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Complex Care at the American Academy for Cerebral Palsy and Developmental Medicine Annual Meeting

In this special Complex Care Journal Club podcast episode, co-hosts Drs. Kilby Mann and Kristie Malik interview presenters of posters and oral abstracts relevant to the care of children with medical complexity at the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) 78th annual meeting in Quebec City, Canada that took place October 23rd-26th 2024. Speakers describe the implications of their study findings, messages for patients and families, and priority areas for research that they hope can be investigated further by the complex care community in the coming years.

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Kilby Mann 00:00
Hello and welcome to the Complex Care Journal Club podcast. My name is Kilby Mann. I'm a pediatric physiatrist at Children's Hospital Colorado, and along with Kristie Malik, your host for this episode. In this podcast series, we seek to discuss emerging evidence in the care of children with medical complexity and its implication for practice. This is a special episode recorded at the American Academy for Cerebral Palsy and Developmental Medicine or AACPDM, 2024 annual meeting in Quebec. The American Academy for Cerebral Palsy and Developmental Medicine, or AACPDM, is an academy of over 1100 health professionals dedicated to advancing the health and well-being of all individuals with cerebral palsy and other childhood onset disabilities. You can learn more at www.aacpdm.org. You will also see the application there to join the AACPDM and the opportunity to take part in the complex care SIG (Special Interest Group) through the AACPDM, as well as if you join the AACPDM, the opportunity to join the complex care committee. This meeting hosts a lot of great information on caring for children with medical complexities, and we thought, what would be a better time and place to discuss some of the practice changing research and complex care being presented? Kristie Malik and I circulated the poster in oral abstract sessions, interviewing presenters about their research. Topics include: polypharmacy in adults with CP, the amount of care coordination done by our parents outside of clinic time, as well as transition work being done. Let's listen.

This is Kilby Mann, and I'm here interviewing Caitlin and Laura about the work they presented here at AACPDM. So if you want to introduce yourselves first?

Caitlin Cassidy 01:38
So I'm Caitlin Cassidy. I'm a physiatrist at Parkwood Institute of St Joseph, Healthcare London in London Ontario, Canada, which is affiliated with Western University as well.

Laura Brunton 01:50
And I'm Laura Brunton. I'm a physiotherapist and an associate professor at the University of Western Ontario in London, in the School of Physical Therapy.

Kilby Mann 01:57
Great. Thank you so much for taking the time to sit down with me. So I want to start with what is one presentation or poster that you've seen at AACPDM that you think will change your clinical practice?

Caitlin Cassidy 02:09
That’s such a good question, because the one that sticks out in my mind most probably won't change my practice much yet, but I'm really excited to think about it, and I think hopefully in the future, there will be more practice-changing elements to it. I went to a session yesterday that was called "Cerebral Palsy: Maybe It's Not So Cerebral" and so the concepts that were presented were all about sort of, what are the spinal and sort of more distal neurologic mechanisms that might be at play with what we're actually seeing phenotypically in people with CP, and how you know how focusing all of our efforts and energies on the brain have served us well for a really long time, but we might be missing the boat on other ways that we could intervene and understand what's going on a little bit better. So I'm really excited to hear more about that as time goes on.

Kilby Mann 02:49
That one appealed to me too, but there were so many good offerings, it's hard to choose what you want to do at any one session. How about you Laura?

Laura Brunton *02:55*
So I went to one yesterday called "Ambulatory Patients with Spina Bifida, a Comprehensive Exploration of (Myelomeningocele Functional Classification) MMFC2 versus MMFC3. And I thought it was really great, because they had some really good concrete case examples of how to use this classification system and really help me hammer home what it is, what's so important about manual muscle testing and using the functional mobility scale, which are two things I use, but don't often put together.

Kilby Mann *3:19*
Tell me a little bit about your project that you presented?

Caitlin Cassidy *03:22*
We know that polypharmacy is, you know, sometimes necessary. Obviously, there's multiple symptoms and comorbidities that we're trying to manage, but at the same time, polypharmacy increases risks for other things as well. So I think any time we can kind of put the numbers on it, give ourselves the opportunity to step back and think critically about it, it also opens the door for us to think about, are there ways we can simplify the medication regimen for these patients? And in particular, it led to this kind of interesting conversation that we're hoping to build out about, you know, there's so many medications that we use that serve multiple purposes. Can we make use of those medications more where we can kind of kill two birds with one stone, and therefore remove another medication from the list for example. So our program in London is called the Transitional and Lifelong Care Program. So it is for, it was purpose built for adolescents and adults who have childhood onset disabilities. So it's a multi-disciplinary program managed and run predominantly through our rehabilitation hospital. And so the medical team includes two physiatrists and a nurse practitioner, and then we have multiple allied health team members who work very closely in collaboration with us. And so we have, like a good, large group of patients who have these childhood onset conditions, and that was the clinical group that we focused on for our study, which Laura will now describe.

Laura Brunton *04:34*
So we did a retrospective chart review where we looked at initial consultations to this clinic for adults with CP. We were really interested in how many of them were taking multiple medications or polypharmacy? And so we found that, on average, we had kind of 208 of our population, which represented about 70% that were actually taking more than one medication. And on average, this subgroup of individuals were taking about five medications per person. They were slightly older, they had a higher GMFCS level and history of epilepsy. We were then further interested in those of this population that were taking multiple medications, how many were taking more than five medications on a regular basis? And that was about 50% of that larger group, and they were taking, on average, almost eight medications a day. Again, had a higher GMFCS level, a history of epilepsy, and this time, we saw a mixed movement type disorder and more bilateral distribution of involvement for this population.

Kilby Mann *05:28*
I think about this on the other end of the spectrum with some of the babies I see in the hospital, where we start things and we're trying to control something, and sometimes we forget to take off the things that maybe aren't working. So it's really interesting, kind of applying more broadly. But what do you think are the implications for clinical practice? Specifically, what do you recommend for members of the interprofessional care team to do based on these results?

Caitlin Cassidy *05:50*
I think that probably the biggest thing is actually back to what you just said, Kilby, is that we have a real tendency to start medications and then not think critically about whether or not they're still needed in the long term. And so, I mean, I hope we do that at least to some degree on a regular basis, but maybe not as much as maybe not as

much as we could or should. And so I think this really kind of opens the door for us to re interrogate our own practices and make sure that we are critically thinking about that medication list every time and not just accepting that it's the same every time these patients come back in for their clinics. And again, I think it gives us that opportunity to think about, are there ways that we can make use of a medication that serves multiple functions, and whether or not that would allow us to trim that list a little bit as well.

Kilby Mann *06:31*
Anything to add Laura?

Laura Brunton *06:32*
Yeah, I think it's just really critical that we, that we really think about why we're doing this, and that we recognize that if there are that many medications, there are so many unmet needs, potentially that maybe we can also look beyond medications to non-pharmacological management.

Kilby Mann *06:46*
So what are the messages for patients and families as you think about your work?

Laura Brunton *06:50*
I think the most important thing is just to be an advocate, right? So you know, know your medications, know why you're on them, and advocate if you think that something isn't working, or that something is kind of in that has just always been there, and do you need to take it? And so really connecting with your healthcare providers and that interprofessional team, to make sure that you have the best approach to your care.

Kilby Mann *07:10*
I think that's great. I'm also like very real world. So what is one article that you've read this year that you think is practice changing?

Caitlin Cassidy *07:48*
I'll just take the opportunity to continue to plug the AACPDM, because I think the one that I've probably thought about personally the most, and have talked about with my learners the most, is the recently published paper related to the new dystonia care pathway. So there's some really kind of, like thought provoking changes in the pathway compared to how it was presented in its previous iteration. And so I think it just really pushes us to keep thinking and, you know, kind of make sure that we're in line with best practices. So I think it's been really important for my practice this year.

Kilby Mann *08:14*
What is one research area that you're hoping can be discussed or investigated by the complex care community in the coming year?

Caitlin Cassidy *8:21*
I think that's such a good question. It's hard to answer, because I think there are so many potential things we can do. If I think about what would be most practice-changing for myself, I think it would be looking at the actual impacts and effects of different types of pain management strategies. So we see pain so commonly in the adult population. We see it across the GMFCS spectrum. It's such a common issue, and even amongst patients who are not able to communicate for themselves, we hear from parents and caregivers all the time that they're concerned that they're concerned that their loved one is in pain. And so I think we know a lot. There's a lot of information out there about, you know, the epidemiology of pain in this population and the characteristics of pain in this population, but there's really not a lot that helps to guide my practice in terms of the best ways to treat them. It's a hard study to do, and I think that's why it's not out there yet, but I'm hopeful that we can evolve towards that.

Kilby Mann *9:10*
That's a great topic and so pertinent to all of us.

Laura Brunton *9:16*
I'm gonna go a different way with it. We have a joint PhD student who's looking at use of cough assist for maintaining respiratory health. And so she's doing a whole PhD study related to that, and that was something that we, we know we can't see in the literature right now. So it's just another little plug that there's kind of some stuff coming with that, but I'd love to see that from a complex care standpoint, is just how do we keep that respiratory health of our of our group here?

Kilby Mann *9:40*
Thank you so much for both sharing your work that you're doing and taking some time with me during this great conference wrap.

Caitlin Cassidy *9:45*
Thanks for having us.

Kilby Mann *9:48*
Hi this is Kilby, and I'm here with Tori and I'm here to talk about the work that she presented here at AACPDM, if you want to introduce yourself Tori?

Tori Bahr *9:55*
Hey, I'm Tori Bahr, I'm a med peds complex care doctor at Gillette Children's in St Paul, Minnesota, and I'm also the section chief of Pediatrics at our institution.

Kilby Mann *10:07*
Thank you so much for taking the time to join us on the podcast today. So we'll focus a little bit on your poster. Can you tell us a little bit more about your project that you presented here?

Tori Bahr *10:15*
So I'm really fortunate to work with Rhonda Cady, who's a PhD nurse scientist. And her interest over the last couple of years has been family engagement, and how do we get them involved into all aspects of our research at Gillette? And in particular, she has started, actually, we have a, a research position that is just to help collate our patient and family researchers and to be able to find folks to be able to participate in studies from the beginning to the end of the studies. This study in particular was looking at care coordination, but what are parents doing? We often describe parents as you know, 24/7 care coordinators of their child's care, but what does that actually break down into, and how can we utilize that information to help us understand, where do we invest resources? So we had for two months a group of parents that were called every two weeks by our research assistant and asked a series of questions of, how much time have you spent on these activities? And this included things like scheduling appointments, so being on the phone, using the portals to do that, also included travel, and how much time are you actually driving to and from appointments? And this was all appointments, therapies, complex care, primary care, all of those things. Communicating with different medical teams. So our institution, and in Minnesota, the care for our patients is often spread across multiple institutions, versus the insurance companies and Medicaid. And lastly, all of those other things, the school, the other DME companies, how much time are you spending on that? And then how much time do you spend supervising and actually providing the one-on-one care for your child? So in looking at that, then we were able to extrapolate, kind of, where do they fall in the less than 30 minutes, 30 to 60, 60 to 90 minutes or over two hours over the last two weeks. And it's quite stunning. I mean, I think anyone that is does complex care is not surprised from having conversations with families that they spend a lot of time on things that are crucial for their children. But really, if we had better systems, we would be able to

really impact their lives, and so that parents could really spend time doing things that are important with their children, making memories, bringing joy, instead of, you know, listening to hold music.

Kilby Mann *12:56*
I actually was talking with someone earlier at this conference that I was just making one specialist appointment for one of my kids, and I spent over 10 minutes on hold with my own institution trying to make an appointment. And I was like, I just can't imagine. So the study, just like, you know, one little experience I had totally validates for our families that are calling multiple specialists and multiple clinics.

Tori Bahr *13:17*
Right, and we're pretty lucky in that we have a model where we have a navigator whose job is to do our scheduling across the institution for complex care patients. But even still, I mean, the amount of time there's on the phone with our institution is appalling. And I think reflecting on, how can we utilize this to go to our administrators and say, 'Hey, this is what we're seeing. This is why it's important'. But actually, like giving it a timestamp of this is meaningful time that these parents can't spend doing other things when they're, you know, calling or arranging and maybe some of the things that we're trying to implement aren't affecting this number, or maybe they are, but if we don't track it, and we're just going based off of like, parent feel, you know, this gives them a larger voice.

Kilby Mann *14:15*
Yeah, I think you talked a little about it, but there are any specific things you want to call out as implications for clinical practice, for people listening today?

Tori Bahr *14:24*
So I think we in Minnesota take care of a lot of patients that are in the metro area, but then in it, a lot of patients that come from out of state or greater Minnesota that are driving four or five hours in one way to come see us. So reflecting on, how is this an important tool to be able to show why it's important to think about having dedicated schedulers that can really be that, that important bridge to figure out, can we get creative around scheduling for patients? Can we be more proactive, especially with those families that live far away and have other barriers to care to really help them get the care that they need.

Kilby Mann *15:06*
What are the messages for patients and families who maybe stumble upon this work or this podcast and think, oh, man, I'm spending all that time too?

Tori Bahr *15:15*
Well, I hope, first of all, it's validating that you're not alone. And then I hope it is a way to go to your providers, and say, Hey, this is happening everywhere. Let's be the change. Let's figure out how we can work together and really come alongside each other to make systems that actually work for our families. Because what I hear over and over and over again is that the medical system is not set up for our families, our medically complex families. It's set up for families that you know are navigating a little bit of healthcare and how can we do that differently?

Kilby Mann *15:54*
Yeah. Thank you so much. What is one article for you that you've read this year that you think is practice changing?

Tori Bahr *16:01*
So one of the many hats that I wear is being the med peds resident education director at our institution. And there's an article that came out in early 2024 looking at disability focused milestones and where they track on the residency GME requirements. And the moral of the story is that they, they don't track very much at all. And it's

quite astonishing how little there is about any disability-focused education. And another one of the hats I wear is I run our transition program so pediatric to adult transition and really struggle to find care for patients as they age into adulthood, which is, is no surprise, right? Everyone is struggling with this everywhere, of how, how do we find the right place for patients? So really thinking about what is my role when I have students with me to capitalize this. Show them like you're not getting this anywhere else, how can you start asking questions and advocating for you? Because my patients are going to come see you, whether you're going to become a cardiologist or you're going to become a nephrologist or primary care, they're, they're going to interface with everyone. And being at AACPDM is a bit of a bubble in that everyone here gets it, but outside of our walls and the people that do this day in and day out, this is just a tiny little sliver of their practice. But there's some amazing things that can happen to just make it that much better and to advance this. And I think if we don't change fundamentally where disability education fits in, you know, medical school and undergraduate and graduate medical education, we're never going to get to the next part where we can have our patients freely interface with care and know that they're going to get quality care regardless of where they end up.

Kilby Mann *18:09*
I think that's so key. Thank you again for taking the time to meet with me today.

Tori Bahr *18:14*
Thank you, Kilby, it was so nice to meet you, and I'm excited for more interaction with the complex care community.

Kristina Malik, MD *18:24*
Alright, this is Kristie, and I'm here with Dr. Cristina Sarmiento and Dr. Julie Stutzbach, who's presenting on "The Social Determinants of Health in Adults with Chronic Low Back Pain and Cerebral Palsy". So thank you for joining us on the podcast.

Julie Stutzbach *18:36*
Thank you so much for having me. I'm Dr Julie Stutzbach I'm a physical therapist by training, and I have my PhD from the University of Colorado in Rehabilitation Sciences. Currently, I'm an assistant professor in the School of Rehabilitative and Health Sciences at Regis University in Denver.

Cristina Sarmiento *18:58*
And I'm Cristina Sarmiento. I'm a physician researcher at the University of Colorado Amschutz Medical Campus. I'm also an assistant professor in the Department of Physical Medicine and Rehabilitation, and clinically, I practice in both the pediatric and adult rehabilitation medicine settings caring primarily for people with cerebral palsy across the lifespan.

Kristina Malik, MD *19:19*
All right, so can you tell me a little bit about your presentation?

Julie Stutzbach *19:22*
Thank you. Yeah. So our team looked at the Cerebral Palsy Research Networks Community Registry study. So these were all self-reported outcome measures of adults with CP, and we were looking at what factors might influence pain interference in these adults with CP. And we had a whole variety of constructs that we were looking at, all within, within the biological and psychological and socio environmental domains. And the ones that we were most interested in were if it was wheelchair use, if it was how long somebody had experienced pain. We thought that maybe people had developed resilience of pain as a result of dealing with it for a long time, or if stigma were playing significant roles in the development of pain interference. And so what we found, which I thought was pretty interesting, is that we didn't find that wheelchair use really had any relationship to pain interference. We

also found that the years since pain onset had any relationship to pain interference either. We did find, however, as we did hypothesize, that stigma was associated with pain interference. And so I think that's that part of our hypothesis was born out and so think that that is another important finding. When we were looking at pain, we're looking at pain intensity, we also saw some other important socio environmental factors and psychological factors that were associated with pain intensity.

Kristina Malik, MD *20:59*
What do you think the implications for clinical practice are from your research?

Julie Stutzbach *21:03*
So I think that the implications for clinical practice are, there are a few here. Anxiety is something that is not necessarily regularly monitored in a clinical setting, but really it should be, of all the factors that we examined, some of them are not really changeable and not really treatable, whereas anxiety is, so I think that in primary care settings and rehabilitation settings and therapy settings, we should be screening for this to make sure that the appropriate referrals are made so that anxiety can be managed. I think that we also need to take a look at stigma further, because what we might not realize is that even as providers, we may have stigma against people with disabilities. And there was actually some research presented earlier today that showed that some physicians had had really negative stereotypes associated with specifically with cerebral palsy, and if we as providers are perpetuating that stigma and creating a barrier to care, we need to take a really close look inside ourselves and make sure that we are not reflecting that onto, onto our patients.

Kristina Malik, MD *22:22*
Cristina, do you have anything that you found from this project?

Cristina Sarmiento *22:25*
Yeah, so I think one of the most interesting things that I'm taking away from this project is so, when we were looking at what variables to explore in terms of their relationship with pain interference and pain intensity, we used a biopsychosocial model of pain. And I was surprised, and not surprised a little bit that it was, you know, the biological factors seemed less important and less significant than the psychologic and social factors, as Julie was saying. And so I think that just really emphasizes and underscores the importance of mental health treatment as well, as, you know, considering the social implications of, of pain and of disability, as Julie was saying, and really making sure we attend to those needs in youth and young adults with disabilities and with medical complexity overall.

Kristina Malik, MD *23:53*
What is one presentation or poster that you've seen here at ACCPDM that you think will change your clinical practice?

Julie Stutzbach *24:01*
So I went to a really interesting platform. Dr. Lenhart presented on her research comparing the quote unquote, "Less Affected Side and Hemiplegic CP Compared to Typically Developed Controls." So she found that cross sectional area was comparable between less affected side and typically developing limb, but that muscle power was not and I just think this is really interesting. I mean, my guess is that this is because kids with CP are doing less powerful activities like jumping, stair climbing and running or but this could be, and this is totally different than the pain question, but it could be because they're overusing their unaffected limb, and that's leading to a lot of muscle stiffness. And what we care about, especially in terms to bring it back to adults, because that's on what I want to do always, is that they end up with very wonky compensatory movement patterns, which, you know, people that treat people with CP know that, and then they can end up with pain on the quote, unquote, unaffected

side. And so I think that's just something we have to take a really close look at in terms of physical therapy, as physical therapists, as we're watching out for overuse injuries on unaffected sides, and also making sure that we're, we're training for power and strength in those areas. And I also have noticed there's been a lot of really great platforms looking into bowel and bladder function.

Cristina Sarmiento *25:24*
And then I also appreciated a platform presentation given by Dr. Laura Brunton on polypharmacy in adults with cerebral palsy. So there's been a lot more interest and research coming about out about polypharmacy in youth with medical complexity, and I think it's been very important work and making us really consider polypharmacy and medication use and prescription in kids with medical complexity. And so I really appreciated the this study, which looked at adults with cerebral palsy and polypharmacy. And this, you know, came in the same session as a presentation by Kari Pederson at Gillette about falls and the qualitative experience of falls in adults with cerebral palsy. And, you know, of course, I think those are so, can be so closely linked as we think about the side effects of medications. What are we treating? What are we causing, especially with our you know, tone management medications. And in cerebral palsy, a lot of them have the side effect of sedation and sleepiness, and are we contributing to increased fall risk? And so I think there's so many functional impacts of, of polypharmacy, and so I think that's going to make me really look at these long medication lists more closely and consider the impacts.

Kristina Malik, MD *26:45*
Is there any area of complex care, or adult complex care that you feel like needs to be explored more in the next year?

Cristina Sarmiento *26:53*
So this, I think this probably ties back into that polypharmacy question a little bit too. So I think there's just there really are, and we hear this from patients and families all the time, these differences in pediatric and adult models of care, where adult care systems tend to be more fragmented, more siloed, fewer interdisciplinary or multi-disciplinary clinic settings. And I think that can really lead to fragmented care and lack of cohesive care. And I worry about that with polypharmacy in particular, because especially in the adult world, a lot of patients are maybe getting care from two or three or more different healthcare systems, and those electronic health records don't always talk to each other, and we may not know what other medications patients are on when we're prescribing other medications, let alone you know what the care plans are. And so I think ways that we can improve the coordination and cohesiveness of care in the adult care setting to better model the medical home style and the pediatric setting is really important.

Julie Stutzbach *28:00*
Yeah. And I think you know Cristina, what a lot of that points out too, is that some of the time that it takes to coordinate all of this is also not reimbursable, and that is a large problem that we're not always going to solve with research. But I know, for example, so Cristina and I actually see some similar patients, and with the more complex patients that I see, they require more equipment. So for example, I just wrote a pretty long letter of medical necessity to get a very important gait trainer for a mutual patient of ours. It took me maybe an hour, hour and a half, and that time was not billable at all. And so I think that we need to create more integrated, more efficient health care systems, while at the same time advocating for better payment policies, because some of these things that we do that are not procedures or not particularly that are not highly reimbursable, have low yield in terms of, in terms of payment. And so that's just another issue that I think we need to we need to consider.

Kristina Malik, MD *29:20*
So I appreciate your time today. This is great. I thank you for sharing your presentation with us. So thank you.

Julie Stutzbach *29:27*
Thank you.

Kristina Malik, MD *29:30*
This is Kristie. I'm here with Dr. Adam Rosenbloom, who has a presentation entitled "A Collaborative Posterior Spinal Fusion Surgical Planning Initiative Between a Pediatric Orthopedic Surgery Group and a Complex Care Medical Home for Children with Medical Complexity". So thank you for joining us on the podcast today. Can you please give us a little bit about your position, where you're affiliated, and I'll ask you about your poster?

Adam Rosenbloom *29:55*
I am a complex care pediatrician at Children's Comprehensive Care, a medical home for children with medical complexity, affiliated with Dell Children's Medical Center of Central Texas and University of Texas at Austin Dell Medical School.

Kristina Malik, MD *30:11*
So can you tell me about your presentation, a little bit about the project that you had, and then some of the things that you're following up from this project?

Adam Rosenbloom *30:23*
Yeah so the presentation is illustrating work that my group has done coordinating care with our pediatric orthopedic surgery sub specialty group for the last four and a half years. We have met on a quarterly basis to case review, to discuss our shared patients together, identifying patients that are likely to become candidates for posterior spinal fusions in the next six months, and then using a tool that is a pre operation optimization checklist to really get our patients as ready as possible for the big surgery coming up, we looked at the reported outcomes of length of stay and complication rates, readmission rates, reoperation rates at 30 and 90 days. And I think that the biggest takeaways that we had were really the importance of care coordination and integration with our sub specialty groups that you know we as the primary care providers, the pediatricians that care for children with medical complexity, that the biggest value that we have to our system is that we know these patients, that we have a relationship with these patients, that we know their stories, we know their goals, we know the things that perhaps other parts of our systems don't know. In that when we work together with our partners, when we are integrated in the care with our subspecialty partners and partners across the systems that we work in, we can leverage that knowledge to improve outcomes in the children that we care for.

Kristina Malik, MD *32:28*
And from your presentation, what are the implications for clinical practice that you have found so far?

Adam Rosenbloom *30:37*
Well, you know, I think working together with our subspecialists in many different ways to review our patients together in a preemptive way, to prepare patients for maybe big surgeries or big things coming in the future in a systematic way. We can improve their care, and that also mostly, we can improve the relationships that we have with other members of our system by meeting with them regularly, by talking about our shared patients, by sharing goals and holding ourselves accountable to those shared goals.

Kristina Malik, MD *33:21*
All right, so I know it's still early in the conference, but has there been a presentation or poster that you've seen that will change your clinical practice?

Adam Rosenbloom *33:28*
So I went to an excellent presentation yesterday about self-injurious behavior that you were a part of, and you know, it's a symptom that I think we all have patients that we think about, that we can really struggle with. It was really helpful, I think, just to get, again, the review of functional behavioral analysis and thinking about how our approach to these patients can be helpful. And then today, the big keynote presentation by Dr. Ibrahim here in

Toronto, talking about the refractory kinds of patients with refractory self-injurious behavior, and how breakthroughs in deep brain stimulation can be an option for those kinds of patients. So it was really an exciting thing to learn more about.

Kristina Malik, MD *34:21*
Yeah thank you for the shout out too. And what is one area of research that you're hoping that can be investigated by the complex care community in the upcoming year?

Adam Rosenbloom *33:30*
You know, I think we're all trying to figure out how to build systems that actually are designed with the most important user experience in mind, and that's families and children with medical complexity. I think a lot of us work in systems that don't always seem designed around that user, but serve other users in those systems and in just different ways in which we can really focus on the things that truly matter to families, and how are the best ways in which we can build those systems that that truly value things like relationship centered care and patient directed outcomes. I always look forward to these, these big national, international meetings where we all get to share some of our experiences in that field.

Kristina Malik, MD *35:28*
Thank you so much for your time today.

Adam Rosenbloom *35:30*
Thank you so much.

Kilby Mann *35:32*
We've highlighted only a sample of the emerging research in complex care shared at AACPDM. To summarize a lot of presenters highlighted the importance of taking a critical look at medications, thinking about the care coordination being done by our families and that crucial timing of transition between care. Kristie and I want to thank all the speakers for their time and for advancing the field of complex care. And thank you for listening to the Complex Care Journal Club podcast. We aim to highlight research that has the potential to be practice-changing, that values patient or family engagement, is relevant across disciplines and diagnoses, and uses high quality or novel research methods. We invite you to join the conversation by suggesting an article that you would like to see discussed in this podcast using the form provided on the OPENPediatrics YouTube channel. Thank you for joining us.

Other references

American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), https://www.aacpdm.org/

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