



Mental Health Awareness Month: Working to Destigmatize Mental Health and MS

Presented by:
Fernando Cuascut, MD, MPH

Alexis Crispino Kline:

Hello and good evening, everyone. My name is Alexis Crispino Kline, and I'm the Director of Mission Delivery and Grants Management with the Multiple Sclerosis Association of America. This evening we'll be discussing the topic of mental health and multiple sclerosis. In just a few moments, I'll hand the evening over to our wonderful speaker to get started. Before I do that, I have just a few items to touch on.

As a friendly note, the information being shared this evening is intended for educational purposes only and does not constitute individual medical advice. If you're in need of support please check with your trusted healthcare provider or connect with an MSAA Helpline specialist to identify resources. Also, this evening's program is being recorded and will be made available on-demand viewing on the mymsaa.org website in the upcoming weeks.

Finally, I wanted to take just a few moments to highlight some of MSAA's programs and services. If you have reached out to us before, you've likely met them, but MSAA hosts a toll-free Helpline staffed by individuals with a background in social work or counseling and who are familiar with MS. Helpline specialists can share information about MSAA's programs and services, as well as your resources available from the broader MS support community. For eligible individuals, MSAA has a durable medical equipment and cooling equipment program, which can provide tangible items that address some of the symptoms of MS, such as cooling vests for those experiencing heat sensitivity or four-prong walkers for mobility support. MSAA also has an MRI access program for eligible individuals who are experiencing financial or insurance related barriers to accessing their cranial or C-spine MRI to receive a diagnosis of MS or track disease progression.

Finally, MSAA also has a robust online community, including the myMSAA Forum and the MS Conversations Blog. If you have any questions or would like more information about MSAA's programs and services, please connect with us. And without further ado, I'm honored and delighted to introduce our esteemed speaker for this evening.

Dr. Fernando Cuascut, MD, MPH is an Assistant Professor of Neurology at Baylor College of Medicine, as well as the Director of the Multiple Sclerosis Clinic and Neurology Clerkship with Harris Health in Houston, Texas. Dr. Cuascut attended the University of Puerto Rico in San

Juan, earning his Doctor of Medicine and Master of Public Health. He completed his residency at SUNY Downstate Medical Center in Brooklyn, New York, and fellowship at Baylor College of Medicine. Without further ado, I am delighted to hand the evening over to Dr. Cuascut.

Dr. Fernando Cuascut:

Thank you so much, Alexis, and welcome, everyone. I'm really excited to be here today. So in order to start, I'm going to go ahead and share my screen. So today, we're going to be talking about mental health and MS. And to start with our objectives, first, we're going to be defining some general concepts about mental health. We're going to be then talking about or discussing factors that can influence mental health and then trying to identify some statements associated with it. We're going to move forward trying to learn about mental illnesses in people living with multiple sclerosis and then trying to understand how mental wellness can contribute to managing our approaches in mental health and MS. And at the end, we're going to have an open conversation and discussion to listen to your questions and concerns and try to come up with some answers for you.

So what is mental health? So mental health refers to our own or one's emotional, psychological and social well-being. So it influences our cognition, perception and behavior. So in other words, it can affect how we think, how we feel, and how we act. And also that determines how well we can handle stress and how we can relate to others and how we can make healthier choices in our daily lives. Mental health is important to say that it's essential in every stage in our lives, not only when we are adults, but also in child and adolescent stages as well.

Some concepts to discuss today is also what are the differences between poor mental health and mental illness. Although these terms are often interchangeably used, poor mental health and mental illness are not quite the same. So when we talk about a person that has poor mental health, this could be a person that doesn't necessarily have to have a diagnosis of mental illness. Like, for example, depression, anxiety, and so on. Likewise, a person living with a mental illness can have experience or episodes or periods in their lives that they can find physical, mental and social well-being.

So mental health problems. So unfortunately, mental health is a problem in our country. And for example, if you talk about some facts and in regards to the numbers based on the National Alliance on Mental Illness, we can find that 1 in every 5 adults in the United States experience some form of mental illness. Not only that, 13.6 million adults in America live with serious mental illness. And what is really disturbing is that it could take 8 to 10 years on average between mental health symptoms and getting an intervention.

Ok, let's move forward. So what are the factors that can impact our mental health? So there's different factors and different ways that our mental health can be impacted. For example, this can include genetics. So biology could be a source. Family history, childhood experiences, even larger societal issues, including violence, discrimination and poverty. And the way those factors affect us can change over time. For example, maybe some children could be more affected from social experiences and discrimination and violence versus an adult, for example. And this can be the other way around, too.

So how genetics and family can change our mental health early on. So biology and family history play a role, an important role actually, in our mental health over the course in our lives. Some people are actually genetically predisposed to have illnesses. For example, depression or anxiety disorders. Also, our family can model the way we handle problems, stress and interaction with others. For example, growing in a family in which mental health challenges are

openly discussed can teach us to do the same when we're facing those problems. However, if you grow up in a family where mental health issues are, we're being taught not to complain about them, that could translate to us growing with fears about talking about our mental health.

How social context can influence our mental health or every aspect of our environment can have an impact on your mental health. For example, where we live, if we feel safe where we live, if we have resources that we need where we live, for example, if we have a park that we can just freely walk and enjoy and interact with other people and we have healthy grocery stores around us. The cultural message we receive, if we're facing racism in our environment, that could also negatively impact our mental health. Making friends and how we connect to them and stay connected to them. So if you live in an environment where making friends is promoted versus an environment that we feel scared or we feel fear to interact with other people, those can definitely impact the way we handle mental health. Stressors in our everyday lives can also impact our mental health, for example, having economical problems to pay our bills can definitely negatively impact our mental health. And also major societal issues. Unfortunately, we can see our news and we see different problems, social problems that we're facing in our current lives. And then those can also have a negative or positive impact on our health. It depends on what the issue is.

Talking a little more about how social problems or social context can influence our mental health. As I mentioned before, so, traumatic things can happen to us and then when they happen, it could be us or families or communities, especially in our early years, this can shape how we see the world, we can respond to stress, and how we can... whether we have a chance to thrive or not. For example, living in a violent household or an unsafe neighborhood, as we'll probably discuss, or being exposed to chronic discrimination, can lead to stress that impacts us physically, mentally, and emotionally later in life.

Our ability to respond to challenges in our daily life is also influenced by the people around us. And then when we have a strong support network or even having at least one person who we can definitely share our feelings and our thoughts without feeling like we're going to be judged, that is definitely a positive impact to our mental health. And ultimately to our physical health, because as we learn more about it, we definitely know that mental health and physical health are directly related.

So big societal and global issues can also have a real impact on our mental health and on our well-being. The more chaos, instability, violence and discrimination or division we experience, the harder it is to maintain positive mental health. Social and political issues can definitely affect us in different ways, and it can influence the way we perceive or the way we interact with others. And also this is true that the different societal problems can affect different groups in different ways, it depends on what is the problem, the main source of the problem.

Moving on and talking about mental health stigmas. So mental health problems are really commonly affecting thousands in the United States, as we previously discussed. Despite this, there's still a strong stigma around mental health, and people with mental health problems can also experience discrimination in different aspects of their lives. So why are people with mental health problems discriminated against? So one problem can be stereotypes, and unfortunately this can come from media and people with mental health illnesses can be perceived as more violent versus other people, which we definitely know that's not true. And this can lead, because of misinformation about what are mental health illnesses and what are the consequences of that. And also because of the fear of the unknown. So people that are not experiencing the symptoms or have not been related to others experiencing these illnesses can have fear

because they don't know how to interact with them. And it's mostly because, again, the misinformation and the stereotypes we have built, you know, society, some of them stemming from the media.

So let's talk a little bit now about mental health and focus our attention on multiple sclerosis. So multiple sclerosis is a disease that impacts our brain, spinal cord, optic nerves, and this compiles the central nervous system. The exact mechanism of MS is unknown, but we know that something triggers the immune system to go attack the myelin around the nerves in the CNS. The destruction of this myelin can impact or interrupt the signals from the brain to the body and because of that, patients can have different symptoms. And this could include numbness, tingling, mood changes, memory problem, pain, fatigue, blindness, and paralysis. Important to mention here is that everyone's experience with MS is completely different and it's because the way the CNS is being affected. And the neurological losses can be temporary or long lasting.

So people with MS often focus on their physical health and neglect their emotional health, and even those it is essential component of their overall wellness. So why is that? It would be... one reason could be is that it would be easier to focus on the symptom as physical because you actually can feel it and you can actually see it. For example, the weakness in my arm and I can show that to my physician so they can address that problem. But different to that would be when we try to address our mental health. If you don't focus or if you don't think about this, we can minimize that problem. And sometimes if a patient doesn't comment those symptoms to their MS provider or their physician, those symptoms can be minimized or not targeted or treated accordingly.

And as we know, a new diagnosis for multiple sclerosis can bring grief and is prompted by a sense of loss, which can definitely impact the mental health of that particular patient. And because MS is incurable, it's a chronic disease, the diagnosis may come with the fear about what lies ahead and the frustration of having to adapt to treatments and the deep sadness that is about to deal with what is unexpected. So that loss of control over what's going to happen in the future can bring lots of mental health problems, which, if not addressed, those can translate to having more physical problems and we're going to be talking a little more about that as well.

So mental health, MS and mental health, can affect everyone with MS in different ways. If you or your loved one have MS, you're probably familiar with the limiting symptoms of MS, and this could be, again, weakness, bladder changes, difficulty walking, fatigue, numbness, and others. And however, emotional changes and mental challenges can be as debilitating, or if not more, than the physical problems that a patient with MS can experience. And emotional, this is really important to highlight here, I want to really make sure that we all understand this, I do get a lot of questions from my patients when they're trying to discuss their mental health problems. They have the doubts if this is a symptom from MS or if this is me reacting to my diagnosis and the fact is it could be both. As we know, emotional changes can be a symptom of, or our reaction to, MS. The good news is that, however, we know that there's treatment options and there's ways we can improve those, and we're going to be talking about those as well.

So let's talk about, a little, of mental illness challenges in MS. And when we talk about those, we can discuss depression, anxiety, bipolar disorder, and pseudobulbar affect. We're going to be discussing each one of them in more detail. So first, let's talk about depression. Unfortunately, depression can occur in up to 50% of patients with multiple sclerosis and is three times more common than in the general population. Up to 40% of support partners or associate caregivers or spouses may also experience depression at some point of their lives. And this is due mostly

because household role changes and financial concerns as well as depression and current symptoms in the person with MS are all factors that may contribute to caregiver distress. As we all know, MS is a really comprehensive and a really challenging disease that, as we keep learning about this, it doesn't only affect the patient but also the close relative members because of symptoms like this, for example.

Talking about anxiety. So anxiety can be affecting up to half of the patients with multiple sclerosis and depression. But also, anxiety can grow independently of depression. So meaning that patients can have anxiety with or without depression, and anxiety disorders are three times more likely to happen in MS than in the general population. And sadly, it also has been linked to decreased social interactions, increased excessive alcohol use and increased levels of pain. It may also impact cognitive skills, such as how fast your brain can process information. And when it comes to living with multiple sclerosis, anxiety often stems from the uncertainty over what's going to happen in the future.

Bipolar disorders. So bipolar disorders are definitely more common in multiple sclerosis than in the general population, are characterized by having depressive and manic episodes. When we're trying to discuss what is mania, it's when a person is having elevated mood, feels "up" or "high", has irritable mood for at least one week, speaks rapidly, is easily distracted, has racing thoughts, maybe has high energy, is overactive or acts impulsively, and also has poor judgment.

Different to that is a pseudobulbar affect. Some of my patients sometimes get confused to if they're actually having symptoms from bipolar disorder or pseudobulbar affect. So let's talk a little bit, what is a pseudobulbar affect? So this is a disconnection depending on how you feel and how you express your emotions. So for example, a patient with pseudobulbar affect could have all of a sudden cry spells, although they don't feel sad or feel upset, or they can have uncontrollable laughter or laughing and for something that they don't find funny, which is completely different from the patient that had bipolar disorder, which can have these episodes of having depression or mania.

So let's talk a little bit now about mental wellness as it relates to living with multiple sclerosis. So we know that how do you feel and how do you talk to yourself and your physical and emotional and social well-being definitely impacts MS symptoms. So how you feel physically is definitely related to mental wellness. And studies show that patients with depressive symptoms or anxiety could have more MS symptom pain. So targeting mental health, this is an important and comprehensive approach where we're trying to discuss the overall wellness of our patients. Not only that, patients that have a healthy mental wellness could have more motivation to attend their health, including going to their appointments with a doctor, taking their medications and taking care of themselves.

Also, it can affect how much and what you eat. So we know that having a healthier diet can definitely impact some MS symptoms. So having mental health or mental wellness can definitely help you make healthier choices, which translates to having a healthy body weight and overall healthier wellness, physical wellness. Also the amount of exercise, if you stay positive, if you have healthy mental wellness, you will tend to pick healthier choices, and then this will also impact the amount of exercise that you do. How you relate to others and how others may actually perceive you. So having a positive attitude towards yourself and a positive attitude towards what's related or what's happening around you can definitely promote healthy interactions with other people, including your family members. That can definitely... you can all benefit from that encounter. Also enjoying your daily activities. So having a mental wellness can

definitely help you enjoy those little things in life, which can definitely make you appreciate life and appreciate what the positive things are happening, after the Diagnosis of multiple sclerosis.

So how can mental wellness contribute to management approaches in MS. As we discussed before, having mental health wellness can definitely positively impact the way we perceive ourselves, the way we relate to others, and the way we interact. So with that, I've been trying to say, it can help us focus on the positive things of life and the positive things that are happening. So patients that have a healthy mental wellness can stay positive and with that, they can make better choices and healthy choices. It can definitely build resilience. So the ability to overcome obstacles in a healthy, positive way, and we've done... patients that... one of the challenges that have patients with newly diagnosed MS is what's going to happen next, what their symptoms mean, what's going to happen next. And then they can feel sad and they can feel anxious about this. So having resilience about those, what things are going to happen and it can prepare patients to better manage their problems and to make them feel better.

Staying centered. So even though there's a lot of challenges that can come with a new diagnosis of MS, staying centered to what's really important and then staying positive about all of the things we do appreciate in life and the things that are important to us, It can definitely help our mental health wellness, and it can help a patient with MS to overcome those obstacles.

Managing stress. Stress, high stress, can definitely make some MS symptoms worse, and then having healthy ways to cope with stress, and managing stress, definitely can improve positively a patient's overall wellness.

Pay attention to mood. So with a new diagnosis of MS, there can come many symptoms, including anxiety, depression or sadness. So try to pay attention to those symptoms, and not just to kind of block them, but actually trying to learn from them and trying to listen and trying to understand why you're feeling that way and focusing on the experience of where those symptoms are coming from and trying to understand what they're trying to tell you. It's important, instead of just trying to neglect them because of the fear. Accepting those challenges, accepting, that's a first step to what's going to come with a diagnosis of MS.

Building, nurturing your relationships. So having people that can support us is really important because when you feel a space that we can say everything that we feel, the way we feel in a safety way, that we don't feel we're going to be judged in any way. Sometimes it could be a person. It could be a family member. Sometimes we need to address that with a mental health specialist.

And practice mindfulness. So being aware, being accepting of what's going on, and be present at the moment, but also calmly accepting your symptoms and your thoughts and your perception of your problems, it's really important way to cope and manage your stress related to a new diagnosis. So when we have all this into place, we can definitely overcome challenges that can come with that new diagnosis of multiple sclerosis.

So when I talk about mental wellness and how when we're trying to deal with a new diagnosis of MS and when I'm trying to discuss this with my patients, I try to promote this approach of validating, reflecting, or resolving the problem. So what I'm trying to say by this is first, when you try to validate, just validate those emotions and let them know that it's OK to feel sad, it's OK to be feeling fear or an anxiety or stress after having a new diagnosis with MS. It's OK. You should learn about why you're feeling that way. Listen to those emotions and listen to what they're trying to say and just try to highlight what is the importance of what is going on at the

moment. Different from that will be patients that would trying to either minimize or actually block those feelings because they don't want to deal with that, which could be an unhealthy way to cope with your mental problems, or trying to... do not validate your emotions.

So once we hit that stage that we can validate those emotions, then we move forward in trying to reflect again to why we're feeling that way. And I like to tell my patients practice observing those emotions, just observe them and don't react to your emotions or your thoughts, just listen and learn about what they're trying to tell you. For example, if a patient is feeling sad after their diagnosis, this could be because of the fact that they have a loss. They lost something that they love. So how we can then cope and try to learn, so, what is important and what is not. So feeling sad, maybe because you value your health and we can then turn that around to them focusing on healthy choices to make sure you live your best life as possible after that diagnosis. And that could be one example. So broadening your view of the problem. So, and I am trying to say, when you have a lot of unknowns, you can focus on the negative side of the diagnosis.

Broadening your view about other possibilities could definitely change the way you see things. And this sometimes, you need to get some help from a mental health specialist or your MS provider or your primary care doctor or any physician. Sometimes patients have a hard time trying to see the other way of things.

And then at the end is to resolve. So try to name or label your thoughts or your emotions. This is stress. This is anxiety. This is sadness. And then trying to resolve those, either with your own tools, but sometimes it's not enough. I need to highlight the importance of finding mental health services if you think you're definitely feeling sad or feeling anxious, definitely it's something that we always encourage our patients to talk about their emotions. And then we definitely use that as part of our comprehensive approach to trying to treat MS. And sometimes we will need help from the mental health specialists, including a psychiatrist or a mental health specialist, like a therapist when patients have a challenging, or they cannot really have healthy ways to cope with their problems and mental health problems.

So in conclusion. So, mental health can affect how we think, how we feel, how we act. There's different factors that can impact our mental health, including genetics, family, relationships, childhood experiences, societal issues like violence, discrimination, poverty. Emotional changes can be a symptom of or a reaction to MS. MS patients carry a higher risk to develop depression, anxiety, bipolar disorder, and pseudobulbar affect compared to the general population. Mental wellness is an important component of comprehensive care for every MS patient.

So I would like to know now the experiences that you have, and I would like to lead this open conversation to hear about your thoughts and your experiences so far.

Alexis Crispino Kline:

Thank you so much, Dr. Cuascut, that was wonderful. You know, and just to build on that, we had so many wonderful questions come in, it would be great to ask you. The first one that I wanted to prompt you with is, so, aside from the mental stress of having a chronic and oftentimes painful disease, are there other ways that MS affects me personally mentally?

Dr. Fernando Cuascut:

Yes. So MS, as we discussed, can actually affect your mental health. And with that, MS can actually increase the risk of having depression, anxiety, bipolar disorder and so on. So MS definitely has a direct impact or it could have a direct impact on your mental health.

Alexis Crispino Kline:

Thank you so much. Yeah. And so just to build on that, too, how can people tell the difference between feeling a little down or sad or actually being depressed?

Dr. Fernando Cuascut:

That's a great question. So one way we can try to solve that problem is asking ourselves is my mood affecting the way I live. And if the answer is yes, that means that most likely your symptoms could be due to depression or clinical depression. However, if you're not sure, you definitely need to talk to your provider and then let them know your emotions and how you feel, so they can definitely let you know and help you, giving the right diagnosis.

Alexis Crispino Kline:

So someone wants to know if you're in remission with your multiple sclerosis, can you still have depression from your multiple sclerosis?

Dr. Fernando Cuascut:

Great question. Unfortunately, yes. Unfortunately in depression it could happen independently of relapses or MS activity. So the answer is yes. And definitely if you're feeling depressed, if you're feeling depressive symptoms, that's something you should definitely address and let them know, let your provider know about those symptoms.

Alexis Crispino Kline:

And so I guess on the other hand, how do you know when you might not need your medicine anymore or you might need to change medicines if you are taking something for your depression?

Dr. Fernando Cuascut:

Great question. So that would be, we'd have to rely on your provider, but you would need to let them know, so if your symptoms are not well-controlled, despite the fact you're taking your medication, or if you have any side effects to the medications, those are reasons to why you should definitely consider changing the medication, definitely under the guidance of your provider.

Alexis Crispino Kline:

Great. And then another question that comes in is how does demyelination cause mental illness? Is that the cause of it for some people?

Dr. Fernando Cuascut:

Great question. So what we think about the mental illnesses that are related to MS is because of this regulation of the connections in different parts of the brain. So, in that, demyelination can affect those connections. So the answer to that could be yes. It's a little more complex than that, but we can say yes because demyelination can affect the communications in different parts of the brain, which can lead to mental illness.

Alexis Crispino Kline:

Really interesting. Thank you for sharing that. And I guess, so someone said that after I got diagnosed with my MS, I became anxious, impatient, and occasionally rude. Is it because of my MS or is it mental health related?

Dr. Fernando Cuascut:

Great question. This is a question that I face almost daily. It can be both. As we previously discussed, so anxiety could be a symptom from or reaction to MS. The good news is that even though it could be either/or, we still have options to treat it.

Alexis Crispino Kline:

That's great. And so I guess if someone feels that their depression isn't alleviated and they've tried drugs, they've tried therapy, they've tried transcranial magnetic stimulation, but they just haven't found reprieve from their mental health challenges, do you have suggestions for that?

Dr. Fernando Cuascut:

It seems that that's a really challenging case and definitely sometimes we need to find experts. And with that, I'm trying to say maybe as an expert, they can deal with more, you know, dedicated to depression. Sometimes patients have to stay in the hospital for a while if those symptoms are not getting better and then find different medications and maybe different medication combos to make them feel better.

Alexis Crispino Kline:

And that's, I guess in terms of trying to approach the symptoms or how folks are feeling, someone also asked about MS causing a sleep disorder, or could it be caused by depression, or both, and how they might address that?

Dr. Fernando Cuascut:

Great question. So we didn't talk much about sleep disorders today, but we do know that sleep disorders are actually in a higher prevalence than the general population in patients with MS. But also depression can, or anxiety, can affect your sleep architecture. So one way we can try to target that, definitely under your physician's guidance, we can start by getting a sleep study or do a screening for depression and anxiety and see how those can impact your quality of sleep.

Alexis Crispino Kline:

That's good to know. And if someone needed or wanted to do something like that, they'd talk to their healthcare provider about it and let them know. It's an important thing for them to let them know.

Dr. Fernando Cuascut:

It's important to let them know, and I cannot highlight enough about my patients, and letting your provider know about your mental health, about your mental symptoms. For the most part, patients, some patients, can feel that they feel fear about talking about their mental health because of different reasons. But there are symptoms that should be addressed for your overall wellness. So it's important for you to let your physician know about if you're having sleep problems. Not only that, but if you also having anxiety or depression or feeling depressed.

Alexis Crispino Kline:

And that's, and I, again, just to build on that one, too, someone asked a complimentary question about taking medications versus working out in a healthy lifestyle and also, in terms of taking a disease modifying therapy, or mental health therapies, just kind of organizing all those different components. And what's right for who?

Dr. Fernando Cuascut:

Yeah, great question. Unfortunately, is not one glove fits all. So when you're trying to approach your mental health and also your multiple sclerosis health, that has to be in combination with different treatments and, with that, different interventions. So those could be definitely guided with your physician. In regards to what you should use, definitely, we always promote physical activity and exercises that can definitely help your physical health, but also your mental health. Definitely a patient with MS should be in a DMT, so disease modifying therapy. We can definitely talk about getting mental health therapists or psychiatrists if we think that those symptoms are not well addressed as part of the comprehensive approach. But again, as not one glove fits all and this has to depend on each individual's needs, for each individual patient.

Alexis Crispino Kline:

Thank you. And so do you have any tips on first how to avoid negative thought patterns, which can be hard to do, but then also search for those resources that might be most helpful for an individual person?

Dr. Fernando Cuascut:

Great question. So I would definitely encourage any patient that are feeling negative thoughts to first practice observing those thoughts, rather than reacting to them. So just watch, listen and see what the message, the underlying message. Try to label your thoughts and learn from what is happening in your headspace, if this is a negative thought or if it's anxiety. Try to label them, because then that could definitely help you organize your emotions and also to address those with your provider.

Also focus on the moment and the experience that you're actually having. And then kind of broaden your view about other possibilities or other solutions to your problem. Those are not easy to address and those are hard, and I understand those are really hard emotions to deal with. Definitely let them come and then validate your emotions, don't let them minimize those emotions or block them. And definitely, always, always, always, you should definitely, if you feel comfortable, to talk to your provider about those emotions. You should definitely not minimize those and you should take them seriously.

Alexis Crispino Kline:

Great. Thank you so much for that advice. And I guess the next question that we had was in regards to someone who was progressing with their MS to primary progressive, and they want to know if you have any ideas or tips on how to deal with the mental pressure of having that transition in a diagnosis to a different diagnosis or progression?

Dr. Fernando Cuascut:

Great question. And we need to realize that any patient with a new diagnosis of MS is definitely not going to feel happy about it. Right? So definitely many emotions can come after diagnosis of MS. And those, again, could include the fear, anxiety, sadness, and particularly with a patient with primary progressive MS, we maybe have more limited treatment options versus a relapsing-remitting course, and that uncertainty of what's going to happen in the future can also impact the way, or the mental health of that particular patient.

So if we go back to the treatment approach, a little exercise that I like to discuss with my patients, the first thing I will encourage that patient is just to validate those emotions, validate the way you feel, and then practice, again, observing those emotions and your thoughts and then reflect upon why you're feeling those. Sometimes is helpful to write things down, as an exercise, and the way that you're feeling. So sometimes you have too many feelings happening

at the same time and it's really hard to cope and trying to find solutions to those. But writing things down could be one option for some patients to try to organize those emotions in a more organized or concrete way. And then with that, if you can practice mindfulness or resilience to try to overcome those, to try to resolve your problems, you need to find help from your provider, from your mental health specialist, and sometimes from the psychiatrist because it's a really challenging diagnosis. But there's definitely the positive side of this, there is definitely treatment and there's definitely options to promote the healthiest possible life for you.

Alexis Crispino Kline:

Thank you. And I saw that somebody had included in the chat that journaling was really incredibly helpful for them, too. So, you'd recommend that as well?

Dr. Fernando Cuascut:

Definitely it is, and it's because any person that's feeling the challenges of having a diagnosis could again have so many emotions, and they're overwhelming emotions. It kind of sometimes blocks the patient from making the right decisions. And then writing things down can definitely help kind of organize that.

Alexis Crispino Kline:

Great. Thank you. And we had a couple of questions come in, too, about communicating with family. So one of them was they would love, appreciate, or would appreciate advice for family members to best provide support to someone living with MS who also might be dealing with a mental health challenge, especially for those who haven't disclosed this information to a lot of people yet.

Dr. Fernando Cuascut:

And that's a really challenging case. As we discussed before, MS doesn't only affect the patient, but also it can affect the family members, or their family members, because the complex interactions that can be happening or not happening anymore after the diagnosis of MS. Again, the first thing is to accept and then be open about your own emotions and the way we feel and then building a safe environment for your family member to talk to you about this. When you have... it's a really complex interaction when you have two people that are experiencing mental illness. But if there's a good relationship between them because they're family members, you can use that to have that openness of a safe environment to let the other person speak of what they feel. And then for them to then try to find help.

Alexis Crispino Kline:

Thank you. Yeah, and that's, and someone kind of asked the same question in managing brain fog and some other invisible symptoms of MS and how they might be able to communicate that with their family and help be more empathetic about the real feelings that they're experiencing.

Dr. Fernando Cuascut:

Great question. Brain fog or mental fatigue is a really disabling symptom for many MS patients. And unfortunately, as you said, it could be an invisible symptom because people are not aware of that symptom from that patient. So it's important again to build that openness about expressing your feelings or your emotions and letting them know that this is a symptom, that this is definitely affecting the way you perform and the way you interact, and sometimes it's even helpful to bring those family members to the visits with their providers so they can all interact and talk about those emotions and those symptoms so they can learn from that as well.

Alexis Crispino Kline:

That's such a great suggestion. And, you know, someone popped in with a really interesting question, too, that kind of accompanies that - if they're managing all of these stressors surrounding living with MS, you know, dealing with the disability and dealing with their employment, would you suggest that using love languages to strengthen family relationships and connect with your community a little bit better and also help kind of address that progression as you move through the process living with MS?

Dr. Fernando Cuascut:

Great question. So I would encourage, yes, I would say yes, I would definitely encourage that person to, one, just to spread their emotion and speak as the way those emotions are affecting you. I think there's a lot of stigma, again, as we discussed before, about people or patients expressing their emotions because of the stigma of mental health for different reasons. So navigating through that is important. And to include family members is also important because they need to kind of comprehend what's going on and to better help you. Having a supportive social group, this is important for every person but definitely a patient with MS, because the fear of the unknown, the fear of what's going to happen can definitely be addressed by discussing the way you feel with others. With that, definitely to the process of accepting the diagnosis and facing those challenges and overcoming those challenges, definitely having supportive family members and the environment is very important.

Alexis Crispino Kline:

Great. Absolutely. And what might you say to someone who wants to decline help from everybody, who doesn't want any help and doesn't want someone to have to take care of them and that's affecting their mental health? I feel like that could be something that's really challenging and prevalent.

Dr. Fernando Cuascut:

Yes, that's a really challenging situation. Patients that could be denying help, that could be, it could be a symptom of severe depression. And that not being addressed could be definitely... can impact negatively that particular patient. So I would suggest to listen to why you're feeling that way. Why... is it because of fear, is it because of the stigma, is it because of other personal reasons to why you don't want to get help. Learn from those. Why are you thinking that way? Again, a mental health problem is as important as a physical problem. So not trying to address that is like not trying to address a physical problem. And with that, implications of not addressing any health problem can be detrimental to your own personal health. So I would encourage that, as an overall approach, just to learn for why you don't want to get help. And then, and definitely, I would suggest, based on that, we know that could be a symptom and depression, should definitely highly consider talking to someone to get help.

Alexis Crispino Kline:

Yeah, that's really great advice and we definitely appreciate that. And I think another question that comes up that we've seen a couple times is how can you tell if your problems are MS physical traits or how can you tell if they're mental health problems or challenges before you consider what your next step is and how you want to approach it?

Dr. Fernando Cuascut:

That's a great question. So as we know, it's a complex interaction about your mental health and your physical health. So you can have both problems at the same time. So you can have patients with physical problems and mental health problems dealing with MS. So one way to know if you're considering, or think you're not sure if this is a mental health problem or not, versus a physical problem, trying to, again, trying to learn how are you feeling, how are you thinking. If you're noticing that you have anxiety, or if you're focusing on the problems, or if you're feeling sadness, or if you're feeling fear those could lead, or could suggest, that you are having mental illnesses or mental health problems. Those problems can affect your physical symptoms. So it's a complex interaction between the two of them. And you definitely are encouraged to talk to your physician or provider to better address those because, again, having one doesn't necessarily exclude to have the other one.

Alexis Crispino Kline:

Great. That's great feedback. And I guess to just pull it all together, folks kind of want to know, and you talked about it a little bit, but antidepressants or a psychiatrist or a therapist or just seeing your primary care provider or getting antidepressants. What kind of strategy do you think people should think about when they're approaching this and your preference in your work?

Dr. Fernando Cuascut:

Great question. So I would say, I would start by saying that, again, every patient is completely different. MS affects every patient in different ways. Now, in regards to what would be the best option. So that's going to be based on what are the symptoms you're having. So if there's an option to see a specialist, a mental health specialist, then I would say that would be kind of the best option. But we have to be honest, some patients living in areas that they don't have a specialist, a mental health specialist, I'm trying to say. So definitely, which for those patients the best resource would be then to talk to a primary care doctor. Right? So again, one glove doesn't fit all, unfortunately, and every patient is completely different. Some patients can find it helpful to talk to a therapist and they might not need antidepressant medications and so on. The first step is to talk to your provider, and if your provider is a primary care doctor, because there's no specialist, that is great. But if you do have, or you have the resources and you live in an area where there's definitely a mental health specialist, then that will be the best option.

Alexis Crispino Kline:

Great. Thank you so much. And I guess when we're talking about what providers and who you see, kind of a more general question, if, someone mentioned in the chat, you know, they had been seeing one provider and they didn't get great information from them, especially early on in their diagnosis and they've progressed significantly. And someone else was put on a similar treatment plan and it just ended up her mental health illnesses might have, or their mental health illness, might have progressed a bit. But what would you say to someone who maybe isn't connecting with their provider that they're seeing or doesn't maybe necessarily agree with what their providers are saying or their treatment approaches that they're planning for them instead of with them? What might you suggest for that?

Dr. Fernando Cuascut:

Yeah, that's a really challenging situation, and thank you for bringing that up. As a patient, you're entitled to your own health, and unfortunately there could be a complex interaction with a physician and patients, and sometimes they're not the best. So there's definitely... I would suggest to, if you don't feel comfortable, if you don't feel happy with your treatment approaches, to definitely reconsider seeing a different provider. For MS, I would definitely suggest, because

it's such a comprehensive and complex disease, to definitely try to see a MS specialist that can definitely, that has a more comprehensive approach. It requires, definitely, a village to help a MS patient, including, you know, your MS specialist, but maybe you're also going to need other providers as well. For example, a rehab, a mental health specialist, ophthalmologist or urologist and so on. So if you don't feel happy with the way your MS is being treated, then definitely consider, you know, changing providers. And definitely, if you're changing providers and you have not seen an MS specialist, then that will be a great opportunity to see one.

Alexis Crispino Kline:

Thank you so much. Yeah, that's great. And we had one more question just pop in and these are pretty neat, the questions that are coming in. So someone wanted to know, and I think this will be the last one, so we want to know, do the brain lesions due to MS affect your mental health? So I know we talked about the demyelination a little bit, but this is another neat question.

Dr. Fernando Cuascut:

It's a great question. I've had to face this question before. So, brain lesions... So if we're trying to say, if we look at an MRI and we're trying to describe and see those lesions when we're discussing in our visits with our patients, I can't say this lesion is causing mental health problems. So it's more complex than that. I can't, we cannot pinpoint one lesion is causing depression and one is just causing anxiety. There's not such a thing. We think there are underlying, and we still need to learn more about this, but the underlying pathology related to mental health problems in MS is actually really complex because it involves miscommunication or communication problems within one part of the brain versus the others. And the way how those complex interactions are disregulated. It's not only one lesion causing depression and one lesion is causing anxiety, and so on. Hopefully that makes sense.

Alexis Crispino Kline:

Definitely. Thank you so much. And so I guess just to close us out, do you have any suggestions or resources that you might point people in the direction to? And also just any closing words of wisdom for us as well?

Dr. Fernando Cuascut:

Thank you. Of course. So there's definitely online resources. If you... definitely your provider... you definitely talk to your provider about this, but there's definitely online resources like, for example, the MSAA has great resources about MS and mental health. So that's one website. Also, the CDC talks about mental health and actually mentalhealth.org is another great website that you definitely can find more information about this topic. So those are some resources that you definitely can look and definitely talk to your primary care. So as a closing sentence here, one of the things I would like to say is, to talk about, mental health is highly prevalent in MS patients, and mental health can be as important as physical health. And because of stigmas, or definitely stereotypes, many patients with MS don't feel comfortable to talk about mental health. But I need you to understand that this is really important because mental health can impact directly the way you feel and the way you live and the way you're going to experience your life and how you're going to perceive your life and your relationships to other people.

Good news is, even though there's a lot of challenges coming from the dosage of MS, there's treatment options, OK, and there's ways we can make you feel better. You definitely need to let your physician hear about your problems and feel comfortable, feel really comfortable to talk about them. And if you don't feel comfortable and you don't feel happy, then, as we discussed

before, maybe reconsidering switching to a different provider that you definitely feel comfortable because this is really important. This is really important to address because it directly impacts your health. And for the last sentence here, learn about your emotions. Don't minimize them, don't block them. Learn from them. Practice observing those emotions and learning about why you're feeling that way and accept those as they come because that is important for you when you're trying to overcome those challenges. And then at the end, I would like to say that even though a patient has MS, MS doesn't have them. So, we have definitely help for you. And thank you so much for letting me talk today.

Alexis Crispino Kline:

Oh, you know, thank you so, so much for this really wonderful and amazing presentation, and the Q&A session that was just really fantastic. And you shared so much.

Dr. Fernando Cuascut:

Thank you very, very much.

Alexis Crispino Kline:

So much warm and really wonderful program information. And we really appreciate it. And just to everybody watching tonight, thank you all so much for being here. So a friendly note, if you have any questions or concerns, if you want to see this recording on demand, you can visit us online at mymsaa.org or you can call us, send us an email, whatever you need.

And also you'll notice we put a link in the chat box for our Patient Education Program survey, if you'd like to fill it out and give us some feedback. But again, we hope everybody has just such a wonderful night and a great weekend and thank you again, Dr. Cuascut. Hope everybody has a great night.

Dr. Fernando Cuascut:

Thank you. Thank you. See you at the next one. Thank you, guys. Thank you, everyone.