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Let's Talk about Transition: Experiences of Young Adults with Cerebral Palsy and Their Caregivers

In this Complex Care Journal Club podcast episode, Dr. Cristina Sarmiento discusses a qualitative study exploring experiences of young adults with cerebral palsy and their caregivers with transition to adult care. She describes the major barriers and facilitators to transition, challenges and opportunities related to conducting the study, implications for practice, and next steps from this work.

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Emily J Goodwin *00:04*
Hello and welcome to the Complex Care Journal Club podcast. My name is Emily Goodwin. I'm a pediatrician in complex care at the Beacon program at Children's Mercy Kansas City, 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'm delighted to have Dr. Cristina Sarmiento, an assistant professor in the Department of Physical Medicine and Rehabilitation at Children's Hospital Colorado and University of Colorado Anschutz School of Medicine, joining me today. She is the lead author of the article "Experiences of Young Adults with Cerebral Palsy in Pediatric Care Transitioning to Adult Care" published online in March 2024 in the Developmental Medicine and Child Neurology Journal. Cristina, thank you so much for being here.

Cristina Sarmiento *00:51*
Thanks so much for having me, excited to be here.

Emily J Goodwin *00:54*
So I wonder if you could share a little bit about your study, starting with the gap you identified and your research aims?

Cristina Sarmiento *01:01*
Absolutely. So, as many of us know, life expectancy in many lifespan or childhood onset disabilities, including cerebral palsy or CP, is increasing. And so the vast majority of individuals with CP live and thrive into adulthood. Adults with CP have unique healthcare needs, and so really do need to transition from pediatric to adult based healthcare in both an age and developmentally appropriate manner. Rehabilitation care, so that involving physical medicine and rehabilitation clinicians like myself, rehab psychologists, therapists from various disciplines, these people are frequently part of the care of individuals with CP across the lifespan, and the transition process, particularly for this rehab-related care, isn't really well developed, particularly at our institution where we conducted this study. And so we sought to increase our understanding of the experiences and values of adults with CP and their caregivers regarding their pediatric rehab care and what they anticipated as barriers and facilitators to that transition to adult care. And our overall goal is to develop a patient and family-centered transition process for young adults with CP. So we conducted this study, which is a qualitative descriptive study, and we use semi-structured interviews with adults with CP and their caregivers. The adults with CP were all at least 18 years or older, but had not yet transitioned to adult rehab care, so we wanted to talk with adults with CP and their families who were at that age that would be appropriate to transition to adult care, but for whatever reason hadn't yet made that transition. So we ultimately conducted 20 interviews: 13 were with caregivers alone, and 7 were dyadic interviews with the adult with CP as well as their caregiver. And we identified four major themes, and each of them had associated barriers and facilitators to transitioning to adult care. The first theme was the value and security of longterm relationships, and so participants placed really high value on the relationships with their pediatric providers, which I'm sure surprises no one listening to this podcast, and saw this as a barrier to leaving pediatric care. You know, a lot of these patients and their families had been seeing these providers for years, if not decades, at this point. And leaving them was like a breakup, some people equated it to. Our second theme was "feeling rudderless", and that was a patient quote, navigating the logistics of transition. So that transition to adulthood obviously felt overwhelming within the healthcare setting, but participants brought up all the other changes that are happening at that time of entering adulthood, and it is really overwhelming. So much seems to be happening at once, things that they weren't expecting to change are changing, and they really felt like they didn't have appropriate anticipatory guidance about all the changes that would occur in all these different domains of life. The third theme that we identified was differences in pediatric versus adult models of care, the general sense that adult healthcare systems felt less warm and inviting, that the pediatric system really felt more supportive with multi-disciplinary clinics and care coordinators and lots of supports in place, and that this transition to adult model of care was really stark and was seen as a source of anxiety for our participants. And finally, the last theme was the perceived lack of provider expertise and comfort in adult care settings. So while

none of the participants in our study had transitioned their rehab care yet, some of them had transitioned other specialties that they'd seen or had tried to transition and come back to their pediatric providers, and they recalled several negative experiences, in the adult care settings where they felt like providers felt overwhelmed with their medical complexity or weren't sure how to best advise or guide their care. And so this perception that adult care systems aren't set up to care for patients with childhood onset medical complexity or disabilities was also seen as a barrier to the transition to adult care.

Emily J Goodwin *05:22*
Thank you. And I wonder if you could elaborate a little bit more about the inclusion of the dyads? I thought that was really great that you included opportunities for both the caregiver and the individual with cerebral palsy. I wonder if you could speak a little bit more about that process?

Cristina Sarmiento *05:39*
Yes, of course. So we wanted to really highlight and include the voices of young adults with CP as well as caregivers. And so we used a shared decision-making process to figure out what structure interview that we would have. We screened patient charts through the electronic health record, and most of the time it was the caregiver that was listed as the primary contact. If it was the young adult themselves, of course we would contact the young adult, but usually it was the caregiver. And so when we were talking with the caregiver and explaining, you know, the purpose of our study and the study procedures, we told them how important it was to us to include the voices of young adults as well. And we discussed potential reasons that that might not be appropriate or possible, things like significant communication or cognitive or behavioral challenges. And after that discussion, we asked their caregiver, do you think that your, and most of our caregivers were parents, do you think that your child would be interested and able to participate? And if the answer was yes, then we talked through in a little bit more detail what that could look like. So we talked about the option for the dyadic interviews, where the caregiver could be a support if the young adult wanted a little extra support, or the option to interview both parties separately, and so we would talk through the pros and cons of these different options, and ultimately made a joint decision with the participants, which I think allowed us to include a lot of young adults that benefited from having a caregiver support in the interview. I think the downside is that no young adult chose to or was able to interview by themselves, so we only had caregiver and dyadic interviews. And we might have captured different information or experiences if we interviewed some adults with CP independently.

Emily J Goodwin *07:31*
What other opportunities and challenges did you identify while developing and conducting your study?

Cristina Sarmiento *07:36*
Great question. I think the biggest opportunity that we identified was really getting a sense of how invested families are in the transition process. You know, I think a lot of us experience this clinically, and throughout our interviews, the participants that we included really appreciated the need for and the importance of transitioning to adult care, but need and deserve a supportive infrastructure to do so, and are really invested in making this better, not only for their young adult children, but for families to come. We're actually now partnering with adults with CP and caregivers, several of whom participated in this study, to help co-design our transition process and resources within our rehab program. Their insights from this study, as well as this new co-design process are so incredibly valuable in really helping us attend to patient and family priorities. Some of the challenges that we experienced, I think one of them related to our participant structure, like I mentioned that most of our participants were caregivers, and that we didn't include any interviews with adults with CP independently. And so adults with CP that were more independent or that may have wanted to participate in an interview by themselves, they may have different priorities or needs from the transition process. And so this is something that we needed to explore further. I think also some of the challenges is that some of the key issues that participants brought up may feel out of our immediate control at this time. So these include things like shortage of adult providers in adult health care systems to transition patients to or difficulties accessing adult health care systems related to things like insurance

barriers. You know, I certainly think these are important long-term issues to address, but are challenging to imagine: How we can address these in a six to 12 month period? And this includes adult providers who don't feel comfortable with adults with childhood onset disabilities. I think other studies, as well as participants in our study, brought up opportunities to improve this. Things like including care of adults with childhood onset disabilities in medical training. But that's another, clearly long-term goal. I think one other opportunity that arose is leveraging providers who already have lifespan training.This includes physicians trained in both internal medicine and pediatrics, also med-peds physicians, which I think a lot of institutions are already doing really well, family medicine providers, as well as other specialty paths that by virtue of their training, include lifespan training. Things like pediatric rehab medicine, where all pediatric rehab physicians are also trained in adult rehab medicine, or pediatric ophthalmology, where the training path, just the way it's laid out includes both adult and pediatric ophthalmology. And that's something we're seeing increase in presence at our institution is leveraging these dually trained providers to care for individuals on both sides of that transition divide.

Emily J Goodwin *11:09*
I wonder, what do you think are the implications for clinical practice? Specifically, what do you recommend for members of the interprofessional healthcare team for children with medical complexity based on your findings?

Cristina Sarmiento *11:01*
That's a great question. And I think despite some of these long-term issues and challenges we need to address, there's a lot that we can do, you know, starting today. One message that we heard over and over again is that families know transition is coming, whether or not their pediatric providers talk about it. And the uncertainty of the process, you know, when's it going to happen? Who am I going to transition to? It really just worsens the fear and apprehension of the process. So participants in our study described, you know, walking on eggshells at their adolescent's appointments, fearing when transition would be brought up, or when they'd get quote, unquote "kicked out". And so I think there's a lot of things that pediatric providers and members of the care team for children with medical complexity can do to help assuage these fears. So I think the most important thing is bringing up transition early and often. And this doesn't have to be a 10, 20, 30 minute conversation each time. It can really start in early adolescence, and should start by just acknowledging that at some point they'll need to transition to adult care, and that you'll help support the process. Even a statement as simple as this can go a long way in both preparing patients and families and easing the anxiety and the uncertainty around the transition process. I think another maybe medium-term goal that care teams can look at is, does their clinic have a formal transition policy? If not, it might take some time and energy at the front end, but I think it's worth creating this. So once created, this can be another easy way to share transition policy early with families, so that again, they have advance notice of what's coming. It can maybe address some frequently asked questions about the transition process. And if possible, I think it is amazing to engage patients and families in creating this policy too, so that you're attending to the needs of people that are going to be receiving the policy. I think another thing that pediatricians and pediatric care teams can do is really engage and partner and develop relationships with adult colleagues. I also care for adults with CP, and it can feel really overwhelming to step into a patient-provider relationship that's been in place for so long and over time, it can be really helpful to have these relationships with even a few adult providers that you can transition patients to. A lot of our participants cited that having a specific provider recommendation was a huge facilitator to transition. Having their pediatric provider vouch for an adult provider that they knew and trusted and had transitioned other patients to went a long way in helping ease that anxiety. Once you have these established relationships, you can help ensure that these adult providers have the information that they need to get off on the right foot with their patients, so that it's a mutually beneficial relationship, and then you can provide specific contact information and facilitate the referral to this adult clinic. I think finally, the last thing that I think pediatric care teams can do is again, to prepare patients and families for the differences in models of care. So I think that can be a longterm goal of maybe changing or addressing the differences in models of care so that adult care systems feel more supportive. But in the meantime, we can empower patients to be more active in their care as they’re appropriate and able. Because in the adult care setting, a lot of adult providers are going to look to the young adult to guide conversations, set priorities for clinic

visits, and similarly, we can prepare caregivers for their potentially changing roles in their child's care. Again, this isn't going to be appropriate for everyone, but for many patients, the young adult is going to be taking a more active role, and the caregiver might be expected to take a less active role. And so we can help prepare patients and families for this when it's appropriate.

Emily J Goodwin *15:09*
Do you have any other messages for patients and families from your study?

Cristina Sarmiento *15:14*
I think I'll highlight two messages. One is the transition period is often overwhelming and anxiety provoking, and it's okay to acknowledge this. We don't have to pretend like this is easy and no big deal. We can acknowledge that this is really hard, and that it's really important, right? So adults, even those with childhood onset disabilities, develop adult medical issues, and they deserve providers that are equipped to diagnose and manage these adult issues. But by again, beginning these discussions early, we can provide more bite sized information, so that not everything is hitting at 18 or 21.

Emily J Goodwin *15:53*
You kind of mentioned this a little bit earlier in thinking about co-designing with patients and families transition programs. Could you talk a little bit about the important next steps from your work?

Cristina Sarmiento *16:04*
Yeah, so that codesign process is an important step that is in progress now. One additional step that we took in the in-between, because we wanted to hear more from young adults with CP themselves, is we also similarly did qualitative interviews with adults that had transitioned in our institution to adult-based cerebral palsy care. And through that process, we still got to interview some caregivers and dyads, but we also interviewed a lot more independent young adults with CP, and so we're able to capture their experiences and priorities. So those manuscripts are forthcoming, but those interviews are completed, and now, yeah, we have shifted to creating a formalized transition process and resources for our program. So we are including those with lived experience, as well as clinicians from a variety of specialties and backgrounds that participate in the rehab-related care of our patients. So different therapists, social workers, learning specialists, psychologists, primary care providers to help co-create this what we envision as a transition roadmap that'll begin in early adolescence and highlight critical or time sensitive events related to the transition season mapped out. And this will include information and resources for common transition related questions that come up. Things like options for medical decision-making after 18 and when to join insurance waiver wait lists, because we found that a lot of young adults that we're seeing and their families weren't aware of these needs and these issues until after the fact.

Emily J Goodwin *17:50*
Fantastic. I really look forward to learning more about what your team is finding. I imagine that a lot of the things you're putting together as that transition roadmap or season could apply to multiple areas, but of course, certain things are regionally or state specific. So I'm just curious, do you have any advice or lessons learned to share with other researchers in this field?

Cristina Sarmiento *18:13*
Yes, that's a great question. And I think one thing that I really saw play out in front of me was how valuable engaging patients and families in research and programmatic development is. And I know this is an area that's getting increasing emphasis, and very rightly so. We have learned so much from our participant's experiences, and they've been so willing to share with us and to stay involved in our future efforts. And I don't think our end result would be even half as effective or comprehensive without having this lived experience engagement, and so I'd really encourage other researchers and other clinicians that are looking to develop similar programs to partner

with patients and families at your institution. And they just have so much knowledge and first-hand experience, and in our experience, have been very enthusiastic about partnering with us in these different efforts.

Emily J Goodwin *19:18*
Fantastic. Anything else that you want to share that I didn't ask about?

Cristina Sarmiento *19:23*
I'll just say, like you mentioned, transition is a challenge across institutions, and we can definitely work together to, step-wise, make it a better process. They're not going to fix all of the issues overnight, but there's a lot of really important and helpful things that we can do now to improve the process for our young adults and families that we see, and a lot of longer-term goals that we can also work towards for the future.

Emily J Goodwin *19:51*
Fantastic. Yeah. I love that you included things that we can do today, both as you know, healthcare professionals, but also empowering patients and families and things that we need to improve moving forward. So thank you so much for your time, Cristina, and thank you to you and your team for advancing the field of complex care.

Cristina Sarmiento *20:10*
Thank you so much for having me.

Emily J Goodwin *20:13*
And thanks for listening to the Complex Care Journal Club Podcast. We aim to highlight research that has the potential to be practice-changing, values patient and family engagement, is relevant across disciplines and diagnosis and uses high quality or novel research methods. We invite you to join the conversation by suggesting an article you would like to see discussed in this podcast using the form provided in the OPENPediatrics YouTube channel. Thank you again for joining us.

Journal Club Article

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