Functionality, school participation and quality of life of schoolchildren with cerebral palsy

Funcionalidade, participação escolar e qualidade de vida de escolares com paralisia cerebral

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Abstract

Introduction: The quality of life (QoL) of schoolchildren with cerebral palsy (CP) should be evaluated considering the functional variability of the child with CP with an extended view on functionality in the school context and the determinants of QoL. Objective: to evaluate the school participation and the QoL of schoolchildren with CP in Recife’s municipal public network, as well as to analyze the influence of GMFCS levels and motor performance on these variables in the study population. Method: This is an exploratory observational study whose evaluation model was structured based on the International Classification of Functioning, Disability and Health (CIF). Children with CP were classified in the Gross Motor Function Classification System (GMFCS) and evaluated according to Gross Motor Function Measure-88 (GMFM-88). The School Function Assessment (SFA) and the Quality of Life Questionnaire for Cerebral Palsy (CPQOL-Caregiver) were answered by teachers and mothers, respectively. Results: In the study population, the higher the GMFCS level, the lower the participation and the lower the independence in school activities, aspects that add to the QoL
construct, mainly with less functionality, less emotional well-being and self-esteem, and lower family health. **Conclusion:** GMFCS levels and motor performance of schoolchildren with CP can affect school participation and QoL, and it is important to consider each child’s individual and contextual factors. These results can help the development of functional, care, inclusion and pedagogical strategies for students with CP.

**Keywords:** International Classification of Functionality, Disability and Health. Special Education. Disabled Children. School Health Services.

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**Introduction**

The biomedical model for understanding disability, restricted to injury and the need for corporate care, confronts the social model of difficulty based on social inclusion and oppression suffered by the person with a disability [1]. The biopsychosocial understanding of the health of people with disabilities was enhanced by the vision of human functionality brought by the International Classification of Functionality, Disability and Health (ICF) that conceptualizes it based on the interaction model of health condition, corporate aspects, performance in activities and social participation, considering environmental and personal factors [2].

In the life cycle of children with Cerebral Palsy (CP), the school can be considered an important space for social participation. School indicators for 2018 point to an increase of 33.2% in the enrollments of special education in the Brazilian school network, however, the census surveys do not consider the information on school inclusion of children with disabilities, this way indicating the need for studies related to this population [3,4].

Studies that evaluated the level of gross motor function and the school participation of children with CP point out a worsening in the performance of school activities and greater restrictions in school participation in children with higher levels of the Gross Motor Function Classification System (GMFCS) [5-9]. However, these studies lack strategies for evaluating the functionality of the student with CP that consider the functional variability of the child with CP and that broaden the view...
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In view of the need for studies that analyze the functionality, school participation and QoL of schoolchildren with CP and considering the national fragility of census data on children with CP, this study sought to assess school participation and QoL of schoolchildren with CP in the network of municipal public health of Recife, as well as to analyze the influence of GMFCS levels and motor performance on these variables in the studied population.

Method

The study was carried out in the public network of Recife (in Pernambuco state (PE)), Brazil, between August 2018 and March 2019, having a descriptive observational character considering data from students with CP, so that teachers and mothers were also accessed to collect information. The age range of 5 to 10 years was defined because it is common to the application of the assessment instruments used and because it precedes the appearance of the physiological effects of adolescence [10].

Students with CP were identified by providing data from the Secretaria de Educação do Recife via Setor de Informações e Ordenamento do Recife, indicating 374 students with physical disabilities in the network in 2018, including 147 children with physical disabilities from 5 to 10 years old. It was necessary for the responsible researcher to access the schools, by means of visits and telephone contacts to check the medical reports proving the CP, established by the International Classification of Disease (ICD) G80.

Students with CP who had associated diagnoses (severe orthopedic changes, neuromuscular diseases, cardiopulmonary decompensation) or severe cognitive changes that limited the application of the motor performance analysis instrument were excluded from the study. For this, medical reports and opinions issued by the pedagogical team were considered.

The collections were carried out at night, with the child, the legal guardian and the teacher who accompanies the child most of the time in the school routine. The procedures were performed by a trained researcher, in a previously prepared school environment, in a reserved space, allowing free mobility of the child, who used light clothes, according to the rules of the instruments application manuals.

The evaluation of students with CP followed the ICF model shown in Figure 1.

Cerebral Palsy
(Disorder or Disease)

GMFCS and CPQoL-Caregiver domains
(FUNC, EWS, PID)

GMFM-88 and CPQoL-Caregiver domains
(SWA, FUNC, PPH)

SFA part I and CPQoL-Caregiver domains
(SWA, FUNC, PPH)

SFA part II and CPQoL-Caregiver domains (SWA, BWS, PID, ACS, FH)

Domains of CPQoL-Caregiver (EWS, PID)

Figure 1 - Proposal for evaluating the functionality of students with CP.

Initially, the students were classified according to the functional level by the GMFCS, an instrument already adapted for the Brazilian population [11], which stratifies the child with CP at the following levels: I - without limitations for walking; II - wanders with limitations; III - walking with the use of manual mobility resources; VI - self-mobility with limitations, being able to use a motorized chair; and V - transported in adapted wheelchairs [12,13].

The evaluation of motor performance was performed using the Gross Motor Function Measure-88 (GMFM-88), a scale used as an observational measure that verifies the
performance and quality of movement in a controlled environment, targeted at the age group from 5 months to 16 years [14]. This instrument has five (5) dimensions that measure scores between 0 (does not start the movement) to 3 (starts the movement). The sum of the scores of the items of the dimensions generates total scores in gross values, which can be converted into percentiles. The total score can be generated from the average of the total percentage score for each dimension.

Participation and the degree of independence in school activities were assessed using the School Functional Assessment (SFA), an instrument divided into three parts (participation, help with tasks and performance) which, although not validated for Brazilian children, American studies support in its validity and reliability [15,16]. The gross SFA scores allowed to quantify, respectively, the variable of participation (part I) and independence in school activities (part II), so that higher scores indicate greater participation and independence of the child in school activities.

Part I of the SFA allows quantifying the child’s participation in seven school environments (regular or special class, playground, transportation, bathroom, transitions and meal times) with scores from 1 to 6, indicating from “extremely limited participation” in score 1, to “total participation” in score 6.

Part II concerns assistance with physical tasks, optional tasks (climbing/descending stairs, written work, use of computers and equipment) and cognitive/behavioral tasks quantified in terms of the level of assistance and adaptation offered for their performance. The scores are presented as: 1. extensive assistance/adaptation; 2. moderate assistance/adaptation; 3. minimal assistance/adaptation; 4. no assistance/adaptation.

To assess the QoL of students with CP, the Cerebral Palsy Quality of Life Questionnaire (CPQoL) was used in the version answered by the caregiver (CPQoL-Caregiver). This instrument has seven domains: Social Welfare and Acceptance (SWA); Functionality (FUNC); Participation and Physical Health (PPH); Emotional Well-Being and Self-Esteem (EWS); Access to Services (ACS); Pain and Impact of Disability (PID); and Family Health (FH). It was developed by international experts [17,18] and allows the choice of scores from 1 (very sad) to 9 (very happy), already adapted for the Brazilian population [19], whose analysis can be done by means of scores converted into scale from 0 to 100, according to the instrument’s manual [20]. In the present study, CPQoL-Caregiver was used, considering the fact that the children’s mothers were primary caregivers of the evaluated students.

The evaluation questionnaire of the Associação Brasileira de Empresas e Pesquisas (ABEP) was used to collect socioeconomic information, answered by the children’s mothers. This instrument uses national criteria for economic classification which stratifies into descending classes A, B1, B2, C1, C2, D-E [21].

For the statistical analysis of the data, the software Statistical Package for the Social Science version 20.0 was used. Qualitative variables were described in absolute frequency and percentile, and quantitative variables by means of standard and standard deviation. Soon after, the Shapiro-Wilk test was performed to verify the normality of the data, being identified the quantitative variables of normal distribution (scores of part I of the SFA and of the domains of CPQoL-Caregiver) and non-parametric distribution (scores Part II of the SFA and GMFM-88). The t test of a sample for intra-level comparison of GMFCS and QoL domains was used.

The Spearman correlation test (ρ) was used to correlate the total scores of parts I and II of the SFA and of the CPQoL-Caregiver domains with the GMFCS levels and the gross scores of the GMFM-88. Therefore, the correlations were considered weak if ′= 0.3|ρ|<0.5′; moderate, if ′= 0.5|ρ|<0.7′; and strong if ′|ρ| >0.7′, positive if directly proportional and negative if inversely proportional, using p<0.05 as the level of significance [22].

To identify whether there were differences in QoL, participation and school independence according to the classification of children’s motor function, the sample was stratified into groups by the GMFCS. The Kruskal-Wallis test was used with the Mann-Whitney post-hoc test for part II of the SFA and the One-Way Analysis of Variance (ANOVA) test with Tukey’s post-hoc test for part I of the SFA and for the CPQoL-Caregiver domains, also considering the level of significance p<0.05.

The study followed the rules of Resolution 466/2012 of Conselho Nacional de Ética em Pesquisa (CONEP), submitted to the Comitê de Ética em Pesquisa do Centro de Ciências da Saúde (CCS) of Universidade Federal de Pernambuco (UFPE), under CAAE 92234618.0.0000.5208, with opinion approval number 2,891,749. All teachers and mothers of schoolchildren with CP were instructed on the importance of research, its risks and benefits, prior to signing the Free and Informed Consent Terms (ICFs), agreeing to participate in the study, so that, in return, informative folders and guidance on care and handling for schoolchildren with CP were distributed.
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Figure 2 - Sample characteristics and total weight score of the GMFM-88$^1$ of children with Cerebral Palsy (CP) enrolled in public schools in the municipal network of Recife - PE/Brazil, 2019.

Results

After an active search in 81 schools and data collection from 92 children, 17 students with CP were included in the study, as shown in Figure 2.

Five children (29.4%) were classified in GMFCS I, five (29.4%) in GMFCS II, four (23.5%) in GMFCS IV and three (17.6%) in GMFCS V. There were eleven (64.7%) male and six (35.2%) female, with a mean age of 8.1 ± 1.8 years, with ten (58.8%) students with CP classified in the economic classes D and E of ABEP. Table 1 presents the descriptive characteristics of the children evaluated, making it possible to identify lower total gross scores and weight averages of the GMFM-88 in children with CP classified in GMFCS IV and V.

Table 1 - Sample characteristics and total weight score of the GMFM-88$^1$ of children with Cerebral Palsy (CP) enrolled in public schools in the municipal network of Recife - PE/Brazil, 2019

| Child* | Gender | Age (years) | GMFCS$^1$ | Topographic Distribution | GMFM-88$^2$ | ABEP$^3$ class |
|--------|--------|-------------|-----------|--------------------------|-------------|----------------|
| 1      | Female | 9           | IV        | Quadriplegia             | 17.9%       | D-E            |
| 2      | Female | 9           | II        | Diplegía                 | 88.91%      | D-E            |
| 3      | Male   | 9           | II        | Hemiplegia E             | 85.75%      | C1             |
| 4      | Female | 5           | I         | Hemiplegia E             | 93.44%      | D-E            |
| 5      | Male   | 9           | IV        | Diplegía                 | 30.12%      | D-E            |
| 6      | Female | 7           | I         | Hemiplegia E             | 96.55%      | D-E            |
| 7      | Male   | 10          | IV        | Diplegía                 | 12.58%      | C2             |
| 8      | Male   | 10          | I         | Hemiplegia E             | 96.55%      | B2             |
| 9      | Female | 7           | I         | Hemiplegia D             | 96.55%      | D-E            |
| 10     | Male   | 10          | IV        | Quadriplegia             | 12.58%      | C2             |
| 11     | Male   | 8           | I         | Hemiplegia D             | 97.35%      | C2             |
| 12     | Male   | 10          | V         | Quadriplegia             | 16.62%      | C2             |
| 13     | Male   | 7           | IV        | Diplegía                 | 35.08%      | D-E            |
| 14     | Male   | 6           | V         | Quadriplegia             | 11.32%      | D-E            |
| 15     | Male   | 10          | V         | Quadriplegia             | 1.56%       | D-E            |
| 16     | Female | 10          | II        | Hemiplegia E             | 93.46%      | D-E            |
| 17     | Male   | 8           | II        | Diplegía                 | 76.09%      | C1             |

Note: Source: Research Data, 2019. Caption: $^1$ = Gross Motor Function Classification System; $^2$ = Gross Motor Function Measure-88; $^3$ = Socioeconomic classes of the Brazilian Association of Research Companies.
As for school aspects, shown in Table 2, significant differences were observed in school participation between children with CP from GMFCS I with those from GMFCS IV \((p=0.007)\) and V \((p=0.002)\), as well as between children classified in GMFCS II with those of GMFCS IV \((p=0.022)\) and V \((p=0.007)\). Regarding assistance in school tasks, a significant difference was found between children with CP classified in GMFCS I with GMFCS IV \((p=0.043)\) and GMFCS V \((p=0.001)\), as well as in those of GMFCS II with those of GMFCS IV \((p=0.011)\) and GMFCS V \((p=0.001)\), with a strong negative correlation for school participation \((p<0.01, \rho = -0.818)\) and help with tasks \((p<0.01, \rho = -0.721)\).

Table 2 - Means, standard deviation, differences between GMFCS levels and the relationship between SFA and CPQoL-Caregiver variables by GMFCS level of students with Cerebral Palsy (CP) in the municipal public school system in Recife, Brazil, 2019

| GMFCS | I     | II    | IV    | V     | ANOVA one-way \(p\) value | Spearman's coefficient (\(\rho\)) |
|-------|-------|-------|-------|-------|---------------------------|----------------------------------|
| Parts of the SFA |       |       |       |       |                           |                                  |
| Participation | 32.6 (±8.96) | 29.6 (±9.07) | 13.0 (±3.16) | 8.0 (±2.64) | <0.001* | -0.818*# # |
| Assistance in Tasks | 134.0 (±28.59) | 142.6 (±14.85) | 84.25 (±30.85) | 43.33 (±2.30) | <0.001** | -0.721*# # |
| Social Welfare and Acceptance | 89.5 (±6.5) | 87.7 (±9.1) | 90.8 (±6.8) | 88.8 (±2.4) | 0.929 | 0.011 |
| \(p – value^{ii}\) | 81.1 (±15.5) | 81.4 (±13.6) | 77.3 (±2.3) | 46.8 (±10.8) | 0.008i | -0.581* |
| Functionality | 82.2 (±12.4) | 74.9 (±17.6) | 79.5 (±14.5) | 56.0 (±18.3) | 0.173 | -0.363 |
| \(p – value^{ii}\) | 93.2 (±9.1) | 86.6 (±10.1) | 85.4 (±11.0) | 78.4 (±10.6) | 0.297 | -0.513* |
| Participations and Physical Health | 68.7 (±14.8) | 74.1 (±21.0) | 60.1 (±19.2) | 49.6 (±14.1) | 0.303 | -0.372 |
| \(p – value^{ii}\) | 42.8 (±30.2) | 43.4 (±28.3) | 35.9 (±19.5) | 46.8 (±20.6) | 0.951 | -0.028 |
| Emotional Well-Being and Self-Esteem | 73.1 (±11.6) | 66.2 (±25.9) | 64.8 (±21.5) | 37.5 (±6.2) | 0.122 | -0.536* |

Caption: * = \(p<0.05\) through Anova one-way with Tukey's post hoc, identifying differences between groups I-IV \((p=0.007)\), IV \((p=0.002)\), II-IV \((p=0.043)\) and II-V \((p=0.007)\). ** = \(p<0.05\) through Mann-Whitney for non-normal distribution identifying difference between groups I-IV \((p=0.043)\), IV \((p=0.001)\), II-IV \((p=0.011)\) and II-V \((p=0.001)\). i = \(p<0.05\) through Anova one-way with Tukey's post hoc, identifying differences between groups V-I \((p=0.01)\), V-II \((p=0.01)\) and V-IV \((p=0.029)\). * = Significant Spearman correlation test for \(p<0.05\) of moderate intensity. #* # = Spearman's correlation test significant for \(p<0.01\) of strong intensity. li = \(t\) test of a sample with significance level \(p<0.05\). Source: Research Data, 2019.

Regarding QoL, also shown in Table 2, only the FUNC domain of CPQoL-Caregiver showed a difference between students with CP from GMFCS V with those from GMFCS I \((p=0.01)\), II \((p=0.01)\) and IV \((p=0.029)\), with a moderate negative correlation for the FUNC domains \((p<0.05, \rho = -0.581)\), EWS \((p<0.05, \rho = -0.513)\) and FH \((p<0.05, \rho = -0.536)\). All QoL domains showed intra-level differences in GMFCS, except for the Principal Idea Domain (PID) in GMFCS V students \((p=0.06)\).

In the correlation of the total gross score of the GMFM-88 with the SFA and CPQoL-Caregiver domains, shown in Table 3, there was a strong positive relationship between motor performance and
participation \((p=0.001, \rho = 0.876)\) and assistance in tasks \((p=0.001, \rho = 0.843)\), as well as a moderate and positive correlation between the motor performance of students with CP and the FUNC domains \((p=0.046, \rho = 0.490)\) and FH of the CPQoL-Caregiver \((p=0.028, \rho = 0.531)\). Thus, these data indicated that students with CP assessed who had higher motor performance had better functionality, greater participation and school independence, and whose caregivers were healthier.

### Table 3 - Correlation of the total gross score of the GMFM-88 with the SFA and CPQoL-Caregiver domains of students with Cerebral Palsy (CP) from Recife, Brazil, 2019

| Correlation coefficient | Participation | Assistance in Tasks | Social Welfare and Functionality | Participation and Physical Health | Emotional Well-Being and Self-Esteem | Access to Services | Pain and Impact of Disability | Family Health |
|------------------------|---------------|---------------------|---------------------------------|----------------------------------|-------------------------------------|-------------------|-------------------------------|--------------|
| Correlation strength    | Strong        | Strong              | -                               | Moderate                         | -                                   | -                 | -                             | Strong       |
| Correlation strength    | 0.876         | 0.843               | -0.054                          | 0.49                             | 0.285                               | 0.374             | 0.351                         | 0.138        |
| Correlation strength    | 0.0001        | 0.0001              | 0.836                           | 0.046                            | 0.267                               | 0.14              | 0.167                         | 0.597        |
| Correlation strength    | Strong        | Strong              | -                               | Moderate                         | -                                   | -                 | -                             | Strong       |

Source: Research Data, 2019.

### Discussion

These findings suggest that, in the population studied, the higher the level of the GMFCS, the lower the participation and less independence in school activities, added to the QoL construct, with less functionality, less emotional well-being and self-esteem and less family health.

The use of assessments based on the ICF allows for a better interprofessional dialogue and direction of strategies for biopsychosocial health [2], so that the concepts of well-being, functionality and QoL are very close and need a good operational direction of the instruments to be used [23].

Understanding that functional aspects are only one of the determinants of QoL of students with CP [24], the use of instruments related to body structure and function and the levels of activity and participation of children, according to the ICF model, enabled a consistent assessment of students with CP. The FUNC domain of CPQoL-Caregiver considers issues related to the use of body parts and the skills of daily routine, comprising the scope of part I of the ICF, aspects complemented by part I of the SFA. Part II of the SFA and other CPQoL domains (EWS, SWA, PID, ACS and FH) include contextual factors of the ICF.

The findings point to less school participation and less independence in routine school activities among students with CP classified at higher levels of the GMFCS. These aspects were better understood with the finding of a strong negative relationship between motor performance and school outcomes. The negative relationship between the scores of the SFA parts and the GMFCS levels was seen in another study, indicating less school participation and independence in children with CP at higher levels of the GMFCS [5]. However, in this study, only one child was classified in GMFCS IV and there were no children classified in GMFCS V and aspects related to contextual factors were not analyzed by the researchers.

National studies indicate the negative relationship between motor performance and school participation of children with CP [25], also with children with CP classified at levels I, II and III. These results reinforce nuances about the functionality of schoolchildren with CP classified in GMFCS IV and V, considering the development of inclusive strategies. For that, the school’s partnership with other professional categories [26,27], structuring of collaborative consultancies [28], specific training on CP [29] and environmental readjustments [25,30] can be suggested.

These strategies do not detract from the focus that should also be given to students with GMFCS CP I, II and III, which also deal with limitations in school activities and restrictions on participation [25].

Functional aspects also influenced the QoL of students with CP, according to CPQoL-Caregiver. The FUNC domain in students with CP from GMFCS V showed a difference with GMFCS I, II and IV, with a moderate negative relationship. Recent studies with other instruments...
for assessing the QoL of children with CP also identified
that children with CP with greater motor limitations and
higher levels of GMFCS had lower scores in the domains
of QoL related to functionality and social interaction
[31,32].

It is important to consider that CPQoL is the first
specific instrument to measure the QoL of children with
CP in clinical practice, with excellent psychometric prop-
erties and adequate application time [33]. In studies
using the two versions of CPQoL, aimed at children and
caregivers, a negative relationship was identified with
GMFCS and FUNC [34,35], a finding that in the present
study was complemented by the functional perspective
in the school context.

Another finding of the present study concerns the
negative influence of emotional aspects and self-esteem
in schoolchildren with CP of higher levels of GMFCS,
corroborating with studies that found lower scores
in emotional aspects in children with CP of level V of
GMFCS, using a general instrument of QoL [36], and
greater influence of emotional well-being rather than
physical well-being, as a predictive factor for QoL of chil-
dren with CP, also found in the scientific literature [37].

In contrast, studies that used CPQoL identified high-
er scores in the domains related to the emotional and
social aspects of Finnish CP children, according to the
parents' perception [34,35]. However, it is worth men-
tioning that part of the questions of the CPQoL-caregiver
that make up this domain ("How do you think your child
feels about life in general?"; "How do you think your child
feels about himself?"; "How do you think your child feels
about his future?") require a broad perception of the
caregiver, enabling a bias to consider the caregiver's percep-
tions more than the child itself.

Socioeconomic aspects are highlighted as factors
that can influence QoL outcomes [38,39]. The social vul-
nerness of children with CP in public schools in Recife
can be expressed by the municipal human development
index of 0.772, being located in the 216th position of
the national ranking [40]. Such a context of vulnerability
may be more prominent in children with CP with lower
motor performance and classified in higher levels of
GMFCS, which showed signs of greater caregiver bur-
den [41]. Studies point out socioeconomic conditions,
type of CP, caregiver's mental health as determinants of
QoL for both [42], where health care and social support
strategies are beneficial routes [43].

It is important to consider that the other EWS,
PPH, PID and ACS domains of CPQoL-Caregiver did
not show differences regarding the levels of GMFCS or
relationships with the motor performance of the chil-
dren assessed, demonstrating the subjective and indi-
vidual perception of QoL, dissociating the view of many
professionals and researchers that QoL is determined
only by functionality and suggesting the need for greater
monitoring of the daily routine of children with CP, as
neuromotor impairment will not always correspond
to low QoL [44]. As demonstrated in the present study,
students with CP of the same functional level showed
differences in the QoL domains of CPQoL-Caregiver;
pointing out the subjectivity of the caregiver's perception
in these aspects and the individuality of the children
in the face of a small sample.

Based on the literature survey, to date, no studies
using the associated GMFM-88, SFA and CPQoL have
been found. The model followed by the present study
facilitated the understanding of CP in the school con-
text, considering tools that analyzed the relationships
of body structure and function, levels of activity and
participation and contextual factors of students with
CP, guaranteeing interprofessional dialogue and helping
functional, inclusive and educational activities for
students with CP.

This study had a clinical and epidemiological nature
when evaluating, in line with the ICF, the functionality
and QoL of students with CP, in view of the data collect-
ed from the municipal public school system. The small
number of children with CP enrolled suggests the need
for better planning of inclusive actions, and epidemi-
ological studies that identify where these children are.

It is worth highlighting the difficulty encountered
by the respondents regarding the development of the
study before an atypical population, in a situation of
vulnerability and heterogeneous in the multiple bio-
psychosocial aspects. In addition, the access difficulties
faced by researchers both in the search for information
and in direct contact with children, reinforce the need
for rearrangements in the information and data control
systems for this population.

Conclusion

Considering the ICF as a guiding tool and interpro-
fessional dialogue, it was possible to detail the function-
ality of children with CP and its relationship with the
health of the caregiver. New studies are suggested to
assess other determinants of school participation and
QoL of students with CP.
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