

Pain in children with cerebral palsy in the postoperative: perception of parents and health professionals

A dor em crianças com paralisia cerebral no pós-operatório de cirurgia ortopédica: percepção de pais e profissionais da saúde

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ABSTRACT

BACKGROUND AND OBJECTIVES: Children with cerebral palsy are affected by postoperative painful processes. These children's pain may be underestimated due to difficult communication especially when a specific tool is not used. The objective of this study was to evaluate the pain in children with cerebral palsy in postoperative orthopedic surgery and the pain perception of parents and health professionals.

METHODS: It is a cross-sectional, observational study performed at Associação de Apoio à Criança Deficiente in São Paulo. Fifty-one children with cerebral palsy were recruited, aged between 6-15 years, 51 parents/caregivers and 51 health professionals. Pain assessment was measured by an observer during the routine procedures in which the child was manipulated. After the procedure, the observer asked health professionals and parents about the child's pain.

RESULTS: Eighty-two percent of patients had postoperative pain, and of these, 50% had moderate and intense pain. In unarticulated patients, parents and caregivers had discordant perceptions from the observer in 65% of the cases ($p=0.05$) and health professionals had discordant responses in 75% ($p<0.001$). In communicative patients, parents had discordant responses from the observer in 58% of the cases ($p=0.20$) and health professionals had discordant responses in 55% of the cases ($p=0.44$).

CONCLUSION: Children with cerebral palsy present moderate and intense pain in the postoperative period of orthopedic

surgeries. In the hospital, it is more challenging to detect pain in unarticulated patients without the use of a specific scale, even by experienced parents or professionals.

Keywords: Cerebral palsy, Pain measurement, Postoperative pain.

RESUMO

JUSTIFICATIVA E OBJETIVOS: A criança com paralisia cerebral pode ser afetada por processos dolorosos relacionados ao pós-operatório, com dor subestimada devido à dificuldade de comunicação, especialmente quando uma ferramenta específica não é utilizada. O objetivo deste estudo foi avaliar a dor em crianças com paralisia cerebral no pós-operatório de cirurgia ortopédica e a percepção de pais e profissionais de saúde sobre a dor.

MÉTODOS: Estudo transversal, observacional realizado na Associação de Apoio à Criança Deficiente em São Paulo. Foram recrutadas 51 crianças com paralisia cerebral, com idade entre 6 e 15 anos, 51 cuidadores e 51 profissionais de saúde. A dor foi avaliada por um observador durante os procedimentos de rotina em que a criança foi manipulada. Após o procedimento, o observador perguntou aos profissionais de saúde e cuidadores sobre a dor da criança.

RESULTADOS: Oitenta e dois por cento dos pacientes apresentaram dor pós-operatória e desses, 50% dor moderada e intensa. Nos pacientes não comunicativos, os pais apresentaram percepções discordantes do observador em 65% dos casos ($p=0,05$) e os profissionais de saúde apresentaram respostas discordantes em 75% ($p<0,001$). Nos pacientes comunicantes, os pais apresentaram respostas discordantes do observador em 58% dos casos ($p=0,20$) e os profissionais de saúde em 55% dos casos ($p=0,44$).

CONCLUSÃO: Crianças com paralisia cerebral apresentam dor moderada e intensa no pós-operatório de cirurgias ortopédicas. Na fase hospitalar, a dor é mais difícil de ser detectada em pacientes não comunicativos sem o uso de escala específica, mesmo por pais ou profissionais experientes.

Descritores: Avaliação da dor, Dor pós-operatória, Paralisia cerebral.

INTRODUCTION

The International Association for the Study of Pain (IASP) defines pain as an unpleasant experience associated with actual or potential tissue injury involving the sensory, emotional and cognitive aspects. The recognition of the stimulus by the nociceptors is called nociception, and pain is a conscientious experience that

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requires a cortical processing and an aversive interpretation of the nociceptive information^{1,2}. The inability to report and quantify pain does not exclude the possibility of its existence since it is an individual, subjective, multidimensional experience and related to a real or potential injury³.

The evaluation of pain in children with cerebral palsy (CP) is a complex and subjective task. In many cases, these children have severe cognitive deficits, difficulty in verbalizing and idiosyncrasies that mask the expression of pain; and because of their condition, they present changes in their facial expression and are not able to clearly signal the presence or intensity of pain⁴. Facing this complex scenario, pain can be underestimated and undertreated if a correct form of evaluation is not established for these patients^{5,6}.

The correct assessment of pain is paramount for the follow-up and success of the treatment, especially when it comes to unarticulated children and with neuromuscular disorders. Failure to use specific instruments can make it difficult to detect pain, leading to under-treatment. In this sense, inadequate analgesia in this profile of children may lead to increased tonus, presence of muscle spasm in the postoperative period and progress to worsening the pain^{6,7}.

Scales for pain assessment are tools that facilitate the interaction and communication between the healthcare team members and the patients. The Face, Legs, Activity, Cry, Consolability (FLACC) scale is an instrument that assesses pain based on observation of the patient's face, leg, activity, cry, and consolability patterns. It is an easy-to-apply instrument initially designed to assess pain in pre-verbal children and subsequently validated to measure postoperative pain in children with difficulty to communicate due to mild to severe cognitive impairment – FLACC-R⁸⁻¹⁰. The modified scale has the same indicators of the FLACC scale and incorporates specific pain behaviors in children with multi deficiencies. An open descriptor was added to each indicator to include specific pain behaviors of each child, described by parents, as increased tone.

Lastly, pain has been a priority regarding education, assessment, and documentation. Increasingly, the pain sensation has received more attention from the healthcare teams, scientific community and quality, and safety accreditation organizations. The American Agency for Research and Quality in Public Health and the American Society of Pain describe it as the fifth vital sign¹¹. In this sense, as important as detecting pain is to assess it properly and treat it with safety¹².

The objective of this study was to evaluate the presence of pain in children with CP in the postoperative period of orthopedic surgeries and to compare the findings with the ability of the healthcare team and the caregivers to detect pain, considering children who can communicate and children who cannot.

METHODS

A prospective, observational study conducted in the hospitalization units of the Hospital da Associação de Apoio à Criança Deficiente (AACD), in the city of São Paulo, from July to August 2014.

The sample was of convenience, chosen due to the limited collection time and availability of the researchers. Regarding the sample calculation, due to the few numbers of research on this matter, the calculation was based on a pilot sample, and the calculated *n*, unfortunately, was approximately 216 subjects for the group of patients (articulated and unarticulated).

The sample consisted of 51 patients and 102 evaluators. The group of 51 patients was divided into 2 groups: Group 1 UA = unarticulated children with cerebral palsy (*n*=20); Group 2 A = articulated children with cerebral palsy (*n*=31); of both genders, aged between 6 and 16 years, diagnosis of CP, hospitalized and submitted to corrective orthopedic surgery in any segment of the lower limbs. Regarding the Group of Evaluators (evaluators of the subjective perception of the pain of the child with CP) (*n*=102), it was also subdivided into two groups: Group 1 P/C = composed by the respective parents/caregivers (responsible) of the patients (*n*=51); Group 2 HP=health professionals, composed by physiotherapists and nursing technicians (*n*=51).

In the preoperative period, the observer completed a form with the patients' clinical and personal data taken from their medical records. Then the following vital signs of the patient at rest were collected: heart rate (HR), respiratory rate (RR) and peripheral oxygen saturation (SpO₂). The period between the 1st and 2nd postoperative day was chosen as the moment of pain evaluation during the hospital routines in which it was necessary to manipulate the patient and the operated segment in bed, in activities such as bathing, change of decubitus position, and physiotherapy. The manipulations were performed by different health professionals, physiotherapists or nursing technicians; and all the professionals participating in the study were randomly selected when they were providing care to the selected patient.

To assess the impressions of the caregiver and the health professional regarding the presence or absence of pain in the patient, both were verbally asked by the observer if the patient has had pain or not during the routine procedure. To serve as a comparison parameter, at the same time, the observer also evaluated the patient's pain, and used specific instruments for pain assessment: In group 1 (UA), the FLACC-R scale was used, with a score between zero and 10^{11,12}. In the patients in group 2 (A) the verbal numerical rating scale (vNRS) was used, which also varies from zero to 10. Both scales evaluate the intensity of pain through the values obtained between zero and 10, being zero absence of pain; 1-3 mild pain; 4-6 moderate pain; 7-10 severe pain.

The research was approved by the Research Ethics Committee of the Associação de Assistência à Criança Deficiente (AACD), with opinion number 835.133 and 32717214.6.0000.0085.

Statistical analysis

The data was tabulated in the Microsoft Excel spreadsheet and then analyzed using the SPSS 17.0 software. For the descriptive analysis, the position and dispersion measures (mean and standard deviation) were calculated. The test for the equality of two proportions was used to calculate the agreement between the answers given by the caregivers and the health professionals, and the responses obtained by the observer regarding the presence or absence of pain in the patients. Regarding the hypothesis that the

vital signs were altered in the presence of pain, the paired Student *t*-test was used. Two scales were used to evaluate the pain, FLACC and vNRS, and to check whether both scales matched, the Pearson correlation test was performed. In this study, the null hypothesis was rejected when the alpha error was less than 5% ($p < 0.05$).

RESULTS

Fifty-one patients were evaluated, 22 female (44.2%) and 29 male (56.8%) articulated and unarticulated. Fifty-one health professionals were interviewed, 24 nursing technicians (47.05%) and 27 physiotherapists (52.9%), as well as 51 parents/caregivers (Table 1).

Taking the observer's assessment as a reference of the presence of postoperative pain during the manipulation of the patient, 82% of the patients had pain, regardless of the group ($p < 0.001$) (Table 2), with 50% of the patients with moderate to severe pain intensity.

The answers given by the caregivers and the health professionals were compared with the ones obtained by the observer, who used the FLACC-R (unarticulated) and vNRS (articulated) scales for the presence or absence of pain in both groups of patients.

The answers obtained by the observer (FLACC-R scale) were compared with the reports of caregivers and health professionals regarding the presence or absence of pain in the unarticulated patient's group. In both groups of evaluators, a statistically significant difference in the answers was observed in relation to the observer's evaluation. Parents and caregivers had discordant perceptions from the observer in 65% of cases ($p = 0.05$), and health professionals had discordant responses in 75% ($p < 0.001$) (Figure 1).

The dark gray bar represents the percentage of disagreement, and the light gray indicates the percentage of agreement in the answers obtained from health professionals and parents/caregivers. The observer responses (vNRS scale) were compared with the reports of caregivers and health professionals regarding the presence or absence of pain in the group of articulated patients, and a significant disagreement was observed in the responses of both groups of evaluators. The caregivers had discordant responses when compared to the observer's in 58% ($p = 0.20$), and the health professionals had discordant responses when compared to the observers in 54% ($p = 0.44$) (Figure 2).

The dark gray bar represents the percentage of disagreement, and the light gray indicates the percentage of agreement in the answers obtained from health professionals and parents/caregivers.

Face, Legs, Activity, Cry, Consolability scale versus verbal numerical rating scale

The agreement between the FLACC and vNRS scales was analyzed in the group of articulated patients, to evaluate whether the responses and intensities were the same. There was a moderate correlation with statistically significant agreement between them, regarding the presence and intensity of the pain (Table 3).

Table 2. Distribution of pain in all patients

Pain	n	%	p-value
No	9	17.6	<0.001
Yes	42	82.4	

Table 3. Correlation between the scales used in the group of articulated patients

FLACC versus vNRS	
Corr (r)	58.0%
p-value	0.001

FLACC = Face, Legs, Activity, Cry, Consolability; vNRS = verbal numerical rating scale.

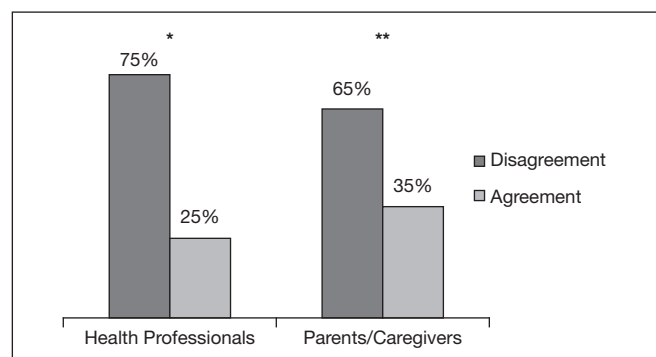


Figure 1. Perceptions of evaluators in unarticulated children
* $p < 0.001$; ** $p = 0.05$

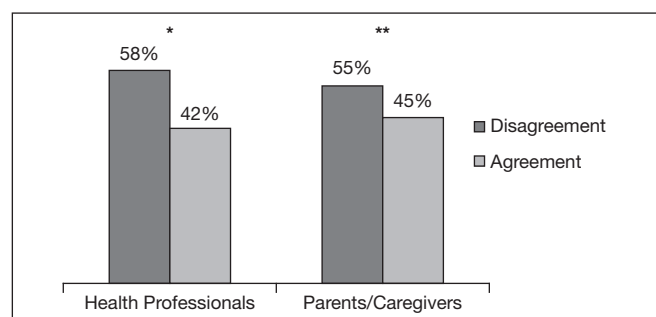


Figure 2. Perceptions of evaluators in articulated children
* $p = 0.2$; ** $p = 0.44$

Table 1. General characteristics of the groups

Groups	Subgroups	n	Time of engagement	Age	Gender		Hospitalizations (previous/year)
			Mean±SD	Mean±SD	F	M	Mean±SD
Group 1	A	31	-	10.97±2.5	48.3	51.6	0.277±0.273
Group 2	UA	20	-	10.10±2.8	35	65	0.692±0.833
Evaluators	HP	51	4.15±4	-	-	-	-
	P/C	51	-	-	-	-	-
General		153	-	10.62±2.6	43.1	56.8	0.435±0.593

A = articulated; UA = unarticulated; n = number; SD = standard deviation; HP = health professional; P/C = parents/caregivers; F = Female; M = Male.

Table 4. Comparison of patients with and without pain for heart rate, respiratory rate and pre-operative and post-manipulation mean arterial pressure

		Preoperative			Post-manipulation			p-value
		Mean	Median	SD	Mean	Median	SD	
HR	With pain	97.6	95	15.7	120.5	123.5	20.9	<0.001
	Without pain	101.1	102	13.6	119.6	113	13.9	0.054
RR	With pain	19.1	19	1.8	21.4	21.5	4.7	0.003
	Without pain	17.9	18	3.2	21.0	21	1.8	0.006
MAP	With pain	59.9	59.5	8.2	65.1	63.5	9.7	0.009
	Without pain	56.4	54	8.9	63.8	64	8.3	0.089

HR = heart rate; RR = respiratory rate; MAP = mean arterial pressure.

In order to evaluate the relationship between changes in the vital signs and the presence of pain in the patients, the vital signs were compared in the preoperative and post-manipulation periods, dividing the patients into those who had pain, versus those who did not to the vital signs of HR, MAP and RR (Table 4).

For patients who had pain during manipulation, the change in the vital signs was statistically significant in relation to their preoperative baseline values, HR ($p < 0.001$), MAP ($p = 0.009$) and RR ($p < 0.003$). However, there was an increase in the RR variable in relation to the baseline values also in patients who did not have pain ($p < 0.006$).

DISCUSSION

Orthopedic surgeries are among the most frequent in patients with CP, and these patients often present intense postoperative muscle spasms, causing pain and stress to the child, parents, and physicians^{7,13}. In this study, the prevalence of pain in the lower limbs between the 1st and 2nd postoperative days was 82.4%, and in 50% the pain was moderate to severe. This result is slightly more than double the percentage found by Goodman and McGrath¹³ in a study that observed pain on the 1st postoperative day in 40% of children with a mean age of 8 years.

The control of acute postoperative pain is the responsibility of the anesthesiologist, the surgeon, and the nursing team¹⁴. On the other hand, all those involved in the assistance process; patients, parents, and health professionals are responsible for the detection and assessment of the pain to be treated¹⁵. Pain relief is a patient's right and must be ensured regardless of its level of consciousness, and the use of valid and reliable instruments for the pain assessment is paramount for its proper handling^{12,16}.

The present study evaluated the perception of "pain" by parents and health professionals in articulated and unarticulated children with CP during potential pain procedures such as the manipulation performed by physiotherapists and nursing technicians. The fact that children could communicate seems to have been a decisive factor for better perception and detection of pain or no pain by parents/caregivers and health professionals, without the use of a specific scale. On the other hand, in the group of unarticulated patients, it was observed in the present study that the perception of the state of "pain" or "no pain" by parents/caregivers and health professionals was more difficult, showing high values of disagreement when compared to the observer's responses.

Although parents and caregivers may be able to assess the sensation of pain in daily activities in patients with cognitive impairment and/or difficulty in communicating¹⁷, the fact of being in a stressful situation in a hospital environment seems to influence their ability to perceive pain in their children, either because they are out of their daily family and professional routines, or because of the possibility of catastrophizing pain¹⁸. Concerning the perception of pain by health professionals, the reactions of fear, such as crying and increased tone presented by the children during the various care procedures and interventions could have made it difficult for the health professional to tell pain from fear since some reactions are similar¹⁹. These results are similar to the ones found in a review study where the professionals also had difficulty in detecting pain without the use of specific scales for the assessment²⁰.

In both groups of this study, however, a high percentage of disagreement in the patient's pain perception was observed, which corroborates the findings by Bacellar²¹, in which the family members identified pain only in 41.2% of the cases, the nursing team in 33.7%, and physicians in 29.6%.

It was observed that the intensity of pain obtained with both the vNRS and FLACC scales had a strong correlation in the articulated patients, but it is important to emphasize that in this study the perception of pain intensity by parents/caregivers and health professionals was not addressed. However, literature provides consistent data regarding the importance of using instruments to assess pain intensity²².

The scales for pain assessment are subjective, and their purpose is to facilitate the detection and measurement of the intensity, and when talking about pain scales for unarticulated patients, these are, most of all, scarce²³. A "gold standard" would be welcome for the detection of pain and its measurement in children unable to self-report, but such a standard pattern does not yet exist. An alternative would be a mixed method, where the pain behavior evaluation would be complemented by a physiological evaluation, that is, by the recording of the vital signs²⁴. It was observed in this study that the pain interferes precisely in the values of HR, MAP, and RR. However, the change in RR seems to have no single relation with the presence of pain since we have also observed a significant increase in RR in the group that did not have pain during manipulation. It is possible that fear is also a determinant for this change.

Another aspect to be highlighted is that although this was not the objective of this study, the presence of previous hospitalizations

as a characteristic of the patients was observed in 100% of the sample. This fact has raised an important issue to be considered in the management of pain in patients with CP. In a systematic review by Petovello²⁵ he reported that children who go through several hospitalizations develop greater fear and anguish due to the memory of stored pain and that in such cases, the painful memory anticipates their reactions to painful procedures that in turn may cause the cycle increase in tone and pain.

Finally, detecting and treating the patient's pain correctly, regardless of their capacity to self-report is paramount for any health service. The National Council of the Rights of the Child and Adolescent, in its Resolution 41 on the Rights of Hospitalized Children and Adolescents, article 7 provides that the patient has "the right not to feel pain when there are ways to avoid it"²⁶. In this sense, the recognition of the painful episode and the application of instruments to assess the pain according to each patient allows health professionals to handle the pain appropriately²⁷.

The limitations of this study are related to the limited time for data collection and, consequently, the small sample size. Considering the importance of the topic, it is necessary to conduct more studies with a larger sample and perhaps to include samples with other characteristics such as different surgical interventions or institutions with established pain protocols.

CONCLUSION

Children with CP have pain during manipulations in the initial lower limbs postoperative period. Even with parents present in the daily routine of the unarticulated patient and professionals of a referral institution in the care of this population, the pain can still not be properly detected without the use of a specific tool. Therefore, in the hospital setting, pain can be detected effectively with the use of specific scales for each population.

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