S3 E14 — Research Roundup: New Insights on Surgical Interventions and Medications for 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 McNealy, and this season, we're 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.

In this episode, I'm going to talk about three new research papers that share updates related to surgical interventions and medicines for managing symptoms of CP.

In the first study, researchers from the Hospital for Special Surgery in New York examined the tilt angle of the pelvis of adults with CP while they were walking. A portion of the people included in this study had previously undergone surgery to lengthen their hamstring muscles in their legs, while others had not. Hamstring lengthening surgery has been commonly used as a treatment for children with CP who have flexed knee gait, also called crouched gait, as a result of short or tight muscles at the back of their hips and thighs. This surgery can help improve walking, standing posture, and pain, but more research is being done now to better understand the longer-term impacts of this surgery.

In this study, scientists evaluated walking in 54 adults with CP, 32 of whom previously had hamstring lengthening surgery. This surgery was done on average when they were around eight years old, and their surgeries were on average about 28 years ago. The scientists used 3D gait analysis to measure pelvic and trunk tilt angles during walking, as well as knee flexion during the stance phase of walking when the foot is on the ground.

They found that adults who had the hamstring lengthening surgery years ago, walked with significantly increased anterior pelvic tilt. This means that their pelvis was rotated further forward during walking, with the front of the pelvis tilted further downward and the lower back more arched.

This is an important finding, because this larger anterior pelvic tilt during walking can lead to a cascade of other changes in the positions of bones in your legs and spine, as well as problematic weakening or tightness of muscles in your body that can lead to pain, injury, or other negative outcomes. Results from this study, along with prior studies with similar findings, have highlighted the need for surgeons and care teams to carefully identify the best surgical approach for each patient, considering potential long-term effects of these surgeries. Detailed gait analysis, modeling and other approaches can help inform the decision-making process.

In the next paper, lead author Anthony Chu from George Washington University School of Medicine and Health Sciences, and his colleagues examine trends in the timing of hip surgery in children with cerebral palsy. We know that hip instability is a concern for children with CP. It can result in the development of hip displacement, which can lead to pain, functional limitations, and lower quality of life. And because hip displacement can worsen over time, undergoing surgery earlier in life may be beneficial.

In this study, a medical claims database was used to examine children with CP who were 10 years old or younger between the years 2010 to 2021. Data from 309,677 children with CP were available. Using this sample, the researchers determined how many children underwent hip surgery when aged one to four years old, or when aged five to 10 years old. The data were analyzed using the patient's age on the date of their surgery and the year that the surgery took place.

Overall, they found that the percentage of children who underwent hip surgery increased from about 10% in 2010 to about 19% in 2021. Results from their statistical analyzes suggest that the rates of hip surgeries in children with CP aged one to four years has been increasing since 2010, whereas the rate in children with CP aged five to 10 years has been decreasing since 2016. So, children with CP may be undergoing hip surgery at younger ages in more recent years.

The decision of if or when to get hip surgery for children with CP is a complicated one, because surgery and recovery can be really challenging for younger children, but clinicians and families also need to consider the possibility that delaying surgery could lead to worse outcomes and the potential for needing more invasive surgery later.

Conversely, earlier hip surgery may increase the likelihood of needing another operation later. This study provides important information on national trends in how hip conditions in CP are being treated in the US, and while factors involved in this shift towards earlier surgeries need to be further investigated, greater adoption of hip surveillance programs in clinical practice in the US to catch and address hip conditions earlier may be one contributing factor.

In the final paper that we'll discuss today, an international group of experts led by doctors Darcy Fehlings at the University of Toronto and Yngve Falck-Ytter at Case Western Reserve University presented an update on the clinical practice guidelines for managing cerebral palsy in dystonia with medications and brain surgery.

Clinical practice guidelines are recommendations for healthcare professionals on how to diagnose and treat specific medical conditions to help optimize patient care. Dystonia is common in people with CP, and it's characterized by slow, repetitive movements that a person can't control, stiff postures, and increased muscle tone or contraction of muscles. When someone has dystonia, it can really interfere with their daily activities, impact their motor function, and cause pain. The researchers in this study used a standardized, systematic approach to assess the existing evidence from the scientific literature and develop 10 evidence-based recommendations with considerations for implementation that combine the evidence with the individuals and their family circumstances, values, and preferences.

Some of the recommendations suggest the use of particular treatment approaches, such as using the muscle relaxant baclofen, or using gabapentin, a medication used to treat seizures and nerve pain. Other recommendations suggest against the use of certain treatment approaches due to a low likelihood of benefits and the potential for undesirable effects. One example from the article is their recommendation against using benzodiazepines, a type of depressant or sedative drugs used for anxiety disorders, insomnia, seizures, and muscle spasms. Unfortunately, there's still not a lot of evidence to support different options for medications or surgeries to treat dystonia, so the author's recommendations are all flagged as being based on very low certainty evidence.

To help strengthen the evidence and inform future recommendations, the expert panel identified key research priorities for different treatments that will help advance care for people with CP and dystonia. Overall, these clinical practice guidelines can help summarize the evidence and help inform clinical decision making for doctors and their patients to ensure the best possible care for people with CP based on the information we have now.

So we discussed three new papers today, listeners, that covered how hamstring lengthening surgery may impact pelvic tilt during walking in adults with CP, trends in the timing of hip surgery for children with CP, and updated clinical recommendations for treating dystonia in people with CP. And now I'm thrilled to welcome Jocelyn Cohen, CPARF’s Vice President of Education, 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 today.

**Jocelyn Cohen** 08:10

Thanks for having me back, Marie. So two major things jump out at me from the information you shared today. And the first is that making decisions about surgery is incredibly complex. The first people who have to make these choices are parents and caregivers, and the best thing they can do is equip themselves with the most recent information possible. Also, don't be afraid to get more than one medical opinion before deciding which procedures to pursue and when to pursue them. Related to this, the studies illustrate that the decisions that parents and caregivers make will affect children for the rest of their lives, and as many adults with cerebral palsy ultimately become the sole decision makers about their own care, they have to contend with how their joints and muscles were managed in prior years. Continuing research in these areas will empower adults with cerebral palsy to make the best choices for the management of their lifelong disability.

**Dr. Marie McNeely** 09:01

Well, Jocelyn, thank you so much for sharing your perspectives and insights with all of us today. We appreciate it.

**Jocelyn Cohen** 09:07

You're welcome. Thanks so much for having me.

**Dr. Marie McNeely** 09:09

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 listeners, we are excited to let you know about CPARF’s STEPtember campaign, which runs for the whole month of September. Join thousands of people across the country to raise funds for life changing cerebral palsy research and assistive technology that will positively reshape what it's like to live with a disability. And if you want to pair any physical activity with your fundraising, you can challenge yourself to get moving all September long. Make a team of up to four people and get your friends and family in on the fun. Sign up today for free at www.steptember.us that's www.S, T, E, P, T, E, M, B, E, R, dot, U, S, and we look forward to connecting with you again in our next episode of changing what's possible.