MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD-LEADING EXPERTS

TRANSCRIPT

IMPROVING CONTINUOUS HEADACHE DISORDERS

TESHAMAE MONTEITH, MD
ASSOCIATE PROFESSOR OF CLINICAL NEUROLOGY
UNIVERSITY OF MIAMI, MILLER SCHOOL OF MEDICINE

Introduction (00:05): There are many things we can do to adjust their treatment regimen where maybe they were on inadequate doses, or inadequate durations of treatments that would have otherwise been therapeutic. So, I think, yes, there's a lot of hope. And then of course, we have newer agents. We're just in a [totally] different conversation from when I was first on the Migraine [World] Summit, to now. We have so many new agents and new therapeutics so, you know, every year there's something new. And so, there's a lot, *a lot*, to have hope about.

Kellie Pokrifka (00:42): Imagine one morning you wake up, and then every second, every minute, every month, every year after, you're in excruciating pain. You try every treatment; you go to every specialist — and still it feels like there are no answers. Hope seems almost impossible. Well, first of all, you're not alone. And second of all, there are treatments and there are answers. And to help us discuss all of these options is Dr. Teshamae Monteith. Dr. Monteith, welcome back to the Migraine World Summit.

Dr. Monteith (01:15): Thank you so much for having me. It's a really important topic. I'm really glad that you want to shed some light on it.

Kellie Pokrifka (01:23): OK, so first of all: Is this a common problem? Because before I joined the migraine community, I thought I was the only person in the world who could possibly have an ongoing migraine attack that lasted eight years — at this point. I thought I was completely alone.

Dr. Monteith (01:40): Yeah, actually, it's a really common thing. Migraine, as we know, is a common neurologic disorder — the most prevalent neurologic disorder, or at least in terms of disability — in women 50 years or less. In headache centers, continuous migraine is a regular thing, a regular visit. We see it all the time in our specialized care centers.

Kellie Pokrifka (02:08): OK, and let's go over these terms to make sure that we're all saying the right things. We've heard continuous, refractory, intractable, status migrainosus: Which one should we be using?

Dr. Monteith (02:20): Yeah. And I think that's a really great question. I think [we] in the medical field need to, you know, spend more time sorting out these terms so we're all on the same page. But when we talk about intractable, generally speaking, we're referring to status migrainosus: A migraine attack that is going beyond three days. And so, in the setting of acute treatments, usual treatments, or sometimes even emergency room visits, that that migraine attack is not going away. So it's intractable to therapeutics; so that's generally what intractable means. When we talk about refractory, we're now talking about continuous migraine that is persisting despite preventive therapies — multiple classes of preventive therapies. So refractory — in terms of the European Headache Federation came out with some consensus guidelines, and they basically said, you have to have tried every prophylactic therapy, class of prophylactic therapy, to be considered refractory.

Dr. Monteith (03:23): That could mean that you didn't tolerate it. So, it could have been that you tolerated, for example, a drug called topiramate — an anticonvulsant treatment — but you had cognitive side effects, so you had to discontinue it. So unfortunately, some of our treatments do have side effects. We do have to keep that in consideration, and that is tied into the diagnosis of refractory migraine. So, for refractory: six months, you know, six months you've tried — and most people, as you mentioned, could go on for years, right? So not just six months, but a minimum of six months. And then for resistant: is for at least three months, and you've

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tried at least three different therapeutics in three drug classes. And so, different than refractory is the resistant, or difficult-to-treat, migraine.

Kellie Pokrifka (04:19): And if we've gone over this six months, do we have any hope of ever getting back to being pain-free?

Dr. Monteith (04:25): Absolutely. Absolutely. Now the interesting thing — just from a science perspective — is we talk about this continuous pain, but migraine is something that even if you don't have an active migraine attack, migraine is always going on in the background. So, there are what we call interictal symptoms: where patients may experience very low-level symptoms, maybe not pain, but there's some photophobia or light sensitivity — but what we care about is the disability and the continuous pain. So absolutely. And I think that when we look at patients that are so-called refractory, or so-called intractable, or continuous, and we look at their med list and their past treatments, there are many things we can do to adjust their treatment regimen where maybe they were on inadequate doses, or inadequate durations of treatments that would've otherwise been therapeutic. So, I think yes, there's a lot of hope.

Dr. Monteith (05:28): And then of course, we have newer agents. We're just in a [totally] different conversation from when I was first on the Migraine [World] Summit, to now. We have so many new agents and new therapeutics so, you know, every year there's something new. And so, there's a lot, *a lot*, to have hope about. And I've had patients that have had continuous migraine for decades, and we put them on some newer treatments, and in some really outstanding cases, they have maybe one or two migraines and they're back to using acetaminophen (or Tylenol) every once in a while. And they don't need to see me anymore.

Kellie Pokrifka (06:09): That sounds so incredible! I can't imagine that moment where you have your first symptom-free moment, and you finally get a part of your life back that you've sacrificed to migraine for so long.

Dr. Monteith (06:22): Yeah. It's incredible to see. We need to see success stories, too, and we do see them. But it's really lovely to see that patient that's intractable or refractory, so-called refractory, really get their life back, you know?

Kellie Pokrifka (06:37): So, I know a lot of us, once we've been dealing with migraine for so long, and we're not getting any relief from any of the drugs, any of the treatments, we wonder: Do we have the right diagnosis? How do we go about making sure that we do have the right diagnosis?

Dr. Monteith (06:53): Yeah, it's really important to think that. And there are some signs, historical signs, that might suggest that a patient doesn't have migraine. They may look like they have migraine, or they may have migraine, "plus." You don't have to just have one headache disorder; you may have multiple headache disorders. You know, asking the doctor's the first thing: "We've been going at this for some years now, and I'm not getting better with the basic standard treatments. Could this be something else? And could I get a referral to a headache specialist?" You know, I think that if you're intractable, if you're refractory, I think that's a time that you may want to schedule an appointment with a headache specialist.

Kellie Pokrifka (07:38): Definitely. And in your clinic, if you find people that are long-term patients and they do look for different diagnoses, are there any common ones that you see come up again and again?

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Dr. Monteith (07:51): Yeah. Well, you know, looking at this: the definition of what we call refractory migraine according to the consensus. They definitely put a list of differentials, or different types of headache diagnoses, that you should consider before you label someone as refractory. And some of that can include patients that have headache related to changes in pressure. And so, the pressure-related headache disorders are just one type. There are patients that have — for example, there's a condition called cluster headache, which is a trigeminal autonomic cephalgia. It's just, generally, a seasonal headache they get at certain times of the year. But there are patients that have chronic cluster headache, and so they're having cluster attacks on a daily basis. And they could have interictal pain that looks similar to a continuous headache. And this class of trigeminal autonomic cephalgias, that cluster headache, is one of them.

Dr. Monteith (08:53): There are other ones. There's one called hemicrania continua, which is a continuous pain on one side, associated with what we call cranial autonomic symptoms. So, these are people that have not just a continuous headache, but they may have watery eyes, red eyes, nasal congestion, drooping of the eyes, so — all on the same side as the pain — and this continuous headache that is exquisitely responsive to a drug called indomethacin. And it's defined by its response to indomethacin. It's a rare disorder, but it's something that you need to think about when a patient has a one-sided headache, to make sure that they're not indomethacin-responsive and they do not have this condition called hemicrania continua.

Dr. Monteith (09:37): There are other types of headache disorders that are not migraine, like one condition called new daily persistent headache. That's a headache that starts within 24 hours, and it becomes a continuous headache thereafter; and it's intractable pain. It can look just like migraine, it can look like tension-type headache, but it's a continuous pain. We know that it's there, because the patient can tell you what they were doing when that happened. They actually remember the day — the day it happened, year, they remember everything. It can sometimes be associated with a number of factors like a viral prodrome. And so new daily persistent headache is important to diagnose. The treatment may overlap with primary headache disorders like migraine or tension-type headache, but it's a different condition.

Dr. Monteith (10:29): And then when a patient's presenting with this headache that becomes continuous within 24 hours, again, you want to think about: "Well, could this be a low-pressure headache that is commonly caused by a CSF [cerebrospinal fluid] leak?" So, it's really important to look for that, because that can be — even though these things can be rare — they're not uncommon in headache clinics and not uncommon amongst people that have refractory headache. And the funny thing about that is that you may have had that postural headache to begin with, but over time those features can be lost. And so, you can look just like a person with migraine, but you're running around with a CSF leak, which could be a slow leak, and so you have these symptoms. And it's important to get that diagnosis because the treatment is not migraine treatments, it's patching that tear.

Kellie Pokrifka (11:23): I had no idea that with CSF leaks, the postural component could be lost over time.

Dr. Monteith (11:29): Absolutely. Absolutely. Yeah.

Kellie Pokrifka (11:32): So how would you even tell if you do have a CSF leak?

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Dr. Monteith (11:35): Yeah, it's hard. You try and — hopefully you have a time machine, so you have to kind of go ...

Kellie Pokrifka (11:42): OK. Perfect. Done!

Dr. Monteith (11:42): Go in your time machine, and you go back to the time where that started. And you could ask: "Well, did you have at first — did you notice?" Some patients may notice; some patients may not. And then there's certain risk factors: patients that had a history of back surgery, a woman that [was] pregnant that had an epidural. So they had like, kind of, an intervention that caused a tear in their dura — and it may be a small tear — and that tear could over time unseal itself. And then there are patients that have had heavy lifting and that heavy lifting can produce pressure on the dura. There are patients that, let's say, they've had pneumonia; they're doing a lot of coughing.

Kellie Pokrifka (12:27): So, before you lose those features with the CSF leak, if you're lying down in bed, are you good to go, symptom free?

Dr. Monteith (12:34): It's defined as a postural headache. So, the headache is worse, generally within 15 minutes of getting up. Lying down makes it better. And that also is the case for migraine. There's movement sensitivity, so that can be complicated, but not every patient is completely symptom free with lying flat.

Kellie Pokrifka (12:51): Interesting. And CSF leaks: Is that the same as the pressure headaches you were talking about previously?

Dr. Monteith (12:57): Yeah, well, there's the low-pressure, so that would be the low-pressure headache. But there's also a high-pressure headache, right? So, idiopathic intracranial hypertension, or IIH, also known as pseudotumor cerebri. And this is more common in women and tends to be more common in women that are obese. There are also drugs that can sometimes cause patients to have this syndrome where the pressure becomes high; so that can be a separate disorder. And it's really important to get the diagnosis of that disorder, because that, in some patients, can lead to blindness, because the pressure in the head can also cause pressure around the eye — the optic nerve — and the pressure around the eye can lead to blindness. So, that is one thing that we absolutely do not want to see, and it's important to get that diagnosis really quickly.

Dr. Monteith (13:50): Of course, if the patient has that high-pressure headache suspect, then you want to do what's called a lumbar puncture — where you're actually putting a needle into the dura and gathering fluid and then measuring the pressure of the fluid. And if the pressure is higher than what is normal, then that is diagnostic of a high-pressure headache, and there's treatment for that. And usually, most patients do well with prophylactic therapies. Topiramate, the drug that we spoke about that can be used for migraine, can actually also be used for IIH, so that's one thing. But there are other diuretics that can be considered, and sometimes patients that are really refractory need to have things like shunts — and that's a neurosurgical procedure — especially if there's a concern of potential blindness. And so, the treatments are different depending on the diagnosis. So, I think the overall thing here is that, yes, continuous headache can be common in the migraine population, but it's important to think about other causes of continuous headache because the treatment can be different.

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Kellie Pokrifka (14:59): So, most patients who have been living with continuous headache have probably had scans at some point. Are these diagnoses — are these findings — something that you've been — that doctors are so used to looking for it that they don't have to double check? Or is this something that patients should ask for?

Dr. Monteith (15:16): So, it's a really good question. Because the MRI of the brain — If you are not suspicious of these diagnoses, first of all, you may not order the right image. For example, patients that have this low-pressure headache or CSF leak, if you don't order the study with contrast, you may miss some of the findings. And so, you really need to have that level of suspicion when you're ordering the exam, and then when you're analyzing the image, as well. And it's really important to try and look at that image yourself and you know, maybe even discussing that with a neuroradiologist because they're — some of these things are very subtle, if they're going to be present.

Kellie Pokrifka (16:01): And is there any way, if we've had a scan in the past, to take this to a doctor and ask them to look back retroactively to say, "Hey, am I a candidate for one of these? Is this a possible diagnosis?"

Dr. Monteith (16:13): Yeah, absolutely. And I do recommend that.

Kellie Pokrifka (16:16): Oh, that sounds great. That would be so ideal. OK, so does identifying treatments which may have worked for us in the past, even if it was just a little bit, or identifying treatments that were horrible for us in the past: Does that help narrow down the search for what it could potentially be, or what potential treatments in the future could work for us?

Dr. Monteith (16:39): Great question. And I think it's really, really important, and I appreciate you asking this question because you know, it just makes our jobs easier. And it's hard for patients. You've had this for 20 years, you're bouncing around, you move from here to there; you don't necessarily have your records. But it's really important to try and track — and I think these days things are easier with some of the health systems that are connected — but to track your medications: the doses that you were on, the duration that you were on, the side effects, and then whether it helped or not, and both for prevention as well as abortive therapies. Because first of all, we don't want to put you on something that you had a horrible side effect to, or we may reconsider something that you were on, but the dose was very low. So, it's very helpful to know, because we don't want to waste your time. So that's the first thing: It's really important to have good notes.

Dr. Monteith (17:39): And then, of course, when we're thinking about other conditions, some of the more rare conditions like the trigeminal autonomic cephalgias, and in particular the indomethacin-responsive syndromes, it's helpful to know whether you've tried something like that or not, if you have a unilateral headache. Because if you did, and you were on a great trial, we're not going to retry that for you; we're going to move on, generally speaking, and reconsider other things.

Dr. Monteith (18:08): So, medications and procedures can sometimes help us understand whether you have a condition or not, with some level of skepticism, because we don't diagnose based on a pharmaceutical response for most of our conditions — with some exceptions, like epidural blood patch. So, if you have the CSF leak that we spoke about, a blood patch — we're getting blood and then putting it to seal the spine, so it's an interventional procedure, to seal the dura of the spine. And you know, if you didn't respond to that multiple times, you may

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question: "Well, is that present?" Also, the same for cervicogenic headache and facet blocks; these are interventional procedures that can sometimes be diagnostic. So the answer's a little bit "yes" and a little bit "no," but super important to have really good history, medication history.

Kellie Pokrifka (19:09): All right, going on to medication, like we were talking about. So, we had a viewer, Ellen, and she asked: We're constantly being told, “You need to look out for a medication overuse headache,’ and you know, it's a huge problem. But she says: If we're having daily headache every single day and we can get some relief, is it still worth worrying about?

Dr. Monteith (19:32): Great question, Ellen, and you're speaking for so many people that have the same question and frustration, so I'm glad you asked the question and had the courage to ask the question. And so, what I would say is, for most people, the answer is: Yes. There may be a small subgroup of people that they've truly tried everything — they're refractory, and maybe frequent triptans are the best for them. But that's really not the standard patient. The issue with medication overuse, or the concern about medication overuse, is that there's an increased sensitization that occurs in the setting of overusing acute analgesics, and so that increased sensitization may lead to worsening pain over time. It's hard to imagine that you could have worsening — worse than where you are right now. It's possible. It could also lead to the acute treatments not working as effectively as they used to work.

Dr. Monteith (20:27): And a third potential concerning scenario is that in the setting of acute analgesic overuse — overusing some of these acute treatments — some of the preventive therapies that are gold standards may not work as effectively in the setting of overusing acute treatments. And so having said all of that, we do have different strategies for addressing patients with medication overuse headache. And it may be reasonable to put a patient on a preventive therapy while they're still using those triptans on a regular basis, because once they have really good preventive therapy, it could be that, because the headaches are less, they passively use [fewer] triptans. It's not a struggle: They have less headache, they're not— it's not something you're addicted to.

Kellie Pokrifka (21:15): And are there any ways that we can tell if there's a difference between medication overuse headache and our daily migraine?

Dr. Monteith (21:23): Yeah, well I think, you know, just the way the International Classification of Headache Disorders 3 [ICHD-3] has labeled it, is that if you're using, overusing, acute analgesics — so depending on the class of medication, it could be more than 10 days — 10 days or more per month, or 15 days or more per month, depending on what that is, and that's been going on for at least three months, you have 15 headache days or more. That is medication overuse headache just by the numbers. I think your question is about, in terms of symptoms. So, there are patients that have been overusing acute treatments and when that medication is wearing off, that headache is coming back: So let's say it's three in the morning, you're waking up with a booming headache. There's a common medication called butalbital — and butalbital can be used in combination with other medications — and it could be that you're using this multiple times per day, and overnight while you're sleeping, that level drops and that headache can come back. So that's the classic way of thinking about medication overuse headache. But not everyone has that.

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Kellie Pokrifka (22:40): And if we have different medications — acute medications — which work for us, is it a cumulative day count? Or is it, you know, can I use a triptan on this day or even different triptans within that class? Do they all count, or are they a separate total?

Dr. Monteith (23:00): Right. Another excellent question. So, it's based on — the way it's defined — is based on the number of days per month that you're using the acute analgesic. So, if you're using a triptan and then a nonsteroidal anti-inflammatory like ibuprofen, and then you use Tylenol, or acetaminophen, all in one day, that doesn't go to your count. If you're doing that twice per week and you're using multiple acute treatments, let's say you have a level nine out of 10 pain — very severe, you have nausea or vomiting, you're using multiple acute treatments within that day: That's OK. It's the number of days in the week or days in the month that matters.

Kellie Pokrifka (23:44): So even if it's the acetaminophen on Monday and the triptan on Tuesday, that still counts as two days within the week.

Dr. Monteith (23:52): Yes, yes. Because combinations — there can be a combination of medications that can still contribute to medication overuse. But that's a wonderful question, as well. I'm glad you brought up the medication overuse though, because when we talk about refractory headache, medication overuse can be a common headache that can be associated with refractory headache. So, it's really important before we label someone as having a new daily persistent headache, that the new daily persistent headache happened before their acute medications. There are some people that, let's say they have arthritis, or they had an orthopedic injury, and they're using analgesics for that — maybe opiates or they're using NSAIDs — and then this is a daily thing, and then they start to develop headache; headache becomes more frequent. And then that, even though they initially have a bothersome headache, that headache now becomes — over time it can be a frequent headache or chronic migraine. And so, we have to be very careful that the headache that is quote unquote, "refractory," happened before the medication overuse to really call it that refractory definition.

Kellie Pokrifka (25:03): I wouldn't have even thought of that. All right. Going off on the comorbidities — which you just spoke on a little bit — one of our viewers, Deanne, she asks: “Is there any way that these continuous headaches may be an autoimmune condition, or a result of something else? And if so, how would we even test that?”

Dr. Monteith (25:25): Right. So, that's a wonderful question. And I think the important thing is to make sure you have a good primary care doctor, and also a good neurologist and headache specialist. And you need a good comprehensive history, which includes not just the headache symptoms, but the general medical symptoms, as well: A good review of systems, and that includes screening for stigmata of autoimmune disease. So, if you have a known autoimmune disease, that makes it a little bit easier, but there's certain symptoms that may suggest this patient could have an autoimmune disorder, and that that can be tested by laboratory workup. So, by clinical history and by laboratory workup.

Dr. Monteith (26:11): And then, even if you do have the diagnosis of autoimmune — tying that to headache, right? There should be some form of temporal association. And then some of the medications can also produce headaches that just add an extra layer of complexity. But for example, patients that have this condition called new daily persistent headache — some patients have thyroiditis or thyroid disorders that can be associated with this new daily

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persistent headache. So, absolutely, a continuous headache can be a manifestation of autoimmune disease, and so it's important to get that comprehensive evaluation.

Kellie Pokrifka (26:54): All right, so before we end, let me see if I can recap this, and I'm going to need your help in filling in some of the details. So, one: Find a doctor who's willing to work with you, willing to be a teammate, and willing to go the extra mile, re-look at scans, reevaluate medication. And two: Medical history is basically everything in these cases, and trying to figure out what has worked, what hasn't worked, what other diagnoses are out there, which we can rule out. And basically: Just keep trying, keep hoping, and someday we can perhaps all have at least a small break. And there's no reason to ever give up hope.

Dr. Monteith (27:33): Never a reason to give up hope — recognizing that there are new advances all the time. If you don't feel happy with your progress, bring it up with your provider. I think providers (doctors), they want their patients to be happy, and healthy, and well. And not every neurologist is a headache specialist, so there may come a time where you may want to seek someone with expert knowledge. The American Migraine Foundation has a provider search that patients can go on and plug in their ZIP codes and find headache specialists in their area. There's also the UCNS [United Council for Neurologic Subspecialties] directory — these are people that have gone on to do the work to have extra certification ... and also, they have to keep up that certification that requires extra education. So, there are places to go to find experts in the field, especially if you're suffering from refractory headache.

Kellie Pokrifka (28:27): Your insight today has been incredible. Where can we follow your work?

Dr. Monteith (28:32): Yes, well, please do. I'm everywhere, I feel like. But I tweet a lot, and I like to tweet about stuff that my colleagues are doing: patient education, advocacy stuff. So, @headachemd, you can follow me on Twitter. I would love that. And then, also, I am on the editorial board for the American Migraine Foundation. I contribute to a lot of what they put out, and so do check out the American Migraine Foundation. I'm also on the editorial board for the *Brain & Life* magazine: This is the patient magazine of the American Academy of Neurology. We have some outstanding headache literature — this is all written for patients — and there's a great search engine that you can go on and plug things [in], and look, and learn about stuff. And so those are the places that I hang out. So do follow those places; tap into those resources. And then also, join the advocacy community, and you can get some emotional support; you can learn about newer treatments and network with patients; and really, I think, take some level of control for the condition that has beaten you down for so long. And it's best doing that in a really healthy and supportive community.

Kellie Pokrifka (30:01): I love that. And Dr. Monteith, thank you so much, not only on behalf of the Migraine World Summit, but on behalf of all patients like me who feel like there really is nothing else besides continuous headache. It seems like we've had migraine forever and sometimes it can feel so insufferable, and it's so wonderful to hear from a doctor like you who really understands it, really supports it, and really believes in all of our recovery. And I thank you so much.

Dr. Monteith (30:30): Thank you so much for being a part of this, and I think you're absolutely amazing. You probably inspired so many people today. You inspired me, and so I really appreciate being here.

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