Study on Pediatric Teleneuropsychology

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GG deFiebre: [00:00:00] Hello everyone and welcome to the SRNA Ask the Expert Podcast Series: Research Edition. Today's podcast is entitled "Study on Pediatric Teleneuropsychology". For today's podcast, SRNA's Rebecca Whitney was joined by Dr. Lana Harder. SRNA is a nonprofit focused on support, education and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org.

[00:00:27] Dr. Lana Harder is a Pediatric Neuropsychologist at Children's Medical Center of Dallas, an Associate Professor with joint faculty appointments in psychiatry and neurology at the University of Texas Southwestern Medical Center. Dr. Harder completed her doctoral training at the University of Texas at Austin, pre-doctoral internship at the Kennedy Krieger Institute and Johns Hopkins School of Medicine, and postdoctoral fellowship in Pediatric Neuropsychology at Texas Children's Hospital and Baylor College of Medicine.

[00:00:55] She's board-certified in clinical neuropsychology by the American Board of Professional Psychology with subspecialty certification in Pediatric Neuropsychology. Dr. Harder was a founding member and is the Co-director of the CMCD Pediatric Demyelinating Diseases Program. Dr. Harder specializes in the neuropsychological evaluation of pediatric patients from infancy to young adults with disorders of the central nervous system. Research interests include cognitive and psychosocial outcomes for pediatric multiple sclerosis, transverse myelitis, acute disseminated encephalomyelitis, optic neuritis, and neuromyelitis optica spectrum disorder.

Rebecca Whitney: [00:01:32] Thank you so much, Dr. Harder, for joining me today. I appreciate you taking the time to talk about one of your most recent research studies.

Dr. Lana Harder: [00:01:42] Thank you for having me. It's great to be here.

Rebecca Whitney: [00:01:45] Thank you. And can you begin by letting us know what the title is of your study?

Dr. Lana Harder: [00:01:53] Yes. So this is a study on pediatric teleneuropsychology. It's a validation study. And happy to provide a link so you can share it with our audience today, so they can read more about it. But that's, that's the general title.

Rebecca Whitney: [00:02:11] Wonderful. Thank you. And what is neuropsychology? What is a neuropsychology assessment?

Dr. Lana Harder: [00:02:20] Yes, it's a great place to start, for those who are not familiar. So, in neuropsychology, we are trained as psychologists first, and then we have specialized training in what we refer to as brain behavior relationships. So what that really means is we want to understand the impact of a biological process or a medical condition on daily life.

[00:02:41] So, I'll give a more concrete example than that. So if we think about the conditions we treat and work within our community, it might be, for instance, what is the impact of ADEM in a child in the classroom or at home? Or how does that affect their mood or their behavior? So our job is to do these pretty comprehensive assessments, usually it takes most of the day to complete an assessment.

[00:03:05] And we're looking at those cognitive skills, like attention and memory, may touch on academic skills, processing speed, a whole host of cognitive things, as well as mood symptoms, behavioral functioning, and really how they complete activities of daily living. And so based on this nice comprehensive evaluation, which ties in interviews with the people who know the child best. So parents, teachers, as well as the standardized assessment, which was the subject of my research study, and those are kind of the paper, pencil, question-answer tests that get at those aspects of cognitive function I mentioned earlier. So we kind of pull all of that together with a goal to better understand the child and how their medical problem is showing up for them in daily life.

[00:03:52] Once we know what those challenges are and what their strengths are, we can start to develop a treatment plan that really leverages those strengths to address areas of difficulty. And what that treatment plan might look like: it could be everything from coordinating with their medical provider, with PT, OT, speech language therapists. It could be classroom accommodations, therapy with a psychologist if coping is a concern or behavioral issues are a concern. So really that treatment plan is completely tailored to that individual child so that we can address their needs and help them be as successful as possible.

Rebecca Whitney: [00:04:29] Okay, great. Thank you. And you touched a little bit about how an assessment works with interviews and whatnot. Is there anything else that it involves that is particular to neuropsychology, and how is it different from being in an office versus for the telehealth visit?

Dr. Lana Harder: [00:04:51] Yeah, so great questions. And I'll kind of start with the first piece of that. Our assessment - and just to kind of walk someone through what it might look like - would begin with a parent interview where we gather information. And then I should say, a parent interview, if the child is a minor, if they are 18 or older, we certainly ask permission of the patient to engage their parent in, in a discussion. We also do an interview with the child. So we're really trying to understand the child's history and what the current concerns are, so that we can design our assessment to address any concerns or questions. And so, as, as I noted, these might be, these tests that we do, might be paper, pencil, question-answer.

[00:05:31] We do some computerized testing. It's very important to mention none of these are medical procedures. There's no, no needles, no hooking up EEG or anything like that. So this is a nonmedical evaluation, but one that includes standardized assessments, meaning we're going to compare kids to others their age to determine if their performance is about where it should be for their developmental level, is it above or below. And so that's how we kind of measure those skills. Of course, we take into account behavioral observations. So how they're doing during the testing itself, because there are many things that could influence how someone performs on any given measure.

[00:06:13] So, you know, and then, from there we would go to a kind of results review feedback session with the family, with the patient, to talk about what we learned and what we think would be the best plan of action for that patient and family to help their child be successful. So that's kind of the step-by-step.

[00:06:32] Now, what does this mean for a virtual environment. And I think many of us have become pretty comfortable whether we wanted to or not, in, or at least really used to getting on kind of these video- based visits. But, if you think about prior to the pandemic, I wouldn't say that this was the norm. It certainly wasn't the norm for our practice in pediatric teleneuropsychology, but out of necessity, of course, we're connecting with our patients and families through this video platform.

[00:07:01] So some of the differences and, and one reason we really needed a research study is because, you know, our traditional method is to sit in the room across a table from a patient. So, just like you would kind of imagine any clinic visit with your providers, that you're in the room with them and interacting with them. So to translate a standardized procedure or test battery to a virtual setting, you absolutely need research to, to validate that method, to show that it works, and to feel like, you know, that's a reasonable way to practice going forward. So I would say some things that are different, you know, in the context of a pandemic, this is of course, I would say, a pro. We're not in the room together, so we are able to take off our masks, especially if we're in an enclosed space, you know, a distance from others around us. So I think our patients and families have really appreciated being able to have that interaction without all of our protective gear on.

[00:08:02] And it just makes for a more natural interaction as opposed to mask and goggles and all the things that we wear. Some kind of drawbacks I've noticed, and noticed prior to COVID-19, were it's harder to see the whole person. So, you know, as we're sitting here talking, we can sort of see from here up, but this is it.

[00:08:21] So, for instance, I can't see if a patient might be, you know, shaking their leg nervously or, or whatever other observations I might gather if I was sitting in the room with them. I'm also not as able to provide support to a patient if they needed me to be in the room with them or give them some kind of hand over hand assistance or some kind of real time more physical support in the room. So that's, that's another factor that we have to be mindful of. I think that, overall, a virtual health model does bring with it many pros or many benefits even outside of a pandemic. So, increasing access to specialty care for patients who might live in rural settings. We address those barriers to travel, you know, everything from transportation, paying for lodging, childcare for siblings, missing work, missing school. I think we, we actually get a better show rate when we have a virtual visit because we don't have the barriers that we normally have when a patient is trying to travel to a large medical center.

[00:09:29] So those are just some things that kind of come to mind, as I think about the differences between our traditional method and the telehealth method.

Rebecca Whitney: [00:09:37] Yes. Well, and I'm sure it was such a shift in, in how you go about and how you do your interviews when the actual in-person, seeing everything that is going on with that individual in that moment is such a critical component of the assessment. And only being able to have this rectangle...

Dr. Lana Harder: [00:10:01] Right.

Rebecca Whitney: [00:10:02] So I, I appreciate the study to validate if this is something that is worthwhile moving, moving forward with and creating opportunities for more and more sessions for individuals. So what precisely was the study attempting to measure and address with the move to telehealth?

Dr. Lana Harder: [00:10:23] Yes. So, I would say it was three main questions. And, and I should mention that in adult neuropsychology, there are many, many studies of adult teleneuropsychology showing it's feasible, it's valid, it's satisfactory. So we had some of those same questions and especially in thinking of working with children. Often children need a bit more support, especially our younger kids, to complete our test measures and to complete those activities we have for them.

[00:10:51] So, number one, we wanted to know is this feasible? Our study went down to age six and that can, that's quite, quite young. And so we wanted to see if our young children all the way through, you know, teens and adolescents could participate in, in this platform. So that was number one.

[00:11:08] Number two, and a really big one, as a neuropsychologist, I wanted to know are my results when I test a child going to differ if I test them, you know, over video as compared to our traditional methods? And you have standardized testing, that means that it's done the same way every time, which means in the room with a patient, that's how the, those tests were developed. So we needed to see, were there differences in the results you get when you change up the testing format into a virtual setting?

[00:11:38] And last, and very importantly, was how would our patients and families feel about this? Would it be satisfactory to them? Would they find it to be as, you know, beneficial as doing the traditional evaluation? So we did have a satisfaction rating as a component of our study. So those were kind of the three areas that we were examining with this research.

Rebecca Whitney: [00:12:01] Excellent. And what were your findings on each of those?

Dr. Lana Harder: [00:12:04] Yes. So, so briefly, we found out that this was feasible. So even our very youngest participants were able to complete the session with us. So, all the way down to six, which was really encouraging to see. So that was, was great. Feasibility also, to us, related to the technology, you know, could this... Did the technology perform the way we wanted it to, were there, what were the distractions like? I should mention this was done in the home environment. So many studies that have been done in tele-assessment, actually all studies in teleneuropsychology and tele-assessment have been conducted in these clinic settings where, you know, you're testing someone who's just down the hall from you. So this was kind of going out on a limb to try out doing this from home because there is such variability in technology, distractions are really common, as we all know, when we're at home. So, those were some, some things that, you know, we really wanted to understand when thinking about feasibility.

[00:13:05] For the second part, we did not find differences when it came to the results that we, we, we got from each of those types of sessions. So, that was also really encouraging to see as well.

[00:13:18] And then finally, patients and their parents told us that this was a, gave us these generally favorable ratings when it came to satisfaction. And we asked that in a lot of different ways and certainly more information could be found in the paper, but overall, the majority did indicate that this was a satisfactory way to complete an assessment for their child. And for the, the child themselves, they rated it that way as well.

Rebecca Whitney: [00:13:43] So all very good news.

Dr. Lana Harder: [00:13:45] I would say so. We were really pleased with the results, and they really do replicate the findings we have had in the adult teleneuropsychology literature, which, you know, in that way it was consistent, and we, we were pleased to see that.

Rebecca Whitney: [00:13:58] Good. Good. And what was your primary motivation for doing this study? Aside from having to do it because of the pandemic?

Dr. Lana Harder: [00:14:08] Right. Well, so I would say, I mean, as you know, I study rare disorders. So our community, you know, AFM, ADEM, transverse myelitis, just the whole, kind of the whole list there. And so our team, and this was actually many years ago, we were fortunate to be in the right place at the right time with finishing a study on, you know, telehealth model just before the pandemic hit. We were noticing that our patients and families were traveling great distances to come to our clinic in Dallas. And we really thought about, you know, when they arrived to our clinic, many times they've... some have driven all night or have, you know, stayed in a hotel or a place where maybe they didn't get the sleep that they would have gotten if they'd been at home. So when they arrive at clinic and we're ready to test them and complete these activities

I've mentioned, they're not necessarily in their usual state or, you know, the best position to complete testing. So it made us think about, what if we could reach them in their comfort of their own homes to, you know, complete these assessments? So we wouldn't have to do it right when they're in the clinic.

[00:15:18] So that was a big motivation. Again, thinking of the barriers to accessing specialty care, to working with a provider who understands these conditions. So that's what really kind of started us off down this road many years ago. And, like I said, we completed our data collection in 2019 and were analyzing the data. And then the timing was, was such that we were able to publish it in the midst of the pandemic.

[00:15:44] And I will mention, when it comes to, you know, participants and patients traveling great distances, this is also a factor in participating in clinical research, which we know is so critical for our community because these are rare conditions. It can be very difficult to gather enough data to answer our research questions. So we also view this as a potential mechanism for research data collection, which I think is, is very exciting.

Rebecca Whitney: [00:16:11] Yes, absolutely. Definitely thinking outside of the box. And an aspect that I didn't think of is with that travel, are you getting an accurate picture of the child's day-to-day behaviors when they haven't had good rest, or they have just completed travel? So I really appreciate that.

[00:16:31] And what, what are the implications moving forward? Where do you see this helping this community and bringing this down the road?

Dr. Lana Harder: [00:16:43] Sure. Yeah. So, it's exciting to have published. This was the very first ever pediatric teleneuropsychology study. As I said, this has been done in adults.

Rebecca Whitney: [00:16:52] Congratulations.

Dr. Lana Harder: [00:16:52] Well, thank you. But, but never in a pediatric setting. And so that was really important.

[00:16:58] The other piece is there's never been a home-based study of any sort when it comes to teleneuropsychology. So, what I think this does for us is it gives us a place to start as far as, you know, having a basis for this clinical practice. And, as I mentioned, potentially for research. We would very much like to see these results replicated, as we do with, with any area of research, so that we can increase our confidence in providing a service in this manner.

[00:17:25] That's really one of the big steps coming from this. Already we're using teleneuropsychology in our clinical practice. And again, this was out of necessity as, as things began with a pandemic. But it does give us something to kind of base that on and to help clinicians feel a bit more confident about this, this practice.

[00:17:48] I would say that, you know, going forward, we'd love to see greater diversity in the sample. Larger, more diverse samples in terms of you know, race, ethnicity. Our sample was 85% white. We'd like to see more diversity there. We'd like to see more diversity in terms of the medical diagnosis.

[00:18:07] We did recruit from the demyelinating disorders program. So our communities are well-represented in this study, but we think about other pediatric populations. We'd like to see that as well just to be sure that this could generalize to those groups as well. I think diversity in age range. So going below age six, which then introduces some other questions that I think research could answer, which is having the role of a parent or caregiver or some type of remote assistant to help facilitate a virtual visit. I think there's some great potential there.

[00:18:42] We'd like to see expanded, more measures than the ones that we used. You know, we had a selection of commonly used test measures, but certainly there are many more that could have been studied. So we'd love to see that.

[00:18:55] And even love to see measures developed for virtual setting. I think that would be really exciting to have tools that were created in, in this environment.

Rebecca Whitney: [00:19:06] All sounds excellent. And I think being able to open the opportunity up to more and as many as possible to receive the, the benefits of neuropsychology is always a good idea, so. And we'll be sure to include information on how to contact you if anyone has any questions, as well as a link to your, your study as well.

[00:19:30] So. Anything else that you'd like to mention about it?

Dr. Lana Harder: [00:19:36] You know, I think it's an exciting time to, as you said earlier, think outside the box. I think 2020 was a year to really challenge us in our creativity, our innovation. And I think, you know, there, there's a lot that all of, all of the specialists I think of that work with our community can do using these virtual tools.

[00:19:56] It's exciting to think about that for neuropsychology and for our colleagues in other areas. We've been using these tools in our multidisciplinary clinic as well.

[00:20:06] I would also mention that neuropsychologists do much more than standardized testing. We frequently provide consultation and intervention and things of that sort. So, there are other activities outside of testing that can be performed also over this virtual environment.

[00:20:22] I definitely welcome any questions about, about any of this as well as just neuropsychology itself and how that might be relevant for our community and our patients.

[00:20:33] for joining me today.

Dr. Lana Harder: [00:20:37] Yes. Thank you.

Rebecca Whitney: [00:20:38] Thank you.