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## Standardizing Chronic Pain Assessment: Using a Toolbox in a Pediatric Rehabilitation Setting

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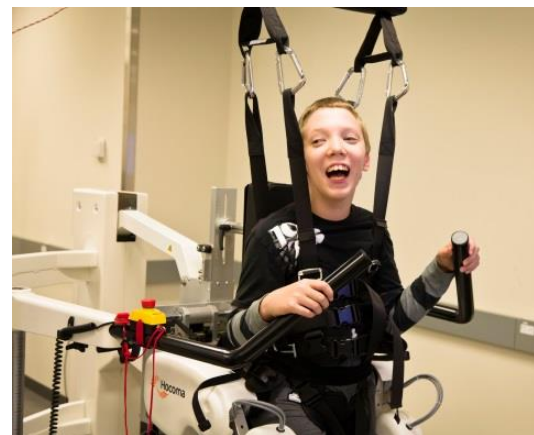
Cerebral palsy (CP) is the most common physical disability of childhood. It occurs in two out of 1000 children, appearing on acute, rehab and tertiary health care caseloads worldwide. It is a non-progressive condition whereby an injury occurs in a child's brain before, during or shortly after birth, and can affect a child's movement and posture, limiting their everyday activities.<sup>1</sup>

CP is a complex physical disability and can affect the whole body, creating many potential sources for pain and can often result in painful associated conditions.<sup>3</sup> This means that the disability of CP does not cause pain, but the changes to the body as a result of CP can create ongoing pain and can further disable a child.<sup>3</sup> For example, children with CP often spend

less time doing weight bearing activities (standing and walking) because they might use a wheelchair or other mobility support. As a result, they are at an increased risk for fragility fractures (broken bones), which cause significant pain. Results from a study on the common causes of pain in children with CP conducted at Holland Bloorview Kids Rehabilitation Hospital found that hip subluxation/dislocation, spasticity, muscle spasms, contractures (shortening of muscles or joints), muscle overuse/fatigue and dystonia (muscle contractions causing involuntary movement) were the primary sources of pain.<sup>4</sup> Other associated conditions causing pain relate to surgery, gastroesophageal reflux disease, constipation, and rehabilitative activities like stretching and strengthening exercises.<sup>3, 5, 6</sup> Many of these procedures or therapies are intended to reduce pain and improve quality of life; however, in the process of achieving this goal they may initially cause pain.<sup>3</sup>

Pain can be described as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."(pg. 1)<sup>2</sup> There are different types of pain that a child with CP may

experience. Acute and procedural pain are the most commonly recognized types of pain, while chronic pain is often underrecognized.<sup>3</sup> Acute pain is "sudden... felt immediately following injury, is severe in intensity, but is usually short-lasting" (pg. 20)<sup>7</sup> and generally lasts less than 30 days.<sup>7</sup> Procedural pain can happen during or after any procedure, such as Botox injections, causing actual or potential tissue damage.<sup>8</sup> Chronic pain lasts three months or longer and can be overlooked in children with CP. This may be because of communication challenges or the fact that there are multiple sources of pain to assess.<sup>4</sup>



Recent research speaks to the scope of the problem. In a large European study, Dr. Parkinson and colleagues found that 75 % of adolescents with CP aged 13 to 17 years, experienced general pain during a typical week with 60% having had pain in the previous week.<sup>6</sup> Similarly, in a Canadian study, Dr. Fehlings and colleagues concluded that 25% of children with CP, aged 3 to 19 years were found to have moderate to severe pain impacting on the child's activities.<sup>4</sup>

The effects of chronic pain for children with CP can significantly impact their daily activities and can result in a lower quality of life.<sup>4</sup> Specifically, pain can negatively affect the quality of a child's moods and emotions, self-perception, autonomy, physical wellbeing, participation in school and their relationship with their parents.<sup>9</sup>

#### Cerebral Palsy and Pain

"It can be hard for kids to explain where the pain is, especially if they've lived with pain their whole life. Maybe they think it's normal, or maybe they are too shy to tell you – either way, you may not know they are in pain" - Mother of a Holland Bloorview Client.<sup>10</sup>

#### Chronic Pain Assessment

Assessment of chronic pain in children with CP is under-recognized and under-treated and it can be complicated by communication difficulties and multiple pain sources.<sup>4</sup> Children with CP often have complex care needs and multiple care providers, making consistent assessment, monitoring and management of chronic pain a challenge within the healthcare system.<sup>4</sup>

Given the high prevalence of chronic pain in children with CP, clinicians should aim to increase their awareness to promote earlier identification, better assessment, and more appropriate management.<sup>4</sup> Without proper assessment, pain cannot be managed, impacting a child's participation in everyday activities.

To help assess pain effectively, using an evidence-based resource like a clinical practice guideline can direct clinicians in a systematic way. For example, the Registered Nurses Association of Ontario (RNAO) has produced a Best Practice Guideline for Pain Assessment and Management.<sup>11</sup> This resource contains recommendations to guide a standardized pain assessment for all types of pain in the general population based on the best available research. In addition to a standardized pain assessment, a standardized tool can be used to better understand the pain experience. Self-report tools are considered the 'gold standard' in pain assessment, although, not all children with CP are able to communicate their concerns around pain and observational or proxy tools provide alternative options.<sup>4</sup>

#### Standardizing Pain Assessment Practices: Moving evidence to care

Holland Bloorview Kids Rehabilitation Hospital has taken the first steps to standardize pain assessment to ensure that every client, regardless of communication ability, is asked about pain.

Evidence to Care, Holland Bloorview's knowledge translation team\* and a group of pediatric rehabilitation specialists conducted a systematic review of the literature to source the best available pediatric chronic pain assessment tools. The results indicated that while there are good tools available, there are not many tools tailored for children with disabilities. Conducting research on tool development for pediatric disability populations could greatly assist the assessment of chronic pain.

Bundling pain assessment tools in a single product, like a toolbox, can create a unified approach and shared vocabulary to pain assessment; narrowing down measures to those that meet the needs of a pediatric disability population.<sup>11</sup> At Holland Bloorview, an interdisciplinary workgroup led the development of a toolbox titled 'A Chronic Pain Assessment Toolbox for Children with Physical Disabilities: A Collection of Pain Assessment Recommendations, Practice Points and Assessment Tools', using the RNAO's Best Practice Guideline pain

assessment recommendations, CP specific practice points and tools sourced from a systematic review. This toolbox is currently being implemented in outpatient clinics in the Child Development Program at Holland Bloorview.

#### The toolbox consists of:

- Pain assessment recommendations from the 2013 RNAO [Best Practice Guideline](#)
- Practice care points specific to children with CP developed by experts at Holland Bloorview
- Seven assessment tools to look at the impact of chronic pain on a child's everyday activities.

Every child can participate in a pain assessment during rehabilitation therapy. The tools in the toolbox are accessible to children with a range of communication abilities.

Over the first six months of toolbox use at Holland Bloorview, 115 clients with CP, ages 1 - 18 years, have had their pain formally assessed and documented in three rehabilitation outpatient clinics. What Evidence to Care has recorded is in-line with existing statistics about the prevalence of pain for children with CP:

- Over a quarter of the children assessed in clinic have pain;
- Of those with pain, the most common type of pain was chronic; and
- The tool most frequently used was developed for non-verbal children, indicating that a standardized tool for this level of communication ability was helpful.

Initial feedback from the clinicians implementing the toolbox indicates that it has influenced the standardization of their pain assessment practice.

We would like to thank Dr. Darcy Fehlings and Lauren Switzer from Holland Bloorview Kids Rehabilitation Hospital for their comments and suggestions to this newsletter.



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One clinician stated that:

*"Because of this particular tool, the child was able to express their pain experience more accurately and the team realized that the child's pain was having a significant impact on important activities in a way that we may not have initially expected."*

This toolbox will be rolled-out to other CP and non-CP clinics at Holland Bloorview to ensure that every child can benefit from this work.

Stay Tuned for updates!

\*Knowledge Translation: is about bringing the right information in the right format to the right people at the right time to have an impact on decision-making.<sup>13</sup>

**More Information**  
**Connect with the Evidence to Care**  
**to find out more about this exciting**  
**project and access the toolbox!**  
[www.hollandbloorview.ca/toolbox](http://www.hollandbloorview.ca/toolbox)

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