

# Functional repertoire of children with cerebral palsy at home and clinical contexts: report of caregivers and professionals\*

## Repertório funcional de crianças com paralisia cerebral nos contextos domiciliar e clínico: relato de cuidadores e profissionais

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**ABSTRACT:** The objective of this study was to evaluate the association between functional profile of children with cerebral palsy at home and at the clinical contexts in the areas of self-care, mobility and social function, respectively reported by caregivers and rehabilitation professionals. Participants were 50 children, 50 caregivers and 25 professionals, physical therapists and occupational therapists, employed in health institutions from the interior of the state of São Paulo. The instrumentation included the Pediatric Evaluation of Disability Inventory, an identification form of the participants and the System to Classify Gross Motor Function. It was used the Spearman correlation test. A significant association with correlation coefficients of large magnitude was found between the functional profile of children in the clinical and home contexts, especially in functional abilities and caregiver assistance; weaker association was observed in the environmental modifications used. Results revealed coherence in functional repertoire of children in both contexts. The assistance provided by caregivers and professionals is relatively similar, however the contexts are structured to offer specific modifications, that give support to the functional performance of these children in their routines.

**KEYWORDS:** Cerebral palsy; Child; Caregivers; Rehabilitation.

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**RESUMO:** O objetivo do estudo foi avaliar a associação do perfil de funcionalidade de crianças com paralisia cerebral em casa e no contexto clínico nas áreas de autocuidado, mobilidade e função social, relatado por cuidadores e profissionais da reabilitação. Participaram 50 crianças, 50 cuidadores e 25 profissionais, fisioterapeutas e terapeutas ocupacionais, vinculados a instituições de saúde do interior Paulista. A instrumentação incluiu o Inventário de Avaliação Pediátrica de Incapacidade, uma ficha de identificação dos participantes e o Sistema de Classificação da Função Motora Grossa. Foi utilizado o teste de correlação de Spearman. Verificou-se associação significativa com índices de correlação de grande magnitude entre o perfil funcional das crianças nos dois contextos nas áreas investigadas, principalmente no que se refere às habilidades funcionais e a assistência dos cuidadores disponibilizada; associação mais fraca foi evidenciada nas modificações utilizadas. Resultados revelam coerência no repertório funcional das crianças em ambos contextos. A assistência disponibilizada por cuidadores e profissionais é relativamente semelhante, entretanto, os contextos se estruturam de forma a oferecerem modificações específicas, que dão suporte ao desempenho funcional dessas crianças em suas rotinas.

**DESCRITORES:** Paralisia cerebral; Criança; Cuidadores; Reabilitação.

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## INTRODUCTION

Children with cerebral palsy (CP) present similar characteristics with respect to symptoms of clinical groups. However, the functional profiles manifest themselves individually, being dependent on the characteristics of the environments in which they live<sup>1-3</sup>.

The International Classification of Functioning, Disability and Health (ICF)<sup>4</sup> highlights the relationship between the health condition of the child and the environment, emphasizing that characteristics of the physical, attitudinal, social environments, among others, and can contribute positively or negatively to the functionality profile. They can therefore act as facilitators or as barriers<sup>4-6</sup>.

Limitations in activities of daily routine are challenges for the functional performance of children with PC<sup>6-11</sup>, which is influenced by the context factors<sup>12-16</sup>, such as: specific demands of the tasks, access to aid equipment for the displacement of the child, attitudes and expectations of parents.

This way, the functional evaluation is important to know aspects of the functionality profile, such as the performance of functional skills of the child, the quantity of aid provided by caregivers and the modification of the physical environment used on the child's routine. Information that may be obtained from the use of the instrument Pediatric Evaluation of Disability Inventory (PEDI)<sup>17</sup>.

Using PEDI, Oliveira and Alves<sup>12</sup> have indicated the existence of differences and similarities in the functional profile of children with CP, from 4 to 7 years. In this study, the format used in the implementation of PEDI, by means of structured interviews with mothers and direct observation of children in households, influenced the results. The authors suggest that the application format of an instrument (i.e., interview or direct observation) interferes directly in the results obtained, even the evaluator keeping constant.

In the area of psychometrics, the real score of an individual (i.e., one that seeks to be the highlight, but that is not known) is a result of the score observed (i.e., obtained from the application of a test) plus an error factor. This error is directly related to the application of the instrument, in such a way that different formats will result in different scores. Strategies specific to each application format should be used to minimize the error factor attributed to the process of measurement, such as training and optimized conditions during application. The effect of the person interviewed in

the observed score illustrates the impact of context on the results obtained.

Mancini et al.<sup>5</sup> compared the functionality profile of children with PC of different severities of the clinical picture (i.e., mild, moderate and severe). The results showed that, in children with moderate severity, incongruity between the repertoire of functional skills and the assistance provided by caregivers, was observed. Considering the repertoire of these children, the relatively higher level of parents' assistance in functional tasks seems to illustrate a lower expectation about the appropriateness of the use of these skills in domestic routine. The low expectations can often trigger a vicious circle, which limits the performance of skills, improvement and the process of child development.

Darbar et al.<sup>14</sup>, after comparing different formats of application of test parameters of the Gross Motor Function Measure (GMFM) test, by direct observation of an examiner and by semi-structured interviews with parents, showed that 70% of parents of children with CP, of any type (paralysis, hemiparesis or diparesia), of age from 3 to 12 years, underestimated the motor capability of the children. The authors discuss the results based on two factors that seem to direct the relative lower expectations of parents about the potential motor function of their child: the low quality of the child's performance and the greater quantity of time required for the son to finish the activity.

The evidence cited suggest that unlike therapists, parents of children with CP tend to not recognize the use of alternate strategies used by their children to meet the demands of the context, in order to maintain a functional process, even in the presence of the organic constraints typical of this health condition. Such information point to distinct functionality profiles of children with PC in different contexts.

Thus, the present study aims to assess the association between the functionality profile (i.e., functional skills of the child, assistance provided by the caregiver, and the modifications of the environment) of children with PC at home and in the clinical context, in the areas of self-care, mobility and social function, by their family caregivers and rehabilitation professionals.

## Methodological procedures

This is a cross-sectional analytic research.

## Participants

The research had as a target population the family caregivers and rehabilitation professionals of children with

CP from 3 to 7.5 years, under treatment of Occupational Therapy or Physical Therapy in rehabilitation centers of municipalities in the State of São Paulo: São Carlos, Araraquara, Limeira and Rio Claro.

All children diagnosed with PC, within the ages established, served by occupational therapists or physical therapists in rehabilitation centers of these municipalities were considered for participation. Thus, the sample was composed of 50 children, 50 caregivers and 25 professionals (since different children were accompanied by the same professional).

### **Ethical aspects**

The study was approved by the Committee of Ethics in Human Research at the Federal University of São Carlos, under the Protocol no. 149/2010. Caregivers and professionals were informed about the objectives of the study and signed an informed consent.

### **Instrumentation**

*Pediatric Evaluation of Disability Inventory* (PEDI) – the adapted Brazilian version of PEDI<sup>17</sup> was used, which measures the typical performance of children from 6 months to 7.5 years in the routine environment. It consists of three parts (part I reports on the child's abilities to perform activities of daily life; part II reports on the independence of the child, equivalent to the inverse measure of the quantity of aid provided by the caregiver for performing functional tasks; part III includes the changes to the environment that are used in the routine of the child), about three performance areas (self-care, mobility and social function).

The area of self-care is evaluated by 73 items including food, personal hygiene, bathing, dressing/undressing, using the bathroom, fecal and urinary continence. The mobility area is evaluated by 59 items covering locomotion in internal/external environment and use of stairs. And the social function area contains 65 items that discuss the understanding/functional expression, problem-solving, playing, self-information, temporal orientation, participation in household chores, self-protection and function in the community<sup>18</sup>. Each area in parts I and II of PEDI can be represented by a continuous score ranging from 0 to 100 points. The higher the score, the better is the functionality of the child<sup>17</sup>. In relation to the changes of the environment, provides information on the use by children of *any modification* (*N*), *child-centered modification* (*C*) *rehabilitation modification* (*R*) and *modification of the extensive type* (*E*). The option *N* refers to any modification

existing for the functional task performance; the *C* refers to the child-centered modification, non-specialized and common in the childhood; the *R* option refers to the modification focused on children with special needs; and the option *E* refers to the modification that involves major changes, such as the architectural modification<sup>18</sup>.

In this research, the functional profile of children was evaluated with the PEDI under two forms: interviews with caregivers and professional judgment.

*Participants Identification Sheet* – two models of sheet for sample characterization. The information about the caregiver and child included information on age, gender, marital status, number of children, education, occupation, time of daily permanence of the caregiver to the child in any routine activity and guidance received about the activities of daily life of the child; composition, income and family housing; treatments already undertaken and current treatments, routine activities, general health condition and temperament of the child. The professional record included personal data of the professional (i.e., training, expertise, long experience in the field) and the child care data, the clinical manifestation of PC and motor impairment level.

*Gross Motor Function Classification System for Cerebral Palsy* (GMFCS) – to characterize the motor level of the children, the GMFCS was used in its version translated and adapted to the Portuguese language<sup>19</sup>. This instrument is based on the criterion that distinctions on motor function between levels are clinically significant, based on functional limitations and the need for assistive technology. The emphasis is on the movement started voluntarily, particularly walking and seating. The evaluation is made by means of observation of gross motor skills of the child, classifying it into 5 levels: I, II, III, IV or V. The Level I applies to those children who are able to move around without restrictions; the level II to those that have constraint to walk in external environment; the level III to those who walk with aid/support; the level IV to those that make use of assistive technology for locomotion; and level V is applied to those children with severe mobility limitations, even when making use of the assistive technology. These levels depend on the age (before the age of 2, from 2 to 4, from 4 to 6 and from 6 to 12 years)<sup>20</sup>.

### **Procedures**

The data collection took place over a period of 4 months, from February to May 2011, in rehabilitation institutions. The individual collection with caregivers occurred in places provided by the services during the

working hours of children, and consisted of the identification record of the caregiver/child and of the PEDI structured interview. The professional who served the child in the service received the material with the instruments to be filled, including instructions on filling. In this way, the professional identification record and PEDI were answered by professionals (self-testing). Caregivers and professionals were asked to answer the PEDI based on the typical performance/routine each child observed.

**Data analysis**

The correlation between the scores which express the assessment of caregivers and professionals about the functional performance of the child was estimated by Spearman’s rank correlation coefficient, after verifying that the scores do not follow normal distribution and after visual exploration that the relationship between the scores has linear pattern. The correlations were considered significant if  $p < 0.05$ . The magnitude of the correlation ( $r$ ) was classified as strong when  $r > 0.80$ , moderate when  $r$  between 0.31 and 0.79, and weak  $r$  when between 0 and 0.30<sup>21</sup>. The sense of the association has been defined by the sign of the correlation

coefficient (positive or negative). Analyses were performed with the software SPSS v 15.0.

**RESULTS**

The descriptive results reveal that the average age of the children was 5.6 ( $\pm 1.51$ ) years, between boys and girls with different types of PC and motor level, with prevalence of serious children (levels IV and V of the GMFCS, respectively, 22% and 36%). In relation to the type of PC, most part had topographic classification of tetraparesis (66%) and spasticity as motor disorder (70%). The average age of caregivers was 34.3 ( $\pm 8.8$ ) years, 94% were mothers of children, most married (54%), living with companion (78%), with two children (42%), elementary school (44%), claimed to have family income of up to two minimum wages (68%) and only 14% of the sample is in the labor market. As for professionals, the average age was 35 ( $\pm 8$ ) years, between physiotherapists (56%) and occupational therapists (44%), with average employment of 7 ( $\pm 7$ ) years in institutions in which children attend, which corresponds to the work experience in the area of child physical dysfunction.

**Table 1** - Association between scores of caregivers and professionals in the scales of self-care, mobility and social function of the parts of functional ability and assistance of the caregiver of the PEDI test

		Area		
		Self-care	Mobility	Social function
Functional ability	<b>r</b>	0.92**	0.88**	0.89**
Caregiver assistance	<b>r</b>	0.87**	0.86**	0.76**

\*\* $p < 0,01$ ;  $r$  = Spearman’s rank correlation coefficient

**Table 2** - Association between scores of caregivers and professionals in the areas of self-care, mobility, and social function in each category of the scale of changes to the PEDI test environment

Area		Type of modification			
		None	Child	Extensive	Rehab
Self-care	<b>r</b>	0.46**	0.35*	ns	ns
Mobility	<b>r</b>	0.41**	ns	ns	ns
Social function	<b>r</b>	ns	.	ns	.

\* $p < 0,05$ ; \*\* $p < 0,01$ ; ns = non-significant correlation;  $r$  = Spearman’s rank correlation coefficient.

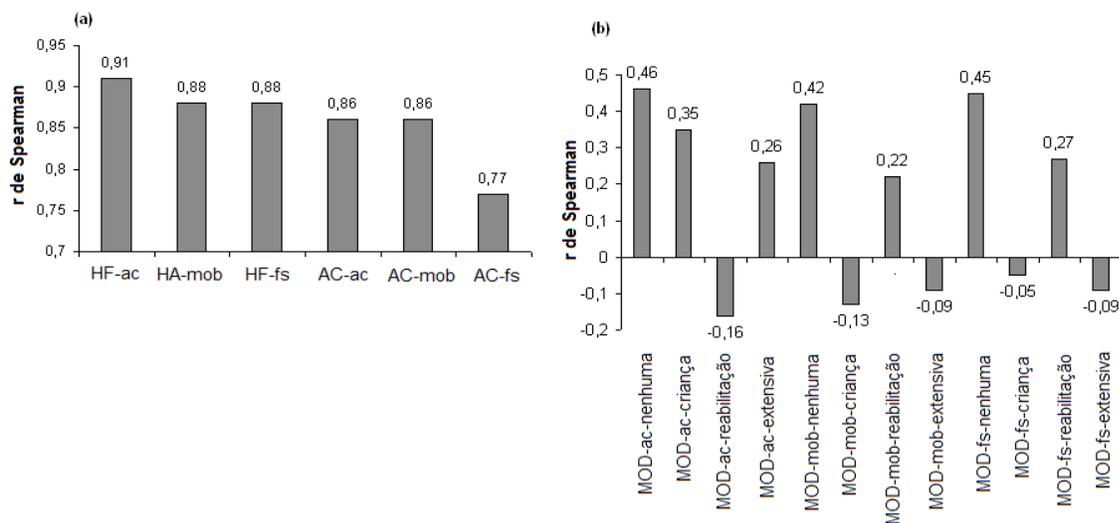
Tables 1 and 2 present the results of correlation analysis.

It is observed that there was evidence of a strong association between the evaluations of caregivers and professionals about the functional abilities of the children and the caregiver's assistance in three areas investigated: self-care, mobility and social function.

With regards to the scale of changes to the environment, the association was moderate in the area of self-care in the categories "no modification" and "child-centered"

modification, and in the mobility area of the category "no modification". In the categories "rehabilitation modification" and "extensive modification" in the areas of self-care and mobility, as well as in the area of social function (for all categories), the associations were not significant.

In Figure 1, there are strong associations between the evaluations of caregivers and professionals in the range of functional abilities, as well as in assistance of the caregiver. In the range of modifications of the environment, the associations were of moderate magnitude.



HF = functional skills; AC = caregiver assistance; MOD = environmental modifications; AC = self-care; mob = mobility; FS = social function.

**Figure 1** - Distribution of the magnitude of all the correlations observed on scales of functional skills and caregiver assistance (a) and on scales of environmental changes (b) of the PEDI test

## DISCUSSION

The results of this study revealed a strong association between the functional abilities of the children and the assistance provided by the caregiver to perform activities and tasks of self-care and mobility, according to information from caregivers and professionals responsible for the treatment. Moderate correlation coefficients were observed in some categories of the modification scale of the environmental in self-care and mobility.

In scales of functional skills, correlation coefficients obtained from the comparison of reports of caregivers with the professionals, showed magnitudes higher than the coefficients observed on the scales of the caregiver assistance, in the same areas of self-care, mobility and

social function. Probably, such results refer to the content in each of these parts of the test, as well as the effect of environmental factors on scales of functional skills and of caregiver assistance. The functional abilities of the child depict the functional repertoire available to be used on different demands required by the routine at home and of the clinical context. The development of the repertoire of functional skills of children is resulting from the cross-relations between the capabilities and demands of the context. Assistance provided to the child by an adult for performing functional tasks includes, among other factors, beliefs and values that are passed through generations by defining a style of parenting and/or therapeutic practices that manifest not only in the expectation about the importance of encouraging and promoting functional independence

of children, often at the expense of a longer and/or less proficiency, considering the age of group covered by the PEDI test. The help offered by the caregiver or therapist to carry out tasks of self-care, mobility and social function also reflects the structure of the routine and the flexibility of the family or the therapeutic setting to review and reflect on the way the routine happens and is conducted, in such a way to allow for the review of the aid provided routinely and to adapt to the real needs of the child.

Considering the contents of each part of PEDI, it was observed that the specificities of physical, social, attitudinal environments, among others, determine a greater impact on the caregiver assistance scale than in the functional skills scale. Such observation is supported by other studies. Mancini et al.<sup>1</sup> and Chagas et al.<sup>19</sup> assessed the relationship between severity of PC condition and functional information: profile of functionality using the PEDI test and functional classifications of mobility and manual function. The results showed that differences in levels of severity of PC are captured by the scale of functional skills of PEDI, however, information on the scale of assistance from the caregiver does not directly depict such differences, being influenced by the caregiver's attitudes and expectations in relation to the repertoire of the child's abilities.

The results presented above differ from some studies that showed differences between the responses of parents and professionals about the motor and/or functional profile of children with neuromotor commitment<sup>12,14</sup>. Such discrepancy can be attributed to the use of different assessment tools, such as GMFM in the study of Darbar et al.<sup>14</sup>, which has different parameters of the ones investigated by PEDI, and the fact that the examiners who performed the direct observation of the children were not their therapists. Besides the disagreement with such studies, it is pointed out that the present research advances in relation to the previous ones in some methodological features, including sample of participants, application of instruments and data analysis. In studies of Oliveira and Alves<sup>12</sup> e Darbar et al.<sup>14</sup>, the sample was 3 and 10 children with PC, with their parents and researchers who responded the assessment tool through interview and direct observation of the child, respectively. In the present study, the sample was differentiated and expanded to 50 children with PC, with their caregivers and professionals responsible for the treatment of children, which responded to PEDI through interview and auto-filling, respectively. This methodology allowed a comparative analysis between the assessment of caregivers and professionals, as central actors involved in the care of the child with PC in different contexts, home care and therapeutic.

Comparatively, the area of social function, in particular with regards to the assistance from the caregiver, presented moderate magnitude of association between the assessment of the caregiver and of the professional. This area also manifested itself differently from the other two in the categories of environmental modifications, not revealing any significant association between the two groups. While the association magnitude between information available by caregivers and professionals was greater than 0.86 in the areas of self-care and mobility, this association in the assistance provided in social function tasks was 0.76.

This magnitude difference of the coefficients between the functionality areas and, in particular, the smallest magnitude observed in the area of social function can be a consequence of the content that is informed by each part of the test, as well as the environment configuration considered for the evaluation. The area of social function involves items for the understanding and functional expression, problem-solving, social interaction skills, household skills, security skills and community function skills<sup>17</sup>. One must consider the content scope of this area, comprising complex activities and tasks to check and judge, when compared to the items in areas of self-care and mobility. As an example, it is mentioned the assessment of the communication type that the child uses and understands, the timing and sequence of events, and the ability to provide information. In addition, the contents of the two scales of social function extrapolate the home context, including information on the performance of children in community environment.

The correlation in the assessment of caregivers and professionals can indicate the sharing of information between representatives of the home and clinical environments. The approach and exchange of information between caregivers and therapists is desirable and consistent with principles of practice centered on the client<sup>25</sup>, a form of service provision adapted to the different professional areas. This practice includes the ability to hear, understand priorities and formulate a contingency plan compatible with the needs and desires of the client<sup>22</sup>. It is believed that the participation of the client and/or family in determining the therapeutic goals facilitates the involvement with the treatment and results in larger or better gains<sup>23,24</sup>. In the client-centered approach, therapists help families to identify and optimize the results of the child, and should encourage the family to consider itself as a contextual unit. To do so, it requires the use of instrumentation that allows the participation of the child and the family in setting goals for treatment. This way, the clinical use of PEDI, by documenting the profile of typical functionality of the child in the routine, it seems consistent with the assumptions of the client-centered practice.

The results showed that the consistency observed in the assessment of caregivers and professionals about the functional profile of children with CP was not maintained in the information about the modifications of the environment used by the child. In this respect, the association between information from caregivers and professionals presented coefficients of moderate magnitude, which were significant only in the categories “no modification” and “child-centered” modifications. It is possible that the home and clinical contexts do not provide equivalently the “modifications of rehabilitation” and/or “extensive changes”, according to the PEDI classification, which should be used in the routine of the children. Considering that the sample was constituted predominantly by children with serious PC, these results should be questioned, since for these children, the modifications of the environment become essential to promote the functionality. In addition, it is expected that the information obtained in interviews with different people, as mother and therapist, who live with children with PC in different contexts, reflect the specificities of the coexistence of the same with the child, in each environment, as well as other features.

Moderate consistency was noted in reports of caregivers and professionals about the absence or the non-specific type of “environmental changes” used by the children in the home and clinical contexts, to perform tasks of self-care and mobility. Such information suggests areas that may be prioritized in their intervention protocols, such as the use of assistive technologies, adapting the home and clinical contexts to promote the child’s performance in daily routine. The investigation of the effects of these technologies on the functionality profile of children with PC should follow the clinical use.

The context influence on functionality is highlighted in literature<sup>6-11,25</sup> and it is not intended to deny it with the results of this study, but rather to introduce elements to expand such discussion. The results suggest that the repertoire of functional skills of children with PC is less influenced by the physical and social particularities of distinct contexts, such as home care and therapeutic, than factors that constitute direct measures and attributes of the environment, such as the help available and the

modifications available for functional tasks. A moderate magnitude of some of the association coefficients found probably reflects the influence of other factors, such as the environmental characteristics, in the relationship between information available for caregivers and professionals about the functionality of the child with CP.

## CONCLUSIONS

In addition to focus disagreements or agreements among the groups that evaluated the functional profile of children with CP, this study considers the importance of understanding that the functionality is undeniably linked to the shape contexts; the routine use of functional skills available in the repertoire of children studied reflects the interaction of individual attributes with the characteristics of the context, including the actors members and demands presented. The human interactions and the daily events implies in the dynamics established between the functionality and capabilities of the child and the demands and conditions of the environment. Thus, the results reinforce the complexity inherent to the evaluation process of the child functional performance.

One limitation of the study refers to the distinct format of application of PEDI between caregivers and professionals of rehabilitation, which may have interfered the results. In the first group, the test was applied by means of interview and the second, by the autofill of the instrument. Despite the different formats, the equivalence in the data collected in both groups can be attributed to the familiarity of professionals with the test content and extensive practice in the performance of interviews with parents of children with CP. It is possible that the error attributed to different formats has been minimized, allowing for comparative analysis.

It is expected that the implications of this study for the rehabilitation professionals focus on importance to critically analyze the information obtained in the application of functional evaluations, as well as to recognize the influence that different contexts require to the functionality profile of children with PC.

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