

Functioning, Disability and Health framework. Noble et al. employed several CP-specific CDEs within the 4th domain of Neuromotor Skills and Functional Assessments: Gross Motor Function Classification System, a 66-item Gross Motor Function Measure, Selective Control Assessment of the Lower Extremity,<sup>4</sup> and Modified Ashworth Score. Version 1.0 of the CP-specific CDEs is now available in *Developmental Medicine & Child Neurology*.<sup>3</sup> It is anticipated that global use of CDEs will help standardize data collection, improve data quality, and facilitate comparisons across studies. By their use of CP-specific CDEs the investigators have done just that.

Results of the study indicate that impaired SMC contributes substantially to gross motor function in children with spastic CP. Impaired SMC occurs when flexor or extensor synergies interfere with isolated joint movements, resulting in impaired functional movements, such as failure to fully extend the knee before initial contact during gait (Fig. 1).<sup>2,5</sup> Children with spastic CP demonstrate consistent coactivation of

quadriceps and gastrocnemius on electromyography<sup>2,5</sup> and reduced complexity of neuromuscular control during gait compared with unimpaired individuals, based on calculation of muscle synergies during gait. Recent studies suggest that spared extrapyramidal motor tracts, such as the rubrospinal tract, may provide imperfect compensation in recovering motor function.<sup>2,5</sup> The rubrospinal tract is thought to mediate flexion and extension movements and is prominent in typically developing infants, but not in children or adults. However, in the case of acute or chronic stroke, the rubrospinal tract develops, yielding characteristic impaired SMC movement patterns post-corticospinal tract injury.<sup>2</sup>

The unique systematic approach by Noble et al.<sup>1</sup> quantifies neuromuscular deficits and examines their influence on motor function in CP. This offers a promising model for further research that can reveal links between neurological injury, neuromuscular deficits, and specific movement abnormalities; knowledge that is essential to developing effective treatment for children with CP.

## REFERENCES

1. Noble JJ, Gough M, Shortland AP. Selective motor control and gross motor function in bilateral spastic cerebral palsy. *Dev Med Child Neurol* 2019; **61**: 57–61.
2. Zhou J, Butler EE, Rose J. Neurologic correlates of gait abnormalities in cerebral palsy: implications for treatment. *Front Hum Neurosci* 2017; **11**: 103.
3. Schiaviti V, Fowler E, Brandenburg JE, et al. A common data language for clinical research studies: the National Institute of Neurological Disorders and Stroke and American Academy for Cerebral Palsy and Developmental Medicine Cerebral Palsy Common Data Elements Version 1.0 recommendations. *Dev Med Child Neurol* 2018; **60**: 976–86.
4. Fowler EG, Staudt LA, Greenberg MB, Oppenheim WL. Selective Control Assessment of the Lower Extremity (SCALE): development, validation, and interrater reliability of a clinical tool for patients with cerebral palsy. *Dev Med Child Neurol* 2009; **51**: 607–14.
5. Cahill-Rowley K, Rose J. Etiology of impaired selective motor control: emerging evidence and its implications for research and treatment in cerebral palsy. *Dev Med Child Neurol* 2014; **56**: 522–8.

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# Can pain assessment tools accurately measure pain experience of disabled individuals?

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Identifying the best method for assessing pain is perhaps most challenging for individuals with cognitive impairment or physical disability, given differences in verbal and body language capabilities. Pain assessment tools meant to most closely reveal the degree of pain experienced by these individuals have been developed to include behaviors commonly associated with pain. The most common observable pain responses include vocalization, social behaviors and facial expression, and (less so) bodily activity and movements.<sup>1,2</sup> These behaviors become exaggerated when pain

is severe and lessen as pain is relieved, thus permitting the scoring of pain severity. Importantly, observable behaviors become less reliable as pain persists over time and as children age and can dampen their distress responses. Additionally, observable pain behaviors are often present in children even when there is no evidence of a pain stimulus, indicating other sources of distress. Similarly, children often report some degree of pain intensity even during ‘no-pain’ conditions. Together, these data suggest that interpreting pain behaviors and self-reported pain intensity scores is fraught with potential confounders.

Findings from the study by Fox et al.<sup>3</sup> describe some of the problems with behavioral observation that have been previously demonstrated, as well as new considerations. Specifically, their data suggest that scores derived from the validated revised Face, Legs, Activity, Cry, and Consolability (r-FLACC) instrument<sup>4</sup> correlate only moderately with

self-reported pain intensity scores of adults with cerebral palsy (CP). Fox et al.<sup>3</sup> also found only moderate reliability of r-FLACC scores between raters who viewed videotapes stripped of all verbal content, and thus not likely to have included the important 'Cry' or verbal category. These investigators describe confounders (including spasticity) that likely impact reliability and interpretability of observed behaviors in individuals with CP.

Similarly, in their original work, Malviya et al.<sup>4</sup> found lower interrater agreement for the r-FLACC categories of Legs and Activity in children with spasticity, but also found highest agreement for the Face and Cry categories and good overall interrater reliability. Others have also found excellent interrater reliability in younger children with CP (intraclass correlation coefficient 0.75).<sup>5</sup> Additionally, r-FLACC scores have been found to be very responsive to procedural pain and treatment conditions (i.e. scores increased on average by 2.23 points after surgery<sup>5</sup> and decreased 4.2 points after analgesia<sup>4</sup>). Together with data from other similar observational scales, such findings suggest that observed distress behaviors can provide an indication of pain severity and response to treatment.

The r-FLACC and other measures<sup>1</sup> have been adapted to address individual variations in pain expression. These individualized scales have higher reliability between parents and nurses, and excellent responsiveness to analgesic intervention compared to observational scales, including the original FLACC, that do not address the child's personal expressions.<sup>2</sup> Still, these scales are not perfect and are not necessarily specific to pain states.

It is now well-recognized that pain intensity scales cannot capture the complexity of the pain experience. Single scores taken out of context have no clinical meaning – particularly observational scores obtained in children whose baseline behaviors are considered abnormal (e.g. spasticity). Changes in pain scores may have more meaning but must still be considered as only one aspect of pain assessment. Behavioral pain intensity scores can provide an indication of distress which may or may not be pain and are thus insufficient to diagnose or guide care. Pain assessment is an imperfect science and scores derived from *any* pain scale must be interpreted with caution and in the context of many other factors. The search for a perfect tool is thus a search in vain.

## REFERENCES

1. Solodiuk JC. Parent described pain responses in nonverbal children with intellectual disability. *Int J Nurs Stud* 2013; **50**: 1033–44.
2. Voepel-Lewis T, Merkel S, Tait AR, Trzcinka A, Malviya S. The reliability and validity of the Face, Legs, Activity, Cry, Consolability observational tool as a measure of pain in children with cognitive impairment. *Anesth Analg* 2002; **95**: 1224–9.
3. Fox MA, Ayyangar R, Parten R, et al. Self-report of pain in young people and adults with spastic cerebral palsy: interrater reliability of the revised Face, Legs, Activity, Cry, and Consolability (r-FLACC) scale ratings. *Dev Med Child Neurol* 2019; **61**: 69–74.
4. Malviya S, Voepel-Lewis T, Burke C, Merkel S, Tait AR. The revised FLACC observational pain tool: improved reliability and validity for pain assessment in children with cognitive impairment. *Paediatr Anaesth* 2006; **16**: 258–65.
5. Pedersen LK, Rahbek O, Nikolajsen L, Møller-Madsen B. The revised FLACC score: Reliability and validation for pain assessment in children with cerebral palsy. *Scand J Pain* 2015; **9**: 57–61.

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## Dealing with a first seizure: accurate diagnosis and good management

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Fear and dread are never far from the bedside of a child presenting to the emergency department with their first seizure.<sup>1</sup> Once the acute event has settled, careful counselling is needed. Whilst febrile seizures are often well managed, counselling regarding seizure recurrence and risk of epilepsy after the first seizure is not universally well

done. It is the senior paediatrician or the paediatric neurologist who often steps in as the 'final' arbiter.

Although there is an abundance of reviews and guidelines on management of the first seizure,<sup>2</sup> the classic epidemiological studies of first seizure are often in combined populations of adults and children, concentrating on either febrile seizures or unprovoked seizures.<sup>3</sup> The study of Sartori et al.<sup>4</sup> is a welcome addition to the literature and acts as a 'real-world' guide for those of us who must counsel families after the child's first seizure. The present study is a follow-up retrospective of all children under 16 years presenting to an urban emergency department, over a 12-month period with first-ever convulsive seizure. Health care workers in European cities will be familiar with the