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Practice-Changing Research in Complex Care at the Pediatric Academic Societies 2025 Annual Meeting

In this special Complex Care Journal Club podcast episode, co-hosts Emily Goodwin, Kristie Malik, and Kathleen Huth interview presenters of posters and oral abstracts relevant to the care of children with medical complexity at the Pediatric Academic Societies (PAS) 2025 annual meeting. 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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Katie Huth *00:05*

Hello and welcome to the Complex Care Journal Club Podcast. My name is Kathleen Huth. I am a pediatrician at Boston Children's Hospital, 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. This is a special episode recorded at the pediatric academic societies or PAS 2025, annual meeting in Honolulu, Hawaii. PAS is a partnership of four pediatric organizations, the American Academy of Pediatrics, the Academic Pediatric Association, or APA, the Society for Pediatric Research and the American Pediatric Society. The mission of the PAS meeting is to connect the global academic pediatric community to advance scientific discovery and promote innovation in child and adolescent health. The meeting has a track dedicated to children with chronic conditions, and the APA hosts a complex care and disability special interest group that highlights presentations that are particularly relevant to the care of children with medical complexity and disability. We thought, what could be a better time and place to discuss practice changing research in complex care? Emily Goodwin, Kristie Malik and I circulated the poster and oral abstract sessions interviewing presenters about their research. Topics include: a readiness evaluation for hospital to home transition interventions, persistence and reappearance of Pseudomonas and tracheostomy aspirates, caregiver perspectives on an ideal system for coordinated care, informing disability education, medical device design and flaws, respite for family caregivers and the association of social needs with acute care utilization. Let's listen in.

Hannah Lane *01:48*
Hi, I'm Hannah Lane. I'm here at the poster session at PAS. I'm an assistant professor at Duke School of Medicine working as a co-investigator on a comparative effectiveness trial looking at two different health care to home transition interventions for children and youth with special health care needs.

Katie Huth *02:07*
Wonderful. And you have a oral abstract presentation tomorrow, and we'd love to hear a summary of the work that you're presenting and what you think some of the implications are for practice?

Hannah Lane *02:15*
Sure, absolutely. So. I am not a clinician. I'm a researcher specializing in Implementation Science. I do a lot of different work, focusing on, how do we get things that work to improve health for kids to actually stick in systems? So not even just health care, but schools, communities, all kinds of things. So that's my area of interest. And so the talk I'm going to be giving tomorrow is all about how we ahead of this trial, we did a readiness and implementation context assessment. So we really wanted to understand the system we were going to go into to implement these interventions, and make sure that they were ready for those interventions to be implemented well. Right? Because if we can have the best intervention in the world, but if you then, if there's no buy-in from the people who need to implement it, or there's something missing in terms of the way that information is communicated within a healthcare system or a site, then that thing is not going to be implemented well. And then we're going to think it doesn't work. But it actually is just that the implementation was poor.

Katie Huth *03:17*
Can you tell me a little bit about what you learned? What are some of the pearls that came from that readiness analysis?

Hannah Lane *03:23*

Sure so we looked at different data sources that were part of the formative work they were doing ahead of this trial. And so the interventions, it's two different dose interventions. Both of them are being implemented by transitional care managers. One of them is just a single post discharge follow up call, and then the second one is a series of calls over a month. And so different kind of doses and intensity, and they're comparing the effectiveness and implementation of those two to understand, you know, which ones might be most appropriate for this population of kids. And so we did this pre-implementation assessment where we took a bunch of different data sources, and by data sources I mean sort of innovatively looking at meetings with hospital's leadership, meetings with transitional care manage leaders. We interviewed some frontline transitional care managers. We have a parent advisory board. We've been looking at kind of the data we're collecting from them. And we pulled them all together with this framework associated with readiness, to really understand the system level things that were missing for this thing to be well implemented. The level of the implementer, so the care managers, and then the level of the patients themselves. A couple of things that we learned. One is that care managers that really lack confidence in their ability to talk to caregivers, many of them only work with adult patients post hospitalization, and so we knew we needed to train them on the intervention, but we didn't really realize that we needed to provide a lot of training on caregiving and communication with caregivers and families and that approach. And so we added a pre-implementation training for that. Another thing that we learned is that communication systems between discharging providers and current care managers is very slow and inefficient and varies across the two health systems that we're doing this intervention in, and so the PIs [principal investigators] developed a series of kind of escalation pathways and smart phrases and things to make things like not only to make them really easy, but also to make sure that everybody was kind of on the same page, and things could be done much, much more quickly. Right? So that call happens in a timely fashion before that patient is lost to follow up. So that's two things we learned.

Katie Huth *05:33*
That's wonderful. It sounds like it was a really valuable approach to take, and one that's helpful for researchers in our community to hear about. Do you have any kind of things that you're excited to see or any directions that you're hoping the field will take, just with your lens as an implementation scientist, where do you hope kind of complex care research is going to go in the coming years?

Hannah Lane *05:52*
Yeah. I mean, I think the value of this kind of pre implementation assessment of systems is just really great, because what we were able to do was get a lot of different folks to the table really intentionally. And because of the nature of this project, there's a, you know, a really strong kind of stakeholder engagement component. And so in addition to getting all this information, just having people at the table and having these regular meetings really helped to generate buy-in, which I think is going to make these types of interventions so much more successful. And I'll say like, I've seen a lot of posters really focus on caregiving and caregivers and their quality of life. And so I think caregivers as like, a really invested group in this type of research moving forward. I think it's really important.

Katie Huth *06:34*
Well, thank you so much to you and your team for your work.

Hannah Lane *06:36*
Thank you.

Emily Goodwin *06:40*
Hi, I'm Emily Goodwin. I'm here at the Pediatric Academic Society conference, I'm here with two researchers that are going to tell us about their study. Do you want to introduce yourselves?

Elaina Schueler *06:49*

Hi, I'm Elaina Schueler. I'm a research coordinator with the Medical College of Wisconsin.

Rebecca Steuart *06:53*
I'm Rebecca Steuart. I'm a physician scientist in the complex care program also at MCW Medical College of Wisconsin.

Emily Goodwin *07:01*
Wonderful. Do you want to tell us a little bit, Elaina, about your poster?

Elaina Schueler *07:05*
Yeah, for the poster looked at the persistence and reappearance of tracheostomy aspirate Pseudomonas after anti-pseudomonal antibiotic use. So we looked at from the date of trach placement, we looked at the trach aspirates every three months when well and then during illnesses, and then looked at the appearance and disappearance of the Pseudomonas after anti-pseudomonal antibiotics. And what we found is that although the Pseudomonas does disappear after the anti-pseudomonal antibiotic, they frequently reappear, and it's typically about one month after the end of the anti-pseudomonal antibiotic use.

Emily Goodwin *07:54*
So what do you think are the implications for clinical practice from this study? I know as a pediatrician in complex care, I see this clinical question come up a lot, and often we're looking at cultures only when kids are sick. So do you want to speak into clinical implications Rebecca?

Rebecca Steuart *08:11*
Yeah, we the strength of the study is that we did collect samples prospectively and for surveillance purposes, as well as during illness. It’s a small sample. We had only seven children enrolled, but we’re growing. The tentative implications might be that pseudomonal colonization is real and is happening, and that even when we treat with both targeted anti-pseudomonal antibiotics or anti-pseudomonal antibiotics for other indications, that Pseudomonas usually disappears, but it comes back surprisingly quickly on surveillance cultures. So perhaps the benefit of treating and targeting pseudomonas, even during illness, might be low.

Emily Goodwin *08:59*
What do you think are the messages for members of the interprofessional care team or for patients and families from this work?

Rebecca Steuart *09:07*
I think it's important for the physicians who are interpreting these cultures proactively to have a sense of what to expect and how to interpret and react to what their results are that they are seeing. And then for families, I've been impressed by some of these families, how engaged and active they are in following their children's culture results, which has been wonderful to see, but it's also informative for them to understand that, yes, we are doing these cultures. Maybe we don't actually have to react to every test that we're obtaining.

Emily Goodwin *09:41*
I saw you both were also presenting on your work related to caregiver collected tracheostomy aspirate culture testing in children with tracheostomies. Do you want to tell us a little bit about that as well?

Rebecca Steuart *09:53*
Sure, yeah. Another poster just down the hall at the same session is our work together, where we have been teaching caregivers, parents predominantly, to collect tracheostomy aspirate culture samples in a sterile fashion in the home setting as well as in the clinic setting or in the emergency room setting. And then comparing for microbiologic concordance to a nurse or a respiratory therapist collection, and we found overall substantial

concordance between those two samples. It seems like families can certainly collect these with a little bit of education on how to do so sterilely and use the equipment. And I'm hoping that if this is something that's of interest to pulmonologists, infectious disease doctors, complex care doctors, moving forward, to have more active or more frequent surveillance sampling, that families could do this in the home setting, especially during, say, wellness, and then just mail their sample in into the microbiology lab, which would be a really interesting and novel use of our family's expertise. Honestly, I think sometimes our families do an even better job than we do in caring for their children's tracheostomy tubes. And I almost wonder if these trach aspirate samples might even be more valid, but the data has yet to be completely analyzed in that respect,

Emily Goodwin *11:19*
Wonderful. What's one presentation or poster you've seen or looking forward to at PAS that may change your practice?

Rebecca Steuart *11:27*
from a from a tracheostomy aspirate perspective, I attended a really good session this morning, led by Anna Sick-Samuels, listening to her research from the B train collaborative, which is a multi-site prospective chart review study of tracheostomy aspirates, and it showed actually that those trach aspirates that have the lowest amounts of neutrophils on gram stains, so none, few or rare. Those children typically did not seem to benefit, at least in this cohort, from antibiotic treatment. And in fact, the results questioned if those children actually were harmed with a longer length of stay by treating those children with antibiotics. So I think that could potentially really change our practice, if, if we're able to do this in a larger way, we could spare some kids antibiotics and maybe also hospital days.

Emily Goodwin *12:23*
Thank you so much Elaina and Rebecca for talking with us today and for your contributions to the complex care community.

Elaina Schueler *12:31*
Yeah, thank you.

Rebecca Steuart *12:32*
It's great. Thanks for having us.

Kristina Malik, MD *12:36*
All right. This is Kristie at PAS, and I'm here with Jennifer Peralta, and I'm going to have her introduce herself and tell us a little bit about her project.

Jennifer Peralta *12:43*
Hi my name is Jenn Peralta. I am a general pediatrician at UCLA with a focus on complex care, and my research focuses on how to better support families of children with medical and social complexity. my project is qualitative. The title was, “What the Ideal System Looks Like: Caregiver perspectives on system level approaches to care coordination for children with medical and social complexity”. Really rich data from a lot of the families who we asked basically how to navigate the system, what their experiences were like with care navigation, focusing on how social complexity really impacted that experience and then, of course, what would a more ideal system look like? Really important things, like how to minimize caregiver administrative burden, which I think many of us know, but how to really further target it and across from a cross sector approach. And as well as how to increase caregiver support, which I think a lot of our complex care programs do, but more targeted during strategic times, critical periods that we know that families will really be struggling, and the importance of peer support as a key component, and how to provide that longitudinally over a family's journey through managing and supporting their child with disabilities and medical complexity.

Kristina Malik, MD *13:56*
That's awesome. Can you tell me what you think your next steps from your study are?

Jennifer Peralta *14:01*
Absolutely yeah. We're really looking forward to further exploring this, the concept of administrative burden, which we know a lot of our families deal with, but how to hone in on that specific sort of phenomenon. What does that look like in different care settings and different health systems and different state policies? How that impacts it, particularly looking at it from the more cross sector approach, not just healthcare, but we know, social services and the education system, which a lot of our families have to navigate extensively, and looking at what are some of the health outcomes for both the caregivers as well as their children, in relation to that. So I'm excited to see what that shows.

Kristina Malik, MD *14:36*
Thank you so much.

Katie Huth *14:41*
All right. This is Kathleen Huth. I'm here at the PAS poster session, and I'm here with Dr .Bruton to tell us about his poster.

Lucas Bruton *14:47*
My name is Lucas Bruton. I am an instructor of pediatrics and attending physician at Lurie Children's Hospital Northwestern University in Chicago. And our study is entitled The ADEPT Study, standing for Advancing Disability Education for Pediatric Trainees. This for us, we are considering the first part of a multi-part project to advance education for trainees of all levels regarding children with disabilities. So initially, before we could even dive into how we're going to teach that we wanted to talk with stakeholders like kids with disabilities themselves, their families, teachers, administrators, like social workers and care coordinators, and ask them, what have your experiences been like with the healthcare system, and what do you want your doctors to know? What sorts of things should we be teaching as the foundational knowledge and foundational skills that physicians in training and practicing physicians need to know in order to take care of these kids. So this research was graciously supported by an Early Investigator Research Award from the Children and Youth with Special Healthcare Needs Research Network. We had a grant to reach out and conduct semi-structured focus groups and interviews. We worked with a lived experience partner to create focus group interview guides, and then we evaluated the transcripts at the end using applied thematic analysis to pull those themes and identify what the core themes and sub themes would be that we could then use to build curricula in the future. We were able to have about 34 people in total across the different focus groups and interviews that we had eight family members in total, including three Spanish speaking family members. We also had 13 patients with disabilities, ranging from age 12 all the way to age 21. Six teachers, seven social workers and care coordinators from different states all across the US, to conducting virtual focus groups, we found that the four big themes that we were able to pull is that while seeking knowledge and being open about knowledge and helping with attitudes is really important. The core foundation for working with kids with disabilities is building trust. And building trust really to us is composed of three things, ego, which is really a lack of ego, a willingness to communicate, a need for assistance, and work with others in a collaborative manner, question previously held beliefs that you have. And then also having humility. So being able to listen and work with patients and families, willing to believe and learn from their lived experience. And that enhances that bi-directionality of a conversation and trust you can have with those families. On top of that, having empathy, you know, being empathetic towards patients, families and colleagues, then adding in a willingness to seek knowledge, learn from patients lived experience, ask questions and explore unknowns, but using that then also adding in a willingness to recognize attitudes that are currently going on and make changes to those attitudes by recognizing structural, structural ableism, eliminating stereotypes and profiling and identifying as an ally that can then lead to innovative access to quality care. And that for us, had four major sub themes: Being

proactive, so thinking ahead of time, whether that's thinking ahead to your clinic visits, thinking about what these patients are going to need down the line in terms of accommodations and working and being proactive about that, moving beyond what we call "plug and play", so a willingness to really break the mold on finding resources and accessing them and then piecing them together in a way that families really need and works for them, making medical knowledge accessible using appropriate verbiage, and providing them access to their own medical knowledge and medical care, and then valuing working with teammates, like people who can provide resources and community partners who can meet the needs of these patients.

Katie Huth *18:38*
Thank you so much for sharing all that. Can you tell me what do you think are the implications for practice or your next steps from this work.

Lucas Bruton *18:43*
So I think for us, complex care education and education related to children with disabilities is so varied across institutions, and a lot of it focuses on more medical aspects of care for these kids: how to change a G Tube, how to manage their feeds, how to manage their secretions. And while all of that's important, I think it's interesting to look at how we're looking at more of these foundational values, and how we're teaching that and almost work backwards to then build up a more universal curricula and universal competencies for educators and for trainees. So using this as well as information that we've gathered from needs assessments that we're doing across the country with pediatric trainees, residents, medical students and practicing providers. Our hope is then to take that information as well as this and use that to build some baseline competencies regarding kids with disabilities that we can share with institutions and with pediatric programs to help them teach their trainees.

Katie Huth *19:41*
That's awesome. Thank you so much for the work that you're doing Lucas, and we'll see you soon.

Emily Goodwin *19:45*
I just came out of a fantastic chronic conditions session, and I'm here with one of the authors who's going to tell us about his work. Do you want to introduce yourself?

Peter Walsh *19:53*
Hi, I'm Peter Walsh. I'm a behavioral research coordinator at Ann and Robert H Lurie Children's Hospital. And yeah, I was just giving a talk on medical device design needs and flaws for children with medical complexity in the home setting. So we conducted semi-structured interviews with 17 parents and caregivers of children with medical complexity, and we talked to them about their experiences with using devices such as feeding tubes, ventilators, suction machines in the home setting, and their experiences with that. So we asked about their top devices that they might use at home, top disposable supplies and durable medical equipment. And really, what we found is that parents face a lot of issues with using devices in the home that often lead to health and safety risks, and so there are a couple of themes that I would like to highlight. First of which is that the communication and education that parents have about in home device uses could be improved by a lot. You know, parents aren't necessarily told about all the available devices that might be the best fit for their child and them. For example, like a suction machine might be pretty loud and it might be too big, and parents aren't told about alternatives that might be softer or smaller for them to use. But parents also implemented a lot of problem-solving strategies. They're really creative in repurposing consumer-based goods, where one parent talked about using a cooler that floats and so their child who was on a continuous feed could have their feeding pump waterproof and could still enjoy a hot water therapy spa. And then I think one of my favorite problem-solving strategies is that we had one parent who took a suction machine, and their child had to be continuously suctioned pretty frequently throughout the day. And so, of course, using that takes a lot of time. It's quite loud. And so to alleviate that, they took a suction machine, they mounted it in their basement, drilled a hole through their floor, strung it through into their child's room, and attached a wireless on and off sensor, so they had on-demand, wireless, quiet, suctioning

whenever they wanted for their kid. So things like that are really cool to display the ways that parents problem solve. But we also want to highlight that there are a lot of values that parents have in terms of what they do like in using their devices. And so parents really value devices that are small, convenient, easy to use, devices that are reliable, perhaps, like if you know that you're going to need to use a suction machine, you want to make sure that it'll keep a charge and that it'll work, especially in an emergency situation. If you're trying to clear a child's airway, you don't want your suction machine to fail in that emergency situation. We really want to emphasize the design of these medical devices, and take to next steps in having parents involved in that process to communicate their needs and what they like and what they don't like within specific devices, I think will go a long way in terms of user satisfaction of people using the devices, but will also help alleviate some of those health and safety risks that happen in the home setting.

Emily Goodwin *22:51*
Fantastic. What do you think are the implications for patients and families in clinical practice, but also members of the interprofessional care team?

Peter Walsh *23:02*
Yeah, I think that greater communication about devices that are available. So I think a lot of times, from what we heard from parents, is that because of insurance and everything that covers a device or a plan, parents are not necessarily told about alternative devices for their child's care, and I think that having that knowledge for parents to be able to pick and choose what device they want can go a long way for usability, and then also the health and safety implications.

Emily Goodwin *23:39*
For sure. And also, I know came up during the discussion, there's certainly a lot of concerns around, how do families share these great ideas with one another, and how can we as teams share them with one another? So I wonder, is that something your team has thought about or for future directions?

Peter Walsh *23:56*
Yeah, and something that we saw is that a lot of parents rely on inter-parent communication through like different Facebook groups or support groups for not only for like, problem solving, but just learning more about what it means to be a caregiver and to take care of a child with their specific conditions. But something that we've been doing, we've been partnering with Northwestern University's freshman year design students, and so we've taken some of the problems identified by these parents, we've given them proposition to the students, and then asked them to come up with prototypes for these design challenges.So these students, they're brilliant. They came up with hand-powered suction devices that you could feed into a tracheostomy, and through a variety of different methods, were able to clear airways without the use of electricity.

Emily Goodwin *24:43*
Fantastic. I look forward to more from your team and the innovative ideas that this inspires. I'm curious, is there any other presentations or posters you've seen at PAS that that you think will impact practice?

Peter Walsh *24:55*
Yeah, there is a great poster session this morning by Makenzie Morgan and she was talking about engaging secondary caregivers within the research practices and retaining them throughout that process. And so I think one of the conclusions that she highlighted was building trust within your participants is really important. And I especially like the fact that she talked about putting the agency, like on the parents to decide if they want to participate in research, not just the primary caregiver, but also the secondary caregiver, taking a step back and letting the parents talk or other caregivers talk within themselves and decide if they want to participate in that research, and so sort of giving the agency to them. I think that goes a long way to build the parent, caregiver and researcher relationship that builds trust within that.

Emily Goodwin 25:44
For sure, yeah, it takes a village, and we need to involve the whole interprofessional care community, but also the caregivers for children at home. Thank you so much for talking with us.

Katie Huth 25:56
I'm with Dr Amy Porter. Dr Porter, can you tell us a little bit about your poster?

Amy Porter 26:00
Sure, my poster is based on conversations that I've had with parents and other family caregivers of kids with medical complexity over the past year or so. I have a background in anthropology, and my initial interest in this project started with listening to families talk to clinicians about how clinicians' questions about, are you getting sleep? Are you getting rest? Should you take a break? I wanted to delve further into that question and try to use anthropological methods and thinking to do it. And so we talked with 21 family caregivers, all of whom happened to be parents, 80% of whom were moms, and a third of whom identified with historically marginalized groups. And then also with eight home-based clinicians who worked in the same household where those parents were living, including nurses, social workers, therapists, care coordinators, school partners and others. And what we were trying to understand was, what is the work that everyone is doing, and how incessant is it? And then what kinds of breaks, if ever, are parents able to take, and how are they interfacing with the existing respite care system? And how could we help them more reliably realize respite amidst all of the work of care over often, decades of time. And parents, as one might expect, were incredibly generous with their deep knowledge of this challenge and in sharing their personal experiences. And we heard, as we expected, that parents work pretty much non stop with very few breaks, and there are long term consequences on their both physical and mental health. Both parents have no reliable access to respite services in the formal sense of the word, and in that context, parents innovate and really think outside the box to find moments of recharge, and that's still not enough. They hope to find more formal respite care, and yet they lack the bandwidth amidst everything else to try to navigate what is out there. And they really feel like if they were to use respite services, it would have to be really specific to them. One parent uses the word "bespoke" as an adjective, and if they were to try to figure out where this respite is and how it could meet their needs, then they would really trust other parents to help them figure that out. So in conversation with parent partners, we have started to develop what we call the RECHARGE Parent-to-Parent peer respite navigation intervention. And it's a relatively brief, just 12 week intervention where a parent who has experience using the respite care system and has more bandwidth at this moment than previous. We identify these parents or family caregivers, hire them and then train them to provide peer navigation to other parents in need of respite. And over on the poster, you can see there's 12 weeks of intervention, just six touch points. The first week is the longest meeting. It's an hour long, and it focuses on rapport building, normalization of the concept of respite, and assessing the specific family's respite need at this specific moment, because, of course, it changes over time. And then the next week, there's a 30 minute meeting between the same two people, the parent navigator, and the parent participant, and they review the respite options that the navigator has identified over this one week period, together, they work to identify which of those opportunities aligns best with the parent participant's needs, identifying the targets for this intervention. But the next week, they have another 30 minute meeting, but this time it's between the parent navigator and a resource expert who's a social worker, case manager or other kind of resource expert who's already a part of the child's team, whether in the medical realm or in the community realm. And the parent navigator says, you know, I've worked with this parent, we've thought together, and we've identified these respite targets. Can you please help us through all of the 15 calls and the 17 emails and the follow-ups needed to actually get this resource that we've identified. And then the parent navigator follows up two weeks later, three weeks after that, four weeks after that, to say, where are you hitting barriers? How could we troubleshoot together? How can I support you, resource expert. It also follows up with the parent participant and says, you know, have you heard anything from the resource expert? What is changing on your end? And the goal is, at the end of these 12 weeks that the parent participant has more access to respite than previous and both the

parent navigator and the parent participant are at least somewhat empowered to do this kind of work moving forward.

Katie Huth *30:54*
Wow. Thank you so much for sharing all of that. Amy, it's incredible work. You spoke a little bit about some of the implications for practice, but can you tell me if you have any other messages for the interprofessional care team, or for patients and families?

Amy Porter *31:10*
Yeah, when I first started thinking with parents about, you know, what to do in response to everything we were hearing, we somewhat joked, and somewhat said, seriously, maybe an intervention is just to start talking about respite, because so many families said, My child is 20-some years old, and, I've never, never even heard about what resources are out there. And I think that there are so many needs that a family of a child with medical complexity has. And of course, there's a hierarchy of needs, and sometimes respite doesn't, doesn't enter the conversation. I think even bringing it up in primary care offices, in complex care offices, in palliative care clinical spaces. This is, respite is a service. Yes, it's hard to find. It is something you're entitled to. Here are the ways it can be funded and like, let's talk through it as a starting point, even before this kind of more structured intervention.

Katie Huth *32:03*
Wonderful. Well, thank you so much for sharing. We really appreciate it.

Amy Porter *32:06*
Yeah, of course, thanks so much for wanting to talk about the project. I really appreciate it too.

Kristina Malik, MD *32:12*
Hi. This is Kristie Malik at PAS and I'm here with Aditi Vasan, and she's going to talk about two of her projects. So go ahead,

Aditi Vasan *32:19*
Hi, I'm Aditi Vasan. I'm a pediatrician and health services researcher at Children's Hospital of Philadelphia, and I'm going to talk about two studies today. The first is a quantitative study looking at the association of social needs with increased acute care use after discharge among kids with medical complexity. So we looked at a population of about 700 children with complex chronic conditions were screened for social needs at CHOP [Children's Hospital of Philadelphia], and the short version of our results is that we found kids with social needs and CCCs [complex chronic conditions] had higher rates of 30 day and 90 day readmissions, longer index length of stay and increased ED utilization at 30 and 90 days. These results weren't super surprising to us, but I think really underscored the magnitude of the challenges that these families face after they go home from the hospital. So the other study I'm going to talk about is sort of a companion qualitative study to that project, where we spoke to caregivers of medically complex kids with social needs, and we asked them what kind of support would be helpful for you after you go home from the hospital? And the big things we heard from families were the importance of aligning the resources and support that we provide for social needs to the unique needs of children with medical complexity. A lot of parents told us we just get the same resource list as any other family with food insecurity, and that might not be right for my child and the things that my child needs. And we also heard a lot about the importance of longitudinal support to kind of prevent that voltage drop after discharge, where families feel like they go from having a whole bunch of people working on their child's care to not having quite as much support. And the last thing we heard was a lot about trying to build trust between caregivers, especially those from minoritized communities, and those who speak languages other than English, and their healthcare teams. Folks said that often they took a lot of time, but were able to build trust with folks in the hospital, and then having to build trust

with a whole new set of providers in the outpatient setting was also a challenge to their engagement in medical care and to addressing their social needs.

Kristina Malik, MD *34:07*
That's great. What do you think the next steps are?

Aditi Vasan *34:11*
Yeah, I think what we're hoping the next steps are to build out longitudinal support for families post discharge that will ideally be primarily from a community health worker, but the community health worker will also help connect families to folks on their medical team and to health and social service programs so that the voltage drop post discharge doesn't feel quite as sharp, and ideally, they'll be that sort of trusting liaison with families to help them rebuild and continue to build trust with the health care system.

Kristina Malik, MD *34:40*
That's great. Any sessions or posters or presentations you've seen so far that you thought was really amazing?

Aditi Vasan *34:47*
Great question. I was just talking to a colleague about the Precision Medicine session from earlier this morning, and the idea of thinking about health, the intersection of kind of health equity and precision medicine, and the idea that precision medicine, which we often think about in gene therapy, is really just the concept of providing the right care for an individual patient in the right moment. And so much of what we heard from our caregivers is really about that. When you think about my care plan, think about how my background and contact feeds into those things, and then support me and have someone who I can trust and I can relate to who's working with me across the healthcare system. So I really love that framing, and I'm definitely going to take that back in thinking about, like you said, trust building, which was a common theme across a lot of presentations, but also the idea of precision medicine and tailoring our care of her patients to what works best for them.

Kristina Malik, MD *35:35*
Great. Thank you so much.

Katie Huth *35:39*
We've highlighted only a sample of the emerging research in complex care shared at PAS. To summarize, a number of presenters highlighted the importance of partnering closely with families in clinical care, research and education. For example, in determining the appropriateness of and readiness for interventions, obtaining and considering how to use information obtained from trach cultures, designing the systems of care that families need, identifying gaps in training, engaging in user-centered design of medical devices, providing peer support in accessing respite care, and ensuring tailored support for families after discharge from hospital. All of this, in the context of trusting relationships between families, clinicians and researchers.

Emily, Kristie and I want to thank our speakers for their time during a busy conference 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 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!

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