



Development of social participation classification system for children with cerebral palsy

Seyed Hassan Saneii¹, Malek Amini^{2*}, Marzieh Pashmdarfard³

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Abstract

Background: Some classification systems have been designed to measure domains of function of children with cerebral palsy (CP), including the Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), Eating and Drinking Ability Classification System (EDACS), and Communication Function Classification System (CFCS). The purpose of the present study was to develop a Social Participation Classification System for children with cerebral palsy (SPCS) with a 5-level sequential scale (level 1 the lowest and level 5 the highest level of participation) and assess its reliability.

Methods: In this cross-sectional analytic study, 274 parents of 6 to 12 year-old children with CP were asked to complete the questionnaires (CPAS-P, MACS, GMFCS, and CFCS) for their child. The expert review consisting of 10 occupational therapists with at least 5 years of experience working with children with CP was asked to rate the level of social participation with a 5-level sequential scale (level 1 the lowest and level 5 the highest level of participation) of these children according to the variables (intelligent quotient [IQ], CP type, walking ability, GMFCS, CFCS, and MACS). Then, these data were analyzed using the polynomial discriminant function. After performing discriminant function, a flowchart model was determined for the level of children's social participation. To calculate the reliability of the model, 53 new samples were collected and their level of social participation was determined based on the flowchart model. The experts were then asked to determine the social participation level of these 53 new samples in the same manner as before, and then to calculate reliability, intraclass correlation coefficient (ICC) and Cronbach alpha. The SPSS Version 22 (SPSS Inc) and discriminant function model analysis was used for statistical analysis.

Results: Based on the discriminant function model, the results between the predicted classification and expert review are over 88% consistent. The ICC and Cronbach alpha values were 0.952 and 0.975, respectively, with absolute agreement and multivariate mixed effects.

Conclusion: Based on the results of the present study, the SPCS was developed in 5 levels (very low, low, moderate, high, and very high) and to determine it, the GMFCS, MACS, and CFCS scores, CP type, and IQ level should be calculated.

Keywords: Cerebral Palsy, Social Participation, Classification System

Conflicts of Interest: None declared

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Introduction

Cerebral palsy (CP) is deemed as the most common childhood motor disorder caused by a lesion in the developing brain. Although this physical disability may occur early in life, its consequences are experienced throughout

life (1). Affected children may experience range of motor, postural, coordination, sensory, and cognitive impairments throughout their lives. Generally, cognitive and motor impairments are among the primary factors placing

Corresponding author: Dr Malek Amini, amini.m@iums.ac.ir

¹ Rehabilitation Research Center, Department of Basic Sciences in Rehabilitation, School of Rehabilitation Sciences, Iran University of Medical Sciences, Tehran, Iran

² Rehabilitation Research Center, Department of Occupational Therapy, School of Rehabilitation Sciences, Iran University of Medical Sciences, Tehran, Iran

³ Department of Occupational Therapy, School of Rehabilitation, Shahid Beheshti University of Medical Sciences, Tehran, Iran

↑What is “already known” in this topic:

In recent years, for having a common language between treatment teams of CP, different classification systems, such as GMFCS, MACS, EDACS, and CFCS, have been developed.

→What this article adds:

The SPCS was developed in 5 levels (very low, low, moderate, high, and very high) and to determine it, the GMFCS, MACS, and CFCS scores, CP type, and IQ level should be calculated.

restrictions on social participation (2, 3). A majority of people with CP face limitations in walking and performing other physical activities, and by and large, such restrictions often limit participation in social activities (2). Moreover, children with CP are often dependent on others for their mobility and self-care because of their movement limitations, which can again impact their social participation, activities of daily living (ADL), and their quality of life (4, 5). Based on the definition provided by the World Health Organization, participation is defined as getting involved in different life situations (5, 6). The Social Model of Disability emphasizes that participation should be investigated with respect to the social and physical dimensions of the community under study and that the identification of the influential factors in social participation should be based on the personal experiences of individuals in social participation (7).

In the past, in the classification of CP, only the aspects associated with movement and involvement were considered. However, such a classification did not provide any information about the abilities of people with CP and the extent their limitations impeded their social participation, communication, decisions, and the degree of their mental participation. This type of information is primarily subjective (8). Some classification systems have been designed to measure domains of function of children with CP, and these classification systems are mainly objective (8). For example, the following have been developed for use with children with CP: the Gross Motor Function Classification System (GMFCS) (9), Manual Ability Classification System (MACS) (8, 10), Communication Function Classification System (CFCS) (11) and Eating and Drinking Ability Classification System (EDACS) (12).

For the assessment of children's social participation, an assessment tool called CPAS-P has been developed. In this tool, the score range of the frequency and diversity dimensions are 0 to 60 and 0 to 12, respectively. The main problem with this assessment scale is that the audience may not have a true perception of the assigned scores because everyone is not aware of the scope of this scale. Furthermore, it is also difficult to adapt this scale, to assess it, and to judge based on it. Therefore, it is necessary to construct a classification system which does not have such problems. To this end, the present study aimed to develop and validate the SPCS with a 5-point scale, with 1 indicating the lowest level of social participation and 5 indicating the highest level. The initial beta version of the SPCS included X participation domains: Children's Participation Assessment Scale, Parent Version (CPAS-P), IQ, CP types, walking ability, GMFCS, CFCS, and MACS.

Methods

Participants

In this psychometric study, the multistage sampling was used. First, Tehran was divided into 4 sections: north, south, east, and west (stage 1); second, one area was randomly selected from each section (stage 2); and third, one of the girls' special physical motor schools and one of the boys' special physical motor schools were randomly cho-

sen from each area (stage 3). After that, some children were randomly selected from the chosen schools. Then, parents of these children completed the consent form and participated in the study (stage 4).

The inclusion criteria of the study were as follows: age range of 6 to 12 years; the ability of parents to read and write, which were required to complete the questionnaires; diagnoses of CP by a pediatric neurologist or neurologist; and willingness of parents to participate in the study. Those parents who did not sign the consent form and those who signed the consent form but did not fill out the questionnaires were excluded from the study. The project was approved by the Ethics Committee of Iran University of Medical Sciences (IR.IUMS.REC 96-04-32-31895). Finally, the Department of Research and Technology of Iran University of Medical Sciences issued a letter of introduction, which allowed for taking samples from the special physical motor schools in Tehran.

Based on the inclusion criteria, 274 parents of 6- to 12-year-old children with CP were asked to complete the questionnaires about their child.

Procedures

After the questionnaires were completed, the data were collected and entered into SPSS. Prior to the analysis, the amassed data were reviewed by both subject matter and statistics experts. All the cases that were considered as scientifically logical were corrected with reference to the existing records, and the cases that could not be corrected were removed from the sample. In the end, 218 out of 274 parents remained in the study and the data gathered from these parents were analyzed.

Next, for the expert review, 10 occupational therapists with at least 5 years of experience working with children with CP were asked to detect the level of social participation of the children under study and to assign participation levels 1 to 5 to the SPCS variables (including SPARCLE Index, CP types, walking ability, GMFCS, CFCS, and MACS). These tests were chosen because evidence has shown that these items are the most influential variables on social participation. Each occupational therapist determined the social participation level of all 218 children from 1 (the lowest level of social participation) to 5 (the highest level of social participation) on an individual basis.

Once all children's participation levels were scored, the "level of social participation" was considered as the level on which more than 70% of the occupational therapists agreed in the expert review; in other words, social participation was determined to be the level for which at least 145 unanimous votes of the panel (out of 218 votes) were obtained.

Because 3 variables, namely, GMFCS, CFCS, and MACS, were well aligned and converged, for the purpose of reducing the number of independent variables included in the model, they were added up and a new ordinal variable, named GMC, was introduced. The value of this new variable was in the range of 3 to 15.

$$GMC = GMFCS + MACS + CFCS$$

Other justification variables of this model included the 3-level IQ ($IQ > 70$, $IQ > 50 < 70$, and $IQ < 50$), the 2-level walking ability (walking ability, no walking ability), and the 6-level CP type. Based on the experts' opinion, the severity of the disorder was coded as spastic Hemiplegia = 1, spastic Diplegia = 2, spastic Quadriplegia = 3, Ataxia = 4, Atetoid = 5, and Dystonic = 6.

The results of the previous study undertaken by the same authors have confirmed that the social participation of children with CP is under the influence of some variables, such as IQ, GMC, type of CP, and ability to walk (18). The initial study has indicated that the social participation variable (CPAS-P) is highly correlated with type of CP; thus, in the present study, it was excluded from the model.

The data were then analyzed using multiple discriminate functions. In this model, the grouping variable was the "level of social participation," which was determined with the expert review data. Then, the discriminant function model was run and the levels of social participation were detected. Based on the results, the flowcharts and models were identified. After that, 53 new samples were collected to evaluate the reliability of the model. The level of social participation of these 53 individuals was measured based on the SPCS model. Subsequently, another expert review was undertaken. In this review, the same experts were asked to identify the participation level of these 53 children. The ICC and Cronbach alpha were calculated for the obtained data.

Measures

Children's Participation Assessment Scale- Parent Version: In order to collect the data associated with the social participation of children with CP, the CPAS-P developed and validated by Amini et al (13) was employed. This instrument has 71 items in 8 domains: (ADL) (11 items), instrumental ADL (IADL) (10 items), play (13 items), leisure (16 items), social participation (12 items), education (4 items), work (2 items), and rest/ sleep (3 items). It evaluates children's participation in these domains for 4 months. In this parent-report instrument, each item examines children's participation in terms of 5 dimensions: diversity, intensity, with whom, enjoyment, and parental satisfaction.

The CPAS-P has acceptable psychometric properties and the values of Cronbach alphas and ICCs are between 0.87 and 0.9 and between 0.79 and 0.94, respectively (13). Among different domains of this scale, the present study only involved the social participation domain.

Manual Ability Classification System: The MACS questionnaire, developed by Eliasson et al (2006), was used to gather the data related to the upper limb skills of children with CP. The MACS classifies the manual ability of children with CP into 5 levels, with level I demonstrating the highest manual function and level VI the lowest manual function. The ICC of the original version of MACS was 0.97 (10) and the ICC of its Persian version is reported to be 0.92 (14).

Communication Function Classification System: The CFCS was developed by Hidecker et al (2011) and em-

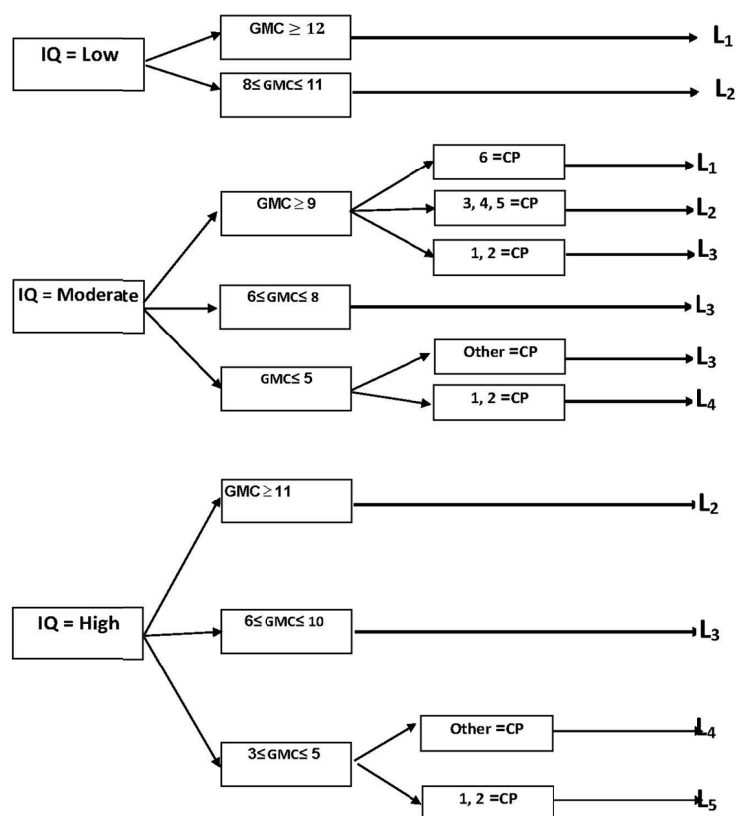


Fig. 1. Social participation classification system

played to collect the data associated with the communication ability of children with CP. The CFCS categorizes the communication function of children with CP into 5 levels, with level I demonstrating the highest communication function and level VI the lowest communication function. The test-retest reliability of the original version was 0.82 (11) and the test-retest reliability of its Persian version was 0.96 (15).

SPARCLE Index: In this study, to assess the cognitive level/IQ of the children with CP, the SPARCLE index was utilized. Children's cognitive level is measured based on the ICD10 scale. The the Study of PARTICipation of Children with CP Living in Europe (SPARCLE) is a 9-center European epidemiological research (UK, [Newcastle], Sweden [Gothenburg], France [Toulouse], Denmark [Copenhagen], France [Grenoble], Northern Ireland; Belfast Ireland, Italy [Viterbo], Germany [Luebeck]) study examining the relationship of participation and quality of life to impairment and environment (physical, social, and attitudinal) in 8- to 12-year-old children with CP. In this scale, children with mild intellectual impairment have cognitive level (IQ) scores of 50 to 70 and are known as children with learning disabilities, and children with severe intellectual impairment have cognitive level (IQ) scores under 50 and are considered as children with mental disabilities (16).

Gross Motor Function Classification System: This classification system was developed by Palisano et al (1197). The parent-report version of the GMFCS was used to collect the data pertaining to the motor function of children with cerebral palsy. The GMFCS classifies the gross motor function of children with cerebral palsy into 5 levels. In the parent version of the GMFCS, level I demonstrates the lowest gross motor function and level VI the highest gross motor function. The interrater reliability of its original version is 0.55 (9). The test retest reliability of its Per-

sian version was 0.92 (17).

Data Analysis

The obtained data were analyzed via the SPSS₂₄ software. Discriminant analysis is a multivariate technique that helps the user explain group membership as a function of multiple independent variables. In particular, discriminant analysis is appropriate when the user is faced with a situation involving a categorical, nominal, or ordinal dependent variable and independent variables that are primarily continuous (interval or ratio), although categorical independent variables can be included under some conditions. The SPCS variables were defined as a classification variable. The prior probabilities were calculated using the "compute from group sizes" option and a flowchart was generated for ease of use by users (Fig. 1). Then, the Cronbach alpha coefficients and ICCs were conducted to check the reliability of the SPCS and the expert panel.

Results

Table 1 shows that 30.3% of the children with CP were not able to walk and 11.5%, 40.4%, and 46.8% of them had low, moderate, and high IQ scores, respectively. Types of CP include spastic hemiplegia (14.8%), spastic diplegia (37.6%), spastic quadriplegia (24.8%), ataxia (8.7%), athetoid (6.4%), and dystonia (7.8%).

Based on the discriminant function model, the predicted classification was highly consistent with the classification obtained from the expert review (Table 2).

In this method, to assign the individuals to the groups, instead of equal probabilities, the option of "compute from group sizes" was used because the levels of social participation were not considered to be equal. Moreover, separate groups covariance matrices were utilized for each group (generally, separate groups covariance matrices are

Table 1. Frequency of Children by CP Type, Walking Ability, and IQ Level

Type CP	Walking Ability	IQ Level			Sum
		> 50	70 >> 50	70 >	
Hemi	No	0	0	1 (0.6%)	1
	Yes	0	10 (6%)	21 (13%)	31
Di	No	1 (0.6%)	2 (1.3%)	4 (2.6%)	7
	Yes	9 (5.9%)	23 (15%)	43 (28%)	75
Quadr	No	7 (4.6%)	20 (13%)	11 (7.2%)	38
	Yes	4 (2.6%)	5 (3.2%)	7 (4.6%)	16
Ataxi	No	0	1 (0.6%)	0	1
	Yes	0	9 (5.9%)	9 (5.9%)	18
Attetoid	No	2 (1.3%)	1 (0.6%)	2 (1.3%)	5
	Yes	0	4 (2.6%)	5 (3.2%)	9
Distonic	No	2 (1.3%)	10 (6%)	2 (1.3%)	14
	Yes	0	3 (1.9%)	0	3
Sum	No	12 (7.8%)	34 (22%)	20 (13%)	66
	Yes	13 (8.5%)	54 (35%)	85 (55%)	152

Table 2. Classification of Social Participation by Discriminant Function and Expert Review- Frequency (percentage)

		Predicted Group					Total
		L1	L2	L3	L4	L5	
Expert review	L1	9 (90.0)	1 (10.0)	-	-	-	10 (100)
	L2	2 (4.2)	43 (89.6)	3 (6.3)	-	-	48 (100)
	L3	-	3 (5.9)	46 (90.2)	2 (3.9)	-	51 (100)
	L4	-	-	5 (26.3)	12 (63.2)	2 (10.5)	19 (100)
	L5	-	-	-	1 (5.9)	16 (94.1)	17 (100)
Ungrouped cases		5 (6.8)	15 (20.5)	33 (45.2)	20 (27.4)	-	73 (100)

Table 3. Frequency (percentage) of Social Participation Levels by Suggested Flowchart and Expert Review (Top-left), Expert Review, and Ordinal Regression (Top-right), and Discriminant Function, and Ordinal Regression (bottom-right)

Regression (Top-right), and Discriminant Function, and Ordinal Regression (bottom-right)													
Level		Suggested Flowchart						Ordinal Logistic Regression					
		1	2	3	4	5	sum	1	2	3	4	5	sum
Expert review	1	13	-	-	-	-	13	10	-	-	-	-	10
	2	-	12	-	-	-	12	1	44	3	-	-	48
	3	-	-	14	-	-	14	-	4	45	2	-	51
	4	-	-	4	4	3	11	-	-	3	14	2	19
	5	-	-	-	-	3	3	-	-	-	1	16	17
	Sum	13	12	18	4	6	53	11	48	51	17	18	145
Discriminant function	1							12	4	-	-	-	16
	2							3	57	2	-	-	62
	3							-	4	79	4	-	87
	4							-	-	-	35	-	35
	5							-	-	-	-	18	18
	Sum							15	65	81	39	18	218

employed for classification). Based on the results of this table, 86.9% of the original grouped cases (126 out of 145 cases) were correctly classified.

Based on the achieved model, Flowchart No.1 was drawn as a guide for users. Then, to compute the efficiency of the model, the social participation level of the 53 new samples was measured based on Flowchart No.1. Afterward, in another expert review, the experts were asked to determine the social participation level of these new samples based on the criteria used in the previous expert review for the 218 cases. Table 3 (top-left) presents the classification of these new samples by expert panel and flowchart.

To calculate reliability, the ICC and Cronbach alpha values were obtained to be 0.957 and 0.978, respectively, based on absolute agreement and multivariate mixed effects.

Since the grouping variable (SPCS) is an ordinal variable, the mentioned classification was done using the ordinal regression. The results were similar to the results of the discriminant function model (Table 3 bottom-right). Based on the results of this table, 88.9% of original grouped cases (129 out of 145 cases) were correctly classified.

Furthermore, the results of the stepwise regression model and the discriminant function model were compared and good agreement between the 2 models was observed (greater than 0.92 = 201.218) (Table 3, top-right). The ICC and Cronbach alpha values were 0.952 and 0.975, respectively, based on absolute agreement and multivariate mixed effects.

Discussion

The purpose of this study was to develop a social participation classification system for 6- to 12-year-old children with CP. The existing classification systems, including GMFCS, MACS, CFCS, IQ, and the type of CP were employed as a basis for the classification system (18). In the present study, to construct a social participation classification system for children with CP, a questionnaire and expert reviews were used. The questionnaire was completed by the parents of the children with CP and the expert review was consistent with the method utilized for constructing other classification systems (GMFCS, MACS,

CFCS, and EDACS) in other studies (14, 15, 19).

Therefore, the GMFCS, MACS, CFCS, IQ, and type of CP were included in the development of the SPCS. This indicates that to determine children's social participation level, it is of crucial importance to examine the GMFCS, MACS, CFCS, IQ, and type of CP. The relationship between each classification system with the social participation of children with CP has been confirmed in previous studies. Pashmdarfard et al concluded that the MACS was strongly correlated with the frequency of the social participation of 6-12 year-old children with CP (20). In addition, in a review study in 2017, Pashmdarfard et al observed that the GMFCS and the MACS were key factors in predicting children's social participation (5).

In a cross-sectional study in 2018, Amini et al came to the conclusion that among the individual factors, the type of CP, IQ, and MACS, as primary factors, and GMFCS and CFCS, as secondary factors, could predict the social participation of children with CP (18).

Based on the results, it can be declared that

- Level I in social participation for children with CP includes children with the following characteristics:

- A. With a cognitive score <50 and a GMC score ≥ 12 , or
- B. With a cognitive score between 50 and 70, a GMC score of ≥ 9 , and dystonic CP.

- Level II in social participation in children with CP includes children with the following characteristics:

- A. With a cognitive score >70 and a GMC score between 8 and 11 (type of CP does not matter), or
- B. With a cognitive score between 50 and 70, a GMC score ≥ 9 , and spastic quadriplegia, athetoid, or ataxia cerebral palsy, or
- C. With a cognitive score >70 and a GMC score ≥ 11 (type of CP does not matter).

- Level III in social participation in children with CP includes children with the following characteristics:

- A. With a cognitive score between 50 and 70, a GMC score ≥ 9 , and hemiplegia or diplegia CP.
- B. With a cognitive score between 50 and 70 and a GMC score between 6 and 8 (type of CP does not matter).
- C. With a cognitive score between 50 and 70, a GMC score ≤ 5 , and any types of CP, other than hemiplegia and diplegia.
- D. With a cognitive score >70 and a GMC score be-

tween 6 and 10 (type of CP does not matter).

- Level IV in social participation in children with CP includes children with the following characteristics:

A) With the cognitive score between 50 and 70, a GMC score <5, and hemiplegic or diplegic CP.

B) With a cognitive score >70, a GMC score between 3 and 5, and any types of CP, other than hemiplegia and diplegia.

- Level V in social participation in children with CP includes children with the following characteristics:

A. With a cognitive score >70, and a GMC score between 3 and 5, and spastic hypoglycemia CP.

Conclusion

In this study, the importance and predictive power of the GMFCS, MACS, CFCS, type of CP, and level of IQ for social participation were confirmed, which was also verified in the previous study (18). Therefore, based on the results of the previous studies and those of the present study, it can be stated that the SPCS should be classified into levels (very low, low, moderate, high, and very high) and the variables that should be included in the SPCS are GMFCS, MACS, CFCS, IQ, and CP types.

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Conflict of Interests

The authors declare that they have no competing interests.

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