When Lyme Attacks the Brain: The Link Between Infection and Mental Health Transcript

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Introduction and guest background

Hi and welcome to another episode of the Healing Lyme Summit. I'm your host, Doctor Myriah Hinchey, and I'm so excited to introduce you to our guest expert today.

She is a good friend of mine, doctor Zendi Moldenhauer. She is a pediatric and psychiatric nurse practitioner, as well as the founder and medical director of Arbor Health.

Welcome, Zendi. Tell our listeners a little bit more about yourself and how became involved in treating Lyme disease, and especially in the psychiatric population.

Thank you so much for inviting me, Myriah. I'm passionate about this topic because I've had personal experience with Lyme disease, and I've had experience with Lyme disease with one of my children.

And so I felt like both as a mother as well as a provider, a need to become proficient in Lyme. And I think so often Lyme is misdiagnosed in the psychiatric world where folks assume that it's anxiety, depression, OCD or whatever, and it's actually an underlying medical disorder like Lyme disease.

And so I love looking at that interplay between physical and mental health concerns and really looking, digging deep for the root cause from both aspects.

So we're located in upstate New York, which is a Lyme endemic area, and unfortunately, there are not a lot of Lyme literate providers in upstate New York.

So I have a specific passion to help patients with Lyme disease. So, you know, it's funny, when I first started, I became Lyme literate, let's put it that way.

You know, it didn't surprise me that most of these Lyme patients had anxiety, depression, you know, severe neuropsychiatric symptoms because, you know, it's like you're sick.

And a lot of these patients were dismissed and nobody believed them. And they were told they were crazy. And it's all in their head. So it's kind of like, you know, in a way, being brainwashed and told, you know, that you have a psychiatric issue.

But then also, it is depressing to know deep in your core that something is wrong with you and you're getting all of these misdiagnosis, or you're being told that you're crazy.

But in addition to that, and what I'm so excited to talk to you about today is that no, there is like a path physiological process that is going on inside of the brain that actually is most of these neuropsychiatric symptoms.

And so the typical Lyme or vector borne disease patient, you know, has like this triple whammy. So it's it is circumstantial. You know. And it is because you've been told that.

But it's also a lot of neuroinflammation driven psychiatric issues. So yeah, it was a huge eye opening experience for me and something that, you know, I sincerely hope and wish that all medical professionals start to figure out and accept.

I agree with you.

Common neuropsychiatric Lyme symptoms

So let's start out by talking. Talking about what the most common symptoms of neuro psychiatric disorders and vector borne disease. Absolutely. Well, I think there's a whole spectrum of neuropsychiatric symptoms, but I think the most common would be anxiety, depression, insomnia, and certainly cognitive impairments as well, like brain fog and memory loss, often known as as, you know, just patients with described brain fog.

I've also seen a lot of mood swings and irritability. And in severe cases, patients might present with things like psychosis. And that looks like bipolar disorder, looks like schizophrenia, looks like hallucinations, looks like a panic attack.

But the underlying root cause is Lyme disease, not primary psychiatric. All right. And and so I would imagine in your field when you use like an antipsychotic drug or an antidepressant on a patient that doesn't have that pathophysiological process going on, that one of those medications would correct.

You're not seeing a response to that medication person. You're not seeing the typical response. You know, patients might it might tamp down or support those symptoms a little bit, but patients wouldn't respond in a typical way to those medications, which should prompt a practitioner to really be thinking more broadly or thinking deeper to see what else might be going on.

Yeah, so huge red flag for all of our listeners out there when you are not responding to a medication and the way the prescriber expects you to, that is a big red flag that something else is going on sending.

When you're doing an intake, do you actually look at physical, systemic symptoms in addition to the neuropsychiatric? Because that's what I was going to add, which is, you know, so often with depression, you wouldn't necessarily expect there to be a ton of physical symptoms like overwhelming fatigue or migratory joint pain, or all of the other host of physical symptoms that come with Lyme disease.

So that very often the psychiatric presentation, if you will, is atypical and and doesn't stand alone. And there's a lot of physical symptoms as well.

And I think that needs to be a red flag for both our patients, but also our providers to be thinking, what else could be going on here? Not just that this might look like depression, right?

So how prevalent would you say neuropsychiatric symptoms are in patients with chronic Lyme disease? Well, studies that of course vary widely because Lyme disease isn't well studied.

How Lyme affects the brain and gut

So there's different, numbers in the literature show that over 40% of patients have more severe, either neuropsychiatric or neurocognitive dysfunction.

But in my experience, I think if you take into account the whole range of neuropsychiatric symptoms from mild to severe, then I think online patients are affected to some degree.

Whether this is, you know, the physical effects from acute or chronic Lyme disease that results in feeling yucky, feeling sick, feeling depressed, or all of the anxiety and stress that comes with having to deal with the financial burden, the lack of treatment providers, the lack of accurate diagnosis, the financial aspects of, you know, coping with Lyme disease.

I feel like, you know, all online patients have some degree of neuropsychiatric symptoms, just having to cope with this horrible illness. Yeah, I would agree.

And especially with even, you know, a lot of like the cognitive deficits and and brain fog, you know, it's very rare to have someone with Lyme or another vector borne disease that doesn't have some sort of emotional or cognitive

functioning issue.

Yeah. It just feels like it makes sense. And so often patients are not listened to and invalidated and made to feel crazy. And I think that doesn't help a whole host of symptoms that they might be experiencing.

Right. So let's get into, you know, more of like the pathophysiology. So how can you explain how chronic Lyme disease leads to these neuropsychiatric symptoms. Oh sure.

So neuropsychiatric symptoms are primarily due to the spirit key Borrelia burgdorferi that invades the central nervous system. The spike heat can cross the blood brain barrier, directly infecting brain tissue and releasing neurotoxins.

So this invasion leads to neuroinflammation, a disruption of neurotransmitter pathways, and even direct neuronal damage. The body responds with a complex immune response, which leads to further inflammation.

Often known as Lyme Borrelia sets the immune response to the infection, may triggers cytokines that affect the brain, further contributing to line symptoms.

Often, this chronic systemic inflammation is critical, in which the body starts releasing a host of other cytokines like IL six and TNF alpha, that are often found in patients with chronic Lyme disease and correlates strongly with depression.

Unfortunately, Lyme doesn't exist by itself and very often comes with its partners, and so very often if you have co-infections like the B0 or Bartonella, these further exacerbate that immune activation, further destabilizing the nervous system.

And so it's important to address the infection, but also the results, if you will, of the damage caused by those infections. Right. And so for the listeners at home that don't know what a cytokine in is, cytokines are basically chemical messengers of inflammation.

And they have all of these different names and whatnot. So Sandy was going over what the specific cytokines are, but they're actually what affects the brain and the brain cells and causes the inflammation there in the brain tissue.

Yeah. I often, you know, try to, you know, when I'm teaching, it's like it's not just about the infection and killing the infection. It's about healing the terrain of the body.

And we can't heal the terrain of the body when it is inflamed, like when it's basically on fire. Right? Nothing is going to function properly. So yes, we have to focus on getting rid of the infections, but we also have to quell that inflammation and restore proper immune function and heal the whole person.

I think the other thing that's really important there is to address and heal the gut brain axis, because chronic Lyme disease can affect that gut brain axis, but also the treatment for chronic Lyme disease like antibiotics, can lead to things like leaky gut and subsequent increased inflammation that further inflames the brain.

So it's a little bit of a catch 22. So over 90% of serotonin is actually made in the gut. So if we are affecting the gut lining with treatment all inflammation is present from the Lyme infection.

We, decreasing that amount of serotonin that's made in the gut and available to travel to the brain. So gut dysfunction further exacerbates depression and anxiety.

And I think that's a critical piece of treatment with regards to healing the gut brain access. Absolutely. And, you know, it's we hear of the gut being called the second brain.

But if we actually look at the various neurotransmitters, you know, like serotonin being actually produced in the gut, but if you look at how, you know, healthy bacteria and how the microbiome actually drives the production of

neurotransmitters, but also inflammation or, and high inflammatory chemicals, right?

You know, there could be a very good argument that like our, our actual like real brain is in our gut. So I think it's so important to address treatment.

Right and right there, you know, starting with the gut brain.

Diagnosing Lyme-related psychiatric symptoms

So whether that's good probiotics, probiotic rich foods, a low inflammatory diet using healing nutrients and healing herbs like glutamine and diglycerides licorice Allah, or using healing foods like bone broth to repair that gut lining, especially if antibiotics are part of the treatment.

And then I love using calming herbs like chamomile or lemon balm to help with the gut brain connection, or supportive amino acids like glycine or inositol or five HTP, Gaba, theanine.

And they can be so supportive of the gut brain axis and they can help restore that healthy, calming and coping neurotransmitters. So we treating Lyme.

But we've got to also be treating that gut brain axis for improvement of neuropsychiatric symptoms. Absolutely. So before we continue down the road of treatment let's back up a step.

How do you decipher between true like neuropsychiatric symptoms? Because of a neuropsychiatric disorder and those that are induced by Lyme or another vector borne disease, I think it requires a very comprehensive and systemic approach, starting with a very detailed patient history.

When I'm interviewing patients, I'm asking for a life span or sort of set of symptoms. I always ask, when were you last? Well, and that includes both physical symptoms as well as emotional symptoms.

And I often find if it's emotional symptoms, there might be a slower onset or an earlier presentation. You don't expect severe psychiatric illness to come on suddenly.

Often symptoms related to Lyme disease come on more suddenly. And so I'm asking for that sort of timeline of symptoms. And also asking about potential tick exposure presents of any physical symptoms associated with tick exposure, like like a bull's eye rash or joint pain or fatigue that comes on.

So that's, I think, a really good starting place to try and tease out the physical and the emotional and then asking about how symptoms change over time.

I think it's really important to do good laboratory testing. So in looking for Lyme disease, I think it's important to assess how patients respond. Like if somebody has true organic depression, starting them on an antibiotic for Lyme disease is not necessarily going to treat true organic depression.

It's going to treat Lyme disease. So paying attention to what treatment is being used. And neither is Lyme disease going to respond to an antidepressant.

And so teasing that out and expecting the symptoms to improve based upon the treatment, I think is important to to keep in mind. So observing of the psychiatric symptoms improve with appropriate antibiotic therapy suggests more of an infectious etiology like Lyme disease.

And then I really think a full functional medicine evaluation is important. Instead of just assuming this is Lyme or just assuming this is primarily psychiatric, I think we need to be looking for things like hormonal imbalance or thyroid dysfunction.

Both of those can result in things like anxiety, depression, or insomnia, looking for gut dysfunction, looking for

heavy metals, looking for mold and other co-infections so that we're really trying to do a very, very in-depth assessment to tease out both psychiatric as well as physical symptoms.

So if you have established that there is an underlying infection, what sort of lifestyle interventions do you use with your patients? I think the first thing to address is stress management.

Any illness comes with a greater degree of stress, whether that's emotional or physical illness. And so mindfulness meditation and yoga and biofeedback can help with regulating the nervous system, can help with regulating the immune system, regulating the gut.

So I think that's a really lovely place to start. I do think diet is very important, specifically a diet that is anti inflammatory. We've been speaking about the fact that Lyme creates a lot of inflammation.

Disruption of gut brain axis creates a lot of inflammation. And so certainly we don't want to be adding to that inflammation with a highly inflammatory diet that might have a lot of colors and preservatives and highly processed foods and inflammatory fats.

So having an anti-inflammatory diet, reducing shadow, reducing processed foods, I think is super important. I think movement is important. So often folks with chronic pain don't want to move, and yet that starts a whole cycle of worsening pain.

So gentle movement as tolerated I think is helpful. Stretching, yoga, walking. Another key component from a lifestyle perspective is adequate sleep. Folks often struggle with sleep, whether they have pain or they have neuropsychiatric symptoms.

So really good supports to help with sleep.

Lifestyle support and prognosis

Both from a behavioral perspective, like establishing a routine and having a dark bedroom and having a cool bedroom and warm covers, as well as supplements like melatonin, for example, which, while supporting sleep is actually also anti-inflammatory, is important.

And then this stuff is tough to deal with. So I really recommend therapy, supportive therapy or cognitive behavioral therapy or personal exercises like a gratitude activity or positive mindset, and then seeking a positive social support because this is so often a very lonely journey and a very isolating journey.

So I think seeking positive emotional support is important. And engaging in some kind of creative activity that brings joy. Absolutely. Those are all wonderful points and all very, very important.

I think that there are so few medical practitioners who are Lyme literate who are looking at, you know, a lot of people now, thank goodness, are looking out all of the systems of the body and not just focusing on killing, you know, the infections.

But I think we often forget that mindset matters, you know, and if we think that we're sick and we're never going to get better, we're probably never going to get better, you know, and if if we're in sort of like that stuck victim mode, it can really paralyze us.

And the treatment and really hold us there. So, you know, coming out of isolation and having the support groups and having hope and getting your mind in the right spot is actually very, very helpful.

And I would even dare say crucial to healing, you know, from these infections. So what would you say the prognosis is for most of these patients experiencing neuropsychiatric symptoms of Lyme?

Well, I think prognosis varies depending on how long somebody's been sick for, what infections are involved, what

other aspects of the body are affected as well, like the dots?

However, I do think that with appropriate assessment and appropriate therapy, the prognosis is really good. But I wish and and I'm on a mission with you to really educate more providers to understand the role of infections like Lyme disease in mental health, because unless we adequately assess and adequately treat, the prognosis is more limited, but really with appropriate treatment, the prognosis is really good.

There are a small number of patients that have persistent symptoms and that can be known as post treatment. Lyme disease syndrome. And that is tough to deal with.

And so I think where we really need to be educating both patients as well as practitioners is about that early detection and appropriate treatment. Because then the prognosis is really good.

Yeah. And I think with the post treatment it's also like well were you fully treated. How were you treated. Was your immune system recovered. You know, that that acronym right there, that sort of thing.

It's like I think that there's a variety of so many different things that are going in that get kind of like put into that sort of catchall. And I think that depending on what's actually going on with that patient really dictates, like what therapies would actually be helpful at that point.

I think if a lot of people are still dealing with a chronic infection or, you know, an active chronic infection, it's like the infection itself needs to still be dealt with at that point.

Okay. So do you use any adjunctive therapies? And if you do, do you have favorites? Yes. So certainly the beside using things like an antibiotic or herbal therapy to address the infection and possibly using psychotropic medication or the equivalent, amino acids and herbal options to treat mood addressing psychotherapy and lifestyle as certainly like to put in a lot of anti-inflammatory herbs like curcumin.

Well, I use low dose naltrexone a lot because it can be helpful for inflammation, for that auto immune response to infection, for pain, for sleep. I think it's also important to really help with protecting and supporting the body's ability to detoxify from all of these infections, as well as treatments.

And then there's some other therapies that are super helpful and employed by lots of patients, like hyperbaric oxygen can be super helpful because Lyme and other infections don't like to live in an oxygen rich environment.

More and more and more folks are starting to use peptides that show promise. I think that there's more folks starting to use psychedelic assisted therapy like ketamine, especially for severe depression and suicidal ideation.

And then I also love using neurofeedback because it can actually help correct and repair neurotransmitter pathways. And neuronal damage. Do I have a favorite?

It really depends on the patient sitting in front of me in terms of what we're trying to address and what resources are available in the community or to the patient.

But those are the the, the breadth of adjunctive therapies. And when you talk about neurofeedback therapy, do you have a handful of favorites? Well, we do do neurofeedback at Arbor Health.

Adjunctive therapies and neurofeedback

And patients really benefit from the actual neuron feedback, interaction especially helpful for things like anxiety, depression, insomnia, trauma and brain dysfunction from prior damage, whether that's a traumatic brain injury or an infection.

Right. So have you developed your own sort of like neurofeedback therapy model, or do you use because there's there are several of them, you know, that various, you know, doctors have developed or different, you know,

gadgets that you can use.

Do you use any of those things or other practitioners or have you developed we, we, partner with brain called, neurofeedback and we use their protocols and we have patients either come into the office or use home units.

But that's a particular protocol that we, we have partnered with at Arbor Health. There definitely are others that that's the one that that I'm most familiar with.

Okay. So let's switch gears a little bit and let's talk about your other specialty pediatrics. So what specific challenges do you see when treating a pediatric patient that has neuropsychiatric symptoms associated with an underlying vector borne disease versus the adult population?

Children can often present very differently. They often can present more with behavioral changes. So they act out how they feeling rather than speaking about how they're feeling.

Depending on their age, we often see children with academic decline or developmental regression. It can be challenging to diagnose Lyme disease in children because they can't necessarily tell you how they feel.

So we really rely a lot on parental Report as well as physical symptoms as well as testing, and it's important to get at that diagnosis as soon as possible, because there are long term impacts on children's development.

That prompts effective diagnosis and effective treatment, and that often requires a multidisciplinary response. You know, a treatment team like I often engage the school nurse for accommodations at school for that, and the parents and a therapist and and the medical team.

So a multidisciplinary response is, is really helpful. And it's important to know that Lyme disease can trigger patterns. And I know you have some lovely presenters that are going to be speaking about pans and pandas, in your summit.

But Lyme disease is a common trigger of pans or pediatric autoimmune neuropsychiatric syndrome. So this is a condition characterized by fairly rapid onset psychiatric symptoms in either children, adolescents or adults.

And I'd love that your your listeners to hear that too, because there's not actually an age limit on the diagnosis of Pans. There is for Pan Does, which is associated with strep infection, but Pans can be associated with a variety of bacterial, viral or tick borne infections.

And so very often symptoms come on more rapidly.

Pediatric Lyme, PANS, and care coordination

And pans like obsessive compulsive disorder or acute anxiety, or separation anxiety or depression or ticks or mood swings or regression in behavior or academic functioning, and often sleep disturbances, and that Pans is considered an autoimmune disorder in which the body's immune system mistakenly attacks healthy brain cells while it's trying to attack that viral, bacterial, or Lyme infection.

And then that creates changes in the brain, which then create changes in a child's functioning both emotionally and behaviorally. I, I really my plea is always to treat this as a medical illness.

Yes, with secondary psychiatric or behavioral symptoms. But it's primarily a medical illness that needs to be evaluated and adequately treated. Absolutely.

And I think, you know, one of the biggest things is if you see an abrupt change in your child's behavior, and I'm going to take a step back in any person's behavior, right.

If somebody starts acting out of character, in a short period of time, that is a huge, huge red flag that something

very serious is going on. That is not how a typical neuropsychiatric illness would present.

And so I think it always needs to have a thorough physical medical workup, not just psychiatric. All right. So what would you recommend for the practitioners that are listening.

What would you recommend to them for supporting these patients better emotionally throughout their treatment. Because that's a very long treatment, no matter which way you go.

Correct. I think Lyme patients so often feel invalidated, misunderstood, dismissed because Lyme is often an invisible illness. It's not like, you know, you break a leg and you have a cast on and it's a physical presentation that something's wrong.

Lying is so often invisible and experienced, sort of in the body and misunderstood by so many people. And the invisible illness can be profound. It can be disabling.

So I encourage all practitioners to provide empathic listening, validation of that experience for the patient. Building trust, I think, is so important between the practitioner and the patient so that there's an environment in which the patients can truly tell their providers how they feel without the fear of judgment or blaming or shaming.

And then I think practitioners really need to offer effective psychiatric treatments and other resources like support groups. And I love to really include patients as part of the treatment team.

Patients need to be part of making those decisions because it completely affects them. So including them as part of the treatment team is important. And then I do think collaborative care models are helpful because it's can be hard for the patient, but it can also be hard for the provider to take care of chronically ill patients over a period of time.

So having a collaborative care model and partnering with psychologists, therapists, other practitioners of different specialties, functional medicine practitioners, Lyme literate, you know, practitioners, I think is ideal.

So that is a group support for the practitioner as well as for the patients over time. Yeah, absolutely. And there's you know, there's a lot of tough patients out there.

And there's not a one size fits all for any patient really model. So having a group that you can go to and you can bounce stuff case studies off of and get, you know, a different perspective, I know for me is is invaluable to a my favorite organizations is the international Lyme and associated Diseases society or I lads as well as maps.

The Medical Academy of Pediatric Special Needs are super important for the physician or the medical practitioner themselves. To actually have that network to go to.

Yeah. Thank you so much for joining me today. This was great. Any last words of advice that you'd like to give our listeners?

Supporting patients and closing thoughts

I would love to just leave your listeners with the hope that this can be adequately addressed, the hope that healing is possible, the hope that training of more practitioners is possible.

So that I'm hoping that in the future, things will only get better for our Lyme patients. Yeah, absolutely. So are you or is your center taking patients?

Yes. We are located in New York, so we we can only take patients that either live in New York or travel to us in New York. We're located in Rochester, New York.

Wonderful. And do you have any upcoming events you would like to share? Not currently. Thank you for the offer. Absolutely. All right. Well, again, thank you so much for joining us.

This has been super helpful. Thank you so much, Mariah. I really appreciate the opportunity. Absolutely. And for all of you at home listening. Thank you for joining us and I hope this was helpful on your journey to healing from Lyme.

I'll see you next time. Bye bye.