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published in

Clinical Rehabilitation
2006

DOI (link to publisher)

[10.1177/0269215506069673](https://doi.org/10.1177/0269215506069673)

document version

Publisher's PDF, also known as Version of record

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citation for published version (APA)

Voorman, J., Dallmeijer, A. J., Schuengel, C., Knol, D. L., Lankhorst, G. J., & Becher, J. G. (2006). Activities and participation of 9- to 13-year old children with cerebral palsy. *Clinical Rehabilitation*, 20(11), 937-948.
<https://doi.org/10.1177/0269215506069673>

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Activities and participation of 9- to 13-year-old children with cerebral palsy

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Received 7th May 2006; returned for revisions 1st July 2006; revised manuscript accepted 15th July 2006.

Objective: To describe the activities and participation of children with cerebral palsy and to examine the relationship with personal factors and disease characteristics.

Design: Cross-sectional study.

Setting: Department of Rehabilitation Medicine of a University Medical Center in The Netherlands.

Subjects: One hundred and ten children: 70 boys, 40 girls, mean (SD) age 11 years and 3 months (20 months).

Outcome measures: Activities and participation, described in the domains of mobility, self-care, domestic life, social life and communication, measured with the Gross Motor Function Measure, the Pediatric Evaluation of Disability Inventory and the Vineland Adaptive Behavior Scales.

Results: Multiple linear regression models showed that the Gross Motor Function Classification System (GMFCS) was strongly associated with mobility (explained variance 87–92%), self-care and domestic life. Apart from the GMFCS, cognitive impairment and limb distribution were less important but also significantly associated with self-care and domestic life (explained variance 65–81%). Cognitive impairment and epilepsy were the most important factors associated with social life and communication (explained variance 54–75%).

Conclusion: Activities and participation can, to a large extent, be explained by only a few associated factors.

Introduction

Cerebral palsy is the most common disabling motor impairment in children. In Europe the prevalence of cerebral palsy is approximately 2.0 per 1000 live-born children.¹ The severity of the

motor impairment as well as the associated cognitive, communicative and behavioural impairments are different for each child. Activities and participation can therefore vary greatly among children with cerebral palsy.^{2,3} Understanding of activities and participation and its relationship with impairments caused by cerebral palsy is necessary in order to provide answers to questions from children and their parents about current and future functioning, to establish realistic goals for treatment, and to improve

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activities and participation.^{4,5} To describe functioning, the International Classification of Functioning, Disability and Health (ICF) is a framework that is well known and frequently used in rehabilitation medicine, also for children with cerebral palsy.⁶ It provides a framework for describing the health outcomes of a disease at the level of body function and structure (impairments), daily activities and participation. In this study, functioning is described in terms of outcomes at the levels of activities and participation.

Studies on functioning and associated factors, mainly concerning young children with cerebral palsy, have suggested that the severity of the cerebral palsy, cognitive impairment and age are important factors that are related to limitations in activities and participation in young children with cerebral palsy.^{7,8} A significant association has also been found between motor functioning and the severity of cerebral palsy, diagnostic subgroups, epilepsy and intellectual capacity.⁹ One study found an association between functional limitations and higher levels of the Gross Motor Function Classification System (GMFCS).¹⁰ In two reports concerning children with cerebral palsy aged 5–18 years, significant limitations were found in all categories of activities of daily living and social roles. The greatest limitations were found in school and social integration, and these limitations were positively associated with the severity of the cerebral palsy.^{11,12}

Few reports on activities and participation of children with cerebral palsy have focused on the age group before and during puberty. In this period in particular many changes take place, such as a growth spurt, puberty itself, behavioural changes and, for most children, transition to secondary school, which may influence the functioning of these children. Consequently, it is important to get insight into functioning of this specific age group. The main aims of this study were:

- 1) to describe activities and participation in the domains of mobility, self-care, domestic life, social functioning and communication in 9- to 13-year-old children with cerebral palsy, and
- 2) to analyse the relationship between activities and participation and personal and disease characteristics.

Method

Participants

The participants were recruited for a three-year longitudinal study. The current study was based on a cross-sectional analysis of the first (baseline) measurement. Rehabilitation centres, special schools for physically and mentally disabled children, and outpatient clinics of departments of rehabilitation medicine in the north-west region of the Netherlands identified 244 children 9, 11 and 13 years of age with cerebral palsy. The study protocol was approved by all the regional medical ethics committees. This research was performed as part of the PERRIN (Pediatric Rehabilitation Research in the Netherlands) programme, which is a longitudinal study of children with cerebral palsy.

Measurements

Activities and participation were described in the following domains: mobility, self-care, domestic life, social life and communication, and were assessed with the Pediatric Evaluation of Disability Inventory (PEDI) and the Vineland Adaptive Behavior Scale (VABS). Mobility was also measured with the Gross Motor Function Measure (GMFM).

The GMFM is a standardized observational instrument that has been developed to measure gross motor function in children with cerebral palsy, based on their performance of 88 gross motor tasks upon instruction in a specific test situation.^{13,14} The GMFM was analysed with the Gross Motor Ability Estimator computer scoring programme (GMAE) to obtain the GMFM-66 score.^{15,13} The GMAE rescales the child's abilities from an ordinal scale to an interval scale, ranging from zero to one hundred.

The PEDI is a standardized instrument for evaluating functioning in the subscales mobility, self-care and social function in disabled or chronically ill children aged 0–7.5 years. It can also be used to assess older children if their functional abilities are below those of children up through

the age of 7.5 years.^{16–18} For each domain three independent scale scores can be calculated: functional skill level, caregiver assistance and modifications. In this study we only used the raw scores for functional skill level. We used the Dutch adaptation and translation of the PEDI.¹⁸

The VABS has been designed to assess functioning in the subscales motor skills (mobility), daily living skills (domestic life), communication and socialization (social life) of children aged 0–17 years, with and without disabilities.¹⁹ We used the Dutch translation of the VABS survey form,²⁰ and used the raw scores and compared them to the raw scores of norm children (American population). Both the PEDI and the VABS were administered in a semi-structured interview with the child's parents or caregivers.

Associated factors

Associated factors were chosen if they could routinely be assessed in regular medical examinations. The 'severity' of the cerebral palsy was classified according to the Gross Motor Function Classification System (GMFCS). The GMFCS is a 5-level classification system by age in which distinctions between the levels of motor function are based on functional limitations, the need for assistive devices and, to a lesser extent, quality of movement, and was developed using GMFM scores.^{21,22} The disease characteristics that were analysed were limb distribution, epilepsy and cognitive impairment. Limb distribution was subdivided into three categories: hemiplegia (unilateral involvement), diplegia or quadriplegia (both bilateral involvement). Quadriplegia was defined as the arms being as severely or more severely affected than the legs; diplegia was defined as the legs being more severely affected than the arms. Children with repeated seizures during the previous two years were defined as having epilepsy. Cognitive impairment was based on school type: children classified as having no cognitive impairment were those who were following a regular education programme in a regular school or in a school providing special education for physically disabled children. Children with a cognitive impairment were those who were following special education programmes in special schools for children with cognitive impairment (with or without physical disabilities), or in special day-care

centres for severely (cognitive and physical) handicapped children. Gender and age were included as personal characteristics.

Data collection

All children and their parents visited the Department of Rehabilitation Medicine at the VU University Medical Center in Amsterdam. During the visit a trained researcher asked standardized questions about diagnosis, epilepsy and type of school, performed the GMFM and classified the children according to the GMFCS. At the same time, an investigator from the Department of Orthopedagogy interviewed the parents to complete the PEDI and the VABS.

Statistical analyses

Statistical analyses were performed with SPSS software version 11.5 (SPSS Inc., Chicago, IL, USA). The GMFM-66, PEDI mobility, VABS motor skills, PEDI self-care, VABS daily living skills, PEDI social function, VABS socialization and VABS communication were analysed as dependent variables. The GMFCS, limb distribution, epilepsy, cognitive impairment, gender and age were included in the analysis as independent variables.

First, univariate analyses were performed to determine the relationship between the dependent variables and each of the independent variables. Multiple linear regression models were then made for each of the dependent variables and the independent factors that were significant in the univariate analyses ($P < 0.1$).²³ The categorical variables limb distribution and GMFCS were analysed as dummy variables.²⁴ Epilepsy, cognitive impairment and gender were included as dichotomous variables, and age as a continuous variable. The models were made without interactions. Post-hoc Bonferroni correction was applied to test differences between the different levels of the categorical variables (GMFCS and limb distribution). Normal plots for residuals were made to check whether the residuals were approximately normally distributed. The PEDI data on self-care and social function were transformed because the residuals showed a skewed distribution, using a log transformation of the reverse scores to obtain a normal distribution. The strength of the observed relationships is described with the partial eta²

(defined as the sum of squares of the factor (SS_{factor}), divided by the sum of SS_{factor} and the error sum of squares (SS_{error})).

Results

The characteristics of the participants are presented in Table 1. Of the 224 children identified, 110 children and their parents returned the informed consent form.

The box and whisker plots (Figure 1) show the distribution of functioning for each GMFCS level. The mean scores for functioning according to the GMFCS levels and levels of significance are presented in Table 2.

Mobility

Table 3 shows the regression models of the GMFM 66, the PEDI mobility and the VABS motor skills with the associated factors that were significant in the univariate analyses ($P < 0.1$). Multiple linear regression analyses showed that GMFCS was the only factor that was significantly associated with the mobility outcomes, explaining 87–92% of the variance, while limb distribution, cognitive impairment and epilepsy showed no significant relationship. Mobility was lower in children with a higher GMFCS level. There was a significant difference between all levels of the GMFCS, except between levels I and II for the PEDI mobility and the VABS motor skills.

Self-care and domestic life

The regression models for PEDI self-care and VABS daily living skills are shown in Table 4. Transformed data are presented for the PEDI self-care. The GMFCS, limb distribution and cognitive impairment, and for daily living skills also age, were significantly associated with self-care and daily living skills, explaining 65% and 81% of the variance, respectively. In these models the GMFCS was the most important associated factor. Functioning decreased progressively with increasing GMFCS level. Children with a cognitive impairment functioned at a lower level on both outcomes, and children with diplegia functioned better than children with quadriplegia (daily living skills) and hemiplegia (self-care). Daily living skills were better in older children.

Social life and communication

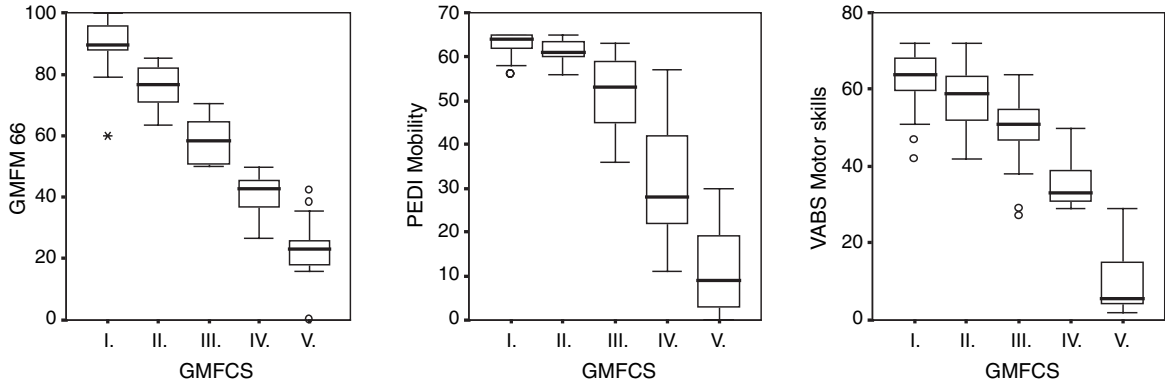
The regression models for social life and communication are shown in Table 5. In these models cognitive impairment and epilepsy were the most important significantly associated factors, while the GMFCS was no longer significantly associated after including cognitive impairment and epilepsy. For VABS communication, limb distribution and age were less important, but also significantly associated factors. The models explained 54% (PEDI social function), 63% (VABS socialization) and 75% (VABS communication) of the variance. Children with cognitive impairment and children with epilepsy functioned at a lower level on all outcomes than children without these impairments. On the VABS communication, children

Table 1 Characteristics of the participants

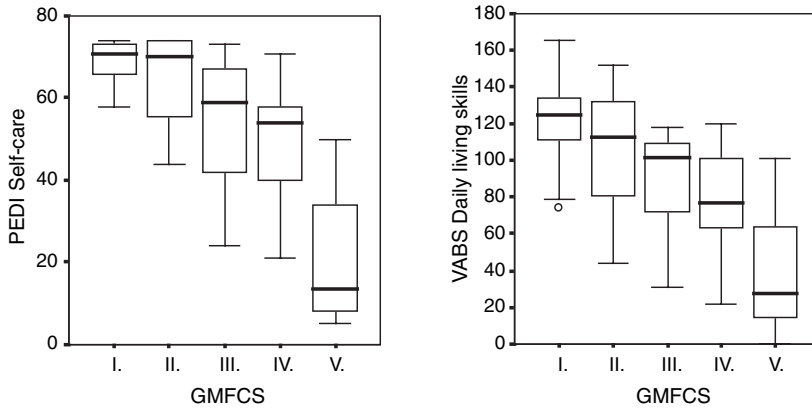
GMFCS level	Associated factors							Age Mean (years) \pm SD
	Limb distribution			Cognitive impairment	Epilepsy	Gender		
	HP <i>n</i> = 42	DP <i>n</i> = 47	QP <i>n</i> = 21			Male <i>n</i> = 70	Female <i>n</i> = 40	
I (<i>n</i> = 50)	38	12	–	1	1	32	18	11.1 (1.8)
II (<i>n</i> = 16)	3	10	3	6	2	10	6	11.8 (1.4)
III (<i>n</i> = 13)	1	12	–	5	2	10	3	10.6 (1.4)
IV (<i>n</i> = 13)	–	10	3	6	2	6	7	11.5 (1.8)
V (<i>n</i> = 18)	–	3	15	14	6	12	6	11.4 (1.6)

GMFCS, Gross Motor Function Classification System; HP, hemiplegia; DP, diplegia; QP, quadriplegia.

(a) GMFM-66, PEDI mobility, VABS motor skills



(b) PEDI self-care and VABS daily living skills



(c) PEDI social function, VABS socialization and communication

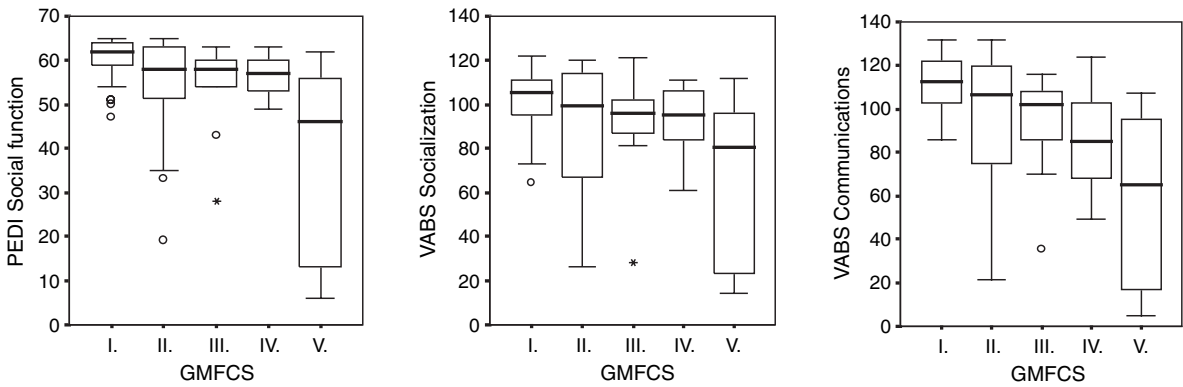


Figure 1 Box plots of activities and participation according to Gross Motor Function Classification System (GMFCS) level. (a) GMFM-66, PEDI mobility, VABS motor skills; (b) PEDI self-care and VABS daily living skills, (c) PEDI social function, VABS socialization and communication. PEDI, Pediatric Evaluation of Disability Inventory; VABS, Vineland Adaptive Behavior Scale; GMFM, Gross Motor Function Measure.

Table 2 Mean scores for activities and participation according to GMFCS levels (95% confidence interval)

GMFCS	Mean (95% CI)		
	GMFM 66	PEDI Mobility	VABS Motor skills
I (n = 50)	89.8 (87.8 to 91.9) ²⁻⁵	63.0 (62.3 to 63.8) ³⁻⁵	63.4 (61.4 to 65.3) ³⁻⁵
II (n = 16)	76.0 (72.4 to 79.7) ^{1,3-5}	61.1 (59.6 to 62.6) ³⁻⁵	57.9 (53.5 to 62.4) ³⁻⁵
III (n = 13)	58.9 (54.1 to 63.7) ^{1,2,4,5}	51.2 (45.6 to 56.7) ^{1,2,4,5}	48.4 (41.8 to 55.0) ^{1,2,4,5}
IV (n = 13)	41.1 (36.9 to 45.3) ^{1-3,5}	30.8 (22.6 to 38.9) ^{1-3,5}	35.5 (31.2 to 40.0) ¹⁻⁴
V (n = 18)	23.3 (18.5 to 28.0) ¹⁻⁴	11.8 (7.0 to 16.7) ¹⁻⁴	10.0 (5.7 to 14.3)
Total: mean (range)	67.5 (0-100)	49.2 (0-65)	48.8 (2-72)
P-value	< 0.001	< 0.001	< 0.001
	PEDI Self-care	VABS Daily living skills	
I (n = 50)	69.2 (67.9 to 70.6) ³⁻⁵	121.4 (115.8 to 126.9) ³⁻⁵	
II (n = 16)	64.7 (58.6 to 70.8) ^{4,5}	104.6 (86.6 to 122.6) ⁵	
III (n = 13)	55.4 (46.1 to 64.7) ^{1,5}	89.4 (72.7 to 106.1) ^{1,5}	
IV (n = 13)	49.2 (40.5 to 57.8) ^{1,2,5}	80.8 (64.6 to 97.0) ^{1,5}	
V (n = 18)	21.0 (13.2 to 28.8) ¹⁻⁴	36.6 (21.8 to 51.3) ¹⁻⁴	
Total: mean (range)	56.7 (5-74)	96.7 (0-166)	
P-value	< 0.001	< 0.001	
	PEDI Social function	VABS Socialization	VABS Communication
I (n = 50)	60.5 (59.3 to 61.8) ⁵	103.0 (99.6 to 106.4) ⁵	111.8 (108.2 to 115.3) ^{4,5}
II (n = 16)	53.9 (46.7 to 61.1) ⁵	91.7 (76.7 to 106.7) ⁵	95.6 (78.5 to 112.8) ⁵
III (n = 13)	54.6 (48.9 to 60.3) ⁵	90.9 (77.9 to 103.9) ⁵	93.0 (79.0 to 107.0) ⁵
IV (n = 13)	56.1 (53.3 to 58.9) ⁵	92.3 (83.1 to 101.6) ⁵	85.2 (70.1 to 100.2) ^{1,5}
V (n = 18)	37.6 (26.6 to 48.6) ¹⁻⁴	65.1 (46.7 to 83.6) ¹⁻⁴	58.4 (38.5 to 78.2) ¹⁻⁴
Total: mean (range)	54.7 (6-65)	92.5 (14-122)	95.8 (5-132)
P-value	< 0.001	< 0.001	< 0.001

GMFCS, Gross Motor Function Classification System; CI, confidence interval; GMFM, Gross Motor Function Measure; PEDI, Pediatric Evaluation of Disability Inventory; VABS, Vineland Adaptive Behavior Scale.

- 1: significantly different compared with GMFCS I.
 2: significantly different compared with GMFCS II.
 3: significantly different compared with GMFCS III.
 4: significantly different compared with GMFCS IV.
 5: significantly different compared with GMFCS V.

with diplegia appeared to function better than children with quadriplegia, and communication increased with age.

Discussion

Descriptions of the activities and participation of children in the transition period between childhood and adulthood are important in order to improve the knowledge about functioning of children with cerebral palsy, to form a basis for treatment goals, and to guide practitioners in their

choice of medical intervention.^{4,5} As the population of children with cerebral palsy is heterogeneous, it is necessary to classify the children according to the 'severity' of the cerebral palsy. The results of this study show that the variability in activities and participation reduces considerably when children are classified according to the GMFCS, particularly with regard to the mobility domain outcomes.

The analyses showed that the GMFCS was the only factor that was strongly associated with mobility. These findings were in line with the findings of other studies.^{7,8,10} For the GMFM a close relationship with GMFCS level was as

Table 3 Models for mobility: GMFM-66, PEDI mobility and VABS motor skills

	GMFM 66				PEDI mobility				VABS motor skills			
	b	95% CI	P-value	Partial eta ²	b	95% CI	P-value	Partial eta ²	b	95% CI	P-value	Partial eta ²
Intercept	25.7				13.5				12.2			
GMFCS												
I	62.6	55.3 to 69.9	<0.001	0.800	49.6	42.9 to 56.4	<0.001	0.760	48.8	41.5 to 56.2	<0.001	0.687
II	50.5	44.0 to 57.0			48.0	42.0 to 54.0			44.0	37.4 to 50.5		
III	33.3	26.0 to 40.7			37.8	31.0 to 44.6			33.5	26.0 to 40.9		
IV	16.1	9.5 to 22.6			17.7	11.6 to 23.8			21.6	15.0 to 28.2		
V (ref cat)	0				0				0			
Limb distribution			0.892	0.002			0.827	0.004			0.238	0.028
Hemiplegia	1.8	-5.6 to 9.1			-0.3	-7.1 to 6.5			1.8	-5.6 to 9.2		
Diplegia	1.1	-5.1 to 7.3			0.8	-4.9 to 6.6			4.3	-1.9 to 10.6		
Quadriplegia (ref cat)	0				0				0			
Cognitive impairment	-3.2	-8.1 to 1.6	0.193	0.017	-2.6	-7.0 to 1.9	0.262	0.012	-2.4	-7.2 to 2.5	0.336	0.009
Epilepsy	-0.5	-5.8 to 4.9	0.857	<0.001	0.5	-4.4 to 5.5	0.827	<0.001	-3.3	-8.7 to 2.1	0.226	0.014
Total explained variance:	92%				89%				87%			

GMFCS level V and quadriplegia are set to zero (reference category); GMFCS, Gross Motor Function Classification System; GMFM, Gross Motor Function Measure; PEDI, Pediatric Evaluation of Disability Inventory; VABS, Vineland Adaptive Behavior Scale; b, regression coefficient; CI, confidence interval; partial eta² = SS_{factor} / (SS_{factor} + SS_{error}).

Table 4 Models for PEDi self-care and VABS daily living skills

	Log PEDi self-care				VABS daily living skills			
	<i>b</i>	95% CI	<i>P</i> -value	Partial η^2	<i>b</i>	95% CI	<i>P</i> -value	Partial η^2
Intercept	3.1				-13.8			
GMFCS								
I	-2.3	-3.1 to -1.5	<0.001	0.358	52.9	35.9 to 69.8	<0.001	0.312
II	-2.1	-2.8 to -1.4			41.2	26.1 to 56.2		
III	-1.0	-1.8 to -0.2			30.0	12.9 to 47.0		
IV	-0.6	-1.3 to 0.1			21.2	6.0 to 36.4		
V (ref cat)	0				0			
Limb distribution								
Hemiplegia	0.6	-0.2 to 1.4	0.040	0.062	8.5	-8.5 to 25.5	0.012	0.085
Diplegia	0.03	-0.6 to 0.7			18.2	3.8 to 32.6		
Quadriplegia (ref cat)	0				0			
Cognitive impairment	1.1	0.6 to 1.6	<0.001	0.144	-30.1	-41.4 to -18.9	<0.001	0.221
Epilepsy	-0.2	-0.7 to 0.4	0.601	0.003	-11.5	-23.9 to 0.9	0.069	0.033
Age (years)					6.5	4.4 to 8.6	<0.001	0.278
	Total explained variance: 65%				Total explained variance: 81%			

For the PEDi self-care transformed data are presented: log-transformation of the reverse of the data. GMFCS level V and quadriplegia are set to zero (reference category); GMFCS, Gross Motor Function Classification System; PEDi, Pediatric Evaluation of Disability Inventory; VABS, Vineland Adaptive Behavior Scale; *b*, regression coefficient; CI, confidence interval; partial $\eta^2 = SS_{\text{factor}} / (SS_{\text{factor}} + SS_{\text{error}})$.

expected since the latter was developed based on GMFM scores. It is however remarkable that the GMFCS explained almost 90% of the variance for the PEDI mobility and the VABS motor skills, because the PEDI and the VABS measure subjective motor performance while the GMFM is an objective measure of gross motor capacity. The fact that also in this study such a strong relationship was found between the GMFCS and mobility, supports the use of the GMFCS to classify a child's mobility performance. For PEDI self-care and VABS daily living skills the GMFCS was also the most important significantly associated factor. Other less important, but significantly associated factors were cognitive impairment, limb distribution and, for daily living skills, also age. This is in line with the findings reported by Ostensjo *et al.*⁸

In the univariate analyses the GMFCS was also found to be significantly associated with social functioning and communication, showing only significant differences between GMFCS levels I through IV compared with V (see also Figure 1). These results suggest that the ability to move independently (GMFCS levels I through IV) is important for social functioning. Another study underlines the importance of the ability to move independently by showing improvements in the social participation of children with quadriplegia after they had been provided with a powered wheelchair.²⁵ However, our results also showed that the GMFCS did not make any significant contribution to the models for social functioning and communication after including cognitive impairment and epilepsy. These findings were in contrast to the findings of recently published studies.^{7,8} This may be because older children were included in the present study. The children may take longer to acquire social skills if the cerebral palsy is more severe, but do eventually reach the same level of social functioning. Another explanation for the non-significant contribution could be that in the present study the GMFCS was specified as an ordered categorical variable, allowing varying distances between levels, while previous studies included the GMFCS as a discrete numerical variable, assuming equal distances between levels.

Other studies have suggested that social life was partially influenced by variations in functional

Clinical messages

- Gross Motor Function Classification System level can be used as an indicator of mobility, self-care and domestic life in children with cerebral palsy aged 9–13 years.
- Cognitive impairment and epilepsy showed the strongest association with social life and communication.
- Although the clinical features of cerebral palsy are very heterogeneous, only a few factors can explain the variance of functioning on distinct domains of activities and participation.

capacity and partially by environmental factors,²⁶ such as restricted information, poor support from caregivers, poverty, insufficient financial benefits, disabling influence of time pressure, and poorly coordinated services.²⁷ However, although environmental factors were not investigated, our results showed high explained variances for participation (54–75%) for personal and disease characteristics. Still, in future research it would be interesting to analyse the relationship between environmental factors and activities and participation to obtain more information about the factors that influence functioning.

Furthermore, some remarks can be made about two of the outcome measures: the PEDI and the VABS. The PEDI showed ceiling effects for all domains, and this may be because children who function at GMFCS level I function better than children with a developmental age of 7.5 years. No ceiling effects were seen on the VABS, and this may be the reason for the higher explained variance of activities and participation in the VABS domains of daily living skills, socialization and communication, than in the PEDI domains of self-care and social function. On the VABS, children with GMFCS level I functioned at almost the same level as non-disabled children in the domains of socialization and communication (ranges for children between 9 and 13 years are 101–113 and 116–127, respectively) and somewhat lower in the domains

of daily living skills (range for children between 9 and 13 years is 136–155),²⁰ based on norms for American children. Children with GMFCS levels II–V functioned at a lower level than norm children. As expected, the scores for the domain of motor skills were lower than those of the norm children.

There was no information available about the non-participating children. Since the main purpose of the study was to describe the level of activities and participation, and its associated factors, the study group is not necessarily representative of the Dutch population of children with cerebral palsy. The unequal distribution between the levels of the GMFCS may have reduced statistical power, but despite this, we were able to identify some important associated factors.

Conclusion

The results of this study showed that a few easily measured factors could explain a large amount of the variance of activities and participation. The GMFCS classification was found to be an important factor that was significantly associated with mobility, self-care and domestic life in 9- to 13-year-old children with cerebral palsy. Cognitive impairment and epilepsy were the most important factors that were associated with social life and communication.

Further research, and especially studies based on longitudinal designs, should be carried out to determine the course of activities and participation and to identify the factors that predict the course of functioning. The data obtained can then be used for the development of intervention programmes and for planning the services that are needed for children with cerebral palsy.

Acknowledgements

This project has been supported by the Netherlands Organisation for Health Research and Development (grant number 1435.0011).

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