



Podcast Transcript

Caring for Long Covid

The following transcript has been lightly edited for clarity. Elite Learning does not warrant the accuracy or totality of audio transcriptions provided by an independent contractor resulting from inaudible passages or transcription errors. An occasional transcription error may occur.

Guest: Candace Pierce: DNP, MSN, RN, CNE

Dr. Candace Pierce is a nurse leader committed to ensuring nurses are well prepared and offered abundant opportunities and resources to enhance their skills acquisition and confidence at the bedside. With 15 years in nursing, she has worked at the bedside, in management, and in nursing education. She has demonstrated expertise and scholarship in innovation and design thinking in healthcare and education, and collaborative efforts within and outside of healthcare. Scholarship endeavors include funded grants, publications, and presentations. As a leader, Dr. PIERCE: strives to empower others to create and deploy ideas and embrace their professional roles as leaders, change agents, and problem solvers. In her position as the Sr. Course Development Manager for Elite, she works as a project engineer with subject matter experts to develop evidence-based best practices in continuing education for nurses and other healthcare professionals.

Host: Robin McCormick, DNP, RN

Dr. Robin McCormick DNP, RN has been a nurse leader for over 23 years in nursing practice, leadership, management, and education. Dr. McCormick earned a Doctor of Nursing Practice (DNP) from Troy University in 2018, a Master of Science in Nursing degree from University of South Alabama in 2007, and a Bachelor of Science in Nursing (BSN) degree in 2000 from Troy University. Dr. McCormick has published and presented on topics relevant to nursing practice and education on the local, national, and international levels. With a passion for improving community health outcomes, Dr. McCormick has a research focus on mental health, maternal-child outcomes, and community health.

Transcript

Candace Pierce: Hello, I'm Dr. Candace Pierce with Elite Learning by Colibri Healthcare, and you are listening to our Elite Learning podcast where we share the most up-to-date education for healthcare professionals. Today, we're going to be talking about caring for long COVID and just long COVID in general and joining me for this discussion is going to be Dr. Robin McCormick, one of my amazing coworkers. Thank you for joining me for, you know, just some discussion on long COVID.

Robin McCormick: Yes, I'm so excited to be here.

PIERCE: Well, I want to start off with just saying, like, do you, when you hear the term long COVID, what do you think about? What do you think long COVID is?

MCCORMICK: I just think of those residual effects and people who are still sick and don't know what to do about it. I know there's several people who live in my area who are experiencing it. It seems different for everybody.

PIERCE: Absolutely, and it is. So right now, long COVID is labeled as an infection-associated chronic condition that is from a virus that causes COVID-19, of course. And it presents for at least three months as a continuous, relapsing, remitting, or even they'll call it a progressive disease state that affects one or more organ systems. Now that's how the CDC defines long COVID currently. But really what we're referring to is this range of symptoms that persist for weeks or months after that acute phase of COVID-19 infection has already resolved. And the problem with long COVID is just what you're talking about. It's different for everybody. The symptoms fluctuate. They have this relapsing remitting pattern. So it's not steady. It's not a linear recovery. And that means that your patients are going to have good days and they're going to have bad days. And because it's so different in how it presents, it makes it really hard to diagnose. Long COVID is a rule out. As far as the most common symptoms, what have you heard are the most common symptoms with people you know who are struggling with long COVID?

MCCORMICK: Lung issues is what I hear a lot about, like COPD symptoms, oxygen needs for people like somebody who is around my age, which I think is still pretty young, even though we might not be, but you know, in their 40s who are suddenly getting tired walking to the mailbox. Those are some of the big ones that I keep hearing and just that it's not ending. It's not getting better.

PIERCE: Yes, and you really hit the nail on the head because the most common symptom that we hear people complain about is actually extreme fatigue, that post-exertional fatigue, like walking to the mailbox probably takes so much out of them that they have to recover in bed, you know, for a day or so. But it's a way to say if you have a child, and this is, I know people who have children who've been diagnosed with long COVID, and it has just been such a struggle, but say if you're a child and you just want to go out and play and you go play at a playground for an hour, you're just, you're being a kid. It may take days to recover and it's the same for an adult, you know, even just trying to run errands for an hour, trying to walk to your mailbox, of course, depending on how far away your mailbox is, but it can take days to recover. It's that type of severely extreme fatigue and it's ongoing. Of course, if this is ongoing, it's really going to disrupt your life because it just becomes so debilitating. Your functional capacity is so limited that the quality of your life is drastically affected. So, I mean, you really hit the nail on the head with what the most common symptom is. Now, another symptom that they complain about that I see too is brain fog. Brain fog, that phenomenon where you have difficulty concentrating, remembering, just being able to process information in a timely manner or just being able to follow through

on your executive functioning. So, I mean, let's tackle extreme fatigue with brain fog, not being able to remember, not being able to concentrate. And then let's talk about how debilitating it continues to become.

MCCORMICK: Absolutely, that is just life-altering. There's no way to just sustain your daily tasks if you have all those symptoms.

PIERCE: Right. And then you have, well, the patients look fine when they come in, right? They look fine. So, you have providers that are struggling with understanding, especially in the beginning of, you know, us not even knowing about long COVID, what is going on with these patients? They look fine. All their tests come back fine. Everything looks fine. But they're complaining of all of these different symptoms.

Other symptoms that they'll start to complain about are heart palpitations, shortness of breath, chest tightness, and chest pain. Like you were just talking about with some people you know who are struggling with long COVID, this long-lasting non-productive cough. And then we can take it further: severe joint pain, muscle weakness, myalgia. There's complaints of neurological symptoms. You have headaches, dizziness, neuropathy with patients who don't have, you know, diabetes that we typically would link neuropathy like this to. You know, they don't have those diagnoses where we'd be like, why do you have neuropathy? Sleep disturbances also go along with their extreme fatigue. You have Gl issues, most commonly abdominal pain with some nausea and diarrhea. And that's actually been reported in about 15 to 20% of long COVID patients. Of course, you're going to see weight changes from loss of appetite.

Mood disorders have also been attached to long COVID. But the question with mood disorders is: is this from the symptoms, that decrease in their quality of life, or is it caused by the actual syndrome? We don't really know. It's hard to say.

MCCORMICK: Yes, I can imagine. Well, since so many of these symptoms overlap with so many other conditions, what are the diagnostic criteria and tools that we can use to really identify that this is long COVID?

PIERCE: Well, and I also want to point out too, thyroid dysfunction and dysregulation of your stress hormones, like your cortisol levels, of course. And then you can have blood glucose abnormalities that we're seeing with long COVID too. So you're right. There are so many symptoms that really link back to other chronic conditions and syndromes.

So, how do we even know what this is? And I would say, well, first we have to recognize that long COVID can happen to anybody: healthy, unhealthy, young, old, middle-aged, anyone. Chronic condition, no chronic condition. It is no longer just limited to people who have, you know, as we described it in the beginning, like, it is for people who've had severe or bad

cases of COVID, those in the hospital, in the ICU, on ventilators. This can happen even with a mild case of COVID.

Long COVID has to stay in your list of differentials when you are trying to figure out a complex diagnosis. And differentiating long COVID from other conditions is really going to require a thorough patient history, symptom identification, and system assessment, considering the time of the symptom onset.

Relating that back to either a confirmed COVID-19 acute infection or a suspected acute COVID-19 infection. You do not have to have an actual confirmed test of an acute COVID-19 infection. Because of course, we do not always test for those. Some are mild and maybe you think you had a cold. Well, maybe it was actually COVID-19.

We have to rule out all the other potential causes of the symptoms through that appropriate diagnostic testing. And of course, that is going to be dictated by that clustered list of symptoms and complaints that patients come in with.

Just like you mentioned earlier, all the presentations are usually so different. I mean, you're going to see, like, extreme fatigue. Okay, red flag. I'm going to definitely write in that we need to figure out if this is long COVID. But there are so many other symptoms that we are seeing that it's just so hard to take it off the list.

And you also want to look at the duration of the symptoms: the timing of when the symptoms started versus when they had that confirmed or suspected COVID-19 acute infection. What systems are involved? Because of course, we're seeing a multitude of systems and symptoms associated with long COVID.

Then on top of that is the unpredictable course of symptoms that we're seeing, where we have that cycle of relapse and remission, or just a complete progression where it just continues to get worse and more symptoms just start adding in. So again, it is all about ruling out everything else.

MCCORMICK: Right. Well, and it just leads me to ask a question while I'm thinking about it. How long are the symptoms before we consider it to be long COVID? How long after the diagnosis?

PIERCE: I usually say right now, about three months after. Like if you are still having symptoms about three months after, then let's start looking at long COVID.

Most of the time, when you are struggling with long COVID, it is not going to go away. It is going to keep getting worse. So three months is the mark with the CDC right now. Of course, that could change as more research comes along.

MCCORMICK: Once you have a diagnosis, how can there be a multidisciplinary approach to it? Like who should be involved in the treatment of long COVID? If I have long COVID, how can I get the best help?

PIERCE: Yes. Well, first I want to kind of walk you through the fact that there is currently no diagnostic criteria whatsoever for long COVID, right? So there's still a lot of research that's happening around long COVID. There's no, like, let's go draw some blood, let's take a lab test, and that's going to distinguish that you have long COVID.

And, you know, as I said earlier, you don't even have to have a positive confirmed COVID-19 swab test either. So it's really, it can just be assumed when, you know, in the diagnosis of long COVID search, if you've ruled out everything else. There's no universally accepted diagnostic criteria. And that's why your diagnosis is going to come with a combination of that clinical evaluation, that in-depth patient history, excluding all your other conditions.

There are tools, I will say that there are tools if you need them, like questionnaires, symptom checklists, and functional assessments that can help you in identifying whether this is long COVID. But again, there is no actual diagnostic criteria, and ongoing research is still aiming to establish more standardized criteria.

And that also, I think, makes it hard with that multidisciplinary approach that you're asking about. But of course, I mean, it'd be so beneficial for those who have long COVID. And I'm going to say that you should use other specialties because if you look at all the symptoms that are involved, all the systems that are involved with people who have long COVID, you see neurological, musculoskeletal, cardiopulmonary, you see endocrine, and you're looking at these symptoms and really it's all about symptom management.

That's your treatment. Your treatment is symptom management. So if a patient is going to come to you, and you have ruled everything out that it could possibly be, and the only thing left on your list is long COVID, if that patient could benefit from the help of specialists that correlate to their symptoms, why would you not use them to help your patient regain some quality of life back? Because right now there's not really a cure for long COVID. It's symptom management. And you have this, like, diverse list of symptoms that patients are coming with from long COVID. Of course, primary care is probably where they're going to originate.

But also, because, you know, as we talked about earlier, you said you see people with lung issues. Sometimes the primary care might actually be coming from a pulmonologist, if they were able to get into or have a pulmonologist. So also cardiology, neurology, endocrinology, psychiatry, physical therapy, and occupational therapy. So there is just an array of specialists that really could help a long COVID patient have a better quality of life.

And, you know, if you really bring in these other specialties, and you're all on board with this is long COVID and how to treat long COVID, I think it really brings in that comprehensive care approach to long COVID treatment, which the patient just really needs.

And I think it's important that we're addressing their physical health, we're addressing their mental health, and all those needs that—the different needs that come with someone who's struggling with long COVID. Because again, it's so different for each patient. The presentation is so different.

MCCORMICK: I know it seems to be. And I'm thinking too, just in general, of a chronic condition—the importance of using multiple providers to manage that condition, but also to coordinate that treatment with your providers so that each provider knows what the other provider is doing, especially when we're looking at symptom management and medications, to make sure that their services are complementing each other.

PIERCE: Yes, and I have a question too when you bring that up. When we are treating the symptoms, and so say we give medications, are we treating a symptom or a side effect? And is the side effect. Do we want the side effect, or do we want the symptoms?

So you really have, the care is so complex for long COVID to try to address all of these different systems that are affected, and the treatment management is really something you have to think about. What does the cardiologist want to treat with? But then the primary care is like, hey, we have these side effects from this medication. So we don't have the symptom, but now we have this.

So is there something else that could work? Is there something else that we could try? I think at the end of the day, the problem is we don't even understand what this is. What is long COVID? We don't really even understand what it is yet.

MCCORMICK: Right, well, and I have to think just from that patient perspective. One question that I would want to know from my provider is, you know, have you treated somebody else with this? Like, am I your first one? Like, what experience do you have to make sure that the provider who's caring for me knows what they're doing? But since it's so new, you know that as a provider, you may not have had very many patients that you've treated with it.

PIERCE: Right, or you don't even know. You don't know that your patient has it. And that's another thing with the research. A problem with the research is it's so diverse in its presentations. And so, you know, not everybody who has long COVID is probably being reported to the research bodies to be able to, you know, bring in those numbers.

Do we really know, do we really understand the broadness of long COVID and who has long COVID and who doesn't? We don't know. That's what's crazy to see.

MCCORMICK: Right. There's probably so many people who have long COVID who've been diagnosed with other conditions, especially things like COPD, you know, because it mimics some of those symptoms. So how do you—how do you differentiate if we're not reporting?

PIERCE: Yes, and your symptoms kind of come and go. And it could be that, and it's almost clustered. It's like this clustering.

So when you have that relapsing, your symptoms might be different in that relapse than it was in the relapse, you know, a couple of days ago or a couple of weeks ago. And so your symptoms, what we're seeing, tends to change.

And I think that's what's so important when we look at effective treatment strategies to help us with managing just the diversity that comes with long COVID. Because of course, your treatment strategies right now—it's centered around how can you optimize the patient's functioning? How can you improve their quality of life?

And right now it's symptom management. I mean, that's what it is. So when you look at the Centers for Disease Control, when you look at the CDC, they really emphasize focusing on the most bothersome symptoms, right? That that patient is going to identify.

And I do think that it's important to listen to the patient, to listen to their symptoms, because the symptoms are so diverse and different and their patterns are so different from patient to patient. That most bothersome symptom could potentially change over time too.

So listening and just focusing on how we can increase their quality of life and recognizing that it might change over time. And so one of the recommendations, of course, is to have patients track their pattern of symptoms and that relapsing-remitting pattern through journaling or even a calendar—like journaling on an actual calendar. And that's really just going to help us with identifying: is there anything that makes their symptoms worse? Is there anything that makes their symptoms better?

How can we not only manage what they're going through with medication but also strategies like physical therapy and occupational therapy? So, you know, going back to what you were asking earlier, that is really where it comes into pulling in that multidisciplinary approach where you can come together and tailor this treatment plan that includes rehabilitation with lifestyle modifications, along with medication management when we need it.

Because I mean, honestly, the nature of the beast here is that this is evolving. It's an evolving, changing nature of just patterns and symptoms. There's going to have to be ongoing management and adjustment of treatment plans in order for us to meet the changes that come with this process. It just has to be like that right now.

And I will say that as far as effective treatment strategies, while the CDC doesn't really come out—because we don't have evidence-based guidance on treatment—what the CDC has put out is just saying, hey, we've seen, it's been reported, I guess you should say, it's been reported to the CDC that patients have potentially benefited from symptom management using the management of fibromyalgia treatment guidelines, post-treatment Lyme disease, post-exertional malaise in general (just as a diagnosis not associated with long COVID), dysautonomia, and mast cell activation syndrome. So they have come out and said it's been reported to us that these treatments for these diagnoses have potentially helped patients with long COVID.

And what that looks like, it could be a combination from all those diagnoses for your patient, because it's again going to depend on what your patient is struggling with. What are those main symptoms that are really affecting their quality of life?

MCCORMICK: That makes sense. You know, that's one of the things that as a healthcare provider, I would really consider is, well, there's no evidence-based treatment guidelines. How do I manage it? And so until there are some, I think these are great guidelines to use.

And it's interesting to me just looking at those different conditions, how many of them are really autoimmune kind of symptoms or systems. So I think in the case of long COVID, it almost kind of makes sense to use those guidelines because a lot of those autoimmune illnesses really are multi-system illnesses, just like long COVID, and some of them overlap in their symptoms.

Also, I really liked what you said about having patients track their symptoms on a journal. I think that's a great idea, because as a person who's living with a chronic condition day in, day out, when you go to your doctor, to have that there to say, okay, this is how I felt on this day and this is what happened, is so much more valuable than, "I just feel really tired," and I can't really give you any day-to-day of the why.

PIERCE: Yeah, I was in bed for three days, but I can't remember what I did on the day before those three days. You know, like, go ahead, write down what you're doing and then write down how it affects you.

What I find really interesting about long COVID is that we really don't understand what is happening in the body with long COVID. And there are a few theories. I just, you know, want to walk us through a couple. There are a ton of theories, but these are the ones that really stick out to me the most.

You know, because we do not have the hard facts of what is actually happening in the body. Is it that this acute infection triggered an aberrant immune response? So now our immune system has started to mount this controlled, targeted attack on the virus, but it's gone into overdrive. And so we're producing this excessive amount of inflammation and it's

really just causing our immune system to mistarget our own healthy cells and our own organs.

So, you know, is it that? We don't know. Or is it that after the COVID-19 initial infection, it is like living in certain tissues in our body after that acute phase has gone away? So now basically what we're saying is your body is a viral reservoir, and that's where this inflammation and continued symptoms could potentially be coming from.

And it's interesting because with other viruses, we do know that we have seen that viral genetic material in general has been found in organs like your brain and your cardiovascular system. So, I mean, it's not a far stretch that theory could be true.

And then, of course, because a lot of your symptoms that you see do tend to live in the nervous system, you know, they're questioning: is this an autonomic nervous system dysfunction that was caused from that COVID-19 initial infection?

And I mean, when you look at the main symptoms that you're seeing, the symptoms do align with those involuntary functions that you see that are associated with your autonomic nervous system, because you have your heart rate issues, you have blood pressure, breathing, and even digestion.

I mean, I have actually seen patients whose treatment centered around nervous system treatments, and they have found recovery from long COVID. I mean, I wouldn't say that they were cured, but they have found recovery. So maybe we call it remission. I don't know, but there are a lot of theories just circling right now. But, you know, they're continuing to study and to learn. We just don't know. And how do you effectively treat what you don't know? You can't. Not really.

MCCORMICK: Now, this is so interesting, this virus.

PIERCE: And I would say that.

MCCORMICK: Go ahead.

PIERCE: Yeah, I was just going to say I would also consider addressing the mental health that comes along with long COVID. You know, here you are struggling with all these symptoms, nobody really understands it, maybe you're trying to figure out treatments. And so really pulling in that psychological support and counseling if necessary, or even the pharmacological interventions for anxiety and depression. You know, we've got to encourage them to communicate. And also, I think it's important that we validate their experiences. Even the CDC is like, hey, we need to validate what they are going through. This is real. Long COVID is real.

And even trying to connect patients with support groups or other people who are also going through this. But at the end of the day, validating is such a huge need for their mental health. Validating, because so many long COVID patients that I've spoken with, they are like—they state that they have felt dismissed and not believed and felt like people thought that they were crazy.

And they'll say, yes, I look fine right now, but something is wrong and nobody's listening to them. So we have to start taking these complaints more seriously, and we have to start working with our patients to rule out what could possibly be happening in their body. Validating. So important with this. So important.

MCCORMICK: I agree, I agree. With any chronic condition, I think when patients feel like nobody's helping me, I'm just crazy, and nobody understands, and it is so real when you have long COVID. And to have a provider say, I get it, I understand, yes, this is a real thing. I think it's so important.

PIERCE: And this is not, it's not unheard of that patients look normal and have a chronic condition. I mean, my daughter struggled with complex regional pain syndrome from a fracture, from the most minute fracture in her foot that we couldn't even see unless it was on an MRI.

But if you looked at her, she looked normal. And so, you know, it's not unheard of for a patient to come in and be like, hey, something is wrong. I know that I look fine. Something is wrong. I know that all of my tests are coming back normal, because that's also the thing with long COVID.

The reason it's considered a rule out is because the majority of the tests that you run come back to normal. They come back negative, normal. And you're like, I have no idea what's wrong with you. So, you know, of course we circle long COVID, because, I mean, we don't have other criteria to go off of. So it's not unheard of to have patients come in who have something severely wrong with them, and they look normal, and all their tests come back normal.

MCCORMICK: Right. As a healthcare provider, exactly, exactly. As a healthcare provider, for that mental health need, what would you refer your patients to do? Is there any support groups out there that you're aware of, even online?

PIERCE: So I'm not aware of any online support groups, but some things that I would recommend would be going to physical therapy, occupational therapy. I really think that that plays a huge role in helping to restore and maintain their physical function, which of course is going to improve their quality of life.

Now, I will say the overwhelming fatigue and that post-exertional fatigue that they're complaining of is going to continue to be the number one symptom that complained about with long COVID patients. But it's how do you function and then just be able to get things done without needing to end up in bed for days. That's huge. That's something that patients really need help with. So physical therapy can help with their mobility and their strength, while of course, occupational therapy is going to help with their daily living activities and the cognitive challenges that they are facing with that brain fog.

But I do want to point out that this is so important. This is not about increasing their exertional capabilities. It's not, in this case, not with long COVID. You need to work with a therapist that understands that. They don't need to spend so much time with a therapist who puts them in bed for two to four days trying to recover after going to physical therapy. That's not going to improve their quality of life or their functional ability. So you really need to work with therapists that understand what is happening to the body and how it needs to be treated and then tailor those treatment plans to their needs. So somebody who understands long COVID, somebody who understands what the patient's complaining of and what they're going through, is really, really important.

And then you can also do nutrition and lifestyle modifications. And that's really just, of course, it's going to depend on if that patient is struggling with GI issues. That's pretty big too. So do they need to change their diet based on what they're experiencing? I don't know.

That's something you're going to have to investigate as far as their overall health in general. Just maintaining, supporting our immune function and our overall health with a balanced diet is still just as important when we're treating long COVID as it is when you're not treating a disease process. And then of course your lifestyle modifications that are still so important like your physical activity, getting sleep. Sleep is so important to our body, and for some reason, it has been pushed aside, and I don't know why. But if you look at the research on sleep and the quality of health and the quality of life that you have, you would see just how important adequate, real sleep is to the recovery of the body and the body's ability to maintain its health. It supports your immune function. I cannot stress enough how important adequate sleep actually is. To the point that I have just emphasized it to my daughters. I have three little girls, and I'm like, sleep is so important that even my high schooler is in bed by like 9:00, 9:30. She doesn't stay up late. And it's just, it's so important, even as parents, that we teach our children healthy lifestyle. And I'm like, it's so funny because I have conversations with my daughters now, and they have started to recognize when they're like, you know, I'm being affected because I have not had adequate sleep. And I'm like, yes, that's right. That's why you have that attitude. That's why you're so stressed right now. So yeah, sleep is so important. Just could do a whole other pod. I think we do have a podcast on the importance of sleep. But also stress management, so important when you're dealing with that stuff. So really just maintaining healthy lifestyle and nutrition habits is so important.

MCCORMIE: I have to emphasize that healthy diet and that adequate sleep is so important for everybody. And especially when you have a chronic illness, it's even more important that we do that. And I agree, it gets pushed aside. We're worried about medicines and different treatments. And really, to me, the importance of nutrition is a medicine. Food is a medicine. And so that adequate diet is so necessary. Yes, I agree with that.

PIERCE: Yes, and we should be taking care of ourselves in such a way that you don't need melatonin every night to sleep. You know, once you start taking melatonin every night, your body's like, I don't need to make it anymore. And then we become dependent upon that. But if you bring in those healthy habits, you know, teach your children healthy habits, and then when they grow up to be healthy, it's just so important. I don't know why so many things have been pushed aside. Even in the hospital, sleep's even, I know this is going down a rabbit hole. But even with long COVID patients or COVID patients in general who are in ICU, ICU and sleep, they don't go together. Mental health and sleep, they don't go together either. Psych ward, you're in there every 15 minutes checking on the patient. Sleep and sickness have just not overlapped for a long time, and they need to. It's so important. It is so important. But yes.

MCCORMICK: I agree. I can't tell you how many times we wake up people in the hospital who just need to sleep. So I agree with you on that. Well, thinking about this, how can we really do that, in that primary care setting? There's a bunch of challenges in trying to manage that—the COVID, the long-term COVID. How can these challenges really be overcome so that we're able to manage that condition well for the patient?

PIERCE: Yeah. Well, you know, the biggest challenge is going to be time. You know, you need time for real discussions with your patient. You need time for real consultations with your patient and being able to get that in-depth assessment from your patient takes time.

And, you know, remember, this is a rule out. So how much time is it going to take to spend enough time with the patient to get your list of differentials, and then to be able to rule out each one of those?

So time—it is so precious in a primary care setting. Especially like if you were to go into an urgent care setting, you know, they have so many patients that they see a day. Primary care settings are the same way. It's almost like push in, rush out, rush in, rush out. You have to have time to really do an in-depth assessment, an in-depth history with these patients to really understand what's going on with them. We need time. We need time. Another challenge is that there's no standardized guidelines for diagnosis or for treatment. So it's, what do you do? You're kind of going, you're kind of flying by the seat of your pants, you know, like, well, I, you know, here's the complexity of the symptoms that you're going to see. You need to be able to have that multidisciplinary collaboration, which is sometimes difficult depending on where you live and who is around you and how well your providers work together. I mean, if you're in a rural area and all you have is a primary care—you

know, a couple of primary care physicians—and you don't, they don't have access to other specialties, you know, that of course is going to make it challenging to bring in that multidisciplinary care. And I think it's also important that we not be afraid to ask for help. Don't be afraid to ask for a second opinion from your peers. Like, hey, this patient came in, and these are all the symptoms that I'm seeing, and, you know, this is all the testing that we've done, and I'm really thinking this is long COVID, and these are their symptoms, and what do you think about my treatment plan? Or, you know, how would you move forward treating this?

Because it's new. It's new for everybody. We don't know what's going to work. So, you know, with no standardized guidelines, no standardized criteria for diagnosis or for treatment, I think it's imperative that we use our peers and we work together.

And then, of course, some other challenges that you really see in primary care as well is just—and this isn't only in primary care—I don't think this is just in primary care, but, you know, practices are continuously at best. Evidence-based practice is continuing to evolve, continuing to change. So you really have to just make sure that you're staying on top of the latest research. And of course, that takes time too. And then how do you know that new research is coming out?

So you got to make sure that you're tuned in to, you know, wherever the new guidelines are live and are coming out. Also, like telehealth is a good way to help with extending our consultation time and our time for discussions and our follow-up. So that's one way we can work to overcome some of the time challenges. And then another way is just trying to foster your partnerships with other specialties and other providers in your area. But again, that takes time as well. So there's definitely some challenges in primary care to taking care of a long COVID patient. So I think that's what also makes it harder to get the diagnosis and treatment that the patient really needs and the validation.

MCCORMICK: I agree, especially in a world where time is money. We go to the doctor's office and, you know, I've been to some practices where the doctors have to see another patient every 10, 15 minutes. And so that doesn't allow for that much time. So taking the time and slowing down and asking the questions for, you know, for your patient, I think. And that's the other thing that I think about as a challenge for a primary care provider is, you know, I'm in this. And a lot of times doctors are viewed as the experts, and the patients don't necessarily volunteer a lot of information. You know, they give the basics, this is kind of what's going on, but they don't challenge what the doctor says, and they don't also add all the details either of what's going on. So I agree. It's, you know, that skillful interview from that primary care doctor and that willingness to ask the questions and to take the time, I think, is so valuable for this diagnosis especially.

PIERCE: Yeah. And for long COVID, I will say, you know, it's hard to know what is coming out because it's so new and there's so many different bodies of research, organizations that are doing research on long COVID.

But the CDC does have a clinical overview webpage, and they do state that the definition of long COVID will continue to be evaluated as the data is collected and analyzed, and, you know, as data is reported. And as we learn more, we should one day, of course, hopefully have a better understanding of the pathophysiology of this infection-associated chronic condition. Because that's, you know, because I'm like, is it a syndrome? Is it a disease? Like, what do we call it? But they call it an infection-associated chronic condition.

Some other places that you can also look for would be the World Health Organization. They also are collecting and disseminating data. The National Institute of Health is also disseminating information. And there are a lot of our big research institutions within universities that are also involved in the research and gathering the data and the information. The three big ones are the CDC, the World Health Organization, and the National Institute of Health, where you can look to see, like, what is out there, what has changed, what do we know.

MCCORMICK: Right. And I think, you know, those are great organizations to look at for information. You know, it's great. There's new things coming out every day. So I definitely would stay abreast on those organizations. But where are we with those developing treatments as they're still trying to figure out what it is? Where are we on trying to figure out the treatments for it?

PIERCE: Oh, that's a tricky question. It's tricky to know the answer to that question, but I can tell you what we do know. So we have the timeframe of that initial recognition and characterization of long COVID, which is about one to two years. So that should have started about 2020, 2021. And this phase of just the recognition and characterization of this infection-associated chronic condition started rolling in globally around 2021. It wasn't even just the US. It started rolling in globally. And of course, that's that red flag for you of wow, what is this?

And then that leads us into the pathophysiological research phase, which usually lasts about two to three years. And so if we're looking backwards, you can see that significant research efforts for long COVID have been underway since about 2020, 2021. So it's almost like the research institutions were able to just quickly move through that initial recognition. They saw the red flag and they started looking into it pretty quickly. So that was very helpful.

But then you have your therapeutic explorations, which come along. And these explorations can last anywhere from three to five to ten years. And it really depends on if

the researchers are able to even find treatments and where we are, you know, somewhere in that phase.

I would say we are definitely evaluating potential treatments, you know, but of course, in order for us to move to evidence-based clinical guidelines, we have to use well-designed clinical trials because we have to determine the safety and the efficacy of these different management approaches.

And when you're looking at the sites, we're not really even offering treatment other than saying, hey, we have had some helpful management using treatment for these other diagnoses, so this might help you. And that's really all you're given. And of course, they're like, hey, manage the symptoms. But managing the symptoms is not curative. I mean, that's not curing long COVID per se. So we don't yet know if there is a real potential cure for long COVID. So I don't see where we are close to the establishment of definitive evidence-based treatment guidelines yet.

MCCORMICK: Wow, it does sound like we're way far away from a cure. But what are those best strategies that we see that people are using to really manage those symptoms?

PIERCE: Yeah, so we are seeing some things that are helpful and being used, you know, because unfortunately it can become just really debilitating and really affecting their quality of life. Basically, really their physical function. So an important area that I did talk about earlier was physical therapy, occupational therapy, but really that's to help them with, you know, musculoskeletal deconditioning, graded exercise therapy, just to help with gradually rebuilding some of that physical capacity that they tend to lose. We see respiratory therapy with using just improving their breathing mechanisms if they're struggling with some respiratory issues. You know, the fatigue is just, it's really severe. And so what they say with the therapies is, you know, just take an incremental patient-centered approach because you don't want to trigger the post-exertional symptoms.

Now, there are some different medicines that we see that they're using. This is based just off the hypothesis that we have this immune dysregulation from that acute COVID infection, which has now led to long COVID. We are seeing providers exploring treatments to help restore normal immune function with corticosteroids to reduce inflammation. We're also seeing them use intravenous immunoglobulin therapy and monoclonal antibodies just to help with targeting these specific inflammatory pathways that we are seeing with long COVID.

But what I will say is that all of these different medications that I'm talking about, the safety and efficacy of all of it is still under investigation for long COVID. These are just some things that we are seeing that have shown some positive progress for long COVID patients. We're also seeing patients, of course, using medications that target symptoms. We're talking about fatigue, so say your anti-fatigue medications or stimulants to help with that,

persistent fatigue that we're seeing with these patients. We talked about how we know that there are some mood disorders that are associated with long COVID, but we don't know if it's from long COVID or if it is actually from the changes that they're having to make in their life. We don't know. But we do see help with providing anti-anxiety medications, antidepressant medications for these mood disorders that we're seeing. Pain relievers are being used. Anti-seizure medications are also being used, especially for the nerve functioning issues that we're seeing.

You'll also see topical creams used for that myalgia to try to help with the muscle pains and also neuropathy if they're struggling with the neurological symptoms. And of course, your pain reliever that is chosen is going to depend on the cause of the pain. Is it nerve pain? Is it muscular pain? Where's the pain? Is it headaches? Where's the pain located? That's going to depend on what's prescribed. We're also seeing bronchodilators and anti-inflammatories for respiratory issues that are being used as well. But these all are typically used in conjunction with some type of rehabilitation service that I talked about earlier.

You know, it's really hard to know what's going to work for your patient, and you're going to have to work with your patient, and you're going to have to be willing to adjust the care plans that you have for these patients—from medications, to treating their symptoms, to what you're doing with your therapy services.

You know, incorporating your allied health providers is super helpful. But at the end of the day, the goal of everything that you use is going to be to address the diverse array of symptoms that comes with long COVID.

And that's going to be a comprehensive, individualized treatment plan, which takes time, which is hard to do when you're in a primary care setting. And so, you know, there's just, there's so many barriers to being able to provide this treatment that our patients need.

So yeah. But again, I really want to emphasize that the different types of medications that I'm talking about, they're still being researched. We don't have the guidelines to use this with long COVID.

So it's kind of like saying I'm using them off-label in a way, but you're kind of not using them off-label because you're treating symptoms. And so, you know, it's definitely a gray area. And I look forward to the day that we have enough data that we can say this is what our evidence-based guidelines for treatment of long COVID could look like. I just don't know when we're going to be there.

MCCORMICK: Right. Or even that day, one day, hopefully where they find a curative approach to not just treat the symptoms but to just hopefully get rid of the condition. It would be amazing. I know we're a long, long way from that.

PIERCE Yeah. And you know, we are. Yeah. It's really interesting too, because the epidemiology currently that we have for long COVID... like how prevalent is long COVID? Do we know? Do we really know?

When I was looking at the data for long COVID, it was suggested that between 10 and 30% of COVID-19 patients may develop long COVID, but the true prevalence is still just... it's still being actively studied. And that's a wide range, 10 to 30. But that wide range really reflects the challenges in accurately quantifying the scope of this condition. We just don't know. And we have a lot of factors that go into trying to determine the true prevalence, which is... you know, well, there are differences in diagnostic criteria. You know, we don't have set diagnostic criteria. There are differences in patient population. There are differences in study methodologies. And all of this contributes to the variability that we're seeing in the prevalence data reported so far. So it's really not clear. I mean, it's clear that long COVID represents a substantial public health concern that we know could potentially be affecting millions worldwide. But we don't really have a clear picture of the prevalence. And even our risk factors are questionable.

MCCORMICK: Absolutely. It'd be interesting too to see the difference in the strains of COVID that we have been presented with, to see if there's a difference in the long-term or the long COVID symptoms based on when they got it, which strain they had.

PIERCE: Absolutely. You know, I find it interesting because they still have out there risk factors. And currently, the risk factors that they say include those who had a severe acute COVID-19 infection that required hospitalization. Well, we know that there are many people who are struggling with long COVID who had mild COVID-19 infections. They weren't hospitalized. They didn't have a severe case.

Another risk factor that you see is older adults, especially those with chronic conditions. But again, we're seeing young—we are seeing children—healthy children, no chronic health conditions prior to infection, with mild COVID-19 infections who are developing the symptoms that lead us to diagnose them with long COVID. So again, yes, this was an identified risk factor, but is it really? Females. That was another risk factor that was identified. Some of the data suggests that women are disproportionately affected by long COVID compared to men. And of course, the reason behind this gender disparity is still under investigation. Is it hormonal? Is it immunological? Or is it due to socio-cultural factors where the disease susceptibility and symptom reporting suggests that women go in for help more often than men? So there's some gender bias within that. And we also know that men and women are being affected by long COVID. And then, of course, another risk factor was just chronic conditions. So, you know, individuals with pre-existing conditions. And I do think that that absolutely could be true—related to that immune dysregulation, the chronic inflammation that comes with pre-existing conditions, and of course the organ damage that can result from COVID-19 itself. But again, even the risk factors require ongoing

research to further explain the mechanisms underlying long COVID and what really causes the heightened vulnerabilities and variability that we're seeing. It's still questionable.

MCCORMICK: Yes. Well, one thing that we haven't talked about, I wanted to just touch upon for a second is... let's talk about the caregiver burden. We've talked about what it's like for the patient but talk about the caregiver burden of what it would be like to care for someone with long COVID.

PIERCE: Yes, you really see this with parents of children who are struggling with long COVID. Because when you have children and you're, first of all, as a mom or a dad, you're trying to take care of your children and you're seeing firsthand what's happening with your children. But when you take them in to see the doctor, you don't get that validation. It's almost like they think you're crazy. And I hear that from a lot of parents because I have seen a lot of children being diagnosed with long COVID and struggling with it. But a lot of people, they miss work, they miss school. How do you stay connected with school? You're going from one provider to another provider trying to find answers. And that gets really hard, especially on someone who is taking care of another person. Whether it be a parent that you're taking care of, whether it be a child that you're taking care of. It's a lot. For some, it's a full-time job to be able to provide the care that comes with all of these symptoms, because they could be bedridden. You know, they might look fine today, but they're bedridden for three days. You just don't know what these symptoms are going to be. And then fighting for the treatment, fighting for the symptom management that you need. It's very stressful. It's very hard.

MCCORMICK: I can imagine just thinking about taking a child to the doctor now. And you know, I've had an issue with my own child of just getting a diagnosis for something simple like a UTI and it was missed. And we're looking at something big, you know, trying to get the provider to really listen to those lists of symptoms and really consider what it could be, especially from a child who may not be able to communicate well their symptoms. I think it...

PIERCE: Yeah, they know something is wrong, but they don't know how to tell you. It's like when your child says that their stomach hurts and you start asking, you know, and so it's a lot like the same thing. We have to inquire because maybe they don't know that they need to tell you. But I will say that, you know, if you don't take much from the podcast today, I hope you'll take this: how can healthcare teams collaborate to really just provide that comprehensive, continuous care that your long COVID patient really is going to need?

It's going to be all about regular communication, which is a barrier we talked about earlier in healthcare, unfortunately, because everyone is overwhelmed and everyone is so busy and it's hard to have those in-depth conversations with your patient or with another specialist. Like, hey, I need to come to you and just bumper this off you and see what you're thinking. Am I going down the right track?

And of course, don't be afraid to ask for help, for other opinions. It doesn't make us less of a provider to ask for help from others. I think it makes us a better provider when we do admit our weaknesses or our concerns to say, hey, what do you think about this? You know, and that's going to help treat all of your patients, not even just long COVID patients. When we admit that, you know, that's collaborative care right there. That's what that is.

And if you're working with therapists, being able to communicate through your electronic health records to really meet the needs of... to keep track of what's happening and see if any changes need to be made. And lastly, just listening to your patient. Listen to them. Affirm their concerns. Affirm their symptoms that they're telling you about.

Long COVID patients may look fine when they come in and see you, but it might take a lot for them to even come in and see you. And they might be so fatigued that they're in bed for days after they come and see you. It's that diverse. It's that complex. So listen. Listen. That's huge. And really, that's all I have left.

MCCORMICK: Yes, I agree. I think that's the biggest takeaway. That's the biggest takeaway that I've gotten. It's just the importance of working together, collaborating as a healthcare team to really wrap around the patient, to provide them with the support that they need.

PIERCE: Absolutely. Robin, we are out of time for our discussion. Thank you so much for just being on here and talking with me about long COVID and learning about long COVID. I really appreciate you being here with me today.

MCCORMICK: Well, you're welcome. It's been a joy.

PIERCE: To our listeners, thank you for joining us. And I encourage you to explore many of the courses that we have available on EliteLearning.com to help you continue to grow in your careers and earn CEs.