

Pediatric Mental Health

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[00:00:05] **Dr. Camille Wilson:** Well, thank you for joining today for our pediatric track. We're glad to have you. I'm Camille Wilson. I'm a pediatric neuropsychologist from Nationwide Children's Hospital. We're really excited. And this is Dr. Hutchinson. She and I are going to be doing the two topics for this afternoon. And I'm going to be focusing on pediatric mental health. So, thinking about the value of the whole and psychosocial considerations for pediatric neuroimmune disease. As we put through, I just wanted to let you guys know, I don't have any disclosures to report. And then this is the plan of some of the things that I'd like to talk about with you today.

[00:00:50] I wanted to spend some time and talk about what are the mental health needs in the neuroimmune population based on the research. I'd like to talk about what are the needs, mental health needs, in a local clinic population, specifically within our institution. And then to talk about what are some important steps that caregivers and treatment providers can do to help meet these needs. Is the volume okay for you guys?

[00:01:15] Okay. I feel like I might have to go down a little bit. Okay. So, originally, we were going to do a fancy word cloud, but technology is working against me today, so I thought maybe what we could do is just open it up to the audience. And so, for those of you out in the audience, if you don't mind just maybe calling out a word that comes to mind as you think about neuroimmune disease either for your own experience, your child's experience. What are some words that come to mind for you?

[00:01:44] **Audience member:** Fatigue. Fear.

[00:01:48] **Dr. Camille Wilson:** Say again?

[00:01:50] **Audience member:** Pain.

[00:01:51] **Dr. Camille Wilson:** Pain. Yes.

[00:01:52] **Audience member:** The unknown.

[00:01:52] **Dr. Camille Wilson:** Yes, the unknown, absolutely. Cognitive issues. Yeah. So, just those thinking skills. Anything else?

[00:02:00] **Audience member:** Change.

[00:02:01] **Dr. Camille Wilson:** Change. Yes, for sure. And so, as you think about all of those words, the implications for, you know, your family or for the child can be huge, you know? And just thinking about a life altering diagnosis, like what does this mean? There's so much, we don't know. There can be fear. There can be anxiety. There can be changes in functioning, right? That you have to transition and adjust to. Or even adapt from a thinking skill side. And so, I wanted to talk a little bit about how that can impact mental health as a whole and why I'm arguing as a psychologist, I have a little bit of a bias, but as a psychologist, why I argue it's so important to think about the mental health side.

[00:02:40] So, up here are just some general slides from our Center for Disease Control. Thinking about pediatric mental health as a whole. And so, what you can see is that depression, anxiety, and behavior disorders are among our most common mental health disorders. And you can see that there's a definite uptick when we hit adolescence, right? So, when you see that 12 to 17 year range, you definitely see that uptick in depression, anxiety, as well as behavior disorders. But what we're seeing in the research is that actually the 6 to 11 years, the pre-adolescents, the childhood to pre-adolescence is also a time of when we're seeing some increasing diagnoses particularly maybe around ADHD diagnosis or some others.

[00:03:22] And then, you know, just some general statistics to think about mental health more generally, is that 50% of all mental illnesses start by the age of 14. So, we are hitting this right in the square of childhood. And that one in five children in the United States have a significantly impairing mental disorder. So, not just a mental health diagnosis, but a significantly impairing mental disorder. Yet less than half of them get the treatment that they need. So, this alone, as we think about mental health in the United States, is a very sobering statistic and one that I think powers our psychology team at Nationwide Children's to think about ways to meet those needs.

[00:04:01] But what I want to do is to home in a little more specifically on what are the pediatric mental health needs in a neuroimmune population. So, what do we know from the research? There have been many studies that have been done that the Duncan & colleagues' study from 2020 is a review sort of putting together a lot of the research that's been done so far and looking at what are some of the trends and so what we see is very similar to the general population, anxiety, ADHD, mood symptoms are the most common disorders that our children with neuroimmune disorders are facing.

[00:04:36] You know, just like we had in the audience, there's a high overlap of cognitive and psychiatric disorders. And I think what's really interesting is what came first, the chicken or the egg? Was it the cognitive disorder that created the psychiatric or was it the psychiatric impacting the cognition? And I think the research often shows it's maybe both directions, but there's certainly an overlap between the two of those. Fatigue, again, as mentioned in the audience is very high report rate with up to three quarters of individuals may be reporting high levels of fatigue, particularly in our MS samples.

[00:05:10] And the lower quality of life ratings, that life feels harder. It's more challenging, especially for those of our patients and children who are facing relapsing disease, right? That again, that unknown. But then when it's happening over and over, what does this mean? How is it affecting my outlook and what my future is going to look like? So, what I wanted to do is to talk to you a little bit about our clinic. We are located in Columbus, Ohio. So, our hospital, Nationwide Children's, began our neuroimmune clinic in 2019.

[00:05:46] As many neuroimmune multidisciplinary clinics, we see patients who have been diagnosed with rare autoimmune or inflammatory disorders of the CNS, or central nervous system. We have been fortunate to have a multidisciplinary clinic that includes these providers here. So, we have just about a weekly multi-half day clinic where we're seeing patients. We have a neurologist, rheumatologist. We have a pretty deep psychosocial team. So, we have pediatric psychology, neuropsychology, which is me. We have a psychiatrist as well as a pharmacist who are all part of our clinic.

[00:06:25] And so, we are able to tailor our appointments with each family as they come into clinic and be able to see them as needed for each of these areas. We also include annual neurocognitive screenings. So, we're following our patients to see how are they doing from those thinking skills side. We also do annual psychosocial screenings. So, we're looking at how our children are doing from that mental health side of things. And that's what I'll be focusing on and talking with you today. So, with our psychosocial screening, our psychology team got together, and we created a series of questionnaires that are put onto RedCap.

[00:07:05] RedCap is sort of like a survey type software that can get pushed out so we can send it out before a clinic visit so families can complete. But they can also do it in clinic with an iPad if they need to. And we've set it up so that we're doing an annual screening. So, we're asking families and children to complete these. And then kind of sharing that feedback during the clinic of what are we seeing, you know? As we're measuring these different areas, what are we noticing? What's high? What's doing well? And so, on. And so, this slide outlines what are the different areas that we're looking at.

[00:07:39] It kind of hits up many of the areas that you were talking about in just that sort of free association. We're looking at fatigue, anxiety, depression. And as you can see with the two parts of the slide there, we have measures that are focused on the child or the teenager. And we also have measures that are from the parent perspective as well. So, we're looking at learning, attention, executive functioning, as well as just general behaviors from the parent's side. In addition to what children are experiencing themselves. And part of the reason why we do that is because we want our pediatric locations to have a voice. And sometimes that voice is more accurate, especially when you're looking at more of those tuning-in disorders like anxiety or depression, that those are often the more accurate voices that we can hear and report of those symptoms. Yes, absolutely.

[00:08:45] **Dr. Camille Wilson:** So, these are age ranges of where the measures have been normed. But at our clinic, we see kids all the way from infancy into young adulthood. So, we span a range, but these are measures that specifically target, that have been at least validated within this age range.

[00:09:05] **Audience Member:** [inaudible]

[00:09:08] **Dr. Camille Wilson:** For like, in terms of the self-report?

[00:09:11] **Audience Member:** [inaudible]

[00:09:14] **Dr. Camille Wilson:** Yeah, yep. So, the way that we've developed this process is that parents are filling them out as soon as a child comes into clinic. The child we're not asking to complete until they're at least about elementary school age. So, if they can read. And then sometimes the parent may be reading out loud to them and providing a little bit of support, particularly if there are some learning needs or if they're on the younger end. So, we are, probably our sweet spot is about elementary school, I would say probably six is where we're consistently getting child report. But we're definitely trying to get parent report as they enter into our clinic process. Yeah, that's a really good question. Thank you. So, I just wanted to present some data

that's been collected over really the last like just over the past year. So, these are questionnaires that were completed between 2020 and 2022.

[00:10:06] We had 54, more than adolescents, child, and adolescents as well as a family caregiver, so it could have been a parent or a legal guardian and so on. Most of our sample was female. And this ranged, again, to maybe answer your question, it ranged from 6 to 19 years of age with the average age being about 13 of the individuals who are completing. You can see the list of diagnoses very much within the realm of our SRNA population with ADEM, optic neuritis, MS, transverse myelitis, and then other types of encephalitis.

[00:10:41] So, maybe La Crosse encephalitis or autoimmune encephalitis as well as some other lesser, more rare diagnoses as well. So, just from the results side, what you can see here are our child and adolescent ratings. And so, this is looking at fatigue levels, depression and anxiety and the orange represent elevated scores. And so, what you can see is that we have a fairly high percentage of individuals that are reporting higher levels of fatigue. So, about just over 30 something percent, almost 40% depression. Almost half of our children and adolescents are reporting some level of depression and about a third are reporting symptoms of anxiety.

[00:11:32] So, this is just from the child perspective, which I think is always striking to me when you have children and teens endorsing, because it's not uncommon maybe for some of like, let's say a teenage boy, to be like, I'm fine, everything's fine, nothing's wrong with me.

[00:11:43] But no, these are kids that are saying, "There is something going on and I can feel it." And I think that is when we should really be listening when they are coming to us and saying, "I'm having trouble with these areas." These are our parent readings. They're using slightly different measures but looking at similar areas. So, the fatigue from the PROMIS scale. We're also looking at inattention, as well as anxiety and depression. The numbers are a little bit smaller, like I mentioned, sometimes the correspondence of parent report to child reports sometimes differ. And when we're looking particular at those more internalizing disorders like anxiety and depression, you'll often get higher rates of report from the teen or child.

[00:12:25] And so, we're indeed seeing that. So, we're still seeing elevations, but maybe not quite as high. But we are seeing very high levels of fatigue being noted by family members, but in addition to our children. So, then this is looking at a questionnaire that looks at how are, from a parent perspective or caregiver perspective, how are our children doing in terms of their learning, their executive functioning, so their problem-solving skills, as well as their attention overall. And so, the blue are non-elevated ratings. But you can see this is a lot of information, but in terms of all the sub domains, but what I want you to pay attention to is we're seeing almost 40, over 40% of parents reporting difficulties with attention.

[00:13:14] Very similar rates of difficulties with processing speed, processing visual information. But you know, you can see that it's generally running anywhere from 20 to 40% of elevations even within our very small clinic sample. So, we're definitely seeing those cognitive difficulties like you mentioned at the beginning. So, then what I wanted to do was just to divide this out by different diagnoses. And so, you know, the blue represents the child perspective the parent is represented by the red. And so, consistent with the literature, we see very high levels of fatigue with our transverse myelitis and ADEM population. You know, teens are also, sorry children are also reporting higher levels of fatigue with MS as well.

[00:14:01] So, again, fitting very much with our literature. I think what's really interesting is looking at just even an optic neuritis and our general encephalitis category. We're seeing very high rates of fatigue as well. So, higher than what we've often seen in the published literature. And then in this scale, I mean on this page, what we're seeing are high self-reported rates of depression across different diagnoses. Again, red represents

the elevations. And so, when you look at ADEM, optic neuritis, encephalitis, you're seeing over 50% of our, you know, group of 50 something children and adolescents reporting depression elevation.

[00:14:47] So, that's pretty notable. I think our transverse myelitis are not reporting a ton, but certainly of symptoms at this time, at least when they took it, but you know, we're continuing to follow them on an annual basis, checking and just knowing that there is a higher risk, but just at the time of the survey, they were not reporting high symptoms.

[00:15:09] Similarly with anxiety, we're seeing very high rates of anxiety as it is in optic neuritis, MS, as well as encephalitis. And so, I think, you know, one of the takeaways in looking at these slides is to really consider the impact of a chronic health condition on mental health, right? And the impact that it can have on those anxiety symptoms, those depression symptoms overall. And then when we look at the learning, again, this is a really busy slide with lots of colors. But what I want you to take away is if we think about ADHD diagnosis in the population and thinking about them happening at about 10% of our population, and that's at a diagnosable level, you can see across our different medical diagnoses that we have very high rates of elevations being reported by parents by diagnosis.

[00:15:56] And so, to me that points out, we really need to be thinking about these and asking about them and assessing what a child's attention, processing speed. How their cognitive challenges may be impacting their day-to-day functioning, right? Again, with our MS folks, we have just a little blip there with processing speed. Again, I think for some of our folks we are seeing sometimes it comes and goes, and so just at the time of screening, you know, this is just a limited sample of what we're seeing.

[00:16:26] Similarly, from a learning perspective, if you look up here at this slide, what we see is that there's a high rate of learning concerns across all the diagnoses. The red horizontal line is just to draw what the average diagnosed rate of a learning disability is in the general population for the United States. And so, that's about 2% of our kids. School age kids have a diagnosed learning disability. And you can see that the amount of concerns are quite high. It's not to say that all these kids have a diagnosable learning disability, but parents are noticing challenges in those thinking skills as it relates to math, reading.

[00:17:04] I think what was surprising to me was how many are noticing challenges with writing, right? So, written expression. The ADEM certainly group surprised me with that. But you know, even across other diagnoses as well. I think the other thing to think about is linkage to behavioral health supports. And so, our psychology team, we got together, and we took a look at those 54 individuals who filled out our screening. And so, 39% of them, so over 30%, are currently linked with psychiatry supports either within our institution or out in the community.

[00:17:40] Over almost 70%, so almost three quarters of our kids are linked with psychology or behavioral health support. Again, within our institution or within behavioral health within the Central Ohio community. And then over half have completed a neuropsychological evaluation. And so, it's a pretty high rate of usage of psychology and psychiatry support. So, these are some of the takeaways that I'd like to leave with you. You know, anxiety and depression do coexist with medical diagnoses.

[00:18:14] We do see high rates of learning concerns expressed by patients and families and there's a high rate of linkage with behavioral health support, be that psychology, psychiatry or even neuropsychology. And I think it really echoes, you know, what you all had talked about at the beginning with your word associations is that it is so important to consider beyond the medical, right? That we need to think about the child as a whole. And you know, I would argue that we need to consider the mental health needs within this population. And so, this slide kind of captured it for me in thinking about that the whole is greater than the sum of its parts.

[00:18:49] So, we can talk about, you know, the functional, we can talk about the medical, we talk about the medications and those pieces, but we also have to be thinking about the integrated whole of the person. So, I think in considering ways that you can be supporting your loved one or patients in your clinic is to really think about regular, ongoing mental health screening, to know what those early signs of mental health concerns are. So, when a child is taking longer to do their homework or when they seem to be having difficulty focusing and maintaining that focus, or maybe if you're seeing irritability that lasts beyond maybe like that steroid treatment and it keeps going, maybe that could be an early sign of depression.

[00:19:30] Because depression isn't always sadness, it can be heightened irritability as well as changes in sleep or appetite or some of those things. So, just being able to keep an eye on some of those early symptoms and communicating that with your provider can be really important. And then to be able to recognize when someone may be having difficulty with learning. So, things are taking longer, they're not finishing their assignments. If you're noticing some kind of disengagement in the learning process, maybe not wanting to do their homework or turning in assignments. That could be masking a learning difficulty, you know. Maybe not a learning disability, but maybe more challenges with executive function or attention that may benefit from some supports.

[00:20:10] And then being able to seek out behavioral health or educational supports when you see signs of struggle. So, you know, you may have a clinic that has all of these resources embedded in. Amazing. If you don't just know, who can you go to, right? So, maybe that school counsellor or maybe asking your pediatrician for referrals for those supports that you might see whether it be from the mental health side or the learning side. And then this is a resource that I just wanted to introduce you to from our hospital. It's called On Our Sleeves. I don't know if you guys have heard about it. But it is a national initiative to provide mental health resources for families and caregivers.

[00:20:50] And so, what I love about this is they have tools and articles to help parents and caregivers and providers to be having conversations around mental health. So, maybe you don't feel as comfortable or it feels awkward to say, do you feel anxious today? No, it might be more, how do you deal with frustrations? So, these are like, operation conversations, so just little conversation cards. And how do you start to talk about, you know, when do you feel excited? Or what makes you feel happy? Or, you know, how do you deal with frustration? And so, just opening those conversations can be a really powerful space to allow a child to talk and process in those pieces. And then World Mental Health Day is coming up later this month, so we've got some nice resources there if you wanted to check out that website.

[00:21:34] So, I did want to say thank you to our neuroimmune team. I love our team. I think we've got a pretty amazing group of clinicians that are part of our team and particularly wanted to thank Dr. Goldstein-Leever and Dr. Harvey who are my psychology counterparts, but also to thank our patients and families. They make themselves vulnerable every time they come to clinic and open up their lives and talk about what are the things that are going well that we can celebrate with them, but also talk about the things that are hard that we can think about and brainstorm how to best support them.

[00:22:05] This is our team of amazing people that we have both on the front end working with our patients, but on the back end of scheduling, talking with them, welcoming them into clinic. And so, I just wanted to acknowledge that we have an amazing team and I'm very thankful for each of them. So, I can open things up for any questions if folks have any. We can also, I think we have time at the end, for Q&A as well. But if there's any questions that people want to jump in and ask, yes.

[00:22:46] A lot of pediatricians are starting to integrate like more standardized questionnaires, looking at depression, looking at anxiety and so you might talk with collaborating with your local pediatric provider

to see if they have any measures. I don't know that you as a parent need to be administering like formal questionnaires. I think it's more just opening the space for those conversations, and you know, kind of watching for any of the changes in behavior that might signal that your child may be struggling. Yeah, really good question. But I think just keeping that on your radar as your, you know, caring for your child for your loved one. Any other questions? Yes.

[00:23:24] **Audience Member:** Do you have supports, like in your clinic for siblings of children who, you know, like my daughter's sister?

[00:23:36] **Dr. Camille Wilson:** Yes. Yeah. So, our clinic does not directly work with siblings, but our pediatric psychologists will see siblings and help with coping and adjustment. So, if we notice if there's like a big strain on the family and thinking about coping from the sibling perspective, kind of how to help navigate, now my brother or sister is really living with this, you know, life changing diagnosis.

[00:23:58] What does that mean for me? How I might feel guilt. And kind of processing through that. Yeah, that's a great question. So, if those needs do come up, I think it's definitely worth, you know, asking your pediatrician or your clinic provider if they have recommendations for folks within your institution, treating institution, or maybe in the broader community. I saw a hand in the back. Yeah.

[00:24:18] **Audience Member:** Yes. At what age do you start getting some type of neuro-psych evaluation for this kind of child that's having, say, cognitive issues with executive function?

[00:24:32] **Dr. Camille Wilson:** Great question. I think that is one that we are still trying to line out. I know we certainly try to see anyone within the preschool age and up who has had an acute episode that may have had any changes in their cognition. So, the parents are noticing changes in processing speed or attention or even just organization and planning. We definitely want to be thinking about following those kids over time. I think, for some of our kids we can see them diagnosed with a demyelinating disease or other autoimmune disease at very young ages.

[00:25:09] So, maybe like ADEM at age 18 months or two years and we might think about that having a hit on development. And so, even being able to do some developmental testing even when they're young. So, we will not be doing academic testing at that time, but we're looking to see over time. How is this child doing? How are they developing? Are there any weaknesses that we're seeing that might benefit from early intervention support? So, be it physical therapy, occupational therapy, or even academic enrichment as they get ready to enter a formal school system. Yeah. Thank you. Yes.

[00:25:58] **Audience Member:** [Inaudible] But how does it compare to the average population?

[00:26:01] **Dr. Camille Wilson:** Yes. So, those elevation scores are that these are considered elevated based on comparison across the population. So, if you gave this survey to, you know, many other people of parents of kids with a similar age. These scores would represent they're higher than what we would have expected to see. Yeah.

[00:26:19] **Audience Member:** [Inaudible]

[00:26:19] **Dr. Camille Wilson:** Yeah, that's a really good question. So, would we treat anxiety any differently if we know that maybe they have lesions and parts of their brain that might make them more vulnerable? You know, certainly some of our kids may have white matter lesions in the frontal part of their brain and that can affect attention. That can affect processing speed and some of those things.

[00:26:51] So, we may tailor like those interventions and maybe thinking about supports for rather than saying, hey, this is going to fix it and make it better, you know, so we might keep that in mind as we're working with a child. But many of our evidence-based interventions still are pretty effective for these different medical populations. But yeah, that's a very important consideration and why I'm a big advocate of our pediatric psychologists. So, that these are psychologists with specialized training in medical conditions and kind of considering how to account for that coping and adjustment as well as just the unique pieces of the, how it can impact the thinking skills and development. So, I think the neuropsychology is important, but also the pediatric psychology.

[00:27:37] **Audience Member:** Any recommendations for parents as far as speaking to them, because there's obviously still such a stigma surrounding mental health, cognition, not being able to perform maybe as they think they should be in school. Any recommendations for parents to talk to their children about the necessity because that in and of itself can be very difficult for a child?

[00:28:02] **Dr. Camille Wilson:** Yeah, absolutely. I think you know going back to that resource with, on our sleeves, the operation conversation. I think that's what can help families create like a normal space to have these conversations and talk about when things are hard, when things feel challenging. Like what do you do? What do I do? Right?

[00:28:20] And kind of creating that give and take conversation, because it is. It can feel awkward. It can feel hard. Like how do I ask this question? But being able to maybe have some of these supports can be good. But then also just unpacking it and asking like how was your day? You know what felt hard today? What felt good today? You know just kind of, I don't know, we have like a review day, right, with my kids and kind of talk about what went well, what was hard, what could have gone better. You know just sort of creating that culture of conversation can go a long way.

[00:28:52] But then also, you know, even reaching out into the local community if you're feeling like you know what I think this might be more than just what I can do. Like it'd be helpful to have someone to come alongside and so being able to reach out to some of those community resources can be helpful. And then the school can be a really valuable resource as well with the school counsellors or even support plans with an IEP or 504 Plan, you can have check-ins around emotional functioning as well and so have other professionals kind of be looking in on your child during that school day and seeing how they're doing with their coping and adjustment. All right, thank you.