Background and Rationale

- A higher prevalence of pain has been reported in children and youth with cerebral palsy (CP) compared to children without disabilities.
- Previous studies examining pain in children and youth with CP have been cross-sectional and no longitudinal studies have examined the stability of pain over time.
- The primary objective of this study was to evaluate the presence and stability of pain in an out-patient population of children/youth with CP over two time-points separated by at least 6 months.
- Primary Research Question: What is the stability of physician and caregiver rated pain presence or absence in children and youth with CP over time?
- Secondary Objectives: To compare self-rated pain between the two time-points. To examine characteristics of pain stability/instability. To examine the clinical causes of pain.

Methods and Analyses

Participant Selection
- Children/youth with CP (aged 3-19) and their caregivers were recruited consecutively from outpatient clinics at Holland Bloorview Kids Rehabilitation Hospital and were interviewed at two time-points separated by at least 6 months.

Physician Rated Pain Measures
- Physician identified pain presence/absence and clinical cause of pain (if applicable).

Caregiver Rated Pain Measures
- Pain subset of the Health Utilities Index 3 Dichotomized (Figure 1).

Participant Rated Measures
- Wong-Baker Faces Pain Scale Dichotomized (Figure 2).

Methods Continued...

Statistical Analyses
- Statistical analyses were conducted using SPSS Statistics v 17.0. All tests were two-tailed, with the significance level, alpha set at 0.05.

Primary Analyses
- Physician and caregiver HUI3 dichotomized pain ratings at the two time-points were compared using McNemar Chi Square tests.

Secondary Analyses
- Wong-Baker Faces Pain Scale dichotomized ratings were compared between visits using McNemar Chi Square test.
- Categories of physician rated pain stability/instability and clinical causes of pain were examined using descriptive statistics.
- To examine characteristics of the pain groups, age and time between visits were compared using ANOVA and GMFCS levels were compared using Pearson’s Chi Square Test.

Results

- 101 children/youth with a mean age of 8.3 (SD 3.7) years participated in the study (response rate 72%), with 71 (70%) males and 30 (30%) females, across all GMFCS levels (Levels I: 21%, II: 13%, III: 34%, IV: 13%, V: 19%). Mean time between visits was 20.5 months (range 6-33 months).

Primary Analyses
- Physician pain ratings were increased at the second time-point [visit 1: 34 (35%); visit 2: 41 (42%); McNemar Chi Square p=0.04], (Figure 3).
- Caregiver ratings of pain (HUI3) were increased at the second time-point [visit 1: 21 (21%); visit 2: 26 (26%); McNemar Chi Square p=0.001], (Figure 3). Self-rated pain (Wong-Baker Faces) was decreased at the second time-point [visit 1: 14 (26%), visit 2: 11 (17%); McNemar Chi Square p=0.001], (Figure 3).

Secondary Analyses
- Classification based on the stability of physician rated pain (Figure 4).
- 61 (64%) had no change in pain presence/absence:
  - 22 (22%) pain → pain
  - 39 (42%) no pain → no pain
- 34 (36%) had unstable pain:
  - 13 (14%) pain → no pain
  - 21 (22%) no pain → pain

Conclusions and Relevance

- This is the first longitudinal study to demonstrate that 1 in 5 children and youth with CP experience persisting pain lasting 6-33 months.
- An additional 1 in 5 children and youth who were initially pain free had developed new pain at the second time point.
- These findings highlight the importance of ongoing assessment and treatment of persisting pain and the prevention of musculoskeletal related pain due to hyper tonia, muscle spasms and hip subluxation/dislocation in children and youth with CP. Improved detection and intervention of pain in children and youth with CP may ameliorate the negative consequences of daily functioning and improve health related quality of life.
- An increase in physician and caregiver pain ratings at the second visit may reflect the development of new pain or an improvement in the assessment and detection of pain.
- A decrease in participant self-rated pain scores may be a due to the small number of children who were able to self-report, and this finding could have been strengthened with a larger sample.
- Children with CP who are in higher GMFCS levels are more likely to experience persisting pain.

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