

# Discriminant validity of a social and functional performance protocol for children with cerebral palsy

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## ABSTRACT

Cerebral Palsy (CP) encompasses a group of permanent disorders of movement and posture development, attributed to non-progressive damage that occurs during fetal development or in the infant brain. As consequences to the motor skills, there can occur impairments in daily life abilities, interfering in independent ambulation, hygiene, and clothing care, but also in social, behavioral, and cognitive activities, causing a negative impact on the health and welfare of the child and its family. The International Classification of Functioning, Disability, and Health (ICF) is a classification system on functioning and disability and, because it is an extensive and complex classification, there is the possibility of grouping the more relevant codes for distinctive disorders forming the Core Sets. Based upon this idea an instrument named *Protocolo de desempenho Social e Funcional de crianças com Paralisia Cerebral* (DFS-PC) (Functional and Social Performance Evaluation Protocol for Children with Cerebral Palsy) was created. **Objective:** To evaluate the discriminant validity of the DFS-PC protocol to verify whether it is sensitive to the functional performance and social participation of cerebral palsy children when compared to typical development children. **Method:** It consisted in the application of the Functional and Social Performance Evaluation Protocol for Children with Cerebral Palsy (DFS-PC) to the caregivers of CP children and children with typical development. **Results:** The DFS-PC was considered sensitive to detect differences between CP children and children with typical development, presenting significant differences in 12 of the 16 domains when using the Mann-Whitney Test. **Conclusion:** This protocol is considered valid and suitable for use within the population of children with cerebral palsy.

**Keywords:** International Classification of Functioning, Disability and Health, Child, Cerebral Palsy

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## INTRODUCTION

Cerebral palsy (CP) encompasses a group of disorders of development of movement and posture, attributed to non-progressive disturbances that occur in fetal development or the infant brain.<sup>1</sup> It is the most common cause of physical disability in childhood, and imposes varying limitations on motor functions, so that some children walk independently with or without auxiliary devices, while others use motorized wheelchair or need to be transported by an adult.<sup>2,3</sup>

In light of the diversity of CP two classification systems have been used; first is the Gross Motor Function Classification System expanded and revised (GMFCS E&R), which classifies voluntarily initiated movement with an emphasis on sitting, transfers, and mobility at five levels based on functional mobility or limitation in activity.<sup>4,5</sup> Then there is the Manual Ability Classification System (MACS), which classifies the performance during activities of daily living at home, at school, or in the community, without focusing on the affected side, or the type of manual dexterity, based on five levels, with Level I including the handling objects easily and level V for those who have severely limited ability to manipulate objects.<sup>6,7</sup>

The motor difficulties present in CP limit the experiences of the affected child as to interacting with people, objects, and events, for manipulating objects, repeat actions, have body control, and develop their body scheme, and may lead to gaps in areas of perception, cognition, language, and socializing.<sup>7,8</sup>

The sensory, perceptual, and cognitive disorders associated with motor function can alter their vision, hearing, touch, and their ability to interpret the sensory and/or cognitive information; these can be consequences of primary disorders, assigned to the cerebral palsy or secondary disorders, as a result of the limitations of activities of expressive or receptive communication, and the ability to interact socially.<sup>1,7</sup>

As a consequence of all the previously listed aspects, there may be damage to the skills for participation in activities of daily living, favoring a negative impact on the health and welfare of children and their families, highlighting the need for a very detailed assessment, providing a broader perspective on functionality and disability, both in research and in clinical practice.<sup>9,10,11</sup>

The changes in the focus of health indicators for the consequences of diseases have mobilized people worldwide to fight for a more inclusive society<sup>12</sup> with recommendations for

a broader perspective on functionality and inability both in research and in clinical practice.<sup>13</sup> In this sense, some approaches suggest a perception of disability that goes beyond the physiological changes, so as to consider this person as a socialized subject.<sup>14,15</sup>

The International Classification of Functioning, Disability, and Health (ICF) is an extensive and complex classification system for function and disability that covers various aspects (body functions, structures of the body, activities and participation, and environmental factors). The main contribution of the ICF is to allow a shift in focus from the consequences of diseases to functionality and how it can be improved in order to achieve a productive and fulfilling life,<sup>16,17</sup> serving as a guide to interdisciplinary communication.

The manifestations of disability and health conditions in children and adolescents are different from what is found in adults in relation to the nature, impact, and intensity, so the WHO presented the first classification derived from the ICF in 2006: the International Classification of Disability and Health for Children and Young People (ICF-CY), which is sensitive to the changes that occur during the development of a child and embraces diverse environments and ages.<sup>18</sup>

Based on the fields of the ICF-CY (version for children and young people),<sup>18</sup> an evaluation protocol was drafted for functional performance and social participation - DSF-PC<sup>19</sup> in an attempt to understand how the functional performance of the child with cerebral palsy is influenced by the environment in which they live and how it interferes in their social participation, according to the vision of the parents/caregivers. As this protocol targets the caregivers of children with cerebral palsy and non-specialists in the area of neuropsychiatry, the choice was to structure it in the form of a questionnaire to facilitate its applicability, following the model of the DSF-84 protocol based on ICF for amputees of lower limbs, proposed by Monteiro et al.<sup>20</sup>

The DSF-PC followed full methodological rigor from its development to its application, being in accordance with the ultimate goal.<sup>21</sup> Its preparation considered practicality, reproducibility, and the cultural and social characteristics of potential respondents (parents of children with CP).<sup>22</sup>

Initially, all codes of the ICF<sup>16</sup> and ICF-CY<sup>18</sup> identified as essential to describe the characteristics of children with a diagnosis of CP were selected, grouping those considered repetitive and excluding those less relevant.<sup>19</sup> The selection of these codes was an attempt

to measure the impact of the disease not only in relation to physical incapacity, but also the problems related to the disease such as the emotional, social, family, and environmental impact in terms of accessibility;<sup>23</sup> it also offered the possibility of measuring the impact of the disease on the subject and the environment around him regarding his quality of life.<sup>22</sup> This comprehensive overview of the subject is extremely important since the onset of motor CP is accompanied by sensory, perceptual, cognitive, communicative, and behavioral problems, as well as epilepsy and secondary muscle-skeletal problems.<sup>24</sup>

By following the suggestions of Alexandre et al.<sup>25</sup> and Mokkink et al.<sup>26</sup> for construction and validation of assessment tools, the Protocol of Social Performance and Functional Status of Children with Cerebral Palsy (DSF-CP), was tested as to its psychometric properties in relation to the face validity, validation of content, inter and intra examiner reliability, and internal consistency and was considered valid, reliable, and with excellent internal consistency.<sup>19</sup>

## OBJECTIVE

Continuing the process of validating the said Protocol, the objective of this study was to examine the discriminant validity of the DSF-PC, in order to see whether it was sensible to differentiate the difficulties presented by the target population in relation to children with motor development with ages and similar socioeconomic conditions.

## METHOD

This was a cross-sectional rather than experimental study and a quantitative analysis. The study was approved by the Ethics Committee of the *Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto* (case No. 6601/2012) and the parents signed an informed consent form.

### Data collection procedure

The DSF-PC protocol was applied to 60 caregivers of children between 4 and 12 years of age, divided into an experimental group comprised of 30 caregivers of children with a clinical diagnosis of CP, called CP group, and a control group comprised of 30 caregivers of children with typical development, called TD Group, with age, gender and socioeconomic classification as similar as possible between

the groups, presented in Table 1, in order to verify the discriminant validity of the protocol.

This step was performed at the Center for Rehabilitation of the *Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto* (HCFMRP). The inclusion criteria for the experimental group was to have a clinical diagnosis of cerebral palsy, regardless of its topography or clinical type, and to be between 4 and 12 years of age; in the control group, the inclusion criteria was to be between 4 and 12 years of age and have no type of physical or cognitive impairment.

The DSF-PC can be self-administered; however, to ensure the reliability of data collection, the decision was for the researcher to read the protocol along with the caregivers and, at the end of each question, they would choose among the answer choices as to what level their child fit: 0 = no difficulty to 4 = complete difficulty, but there were variables: 8 = unspecified difficulty, and 9 = does not apply. During the application of the domains the questions O = Assistive products and technology and P = Services, Systems, and Policies, which included characterizing barriers and facilitators. In order to facilitate the understanding of these terms by caregivers, a leaflet was given to the parents containing a visual scale with color and explanations of the graduations of responses, as shown in Chart 1.

**Analysis of the data collected**

Comparing scores between the groups used the calculated the average of the scores by size, and to calculate if there was a significant difference between the answers given by caregivers of children with Cerebral Palsy compared to children with typical development, the non-parametric Mann Whitney Test was used (comparing two independent groups) with correction for multiple comparisons by Holm-Bonferroni,<sup>27</sup> allowing a probability of error of the first kind an alpha value of 5%.

In relation to the score of 8 and 9, because these items do not mean a quantitative measurement, item 9 received a value of 0, because it is an item not applicable and the item 8 was treated as missing data, being replaced by the mean of the remaining items for that particular dimension.

**RESULTS**

The Protocol of Social Performance and Functional Status of Children with Cerebral

**Table 1.** Characterization of the participants

	The experimental group (%)	The control group (%)
Caregivers	Mothers (86.66%)	Mothers (73.33%)
	Mother/Father (6.66%)	Mother/Father (6.66%)
	Grandmother (6.66%)	Mother/grandmother (3.33%)
		Grandmother (6.66%)
		Aunt (3.33%)
		Shelter (3.33%)
Socioeconomic level	A2 (0%)	A2 (6.66%)
	B1 (6.66%)	B1 (20%)
	B2 (16.66%)	B2 (23.33%)
	C1 (46.66%)	C1 (26.66%)
	C2 (20%)	C2 (16.66%)
	D (3.33%)	D (3.33%)
GMFCS	23.33% Level I	
	30% Level II	
	16.66% Level III	Does not apply
	16.66% Level IV	
	13.33% Level V	
Topography	76% spastic Bilateral	
	10% Unilateral R	
	10% Unilateral L	Does not apply
	3.33% Ataxia	
Therapies	16.6% Physiotherapy	
	16.6% Physiotherapy/Hydrotherapy	
	40% Physiotherapy/Occupational Therapy	
	3.3% Physiotherapy/Occupational Therapy/Hydrotherapy	Does not apply
	10% Physiotherapy/Speech Therapy	
	10% Physiotherapy/Speech Therapy/Occupational Therapy	
	3.3% Physiotherapy/Speech Therapy/Occupational Therapy/Psychopedagogy	
Orthoses	30% fixed AFO	
	53.33% Bilateral articulated AFO	
	3.33% orthosis of reaction to the ground	
	3.33% Sling	Does not apply
	3.33% Extending brace	
	3.33% Palmar Splint	
	10% does not use	

**Chart 1.** Visual Scale for the areas O and P to facilitate understanding of the concepts of barriers and facilitators

Barriers		Facilitators	
0	No barrier (Nothing hinders their activities)	0	No facilitator (No adaptation)
- 1	Slight barrier (Hinders, but does not prevent the activities)	+ 1	Slight facilitator (Some help)
- 2	Moderate barrier (Hinders and prevents some activities)	+ 2	Moderate facilitator (Facilitates, but less than half of my activities)
- 3	Severe barrier (Hinders and prevents most activities)	+ 3	Moderate facilitator (Facilitates most of my activities)
- 4	Complete barrier (Hinders and prevents all the activities)	+ 4	Complete facilitator (Facilitates my whole life)

Palsy (DSF-PC), has 109 questions divided into 16 dimensions as follows: A - General State of Awareness, B - Capacity for Attention, Memory, and Planning, C - Auditory Perception, D - Communication, E - Visual perception, F - Sensory Perception, G - Feeding and Swallowing, H - Sphincter Control and Hygiene, I - Functions Related to Movement, J - Postural Changes, K - Manual Skills, L - Walking and Getting Around, M - Personal Care, N - Social Participation, O - Products and Assistive Technology, and P - Services, Systems, and Policies.

Each question can be classified in terms of severity between 0 and 4, meaning that the more severe the higher the final score. Despite the average scores of children with CP being higher in almost all dimensions (except in the dimension O), a significant difference was observed with the TD children in most aspects evaluated, except for the auditory perception (domain C), visual perception (domain E), sensory perception (domain F), and products and assistive technology (domain O), as shown in Table 2.

The significances observed in the table above can be anchored together at an alpha level of 0.05.

These results indicate that the DSF-PC was quite sensitive at detecting differences between the patients with CP and the typical children, because all areas that have significant differences between the groups (H - Sphincter Control and Hygiene, I - Functions Related to Movement, J - Control and Postural Changes, K - Manual Skills, L - Walking and Getting Around, and M - Personal Care) are related to motor skills; hence it can be concluded that children with CP have worse functional performance than those in the control group. There was also a significant difference between the TD and CP group regarding social participation, i.e., children with Cerebral Palsy have less social participation than children with typical psychomotor development.

## DISCUSSION

Comparing the performance of children, significant differences were found between the scores of the CP group and the TD group in most areas, except in the areas C (auditory perception), E (visual perception), F (sensory perception), and O (products and assistive technology), according to the Mann-Whitney Test.

In domain A - general state of awareness and in domain B - capacity for attention, memory, and planning, there was a significant difference between the groups, since the

**Table 2.** Average values of scores in each domain, according to groups (results of the Mann-Whitney test was used for comparison of scores between the groups)

DOMAINS	GROUPS		MANN-WHITNEY TEST	
	CP	TD	p Value Observed	p value (*) Corrected
A - General State of Awareness	0.93	0.17	0.0012	0.0071
B - Capacity for Attention, Memory, and Planning	1.19	0.23	<0.0001	0.0031
C - Auditory Perception	0.18	0.10	0.9455	0.0500
D - Communication	0.79	0.11	0.0014	0.0083
E - Visual Perception	0.16	0.03	0.8993	0.0250
F - Sensory Perception	0.04	0.03	0.3299	0.0125
G - Feeding and swallowing	0.33	0.01	0.0015	0.0100
H - Sphincter Control and Hygiene	1.94	0.00	<0.0001	0.0033
I - Functions related to Movement	1.63	0.00	<0.0001	0.0036
J - Postural changes and control	1.04	0.00	<0.0001	0.0038
K - Manual Skills	0.94	0.01	<0.0001	0.0042
L - Walking and Getting around	2.00	0.00	<0.0001	0.0045
M - Personal Care	2.11	0.12	<0.0001	0.0050
N - Social Participation	0.89	0.12	<0.0001	0.0056
O - Products and Assistive Technology	0.19	0.23	0.3559	0.0167
P - Services, Systems, and Policies	2.04	0.71	<0.0001	0.0063

(\*) CORRECTION FOR MULTIPLE COMPARISONS:(Holm-Bonferroni Technique)

questions related to the alert state, understanding, planning, and memory, praxis and some cognitive aspects, because half of the children with CP have some cognitive deficit.<sup>28,29</sup> The inability to interpret cognitive information can occur as a result of primary disorders stemming from cerebral palsy itself or from secondary disorders, as a result of the limitations of activities that restrict the learning and the development of sensory-perceptual experiences and cognitive abilities.<sup>1,7</sup>

Since motor impairment is the most common aspect of children with CP,<sup>29</sup> reviews and ratings specific to children with CP tend to focus more this aspect, to the detriment of others, such as the cognitive function that ends up being neglected-not being well explored.<sup>30-32</sup> It is important to pay attention to this aspect, because the cognitive abilities of children with CP can easily be masked by the limitations of the skeletal musculature and activities related to mobility.<sup>30</sup>

Auditory perception (domain C) showed no significant difference between the two groups and the response referring to the perceptions of the caregivers in relation to the hearing of the patient, may end up being different from the real condition of the child, since an evaluation done by a specialist showed that hearing impairment is not common in children with CP, appearing only once in every 25 cases.<sup>28,29</sup>

Communication (domain D) justifies the significant difference, because one in every four children with CP has some language difficulty.<sup>28,29</sup> The communication level of these children varies from light articulatory disorders, very close to normality, to severe delays in the acquisition of speech or total inability to deliver a comprehensible sound, with limited motor skills hampering expressive language.<sup>33,34</sup> Language development involves the integrity of the CNS, the maturation process, sensory integrity, cognitive and intellectual abilities, the processing of information or perceptual aspects, emotional factors, and the influences of the environment.<sup>7,35,36</sup>

One in every 10 children with CP has some visual deficit,<sup>28,29</sup> however, in the present study, although the CP children with had an average score higher than the TD children, no significant difference was found between the two groups regarding visual perception (domain E). Alterations in eye movements are frequent, and convergent strabismus due to an injury of the abducens nerve is most common alteration. Visual difficulty can be the result of cataracts in cases of congenital toxoplasmosis, hemianopsia resulting from chiasmatic or post-chiasmatic injury, or other visual disorders.<sup>37</sup> However, the questions pertaining to this field have been focused on the mother's perception as to how much the child sees, which may differ from the actual visual capacity of the

child through clinical examinations performed by a specialist, but since this information was not investigated in the medical charts, this cannot be confirmed.

Children with CP are forwarded later on for ophthalmologic evaluation, which reduces the possibilities of visual development at the proper time,<sup>38</sup> which is worrisome since the lack of visual stimuli in the first months of life can lead to irreversible alterations (anatomical and functional) that interfere with the child's ability to respond to environmental stimuli, restricting his participation in daily activities, in the emotional looks between mother and baby, and in his motor and cognitive development.<sup>7,39</sup>

In relation to sensory perception (domain F), the responses were similar in the two groups and this is consistent with the literature, because many times the ability to interpret the sensory and/or cognitive information occurs as a result of primary disorders, resulting from the CP itself or from secondary disorders, as a result of the limitations of activities that restrict learning and the exploitation of the environment and active movement, which hampers the development of sensory-perceptual experiences and cognitive abilities. In addition, the associated disorders are not always present in these children.<sup>17</sup> Furthermore, in this domain of the DSF-PC, the sensory perceptions assessed encompass only olfactory, gustatory, tactile pain, and thermal perceptions, leaving out the vestibular and proprioceptive perceptions; this is a fact that may justify the similarity between the groups' responses.

In relation to food and swallowing (domain G) the significant difference is justified because some factors related to cerebral palsy, such as cognitive impairment, seizures, and severe motor impairment are considered risk factors for eating disorders: the motor alterations of the oropharyngeal dynamics, lack of understanding of the nutritional context, and difficulty in voluntary oral motor activity may alter the sequencing of the pharyngeal phase, and the severity of tracheal aspiration. The basic motor difficulties of these children can affect the oral motor function, influencing the performance of the functions of sucking, chewing, and swallowing, also developing changes in articulation and respiration, understood as the motor aspects and sensory structures from the oral cavity and pharynx to the entrance of the esophagus.<sup>40,41</sup>

In relation to control of sphincter and hygiene (domain H) there was also no significant difference found, which is justifiable since it is known that cases of enuresis, frequency,

urgency, and incontinence to stress occurs in many children with CP; these disturbances are related to decreased mobility, difficulty of cognition and communication, loss of the upper limb function, and neurogenic dysfunction. It is also known that urinary stasis and hygiene problems make children with CP more prone to urinary tract infections.<sup>42-44</sup>

In functions related to movement (domain I), control and postural changes (J), manual skills (domain J), and walking and getting around (domain L), the differences are justified since most of the ICF and ICF-CY categories are related to body structures and functions, a fact which reflects the main characteristics of CP, which are difficulties in control motor and motor function.<sup>17</sup>

Interesting observations were verified in relation to postural changes and control (domain J) since, during the application of the questionnaire, some caregivers reported that most of the time instead of stimulating the child to change postures, they just put the child in the desired position, using their busy daily routine as justification. However, most of them did not realize that this way would not allow the child the motor experience and they themselves also would not witness the real motor capacity of their children; so, during the interview, when the caregiver was asked whether the child was able to adopt a particular posture, many did not know how to respond. The same thing happened in domain M- personal care: although significant differences were found between the groups, it was observed that in some questions related to self care and clothing, playing during bath time, although they were asked if the child was able to do a certain activity or function, some caregivers responded that they had never let the child try, while others assumed that doing it for the child would be faster.

These data are very important and emphasize that it is essential that parents/caregivers be made aware and welcomed by rehabilitation professionals along with their children, to obtain information about the child's performance in other environments as well as showing them the possibility the facilitators to improve their performance. Morris, Galuppi, and Rosenbaum<sup>45</sup> claim that the caregivers tend to functionally classify their children as more limited, however, they know the functional performance of the child in more varied situations than the health professionals, who have contact with children in specially designed clinical environments enabling better functional ability, with fewer barriers, something that emphasizes the importance of

the caregivers' participation and vision in the rehabilitation process of their children.<sup>45,46</sup> This suggests the need for therapeutic planning to include the guidance and awareness of parents as to the real ability of their children so that they can actively participate in their activities of daily living.<sup>47</sup>

In domain N - social participation, a significant difference was found between the groups that corroborates with Palisano<sup>48</sup> who says that the participation of young people with Cerebral Palsy is influenced by many factors such as their personal characteristics and their relatives and that the greater their impairment, the greater the restriction on participation. Another factor that also interferes with the social participation is the behavioral change that is more frequent in children with cerebral palsy than in children with typical development.<sup>7,49</sup> Trauner et al.<sup>50</sup> found more social problems in children with cerebral injury than those in a control group, possibly suggesting a higher risk of social problems in the presence of brain injury. Since one in every four children with CP have some behavioral disorder,<sup>28,29</sup> Schariti et al.<sup>17</sup> underscore the importance of evaluating the participation of children with CP in recreational and leisure activities, since the literature shows that children with CP report having fewer social experiences than children without disabilities.

However, it is worrisome that for products and assistive technology (domain O) the results are similar between the groups, because the group of TD children values were all practically zero, which means they had no need of technology, which means that the child does not present a barrier for this participation because it does not need this type of technology. In the case of the group of CP children, the score was similar, because in most cases, the responses were: I don't have access, which means a barrier, but when it was time to grade this barrier most of the answers ranged between - 1 (light barrier: the absence of equipment hinders, but does not prevent the activities) and - 2 (moderate barrier: the absence of equipment hinders and prevents a few activities), i.e., most of these patients do not have access to this technology, but they are so accustomed to living without it, that this was not considered a barrier. They have not experienced an easier life full of adaptations, i.e., they do not have a parameter for "good" to consider their reality as "bad".

The study by Granlund et al.<sup>51</sup> affirms that the type of opportunities and resources needed for well-being probably varies between people depending on their life circumstances

and personal characteristics. A study conducted by Andrade et al.<sup>24</sup> found reports from caregivers of CP children regarding public transportation, mobility equipment, health professionals, medicines, and family which emphasize the importance of knowledge of these barriers reported by families to achieve improvements in the rehabilitation and public health services.

The domains related to functional skills and to social participation showed scores significantly higher for the CP group, indicating greater difficulty for the children performing and participating, thus demonstrating that the protocol is sensitive enough to differentiate groups and therefore suitable for the target population.

The findings of this study corroborate the study conducted by Schiariti et al.<sup>17</sup> who reported that the large group of categories of the ICF-CY can identify the main difficulty of CP children not only in motor aspects, but also in their associated factors (the cognition, communication, behavior, and sensory areas) and the impact of these difficulties on the limitations to activities and participation.

## CONCLUSION

The results of this study demonstrate that the DFS-PC is sensitive for detecting the difficulties of a child with CP, and are thereby an important protocol for triage, presenting an overview of the functional performance and social development of these children.

It is concluded that the DFS-PC is valid and suitable to be applied to the target population of caregivers of children with Cerebral Palsy.

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