

Characteristics of Pain in Children and Youth With Cerebral Palsy

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KEY WORDS

pain, cerebral palsy, pediatrics

ABBREVIATIONS

CP—cerebral palsy

GMFCS—Gross Motor Function Classification System

HUI3—Health Utilities Index 3

MSK—musculoskeletal

Dr Penner conducted initial analyses, interpreted the data, and drafted the initial manuscript; Ms Xie carried out data collection and the initial analyses, drafted the initial manuscript, and contributed equally with Dr Penner on the development of this manuscript; Dr Binopal drafted the data collection instruments and drafted a component of the manuscript; Ms Switzer designed the data collection instruments, coordinated and supervised data collection, and critically reviewed the manuscript; Dr Fehlings conceptualized and designed the study, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

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WHAT'S KNOWN ON THIS SUBJECT: Pain in children with cerebral palsy is underrecognized and undertreated and negatively affects quality of life. Communication challenges and multiple pain etiologies complicate management. There is a wide range of pain prevalence reported in the literature (14% to 73%).



WHAT THIS STUDY ADDS: The impact of pain on activities in children with cerebral palsy across a wide age range and motor abilities is investigated. Physician-identified causes of pain are systematically assessed and reported. Concordance of physician and caregiver identification of pain is evaluated.

abstract

OBJECTIVES: Pain in children with cerebral palsy (CP) is underrecognized, undertreated, and negatively affects quality of life. Communication challenges and multiple pain etiologies complicate diagnosis and treatment. The primary objectives of this study were to determine the impact of pain on activities and to identify the common physician-identified causes of pain in children and youth ages 3 to 19 years across all levels of severity of CP.

METHODS: The study design was cross-sectional, whereby children/youth aged 3 to 19 years and their families were consecutively recruited. The primary caregivers were asked to complete a one-time questionnaire, including the Health Utilities Index 3 pain subset, about the presence and characteristics of pain. The treating physician was asked to identify the presence of pain and provide a clinical diagnosis for the pain, if applicable.

RESULTS: The response rate was 92%. Of 252 participants, 54.8% reported some pain on the Health Utilities Index 3, with 24.4% of the caregivers reporting that their child experienced pain that affected some level of activities in the preceding 2 weeks. Physicians reported pain in 38.7% and identified hip dislocation/subluxation, dystonia, and constipation as the most frequent causes of pain.

CONCLUSIONS: One-quarter of our sample experienced pain that limited activities and participation. Clinicians should be aware that hip subluxation/dislocation and dystonia were the most common causes of pain in children/youth with CP in this study. Potential causes of pain should be identified and addressed early to mitigate the negative impact of pain on quality of life. *Pediatrics* 2013;132:e407–e413

Pain in children and youth with cerebral palsy (CP) is poorly understood and is consequently underrecognized and undertreated. Studies have shown that children with CP and pain are less likely to participate in life situations and have a lower quality of life.^{1,2} Although clinicians are responsible for identifying and treating pain, communication challenges of the child with CP and multiple pain etiologies often complicate this process.³

Pain in children and youth with CP is reported in the literature by 14% to 73% of caregivers and in 60% of subjects who can self-report.⁴⁻⁶ Kennes et al⁶ reported on quality of life of a community-based sample of 408 children with CP aged 5 to 10. The pain subset of these data showed that 9.6% had pain that limited their daily activities. A subsequent study on 230 of these subjects in adolescence showed a significant association between intensity of pain and interference with activities.⁷ One smaller study on 77 ambulatory children with CP found that 33% were limited by their pain.⁸ Presently, no studies exist focusing on the impact of pain on activities and participation in children and youth with CP across a broad range of age and motor abilities (ambulatory and nonambulatory). One of the major problems in identifying pain in individuals with CP is the heterogeneity of possible contributors to pain.⁹ Parkinson et al⁵ found that risk factors for pain in this population include severity of motor impairment, seizures, and parental unemployment. No published work has focused on evaluating clinical causes of pain; such work would provide clinicians with information on the sources of pain to help prioritize investigations and treatments.

Regardless of the challenge, physicians aim to correctly identify and treat pain; however, no data exist surveying the accuracy of physician assessment of

the presence of pain in children and youth with CP. In a study of nonverbal patients, Stallard et al¹⁰ found that 67% of participants had moderate to severe pain, yet none were receiving active treatment. This underrecognition and undertreatment of pain may limit participation and negatively affect quality of life.^{2,3}

The primary objectives of this study were to determine the impact of pain on activities and to identify the physician-identified causes of pain in an outpatient population of children and youth with CP. Secondary objectives included assessing the concordance between physician and caregiver reports of pain, and examining the relationship between pain and age and pain and gross motor capabilities as measured by the Gross Motor Function Classification System (GMFCS).¹¹

METHODS

The study design was cross-sectional. Ethical approval for this study was obtained from the Holland Bloorview Research Ethics Board and participants and/or their caregivers provided written informed consent.

Participants and Procedures

Children/youth with CP, aged 3 to 19 years of age, and their families were identified and recruited consecutively through outpatient clinics at Holland Bloorview Kids Rehabilitation Hospital, a tertiary rehabilitation center. The primary caregivers and participants (if able) were asked to complete a one-time questionnaire about the presence of pain and pain characteristics if applicable. After assessing the child, the treating physician was asked about the presence or absence of pain and to provide a clinical diagnosis for the pain, if present. The participants' health records were reviewed and their GMFCS levels and age were recorded.

Presence of Pain and Pain Characteristics

The primary measure of pain was the pain attribute of the Health Utilities Index 3 (HUI3), a measure of generic health status and quality of life.¹² The HUI3 pain attribute has 5 levels that describe the severity of pain as it relates to disruptions or limitations to normal daily activities. It ranges from 1, "no pain," to 5, "severe pain that prevents most activities." The HUI3 pain attribute was reported by the participants' caregivers. The caregivers were also asked a yes/no question about the presence or absence of pain in the past 2 weeks, completed a pain location body diagram, and identified any pain medications taken in the last 2 weeks. If able, the children and youth were asked to complete the Wong-Baker Faces Pain Scale and identify the face that best described how much pain he or she felt over the past 2 weeks.¹³ The Wong-Baker Faces Pain Scale has 6 gender-neutral faces that range from no pain (0) to a score of 5, representing the most pain possible.

Clinical Diagnosis for Pain

The outpatient physician was asked to report on whether the participant experienced pain and, if present, to designate the main cause of pain and to identify multiple causes, if applicable.

Statistical Analysis

Data analyses were completed by using SPSS version 19 (SPSS Inc, Chicago, IL). Descriptive statistics were used for frequency descriptions of demographic characteristics, percentages, and frequencies of the HUI3 and Wong-Baker Faces Pain Scale scores, and of the common clinical causes of pain in children and youth with CP. These data were then subdivided into groups to determine the common clinical causes of pain in those who were experiencing moderate/severe pain (HUI3 levels 4

and 5) and in ambulatory and non-ambulatory participants. To assess concordance between physician and caregiver reports of pain, Cohen's κ coefficient was used. For this analysis, HUI3 scores were dichotomized, where HUI3 levels 1 or 2 represented "no pain impacting on activities" and HUI3 levels 3, 4, or 5 represented caregiver reports of "pain impacting activities." The Goodman and Kruskal's γ statistic was used to investigate the relationship between severity of pain (as measured by the HUI3) and GMFCS level and the HUI3 and the Wong-Baker Faces Pain Scale (where available). Finally, a 1-way analysis of variance was used to explore the relationship between HUI3 scores and age.

RESULTS

Participants

A total of 274 children and families were consecutively approached, and 252 children and youth with CP were recruited (92% response rate) from outpatient clinics at Holland Bloorview Kids Rehabilitation Hospital between July 2010 and August 2012. The mean age was 9.5 ± 4.2 years. There were a total of 161 boys (63.9%) and 91 girls (36.1%). Motor abilities ranged across all GMFCS levels: I, 24.1%; II, 13.2%; III, 20.9%; IV, 18.5%; and V, 23.3%.

Caregiver Report of Pain

The results of the HUI3 pain subset are outlined in Fig 1. A total of 54.8% ($n = 137$) reported some pain (HUI3 levels 2–5), with 24.4% ($n = 61$) of the caregivers reporting that their child experienced pain that affected some level of activities in the last 2 weeks (HUI3 levels 3–5). When caregivers were asked a yes/no question about the presence of pain, 55.6% ($n = 139$) of caregivers reported that their child experienced some level of pain in the 2 weeks before their clinic visit.

Of the 136 children (54.0%) whose caregivers identified pain on the pain

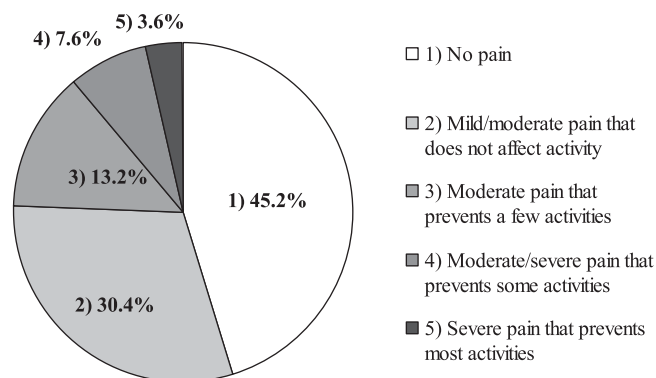


FIGURE 1

Distribution of caregiver reports of pain on the HUI3 Pain Subset.

location body diagram, 82% ($n = 112$) of children had pain in their lower limb(s), 19% ($n = 26$) had pain in their upper limb(s), 14% ($n = 19$) had pain in their back, and 11% ($n = 15$) had pain in their abdomen. Finally, 10% ($n = 13$) of children had pain in their head/neck area (neck/throat pain, headaches, ear infections, and insect bites).

Twenty percent ($n = 51$) reported that their child used pain medication within the last 2 weeks, with 2.4% ($n = 6$) identifying >1 pain medication. Of those taking pain medication, 59% ($n = 30$) of children took non-narcotic analgesics (eg, acetaminophen), 51% ($n = 26$) took nonsteroidal antiinflammatory drugs, and 2% ($n = 1$) took narcotic analgesics (tramadol and acetaminophen with codeine).

Participant Self-Report of Pain

A total of 49.6% ($n = 125$) of children and youth were able to self-report their levels of pain using the Wong-Baker Faces Pain Scale. This sample of self-reporting participants was characterized as 55% boys ($n = 69$), 78% ambulatory ($n = 98$) (GMFCS levels I–III), and had a mean age of 11.2 ± 3.7 years. Forty-seven percent ($n = 59$) reported some pain (Faces scores of 1, "Hurts a little bit" to 5, "Hurts worst"). The correlation between participant self-report and parental report of pain (as measured by the HUI3) was good

(Goodman and Kruskal's γ statistic = 0.57; $P < .001$).

Physician Report of Pain

Physicians reported pain in 38.7% ($n = 94$) of the participants. Table 1 outlines the physician-identified primary causes of pain in the cohort. The most frequently identified cause of pain by physicians was hip dislocation/subluxation (16%) followed by dystonia (12%). Table 2 outlines the physician-identified causes of pain in participants who were experiencing moderate to severe pain preventing some or most activities (HUI3 levels 4 and 5; 11.2%, $n = 28$). Of these 28 participants, 25 had physician diagnoses of pain and the remaining 3 were not identified as having pain by the physician. Hip dislocation/subluxation (24%) and dystonia (16%) were also the top 2 physician-identified causes of pain. In participants who were identified by physicians as having pain, 66% were identified to have 1 primary cause for the pain, 26% had an additional cause, and 8% had multiple pain etiologies. The most frequently identified cause of pain by physicians in children and youth who were ambulatory (GMFCS levels I–III) were focal muscle spasms (16%), muscle weakness/overuse/fatigue (16%), and an abnormal gait pattern (11%). Pain in nonambulatory participants (GMFCS levels IV and V) was

TABLE 1 Physician-Identified Primary Causes of Pain

Physician-Identified Primary Cause of Pain	Prevalence, % (n)
Hip dislocation/subluxation	16 (15)
Dystonia	12 (11)
MSK deformity ^a	11 (10)
Constipation	9 (8)
Focal muscle spasm ^b	9 (8)
Muscle weakness/overuse/fatigue	9 (8)
Spasticity	9 (8)
Abnormal gait pattern	6 (6)
Muscle contractures	6 (6)
Other ^c	6 (6)
Postoperative MSK pain from orthopedic surgery	4 (4)
Gastroesophageal reflux	3 (3)
Pain related to falls	1 (1)

^a MSK deformity excludes hip dislocation/subluxation and muscle contractures, which are listed separately and include foot and hand deformity, scoliosis, and lumbar lordosis.

^b Focal muscle spasm was identified by physicians if the child reported a focal area of tenderness in 1 or 2 muscles.

^c "Other" causes of pain include muscle soreness after massage therapy, seizures, headaches, knee bursitis, and osteomyelitis.

TABLE 2 Physician-Identified Primary Causes of Pain in Children and Youth Experiencing Severe Pain (HUI3 Levels 4 and 5)

Physician-Identified Primary Cause of Pain	Prevalence, % (n)
Hip dislocation/subluxation	24 (6)
Dystonia	16 (4)
MSK deformity	12 (3)
Gastroesophageal reflux	8 (2)
Postoperative MSK pain from orthopedic surgery	8 (2)
Constipation	8 (2)
Muscle contractures	8 (2)
Other ^a	8 (2)
Abnormal gait pattern	4 (1)
Focal muscle spasms	4 (1)

^a "Other" causes of pain include osteomyelitis and wrist pain from falling.

attributed to hip dislocation/subluxation (27%), dystonia (17%), and constipation (15%).

The interrater agreement (κ statistic) between the physician report of pain and caregiver-completed HUI3 pain subset score was $\kappa = 0.42$ ($P < .001$), and between physician report of pain and the yes/no caregiver question about presence of pain in the past 2 weeks was $\kappa = 0.42$ ($P < .001$). In

further analysis of the HUI3 data, the physician identified pain in 11 participants (4.4%) when the caregiver did not. In 44 participants (17.4%), the caregiver identified pain when the physician did not. In 33 (75%) of these 44 participants, caregivers had identified pain in their child's limb(s) (arm or leg) on the pain location body diagram. A one-way analysis of variance indicated a significant positive relationship between age and severity of pain as reported by the HUI3 subset ($F = 2.99$, $P = .02$). The correlation (Goodman and Kruskal's γ statistic) between the HUI3 and GMFCS level was 0.36 ($P < .001$) (Fig 2).

DISCUSSION

Our results show that 1 in 4 children and youth with CP experience moderate to severe pain that limits activities with hip subluxation/dislocation and dystonia identified as the commonest causes. In addition, close to 4% of children/youth with CP were experiencing severe pain that prevented most activities despite being actively followed in a tertiary rehabilitation center. Our findings compare with a smaller study by Tervo et al⁸ ($n = 77$) who found one-third of ambulatory children with CP were limited by their pain. To our knowledge, this is the only study reporting on pain in children/youth with CP that includes all GMFCS levels paired with a wide age range spanning preschool to late adolescence. In addition, it is the only study to date that links pain assessment with a concomitant physician-diagnosed cause of pain. Clinicians need to be aware of the common causes of pain in this population to expedite the investigation and treatment of pain, or to prevent pain where possible.

Many musculoskeletal (MSK) and neurologic conditions were identified as the primary cause of pain, including hip dislocation/subluxation, dystonia, spasticity, focal muscle spasms, contractures,

and muscle weakness/overuse/fatigue. It is important to note that there is overlap in many of these conditions. For example, long-standing spasticity is associated with the development of contractures and the presence of focal spasticity or dystonia can create a focal muscle spasm. Our study also identified that more than 12% of our population experienced multiple sources of pain, highlighting the complexity of pain assessment in individuals with CP. Additional sources of pain should be sought, especially when the patient is not having the expected response to treatment.

Studies have shown that hip subluxation/dislocation is associated with chronic pain, with full dislocation representing a preventable complication of CP.^{14,15} Hip surveillance programs consisting of routine hip x-rays help to identify subluxation and allow for a range of interventions, such as stretching, hip abduction bracing, botulinum toxin, and orthopedic surgery, before hip dislocation and chronic pain develop.¹⁶ Evidence from this study suggests that hip subluxation should routinely be assessed and, if present, management strategies should be actively introduced. This should include a focus on early parent education, particularly concerning surgical options to allow families to make a timely informed decision about proceeding with orthopedic surgery if required, to prevent progression to full hip dislocation and chronic pain.

Dystonia remains an important cause of pain that should be recognized and diagnosed. The Hypertonia Assessment Tool can be easily used by clinicians to accurately identify dystonia and distinguish it from other forms of hypertonia, such as spasticity.¹⁷ In our study, dystonia was identified more frequently than spasticity or focal muscle spasms as the primary cause of pain. A number of treatments exist for dystonia, ranging

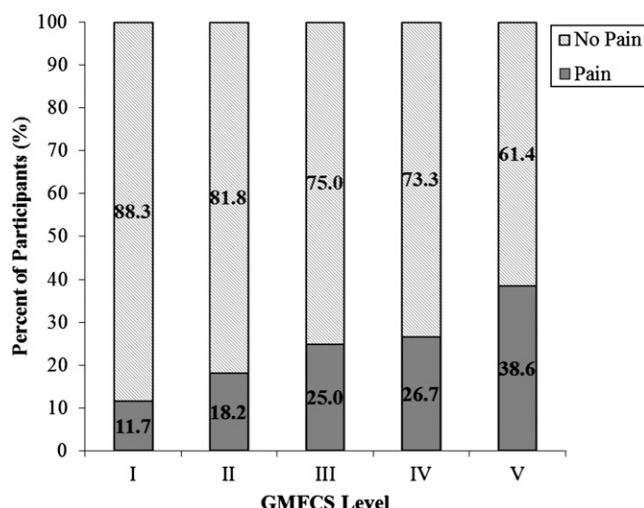


FIGURE 2

Amount of participants experiencing pain as reported by HUI3 distributed by GMFCS level. Kruskal and Goodman's $\gamma = 0.36$ ($P < .001$).

from oral medication (trihexyphenidyl, baclofen), botulinum toxin, intrathecal baclofen pumps, and, more recently, deep brain stimulation, to help prevent children from becoming “stuck” in painful postures.^{18–21} Response to treatment of dystonia is often variable and patient-specific. Therefore, developing and enhancing the effectiveness of treatments for dystonia is a high priority for future research.

It is important to note that many of the common causes of pain have specific treatments. Initial treatment of the symptoms of pain with analgesia may be useful to determine whether pain is present in children with communication difficulties; however, whenever possible, a treatment aimed at the etiology of pain is preferred. An excellent example of this is constipation, which was the primary cause of pain in nearly 10% of our population. Through treatments, such as polyethylene glycol, constipation can be effectively and safely treated.²²

In our study, there was a strong relationship between child/youth self-report and that of their caregivers. In contrast, the physician detection of pain showed only fair agreement with caregiver reports of pain. Seventeen percent of our participants were

identified by the caregiver but not the physician as having pain, with most of these participants having pain in their limbs (as identified on the pain location body diagram). This suggests that most pain that is missed by physicians is MSK in origin. These results highlight the need for improved clinician awareness and assessment of the presence of pain in children/youth with CP.

Previous studies have shown an inconsistent relationship between the severity of the physical disability (as measured by the GMFCS) and the experience of pain.^{5,6,23} Our results show a fair correlation between the GMFCS level and pain that affects activities. Intuitively, more severe CP leads to potential sources of pain throughout the body, as well as higher rates of MSK deformity, including hip subluxation. We also found a significant relationship between age and severity of pain on the HUI3. From a clinical perspective, many of the identified causes of pain, such as MSK deformity, have a progressive natural history, which may help to explain the increased frequency of pain with age.

Our group has found that asking about pain in the context of its impact on activities has proven an efficient tool to discriminate children and youth with CP

who are in pain from those who are not and gauge its severity. The experience of pain is individualized, as is the caregiver's interpretation of painful behaviors, especially in nonverbal children, which may include symptoms/signs, such as frequent night awakenings, irritability with feeding, facial grimacing, and crying with movement, such as diaper changes.²⁴ Pain that is significant enough to limit activities allows for a common language to communicate pain severity as well as have an impact on daily life. Additionally, this approach aligns with the World Health Organization International Classification of Functioning, Disability, and Health, in which health conditions are understood in terms of their impact on body functions, activities, and participation.²⁵

Currently, our group is evaluating pain assessment tools relevant for children and youth with CP with chronic pain syndromes that can routinely be integrated into the clinical environment. Identification of pain on screening must be followed by a thorough, systems-based history and physical examination, with special attention to common sources of pain, such as hip subluxation/dislocation and dystonia. It is also important to note that sources of pain, such as ear pain and headaches, common in typically developing children, can also be seen in children and youth with CP.²⁶

Our study has some important limitations. The cross-sectional nature of the study design provides a snapshot of our population and does not permit analysis of how the experience and impact of pain changes with time. In addition, our participants are drawn from outpatient clinics rather than a community sample. This may elevate the reports of pain. The physicians were aware of the study and this may have given them a bias toward identifying pain. The identification of pain in children and youth with CP by physicians in

practice may be lower. The gold standard for pain measurement is always self-report; however, the inclusion of nonverbal children and children with intellectual disabilities necessitated caregiver reports of pain. We chose to use the HUI3 pain subset to evaluate the impact of pain, although this subset has not yet been validated for use apart from the complete HUI3 questionnaire. A limitation of this tool is the inability to determine whether pain limits the activity level or if activity triggers more pain. Also, our decision to use a score of 3 on the HUI3 ("moderate pain that prevents a few activities") as the level to dichotomize our data were subjective, but fit with our aim to report on clinically significant pain causing activity limitations.

In conclusion, one-quarter of our sample of children and youth with CP experienced pain that limited activities and participation. Potential causes and risk factors for pain should be identified and addressed early to mitigate the negative effects of pain on daily activities and well-being. Clinicians should be aware that hip subluxation/dislocation and dystonia are among the most common causes of pain in children/youth with CP. Research by this group is currently under way to evaluate the effectiveness of interventions to relieve pain in children with CP and improve their quality of life.

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