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ORIGINAL ARTICLE / ОРИГИНАЛНИ РАД

# The difference between the pain self-perceptions of children with cerebral palsy and those of their caregivers

Rastislava Krasnik[1,2], Jelena Zvekić-Svorcan[1,3], Čila Demeši-Drljan[1,2], Lidija Dimitrijević[4,5], Nensi Lalić[1,6], Aleksandra Mikov[1,2]

[1]University of Novi Sad, Faculty of Medicine, Novi Sad, Serbia;
[2]Institute of Child and Youth Health Care of Vojvodina, Novi Sad, Serbia;
[3]Special Hospital for Rheumatic Diseases, Novi Sad, Serbia;
[4]University of Niš, Faculty of Medicine, Niš, Serbia;
[5]Clinical Center Niš, Physical Medicine and Rehabilitation Clinic, Niš, Serbia;
[6]Institute for Pulmonary Diseases of Vojvodina, Sremska Kamenica, Serbia

**SUMMARY**

**Introduction/Objective** Pain is often an underrecognized entity in children with cerebral palsy. The aim of this study was to determine whether there are differences in pain self-perception between children with cerebral palsy and their caregivers.

**Methods** This retrospective study included 70 children with cerebral palsy and 70 of their caregivers, treated at the Institute of Child and Youth Health Care of Vojvodina, Serbia. Pain intensity ratings on the Visual Analog Scale (VAS) provided by children and/or their caregivers were analyzed.

**Results** The research involved 70 children with cerebral palsy and the same number of their caregivers. While only 43 (61.4%) of these children were testable, all 70 caregivers participated. Pain was reported by 19 (44.2%) children and 42 (60%) caregivers, while 17 (39.5%) children suffered from musculoskeletal pain, which was noted by 39 (55.7%) caregivers. Average caregiver rating for musculoskeletal pain for children at Level V, I and III on the Gross Motor Function Classification System (GMFCS) was 6.20 ± 2.10, 2.67 ± 2.18, and 2.50 ± 2, respectively. Average self- and caregiver-reported VAS rating for headache/stomachache was 2.73 ± 1.86 and 2.35 ± 1.49, respectively ($p > 0.05$). Statistically significant differences were noted in the musculoskeletal pain VAS scores provided by the caregivers for children at different GMFCS levels ($p < 0.01$).

**Conclusion** Although no differences in pain perception between children with cerebral palsy and their caregivers have been established, in children with the most severe level of motor disability, caregivers report a statistically higher level of musculoskeletal pain.

**Keywords:** pain; children; pain intensity; cerebral palsy

## INTRODUCTION

Cerebral palsy (CP) is a heterogeneous group of non-progressive neurological disorders caused by brain damage either in utero or in early infancy, adversely affecting the development of posture and movement [1]. It is frequently accompanied by pain of diverse etiology, localization, intensity, and duration, often compromising the quality of life of both children and their caregivers [2]. In extant literature, pain is estimated to affect 27–75% of children with CP [3–6]. Moreover, 25% of children and youth with CP experience moderate to severe pain, and multiple sources of pain are present in more than 12% cases [7]. In CP, pain can have numerous origins, and is often the result of many factors, especially if caused by musculoskeletal deformities, hip dislocation/subluxation, hypertonia, dystonia, constipation, surgical intervention or presence of contractures [3, 7, 8]. In children with CP, headaches can occur for many reasons. Presence of motor disability, especially muscle weakness, muscle contraction, increased muscle tone, and inadequate positioning of the head and neck may lead to impaired sleep quality, increasing the occurrence of headaches, and thus compromising the ability to partake in daily activities, such as playing with peers and completing school assignments, even in children in whom cognitive functioning is not compromised [2, 4–7]. Abdominal pain can be caused by certain medications, as well as by feeding difficulties (those arising due to insufficiently coordinated and inefficient chewing and swallowing in particular), gastroesophageal reflux, slow passage, and constipation, especially in patients who spend a long time in a sitting position and are unable to change body posture on their own [3–7]. Greater understanding of the causes and the severity of pain in children with CP is frequently hindered by the unfeasibility of self-reports in non-verbal children. Although in such cases valuable information can be provided by health care professionals, caregiver-reported pain in children is particularly important [9]. Several single- and multi-dimensional scales and questionnaires have been developed for assessing the pain level in infants, children and adolescents [10, 11], some of which are not applicable to CP,

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**Correspondence to:**
Nensi LALIĆ
University of Novi Sad
Faculty of Medicine
Hajduk Veljkova 3
21000 Novi Sad
Serbia
**nensi.lalic@mf.uns.ac.rs;**
**nenslialic@gmail.com**

or cannot be applied for evaluating chronic pain in children with severe cognitive and motor deficits [12]. Consequently, authors of existing studies tended to rely on a combination of several self-reported questionnaires and the corresponding parent versions, where available, as a means of obtaining more comprehensive data, especially if intended for use in evaluations or when planning rehabilitation interventions [6, 8, 13]. One-dimensional scales, such as Visual Analog Scale (VAS), Numerical Rating Scale (NRS-11), Wong-Baker FACES Pain Rating Scale (FACES) and 6-point categorical Verbal Rating Scale (VRS-6) [11, 14, 15] can be combined with observational data collection instruments, such as FLACC (Face, Legs, Activity, Cry and Consolability) and the revised FLACC (r-FLACC) scale. These scales are reliable and are associated positively with each other, providing a valid framework for the assessment of pain [15–19]. Application of the same questionnaire for assessing pain severity in children with CP may yield inconsistent results, depending on whether the pain is self-reported by the child, or is perceived by caregivers and various healthcare professionals. The differences are particularly pronounced if pain severity is assessed before and after a medical intervention or physiotherapy [20–24].

The aim of the present study was to establish presence of any differences between the pain levels self-reported by children with CP and the ratings given by their caregivers using VAS.

## METHODS

This retrospective study was conducted between September 2014 and September 2015 and included 70 children with CP aged < 18 years of both sexes, and 70 their caregivers receiving inpatient and outpatient treatment at the Institute of Child and Youth Health Care of Vojvodina, Novi Sad, Serbia. The study was approved by the institutional Committee on Ethics, and the receipt of written consent from the children's parents/caregivers. Gross motor function was classified using the Gross Motor Function Classification System (GMFCS) [25], and pain intensity was measured using VAS, whereby ratings were provided by the children and/or their caregivers (parents, grandparents, or foster carers). The VAS is a valid and reliable measure for rating pain intensity, requiring participants to mark subjective pain experience on a 10 cm-long line, ranging from 0 (no pain) to 10 (unbearable pain) [14, 26, 27]. In the present study, the scale was used to rate musculoskeletal pain, headache and/or stomachache. Children that underwent a surgical procedure in the preceding month, presented with current trauma or pain related to other pre-established condition were excluded from the study.

### Statistical methods

The minimum sample size (68) was determined based on the α error of 0.05 and β error of 0.1 (corresponding to the power of 90%). Numerical variables were expressed as mean (median, arithmetic mean) and variance (standard deviation, range), depending on the data distribution type, whereas frequency and percentage was reported for categorical variables.

Statistical analyses included paired-samples t-test, ANOVA test, and Pearson correlation coefficient, with $p < 0.05$ indicating statistically significant difference. Tukey multiple comparison test was adopted for between-group comparisons. All analyses were performed using the SPSS Version 24.0. (IBM Corp., Armonk, NY, USA) statistical software package.

## RESULTS

The study included 70 children with CP, 33 (47.1%) of whom were boys and 37 (52.9%) were girls, aged 8.65 ± 3.66 years. Self-reported data was obtained from 43 (61.4%) children that were testable and capable of providing required information, while their caregivers provided data for all participating children. Most of the caregivers were mothers 58 (82.9%).

In the examined sample, 27 (38.6%) of children had spastic hemiplegia, 19 (27.1%) each had spastic quadriplegia and spastic diplegia, three (4.3%) children had ataxic form of CP, while two (2.9%) children had a dyskinetic form. GMFCS Level I was noted in 26 (37.1%) of participating children, 14 (20%) were at Level II, 10 (14.3%) at Level III, seven (10%) at Level IV, and 13 (18.6%) of children were at Level V (Table 1).

**Table 1.** Participants' sociodemographic and general characteristics

| Variables | | n = 70 (100%)<br>M ± SD |
|---|---|---|
| Sex | Male | 33 (47.1%) |
| | Female | 37 (52.9%) |
| Age (years) (min–max) | | 8.65 ± 3.66 (4–17.58) |
| Self-reported data available | Yes | 43 (61.4%) |
| | No | 27 (38.6%) |
| Participating caregiver | Mother | 58 (82.9%) |
| | Father | 2 (2.9%) |
| | Grandparent | 8 (11.4%) |
| | Foster mother/father | 2 (2.8%) |
| Cerebral palsy type | Spastic hemiplegia | 27 (38.6%) |
| | Spastic quadriplegia | 19 (27.1%) |
| | Spastic diplegia | 19 (27.1%) |
| | Dyskinetic | 2 (2.9%) |
| | Ataxic | 3 (4.3%) |
| Gross Motor Function Classification System level | Level I | 26 (37.1%) |
| | Level II | 14 (20%) |
| | Level III | 10 (14.3%) |
| | Level IV | 7 (10%) |
| | Level V | 13 (18.6%) |

M ± SD: mean ± standard deviation

Pain was reported by 19 (44.2%) children and by 42 (60%) caregivers, who respectively rated it using VAS at 1.62 ± 0.95 and 1.65 ± 0.94. Musculoskeletal pain was experienced by 17 (39.5%) children (with an average 1.62 ± 0.95 VAS score), whereas it was perceived by 39 (55.7%) caregivers (who rated it at 1.65 ± 0.94 on average). On the other

hand, children and their caregivers rated stomachache/headache at 2.73 ± 1.86 and 2.81 ± 1.86, respectively. For testable children, i.e., those that were capable of rating their subjective pain experience (n = 43), paired-samples t-test was conducted to assess the differences between self- and caregiver-provided VAS scores. For these reasons, the caregiver-provided VAS scores for this subsample do not coincide with those pertaining to the full sample (n = 70). Children in this subgroup self-rated stomachache/headache at 2.73 ± 1.86, while caregiver-rated scores were 2.35 ± 1.49, and this difference was not statistically significant ($p > 0.05$). For this subsample, self- and caregiver-provided musculoskeletal pain VAS scores were 2.94 ± 2.16 and 3.88 ± 2.36, respectively. Once again, this difference failed to reach statistical significance ($p > 0.05$) (Table 2).

Further analyses were conducted to ascertain if the VAS scores differed across the GMFCS levels. Statistically significant differences were noted only in the caregiver-reported musculoskeletal pain ($p < 0.01$). Tukey multiple comparison test was also performed for between- group comparisons, and the results indicated statistically significant differences between children at GMFCS Level V (the most severe CP form) and those at Level I and III. On average, caregiver-reported musculoskeletal pain in the Level V group was 6.20 ± 2.1, while for children at GMFCS Level I and III the caregivers rated musculoskeletal pain at 2.67 ± 2.18 and 2.5 ± 2, respectively (Table 3).

**Table 2.** Differences between self- and caregiver-rated VAS pain scores

| Variable | M ± SD | Pain | | p |
|---|---|---|---|---|
| | | Yes | No | |
| Self-reported pain | 43 (100%) | 19 (44.2%) | 24 (55.8%) | > 0.05[a] |
| Caregiver-reported pain | 70 (100%) | 42 (60%) | 28 (40%) | |
| Self-reported musculoskeletal pain | 43 (100%) | 17 (39.5%) | 26 (60.5%) | > 0.05[a] |
| Caregiver-reported musculoskeletal pain | 70 (100%) | 39 (55.7%) | 31 (44.3%) | |
| Self-reported headache/ stomachache | 43 (100%) | 18 (41.8%) | 25 (58.2%) | > 0.05[a] |
| Caregiver-reported headache / stomachache | 70 (100%) | 30 (42.8%) | 40 (57.2%) | |
| Self-reported headache (min–max) | 1.62 ± 0.95 (1–10) | | | > 0.05[a] |
| Caregiver-reported headache (min–max) | 1.65 ± 0.94 (1–10) | | | |
| Self-reported headache/ stomachache VAS score | 2.73 ± 1.86 | | | > 0.05[a] |
| Caregiver-reported headache/ stomachache VAS score | 2.35 ± 1.49 | | | |
| Self-reported musculoskeletal pain VAS score | 2.94 ± 2.16 | | | > 0.05[a] |
| Caregiver-reported musculoskeletal pain VAS score | 3.88 ± 2.36 | | | |

p – statistical significance; [a] – paired-samples t-test; VAS – Visual Analogue Scale; M ± SD – mean ± standard deviation

**Table 3.** Self- and caregiver-reported VAS pain scores across five Gross Motor Function Classification System levels

| Variables | Self-reported headache/ stomachache VAS score | Caregiver-reported headache/ stomachache VAS score | Self-reported musculoskeletal pain VAS score | Caregiver-reported musculoskeletal pain VAS score |
|---|---|---|---|---|
| Level I (n = 26) M ± SD | 3.17 ± 2.4 | 2 ± 1.55 | 3.2 ± 2.59 | 2.67 ± 2.18 |
| Level II (n = 14) M ± SD | 3.20 ± 1.64 | 3 ± 1.55 | 2.86 ± 1.95 | 3.88 ± 1.64 |
| Level III (n = 10) M ± SD | / | 2.6 ± 1.67 | / | 2.5 ± 2 |
| Level IV (n = 7) M ± SD | 1.67 ± 0.58 | 3.33 ± 2.31 | 4 ± 2.65 | 5.6 ± 2.79 |
| Level V (n = 13) M ± SD | / | 3.29 ± 2.5 | / | 6.2 ± 2.1** |
| Full sample (n = 70) M ± SD | 2.73 ± 1.86 | 2.81 ± 1.86 | 2.94 ± 2.16 | 4.13 ± 2.53 |
| p | > 0.05a | | > 0.05a | |

p – statistical significance; VAS – Visual Analog Scale; M ± SD – mean ± standard deviation; [a] – ANOVA test;
**$p < 0.01$[a]

## DISCUSSION

Subjective pain experience, which in a wide range of difficulties affecting children with CP often remains unrecognized, adversely affects their quality of life [7, 12]. Speech and language impairments, as well as compromised intellectual functioning, limit the child's ability to self- report the presence of pain. As pain is a subjective experience, it cannot be accurately captured by caregiver reports, but it could be important, especially in non-verbal children [2, 9].

In our study, the majority of respondents was female, which is consistent with the sample composition in several prior studies [14, 20, 28], but does not align with the designed trials based on larger cohorts of children with CP [3–7, 29]. Self-ratings were obtained from 61.4% of the children that took part in the study. In the survey conducted by Penner et al. [7], involving 252 children and youth with CP, only 39.6% of the sample was able to self-report presence of pain, which hinders pain evaluation in this population. More recently, Giray et al. [2] found that children with CP who are dependent and non-verbal are more likely to experience pain.

Similarly, according to Jayanath et al. [9], caregivers of non-verbal children with CP report a high frequency of pain. In our study, caregiver reports were predominantly provided by mothers (82.9%), which is to be expected, as parents are the ones shouldering the greatest burden of care for children with CP. In our sample, all CP forms were represented, concurring with the participant composition in earlier studies [2, 6, 28].

In our study, pain was reported by 19 (44.2%) children and by 42 (60%) caregivers. Based on a survey of 429 children with CP aged 13–17 years and 657 parents conducted by Parkinson et al. [6], pain was self-reported and parent-reported in 74% and 77% of the cases, respectively. Pain prevalence in children with CP, as established by healthcare professionals, tends to be lower compared to the data provided by parents or other close family members. In the study conducted by Badia et al. [21], physiotherapists reported presence of pain in 51.4% of the evaluated children and youth with CP.

In the present study, musculoskeletal pain was self-reported by 39.5% of the children, while the caregivers reported this type of pain in 55.7% cases. According to the respondents, musculoskeletal pain was of a greater severity compared to headache/stomachache. Similar differences between self- and proxy-rated (parent or a health professional) pain levels were noted in other studies where different pain intensity rating scales were employed. For example, in Ramstad et al. [22] study, 62% of the participating 153 children with CP aged 8–18 reported musculoskeletal pain, and its severity was rated higher by their parents compared to self- evaluations. The differences in the results can be attributed to a smaller sample size and younger age of children in our study. More recently, Westbom et al. [28] reported that pain experienced by children with CP tends to be most frequently localized in the lower extremities, feet and knees in particular. Penner et al. [7] assessed the pain experienced by children with CP aged 3–19 using the Health Utilities Index 3 (HUI3) questionnaire, and found that pain is localized in the lower extremities in 82% of respondents that report pain, and is typically attributed to hip dislocation/subluxation, dystonia and constipation. In our study, 39.5% of children reported musculoskeletal pain, while 41.8% reported headache/stomachache. In the study conducted by Parkinson et al. [6], 40% of children with CP complained of lower extremity pain, while 34% reported headaches, and 26% stomachache. Parent- and self-reported pain intensity was significantly correlated (Spearman rank correlation = 0.45; $p < 0.0001$).

All GMFCS levels were represented in our study sample, in line with larger cohort studies [7, 9, 28]. Jayanath et al. [9] conducted their research on a sample of 104 children with CP of both sexes (51% of whom were at GMFCS Level V, and 65% had spastic quadriplegia). Parents reported pain in 65% of these children, which was rated as intense in 17% of the cases, and was noted to occur daily in 28% cases [9]. The VAS was adopted in this study due to its demonstrated reliability and validity as both child self-report and parent-proxy report instrument. It has been employed in a significant number of prior studies involving children with CP, as it is a simple and quick method for assessing spasticity treatment efficacy [11, 14]. Alriksson-Schmidt and Hägglund [4] reported that pain localized in the abdomen and hips was most frequent in children with CP at the GMFCS Level V, while knee pain was most prevalent at Level III and foot pain at Level I.

In the present study, the greatest musculoskeletal pain caregiver-ratings were given for children at GMFCS Level V. Similarly, in a sample of 2777 children with CP aged 1–14 years, Alriksson-Schmidt and Hägglund [4] reported correlations between pain severity and the degree of gross motor impairment. In particular, pain was more frequently reported for children at GMFCS Level III and V compared to those at GMFCS Level I. Similar to our study, in the study conducted by Westbom et al. [28] 37% of children with CP were reported to experience pain, and GMFCS Level V was associated with the highest pain prevalence (50%). Eriksson et al. [5] assessed pain intensity in 3545 children with CP and concluded that it was positively correlated with the GMFCS level. However, no statistically significant difference in pain prevalence was found between self and proxy pain ratings. In an earlier cross-sectional study, Penner et al. [7] found a good agreement between the children's self-reports and parental pain severity/frequency reports. In a sample of 3783 children with CP representing all GMFCS levels, Hägglund et al. [29] parents and children reported presence of pain with comparable frequencies. It is, however, worth noting that changes in pain status are common in children with CP. For example, Christensen et al. [30] followed up 148 children with CP at all GMFCS levels, and found that pain severity tended to decline over time in children with more severe initial pain and higher gross motor function.

Continual monitoring of children with CP (which should include pain assessment) by their healthcare providers is essential for early detection of symptoms. The one-dimensional VAS pain rating scale can be adopted for this purpose, as it allows for rapid evaluation, facilitating longitudinal pain monitoring.

The study limitations include uneven sample distribution in terms of GMFCS levels, as well as failure to account for the influence of pharmacological and non-pharmacological therapy in the analysis.

## CONCLUSION

In the present study, no statistically significant differences between self- and caregiver-provided VAS pain ratings were noted. Statistically significantly greater musculoskeletal pain caregiver-ratings were noted for children at GMFCS Level V compared to those at Level I and III. For this reason, it is essential to detect pain in children with CP at all GMFCS levels, as this would ensure that the appropriate treatment is initiated in a timely manner, thus reducing the likelihood of its adverse long-term effects on the child's quality of life.

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**Conflict of interest:** None declared.

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# Разлика у самоперцепцији бола између деце са церебралном парализом и њихових неговатеља

Растислава Красник[1,2], Јелена Звекић-Сворцан[1,3], Чила Демеши-Дрљан[1,2], Лидија Димитријевић[4,5], Ненси Лалић[1,6], Александра Миков[1,2]

[1]Универзитет у Новом Саду, Медицински факултет, Нови Сад, Србија;
[2]Институт за здравствену заштиту деце и омладине Војводине, Нови Сад, Србија;
[3]Специјална болница за реуматске болести, Нови Сад, Србија;
[4]Универзитет у Нишу, Медицински факултет, Ниш, Србија;
[5]Клинички центар Ниш, Клиника за физикалну медицину и рехабилитацију, Ниш, Србија;
[6]Институт за плућне болести Војводине, Сремска Каменица, Србија

**САЖЕТАК**

**Увод/Циљ** Бол је често недовољно препознат ентитет код деце са церебралном парализом.

Циљ рада био је утврдити да ли постоје разлике у самоперцепцији бола између деце са церебралном парализом и њихових неговатеља.

**Методе** Ретроспективна студија је укључивала 70 деце са церебралном парализом лечене на Институту за здравствену заштиту деце и омладине Војводине и исто толико њихових неговатеља. Анализиран је интензитет бола процењен од стране деце и/или њихових неговатеља применом визуелне аналогне скале (ВАС).

**Резултати** Укупно 43 детета (61,4%) била су тестабилна, као и свих 70 неговатеља. Присуство бола пријавило је 19 деце (44,2%) и 42 (60%) неговатеља. Мускулоскелетни бол имало је 17 деце (39,5%), док је према процени неговатеља бол имало 39 (55,7%) деце. Просечна вредност мускулоскелетног бола према процени неговатеља износила је 6,20 ± 2,10 код деце са нивоом V, за I ниво 2,67 ± 2,18 и III ниво 2,50 ± 2 на скали за процену грубе моторичке онеспособљености (*Gross Motor Function Classification System*). Просечан ВАС за бол глава/стомак по процени детета износио је 2,73 ± 1,86, а по процени неговатеља 2,35 ± 1,49 ($p > 0,05$). Статистички значајна разлика између деце са различитим нивоом церебралне парализе потврђена је на ВАС за мускулоскелетни бол-одговор неговатеља ($p < 0,01$).

**Закључак** Разлике у перцепцији бола између деце са церебралном парализом и неговатеља нису утврђене, али код деце са најтежим нивоом моторичког онеспособљења неговатељи наводе статистички виши ниво мускулоскелетног бола.

**Кључне речи:** бол; деца; јачина бола; церебрална парализа