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Where You Live Matters: Psychotropic Polypharmacy and Psychotherapy in Children with High-Needs

In this Complex Care Journal Club podcast episode, Dr. Kathleen Thomas discusses a cross-sectional study of associations of neighborhood context with psychotropic polypharmacy and psychotherapy among children with high-needs for medical or psychiatric care. She describes inclusion of parent advisors on the study team, inclusion of children with medical complexity in the study population, key insights including the importance of non-medical supports, and the next steps from this work.

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Kristina Malik *00:04*
Hello and welcome to the Complex Care Journal Club Podcast. My name is Kristie Malik, and I am a pediatrician at Children's Hospital Colorado, and 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 implications for practice. I am delighted to have Dr. Thomas from the University of North Carolina at Chapel Hill joining me today. She is the lead author of the article "Association Between Neighborhood Context and Psychotropic Polypharmacy Use Amongst High-Need Children", published online in Psychiatric Services in September 2024. Dr Thomas, thank you so much for being here.

Kathleen Thomas *00:41*
Thank you for having me.

Kristina Malik *00:43*
So I was hoping you could start with a brief overview of the paper, referencing your aims and your methods, and also the summary of your key findings?

Kathleen Thomas *00:51*
Sure, so we were concerned about kids coming to our hospital system in crisis, either with too much polypharmacy or nothing and really needing a quick help. And our physicians were aware that kids who come to us in crisis often come from neighborhoods with few resources. So that kind of jump started our plan to look at neighborhood context and experience of psychotropic polypharmacy. So we used data from our electronic health records on high-need kids, that was kids with complex medical conditions, with intellectual and developmental disabilities and/or psychiatric conditions. And we looked at how neighborhood context measured with an index called the child opportunity index was associated with polypharmacy, with nice data to control for clinical need, and we found that kids in, the findings were more complex than we had thought they might be, but kids in moderate opportunity areas are more likely to experience psychotropic polypharmacy, while kids in low resource areas and high resource areas are less likely to.

Kristina Malik *02:26*
Yeah, and one of the reasons why we invited you on this podcast was the fact that you looked at children with medical complexity as one of your groups, along with children with intellectual disability and mental and behavioral health needs. Which we don't see commonly as a group that's studied always because of the heterogenicity, of that population. So we really were excited to talk to you about this, and I just wanted to let our listeners know that in this study, children with medical complexity was defined by Feudtner's Pediatric Complex Chronic Conditions Classification System. So going from there and like this initial concern about kids coming in crisis. Tell me how you as a team, defined, identified this gap and developed your team to solve, the aims that you had.

Kathleen Thomas *03:17*
Well, what happened is that our state of North Carolina held a summit on kids with IDD, Intellectual and Developmental Disabilities, to try and come together and understand as a group how kids were being treated and what we could do to improve. And I was there and bumped into two physicians who are co-authors, Rob Christian and Neal deJong. Rob is a child and adult psychiatrist, and Neil directs our services for kids with medical complexity. And that's when we just started talking about this issue of neighborhood and how concerned we were.

So we decided to use our medical records, which we can get fairly rapidly, and have nice information on diagnoses and service use and complexity, comorbidities, things like that, to try and just look at the situation and see what we could learn from it, and kind of see what new hypotheses might be generated.

Kristina Malik *04:29*
Yeah and I also love to hear about your background. I know you're in the School of Pharmacy, but you have different training than I do. So tell me a little bit how your background helped shape this project?

Kathleen Thomas *04:42*
Yeah, so I'm trained as a behavioral economist out of the School of Public Health. It's interesting I tend to think about more so concerns in terms of the populations affected, rather than people with particular conditions. And so we approach this paper thinking about kids who, we call them high-need kids, kids at risk for behavior problems that are commonly treated with psychotropic medication. We've known, you can see in the literature that rates of psychotropic medication use just rose for about 25 years, and they're now beginning to taper off, but psychotropic polypharmacy rates continue to rise, and so it can be a concern. You know, it leads to increased risk of harms. The doctors in our team also talk about how there's little guidance on de-prescribing, and so kids just kind of get stuck in this pattern. And so we wanted to explore that further. We also worked with a group of parents advising us through this process, and they talked a lot about their reluctance to rely on medication and how they're inclined to try a lot of other things first, if they can, and then only move to medications if nothing else works. They talk about how difficult it is to find a physician who can be a trusted partner in figuring out that process.

Kristina Malik *06:21*
So tell me a little bit more about how the parents were involved in your research process and how they're continuing to influence your current grants if you don't mind?

Kathleen Thomas *06:31*
Yeah, so we got a small grant from our CTSA, our Clinical Translational Services Award group, to put together a parent advisory group. We met with them regularly to talk about study design, talk about measures and modeling, and then look at findings and kind of refine those findings and get their interpretation on things. I feel really proud of their involvement. They are all listed as co-authors on the paper, and that's still not an easy process to go through. Every journal handles that differently, and every parent has different preferences about whether they want to be named or not, but our group of parents we're all really excited about this, so they're all there.

Kristina Malik *07:24*
That's awesome. And you also mentioned that they've helped you through this work, have spurred you with further ideas.

Kathleen Thomas *07:34*
Yeah. So while we were working on this paper, PCORI, the Patient Centered Outcomes Research Institute, came out with a notice saying that they wanted to expand their portfolio in IDD, intellectual and developmental disabilities. And we felt like, well, we've been thinking about that a lot, let's try. It took us a while to get there, but we did get a nice, big comparative effectiveness research study funded. So the parents are partnering with us in that effort too.

Kristina Malik *08:04*
That's awesome. It's so amazing to hear researchers in so many different disciplines seeing the value of persons with lived experience. And you know, that's something we've tried to highlight on this podcast. So it was so wonderful to see it in your paper that we typically see parents involved in qualitative studies or maybe some randomized control trials. But you know, having parents involved in even your data set analysis was a great realization of how beneficial they can be to any research process.

Kathleen Thomas *08:34*
Yeah, thank you.

Kristina Malik *08:35*
So I'm going to go back to a little bit about the study. What opportunities and challenges did you identify while developing and conducting your study? And we talked about this a little bit your perspective from public health, just like how you were able to focus on children with medical complexity and their outcomes?

Kathleen Thomas *08:53*
Well, we never really thought of excluding children with medical complexity at any point. We started from the beginning talking about psychiatric conditions and IDD (Intellectual and Developmental Disabilities) and kids with medical complexity from the beginning, and I just think of them as high-need kids as I said. Challenges along the way, getting, you know, we used our electronic medical records, and I think it was challenging to extract exactly the right sample that we wanted. We had to it sounds like it should be straightforward. You say, I want these diagnoses, but it's a little more complex. Our inclusion criteria included that the kids had to come at least once a year so we could actually see their patterns of service use. We wanted to study polypharmacy and psychotropic polypharmacy, and that's a laborious process, I would say. We created a drug, a daily drug diary. So if you got an order, how many days did it last for you. And polypharmacy is, did you have two different classes of that? And then we worked with our clinicians to exclude certain pairs of medications that commonly go together and wouldn't be considered polypharmacy. Things like anti-epileptics and some sleep medications fall into that. There are a lot of steps involved.

Kristina Malik *10:35*
From the results that you developed, what do you think are the implications for clinical practice? What do you recommend for members of the inter-professional care team?

Kathleen Thomas *10:45*
Well, one thing it makes us think of is that it's pretty clearly defined. If you choose to use a medication, the impact in the kid is well defined, and the timing of the impact is fairly well defined, and you have a guidance on when to try it and what to look for and how long to look for it before you decide that it's working or not. Health insurance is good typically at paying for the medication, and so it's so straightforward that it can be a strategy that people are inclined to try instead of other things that might also work, like behavioral therapies, which are not as well defined, and take lots of different providers and a lot of you know, parent persistence, advocating and navigating the system to get all those pieces in place. And it's also not clear how long you're going to need it, maybe a really long time, and it's not clear how much health insurance is going to cover. So I think our system is set up to push people, perhaps, toward medications, and I think that's something to be aware of. There's also guidance on de-prescribing is much more sparse, and so you kind of end up sticking with medication. But you know, as we thought about that, our doctors talk about the importance of non-medical supports like care coordination or a personal aid, and how they may really have the potential to support a kid and support a parent, managing the household and the kid, to reduce crises and stress so that maybe medications aren't needed as much. And we really wish we could do a study comparing non-medical supports with with psychotropic meds. That's tough to design, though, because -one's well defined and one's not.

Kristina Malik *12:53*
Yeah, for sure. Another thing that I really liked about this article is the estimate of a breakdown of children with medical complexity's childhood opportunity index (COI). Now, granted, yours is for kids within the UNC (University of North Carolina) Health Care System, but it aligns with what we know about children with medical complexity, that often their socioeconomics are less favorable than other populations, and that was also seen in your child opportunity index, that while you didn't do a comparison between the different groups, because they weren't

mutually exclusive, the children with medical complexity group had a higher proportion of children with low COI (Childhood Opportunity Index). I think just honestly, a lot of things within your table 1, talking about prescription, polypharmacy and psychotherapy prevalence of children with medical complexity was quite novel in the literature. So there is a lot of great clinical takeaways that I found really helpful for my clinical care is just understanding these this group of children and how frequently they're on different medications.

Kathleen Thomas *14:00*
Thank you. I've learned a lot about the difficulty of getting medications through this project, too. I kind of always thought of it in terms of, well, health insurance does a pretty good job covering medication, and that's the end of the story. But actually, especially in the kids with complex medical conditions, they need compounded medications, and they can be really hard to find. And so our physicians talk about how they have this serious conversation with parents if you think you want to try this, that is a medication approach, you need to be aware of how much work it's going to be for you to buy the stuff, pay out of pocket, get health insurance reimbursement, find the compounding that you need. So parents talk about how they may be able to go to one pharmacy to get a compounded med one month, but then the next month it's no longer available there, and they have to start all over again and find somewhere else. It's just a huge job.

Kristina Malik *15:11*
Yes, for sure, and I think that definitely your study kind of highlights the complexities of mental and behavioral health care for children with IDD (Intellectual and Developmental Disabilities) and children with medical complexity, for sure, it's not like you said initially, as clear cut as you thought it would be is you know, the results. So you know, one of the things you looked at was also the use of specialty mental health services, and these, once again, were not compared across groups, but the odds of children medical complexity and children with IDD (Intellectual and Developmental Disabilities), using a specialty mental health was much higher than what we saw with the mental health group. So I mean, it definitely tells you that in itself, is like, while kids might be able to access services, it might be a little bit harder or a longer wait list, or, like you said initially, even just how long will insurance cover these services too?

Kathleen Thomas *16:06*
Yes, exactly.

Kristina Malik *16:08*
So I would love to hear if you have any advice or lessons learned to share with other researchers in this field based on your study?

Kathleen Thomas *16:18*
I was surprised when you told me that you feel like people are often reluctant to study kids with complex medical conditions, or tend to exclude them from their data as they pursue different studies. And we just never thought of it that way. A number of our parents, our advisors, are parents of kids with medical complexity. So it just it's always been integral to the way we're thinking, and I think that's an important message that has worked really well. I guess another thing that I'm really excited about that we have some emerging evidence coming out of our PCORI study, where we invited kids, this is all kids with IDD to some extent. We invited kids to do a short survey using the patient reported outcome measurement information system measures on quality of life. Very short and present oriented, and about a third of the kids were interested and able to do that, and have reported those on those measures, and we've started to do some analysis of validity, and it's looking really good. And that's new evidence. Very exciting.

Kristina Malik *17:36*

Yeah, that's great, because I know that's a huge interest right now in the field of complex care is looking at quality of life. We know it's a huge impact to healthcare outcomes. So I am very excited for your upcoming publications from that study.

Kathleen Thomas *17:54*
Thanks. Well, and not just quality of life, we've got parent proxy reports of quality of life, but to actually hear from the teenagers and young adults themselves has not been an easy pathway, and we're excited that it's working.

Kristina Malik *18:10*
So tell me a little bit what you think the next steps from this work is?

Kathleen Thomas *18:15*
Yeah. Well, as I say, I do want to, I would love to do a study that compares non-medical supports to medical treatments. And I'm not sure how to do that yet, something that we have been feeling that the these findings raised is, what is it about the neighborhood, maybe the geographic area, maybe pollutants or stress, that is, we need to learn more about why we seem to be seeing that some places either are increasing kids needs for these medications, or they're decreasing the effectiveness of these medications? And so kids end up with more psychotropic polypharmacy. And that's a lot to unravel. It may be pollutants, it may be drug-drug interactions with pollutants or something, or it may be genetics. So I think that this does kind of raise a lot of interesting questions about precision medicine that are a new direction for us.

Kristina Malik *19:26*
For sure. Did you happen to, like, break out geographically, like GIS (Geographic Information System), kind of with some of the COI's (Childhood Opportunity Index)? Or no?

Kathleen Thomas *19:37*
No we haven't done that, but we could. So we want to look at characteristics of the physical environment a little more.

Kristina Malik *19:48*
Yeah, that would be really interesting, because, you know, COI (Childhood Opportunity Index) is just, I mean, it's a new measure that a lot of people are using. And it's really great to show us a lot about a community someone grows up in, but we know that, you know, North Carolina is very different than Colorado, even probably within each COI (Childhood Opportunity Index) group, so that would be really interesting to hear more about that. You know, I really have enjoyed reading this article, and thank you for your time today, before we wrap up, is there anything else that you want to share with our listeners?

Kathleen Thomas *20:21*
Thank you. I think this has been a great conversation, and I don't have anything further. I really appreciate the opportunity to come talk with you.

Kristina Malik *20:30*
Well thank you so much for your time, Dr Thomas, and thank you to you and your team for advancing the field of complex care. And thank you for our listeners for listening to the Complex Care Journal Club Podcast. We aim to highlight research that has a potential to be practice-changing, that values patient and 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.

Journal Club Article

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