MIGRAINE WORLD SUMMIT

TRANSCRIPT

INTERVIEWS WITH WORLD-LEADING EXPERTS

CONTROLLING CHRONIC MIGRAINE

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Introduction (00:05): I think the first and foremost thing in a patient with chronic migraine is giving them a diagnosis. I think that seems so silly, right? Like, what? Just naming the disease. But as I had mentioned before, they spend a lot of time hiding some of the symptoms. So giving a name to the disease is extremely important. And explaining to them what that means. You have chronic migraine, that means you're spending most of the month having not only headaches but other symptoms. And sometimes, when you tie that together, they'll start to tell you, "Oh my gosh, I spend so much time having this symptom or that symptom. And a lot of times some mild, low-grade headache with it, and I never thought that was migraine."

Elizabeth DeStefano (00:45): We've heard the plea from the Migraine World Summit community to include a focus on the most extreme cases of migraine: those whose lives are impacted constantly and severely by chronic migraine. When quality of life suffers dramatically because of migraine, it can be particularly hard to see the best way forward. Many of you, our viewers, have expressed your desperation about living this way and the need for guidance and hope. We're grateful to have Dr. Jessica Ailani here to discuss some of the most challenging aspects of living with and managing chronic migraine. Dr. Ailani, welcome back to the Migraine World Summit.

Dr. Ailani (01:25): It's my pleasure. Thank you so much for having me back.

Elizabeth DeStefano (01:30): To start, what is the definition of chronic migraine? How is it diagnosed, and how does it differ from episodic migraine?

Dr. Ailani (01:37): Yeah, so I think this is a really great place to start. Chronic migraine is when you're having headaches more than 15 days a month, and out of those headaches, at least eight of them are migraine in nature. Now, when a person has chronic migraine, they tend not to focus on the most common type of headache they will have, which is this low-grade, dull type of pain that they're having most of the days. And instead, when they come to speak to someone like myself in the office, they focus in on that more severe pain — the migraine-like in nature because that's the one they think is the most challenging for them to treat. And so chronic migraine can be difficult to diagnose if a person isn't telling their healthcare provider about *all* of the headaches they're having. But when we're asking the questions, we're trying to figure out: What are all the days you're having headaches? What are the days you're completely symptom-free? Because that's really important when we're looking to make that diagnosis of chronic migraine.

Dr. Ailani (02:39): What makes the diagnosis of chronic migraine different than episodic migraine? Well, those with episodic migraine are completely symptom-free between migraine attacks. They don't have mild-grade headaches in between their migraine. They don't have anxiety about the next migraine attack. They don't have constant light sensitivity in between attacks. They don't have constant neck and low-grade head pain. There's a lot of differences between these two patient categories. So with episodic migraine, you have your attack; it can last a couple of hours to a few days, and it goes away. And the average patient with episodic migraine has two to four attacks per month, whereas the chronic migraine patient's already having more than half the month with some form of headache day to day.

Elizabeth DeStefano (03:31): Why is it so important to get the diagnosis right in chronic migraine?

Dr. Ailani (03:38): I think the reason making the diagnosis of chronic migraine is so important really goes for several things. One is treatment options can be a little bit different. For chronic migraine, we know that our newer treatment options that focus on CGRP [calcitonin gene-related peptide] are effective. We know that onabotulinumtoxinA is effective. Some of our older treatments may or may not be effective. So this might be why patients with chronic migraine have gone several, several, several years trying treatments and feeling they don't work because they really weren't studied in that patient population. The other reason making the diagnosis is important is this patient population is extremely burdened and disabled by this disease. And because they tend to underrepresent their headache burden because they're embarrassed or they feel like, "If I actually tell somebody I have a headache almost all the time, nobody's going to believe me."

Dr. Ailani (04:38): I mean, they're carrying this tremendous burden. And we have data that shows that this patient group tends to have a higher burden overall. They have a harder time holding down a job. They have a harder time at home with relationships in their families. They have a harder time in their marriage. They have a harder time raising children. They have a harder time keeping friendships because it's very difficult for them to be reliable because they're constantly struggling with pain and associated symptoms. They have higher rates of anxiety and depression. They have higher rates of other comorbid conditions. And just imagine not feeling like you can talk to anyone about this. So when we make that diagnosis, sometimes it just opens up the ability for this person to be able to talk to someone about this issue that they've been dealing with probably for many years and not really coming to terms with it.

Dr. Ailani (05:34): And it might be the first step in acknowledging that they have a lifelong disease that really has been taking over their entire life and kind of making the steps to come to a solution with how are we going to work together to not only take care of migraine, but all the other aspects in their life that have kind of fallen apart because of this disease. How are we going to talk about comanagement of anxiety and depression? How are we going to talk about being more reliable at setting up a goal? How are we going to talk about being able to exercise a little bit when you're constantly in pain? How are we going to set up some goals? So, I think the diagnosis is not only important for the right treatment options, but really to allow that individual with this disease to identify it as a disease and start to have these discussions that are very important.

Elizabeth DeStefano (06:27): How do you differentiate chronic migraine from other types of migraine or headache disorders that have high frequency and severe impact on quality of life? For instance, refractory migraine, status migrainosus, or new daily persistent headache (NDPH)?

Dr. Ailani (06:42): So chronic migraine actually comes under one of four daily headache types: There's chronic migraine, chronic tension-type headache, new daily persistent headache, and something called hemicrania continua. So, when we take a history, we're listening to what type of headache a person is having, what are the features associated with the headache, and we're trying to differentiate between these different types. Somebody with chronic migraine usually tells you a history going back into earlier years, either childhood or in their 20s, when they used to have episodes of migraine that would resolve. There were clear periods of time they weren't having any pain or any headache. And then, over time, gradually, they started to have increase in frequency of headache. Someone who has new daily persistent headache can usually name the day the headache started and within three days that headache became daily and continuous from onset. People with new daily persistent headache can actually have headache that looks

very much like migraine and chronic migraine in nature. So that history is extremely important to differentiate the two.

Dr. Ailani (07:47): Someone with chronic tension-type headache never really has any migrainous features in their headache and will often feel like activity, and physical movement and distraction makes them feel much better, which you won't see with migraine. And then hemicrania continua is actually probably the hardest to diagnose because they have features of migraine, but they also have autonomic features with their headache, and their headache is always, always, always on the same side. It's never on the other side, and it's uniquely responsive to a treatment called indomethacin. So sometimes, if we're a little suspicious and we're not sure if it's chronic migraine or hemicrania, we might give the patient a test of indomethacin to see if they respond. And that's a way we're trying to make that differential between the two diagnoses.

Dr. Ailani (08:37): Status [migrainosus] is a very unique situation where someone who has episodes of migraine ends up in a migraine that doesn't get better within three days and just keeps going. In that case, we're giving them a lot of treatments to break a cycle of migraine. And in rare cases, a person with chronic migraine started their chronic migraine journey with status migrainosus. This isn't very common, but it can happen.

Elizabeth DeStefano (09:05): Which of these or other diagnoses are the most common misdiagnoses for someone with symptoms of chronic migraine?

Dr. Ailani (09:14): So one thing that is very important to pick out is hemicrania continua. As I mentioned, it's actually very hard to diagnose because it can look a lot like chronic migraine. But it's uniquely treated by indomethacin, and if you're not given a trial of indomethacin, it can be completely missed. And you can go around thinking you have chronic migraine, and this would be a sad thing to miss because that can really change your life if it's hemicrania continua. It's a pretty simple treatment. I think the others are pretty easy to distinguish from chronic migraine, again, based on the history, so they're easier to piece through. And the other things to consider are secondary headache types. So sometimes in clinical practice, if we have a patient with chronic migraine who's been diagnosed [with] chronic migraine and they haven't been responding to typical treatments, the general recommendation is to stop and retake the history from the start. And to consider, is it possible this person might have what we call a secondary headache, not a primary headache?

Elizabeth DeStefano (10:23): That's very good to know. How and why does migraine become chronic?

Dr. Ailani (10:31): Yeah. So, we know of several risk factors for people who go from episodic migraine to chronic migraine. Some of these things, there's not much you can do about. Examples are: If you're a 40-year-old woman, we're kind of all in that bucket of becoming at risk for chronic migraine, and we think this might have something to do with hormonal changes that occur in your 40s. Other things, if you're of European heritage, this puts you more likely to becoming someone who has chronic migraine over time. But there are other things, there are other risk factors that we could do something about over time. For example, if you have higher-frequency episodic migraine — your frequency of migraines approaching six, seven, eight days a month — we think that starts to put you at higher risk of what we call transforming to chronic migraine over time. So that's usually a time the idea of being on a preventive treatment to reduce the frequency of migraine is a good idea. And that's because when you're at six, seven,

eight days a month, we get you started on something to reduce the frequency, we reduce your risk of getting to chronic migraine.

Dr. Ailani (11:40): Other risk factors can include things like obesity, so not being at your ideal body weight, we think, can be a risk factor. And there's a lot of research being done as to why that might be. Is that because of the chemicals that are released? Is it because there's more CGRP in fat cells? Is that because estrogen levels are higher when we're overweight? And so really trying to — and I think this is actually a very hard thing for me to say because trying to exercise and keep your body weight under control when you're not doing well — I think is probably one of the hardest things to do for our patient population. We think the other things that — one I think, big risk factor that can cause risk to become chronic migraine — is when you're having migraine attacks and they're not well treated. So it's important when you're at a point where you have infrequent attacks, when you get an attack, you treat it and you treat it aggressively so that the brain doesn't get used to having these attacks often. Because what we've seen is that more often you have these attacks, the more often they happen.

Elizabeth DeStefano (12:45): A number of our viewers have expressed their frustration over being told that using medications too often is the reason for their chronic migraine and the blame aspect that feels inherent in that. In fact, one of our viewers, Jill, expressed her wish that medication overuse headache (MOH) instead be referred to as "poorly controlled migraine." An expert talk last year on the Migraine World Summit had quite a reaction from our community in its challenge to the role of triptans in medication overuse headache. Can you offer your insights on this?

Dr. Ailani (13:22): So I didn't actually watch that particular discussion last year, but I do know that it is very tough – the idea of medication overuse headache and the idea of blaming the patient. And for many reasons: One, when you live with chronic pain and then you're told not to take a treatment when you're having headache every day. It's one of the things I hate most in clinical practice. It's hard. It's hard to tell someone, "You have to be a bit careful here. I'm giving you a few other options." Especially if those other options end up not working as well as their triptan. But unfortunately, the data that we have shows that some of the medications we have to treat migraine just turn some of these signals on in the wrong way. And I wish triptans weren't as effective as they are. We have many patients who they are the only treatment that works well.

Dr. Ailani (14:14): And so, we do have a trial that's been published over the last year and a half called the MOTS trial, the Medication Overuse Treatment [Strategy] trial, that shows that really, if a person is able to get on a good preventive treatment, you can kind of do it the way I just mentioned. Where the focus really is on starting a good prevention that the patient tolerates and not focus so much on stopping the overused treatment. The data from that shows that whether we stop the overuse with education and stop the overused triptan or other overused NSAID [nonsteroidal anti-inflammatory drug] or we just let them continue to overuse and let the preventive start working, the results were about the same.

Dr. Ailani (14:59): And so, I think the idea of blaming the patient, "It's all your fault, you're doing this," really needs to be reframed to, "You know, your disease is pretty terrible. Let's try to find a good preventive treatment. Let's focus in on that. Let's try to rely less on the acute treatments, which are continuing to cause changes in the brain that allow this disease to continue to flourish. In the meantime, let's work on other treatment options that might help with the pain,

like neuromodulation, which isn't going to cause medication overuse headache. Let's see if a gepant would work well for you, which won't cause medication overuse headache."

Elizabeth DeStefano (15:39): I think your idea of reframing is so important. Even that when we're using the word "overuse," it's not condemning one of us for using medication when we don't need it. We certainly do. It's really in relation to what the data show about the risk for worsening the condition over time.

Dr. Ailani (16:01): My biggest trouble always with overuse is there's probably the … damage we're doing to cause more headache — but actually I'm always concerned about it. I'm laughing, but not really laughing. NSAIDs: I absolutely adore NSAIDs for headache. I have to say all my patients know this, but NSAID overuse — over-the-counter NSAID overuse — is probably the biggest issue we have in migraine. Our data shows us that patients naturally preferentially prefer NSAIDs. They're very easy to access. Most will use them as first-line treatment. They often don't even tell if they're seeing a headache specialist that they're using NSAIDs because, "It's over the counter. It's no big deal." But we have such a high rate of peptic ulcer disease (PUD) in young women because of the damage it creates. And then once they're off the table because of something like that, they're off the table for pretty much ever. And we're starting to see over time more and more that NSAIDs are linked to high blood pressure, they're linked to heart disease, they're linked to GI [gastrointestinal] and renal failure.

Dr. Ailani (17:04): And for someone like me who absolutely adores NSAIDs, it's really hard when I'm like, "Man, even myself, I have to be careful about how often I'm giving them to patients." And I'm watching carefully for blood pressure changes that if we are using it frequently in a particular patient during a difficult time period that we're like, "OK, let's just recheck your labs. Have they been done recently?" Because it doesn't take very long before changes happen to the kidney and liver on those treatments. So when I think of overuse and when I'm talking to people about it, part of it is that overuse and the damage it's causing on the body; forget headache, but all the rest. And a lot of times, that's what I'm focusing on. So there's always the reset of, "Do we need to pause and think about changing your management, changing your treatments? Are you feeling OK?" And you'll always hear from people when you are able to take something away. They're like, "Wow, I feel so much better. I didn't realize that this was causing me some kind of side effect." And you're like, "Well, neither did I." You get used to how somebody does on treatment for a long period of time. And I think these are the other complications of having chronic migraine that we often don't talk about.

Elizabeth DeStefano (18:14): I'd like to ask you, first of all, what your primary goals of treatment are for chronic migraine. And to our previous point, how [do] short- and long-term management plans help achieve those primary goals?

Dr. Ailani (18:29): So my primary goal when treating chronic migraine is to really understand what the patient is looking to achieve. I know that sounds very backwards in this answer, but it's really true. Every person is looking for something different. I always hope that at some point the patient and I are on the same page about how I can't cure this at this point. And so, once we kind of set this idea of a goal, we talk about preventive treatment and acute treatment with the idea of the steps we're going to take to try to make those goals. Sometimes I feel like a patient might set the goal too low, and I let them sit there for a little while, and then we kind of work through that. And I think that a lot of that comes from management they've had in the past. If they've been on treatments that haven't worked, they've been through difficult treatments with prior healthcare providers or people who haven't really listened to them before.

Dr. Ailani (19:24): Examples have been people who think that it's normal to have a migraine that lasts five days. And with each visit, we might start to talk about, "Well, let's try this," and the next visit, "Let's see if the migraine only lasts one day." And it's always amazing when they're like, "Wow, that's a thing?" And it's actually a bit heartbreaking for me, like, "That should have always been the thing. This should not be a goal that I set for you. This should have always been the goal." But it just shows you everybody's coming from a different place in their treatment plan and their treatment background.

Dr. Ailani (20:03): So that's an example of an immediate acute goal versus a preventive goal, which would be like if you're daily continuous, our first goal would be having moments in the day when you're feeling more functional and the migraine is in the background. Or if you're half the month, then your first goal might be treatment with prevention, will get us down to maybe a handful of days in the month. And then, over time, as you stick on treatment, the days will get less and less. Your functionality gets more and more. Your tolerability to treatment is always of utmost importance. So that's kind of how we talk about goals: setting up treatment with our long-term preventive goals and short-term acute goals.

Elizabeth DeStefano (20:48): In your experience, what is the likelihood of transitioning from chronic to lower-frequency migraine?

Dr. Ailani (20:58): So the data shows us about 30 to 40% of patients, especially with some of our newer treatment options, are able to transition down to episodic migraine. I will say in our clinical practice, especially with these new treatment options that have come out, I think we're probably a little bit more than that number. It's been pretty amazing since we first saw some of these CGRP treatments come out, that not everybody responds to them, but it really allows us to move through treatment options a lot faster. So if people don't respond to those treatments, we're very quickly able to find other treatment options that perhaps work for them.

Elizabeth DeStefano (21:37): Starting more fundamentally, how do you go about tackling chronic migraine for your patients? What strategies have you found work best?

Dr. Ailani (21:48): So, I think the first and foremost thing in a patient with chronic migraine is giving them a diagnosis. I think that seems so silly, right? Like, what? Just naming the disease. But as I had mentioned before, they spend a lot of time hiding some of the symptoms. So, giving a name to the disease is extremely important. And explaining to them what that means. You have chronic migraine, that means you're spending most of the month having not only headaches but other symptoms. And sometimes, when you tie that together, they'll start to tell you, "Oh my gosh, I spend so much time having this symptom or that symptom and a lot of times some mild, low-grade headache with it, and I never thought that was migraine. And now that you say that, yeah, actually, I kind of don't feel great most of the time, and nobody's ever made sense of it before."

Dr. Ailani (22:35): And they start to, you can see them start to loop this all together as you're talking to them. And I think that starts to give them that process of healing. Retrying certain treatments might be important, especially if it's one of our gold standard, best-of-line, level A, best evidence. You don't want to just throw that treatment out. You might want to consider coming back to it, especially if this patient has had difficult-to-treat migraine in the past, because that treatment might be the one and it just wasn't given enough time. You want to track symptoms and headaches for the first few months, at least when they're under your care, just to really get a better sense of what's going on. And that's important because, again, you're

looking at burden of disease, and if you're trying as a goal to reduce burden of disease, you need to understand the full burden.

Dr. Ailani (23:23): So, keeping track of that and having that as a sense of what's going on is important. We're going to talk about lifestyle changes, healthy diets. Just: Are you eating three meals a day of some sort? Are you hydrating? Are you drinking too much caffeine? For someone with chronic migraine, exercising might be difficult, but I talk to my patients a lot about any kind of exercise on a daily basis. While moderate-grade cardiovascular exercise like brisk walking or doing yoga or Pilates is recommended for improvement in migraine, I tell my patients, "Listen, if it's a bad day, if you can just stretch your shoulders, stretch your neck, do a little bit of gentle stretching on the ground that day, I'll take it. I'll take anything just to get your body moving. Because when you're in bed the whole day, it's not so great for your body, and any amount of stretching is good for the brain. Even better if you can do your stretching outside, surrounded by green. Meditation, mindful breathing, guided meditation."

Dr. Ailani (24:31): We talk about what kind of behavioral therapy and techniques are going to be acceptable to the patient. We pick one, we discuss if that was something they could layer in. The more refractory a patient with chronic migraine has been, the more behavioral therapies we're going to layer in, but only one at a time. Even the nonpain psychologists are full. So we've been really relying heavily on a lot of apps that we've been advising to patients for some of this therapy. But these do cost money. They're not something that's available through insurance. So, a lot of it is, "Well, if this is out of affordability, let's talk about relaxation breathing, which is free. Let's talk about guided meditation apps that are free. Let's talk about which one of these you can do, and how are you going to maintain this practice every night."

Dr. Ailani (25:18): We also talk about neuromodulation because, again, if these patients are having pain every day, they need maybe a pill and a nonpill to treat their attacks. This is a plan that takes time, that's going to require a lot of tweaking. Perhaps we tried relaxation breathing, and that was a fail. We're going to have to try something different. Perhaps we tried one preventive treatment, and that was a fail. We're going to have to try something different. So it's a lot of trial and error over time, and it's a very long process. And this I think is probably one of the most difficult things for our patients to hear because, by the time they see us, they're often at the end of their rope and at the end of the line. But I feel that that conversation is important to have, especially that first visit, and knowing that we have so many options and sometimes we don't want to throw everything at once because it can overwhelm a person — [and] sometimes can be helpful for them to hear about as well.

Elizabeth DeStefano (26:19): How do you approach care for those for whom migraine dominates their life, and treatment has not yet been effective or has not remained effective?

Dr. Ailani (26:30): Sometimes you're looking at what has the patient responded to, even for a short period of time in the past; what kind of side effects they might've had; and then restarting some of those very slowly and then layering them together. It's important, though, when this is being done, a couple of things are being watched very carefully — side effects. When you're combining treatments together, you might have amplified side effects. So that thoughtful approach, but very carefully done. It can take a long time, but that's part of how we might approach the patient. Another approach in these patients are inpatient headache admissions, and very few centers that do this in the country. You've got Jefferson Headache Center, Diamond Headache [Clinic] inpatient admission center, and then you've got Michigan Head and Neck, which does this at Ann Arbor. So these are just three that I know of in the country that do

long-term inpatient admissions, so that's another option for patients. In these patients, that behavioral therapy I mentioned is a huge thing. Neuromodulation is usually a part of their treatment plan. We might be adding things that are physical, like physical therapy for massage, acupuncture, dry needling, trigger point injections.

Elizabeth DeStefano (27:45): Are there any treatments or research on the horizon that offer hope for people living with chronic migraine, and how is that different than what exists currently?

Dr. Ailani (27:58): There are definitely molecules that are being looked at ... that are studies ongoing. There's PACAP [pituitary adenylate cyclase-activating polypeptide], which is — we think of — the other half of CGRP. So, there's always this thought that there were going to be those who respond to CGRP and then those who don't. And those who don't, the hope was they would respond to this other molecule. Patients always coming and asking us about ketamine and psilocybin because there are small studies that are ongoing looking at these types of treatment, as well as CBD [cannabidiol] and THC [tetrahydrocannabinol], which there's a small ongoing study I think that has been completed at two different centers. What I'm most hopeful of is there is a treatment that's being looked at that works similar to psilocybin without the hallucinogenic effects, and they've been working for some time on developing this molecule.

Elizabeth DeStefano (28:50): Are there any final thoughts on living with or treating chronic migraine that you'd like to share with the audience?

Dr. Ailani (28:58): I think living with any chronic disease can be a difficult thing. And one thing — a couple of things — that can really help in those instances is having the right care team behind you. So, finding a healthcare provider that listens. I think that's the one thing I've gained the most from my patients is they tell me they know that they have found the right team because the team listens to them. I kind of hear that over and over again. And that being able to try options that work for you, but that might mean retrying old options that you have tried before but not quite the right way. And then having a team at home that cheers you on, I think, is an extremely important thing.

Elizabeth DeStefano (29:43): I agree with your comments about how important it is to have a good supportive care team at home, and the reality is not everyone with chronic migraine has that. We will link below this interview in the show notes to some great resources about how to find support if you don't have it at home or how to help educate those at home or in your lives about living with a condition like migraine. Dr. Ailani, thank you so much for speaking with us about this incredibly important topic of chronic migraine. We appreciate you being here.

Dr. Ailani (30:23): It's been my pleasure. Thank you so much.