Episode 229: Headache-Specific Locus of Control: What You Can (and Can't) Control

Lindsay Weitzel, PhD:
Hello everyone, and welcome to HeadWise, the videocast and podcast of the National Headache Foundation. I'm Dr. Lindsay Weitzel. I'm the founder of Migraine Nation, and I have a history of chronic and daily migraine that began at the age of four. I am very excited to be here today with someone many of us know and love. This is Dr. Elizabeth Seng. Hello, Dr. Seng, how are you?

Elizabeth Seng, PhD:
I'm doing well. Thank you for having me.

Lindsay Weitzel, PhD:
Thank you so much for being here. Dr. Seng is a professor of psychology at Yeshiva University and of neurology at the Albert Einstein College of Medicine. Dr. Seng is widely published in the field of headache psychology and is just an awesome person. And pretty much everyone who watches our podcast agrees. We are lucky to have her here today.

We have a topic that I really, really enjoy thinking about, pondering on, and I really believe in. We are going to talk about locus of control and how it relates to headache, migraine, chronic pain, etc. So, Dr. Seng, let's begin by just defining and discussing what locus of control is, as it's something that's discussed in relationship to everything in our world from career to relationships and health. So what is it?

Elizabeth Seng, PhD:
Locus of control was originally conceptualized by Rotter in the 60s, and then was also taken up by Bandura, very famous psychologists, to describe how people view interactions between themselves and to their world. Early on in the theoretical understanding of locus of control, it was conceptualized as a single line where it would go from internal, I believe I have control over this phenomenon, over the world, over my career, over my relationship, all the way to external where I believe someone else, something else has control over the world, over things, over my relationship.

One of the things that was noted early on about locus of control is that it does interact with some other constructs. The most important of which we're going to talk about in a little bit, self-efficacy. So, from the very beginning, there was a recognition that locus of control's impact on outcomes is also going to matter on how much actual control you have.

So, this has always been kind of acknowledged in this. But as locus of control went through the decades, another psychologist named Wallston started to apply it to health. And he is the first person who noticed, jeez, this internal to external idea doesn't work perfectly. It doesn't really wrap on that way. Because sometimes people can have internal locus of control, but they also have powerful others locus of control. So, he conceptualized people, for example, who may have a life-threatening illness or may be diagnosed with cancer. He noticed that a lot of people felt that God had control, that a higher being had control over what was going to happen to them. And that's not internal and it's not external, but it's also not bad. He recognized that these things kind of exist together.

Which brings us to where we are today, where we talk about people having internal locus of control. This is the idea that I am the one who controls my health and controls my health outcomes. We have chance external locus of control. This is the idea that nothing, chance, fate, it's all capricious, controls my health and my health outcomes. And then finally, a variety of powerful others which can include God, but often also includes healthcare professionals. So, my doctor, my medicines, the medical field, can control my health and can control my health outcomes.

Lindsay Weitzel, PhD:
For our purposes today, we're going to discuss something specific called headache-specific locus of control, which is a thing. And you have published on this topic. So, talk to us about how headache-specific locus of control is measured and categorized.

Elizabeth Seng, PhD:
So the headache-specific locus of control scale was developed around 1990. It's got three subscales, and they are [1] internal, so this is the idea that I control my headache symptoms and I control my headache outcomes, whether or not they get better, [2] external chance, so my headache symptoms happen by chance, nothing can control them, and then [3] healthcare professionals as the powerful others that this scale and that we in the headache field really think about a lot. So this is the idea that my doctors and the interventions that they give me control my health and they control my healthcare outcomes.

Lindsay Weitzel, PhD:
You just talked about what the three subscales are. What does your data show about how these subscales are related to outcome and people with migraine? In other words, how we do, how we feel.

Elizabeth Seng, PhD:
One of the reasons why locus of control has been so interesting is because it's surprising. In every study anyone has ever looked at, chance locus of control, the idea that chance or fate controls my headaches, that they're capricious, that nothing can help me, that's always bad. It's always associated with more disability, even when you adjust for headache days. It also improves over treatment. Interestingly, it improves over any treatment, drugs, behavior, doesn't really matter. If you have something that is efficacious to help you manage your symptoms, your belief that your symptoms can't be controlled and are up to fate or up to chance, that goes down.

So we feel pretty confident that high chance locus of control is bad and that that is something we want to reduce. We want people to feel like something controls your migraine disease, your headache symptoms. Headache locus of control can be used across all the other all the headache disorders, not just migraine disease. So we sometimes look in tension type headache. We sometimes look in cluster. So, it's important to know that it can be generalized beyond just migraine.

So chance, we're always trying to reduce chance locus of control. We're always trying to give people a sense that something can help. The question is what can help. And it turns out that that's not an easy answer because in many studies, both healthcare professional locus of control and internal locus of

control, at best, they're neutral. They don't really matter. And at worst they're bad. They're actively bad. So in some of our studies, we've seen that higher internal locus of control, the sense that you are responsible for your migraine disease and for your symptoms, is actually associated with higher levels of disability. And that really hit us and was really, really interesting to us.

The other thing that happens is that over the course of effective treatment, behavior or drug, over the course of effective treatment, internal locus of control does improve and it improves significantly. So the question is, how can this thing that's bad, improve with treatment, but you get better with treatment too. How does that work. How does all this fit together.

So, putting together findings from a variety of studies, the basic picture is that internal locus of control is only bad when you don't have tools to be able to manage your disease. So, feeling personally responsible for your migraine disease is maladaptive if your migraine disease is out of control and you don't have a good toolbox to help treat. But if you have been provided a toolbox, again, most of this data comes from clinical trials, right? So, we're providing you with the toolbox of interventions, acute medications, preventive medications, behavior change. All three, depending on the trial.

And then we track your internal locus of control and your outcomes over time. What happens is that your internal locus of control improves and it becomes less entangled with disability. So, the higher internal locus of control is no longer so bad, once you have more treatments on board and you're confident in using them.

Healthcare professional [locus of control] is also interesting. You would think that healthcare professional locus of control would have strong relationship with outcomes, but it rarely turns out at all. And I think that a lot of that has to do with the fact that people have different relationships with their healthcare providers and they have different interventions that they're trying to use. So again, if you have a really effective relationship with your healthcare provider and you have effective treatments in your toolbox, it's probably really adaptive to say, yeah, I feel pretty confident in those things that they give me, and I feel pretty confident that they'll make good decisions in the future. Whereas if that's not the situation that you find yourself in, and in many of our studies people join them because they're not receiving the treatment that they need, then it kind of comes out in the wash and no longer has strong relationships.

Lindsay Weitzel, PhD:
When you were talking about the internal locus of control and how it can be a negative thing, there was a word coming into my head that I'm wondering about. Tell me if I'm going down the wrong road, but it was blame, self-blame. Is it possibly related to self-blame? For example, I think of people who I run into who every time they have a migraine attack, they are wondering what they did wrong, what was the trigger that they failed to avoid, and that it has to be their fault. Those are the kind of people I was thinking of. Do you think this could be related to that concept?

Elizabeth Seng, PhD:
Yes. So that's certainly our working hypothesis, but I'm going to be the first person to say that we don't have empirical data. But my working hypothesis is that what's causing high internal locus of control to be associated with poor outcomes in pretty much every study that's asked that question cross sectionally, is that there's this group of people who experience high levels of self-stigma. They believe

these stereotypes about migraine and the environment. One of the most pernicious of which is that people with migraine did something wrong and that caused the attack. And I think that idea, and we may have spoken about it on this podcast before, but I think it's worth repeating. I think that that idea comes from… so this is stereotype, it's cultural health stereotype. That's where stigma comes from, right? And I think it comes because most people's experience with headache as a construct is not migraine disease. Most people experience headache due to caffeine withdrawal or alcohol withdrawal. So, for most people, when they think of a headache, they think of a comparably mild pain that happens after they ingested something and then stopped.

And at least one of those things, but potentially both, depending on who you are, have a strong moral connotation, right? So, I think that this stereotype is derived very organically and not maliciously from most people and culture's experience with headache. If the last time I had a really bad headache it was because I had a hangover, and you're telling me that you have a headache now, it's difficult to understand this is a migraine disease.

This is different. This is a neurologic condition. The threshold is much, much lower. Barometric pressure, totally uncontrollable things, can be associated with the onset of symptoms. Some people have symptoms continuously. It's just a completely different beast. But you can see where it comes from. So, for people who have this strong sense of that stereotype that I did something wrong and it caused my attack, that has obvious negative impacts on mood. Of course, you would feel terrible.

It also though has negative impact on disability. You end up beating yourself up instead of being able to look forward and say, oh, my symptoms are coming, it's time for me to treat. It's time for me to do my coping strategies, to find my different room to get out of the situation. When you beat yourself up, it interferes with your ability to cope and in a proactive, effective way, which of course will then increase symptoms and disability.

Lindsay Weitzel, PhD:
I love that you said that and thank you for that. And I would even add that I feel as someone who's had migraine since my earliest memory, I feel that that stigma comes from in our culture, it's sort of we have this belief that you're born healthy and humans stay healthy unless they do something wrong. So, if you smoke, you get cancer. If you eat too much, you get type 2 diabetes. If you're stressed, you get a tension headache or a migraine.

And so they always ask, oh, you have a migraine. Why. And I have always traditionally felt compelled to just make up a reason. So I love that you said that. Everyone feels like there must be a reason if you're not feeling well, and it's something that you did. And I think that that's something that I think we should talk about more in our community.

Elizabeth Seng, PhD:
Medical anthropologists, who are the most fascinating groups of people that I love having various conversations with, have described to me that it harkens back to our Puritan culture. The idea that disease has a moral characteristic, and that we are born healthy. And that if one is diseased, that implies something about one's moral character. Which is obviously completely untrue. But just such a

subtle thread that pulls through at least the American culture and how we think about health and disease.

Whereas I prefer to, so I often tell people that one of the reasons why I love working with people with migraine is because they're the most resilient group of people I've met in my life, because they have this episodic, disabling disease that's hitting them in the prime of their lives when they're trying to work. And they're trying to have kids and they're trying to go to school. And yet they still do all these things with this disease. And the amount of symptom that people with migraine continue to thrive with is astonishing to me. And so I love working with people with migraine because of the resilience. And that's such a different perspective than this moralistic, puritanical way of thinking about disease and morality.

Lindsay Weitzel, PhD:
So my next question, getting back to, originally, our train of thought here, is locus of control, as a concept, is it related to self-efficacy?

Elizabeth Seng, PhD:
Yeah. So earlier I brought up Bandura. And Bandura is the guy who made up the self-efficacy concept that has just really helped us understand a lot about ourselves in culture and ourselves in the world. And he has this amazing table that I refer to all the time, where he has locus of control and self-efficacy kind of orthogonal to each other.

So one's up and down, and one's left to right. And he basically says, look, if you have, we were going to assume that we're talking about this internal locus of control and internal only. The sense that you can do something about it. If you have a high internal locus of control, but low self-efficacy, that's self-blame. You're just going to blame yourself. If you have a low internal locus of control and a low self-efficacy, you're just dead in the water. You don't know what to do. And nothing can help.

Lindsay Weitzel, PhD:
That's like victimhood, right?

Elizabeth Seng, PhD:
Yeah. It's somebody else, something else. Despondency is what he [Bandura] says about men. If you have low internal locus of control but high self-efficacy, this one is actually my favorite. So these are the people who, self-efficacy, remember, so self-efficacy is confidence in your ability to engage in a behavior. So if you have low locus of control but high self-efficacy, it's kind of like yeah I could exercise, that wouldn't help. It's like sure I could try taking that drug, but the drug isn't going to do anything. So it's this almost sense of defeatism that it's like, sure, I don't need to be convinced that I could do things, but I just have no expectation that that's going to help me.

So really, where we want to go is high internal locus of control, or at least moderately high, like a little bit higher. Internal locus of control in his conceptualization isn't bad, as long as you also have high self-efficacy. And high self-efficacy has consistently been shown in the headache field, but also in many

other fields, to be a very helpful thing, as long and it's a thing that you have, that you can actually accomplish.

Early studies of self-efficacy that many people will cite, they'll say, oh, of course you can have too high of a self-efficacy. It's true. Early studies of self-efficacy would bring people in, and they would say, do you think you can play the piano. And some of them could, and some of them couldn't. So, look if you can't play the piano and you're overly confident that you can play the piano. Yeah. No, that does not impact your performance.

But what we're talking about here are things that are behavioral targets, like taking your medication, that we do you think you can do. That we do think you can accomplish. One of the places where I think the discourse around locus of control, the idea who controls my disease, should I think I control it, am I blaming myself, there's a lot of conversation and confusion around that. Same thing with self-efficacy. It's like, well, so if I just feel more confident, I'm going to feel better. That seems silly.

I think a lot of where the discourse totally breaks down is that we're talking about these constructs in the abstract and not in the relationship to the actual behavioral targets we're talking about. You don't have self-efficacy for migraine management as a whole idea. It's self-efficacy for can I take my migraine-specific medication early on in the attack next time. How confident am I that I can do that. And then to what extent do I believe that my healthcare provider has made an adequate decision that this drug has the capacity to actually change my symptoms. It's locus of control or outcome expectancy.

So, we need to remember that the constructs aren't pie in the sky. An easy way to think about that is with exercise. So, do I have self-efficacy that I can run a 5K? You betcha. Give me the running shoes, I'll go right now. Do I have self-efficacy that I can run a marathon? Nope. So, it's silly to say, well, I have self-efficacy for my migraine management. It's like, ok, what parts of it do you feel very confident you can do.

And we all have parts that we feel less confident about and that's okay. It provides avenues for intervention. But I think that's where it breaks down. We're not talking about Pollyannaish, pie in the sky, I'm going to think better and the thinking will magic my symptoms away. We're saying that changing your behavior is really hard. It's really hard to do new things. Even if the new thing is just taking a new drug. It's hard to do that. And what leads us to actually do the things that actually change the symptoms and improve our lives, is if we think that doing the thing will matter, and we feel confident that we can do it.

Lindsay Weitzel, PhD:
So again, this is possibly, it's one of, if not my favorite topic. So, I have a lot of questions. But I want to know now, sort of the flip side, is it also related to other things? What else is it related to? Anxiety, self-blame? What other important concepts is locus of control related to for people with head pain?

Elizabeth Seng, PhD:
So locus of control is intimately related with depression. And I think that one of the reasons why, so depression and migraine are related because they share similar neurologic, underlying mechanisms. They're also related because everybody listening to this podcast has had migraine disease or some other headache condition that's disabling. That's depressing. It's hard to live with.

Lindsay Weitzel, PhD:
Sorry everybody. Yeah. Go ahead. Sorry to bring it up.

Elizabeth Seng, PhD:
One of the things that we don't always think about in this community, but which is worth saying out loud and which is related to locus of control, is that when you have depression, one of the characteristics is self-blame. If you have high self-blame and high internal locus of control, that's rough That internal locus of control is no longer helping you. Now it's hurting you.

Lindsay Weitzel, PhD:
I just got depressed because you said that.

Elizabeth Seng, PhD:
The other thing about depression is that it makes it hard for you to get out of bed. It makes it hard for you to do anything. That's called activation energy. And that's a real thing. So, when you really feel like I know that I should do X, Y, and Z, but I just can't. That is a high-level cognitive skill, the starting something new. And depression really interferes with it. So much so that some people who have depression literally can't get out of bed.

When you feel like even a shade of that kind of depression, it makes it hard to change new things. It makes it hard to go for the walk that you need to go to in order to regulate your circadian rhythm and get a little bit of physical activity in. It makes it hard to eat consistently. And all of those things that are associated with migraine management, and it's associated with the extent to which you think that those things may be controlling, can control your headache disease.

So, yeah, I think that it's particularly important for people who know that they're struggling with depression, to pay attention to the balance between I feel, because we don't want you to have chance locus of control. That's bad. A little bit of internal locus of control is helpful, but we don't want you to feel so much that you have self-blame.

What we need for you to feel is self-efficacy. We need for you to feel, I am confident in the tool that I have to manage my disease right now. And if I'm not, which for many people listening to this podcast, you're working with your neurologist and you're going through, you're trying something new and it may or may not work and you're going to try something new in a couple months, and it may or may not work. Right. You're going through the through the wringer.

We don't need to feel confident that this drug is going to work. What we want to have is some healthcare provider locus of control that my doctor knows what they're doing, and that this drug at least has the possibility to help me. And then we want to have self-efficacy, again, not I know this will work. We will have self-efficacy that I know how my doctor wanted me to take this drug, and I feel very confident I can take it that way. That's what we want. Having higher expectation can lead them to be dashed, and then we lose confidence. These constructs are not about being unrealistic. They're actually

not, when truly kind of brutally realistic about what we can expect to happen with our behaviors right now.

Lindsay Weitzel, PhD:
I wanted to sort of translate something and tell me if I'm getting it wrong, because a few times in the beginning, we were both using language having to do with sort of attack frequency, having control over when and if the pain and the migraine attack came, which someone like me been like this and had migraine since I was born. I personally have learned that I have absolutely no control over when, if, how bad, how often, either for myself or my child it's going to be. The one thing I know I have control over is I am going to continually take steps, and I am taking the right steps, and that's what I focus on. Is that also, self-efficacy and sort of a locus of control concept?

Elizabeth Seng, PhD:
Yeah. So the idea there is that I don't have control over my disease. And so that's a low internal control. This is a disease that I didn't cause, that I don't have a lot of control over. But you do have control over the management of the disease. And this is what the validated scales as they're made right now, it misses some of these nuances.

We developed the scales, I say we, 1990, was well before my time in the field of medicine. But they were developed by a lab that I had been a part of, by Ken Holroyd lab at Ohio University, for a specific reason to try to help understand change mechanisms in a specific treatment.

So, it was created in the specific context, and it's difficult to generalize that to every context in the world. That's why the scales missed some of this nuance. It's also important, I just want to highlight, that the way that we are talking about locus of control of efficacy right now being very behaviorally specific, that's exactly how Bandura intended us to talk about these things. Because he noted, in some of his early writings on the topic, I did my doctoral dissertation on self-efficacy, so I've read more than I would expect around these topics. In some of his earliest writings on self-efficacy, he said that you need to ask self-efficacy not just for the specific behavior, but also its difficulty.

So that's my 5K versus marathon example. You have to know, not just do you feel confident that you can run, but what does that mean. Do you feel confident that you can take the medication that your doctor just prescribed to you and then report back to your doctor how it worked? Yes. Do you feel confident that you can take the medication and that the medication is going to be perfect, and your migraine is going to go away forever? No.

Lindsay Weitzel, PhD:
That's not in your control.

Elizabeth Seng, PhD:
Yeah exactly. And it's because it's outside of your control. It's maladaptive for me to think that I have all the control over essentially a neurologic disease that I'm struggling with, that only my own behavior matters for a portion.

I just want to take it one step further. There are going to be people right now who are thinking, well, I control when I get my migraine attacks because if I skip a meal, I get a migraine attack. I have control over my migraine attack, so if I have a terrible night's sleep. I stay up too late, and I have a terrible night's sleep, then I know that I'm going to wake up with a migraine attack. So I know that I have more control.

And I just want to gently suggest that we may have less control over things like our appetite. We assume that we have perfect and complete control over our eating behaviors. But if it was true, we would not have an obesity epidemic in the country, right? We assume that we have all of this control over our sleep, but if that were true, we wouldn't have an insomnia epidemic in this country, right?

There are a lot of things that we feel like because our own behaviors and decisions do matter, that they are therefore entirely in our control. And that's not accurate. Our symptoms are this complex interaction between our brains and our behavior. And our brain impacts our behavior too. It's not just one direction. So, my message is always like, give ourselves a little bit of grace. But in this context, my message is also try to like self-examine your control beliefs a little bit, because you may surprise yourself. Try to examine a little bit over, am I really blaming myself for my migraine disease, or do I have a lower internal locus of control there?

On the other hand, do I believe that I am the one who controls my migraine management? Or I have low internal locus of control there? Am I having an expectation that the doctors will figure it out or that something else is going to have to change. Some level of internal locus of control allows us to build self-efficacy and build the skills and tools that we need in order to get better.

Lindsay Weitzel, PhD:
So, I have just a couple more questions that I think will help. People maybe intervene on themselves if this is the concept that they're interested in working with. In your estimation, what do you think is the healthiest balance of headache-specific locus of control when it comes to the three? We've hinted at this with a lot of words, but if you were to summarize for someone with migraine, what is the healthiest balance of the three?

Elizabeth Seng, PhD:
So, I think that, and this is clinical informed by empirical. But I think that we should have a pretty low internal locus of control when it comes to why I have migraine in the first place. But I think that we should have a moderate to high internal locus of control around I can do something now to reduce how much symptom I have. And that's where we then look to self-efficacy and say, what are the things that I can do. And which of those things am I confident in and which am I less confident in. How do I get more confident.

That I think is the best strategy. We always want low chance or fate locus of control. Like migraine, is a manageable disease, and both the belief that it is solely due to chance or fate is just maladaptive in every circumstance and is something that we should strive to identify in ourselves and identify alternative.

For healthcare professional locus of control. I think that it's a really great indicator of the extent to which you have a productive relationship with your healthcare provider. Remember that healthcare

professional locus of control, we don't expect our healthcare providers to be our saviors. And we don't expect them to do all of the work for us. In fact, in migraine disease and especially, we need to take the tools they give us, go home and try to implement them in our lives. But we should have a moderate belief, at least, that the tools that I'm being provided with by my healthcare provider could help me. And that if these tools don't, my provider will help me find tools that will.

Lindsay Weitzel, PhD:
If someone were to go take the headache-specific locus of control test for example[1], are their results from that test that can be seen as a warning sign? I by the way did go take it before we did this episode, and I found it a little bit interesting, and I was a little bit surprised by it. Can there be results that would be seen as a warning sign where a person would want to look at themselves and perhaps work on changing certain thought patterns?

Elizabeth Seng, PhD:
Yeah. If you are finding that you're endorsing a lot of those chance locus of control items, nothing can help me, nothing can change my migraine, my migraine is up to whims, it's up to fate, that is a really good indicator that you want to think a little bit about your migraine management plan. If you're not already on prevention, you may want to really strongly consider it. It doesn't have to be a drug. But you really may want to strongly consider some type of prevention. And you might want to consider seeking help from a mental health provider.

Obviously, there are those of us who work with headache disease, and that's great. But pretty much any cognitive behavioral therapist, if you can come and say, look, you know, I'm struggling with this, with a chronic illness. And I was taking this test, and it really showed me that I am really struggling with feeling like there's nothing that I can do and everything's just going to get worse.

That is something that you may be surprised again, I do not think that changing the thought alone is what changes migraine disease and migraine related disability at all.

I think that our thoughts are the avenue by which we act. And that it is difficult to manage disease when the person in your head is talking to you all the time saying, this isn't going to matter, why are you even trying. This is silly. Stop trying. Just go to bed. And that person is saying those things. Of course, it's going to be harder to do the things you want to do. So, changing your thoughts is not this distinct magic way that symptoms change. Symptoms change through management behaviors and using a toolbox. Okay. But man, some of those thoughts can make doing that a whole lot easier and a whole lot harder.

Lindsay Weitzel, PhD:
Our thoughts can be blocking us. ~~So is there anything else~~ That was awesome. I really loved this episode. Thank you so much. Is there anything else you'd like to add to this topic before we go today?

Elizabeth Seng, PhD:
As always, I just want to make sure that I emphasize to everybody listening that your migraine disease, your headache disease is not your fault. And at the same time, there is a lot that we can do to try to help you feel better. And more than feel better, there's a lot that we can do to try to help you get to your kid's next soccer game. You are to get to the events in your life and the pieces of your life that are important to you to improve your relationships with people.

So if you have found yourself and your migraine journey where you're no longer engaging with a healthcare professional around migraine because it's just been so overwhelming and disappointing, I would ask that you use this episode to consider reengaging, to consider using some of the resources from the organization to find a headache provider in your area.

And if you're struggling with some of the stuff we've been talking about, to try to maybe even find somebody who does CBT for a couple sessions to see if there's a way maybe that we can think about migraine a little bit differently. We are not to blame for the symptoms, and there is hope.

Lindsay Weitzel, PhD:
Thank you so much Dr. Seng. It was just an awesome episode. That was so fun, and I hope everyone got something out of it. And thank you everyone for joining us today. Please join us for our next episode of HeadWise. Bye bye everyone.

1. This is an example of one locus of control test (there are others as well). National Headache Foundation does not endorse one over another. We are offering this link as an example of one version. Please discuss your results with your healthcare provider if you want to learn more. https://www.psychologytoday.com/us/tests/personality/locus-of-control-test