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Original article

Prevalence of pain in 240 non-ambulatory children with severe cerebral palsy



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ARTICLE INFO

Article history:

Received 14 October 2016

Accepted 28 March 2017

Keywords:

Cerebral palsy

Pain

Children

ABSTRACT

Background: Several studies have given frequencies of pain in children with cerebral palsy, but comparing the findings is difficult. We aimed to estimate the prevalence of pain in non-ambulatory children with cerebral palsy and describe their characteristics by presence or absence of pain.

Methods: Data were extracted from an ongoing longitudinal national cohort following non-ambulatory children with severe cerebral palsy aged 3 to 10 years over 10 years. We described and compared data for the first 240 children at inclusion by presence or absence of pain. Pain was assessed by a visual analog scale and the Douleur Enfant San Salvador scales and by investigator interview.

Results: Overall, 65 children experienced pain, for a prevalence of 27.1% (95% confidence interval 22–33%). All children experiencing pain had orthopaedic pain and 45.6% had pain from another origin. The main pain sites were hips (43.4%) and feet (26.9%). Joint mobilisation was the source of pain for 58.3% of children experiencing pain, and sitting was identified as painful for 10.3%. Pain was greater with scoliosis (43.1% vs 24.1% with and without pain; $P = 0.006$) and spasticity treatment (32.3% vs 17.2%; $P = 0.020$).

Conclusion: Children with cerebral palsy frequently experience pain and also early pain, mostly articular and orthopedic. The assessment of pain should be systematic because of its high prevalence. Interventions to prevent scoliosis, hip luxation, and foot deformities and to reduce spasticity, such as the use of analgesics before joint mobilization exercises, may reduce the prevalence of this pain.

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1. Introduction

Cerebral palsy (CP) is a group of disorders that occurs in 2 to 3 per 1000 live births [1]. This group includes permanent disorders of motor function (movement, muscle control, posture, and/or balance) due to a non-progressive injury or malformation that affects the immature brain before, during, or immediately after birth. Among the children with CP who do not acquire the ability to walk (levels IV or V of the Gross Motor Function Classification System [GMFCS]) [2], one third would have a high risk of orthopaedic contractures, especially hip dislocation, scoliosis, knee flexum, and foot deformities (equinus, with or without varus or valgus) [3]. In these children, pain is frequent, sometimes triggered or aggravated by care, and may affect the quality of life of children and their families [3].

The assessment of pain in these children is encouraged and involves questioning children and their families. The Fondation Motrice, in partnership with family associations, carried out the first major national survey (ESPaCe; (<http://www.fondationparalysiecerebrale.org/>)) to give children and adults with CP and their families the opportunity to discuss motor rehabilitation practices so as to appreciate their content and feelings, especially painful experiences.

Several studies have given frequencies of pain in people with CP, but comparing the findings is difficult. Indeed, the prevalence of pain in CP is not the same in young children as in teenagers or young adults: it increases with age [4,5] and disease severity [6,7]. In the current literature, the frequency of pain ranges from 14% to 70% depending on the characteristics of pain, how pain is defined, and the study population [8–14]. Specifically, some studies showed very different pain prevalence values because of wide age ranges: 11% of pain prevalence in 198 children aged 5 to 18 years [10], 62% in 153 children aged 8 to 18 [14], 56% in 73 children aged 4 to 18 [11], and 78% in 94 children aged 4 to 18

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[6]. As well, other studies had very wide-ranging disease severities (GMFCS levels): the whole spectrum of severity in studies by Kennes et al. [12] and Ramstad et al. [14] and GMFCS levels III to V in another study [10]. In the study by Kennes et al. [12], the prevalence in young children aged 5 to 13 years was 14%, but the study considered the whole spectrum of disease severity and the pain was declared by the parents. Finally, some studies gave prevalence values for small samples: 70% in only 20 children [8] or 34.9% in 19 children [9].

The aim of this present study was to estimate the prevalence of pain among a homogeneous population of young and non-ambulatory children with CP and to identify the factors associated with a high risk of pain.

2. Material and methods

2.1. Sample

A multicentre national cohort study was implemented by the *hospices civils de Lyon* in September 2009 and is ongoing (385 children are expected; study title “Étude longitudinale d’une population d’enfants atteints d’une forme bilatérale sévère de paralysie cérébrale : incidence et évolution des complications orthopédiques et des douleurs en lien avec ces complications”; ClinicalTrials.gov identifier: NCT01840930). This non-interventional study involves the follow-up of children aged 3 to 10 years old at inclusion, with CP GMFCS level IV (self-mobile with limitations, assisted transportation or self-mobility with power chairs) and V (extremely limited self-mobility even with an assistive technology) over a 10-year period, at a frequency of 1 visit per year. At each visit, the investigator uses a case report form to collect clinical, orthopaedic, radiological, and environmental data. Children can be recruited by the *centre hospitalo-universitaire, centre hospitalier général, Institut médico-éducatif, Institut or Centre d’éducation motrice, Service d’éducation spéciale et de soin et à domicile, and Centre d’action médico-sociale précoce*.

The primary objective of this cohort is to measure the incidence of orthopaedic complications (scoliosis and hip joint) according to age. The secondary objectives are to describe the sequences over time of these complications and the related pain; to explore the impact of nutrition, surgery, asymmetric postures and environmental factors; and to describe the medical and rehabilitative follow-up of these children.

This prospective study was carried out in accordance with the ethical standards of the 1994 Declaration of Helsinki and was approved by the medical ethics committee of Lyon Sud Est 2. Informed consent was obtained from the parent for the inclusion and follow-up of all children.

In this present study, we extracted data from the inclusion visit for the first 240 children included in the cohort at the 51 investigator sites between September 2009 and September 2014.

3. Methods

The present study focused on pain. First, the criterion “presence of pain” was determined by a positive answer to either of the 2 following questions during the baseline visit:

- Is the child experiencing pain today or has he/she been experiencing pain during the last months?
- Does the child experience pain during joint mobilisation?

During the visit, the investigator directly posed these questions to the child’s family and to the child, if the child could communicate and was able to understand the questions. The

investigator could also question the child’s physiotherapists to take into account their experience. We also asked whether the child was given analgesics occasionally, which represented a way to better detect the criterion “presence of pain.”

Second, for children with the criterion “presence of pain,” the investigator was asked to measure the level of pain: 1) with a visual analog scale (VAS) for children able to communicate or 2) by questioning the caregivers of the other children and completing the *Douleur Enfant San Salvadour (DESS)* scale, a specific scale for non-communicating children [15].

The study also collected data related to the origin and site of pain and treatments. These data are recorded at the visit by the investigator, according to the investigator’s experience and that of the caregivers, and according to the family/child interview (when applicable). The pain to be recorded included osteoarticular pain (spine, hip, knee, foot), other pain (muscular/contractures, other than neuro-orthopedic) and painful joint mobilisations, painful sitting position.

We also extracted the GMFCS level (IV or V), the ability to communicate, and the presence of seizures, hip subluxation > 50%, scoliosis (clinical scoliosis, as evaluated by the investigator), prematurity (according to the diagnosis completed by the investigator at the inclusion visit), gastrostomy, and treatment for spasticity (lioresal [by mouth/intrathecal], rivotril, dantrium, valium, myolastan, other).

3.1. Statistical analysis

The characteristics of children are described by the mean (SD) for quantitative variables and number (%) for categorical variables. The prevalence of pain was estimated by the proportion of children identified as experiencing pain, with an exact 95% confidence interval (CI). The characteristics of children were studied in the entire cohort and by those with and without pain by Fisher’s exact test. Statistical analyses involved use of SAS v9.3. $P < 0.05$ was considered statistically significant.

4. Results

The study population included 240 children (133 boys [55.4%]) with mean age 6.79 ± 1.93 years (median 6 years and 8 months). Most children ($n = 211$; 87.9%) presented a spastic form of CP, and 69.2% ($n = 166$) were non-communicating children. Overall, 65 children experienced pain, for an estimated pain prevalence of 27.1% (95% CI 22–33%); 114 children (47.5%) were occasionally given analgesics (Table 1).

Among the 65 children with pain, the pain could be measured in 44 (67.7%) with a VAS in 8/17 (47.1%) children able to communicate and the DESS in 34/48 (70.8%) unable to communicate (Table 2). Pain measured by the VAS and DESS could not be measured in 8/17 children (47.1%) able to communicate and in 13/48 (27.1%) unable to communicate.

Table 1

General characteristics of 240 non-ambulatory children with severe cerebral palsy.

Sex	
Girls	107 (44.6)
Boys	133 (55.4)
Age (years) ($n = 239$)	
Mean	6.79 (1.9)
[Min–max]	[3.21–10.98]
Spastic cerebral palsy	211 (87.9)
No oral language	166 (69.2)
Presence of pain	65 (27.1)
	95% CI (22–33%)
Occasional analgesic treatment	114 (47.5)

Data are n (%) unless indicated.

Table 2

Pain measured in 65 communicating and non-communicating children with severe cerebral palsy who experienced pain.

	Communicating children	Non-communicating children
No. of children with pain (<i>n</i> = 65)	17 (26.2)	48 (73.8)
Pain scales		
VAS	8 (47.1)	1 (2.1)
DESS	1 (5.9)	34 (70.8)
No scale used	8 (47.1)	13 (27.1)

VAS: visual analog scale; DESS: Douleur Enfant San Salvador. Data are *n* (%).

Table 3

Pain sites for the 65 communicating and non-communicating children with severe cerebral palsy who experienced pain.

Pain site	Missing data (<i>n</i>)		
	Total	Communicating children <i>n</i> = 17	Non-communicating children <i>n</i> = 48
Back	5 (9.6)	13	3
Hip	23 (43.4)	12	3
Knee	13 (24.1)	11	2
Feet	14 (26.9)	13	3
Muscle pain/cramps	24 (43.6)	10	4
Another origin	26 (45.6)	8	4
Joint mobilisation	35 (58.3)	5	2
Sitting position	6 (10.3)	7	2

Data are *n* (%).

All 65 children with pain had pain of neuro-orthopedic origin, and 26 of them (45.6%) also had pain of another origin (8 missing data) (Table 3). The most frequent pain sites were the hips (43.4%) and the feet (26.9%). The circumstances of pain were joint mobilisation in 35/60 children (58.3%, 5 missing data). The sitting position was mentioned as painful for 6/58 children (10.3%; 7 missing data).

Among the 240 children, 8 (3.3%) were on long-term treatment for pain (Table 4). Paracetamol was used by all children; one also received level II analgesics (codeinetramadol); 52 (21.7%) received treatment for spasticity, with lioresal given to 37 of these children (71.2%; Table 4).

The proportion of girls and boys experiencing and not experiencing pain was similar (47.7% and 52.3% with pain, 43.3% and 56.6% without pain, *P* = 0.56) (Table 5). The frequency of scoliosis was greater with than without pain (43.1% vs 24.1%, *P* = 0.006). The frequency of unilateral hip subluxation >50% was also higher with than without pain but not significantly (23.3% vs 13.9%, *P* = 0.1). Treatment for spasticity was more frequent with than without pain (32.3% vs 17.2%, *P* = 0.02).

5. Discussion

In this prospective study, the prevalence of pain in 240 non-ambulatory young children with CP (GMFCS levels IV or V) aged 3 to 10 years was estimated at 27%. This prevalence is close to that found by Alriksson-Schmidt et al. in their recent study of 2777 children with CP aged 1 to 14 years, among whom 32.4% reported pain [16]. A 27% pain prevalence indicates that the problem is already important before age 10 and that preventive measures should be taken quite early [17].

The present study used 2 different scales to assess pain according to the ability of the child to communicate: VAS and DESS scales. For half of the communicating children (47.1%) and one third of the non-communicating ones (27.1%), the investigator did not measure pain probably because the children reported pain

Table 4

Analgesic medication and treatment for spasticity in the 240 non-ambulatory children with severe cerebral palsy.

Medication type	<i>n</i> (%)	<i>N</i>
Long-term treatment for pain	8 (3.3) ^a	
Level I (paracetamol, NSAID)		8
Level II (codeine, tramadol)		1
Level III (morphinic drugs)		0
Treatment for spasticity	52 (21.7) ^a	
Lioresal		37
Rivotril		13
Dantrium		3
Valium		9
Myolastan		0
Other		12

NSAID: non-steroidal anti-inflammatory drug.

^a 1 missing data.

Table 5

Characteristics of the 240 non-ambulatory children with severe cerebral palsy by presence or absence of pain.

	With pain	Without pain	<i>P</i> -value ^a
Total	65	175	
Sex			0.56
Boys	34 (52.3)	99 (56.6)	
Girls	31 (47.7)	76 (43.4)	
Non-communicating children	48 (73.9)	118 (67.4)	0.43
GMFCS level V	47 (72.3)	120 (68.6)	0.64
Subluxation > 50% on right or left hip ^b	14 (23.3)	23 (13.9)	0.10
Scoliosis ^c	28 (43.1)	42 (24.1)	0.006
Prematurity	23 (35.4)	66 (37.7)	0.77
Seizure	16 (24.6)	35 (20.0)	0.48
Gastrostomy	9 (14.5)	22 (12.8)	0.83
Treatment for spasticity	21 (32.3)	30 (17.2)	0.02

Data are *n* (%). GMFCS, Gross Motor Function Classification System.

^a Fisher's exact test.

^b Missing: 14 (5 with pain; 9 without pain).

^c Missing: 1 without pain.

during the past months or during mobilizations but were not painful at the baseline visit. The investigators were all sensitized to the problem of the difficult expression of pain in non-communicating children, so they were probably more inclined to evaluate pain systematically with a scale in non-communicating than communicating children expressing no pain.

In pain evaluation, there are 3 essential points: the presence of pain, its intensity, and its site. Regarding the first point, the investigators found no difficulties in patients giving information: only one datum was missing. Regarding pain intensity, the information could be obtained for 52% of communicating children versus 70.8% of non-communicating children. The intensity of the pain is to be measured for all patients; a hypothesis to explain this difference in gathering data can be the use of a scale to detect and assert the pain more than measuring the intensity for the non-communicating children. Indeed, in these children, the interpretation of the behaviour and the mimesis is subjective and difficult and can be supported by an objective and reproducible measure by means of a scale.

Regarding the pain site, the number of missing data reflected the difficulties investigators had in locating the pain in non-communicating children (Table 3). The missing data shown are data not reported by the investigators during the visit. For missing data, we systematically contacted the investigator to avoid any oversight in the completion of the study report. These missing data are considered by nature difficult to collect.

The description of the missing data presented in Table 3 also serves to highlight the difficulty in qualifying pain in non-communicating children in particular and the need to disseminate and develop valid assessment tools in this context.

In the present study, 47.5% of children received punctual analgesics even though the prevalence of pain was estimated at 27% in our population. This proportion of analgesics consumed reached 85.3% in the literature if the assessment of pain concerned the last 3 months [18]. In the general population, for example, in a large-scale European study, the prevalence of pain (at least once a week) in children aged 3 to 17 years was reported to be about 16% and the analgesic consumption about 8.9%. This large epidemiological study showed that the consumption of analgesics remained low in terms of the pain experienced [19], which suggests that pain is under-treated in the general population. In contrast, our results suggested a greater awareness of families and the medical profession in treating the pain of handicapped children. Thus, when pain is detected by the consumption of analgesics, the result is close to that found in the general population of children.

The orthopaedic pain concerned most often the hips (43.4% of children with pain). This result agrees with previous studies (56% in a study by Jozwiak et al. [11] and 45.2% in a study by Hodgkinson et al. [20]). The second most frequent site was the feet (26.9% among children with pain). Non-ambulatory children have usually more contractures in equinus, valgus, and varus than those who can walk and that the causes of pain are the use of orthosis or attempts to stand or move on deformed feet or immobility pain.

Joint mobilization was source of pain in 58.3% of the children experiencing pain (35/60 children; 5 missing data). All children had physiotherapy (once or twice a week) that was mainly dedicated to joint mobilisation to prevent contractures [21]. This pain related to joint mobilizations are often reported in the literature, and taking analgesic treatment before mobilizations is advised to alleviate the pain [22]. We also observed a significant relation between the presence of pain and treatment for spasticity (Table 5). Only 52/240 children (21.7%) received spasticity treatment, even though 211/240 (87.9%) had a spastic form of CP, probably because anti-spastic treatment is mainly prescribed for the most severe form of spasticity and CP. Pain is known to increase with CP severity [7,18], which well explains this link between the presence of pain and treatment for spasticity. Rarely, anti-spastic treatment may also be prescribed in some cases for pure analgesia in case of pain caused by spasticity.

Pain was also associated with scoliosis, scoliosis being the sign of a severe orthopaedic status. Furthermore, contractures seem to cause most of the difficulties in making the child comfortable. Indeed, pelvis obliquity and hip excentration are often present together with scoliosis [20]; therefore, the child cannot move to change positions. Hence, scoliosis is a source of multiple pains, not only in the back (9.6% in this study) but also in the hip, ischium, sacrum, knees, etc. Our experience confirms that after vertebral arthrodesis, children have less pain and can be more easily and comfortably placed.

5.1. Limitations

The study describes the first 240 children recruited from an ongoing cohort. It provides a good estimation of the prevalence of pain, but the interpretation of the sources of pain will be confirmed at the end of the cohort inclusion process (385 children expected). As previously stated, some analyses were limited because of a relatively high rate of missing data. With the high percentage of non-communicating children (69%), the analysis of the site of pain was difficult.

6. Conclusion

Pain is a problem in young, non-ambulatory children with CP and is highly under-noticed, and the site is difficult to find, as

confirmed by this study. We point to the importance of systematically evaluating pain in these children, especially by therapists and caregivers, as a recommendation or at least as questioning. The treatment of pain should begin as soon as possible, to prevent not only the excentration of hips but also deformation of feet and scoliosis.

Funding

The Study PC Cohort is funded by a National PHRC (*Projet hospitalier de recherche clinique*, 2009) by La Fondation Motrice, TFWA Care, the *Association lyonnaise de logistique posthospitalière* (ALLP), and *Société francophone d'études et de recherche sur les handicaps de l'enfance* (SFERHE).

Disclosure of interest

The authors declare that they have no competing interest.

Acknowledgements

The authors thank Jean Iwaz and Philip Robinson (*hospices civils de Lyon*) for helpful comments and for a thorough revision of the final version of the manuscript. The authors acknowledge all the associated investigators; Dr Capucine de Lattre, Dr Geoffroy de La Gastine, Dr Marie-Charlotte D'Anjou, Dr Jean-Claude Bernard, Dr Emmanuel Chaleat-Valayer, Dr Fabienne Roumenoff, Dr Véronique Bourg, Dr Catherine Donskoff, Dr Sylvie Brau, Dr Anne Descotes, Dr Laure Yvart, Dr Stéphanie Fontaine Carbonnel, Dr Christine Fichtner, Dr Elodie Seeman, Pr Vincent Gautheron, Dr Béatrice Bayle, Dr Véronique Jomain-Guedel, Dr Claire Mugnier, Dr Izabel Joubrel, Dr Claude Simonnot, Dr Véronique Lavarenne, Dr Claire Miettton, Dr Celine Delvert, Dr Daniel Le Bellego, Dr Véronique Morvan, Dr Pascale Bonnet, Dr Dominique Pichancourt, Dr Elisabeth Porsmoguer, Dr Elisabeth Grimont, Dr Marie Ange Rohon, Dr Chantal Tessiot, Dr Trung Vo Toan, Dr Valérie Marianski, Dr Isabelle Chapurlat, Dr Véronique Quentin, Dr Claire Do Ngoc Thanh, Dr Mireille Birck, Dr Christelle Rougeot, Dr Jean-Pierre Vadot, Dr Véronique Bombart, Dr Christophe Charbonnier, Dr Hélène Le Tallec de Certaines, Dr Véronique Tsimba, Dr Mathilde Creusat, Dr Véronique Bernier-François, Dr Denis Colin, Dr Bertrand Chupin, Dr Pascal Granier, Dr Vincent Medart, Dr Anne-Emmanuelle Piquet-Massin, Dr Dominique Dipanda, Dr Emannelle Blangy, Dr Anne Vielh, Dr Clotilde Rivier Ringenbach, Dr Barbara Bouchut, Dr Houcine Jabbari, Dr Chrystelle Schepens, Dr Martine Schmuck, Dr Catherine Vanhulle, Dr Guy Letellier, Dr Christine Ekstrom-Montuclard, Dr Hervé Carlier, Dr Hélène Rauscent, Dr Coline Ginat-Cousin, Dr Calogera Dovico, Dr Charlotte Lernout, Dr Liliane Schneider, Dr Corinne Demoutiez, Dr Jean-Pierre Decroix, Dr Véronique Leforestier.

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