



Mental Health: A Candid Community Discussion

Presenters:

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Humberto Cruz Esparra, PsyD, MPsy
Diana Andino, MD
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Yahaira Rivera:

Hello. Good evening. On behalf of the Multiple Sclerosis Association of America, we extend a warm welcome to all of you. Thank you for participating in our seminar: Mental health, An Honest Community Conversation. The seminar will be presented by experts in multiple sclerosis, mental health and public health. My name is Yahaira Rivera Bobadilla, I am Director of Mission and Program Development for the Multiple Sclerosis Association of America and together with Dr. Fernando Cuascut I will be the moderator of this program.

This seminar is part of our initiative *Together Finding Resilience, Living with Multiple Sclerosis*, an initiative dedicated especially to the Hispanic/Latino community living with multiple sclerosis. This program is brought to you by the Multiple Sclerosis Association of America in collaboration with Impact Education, and is made possible through the generosity and support of our sponsors: Biogen, Bristol Myers Squibb, Genentech, and Sanofi Genzyme.

Before we start today's program, I want to give you some information about who we are and our services and also share some reminders. The Multiple Sclerosis Association of America is a national nonprofit organization dedicated to improving the quality of life for the community living with multiple sclerosis through vital services and support. Services include a nationwide toll-free hotline that provides services in English and Spanish, Monday through Friday from 8:30 a.m. to 8:00 p.m. Eastern Time. We also have an equipment distribution program with products designed to improve safety, mobility and to help with heat sensitivity. We also have an MRI access program where individuals living with multiple sclerosis, if they qualify, receive monetary assistance for the cost of this exam. In addition, we offer educational programs in English and Spanish, publications, and digital resources to keep you informed. All programs are available to people living with multiple sclerosis in this country and its territories. Many of these resources

are available in Spanish. For more information, I invite you to visit our website, as you see on the screen, mymsaa.org, you can contact us or call us and follow us on social media.

We want to remind you that this program is for informational and educational purposes only and does not constitute official recommendations. If you have any questions that are specific to your treatment and diagnosis, you should contact your doctor or healthcare provider.

During today's show you will have the opportunity to participate and share your comments in the chat to interact with our panelists. If time permits, we will try as much as possible to have a Q&A section at the end of the seminar. I also remind you that this program will be recorded and will be available in our digital library, so you can watch it again or share it with your loved ones. At the end of the program I ask you to please fill out a brief survey. Your comments and suggestions are important and help us develop future programs. The link for the survey will be included in the chat.

As part of mental health awareness, we want to let you know that if you or someone you know is experiencing suicidal thoughts or is in crisis, you should immediately contact the lifeline through the phone number you see on the screen or you can contact your healthcare provider.

And now, without further ado, I want to introduce you to the great panel that we have invited tonight. Joining us as moderator is Dr. Fernando Cuascut, Dr. Cuascut is Assistant Professor of Neurology at Ballard College of Medicine and Director of the Multiple Sclerosis Clinic and Neurology Internship at Harris Hall in Houston, Texas. He attended the University of Puerto Rico, earning an M.D. and a Master's in Public Health, completed his residency at Soni Medical Center in Brooklyn, New York, and his fellowship at Baylor College of Medicine.

We also have as a panelist Dr. Diana Andino. She is a neurologist and clinical fellow at the Center for Multiple Sclerosis and Neuroimmunology at the University of Texas at Austin. She is currently completing her fellowship in the care of patients with multiple sclerosis and other central nervous system disorders. She completed her neurology residency at Loyola University Chicago Medical Center and earned her medical degree from Loyola University Chicago Stritch School of Medicine.

We also have Dr. Humberto Cruz Esparra, Clinical Director of Special Projects and Employee Assistance Program at CIMA Mennonite Hospital in Aibonito Puerto Rico. He completed his training in Psychology at the University of Puerto Rico, graduate and doctoral studies in Behavioral Sciences and Psychology at the Ana G. Méndez University and Postdoctoral studies in Clinical Psychology at the South Carolina School of Medicine.

Another panelist who honors us tonight is Dr. April Moreno. She completed studies in Anthropology and Public Health at the University of California. PhD in Health Promotion Sciences and Systems and Information Technology and a Postgraduate in Biomedical Informatics. Dr. Moreno is founder and Executive Director of the Autoimmune Community Institute in San Diego, California.

Welcome everybody. Thank you for being here educating our audience about the importance of mental health in multiple sclerosis. Dr. Cuascut, we'll pass it to you.

Dr. Fernando Cuascut:

Thank you very much Yahaira. Welcome everyone and it's definitely a pleasure to be here sharing with you today. Thank you for taking the time to allow us to connect with you. Today we

are going to focus on a topic that I think is very, very important, which is mental health, specifically in patients with multiple sclerosis. And since I always recommend it at the same time, I tell my patients that mental health is as important as physical health and they should not be minimized in this regard.

But many times when we try to understand what mental health is or try to define it, we find it a bit difficult. Well, and I want to start by talking about trying to define what we mean when we say mental health. Mental health refers to the emotional, psychological or social state of a being. Right? It is influenced by cognitive processes, the perception of the situations that surround us and our behavior.

And why is mental health so important or emphasized? Because it can affect many components, particularly how we express ourselves, how we feel, how we handle stress, and how we relate to other individuals. Therefore, a healthy or intact mental health allows us to better manage stress and relate to other people in an appropriate way.

Mental health is not a factor that should be associated only with adulthood, but mental health is part of us from childhood. It is important to emphasize that children also have mental health and we have to address it. When we talk about mental health, it is also important to say that there are different mental health disorders, and I want to make a point of emphasizing a very big difference that with mental health, there is a difference between talking about a mental disorder, which is a diagnosis, versus overall mental health. When we talk about poor mental health, we are referring to a patient, for example, who has relationship problems, management problems, stress due to problems, perceiving their problems, and that does not necessarily mean that it is a mental health disorder.

When we talk about a mental health disorder, like here on this slide, with this graphic representation, I have some of the health problems or mental disorders that multiple sclerosis patients can have. And I would like to hear a little more from the panelists, for example Dr. Andino, when you have met with multiple sclerosis patients, what are the mental health disorders that you have faced? Or, for example, mental health problems that you have noticed with your patients?

Dr Diana Andino:

Good evening everyone. It is a pleasure to be here sharing this talk and to be present with your company. As you said, there are many factors that will happen during the process of diagnosis or treatment and even living with multiple sclerosis. Not only for the patient, but also for the family members or friends around them.

In terms of patients, one of the things that is quite common is a lot of anxiety and a lot of depression and sadness. There is usually that fear and anxiety that comes with the ups and downs of illness and that creates a bit of apprehension about being able to continue doing all of the activities that you were doing before. And it is important that as doctors we tell patients from the beginning that this can happen, that it is normal to have those fears, that anxiety and a little bit of trauma and confusion during this process and to normalize it around our visits that we have with them is important. In terms of depression, it is something that sometimes happens before the diagnosis of multiple sclerosis is given, based on magnetic resonance imaging or with neurologists. Many patients and studies say that depression and anxiety are the first symptoms that happen before the first disturbance happens.

So, to recognize what is part of the system that is affected and treat it in that way, not only with the medicine that is given to control multiple sclerosis, but also to treat mental health, so always with the patients. And then I try to have time during each visit to talk about how they feel and how they are, specifically in those two areas that are most common. But there is also a lot of education about the guilt they feel, if they did something that gave them this disease or the trauma that it caused them, and unfortunately, we don't always have time during the visit to discuss that. But it is important to create that space.

Dr. Fernando Cuascut:

Yes, thank you doctor Andino. It is very important to emphasize that patients, a multiple sclerosis patient can present with many problems, as you well mentioned, of disorder, a mental health disorder and also that it can affect the general mental state of the patient. We can imagine when a patient has just been diagnosed, all the frustration and anxiety can feel like a response to the illness, to what is happening to them, to the situation that is happening to them. The uncertainty that a patient may have about a diagnosis can once again create a lot of anxiety, a lot of uncertainty. And this will inhibit you from many social interactions or intimate interactions with your loved ones.

And many times they don't talk like you do, they don't talk about this. The patient when he has so many concerns that he has to attend to, he focuses a lot on physical condition, and mental health moves away a little bit, moves a little to the side and it's about dealing more with physical health. It is something that unfortunately patients interpret it that way, feeling that physical health is more important when it is known that it is not. Mental health, if we don't have a clear mental health, we can make wrong decisions and that can affect our physical health. For example, a patient who does not have adequate mental health because they already have anxiety or have problems perceiving what is happening to them, does not take the doctor's recommendations seriously and does not take the medication, and therefore they relapse.

That is why it is so important as a doctor or specialist that you have to talk about this very early in the diagnosis. As you well mentioned, many of the patients, up to 50% of patients with multiple sclerosis feel depressed at some point in their life. And not just that, if we also talk about the relatives who are caring for these patients, up to 40% of these relatives could also present symptoms of depression at some point in their lives. It is also important to emphasize that loved ones can also be affected. It is related to the diagnosis. Anxiety, as mentioned, up to 50% of patients with multiple sclerosis, which is a much higher number, up to three times higher than the general population, could also suffer from anxiety as well, related to the uncertainty that is happening. With the diagnosis, the fear of what is going to happen and the loss, the patient often feels a sense of loss and fear of what is happening to them.

A very important fact to emphasize is that there are other mental disorders that could be associated with patients with multiple sclerosis. As we see here on the slide, we have already talked about depression and anxiety, but also bipolar disorder is another disorder that is seen to be more associated with multiple sclerosis patients in higher numbers than compared to the general population. And there are patients who may present with symptoms of depression and symptoms of mania. Mania is a symptom where the patient feels an energy that they cannot control, their behavior can change, a bit erratic, and that is why it is also something that is important to determine and understand that this may be happening in patients with multiple sclerosis.

When a patient presents with these symptoms, or as a patient may develop those symptoms, they need to let their doctor know or to seek help to find some resources or to start that conversation, which is a little difficult sometimes.

Dr. Humberto Cruz Esparra:

Well, first of all, good evening everyone, thanks for the invitation. Greetings to all who are joining from the island of Puerto Rico. It is a great pleasure for me to be here with you tonight. It is certainly an issue that calls the attention of all patients with multiple sclerosis. We have a particularity in terms of how this process is carried out and documented, where the patient prepares to face a condition that will certainly be a "long-lasting diagnosis."

We do really take into account that this is very important, and I am very happy that it is the MDs who are starting this conversation, since there is still a lot of stigma around the search for mental health services, specifically in the Latino community. But there's still a stigma attached to seeking services, since a person in need of a psychiatrist or psychologist is typically labeled, right? The one with a "mental condition."

And here in Puerto Rico we say, Look, he's crazy. The reality is that no, the reality is that there is a call that is being made, and thank God, right? We have seen how there has been a greater openness in the search for these services that are so vital, and if we see it from a holistic perspective, the patient is not just a physiological matter, there is also an emotional matter, intrinsically linked to the process. And when we're talking about patients who have multiple sclerosis, it's extremely important to get your doctor involved. You should not even consider it, it is not even giving the patient the option, that is, if you are with me, part of my treatment is that you attend a mental health professional and not that you are obligated, but literally, it is part of the process.

But when we are talking about a new mental health intervention, we are talking about constant psycho-adaptive changes. And to move from one stage to another, we are talking about this patient beginning to experience these symptoms of shock, fear, anxiety, even anger, guilt, or all of the above. And it even becomes a duel. A duel because that's who I'll be now, right? After this diagnosis, who am I going to be and how am I going to develop in my daily life? Who is going to take care of me? Am I the one who keeps the house? Who is going to watch me? And all these questions begin with the nervous system. And finally, they start to freak out. There is an agglomeration of thoughts that gives a signal to the adrenal gland to release cortisol and then we are always in a fight or flight response. Uncertainty will always bring a lot of emotional activity. However, there are mental health treatments to help mitigate and reduce the symptoms that could occur, either as a result of the organic cause of multiple sclerosis or as a consequence of the constant thinking that is generated in the face of uncertainty and the diagnosis that is made or presented to the patient.

Dr. Fernando Cuascut:

Thank you Doctor. What you just mentioned is a very important point that the health or emotional state of an MS patient who may be affected is the response to the diagnosis. But it can also be a symptom of the disease and it's important to understand that patients understand this, that multiple sclerosis has been shown to biologically affect a person's emotional state. The good thing about it is that it can be treated respectively if it is a symptom of the disease or if it is a response to what is happening. It can be treated. It's something that's important that as a patient you finally start that conversation with your doctor and that you understand that mental health again is just as important as physical health.

Now, there are many, many components that could affect mental health. And there can be factors, for example socioeconomic factors, factors that are not economic, social, cultural factors, for example, that could affect how we feel in our environment and how we respond to what happens to us and how we relate to other people. Dr. Moreno, could you talk a little about how culture might affect a patient in their environment or how they respond to their mental health?

Dr. April Moreno:

Yes. Hello, good evening and thank you for attending this talk. I'm here to talk about the perspective of the community of people living with this disease and other autoimmune diseases. And there are many, many cultural factors. Many times we do not have the confidence to talk about our experiences and thoughts with a person we do not know very well, or with doctors or psychologists or psychiatrists. We don't have the confidence in the beginning. And there is also the stigma of having a mental illness. So, in our culture, we don't talk much about mental illness. Sometimes, too, we don't talk much about physical illness either, but with mental illness there is more stigma and it's very difficult to talk to our family as well. And it is also more difficult for men, although, cruelly, men are expected to have more strength than other people, other people in the family, and that is difficult.

But it is important to know that your health depends on the health of the other people in your family as well. That's why it's important to talk to someone about your mental health. And as Dr. Cuascut said, these are sometimes called the relapses, the symptoms of MS. Sometimes it all starts with mental health conditions. We see this situation in our organization when someone has a lot of stress from their work, or something like that from relationships with their family. And after this anxiety and stress, the physical MS symptoms begin. After the anxiety, after the depression they have, sometimes, they can't feel their feet or they can't see with one eye. Sort of like common MS symptoms. In our culture, it is important to talk to someone about these conditions, because they are no different than the physical symptoms of MS. So it is very important to understand what is happening culturally.

Dr. Fernando Cuascut:

Yes, yes, definitely, Doctor Moreno, it is important, as you were saying, that the cultural environment, the cultural and social aspect that a patient is under could affect their mental state or mental health. And this is often addressed by asking what is the cultural message that the patient is receiving? How did the patient who grew up in your environment relate to your family? How permissible were you as a child and as an adult to express your emotions? How do you feel your culture compares to cultures that are a little more repressive? And as you mentioned, it may be in the culture, some Latino cultures, or the "LatinX" culture, that men in particular show that they have that pride in being strong and therefore do not express those emotions for fear of how society will treat them or stigmatize them, for example, right?

And how that is brought to the clinic and how they interact with their doctors or how it prevents them from expressing, for example, symptoms of anxiety and symptoms of depression, they may not express to their doctors because they have that cultural trait that affected them so much, either because of personal barriers, barriers that were created because of their family environment, or their community. And that again impacts how a patient responds to diagnosis and responds to how they stay healthy based on what their doctor recommends, right? Patients who have anxiety, patients who have anxiety and have multiple sclerosis have been shown to have more pain than patients who do not have anxiety. There have been clinical studies that have shown that pain can also... anxiety, sorry, which is a mental health disorder, can affect physical health at that particular time. Yes, Dr. Cruz, do you have a comment? You are on mute.

Dr. Humberto Cruz Esparra:

Yes, I wanted to expand on the topic. It is true that when we talk about the intervention already within the therapeutic process with patients, we are talking about one of the things that is done is precisely to look for those cultural factors that have an impact on the way in which this patient develops the idea of how to live now, commute, and live the rest of their days with a diagnosis of multiple sclerosis.

Something that we hide is precisely the perspective that has to do properly with those inherent factors such as the patient's intrinsic values. What do I believe? What is my faith? What if I'm holding on to something? Or the values that this patient has, right? And that, because basically we are looking at the patient as a whole and it becomes a biopsychosocial model where we understand not only how the patient interacts with the symptoms of the condition, but we see the patient as a social being, watching over which people around them who are could be support for this patient. We look at the psychological aspects of how this patient is processing information and then how the physiological factors of the condition affect the patient's health.

So the context is important. Many studies indicate that one of the most important productive factors within the cultural context and the culture of the human being is the religious part. Right? In the religious part, the aspect of faith becomes a very important aspect because at the same time that the patient brings this element to therapy, we as therapists intervene in it and look for ways to establish links with their condition, so that in this way, the patient can have more advanced processing and develop something very important that I mentioned at the beginning, which is the word "resilience." Resilience by definition is how I can put myself before my crises. And certainly the factors associated with the development of this condition have a lot to do with that spiritual factor. In other words, how do I begin to see what I am seeing now as a crisis, as a platform for building a new version of myself, and then a worldview is created, creating an alignment between the projective factors of this patient and as the therapist can be an encouragement in this process. So we look at this biopsychosocial model from the perspective of this patient, from a biopsychosocial model. Starting from the premise that the human being is a spiritual being, is a corporeal being, is a loved one. He has emotions, he has thoughts, he acts with respect to what he is, to what he lives, to what he experiences around him, and it is important to conceptualize it under this model.

So I think that if we look at cultural aspects within this process, it is also appropriate to talk about your support system - what resources are available to me and do the medical plans cover my treatment? It is true that this also tends to be a good thing that you, the association, have "funding" help for these patients, it is true that they need it so much. Not everyone can afford MS treatment, right? And there are patients who can afford it, perhaps because they have a little better economic capacity. But there are other people who can not, and the behavior of the Latino community is also a factor that is sometimes revealed to many people in the United States - not to say anything. But we have an immigrant population that we also have to see. There are many immigrants who have the condition who do not dare to approach a physical health provider for a diagnosis because they do not have the resources, becoming a significant barrier in terms of offering this, this very important medical process, which is inherent. So I wanted to add that, taking into account that the biopsychosocial model is a model that we look at, we use a lot, and that we look at those social determinants of health, the factors that could influence the development and well-being of this person who has a disease.

Dr. Fernando Cuascut:

Thank you Dr. Cruz, definitely, for emphasizing again that a patient with multiple sclerosis, as we have already explained many times, at any point in his diagnosis, be it at the beginning or in any part of his journey, with the diagnosis, could at some point present with mental health problems. And I want to stress that because it's important. Many patients feel alone, they feel that it only happens to them, and we already see that the numbers say the opposite, although the majority, at least half of the multiple sclerosis patients can present with mental health disorders or problems with mental health. Dr. Andino, do you have a comment for us?

Dr. Diana Andino:

Yes, I also wanted to add a bit that it is very important as patients and as a family and as a doctor, to know the possible environments and circumstances that each patient is having so that we can help quickly and not wait until the symptoms continue to grow because we know that anxiety and depression make the fatigue worse, the pain worse, everything still not getting better. So it is important that we know how to ask these things from the first visit. Tell us about your life and how your environment is right now. What are the things that worry you? Many times, as Dr. Cruz said, it is economic, that it will be... or immigrants, so he is very afraid of that. But having that conversation open from the beginning, I know it helps a lot. As a patient myself it's important to say, You know, doctor, I understand this, but I don't think I can have the medicine or I don't have someone to visit me, and understand everything that comes with this diagnosis and understand that it can affect a lot of areas of your life. and to know that they are part social, part cultural, economic, religious, that all of that is important and we talk about doing a better job of asking patients in the beginning.

Dr. Fernando Cuascut:

Thank you. Thank you Dr. Andino. Dr. Moreno, do you want to say something too?

Dr. April Moreno:

Yes, as Dr. Andino said, it is important not to have, or to have, clinical help, as fast as possible, because with the mental conditions it is very difficult. It is important to know for someone who has this diagnosis that they have to ask for help as quickly as possible, because it is important.

Dr. Fernando Cuascut:

Thank you Dr. Moreno. Yes, it's important to stress that health in multiple sclerosis has already become a chronic diagnosis, right? Often becoming not only chronic, but now with medications it has been able to remain stable and mental health is as important, as we have said, as physical health, and we have discussed that up to 50% of patients with multiple sclerosis could present with symptoms of depression. If you know someone who has depression, or who is exhibiting suicidal symptoms, or you have felt that way, we have already shared a slide to please contact the line as soon as possible. Ok?

It is important to emphasize, returning to the subject of mental health, and how a patient can start that difficult conversation with their provider. There are many barriers. Right? One of them we have already talked about, the cultural factor and how this affects the perception of the patient. But it can also be the stigma, as we have discussed, the stigma of social media stereotypes, misinformation, bad information that can be presented on social networks, and also fear. Right? And that also creates obstacles for a patient to open up and communicate with or seek help with their providers or their personal physician.

And I want to emphasize here to the entire audience and to the patients, the people who are also living with multiple sclerosis, that again I want you to understand that we should begin to break down these stereotype barriers that discriminate against patients who have mental disorders, that are made worse by discrimination. And please seek help to get started. Those difficult conversations, which sometimes, if you don't feel comfortable bringing it up with your doctor, start with your loved one, and listen to how they feel and why. Sometimes, a patient thinks or feels one way and forgets that there are other ways of thinking. And it is important when a patient seeks help that they understand that they are part of the situation and that they have treatment. Doctor Cruz, do you want to say a comment?

Dr. Humberto Cruz Esparra:

Yes, it is that Dr. Andino brought up the fact of suicide and you mentioned it, if there was any person that you identified the signs and symptoms of constant anxiety or prolonged anguish, who could not sleep well, who does not stop eating, who doesn't want to go outside, he doesn't want to take his medications routinely, he's down. So it's time to talk or it's time to call the hotline and speak and express your feelings. I think that speaking, linking it to the topic of "self-advocating," and the importance of self-advocacy, right? I think it is important to emphasize that the doctor, when beginning to talk about this issue with the patient, must show impeccable empathy. To hook this patient, to bring this patient to the understanding that "this is not the end of the world," right? For the patient it may be something catastrophic, but letting him know that there are solutions, and it is true, only experts know, but it is very important that it develops. I always tell the patient that we have to develop contingency plans for us to attack, and "to tackle" the anguish that may come, so that anxiety always visits us and a bit to normalize the issue of anxiety.

We need anxiety. We need to feel the stress. And you will tell me, but why do I need to feel stress or feel anxiety? Because biologically we need to feel that adrenaline that will move us to do something that will move us, to seek help, that will move us to seek an answer. Anxiety is not bad in all scenarios. Anxiety does become pathological when it stops me, when I don't do anything about it.

So part of what we do with patients is we develop a contingency plan. I call it a "Wellness Recovery Plan." We use this plan to see where the patient is in their cognitive behavioral framework, we work on behavioral and cognitive strategies, actions and thoughts to elaborate different emotions, see the strategy and contingency plans, and are directed to make a behavioral activation plan, where the patient is given a guide on what things they can do, what things they should not do at the moment because they are undergoing treatment. If this happens to me, what am I going to do? We always watch, we look for that contingency plan, it is very important. Having a plan when it comes to the importance of "self advocacy." When I have a plan, I will have logical and coherent ways to respond to the irrationality that could arise as a result of negative, distorted, black and white thinking.

So, the plan for my future I see more clearly. We are going to have a greater capacity for conflict resolution, which is going to keep me empowered about what I am living, feeling and experiencing as a change to this process and we are going to have to take concrete actions, we are going to be assertive. So it seems important to me that we defeat these thoughts, we have a contingency plan, call someone, call someone and tell them look, I don't feel well right now, don't be silent, don't stay there with that thought, go out, search, eat a shortbread, go for a walk in the fresh air, sunbathe. There are things that can be done, those are things that are elaborated in therapy.

And I always send my patients to make a list, a “thought log.” Let's think about the “What,” the “Why,” the “Where,” and the “When.” Why do I identify the thought, why am I thinking it and when did it happen to me? There are many people who realize that they think more at night, because I already have this day, it is ending and there I have more space to think. And as you very well mentioned, Dr. Cuascut, our signaling system in terms of perceived pain is going to increase because the pain receptors are going to sharpen and that is a very biological issue. So the emotions have a direct repercussion with what is the chemical, biochemical functionality and all metabolic processes that are so proper to attend to. Right? So emotions can address a significant area that has to do with the development of symptoms. Right now we mention that there is the most extreme case of a mental health condition, which can also occur in the patient, where the patient can sometimes feel that they are laughing a lot or feel that they are crying a lot. That, when we have a more advanced patient, we can begin to see even this type of condition and how to lead that patient to understand it. Right? So I have so many things to say and I want to be fair with time, but I wanted to add this.

Dr. Fernando Cuascut:

Thanks. Thank you. Thanks for sharing those thoughts and information. Again, going back to the issue of self-advocacy, as Dr. Cruz was mentioning, when I try to talk to my patients and I start the conversation to talk about mental health, some things that also have to be addressed is well-being of mental health. We've talked a lot about the negative effects in the conversation we've had so far really, how mental health can be good, mental health disorders can again be a symptom of multiple sclerosis, but also how we respond to the diagnosis. The response to the diagnosis can affect our mental health. But what about... how can we make that better? How can we... what options are there? What structures exist? What aids exist for the well-being of mental health?

One of the exercises that I do with my patients when I'm talking about it is a three-step exercise, to try to get them to understand and to try to get to where...how they feel and to get to where they are in their diagnosis. The first step is to validate. Right? It is validating emotions as they come. Do not become friends with emotions, if you feel anxiety about it, feel that you are not alone, that many patients are going through the same thing. Anxiety is a response from the body trying to let you know something. Perhaps the anxiety is telling you that at that moment you will do something important for yourself. It is true that you have to focus because you have anxiety when talking about the diagnosis. Right? That trying to go against emotions, suppressing emotions, is not a healthy way to deal with them. That is why I always say the first step, validate the emotions as they come. If you feel, again, sadness about the diagnosis, feel, again, that you are part of the process. Don't feel left out, don't feel like you're an alien, or that it's something that isn't common, because it is.

Once you validate that emotion, then you move on to reflection. One then begins to reflect, why am I feeling the way I am feeling? Why do I feel anxious? Why do I feel sad? What is the message that is hidden with that feeling regarding the diagnosis or during the process or any stage of the diagnosis process? What is that message that is telling my psyche, my mind that I feel sad about this? Could it be because I lost something that was important to me? Is it because I thought I had some plans and had to change them?

Now, once one reflects and tries to understand the root of that feeling, then the last step is that I, as an exercise with my patients, try to resolve it. Right? Once it is identified, the message is validated, the emotion is validated, the matter is reflected and the root is understood, a way of

being resilient is sought to try to face the problem of the matter, such as finding plan B or plan C or plan D or plan Z of life. Right?

Life has not ended through an MS diagnosis. MS no longer means ending up in a wheelchair. The MS no longer means many of those stigmas that had been created many years ago. MS has changed a lot and so has the way we handle it. Right? And all those fears that come through a new diagnosis and all those negative thoughts, how can they be resolved? If one understands well, it validates their emotions and understands what the root of the problem is. Instead of just oppressing it, overshadowing it, pushing it aside and letting it affect the way you put yourself, as Dr. Cruz was mentioning a few moments ago, since that is your anxiety, that depression remains in the back of your mind and that is affecting the physiological processes and that is going to affect the symptoms of MS. Right? Doctor Andino, do you have a message?

Dr. Diana Andino:

Yes, very right with everything that everyone shared and one of the important things is also that they do not suffer alone. Sometimes it is very difficult to be able to say these things to someone else because they do not want to upset anyone, they do not want to be the weak person in the relationship or have more burdens for other people because they already feel that they are already putting a lot of things on themselves and they are not going to bring anything of benefit. But it is important to recognize that they are not alone and to be aware that if I do not take care of this I will not be able to take care of my children, I will not be able to take care of my family. And keep that very much in mind during your diagnosis, but especially in the beginning, and throughout the rest of your life, as you said, it's a chronic problem and knowing that you're not alone, seeing who is the person that can be your confidante, whether it's from your relationship or from your family, friends and having an open conversation is important so that you and your own friends, or siblings, or relatives are educated about this multiple sclerosis process.

Many people do not know how it affects and what are the things that affect it, so you are going to be the best person to be able to explain those things that you feel and do not feel to your loved ones. And having that empowerment where they tell you that I feel that way, am I right to feel that way? But who will help me today? You don't need to help me until another day. It's an improvement. It's super important.

Dr. Fernando Cuascut:

Thank you, thank you Dr. Andino. Also, we are running out of time, but if someone from the audience wants to leave us comments about, for example, the barriers, most of the barriers they have faced in relation to mental health, they can share them. Or about cultural issues that you think have affected the way you have dealt with your health or mental health problems, you are welcome to write them in the chat. Or if you have any other questions as well. Yahaira, I think we're running out of time a bit. Do we have a little time here for questions?

Yahaira Rivera:

Yes, we have a few minutes to ask. Thank you very much to all the panelists for sharing with us such important, necessary and valuable information for our community. We have a question in the chat: Is depression and anxiety in multiple sclerosis patients a reaction or a symptom?

Dr. Fernando Cuascut:

It's a good, good question and the answer is both. It could be a reaction to the disease, it could be a symptom of the disease. We think it could be both. Mental health disorders can be symptoms of multiple sclerosis. The entire process that leads to developing a mental health

disease disorder is not known for sure. With MS, it is understood that it goes through the deregulation of nerve connections, which help us control and manage our emotions. Whatever it is, if it's an associated mental health disorder like anxiety, or depression associated with illness as a symptom, as a response, it can be treated. This is the good news. I recommend that you communicate this with your doctor. It can be treated and can definitely be improved; to improve their quality of life.

Yahaira Rivera:

Thank you so much. Another question is how can we emotionally handle a relapse or worsening symptoms?

Dr. Fernando Cuascut:

It's very, very, very complicated. During a relapse, again, feelings can be affected and it is something that is not yet understood for sure. But again, you can feel more sad, anxious because of the physical symptoms due to this symptom that you are presenting, but it can also cause dysregulation of the nervous system, which can also be a symptom of your disease. How is this handled? First, understand and accept what is happening. Seek immediate help. Right? Understanding that it is part of the process and understanding that there is help and that despite the uncertainty of what will happen in the future, understanding that now the treatments have good effects in controlling the disease and that the symptoms can often improve. If there are severe anxiety or depression problems, again, they have to be taken into account as part of the active treatment of a relapse. What I mean by that is that it is a relapse, it would have to be treated with steroids, you also have to talk to the patient about offering emotional therapy and at some point you may also have to take a medication.

Yahaira Rivera:

OK, thank you very much. We have a few minutes for one last question to any of the panelists, but also to Dr. Cruz Esparra. How can we motivate a family member who needs help for their mental health or motivate ourselves to take that first step; dare to ask for help? Any advice?

Dr. Humberto Cruz Esparra:

Yes, I think it is one of the most important things. If you are the person who has the diagnosis, you can locate a friend, a trusted person, a relative with whom you can vent. The part of expressing your emotions, expressing how you feel about how you are living in this new reality of yours, you can let yourself feel internally, obviously from the inside out, because it has been shown behaviorally that whatever science was in the behavioral part of the human being, that when I say something, what is inside me begins to lose strength. That emotion begins to regulate itself.

So once we identify this person and vent emotion, it is important that we consider seeking help from health professionals who specialize in mental health. Health psychologists. There are groups and there are support groups in Puerto Rico. I have the great opportunity to lead a group for patients who have chronic physical health conditions and to train them in a program called Wellness Self Management. So I think that when it's the person who is listening to someone like me, then I can do it, it's the same. It is the same but "backwards." Right? Listen to this person, let them vent, let them cry, let them express themselves, let them show their vulnerability, because certainly once that emotion is vented, this person will feel more relieved and later seek to persuade the person to find a support group, call a talk line where you can also vent in case it comes up at some unexpected time and not wait for symptoms to take over.

Emotional symptoms that take over, as the others have said, do not become friends with emotions. I always say, Know the emotions, but don't make friends with them. Because many times they will sabotage the process of living a life. You can live with MS, the patients that are seeing me have multiple sclerosis, you are not a diagnosis, you are not that, you have that, but that doesn't define you. So you are not a diagnosis. Whenever life throws us difficult situations, we don't see it as walls that enclose us, we use it as a step to move up. In order to understand that, we need a mental health specialist. So I would be very, very happy to assist in any need that may arise later or questions that may arise.

Dr. Fernando Cuascut:

Thank you. Thank you.

Yahaira Rivera:

Thank you so much everyone. Well, we've come to the end of this program. There is a lot to talk about, but this is the first talk and hopefully we will continue learning and growing together. On behalf of the Multiple Sclerosis Association of America, we thank our panelists, thank you very much for giving us your time, for giving us such valuable information and empowering our Hispanic and Latino community, to know that there is hope, that there are resources, that there is help, the important thing is to talk, talk and always share about your physical health and your mental health with your healthcare provider.

To our dear audience, thank you very much for participating and supporting this educational program. I remind you that this program was recorded and will be available in the coming weeks in our digital library, so you can watch it again and share it with loved ones. I remind you to please fill out the survey and let us know what you thought of today's program and also leave us your suggestions and comments. For more information, please visit our website. We wish you all good night, blessings and many thanks to all. Until next time. Bye bye.