S3, E18 — Research Roundup: New Studies to Support Lifelong Management of CP

**Dr. Marie McNeely** 00:01

Hello and welcome to Changing What's Possible: The Disability Innovation Podcast brought to you by Cerebral Palsy Alliance Research Foundation or CPARF. I'm your host, Dr Marie McNeely, and this season, we are excited to bring you cutting-edge stories and insights on research, technology, and innovation for people with CP and other disabilities.

Our Research Roundup episodes can help you stay up to date on what's new in CP research. All of the studies featured in today's Research Roundup represent interesting, innovative work happening in the CP research space outside of the projects that CPARF has funded.

Today, I'm going to share three new research papers focusing on managing CP across the lifespan.

One study from Dr Lori Rosenberg and colleagues at Hebrew University and the Grabski Rehabilitation Center aimed to better understand aspects that are important to adults living with more involved CP as they prepare to move from assisted to independent living. Major lifestyle transitions can be challenging for anyone, regardless of age or disability, but little research has been done on the particular concerns and considerations of adults with more involved CP as they prepare for and navigate these transitions.

Some adults with more involved CP may move from a family member's home or assisted living residence to live independently in the community with help from a caregiver. And in this study, researchers used semi-structured interviews to gather information from seven participants with more involved CP who were preparing to transition from a residential home for adults like them to independent living.

The interviews covered the participants' expectations about living independently, their relevant fears and personal strengths skills they wanted to learn, their daily schedules and interactions with others, and any information that they needed about living independently. The research team later analyzed these interviews to identify the key themes.

Four themes arose, each with a few subthemes. Participants expressed concerns about (1) house management and all of the complexities and responsibilities surrounding finances, meals, and maintenance and housework, and (2) interactions and boundaries. These spanned the participants relationships with a caregiver, their family, friends, and romantic partners. The third theme that emerged was related to schedules, and this encompassed everything — work, leisure, volunteering, education, as well as health management.

And the fourth theme was the most common to arise in conversations, and the participants termed it “my way.” This encompassed autonomy, independence and self-advocacy, as well as the emotions they were experiencing surrounding this transition and group power, or the power of going through this process with a group of peers. These themes were then used to co create a group intervention to help these individuals with CP prepare for their transition to independent living. And the researchers inclusive approach and intervention could also help others with CP make this transition more smoothly.

In another study first author Dr. Mary Gannotti from the University of Hartford, and her collaborators, examined functional decline in adults with CP living in the community in North America. In this study, functional decline refers to changes in gross motor, hand function, and communication. Gross motor includes movements made with our legs, arms, and torso. Adults with CP are at high risk for functional decline, and better understanding the risk factors associated with functional decline could help improve care and prevent or delay these changes. This study used patient reported outcomes collected by the CP Research Network community registry, which uses surveys to gather data directly from people with CP and their caregivers.

This provides researchers with valuable information on topics that people with CP have identified as research priorities. When assessing gross motor function in individuals with CP, clinicians and researchers typically use a tool called the gross motor function classification system, or GMFCS. There are five different GMFCS levels, ranging from level I, where an individual is least affected, to level V, where an individual is most affected. The GMFCS was used in this study to understand participants' current and past gross motor function.

Analyzing data from 263 participants, the researchers found that 60% reported functional changes since childhood, and a decline in gross motor function was most commonly reported all types of decline they measured — again, this is motor function, hand function, and communication — increased with increasing age. The prevalence of motor decline specifically varied depending on GMFCS level.

In contrast, the prevalence of hand function decline and communication decline did not differ by GMFCS level. Individuals with spastic CP most commonly reported gross motor function decline, but gross motor function decline occurred at similar rates in people with and without spastic CP. Results from the study highlight the prevalence of functional decline in individuals with CP and the need for future research on risk of functional decline, as well as preventive and rehabilitative measures to address these functional declines as individuals with CP age.

A final study led by doctors Sonali Shah and Pip Logan at the University of Nottingham focused on falls — their consequences and falls management in adults with CP over the course of their lives. Despite the relatively high risk for falls in people with CP, there is relatively little information available about falls and a lack of falls-related support or rehabilitation services for this population.

This paper uses qualitative information from life-course interviews. During the interviews, participants reflected on their falls experiences, the physical and mental health consequences, how they've managed and prevented falls, use of mobility aids, and how falls and fear of falling has shaped their activities, their choices and opportunities throughout their lives.

Of the 26 participants, 19 experienced falls and felt at risk for falling, and seven reported they did not have falls or fear of falling because they were quadriplegic, non-ambulatory, and used wheelchairs full time for most of their lives.

Three distinct themes emerged in analyzing those interviews. One key theme was that falls in fear of falling limited what participants did and where they went. While this was reported by participants as early as in their 20s, it became more pronounced with age. A second theme was related to loss of autonomy and independence. Participants often referenced using assistive devices or support from others to prevent or reduce falls and fear of falling during their activities. In some cases, the participants felt dependent on these devices or people, while in other cases, participants reported that these assistive devices helped them feel more independent.

The third theme focused on managing falls as well as adaptation practices. Even though participants had more falls and experienced other physical decline, they reported that they didn't receive much support or advice from healthcare providers and how their environments or activities could be adapted to meet their changing needs. It was often up to them to develop solutions and ways to manage their falls and fall risk.

These interviews highlighted how people with CP can experience falls and fear of falling throughout their adult lifespan, and this can have physical, psychological and social consequences, and it can impact their independence and participation in employment as well as social activities. Now, more work needs to be done to develop specific rehabilitation programs to help adults with CP manage falls, incorporate supports like assistive devices into their everyday lives, and provide mental health support.

And I know we're just starting to scratch the surface in terms of research being done in adults and across the lifespan in CP, and these papers that we talked about today on transitioning to independent living functional decline over time and falls and fall management provide important data to inform future research. And I'm very excited to welcome Jocelyn Cohen CPARF’s Vice President of Education back to the show to talk about the findings of these studies and what they could mean for people with CP. So Jocelyn, welcome to the show.

**Jocelyn Cohen** 08:35

Thanks, Marie. It's great to be here again, especially as an adult with CP. Cerebral palsy is the most common lifelong physical disability — affecting 18 million people worldwide — and it's energizing to know that more adult-centric research is being done in the CP field, in addition to the studies CPARF currently funds. When I was younger, I thought that my cerebral palsy wouldn't change, and I was wrong — and it was shocking and scary to realize that. But the research being done in this space will help manage that stress for millions of my fellow adults with CP.

Information is power and understanding how our movements and abilities may change and what we can do to slow or prevent those changes will make a huge difference for us. Along with that, self- perception can shift based on someone's experiences and goals. The more someone feels comfortable with their own abilities and their personal environment, the more they can learn about themselves and the world by doing new things, and the more people understand how they're impacted by their movement, falls, and the ways they get up and recover from those falls, the more they can pursue the resources and equipment that they need. Finding the sweet spot between staying informed, retaining or claiming autonomy, and embracing interdependence is key for any adult with cerebral palsy.

**Dr. Marie McNeely** 09:50

Well, Jocelyn, I definitely agree, and I truly appreciate you sharing your own experiences and perspectives with all of us today.

**Jocelyn Cohen** 09:56

Thanks so much for having me on so that I can share what I've experienced and how it will help the cerebral palsy community.

**Dr. Marie McNeely** 10:03

And listeners, thank you for joining us as well. You can find links to the abstracts for the papers we talked about today with the notes for this episode on CPARF’s website.

And now I'd like to take a moment to tell you about 3forCP — CPARFs grassroots fundraising initiative for cerebral palsy research and disability innovation. Whether you level up a read-a-thon, a sip-and- paint event, a comedy show, or something else that you love, 3forCP gives you the chance to make a difference in your own signature way. Head to 3forCP.org to get started. That's the number 3, F, O, R, C, p.org — And we look forward to connecting with you again in our next episode of Changing What's Possible.