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## Evaluate of pain, motor function and quality of life in children and adolescents with cerebral palsy

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### Abstract

Cerebral palsy is a condition that affects motor control and activities of daily living. This study aimed to evaluate pain and motor function and its relationship with quality of life in children and adolescents with Cerebral palsy. 40 children and adolescents with Cerebral palsy with age range of 3 to 18 years; (mean age 9, 8 + 4, 2) took part of this study. To investigate the pain, motor function and quality of life of these patients we used the scales Pediatric pain profile, Gross motor function classification system and The Pediatric Quality of Life Inventory. The presence of pain in children and adolescents with CP was 30%, and there was no significant correlation between pain and GMFCS. We found a significant correlation between motor function and general Quality of Life, motor function and the "physical aspect" dimension of Quality of Life and between pain and emotional aspect. This study indicated that although pain is a common impairment in children and adolescents with Cerebral Palsy, it could lead to a low Quality of life only in the emotional aspect domain. In addition, it seems that motor function level reduced quality of life only in the physical aspect domain.

**Keywords:** Cerebral palsy, pain, quality of life

### Introduction

Cerebral palsy (CP) is a condition of motor deficiency caused by non-progressive damage to the developing fetal or infant brain. Motor alterations in cerebral palsy are often accompanied by disturbances of cognition, communication, perception and behavior [1]. Consequences of cerebral palsy can affect physical, psychological capabilities and health-related quality of life (HRQOL) [2].

Levels of functioning and comorbidities vary greatly in individuals with CP. In the last few decades, it has become increasingly common to classify the gross motor function of individuals with CP according to the Gross Motor Function Classification System (GMFCS). The GMFCS is an instrument used by both clinicians and researchers to classify gross motor function based on self-initiated movement. There are five levels, with level one describing the highest level of function and level five the lowest [3].

Pain is a secondary complication of CP and is receiving more attention, although research on the etiologies and pathways that lead to pain in individuals with CP remain scarce [4, 5, 6]. More than 50% of children and adolescents with CP suffer pain from moderate to severe intensity, which usually interferes with physical function, school, daily care activities, sleep and mental health [4, 6, 7, 8]. Moreover, suffering from persistent pain seems to reduce emotional, social and physical domains of HRQOL in patients with CP. In this sense, HRQOL is considered a multidimensional construct that embraces several domains of physical and psychological well-being [4]. Norwegian researchers have reported that recurrent musculoskeletal pain is common and associated with higher levels of mental health problems and worse health-related quality of life [5]. Although self-report is the gold standard for pain and HRQOL assessment in pediatric settings, it may be difficult to obtain reliable information from children with severe intellectual impairments or significant communication problems [9]. In this sense, some authors have suggested the possibility to assess children's HRQOL and pain by using reports from parents, health professionals and teachers [10]. The aim of the present study was to evaluate pain, motor function and its correlation with health-related quality of life in children and adolescents with cerebral palsy.

**Subjects and Methods**

A convenience sample of children and adolescents with CP were recruited from associations for the care of individuals with cerebral palsy and related disabilities in Brazil. The children and adolescents with Cerebral Palsy initially totaled 60. In order to determine the sample size, a significance level of 5% (corresponding to a 95% confidence interval,  $z [\alpha] / 2 = 1,96$ ) and a tolerable sampling error of 5% was adopted, resulting in a necessary sample of 53 patients to estimate the prevalence, however, only 40 patients met the inclusion criteria.

Forty children and adolescents with CP were enrolled in this study between July 2016 and October 2016. Parents or caregivers of patients with CP were asked to participate in the study and to answer several questionnaires concerning pain, HRQOL and level of motor function. Inclusion criteria were: 1) individuals with CP with age between 2 and 18 years old and 2) Patients accompanied by their parents or caregivers. Parental informed written consent was obtained for all individuals with CP. The study was approved by Ethics Committee of State University of Minas Gerais (Brazil) under protocol number 56029316.0.0000.5525.

The standard data collection form for the study included:

- Gross Motor Function Classification System (GMFCS)
- Pediatric Pain Profile (PPP)
- The Pediatric Quality of Life Inventory – generic core 4.0 (PEDSQT<sup>TM</sup>)

The Gross Motor Function Classification System (GMFCS) was developed in response to the need to have a standardized system. This system helps in classifying and assessing the severity of child's motor disability and includes five levels. Level I represents children with the most independent motor function and level V represents children with the least. The GMFCS for CP is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. GMFCS helps to predict gross motor development as most children will remain at the same level from age 2 to 18 years [3].

The Pediatric Pain Profile (PPP) is a scale developed to assist health professionals and caregivers in the assessment of pain in patients with cerebral palsy [11]. This has been used to evaluate pain before and after treatment with botulinum toxin and orthopedic pain [12, 13]. The scale is based on the psychometric properties of the behaviors

presented by the children, as the most important indicator of the presence of pain. The scale shows the pain behavior of the child with cerebral palsy, with essential participation of parents or caregivers during the application process. The instrument was validated for Brazilian Portuguese by Pasin *et al* [14]. PPP is an instrument with 20 items used to evaluate the behavior that indicates the presence of pain and other neurological conditions. Each item is evaluated through an ordinal scale of four points, where "not a little" is 0; "A little", 1; "quite," 2 and "a lot", 3. The final score may vary from 0 to 60. For the total the minimum score is 0, which indicates that the child has no evidence of pain, and the maximum score is 60, which indicates that the child has all 20 behaviors that indicate the presence of pain. The authors propose the cutoff value equal to or greater than 14, as an evaluation index for the presence of pain [11].

PedsQL<sup>TM</sup> was developed to measure health-related quality of life in children and adolescents aged 2 to 18 years, divided by age group: infant (2-4), young child (5-7), child (8- 12) and adolescent (13-18). The generic core of PedsQLTM 4.0 is multidimensional and applicable to the child / adolescent and the caregiver [15]. The instrument was translated and validated for Brazilian Portuguese by Klatchoian *et al* [16]. It has 23 items that deal with the following dimensions: (1) Physical Functioning (eight items); (2) Emotional Functioning (five items); (3) Social Functioning (five items); and (4) School Functioning (five items) [15].

Descriptive parametric statistics were presented as mean and standard deviation (SD). Using the software Statistical Package for Social Sciences (SPSS) version 13.0, the Shapiro Wilks and Kolmogorov-Smirnov tests were performed to verify the normality of the variables. As the data showed normal distribution, Person correlations were computed to test the relationship between different domains of HRQOL and levels of motor function, as well as pain intensity. The significance level was set at  $p < 0.05$ .

**Results**

Forty children and adolescents with CP, aged between 3 and 18 years, participated in the study. The mean age of participants was 9.8 years (SD = 4.2), of whom 50% were female and 50% male (table 1).

A total of 35% (14) of the patients presented level I of motor function (GMFCS), 10% (4) level II, 15% (6) level III, 20% (8) level IV and 20% (8) level V.

**Table 1:** Distribution of age, gender and gross motor function classification system in population of children and adolescents with cerebral palsy

Age (years)	n (%)	Gender		GMFCS Level				
		Male (%)	Female (%)	I	II	III	IV	V
3-4	6	2	4	4	0	0	0	2
5-6	4	2	2	0	0	0	2	2
7-8	2	0	2	0	0	2	0	0
9-10	8	4	4	0	2	2	4	0
11-12	12	6	6	4	2	2	2	2
13-14	4	4	0	4	0	0	0	0
15-16	2	2	0	2	0	0	0	0
17-18	2	0	2	0	0	0	0	2
Total:	40	20	20	14	4	6	8	8

Table 2 displays mean and standard deviation (SD) of HRQOL according to GMFCS of the studied sample. The mean of general HRQOL score in patient with level I of

GMFCS was 68.5 (SD = 11.5), level II was 48.8 (SD = 33.4), level III was 64.2 (SD = 6.06), level IV was 58.6 (SD = 8.6) and level V was 48.2 (SD = 6.8).

**Table 2:** Mean and SD of health-related quality of life according GMFCS in patients with CP

GMFCS	n (%)	Mean (SD)	Minimum Score	Maximum Score
I	14 (35%)	68.5 (11.5)	51.25	77.9
II	4 (10%)	48.8 (33.4)	25.16	72.5
III	6 (15%)	64.2 (6.06)	58.12	70.25
IV	8 (20%)	58.6 (8.6)	46.25	66.25
V	8 (20%)	48.2 (6.8)	42.19	55.9

\*The health-related quality of life score ranges from 0 to 100, where 0 poor quality of life and 100 excellent quality of life.

In general, the mean pain score was 10.5 (SD = 4.5). Parents or caregivers reported that pain (defined as persistent physical pain perceived during the last four weeks) was present in 30% (12) of children and adolescents with CP.

The mean of general HRQOL score was 59.8 (SD = 14.1). The mean of the HRQOL domains was: 49.2 (SD = 23.05) for physical aspect, 75.7 (SD = 18.8) for emotional aspect, 62.5 (SD = 20.5) for social aspect and 52.07 (SD = 25.9) for school activity (table 3).

**Table 3:** Mean of pain, general HRQOL and its domains in children and adolescents with cerebral palsy.

	Mean (SD)	Minimum score*	Maximum score*
Pain	10,5 ± 4,5	3	17
General HRQOL	59,9 ± 14,01	25,16	77,96
Physical aspect	49,2 ± 23,05	18,75	96,87
Emotional aspect	75,7 ± 18,8	30	100
Social aspect	62,5 ± 20,5	5	95
School activity	52,07 ± 25,9	0	80

\* The pain score ranges from 0 to 60, where 0 means no pain and 60 severe pain. The cut-off point is 14, which means moderate to severe pains.

\* The health-related quality of life score ranges from 0 to 100, where 0 means poor quality of life and 100 excellent quality of life.

There was significant correlation between pain intensity and the emotional aspect domain of HRQOL, indicating that high levels of pain were associated with lower HRQOL in this domain. Significant correlations were also found between motor function (GMFCS) and general HRQOL and the physical aspect domain of HRQOL.

There were no significant correlations between pain and the physical aspect, social aspect and school activities domains of HRQOL. There were also no significant correlations between pain and general HRQOL; pain and GMFCS; GMFCS and school activities, GMFCS and social aspect and GMFCS and emotional aspect domains of HRQOL (table 4).

**Table 4:** Correlation between general HRQOL and its domains, pain, GMFCS and age in children and adolescents with CP

		General HRQOL	Physical aspect	Social aspect	Emotional Aspect	School Activity	Pain	GMFCS
Pain	RP	-0.2420.3	-0.3500.1	0.0850.7	-0.5340.01*	0.1100.6	--	0.3710.1
GMFCS	RP	-0.4600.04*	-0.8620.0*	-0.1190.6	-0.2630.2	0.0590.8	0.3710.1	--
Age	RP	-0.0310.8	0.0420.8	-0.2710.2	0.0650.7	0.0640.7	-0.3940.08	-0.1070.6

\* Significant correlations when.  $p < 0,05$ .

**Discussion**

In the present study, parents or caregivers reported that pain was present in 30% of children and adolescents. Of patients with pain, 10% presented level I of motor function, 5% presented level III, 10% level IV and 5% level V. Although this percentage is high, it was still lower than the 51% - 78% reported by other studies [4, 6, 17, 18]. In a European multinational longitudinal study on CP, 54% of children with CP reported having experienced pain in the previous week and this was also associated with poorer quality of life<sup>4</sup>. Pain was even more frequent in a subsequent follow-up study in adolescents, where 75% of the participants reported that they experienced pain in a typical week and with girls reporting pain more often than boys<sup>6</sup>. The results found in our study were consistent with previous study performed in patients with CP, who found pain in 32.4% of the patients<sup>19</sup>.

We found that pain is associated with a low HRQOL in the emotional aspect domain, but is not related with low HRQOL in the physical aspect domain, in agreement with previous studies showing that pain reduces positive emotions, life satisfaction and their participation in daily

activities [4, 6, 7, 18]. This could be explained by the higher levels of stress of the parents being more likely to report poor quality of life in the emotional domain of HRQOL, which suggests that factors other than the severity of the child's impairment may influence the way in which parents report quality of life. In contrast, data obtained from children and parents' reports, showed significant correlations between pain and physical components of quality of life and mobility<sup>8, 20</sup>.

In the present study, the presence of pain did not differ between males and females, in contrast with previous reports<sup>6, 19</sup>. We found no significant relationship between pain and GMFCS levels, in agreement with previous reports<sup>4, 20</sup>, whereas Penner *et al*, who used reports by parents and physicians, did find significant associations<sup>21</sup>.

For children and adolescents with CP, changes in the level of motor function (GMFCS) were associated with poorer HRQOL in the physical aspect domain. However, changes in the GMFCS level were not associated with HRQOL in three domains: emotional aspects, social aspects and school activities, although the severity of disability is considered as one of the main factors affecting functional status in both children and adults with CP<sup>20, 22</sup>.

The present study indicated that although pain is a common impairment in children and adolescents with CP, it could lead to a low HRQOL only in the emotional aspect domain in these patients. In addition, it seems that GMFCS level reduced HRQOL only in the physical aspect domain. Although HRQOL seems to be more affected by parameters related to physical condition, emotional aspects may be more important indicators related to HRQOL, underlining the importance of psychological and emotional factors as predictors of pain.

There were a number of limitations to our study. First, only one generic screening item was available to assess the presence of pain, which meant that we were not able to assess the pain site, severity, duration or type of pain. Second, the cross-sectional design, convenience sampling and relatively small sample size may be factors affecting the interpretation of the results. However, larger studies should be conducted to determine the relationship between pain with these variables.

These results may contribute to incorporate standard measures for the assessment of pain, and also, a combination of self-report with parents-report should be investigated to provide a better understanding of pain and health-related quality of life in this population.

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