

Cognition, depression; psychological impacts and rare neuroimmune disorders

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[00:00:00] **Dr. Varun Kannan:** It's me again. Varun Kannan. So, we have a really interesting topic here. Sometimes we focus a lot on movement, symptoms, strength, weakness, but something that sometimes get pushed under that probably shouldn't is how this affects cognitive health and mental health. So, we have some excellent panelists here that'll help address some questions. I think we can start with introductions.

[00:00:26] **Dr. Avjola Hoxha:** My name is Avjola Hoxha. I am a child and adolescent psychiatrist, as well as an adult psychiatrist.

[00:00:34] **Dr. Yuri Shishido:** I am Yuri Shishido. Can you hear me? Is that good enough? Thank you. I'm a pediatric neuropsychologist.

[00:00:42] **Dr. Varun Kannan:** I'm gonna go a little out of order here just because these terms of your careers are very similar. Maybe we start with what is your role as a psychiatrist versus neuropsychologist. What do you do differently? How do you work together?

[00:00:57] **Dr. Avjola Hoxha:** As a psychiatrist, I'm actually a medical doctor, so I go to medical school, just as our wonderful colleagues that have previously talked to you all. My role is to do evaluations and to see if symptoms rise up to levels of what we would be considered psychiatric disorders.

[00:01:16] My other role is to manage those symptoms with medications. We can also do some therapy, but we also defer and work with our colleagues a lot for the therapy interventions as well.

[00:01:29] **Dr. Yuri Shishido:** So, neuropsychology is the special specialization within psychology. So, my training is on clinical neuropsychology and neurosciences.

[00:01:41] And my job basically is to assess how medical conditions impact children's thinking skills or cognitive skills development. So, we, and like I, we are known for assessing cognition. That includes things like memory, attention, learning, as well as emotional behavior and quality of life like fatigue. Because all of these factors impact how children learn and behave and function every day.

[00:02:16] **Dr. Varun Kannan:** So, I guess we can start with kind of the psychiatric aspect. So, what are the common psychiatric symptoms that we see associated with these rare neuroimmune diseases? How do we address them? How do we diagnose them and how do we treat them?

[00:02:30] **Dr. Avjola Hoxha:** So, we see a lot of kind of mood symptoms that sometimes arise from this. So, we can definitely see a lot of anxieties associated with being in the process of being evaluated, diagnosed, and treated for these disorders. And anxiety specifically about the disorder or anxieties related to the treatment aspects of it. I know one of the things that has been talked a lot about so far is the treatment modalities, which a lot of those involve needles and there's a lot of children who have a lot of needle phobias.

[00:03:04] So we try to identify those kids and try to make sure that we are addressing those phobias, those fears, appropriately so that it does not impact treatment. So, there's a wide range of anxieties that can come out of this process. The other major mood that kind of comes up is depression or sadness.

[00:03:25] So as you all know better probably than us sitting up here, this is a major life disruption. When you get one of these, things come up and it can really impact what you're able to do and how you're able to do things. And that then triggers episodes of sadness, episodes of clinical depression.

[00:03:46] So we monitor for those things, and we evaluate and treat if they do come up. In addition to the mood stuff, we also can, with the help of our neuropsychologist, cognitively what's going on and some of the limitations that might come up because of this diagnosis. So, the big one for me is ADHD.

[00:04:09] So are you having difficulties with sustaining attention, with focus, with being able to complete tasks, where you did not have these difficulties before? And would then medications be indicated to help, especially in children who are going to school who need to continue to learn and grow? Are medications appropriate? Are they safe? And so, we work with our colleagues in neurology to determine if it would be appropriate and to do those trials for these kids.

[00:04:40] **Dr. Varun Kannan:** And a follow up question from a neurologist standpoint is a lot of these conditions do physically affect the brain. So sometimes it can be tough for us to determine are symptoms like depression and ADHD and focus issues, a symptom of inflammation or is this part of the emotional toll of living with something that's incredibly stressful? And how do you tell the difference and does that affect your treatment as a psychiatrist?

[00:05:05] **Dr. Avjola Hoxha:** It's, I agree, it's incredibly difficult. Because we have the whole presentation and there's no way for us to determine very specifically, would you have had this if you didn't have this disorder or would this even have come up?

[00:05:20] And sometimes I'm even gonna add that a lot of times that what we see is probably a side effect of some of the treatment. Because sometimes we also step in the hospital setting. So, if there's side effects that kind of rise up when we have treatment with IV steroids, for example, there's certain things, mood disorders, mood things that can come up in that setting.

[00:05:41] That's acutely because we introduced steroids into the picture. In those settings we treat because we know there was nothing before. We treat very acutely in that setting and we try to get you off of it. We do a lot of history when it's in the outpatient setting. Were there any signs or symptoms before all of this started?

[00:06:06] Is there any family history that can complicate the picture a little bit? A lot of our disorders are

hereditary. There is at least a hereditary component to it. So, we do a lot of history taking and just figuring out what is going on. But at the end of the day, what we look at is what is the impact on day-to-day life and how much is it impacting life and is it fluctuating with treatment?

[00:06:33] If it's fluctuating with treatment, then we get the understanding that maybe it is more related to the physical, what is going on within the brain, versus, no, this is more of a psychiatric presentation. But in either case, the treatment, the medication treatment that we have for it, it is based on what's going on.

[00:06:55] But it is not FDA-approved because we do not have the trials and we are talking about clinical trials, but we do not have the clinical trials to have that FDA approval to yes, you can use these medications in this acute setting. We just go by what's going on, what we think might be the most helpful for you to give you parts of your life back. To make it so that you're able to enjoy the everyday things again.

[00:07:23] **Dr. Varun Kannan:** Ok. So, switching more to neuropsychology, what exactly is a neuropsychology evaluation? What are the expectations of what that testing is and what does it mean?

[00:07:32] **Dr. Yuri Shishido:** Ok, so in neuropsychology we really focus on individual needs, and it really depends on what your concerns are, right? As a parent, family members, as well as medical history symptoms.

[00:07:50] And like we just talked about, the different history because when you evaluate children, it's really important for us to figure out was it like, is this something that was there before or is there a family history and is this a combination of it? And so, one of the things that not only that we look at history, but we really have a parent and family members as well as patient's involvement.

[00:08:21] We ask a lot of questions, and we ask you to tell us how your children are like at home. We sometimes reach out to teachers because children do behave and perform differently across different domains. And I may only have a day to work with patients. So based on that and having discussions with the parents because your children the best. Then we determine the type of the testing that requires. It can be more focused in certain cognitive domains from a couple of hours to more comprehensive three, four hours.

[00:08:58] Again, it really, we try to tailor to individual patients' need and the result and recommendation that we come up with also should be and are tailored for individual families.

[00:09:15] **Dr. Varun Kannan:** And this is a question I truly do not know the answer to. I'm very familiar with neuropsychology testing in the context of pediatrics, which is focused a lot on learning and school supports. What's different about neuropsychology testing for an adult?

[00:09:30] **Dr. Yuri Shishido:** I'm not an adult neuropsychologist, but I do have a training. My knowledge is that limit. With adults, it's all about everyday functioning, right? Your decision making, your medication taking, adherence to it. How about can you be independent in living? Those more everyday functions that we would be focusing on with children, their everyday functioning is learning and behaving, and listening to parents.

[00:10:06] **Dr. Varun Kannan:** Ok. Any questions from the audience for our psychiatrist or neuropsychologist?

[00:10:12] **Audience Member:** I just want you guys to talk about brain fog and how that, I want you to talk about brain fog. Ok. Yeah. Is brain fog, is it somewhat normal? How do you know it's something caused by your autoimmune disease? How do you know it's something else? Brain fog.

[00:10:39] **Dr. Avjola Hoxha:** So, it's a really complex and multi-part answer to this, but, so there's a lot of factors that can cause it. And as you alluded to, is it part of the autoimmune disease? Is it something else that kind of is triggering it? If it's, again, if it's the nature of it, if is it coming, is it going, is it permanent?

[00:11:01] Those are some of the first things that we take a look at. Because those can tell us where it's coming from. And, but from my aspect of things as a psychiatrist, we see a lot of cognitive impact when we are talking about clinical depression or clinical anxiety. And that can also present somewhat similarly to that.

[00:11:22] If we are in a pretty significant episode of depression, we are gonna get cognitive slowing down. We are going to get difficulties in doing the everyday things. And that is one of the criteria that we look for, and we treat when we are talking about depression. So again, we kind, we have to take a look at how it is presenting, when is it presenting, the nature of the impact and then how do we differentiate that. So multifactorial?

[00:11:59] **Dr. Yuri Shishido:** Right? I agree and I think I do hear this a lot, and your experience actually is important for us. And I do agree that if you are depressed, if you have fatigue, right? Oftentimes I hear this all the time, wouldn't you have a problem focusing on something if you are not feeling well or tired? So that absolutely may be part of it.

[00:12:24] And our job becomes for me, right, I would like to make sure that I'm gonna rule out there is no underlining attention program or slowing down the processing speed or is it more psychological? I work with my colleague here to rule out and try to figure out and come up with more individual recommendations for you to really reduce that experience.

[00:12:49] Even with children, that interferes a lot and sometimes they need more, extra time, they need accommodation. Sometimes they just cannot focus. Then maybe take a test outside of the classroom in quiet place. So again, all depends on what your needs are.

[00:13:09] **Audience Member:** Hi, I have MOGAD, and I've been living with it for about three years. I've had multiple relapses, but I've been relapse free for the past almost two years. Year and a half, I guess. And you had made a comment about ADHD, and I didn't really have the problem when I was going through the active attacks over a year and a half timeframe.

[00:13:40] And then they put me on IVIG. And it worked great for a year and then insurance came around and denied it. And I've gone without for four months now, and I'm finding that from a psychological perspective, I am having very ADHD like side effects. I have been working during this entire time, and I find the level of mistakes and the inability to focus on anything has been progressively worse.

[00:14:19] Is that something that is coming from the medications because of the fact that we're still fighting to get back on the IVIG or is that something that just happens over time? I never had ADHD before, so this is really new to me and it's really concerning to me. And I reached out to my neurologist, and she blew me off. So, like, I don't even know where to go about this. So just curious about that.

[00:14:55] **Dr. Yuri Shishido:** If you did not have ADHD or attention issues when you are growing up, so this is more acquired, which we see this from the medical event, and I'm sorry that your neurologist blew you off, but hopefully it's not one of ours. Right. But you can't, but there are a couple of things.

[00:15:18] Number one, I think we want to know if it's really attention or something else. Because I often have a patient coming in that I have an attention problem, it turned out to be not something else that you might have had it, or maybe it's more efficiency in processing speed. So that would, the intervention's gonna be different.

[00:15:39] So I would really like to for your better neurologist or your primary physician to refer you to adult neuropsychologist, to walk with you to really pinpoint what might be happening. If it's ADHD, then obviously there are, yes, you can go to her. For medication and there are other everyday life strategy and tips that we can share with you.

[00:16:10] **Dr. Avjola Hoxha:** And along the same lines there is a very specific type of occupational therapy that does deal with helping people with ADHD symptoms. So those are techniques and things that you can learn to incorporate in your day-to-day life that does not rely on medication. Because sometimes we have patients that we cannot place on medications for these kinds of symptoms. So, we do also encourage that other avenue, so another avenue of treatment potentially.

[00:16:37] **Dr. Yuri Shishido:** Right. And some of those programs are called cognitive remediation, which means that you had a skill, you feel like you're not effective anymore. So, there are people work with you to try to help you get it again or go about different ways like learning different strategies to help your everyday skills.

[00:17:00] **Audience Member:** I'm actually really glad that she mentioned that because I had similar confusions just to reinforce maybe the significance and importance of this. Because you were speaking about it in children. But I, similarly, after my diagnosis, I got diagnosed with ADHD as an adult because I was having all these cognitive issues. And you were speaking to other causes like depression and anxiety, which certainly come with a diagnosis.

[00:17:26] But post that, I've been diagnosed for like three years now. I'm fine, for the most part. And no depression, no anxiety. But I had recently gotten diagnosed with ADHD and I was so confused because I was having these bouts of brain fog and not able to focus and it hadn't impacted me previously that we can tell.

[00:17:45] So I was just wondering if maybe there's potential for research in this area. I know a lot of these diseases are often hard to study and they're very rare. But if there are opportunities for research or things in the future maybe that can be done about this kind of cognitive impact.

[00:18:11] **Dr. Avjola Hoxha:** I do know that there has been some research, I don't know in specific disorders. Not like across the board in all of these, but there have been some research looking at the cognitive impact that the disease itself has. And then sometimes also how the treatment also impacts the brain. We're still in the early infancy.

[00:18:31] **Dr. Yuri Shishido:** So, I'm gonna speak for pediatric aspect and I think the doctors previously said things like MOGAD are new and we didn't know this until 2017. And unfortunately, things like neuropsychological outcomes, a cognitive outcome study is even new. We don't know much about it unfortunately, but we do have some emerging research.

[00:18:59] And actually Dr. Gombolay and I, we do have research going on because we do have enough patients that really looking at what are the cognitive impact of this different combination of the disorders. And is this relapse? Is it some of the clinical factors? Is it the age? Is it if you have other attention symptoms. So, what are the predictors, right?

[00:19:26] What predicts that future cognitive outcomes so that we are actually actively engaging in that. We are also combining some of the brain imaging study that can we even look at it in imaging? So, try to really develop predictive model for this. So excellent question. Appreciate that.

[00:19:47] **Audience Member:** Thank you.

[00:19:49] **Dr. Varun Kannan:** Just to add onto that, from the neurology standpoint, there's research grade MRIs that can actually correlate really subtle areas of brain changes after brain inflammation. And we can actually directly correlate that to data from neuropsychology testing. So again, a regular MRI is not built for that capability yet, but we're hoping in the near future that we can turn this kind of high-resolution MRI data into actionable information for how to help with cognitive symptoms.

[00:20:16] **Audience Member:** Can you provide guidance when it comes to finding or determining if we need to see a neuropsychologist first for assessing and then a psychiatrist or start with a psychiatrist and then go. And recently when I asked my neurologist to recommend someone, they just referred me back to my insurance and who they would cover.

[00:20:45] But there's, I thought that they would have someone that had dealt with MOG patients in the neuro space. That didn't happen in Tennessee. So curious in terms of guiding decision making for looking for assistance.

[00:21:04] **Dr. Yuri Shishido:** We might fight over this answer. I'm first maybe. Come to me first. But it actually doesn't matter. If you are, right, if you are being followed by neurologist and they are, we work as a team. So, if there are concerns, if it's cognitive concerns, you may start, you may be referred to us first. If there are more of the mood and other concerns, then you might be referred to, right, psychiatry first.

[00:21:36] And we know we work as a team. So, if I have concerns about mood, I feel like it's more about mood, then I would refer, right, the patients to her. We refer to each other just to make sure that you are seen by all the specialists to get to the bottom of it and again, to get tailored intervention recommendations for you.

[00:21:59] **Dr. Avjola Hoxha:** I would agree. So not so different. And we definitely want the neuropsych testing, especially if we're talking about cognitive stuff. Because we want to drill down to what is actually causing the difficulties that you might be experiencing. Because that is also gonna impact treatment. So, we can screen for, and we can diagnose if you have depression or anxiety.

[00:22:26] No, it's a different, it's a little bit of a different topic because one of the criteria for all of our psychiatric disorders is that it is not due to a medical condition. So, it's always other specified in that realm of things. But that does not mean that we withhold treatment. Just if you have the symptoms, if you meet the criteria for it, we will discuss what medications might be appropriate for what's going on with you. But cognitively, if there are difficulties, we do want to drill down to what is causing it, because treatment can be different.

[00:23:02] **Dr. Yuri Shishido:** And I think that's what neuropsychologists do is that we will get to the bottom of it, right? That a lot of patients come in with learning programs, brain fog is another one, and memory problems. That can mean all kinds of different things. And we will try to figure it out what really is causing that and work with our specialist colleagues to help you.

[00:23:30] **Dr. Varun Kannan:** I think a specific challenge with our geographic region is access to expertise, like we have here. We're looking in Atlanta, still long wait lists. But if you live in the rural parts of the southeast and you're really gonna be driving to one of the big city medical centers, which is unfair, but that is the reality.

[00:23:49] **Dr. Avjola Hoxha:** I can't really speak to the adult world because I do work at CHOA, but if you have kids or anybody under the age of 18, we've grown significantly our behavior mental health department. So, our ability from a psychiatric and from a therapy standpoint to be able to get you in has improved significantly for the child and adolescent population. So more than likely you might come to see one of us first, you'll be referred to both from neurology, but you might come to see us first just based on availability.

[00:24:25] **Dr. Yuri Shishido:** I'm going to beg to differ. The neuropsychology at CHOA, we, just kidding so you know, we work very closely with our doctors here so that actually your wait time is shorter because we do have a pipeline.

[00:24:46] The other thing, what we are trying to do is we do recognize we have a long wait list. And it's not just CHOA; it's the nationwide problem. But we are trying to really customize, like if you just, you may just need consult. That's one hour. I have more consult slots than that. We may see two or three patients with a brief evaluation because that's all you need. So, we are working very hard and try to be more flexible and get you in as quickly as you can, we can.

[00:25:19] **Audience Member:** Hi, any tips or tricks for pediatric patients with severe needle phobias? My daughter, she has a port. She receives monthly IVIG. And while things have gotten better, big thanks to our home infusion nurse here who's awesome with her. There is still just this monthly anxiety that we know she experiences a couple days before the infusion, the day of the infusion.

[00:25:50] We have, she has met with a psychiatrist who suggested something like Prozac, but I'm like, is it worth taking something daily for those couple days a month of anxiety? But we also worry like over the long term chronically, like what is this doing to her mentally.

[00:26:13] **Dr. Avjola Hoxha:** So, when we're talking about phobias, the treatment modality that is recommended for those is actually therapy. And with this one specifically, it would be exposure therapy. That being said, your child is having lots of exposures. Medication can have a role. It depends. If you're not comfortable with a daily medication there, we can certainly try as-needed medications or just time-focused medications.

[00:26:45] For those couple of days before, just to lower that anxiety a little bit and make it so that she is able to start understanding that, this is not something to fear. But if we're going into it like really high anxiety, we're prepping ourselves for a really bad outcome or something to really hurt when we get the poke or things like that

[00:27:07] because we've built it up so much in our minds. So, if we can lower that response when we actually have the event, we're more able to understand like, hey, this is not as scary as we're thinking it is. So more targeted medications around that time might be more helpful, especially if you don't want her to be on something long term.

[00:27:41] **Audience Member:** About, ok, (inaudible) so let's do super hyperactive.

[00:27:48] **Dr. Avjola Hoxha:** Gotcha. The second part of us, what is this long term? And that is something that we do monitor from our end of things. We are learning more and more about medical PTSD, so events that happen in the hospital, in the clinics or things like that. And how they're being created and how they're impacting people long term.

[00:28:15] So that being said, as we're monitoring and if it's becoming a really traumatic event for her every single time that she needs something like this, then a medication like the fluoxetine that was recommended, can potentially help with anxiety but also help potentially alleviate some of those and make it so that it does not transition into the medical PTSD realm.

[00:28:43] **Dr. Varun Kannan:** I think stories like that are really important for us to hear as neurologists. We measure things like labs and MRIs and physical exams to say we have you on a treatment, it's controlling the disease, but often we probably don't pause, and think is the treatment actually causing you psychological distress. So, working with our mental health colleagues is really important.

[00:29:05] **Dr. Ajola Hoxha:** And if she's ever in the hospital, we do have Child Life, and they do wonderful job and kind of coming over anytime that she might need a procedure and just helping walk her through it. And we do have our wonderful facility docs as well.

[00:29:19] **Dr. Varun Kannan:** For those that don't know Child Life, these are professionals whose job it is to help the medical experience for children be less traumatic and almost fun. They're amazing. I wish we had that service for adult patients too. I've been an adult patient in a hospital. It was not like, my clinicians were great, but it was not a pleasant experience. So.

[00:29:41] **Dr. Yuri Shishido:** They're wonderful. They're really, they're warm. They make it fun, believe or not.

[00:29:49] **Audience Member:** So, my daughter was diagnosed with transverse myelitis at four and a half months old. So, she has known no other life, but life in a wheelchair and with a walker. But now that she's transitioning into school, she realizes that she's different. Sorry. So, I guess my question is how do I support her in that transition? And should we be considering for her mental health basically like a treatment plan, like we would for any other specialty to incorporate that into her life as well? Or do we wait for symptoms to show up or signs of maybe she's experiencing depression? How proactive should we be?

[00:30:45] **Dr. Yuri Shishido:** Great question. How old is she now? She's five. Five. Ok. So, she's getting to school age and that's where we probably, I would see a lot of my young patient first because this is very important that transition to getting into the school system. And this is where the academic demand or cognitive demand starts. And I would if you are thinking about or if you have any concerns, learning wise, language, cognitive then I would certainly recommend that you consider initial evaluation.

[00:31:28] **Dr. Ajola Hoxha:** And from my perspective, even if it's not medications, just to touch base and to have an established care, I think is important. Because we also, as I've said previously, we have the therapy arm of things as well. So, as potentially things come up, we'll be able to address them a lot quicker. And just react more, if there is a need to react, more promptly than if trying to wait to establish care.

[00:31:54] **Dr. Yuri Shishido:** And one of our jobs as a neuropsychologist is to help school be educated about what your daughter has to go through because it is rare disease, right? So, they don't understand it to start. And if you can't establish what we call baseline cognitive and psychological functioning then from which you can keep track. Because going through the school, the demand for academic, behavioral and cognitive thinking skills, that demand for that will increase.

[00:32:30] It's not like this, it's exponential. So, we wanna make sure that she's served, right. She, you want to be ahead of the game before that demand start increasing, that she is set up to be successful through the school system.

[00:32:46] **Dr. Ajola Hoxha:** Yeah. And to piggyback a little bit off of what you just said, there are programs if you're not aware, I don't know if you're aware or not, but there are 504s and IEP programs within the school system.

[00:32:57] And there can certainly be cognitive and behavior components to those programs and that they're not just medical. So, the more we have that filled out and more complete, the more the school is gonna be able to properly support your child.

[00:33:12] **Dr. Yuri Shishido:** 504 and IEP, I know there are some parents who are very experienced and great advocate, and I learned so much from those parents. And one of the roles that we play is to help you

go through it as well, to just help you get the right support. Because there is a big difference between 504 versus IEP and going through the process and experience can be daunting and we are gonna be right there to help you through it.

[00:33:45] **Dr. Varun Kannan:** Thank you for sharing and thanks everybody for sharing their own stories and struggles with the mental health and cognitive aspects. And thank you to our panelists. It was a good discussion.

[00:33:54] **Dr. Yuri Shishido:** Thank you.

[00:33:55] **Dr. Avjola Hoxha:** Thank you.