

Addressing Mental Health and Rare Neuroimmune Disorders

You can view this presentation at: youtu.be/BDC1BZ7invc

[00:00:00] **Dr. C. Virginia O'Hayer:** Hi, I'm V O'Hayer and I am a clinical psychologist with expertise in working with people with neuromyelitis optica spectrum disorder. And I'm here to chat with you today about our findings and a cool new treatment, a deep dive into ACT with NMOSD. What we're going to be talking about today in the next 20 minutes or so is, what is the psychological burden associated with NMOSD? what's ACT? and how could ACT be a pretty cool treatment to match the psychological burden and give people with NMOSD ways to live their best lives with NMO. We're going to talk about results of our clinical trial and then, if you're interested in receiving this treatment for yourself, how you can, and then I'm also going to tell you a little bit about this tool we have called SMART NMO which is a good indicator of who might benefit from a talk therapy, specifically to help with the psychological burden of NMOSD. So, let's get started. This graphic is taken from the Alexion website.

[00:01:23] They have been the research sponsor for all of our research trials. So, thank you. Just to go over some symptoms of neuromyelitis optica spectrum disorder, otherwise known as NMOSD or NMO. It comes with a variety of full-system symptoms, including problems with vision, intense pain, fatigue, coordination or movement related issues, loss of bowel or bladder function, abnormal skin sensations.

[00:01:58] People will talk to me about what they refer to as the NMO hug, where they might be feeling like they're getting squeezed. Also, sensitivity to heat, to light, to cold, nausea, uncontrollable vomiting, and hiccups, just to name some. So, the mental health burden of NMO can actually be quite heavy.

[00:02:21] This is a disease that is unpredictable, progressive, painful, debilitating, comes with unpredictable relapses and flares. And each one of these relapses can lead to neuronal damage, damage of neurons that are associated with vision, associated with movement, such that each flare can get people worse and worse off regarding mobility and vision.

[00:02:50] That said, mental health is very rarely addressed at the time of diagnosis with NMO, and there currently isn't a treatment that people are recommending in order to deal with the mental health toll of NMO. What I want to talk a bit about is what does it look like for real people living with NMO and their loved ones in terms of what is the mental health burden?

[00:03:16] And to answer this question, our team, supported by a grant from Alexion, our mission was figure out from real humans, what is it like living with NMO and what is it like taking care of someone or having a loved one who has NMO? Instead of just looking at the scientific literature, like journal articles, textbooks, et cetera, we did a really deep dive into patient-generated literature as well.

[00:03:46] Here you want to think like forums, blogs, Facebook groups, anything that somebody wrote about their experience of living with NMO or that someone wrote about their experience of taking care of someone with NMO. We read it, and we synthesized this knowledge and put it into our phase one trial which involved individual interviews, really hearing the stories of people living with NMO and their loved ones.

[00:04:15] We did about an hour-long interview with a variety of people living with NMO and also with their loved ones, one-on-one. We also had focus groups because sometimes when you're in a group of people with the same issue, ideas and thoughts and reactions might come out that maybe didn't come out in an interview one-on-one with someone like me.

[00:04:38] We had patient interviews, patient focus groups, loved one interviews and one focus groups. We also gave people a variety of self-report questionnaires, measures of anxiety, depression, rigid thinking, how much are people living their values, et cetera. This was published and open sources in a journal called PLOS One.

[00:05:00] If you ever wanted to do more of a geek out and read this yourself, it's open source, free access for everyone, and the title is The Psychological Burden of NMOSD. And it's written by Darcy Esiason, some other colleagues and me. 30 patients participated in our phase one study, 90% female, 10% male. 80% were aquaporin-4 positive.

[00:05:31] People really ranged in age from lower twenties to upper seventies, with the median age, the average age of 41. We tried to sample across all races. As we know with NMOSD, African Americans and Asian Americans are more affected than white Americans or more likely to be diagnosed with NMO than are white Americans.

[00:06:00] However, our sample unfortunately was mostly Caucasian, so we got about 70% of the sample Caucasian. We've got about 7% African American and 13% Hispanic and 10% Asian American / Pacific Islander. All these people were actually in the US or Canada. And now this is a word cloud where on one side of the image here, you'll see patient words and on the other side are listed a bunch of caregiver words.

[00:06:39] Now, in a word cloud, if a word is said a lot when asked to describe "what's it like living with NMOSD," if a lot of patients give the same answer, that word will be in larger font. For patients "pain" was the most commonly cited word, followed by "vision," "blind," "relapse," "diagnosis."

[00:07:06] For caregivers "pain" and "work" were both seen as major aspects of the experience of what is it like to take care of someone living with NMO. Not to say that it feels like work, but more like impact on the caregivers' paid job and seeing their loved one in pain. And also, from all of the responses that we got from patients and their loved ones, we digested this down into five themes.

[00:07:39] The first theme that people talked about a lot was distrust and lack of respect for medical professionals. This makes sense when you hear people's stories. A lot of people talk about going on these, what they refer to as like a diagnostic odyssey. So, taking a long time, often years, between first symptom and accurate diagnosis.

[00:08:02] This 30-year-old lady told us living with NMOSD, “The first time I got sick, I ended up being in the hospital for five weeks, three different hospitals, because I was sick for an entire month, and everyone kept sending me home. They kept saying, we don't see anything, we don't see anything and sending me home.

[00:08:24] It started in February 2012, and I didn't get it officially rightly diagnosed until February 2015.” We also heard a lot of people talk about medical professionals minimizing pain. A 28-year-old woman living with NMO told us “The biggest thing I struggled with was pain. Like I was paralyzed, but pain was worse than paralysis because it was just so mentally hard because they couldn't do anything for me.

[00:08:58] I was on a bunch of opioids and NSAIDs and SSRIs and nothing helped.” The second theme that came up was lack of support and resources immediately after diagnosis. First of all, symptoms of trauma and depression upon diagnosis. A 33-year-old woman living with NMO told us, “My immediate question was, am I going to die from this?

[00:09:26] I was in like survival mode. It was a fight or flight moment. What do I do?” And the other part of this theme is patients and caregivers relying on peer education and support. One 35-year-old woman told us, “Facebook is a huge source of information and that's very helpful, especially if I'm at an ER and the doctors are not trained in NMO.”

[00:09:52] This lady is telling about her experience of being in the ER with an NMO related flare and having to look on these Facebook groups to get information about NMO in order to relay that to her ER doctor. Third theme is the impact of NMOSD on relationships, both positive and negative. So negative, thinking about invisible illness negatively affecting interpersonal relationships.

[00:10:18] We heard a lot of stories here about people who've lost friendships because they often have to cancel due to illness. And their friends saying, “You don't really look ill.” So really getting at this invisible illness and the toll it can take not only on the body, but also on friendships and relationships.

[00:10:37] Then we also did hear, conversely, some people who would report that their illness actually helped the patient-caregiver relationship. Typically, this would be maybe spouses or mom and daughter, where the person living with NMO was actually able to get support and connect with their loved one, maybe in a way that let them see what's really important in life for both of them.

[00:11:06] Instead of spending time talking over to-do lists and tasks and chores we've got to do for the rest of the day, thinking more about like, all right, let's connect together on a deeper and more supportive level. The fourth theme is deviation from valued living. That's like no longer living the life that you want to be living.

[00:11:28] So diagnosis, interfering with how you thought life was going to go and grieving the loss of family identity. This 74-year-old mom of someone with NMO had said “The saddest thing for me was that we couldn't go see the Christmas lights as a family anymore because she could just no longer see.”

[00:11:52] It's like that part of the holidays is ruined. And thinking about anxiety, about engaging in life due to physical deficits, thinking about “[I] don't want to make plans because what if I get sick and can't do it? I don't want to go to a big event because what if the lights are bothering me, or what if I'm not feeling well that day?”

[00:12:13] All of these things, taking people away from what's really important to them. And then the final theme is internalizing feelings or bottling feelings inside as a coping strategy. This is both avoiding thinking

or talking about NMO, maybe even with loved ones, and then caregivers or loved ones really staying stoic in the face of the patient's illness.

[00:12:38] We had a 61-year-old man who said regarding his wife, "One of the doctors told me that I needed to prepare for the worst. I just kept my energy high, just to not let her know that I was worried. We were always positive." That can take a toll on the loved one as well, bottling up that fear or not joining with the patient together about fear that maybe they're both having, but keeping that siloed and bottled in, maybe as a way to not bring each other down.

[00:13:14] Then we had data from self-reports, from these measures of anxiety and depression that patients filled out. What we found is that 33% of people in our trial of 30 patients living with NMO were experiencing clinically significant depression, and even more than that, 72.5%, were experiencing clinically relevant anxiety.

[00:13:45] When we assess for rigid thinking, so when thoughts, particularly unhelpful thoughts or negative thoughts, really feel like a truth. For example, if I'm rigidly thinking "I'm a bad partner because I'm always sick," then if I'm really stuck on that thought and if I really think that thought is true, "I'm a bad partner because I'm always sick," then that thought might actually make me give up trying to connect with my partner in any way.

[00:14:13] Clinically relevant rigid thinking is something that we're really trying to target in our next phase, which we'll talk about in a moment. 63% of people living with NMO were engaging in this really rigid thinking and buying those thoughts as truths. Then we ask people, "would you be interested in a telehealth talk therapy designed particularly to help you live your best life with NMO?"

[00:14:41] What we found was the vast majority of patients and loved ones said "yes." We got a resounding "yes" from two thirds of patients and a "maybe" from about 27% of patients. When we asked, "would you want your loved one to be part of this therapy?" - results were really mixed. We got about 20% of people said, "nah, I don't want them to come to my sessions."

[00:15:08] And then similarly, we got about 20% of people saying, "I'd like them to come but to get their own sessions separate from me." And then we had about a third, 32-ish percent, of people saying, "yeah, I'd like for them to come to some sessions, maybe have some other sessions by myself."

[00:15:25] Really results were all over the place as to whether people would want their loved one there or not. Before we get into the trial, I want to tell you just in a few moments about what is ACT. Just to give you a quick little taste of this treatment, that really, it's awesome, it's experiential, it's fun, it's flexible.

[00:15:48] I've received it as a patient and found it life changing. I like to give this treatment as a provider, I've given it to hundreds of people, and it's awesome and it's fun. ACT is a new form of cognitive behavioral therapy created by Steven Hayes in 2004. So, it's relatively recent and it's been found to be effective as a treatment for anxiety, depression, pain, cystic fibrosis, HIV, substance use, and really ACT is good for adjusting to any situation where avoiding painful thoughts or painful feelings makes things worse.

[00:16:30] So you think about if avoiding painful thoughts and painful feelings leads to bottling things up and feeling more stressed, ACT can help. What if avoidance leads to people avoiding engaging in their medical treatments? ACT could be good there too. Or what if avoidance leads to people engaging in behaviors that maybe aren't so helpful, like scrolling at home or rotting or watching way too much Netflix or drinking/drugging, risky spending, et cetera?

[00:17:03] Any negative that comes from avoidance, ACT can help with that. ACT helps people live the life they want without struggling against painful thoughts and feelings. ACT really helps us to change our relationship to anxiety, depression, worry, thoughts, any of that. Taking a closer look at ACT: ACT is all about what's important to you, how do you want to live your life, and can you take a step towards that right now?

[00:17:34] Don't wait until everything is perfect. How can you, right here, right now, take one step towards something that might be important to you? I think about in my own life, I often live as though my most important priority, my top value is responding to emails in a timely manner. Someone writes to me; I've got to write back right away.

[00:17:54] But really my most important value, I guess I've got two. One is being a fun mom and the other is helping people with chronic illness. Oftentimes responding to emails in a timely manner doesn't really hit on either of those versus being present, doing something fun with my kids, or really taking time to understand and try to help and join with someone who's really going through it during maybe an illness flare.

[00:18:21] Either of those, I feel like I'm living my best life. Responding to emails fast, meh, takes a lot of time, doesn't really get me there. That's really what ACT is about, like what's important to you and how to take a step towards that right now. And ACT is filled with these in-session interventions where even if you change nothing outside of the session, you'll be changed by these experiences you'll have in the session.

[00:18:50] And one of these is demonstrated right here. Thinking about values, what brought you today to this talk that you are sitting through and listening to, what was it that made you think, yeah, I really want to hear about this. And let me ask you another question - right here, right now, are you living the way you want to live?

[00:19:17] Maybe you are, maybe that's great. Or maybe there's room for a little bit of improvement. What could you do to take a small step toward living how you want to live right now? It could be something small; it could be taking a moment to look at the leaves outside. It could be taking a moment to send some good thoughts or wishes to a loved one.

[00:19:40] It could be, let's take a moment to look within and think about a couple of things I'm grateful for. Another concept that ACT brings up is that your mind is not your friend. So unhelpful thoughts can be stickier than brain fog, and our brains evolved to detect any possible threat. Think about we're all the descendants of neurotic ancestors who would see a blade of grass moving a hundred thousand years ago and think "lion!" All of our ancestors who would see the blade of grass moving and think "ooh, isn't that cool?"

[00:20:21] They all got eaten by lions and didn't pass on their genes. We can't change our learning history, but we can lay down new learning to help us get more flexible. You think about our minds can often be set to a doom-and-gloom radio station, looking for any possible thing that could go wrong.

[00:20:41] However, what if we can change our relationship to some of our worry thoughts, some of our regrets, some of our if-onlys, such that they don't maybe influence our behavior as much? What if the next time someone has that thought like, "ugh, I can't be a good partner because I'm always sick."

[00:21:05] What if you could hold that thought lightly, like you might hold a butterfly? Like, "Hey, there's that thought. All right, what do I want to do next? Maybe I still want to find a way to let my partner know that I love them. Yeah, sick and love you both at the same time." Here are our findings from our trial ACT with NMOSD. Also, this was sponsored by a grant from Alexion.

[00:21:24] If you want a deeper geek out, it's also published open source, so free to anyone. Its title is "ACT with NMOSD: A targeted telehealth-delivered mental health intervention for patients and caregivers." If you just Google "ACT with NMOSD," you'll find this in "Multiple Sclerosis and Related Disorders" [journal].

[00:21:47] Here it is in a nutshell. People living with NMO got six sessions of ACT with NMOSD, one a week. Each one takes about 50 minutes. It's a manualized intervention, six sessions in a manual. We based this manual on our findings from phase one: what's the psych burden of NMOSD? And super cool is that one of our authors on this manual is a person living with NMOSD who made such a big contribution that she deserved to be an author.

[00:22:21] Thank you to Lelania Lloyd. All of this was delivered over telehealth using HIPAA-compliant Zoom so that people could engage even if they felt terrible and they were lying in bed, that's fine, pop on your telehealth. Or if someone was in the hospital, they could still engage, or if visiting with family in another state, wherever.

[00:22:44] We gave people the choice of, do you want to participate with a loved one? If so, the patient and loved one could choose: do you want the loved one to come to no sessions, all the sessions, some sessions, or have the loved one get their own separate sessions?

[00:23:05] Here are our demographics. We had 43 patients, 43 people living with NMOSD. We had about a 7:1 female to male ratio. So, we had five men, we had two transgender people, and we had 36 women. Regarding race, we're still at about 56% Caucasian. We did manage to recruit 28% African American or black people, 7% Hispanic and 9% who identified as multiracial.

[00:23:43] Regarding the caregiver/loved ones, the most common relationship between the caregiver and patient was spouse. 55% of the caregiver/loved ones were spouses, followed by mother 32%, sister 9%, and daughter 5%. The six-week telehealth-delivered ACT with NMOSD intervention significantly improved depression.

[00:24:13] I'm showing a graph now that shows that the baseline score on the Beck Depression inventory was about 15.5, and this reduced to 11 after the six-week treatment. There was a slight rebound three months later. After you get the treatment for six weeks and then three months of nothing after that point, the score was back up again

[00:24:36] a little bit to a 12 but still reduced from 15.5. Also improved anxiety. Anxiety reduced from about 13.5 on the Beck anxiety inventory to about a 10 after the six sessions. Then again, there's a slight rebound to about a 10.5 at the three-month later, but still a good reduction from 13.5. Now, psychological flexibility, that's really what ACT is all about.

[00:25:04] How to get more flexible, how to turn off that doom-and-gloom radio station and find a different way to respond. Now here's something pretty awesome. Psychological flexibility improved from baseline. This one's a reverse score, so the higher the score, the more rigid you are, the lower the score, the more flexible you are.

[00:25:26] People started fairly rigid at a 20 on this scale and then dropped down to about a 16.5 after the six weeks. Now change still was happening three months later, after three months and nothing, now rigidity is down to a 14. This ongoing improvement, getting more flexible over time, is showing that the ACT with NMO intervention is actually fundamentally changing the way that people with NMO are dealing with their thoughts, their feelings, even with just living with NMO, getting more flexible psychologically.

[00:26:04] Also, we saw an improvement in valued action, living your values. For me, that's being a fun mom who's helping people with chronic illness versus being someone who's compulsively checking my email and

writing back right away. Here we've got people engaging in more valued action. We got about a nine-point increase in valued action from baseline to after the six-week intervention.

[00:26:31] We saw people getting a bit further away from their valued action at the three-month mark such that there was only maybe like a seven-point increase from baseline. Good gains to six weeks and then a couple point drop off after that, but still pretty good gains at the three-month mark, after three months of nothing.

[00:26:56] Here's our summary. After the NMOSD six-week intervention manualized, 43 patients with anxiety and/or depression got this treatment, 22 of their caregivers/loved ones were also included. What we found is that participants showed improvement in depression, anxiety, rigid thinking, acceptance, psychological flexibility, valued action, and even sleep quality improved, and these gains were still present three months after the treatment ended.

[00:27:33] Before I tell you how to get this treatment, if you are interested, I want to tell you about this SMART NMO screening tool, which we piloted during our trial. SMART NMO stands for Systematic Mental Health Assessment and Response Tool for NMOSD, and the acronym is SMART NMO. This is a self-report measure that's designed to capture symptoms of anxiety and depression that might be missed or confounded by NMO symptoms or confounded by treatment side effects.

[00:28:08] So ways of thinking and being that might otherwise be written off as, oh, this is just because of your illness, or, oh, this is just because of treatment side effects. We are also assessing for medical trauma, quality of the relationship with the physician, impact of NMO on relationships and future planning.

[00:28:28] The goal of this SMART NMO tool is for it to be a screening tool that's given at the time of diagnosis. Even if that's all that happens, full stop, this is given at time of diagnosis, this is designed to meet that unmet need of "mental health is not discussed when I'm given this diagnosis,

[00:28:48] I've waited all this time, get the diagnosis and mental health is never mentioned." We're trying to disrupt the current narrative by having this tool that's free, it's easy access, open source, and it can be given: "Here's your diagnosis of NMO. Here's this screener, fill it out.

[00:29:07] If it looks like you could use a mental health intervention, we'll tell you where to go for that." The goal is this screening tool, giving it at time of diagnosis and at other clinic visits to help decide, would a mental health referral be useful. It's seven items long, and it assesses three main domains: current mental health burden, symptom burden, and worry/concern about future relapse.

[00:29:36] If you score over 24 on this measure, then you might benefit from a mental health intervention to help cope with NMO. Our summary is: the psychological burden of NMOSD is complex, affecting patients and their loved ones. ACT with NMOSD is a six-session telehealth-delivered intervention that did effectively meet this burden.

[00:30:00] It improved depression, anxiety, value-based living, cognitive flexibility, acceptance, and sleep, even three months after treatment ended. SMART NMO is a tool, a self-report measure, that can help you decide if a mental health intervention could help, and great news, in early 2026, you'll be able to get ACT with NMOSD if you so choose from a certified provider.

[00:30:27] That's where we're at right now. Thanks to a grant sponsored by Alexion: AstraZeneca Rare Disease, we are now doing what we're calling this ACT with NMOSD implementation program, where my team is training providers across the country, psychologists, social workers, other mental health providers.

[00:30:49] We're training them and certifying them in the ACT with NMOSD protocol. If you want to get on the list for this treatment, if this sounds like something you might be interested in, it's for adults living with NMO, delivered over telehealth by a certified ACT with NMO provider who's licensed in your state,

[00:31:08] then feel free to shoot me an email. I'm at "Virginia.OHayer@jefferson.edu." If you shoot me an email, I will get you on the list for this and find someone in your area who is trained and licensed in your state. This will be coming out hopefully in January. We're about to do the training in this next week. So, stay tuned. Thank you.