making sure that this is a highly diagnosis and not that there's something else happening that we have to evaluate for.

Lindsay Weitzel: Okay. is there is there any particular reason, any of these types of auras that you want to go deeper into?

that could be dangerous or that, that maybe they people should be getting a different treatment for than what they're getting, because it's sort of been lumped into this complex migraine diagnosis.

Fred Cohen: You know, I don't know if I want to throw the term dangerous. You know, I sort of like, you know, it is important to have instead of just being live with complex migraine. Know what you have. For instance, we do know women with migraine with or all or, you know, it doesn't matter which kind of all or have an inherent small increased risk of stroke.

And therefore, when I meet a patient that I make that diagnosis, I do discuss other I evaluate for other risk factors. Do they smoke tobacco? Are they on estrogen-based birth control? Do they have high blood pressure. Because I don't want to, you know, scare those listen like I migraines or I'm going to have a stroke. You know the risk.

It's there. But it's small. But we make sure there's no other risk factors that further increase that risk. So, and that's why it is important to have an and I don't want to say actual diagnosis but a more concrete diagnosis than complex migraines. So that risk stratification, could go into, you know, that the US as providers could do that.

So that's why I think it is to have that kind of at least a visit with a specialist such as myself.

Lindsay Weitzel: Okay. so, if some people get symptoms with their complex migraine attacks, that might be more likely to be categorized as psychogenic. so, can you maybe comment on that?

Fred Cohen: Sure. You know, so just to give, I guess, context, the term psychogenic is essentially the symptom because people think when they hear that, oh, it's in my mind, you know, what is the brain meaning? Pain is all in your mind. Technically, no. Pain is not an organic thing. It's your brain thinking that there's a signal there, you know,

so psychogenic essentially when that term is used is let's say I'm having, you know, tons and pain in my hands give an example and I get tested, you know, I get nerve testing all this.

It all comes back clean, normal. Oh, well, it's psychogenic, meaning the brain is interpreting that there's some there's a stimulus there, but there's in my hand isn't actually in danger. So, you know, we go back to sort of with migraine and that what is migraine is sort of this you know, inflammatory cycle going on that all these various nerve circuits, if you will, are going off.

It's heavily affecting your autonomic symptom. So that's why other symptoms could happen. I'll give myself as an example when I was an intern in residency, I was with my attending and all of a sudden of my attending, such shining as penlight in my eye and he looks at me, goes, your left pupil is blown. It's dilated. Look in the mirror.

And yep, it is big, like visibly big. And it's never been like that. And that's a scary symptom. I got sent to the emergency room. You know, they did a whole work up there. Like everything else was fine. I saw my headache doctor, and she was like, there's nothing really accounted for this. They got me an MRI because that has to be worked up all normal and it went away.

Why did that? Why did I have that? You know, and it was just ruled to me. You know what? It was likely your migraine that when the migraine cascade, when that attack happened, that's something either in the autonomic, system or what have you went off and caused that, you know, so that's why I don't per se like it when patients get labeled as, oh, that's like, oh, interesting.

You had a psychogenic, like it's likely from what's happening in this migraine cycle. However, it must be worked up. Right? I get a lot of various other symptoms. I come to my office like a, like I was saying earlier, while we have what we call typical, not typical, every headache is unique. I've seen pretty interesting things, and for the most part they're accounted for by aura.

But some of them from maybe different kinds of bloodwork, imaging, we make sure that's the case, that it's from this migraine cascade and not from another process going on. So, when you hear that term psychogenic, you know, I don't like it being like, oh, it's just in my head. Well yeah. All your brain is there. So technically it is in your head, but it's just your brain is interpreting one of these inflammatory signals as a symptom and thinking that there's actually a real, if you will, stimulus.

And, you know, your brains like computers misinterpret it. Think of it like that.

Lindsay Weitzel: Right. I'm glad that you said that, because there's so much stigma that goes along with my life again with. And then if you're given a diagnosis that that that's different and that you can't really find online, and then to add it all together, sometimes the doctor will be like the one of your symptoms was psychogenic. Going home with all that can be a lot to deal with.

And I'm and I am seeing it happening a lot surrounding this term complex migraine. So, I hope that that put people's minds at ease.

I hope that this episode put some people's minds at ease. is there anything else you'd like to add to this topic before we go today?

Fred Cohen: Yeah. Just that, you know, I have a lot of patients sort of want to see an answer, if you will. Why am I having some of this? Why this happening? And we have some answers to why migraines happening. We don't have the full picture. I always joke, and maybe this will be dated in 5 or 10 years to whoever figures us out, but if you figure out entirely what's happening in a migraine, you know you win the Nobel Prize in medicine.

We know, we know part's the piece of the puzzle, but we don't have all the parts. And I talk patients like they might I might not be able to give you full, exact answer. Meaning, I can tell you what in your, you know, brain circuits essentially is leading to the you feel the system, but what, you know, sparked it.

You know, I don't want you to sort of stress finding the answers, but just, you know, there's something that accounts for it because that's a question we all have. Why am I in pain? Why is this happening? You know that again, migraine is in essence, an inflammatory condition.

and we for treatment, find ways to reduce that inflammation.

and that I some patients it stresses them out a lot. And I understand that, you know, again I'm someone who gets migraine myself. But, you know, know that we might not always get full exact answers.

Lindsay Weitzel:

Yes. I always like to tell people that, medicine is often approached like we already know everything. And, and in this field I'm sorry, we just don't. So never just assume you know that you're.

Fred Cohen:

Doing doctors only know 50% of medicine. And that's so very true.

Lindsay Weitzel:

Right? Right. So never assume that all the answers are there. just assume that you're getting the best that you can. and we have so many new medicines, etc. So,

so anyways, thank you so much for your time and I hope everyone enjoyed this episode and learned something. And everyone, please join us again on our next episode of Head Wise.

Have a wonderful day. Bye.