# Daily activities of school-age children with cerebral palsy: development and learning

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# Daily activities of school-age children with cerebral palsy: development and learning

Dagelijkse activiteiten van kinderen met cerebrale parese: ontwikkeling en leren

(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de
Universiteit Utrecht op gezag van de rector magnificus,
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# Contents

# 1

# General introduction

## Introduction

Cerebral palsy (CP) is a neurodevelopmental condition beginning early in life and persisting throughout the lifespan.[1] It is one of the most common causes of disability in children. The prevalence is around 2 per 1000 live births[2,3] and is reported to be stable over the past two decades in western countries.[4] CP is defined as "a group of permanent disorders of the development of movement and posture, causing activity limitation, which are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems".[1]

There is general agreement that CP is a heterogeneous condition, both in its etiology and in its clinical manifestation.[1] The etiology of CP can be described as *prenatal* (e.g., congenital malformation), *perinatal* (e.g., birth asphyxia), or *postnatal* (e.g., meningitis during the first year of life). Currently, the etiology is often not known and, therefore, it is not a common part of the classification of CP. The classification of CP is above all characterized by the clinical manifestation, in terms of 'subtypes' and 'functional abilities'[1] (**Table 1.1**).

Subtypes relate to the predominant type of the motor impairment (i.e., spastic, dyskinetic, and ataxic) and – within the spastic subtype – to the limb distribution (i.e., unilateral and bilateral).[5] *Spastic* CP is characterized by at least two of the following features: abnormal pattern of posture and/or movement, increased muscle tone (not necessarily constant), and pathological reflexes (hyper-reflexia or pyramidal signs). Spastic CP can be either *unilateral* if the limbs on one side of the body are involved or *bilateral* if the limbs on both sides of the body are involved. *Dyskinetic* CP is described by both abnormal pattern of posture and/or movement and involuntary, uncontrolled, recurring, and occasionally stereotyped movements. *Ataxic* CP is defined by both abnormal pattern of posture and/or movement and loss of orderly muscular

**Table 1.1** Clinical manifestation of CP

| | | | |
|---|---|---|---|
| 'Subtype' | Spastic CP<br>• Unilateral<br>• Bilateral | Dyskinetic CP | Ataxic CP |
| 'Functional ability' | GMFCS<br>• Level I<br>• Level II<br>• Level III<br>• Level IV<br>• Level V | MACS<br>• Level I<br>• Level II<br>• Level III<br>• Level IV<br>• Level V | |

GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System.

coordination, so that movements are performed with abnormal force, rhythm, and accuracy.

Next to subtype classifications, classification systems relating to children's functional abilities have been developed in recent years. Such functional classifications provide additional information about the severity of the condition.[6] For mobility function, the Gross Motor Function Classification System (GMFCS) has been developed. The GMFCS is a five-level classification system for gross motor activity, based on functional limitations, the need for assistive devices, and, to a lesser extent, quality of movement.[7] Children classified as *GMFCS level I* (i.e., most functional abilities) can walk at home, at school, outdoors, and in the community. They can climb stairs, run and jump, but speed, balance and coordination are impaired. Children classified as *GMFCS level V* (i.e., least functional abilities) are transported in wheelchairs in all settings, their ability to maintain head and trunk postures against gravity is limited, and their self-mobility even with the use of assistive technology is severely limited. For hand and arm function, the Manual Ability Classification System (MACS) has been developed. The MACS is a five-level classification system for fine motor activity, reflecting the child's typical bimanual performance in daily activities.[8] Children classified as *MACS level I* (i.e., most functional abilities) handle objects easily and successfully, while children classified as *MACS level V* (i.e., least functional abilities) do not handle objects and require total assistance.

CP cannot be cured, but some of the detrimental consequences of this condition can be treated. Traditionally, treatment of CP has focused on influencing the primary impairments, such as spasticity, or the secondary impairments, such as joint contractures. Strategies in this respect can be divided in conservative interventions (e.g., casting, splinting), pharmacological interventions (e.g., botulinum toxin, baclofen), surgical interventions (e.g., muscle lengthening, selective dorsal rhizotomy), and neurophysiological interventions (e.g., muscle strengthening, neurodevelopmental treatment).[9,10] Recently, treatment of CP is increasingly focusing on influencing activities, such as ambulation and self-care. Promising strategies in this respect are task-oriented interventions[11-13] and environmental interventions.[14-16] Although many interventions have been studied, evidence is still lacking about the effects in children with CP.[17,18] Especially regarding daily activities, evidence-based practice is in its infancy and requires more knowledge, for instance, concerning the natural development in the heterogeneous CP population.

To conclude, treatment and research in children with CP has traditionally focused on medical and motor aspects. With regard to children's daily activities, however, little information exists. Therefore, the present thesis aimed to explore daily activities and multiple influences on daily activities in children with CP.

## The concept of daily activities

Activities of daily living, in short 'daily activities', is used as an umbrella term comprising *those activities or tasks that people undertake routinely in their everyday life.*[19] With respect to contents, daily activities are historically subdivided into personal care (e.g., feeding, toileting, bathing, dressing), functional mobility (e.g., ambulation, wheelchair mobility, bed mobility, transfers), and domestic and community tasks (e.g., housekeeping, cooking, managing money, using the telephone).[20-22]

In the past decade, the conceptual framework of the International Classification of Functioning, Disability and Health (ICF; see **Figure 1.1**) has played an important role in introducing daily activities as a component of health in which medical and social components are integrated.[23] In addition, the ICF has played an important role in distinguishing two constructs for daily activities. In one construct, the person's execution of a task – or what a person does do – is accentuated. In a second construct, the person's ability for a task – or what a person can do – is accentuated. For the first construct, the term 'performance' is commonly used. For the second construct, both the term 'capacity' and the term 'capability' are used in the literature.[24-28] It makes sense, however, to reserve the term capability for tasks related to a daily environment, for instance the home environment, and the term capacity for tasks in a standardized environment (i.e., apart from a daily environment), for instance an exercise room.[29] With such a conceptualization, both performance (does do in a daily environment) and capability (can do in a daily environment) are direct qualifiers of daily activities, while capacity (can do in a standardized environment) is not.

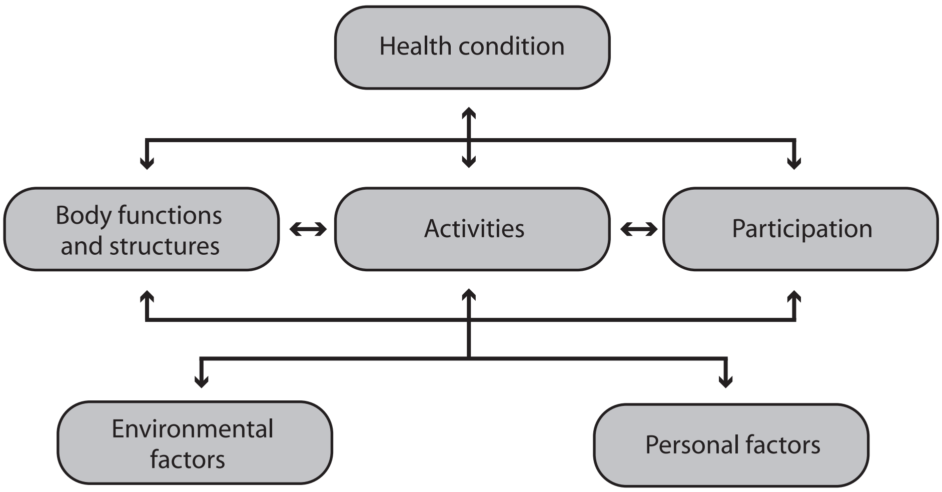


**Figure 1.1** Conceptual framework of the International Classification of Functioning, Disability and Health.[23]

To measure daily activities in pediatric rehabilitation and, particularly, in children with CP, the Pediatric Evaluation of Disability Inventory (PEDI) is currently a commonly used standardized instrument.[30] Introduced in the early 1990's, this instrument has been designed to identify both capability and performance in children with chronic illnesses and disabilities.[31] The PEDI is administered through parental report in a structured interview covering three domains: self-care, mobility, and social function. The PEDI can be used for discriminative purposes (i.e., measuring deficits or delays) as well as evaluative purposes (i.e., measuring changes).[32] With the PEDI, a measurement tool is available for exploring the development of daily activities in children with CP.

## Development of daily activities

Exploring the development of daily activities in children with CP is important in order to provide information about functioning of the heterogeneous population of children with CP. This information may help answering questions of children, their parents and their families, for instance about self-care activities (e.g., toileting), choice of school (e.g., regular or special education), learning of academic skills (e.g., literacy and arithmetic), playing with peers, and joining sport clubs. Furthermore, information about functioning of children with CP may help establishing realistic expectations and treatment goals, and improving their daily activities.

Exploring the development of daily activities has two parts. The first part concerns exploring the *course* of daily activities. In this part, the main question is whether, and if so to what extent, certain daily activities increase, decrease or stabilize over time. The second part relates to exploring the *determinants* for the course, i.e., what influences the course. Looking at the ICF framework, various influences can be considered, including characteristics of CP (the health condition), characteristics within the child (the body functions, the capacities, and the personal factors) and characteristics outside the child (the environmental factors).[23]

Alongside the conceptual framework of the ICF, empirical research has also provided a relevant background for exploring the development of daily activities in children with CP. For instance, large variability has been shown in the level of daily activities among children with CP.[33-35] In addition, some important determinants have been found for the level of daily activities, such as severity of CP,[36,37] children's motor capacities,[38,39] children's cognitive capacities,[35,40] and family factors.[41,42] However, since most studies used cross-sectional designs, current knowledge does not inform us yet about the course of daily activities and its determinants. For such information, studies with a longitudinal design are necessary.

## The PERRIN research program

In 2001, the Pediatric Rehabilitation Research in the Netherlands (PERRIN) research program was initiated with three aims: 1) to develop an instrument to measure daily activities of children with CP (i.e., a study on cross-cultural validation of the PEDI), 2) to describe form, content, and coordination of rehabilitation programs in Dutch pediatric rehabilitation of children with CP (i.e., a study called PERRIN Pro-CP), and 3) to describe the course and determinants of daily activities, participation, and quality of life of children and adolescents with CP in different age groups (i.e., studies referred to as PERRIN CP 0-5, PERRIN CP 9-16, and PERRIN CP 16-24).

## The PERRIN CP 5-9 study

In 2005, PERRIN CP 5-9 was added to the PERRIN research program, filling the missing school-age period. The age of 5-9 years was considered of particular interest. Normally, this period is characterized by a major expansion of a child's world, e.g., going to primary school, and thus by an increase of a child's daily activities.[43] It was, however, unknown if children with CP develop along similar lines in their daily activities as non-disabled peers normally do.

PERRIN CP 5-9 is a longitudinal study on the course and determinants of daily activities in school-age children with CP. This cohort study was set up in line and in collaboration with the PERRIN CP 0-5, PERRIN CP 9-16, and PERRIN CP 16-24 studies. The study was performed by a multidisciplinary team of researchers working in the field of rehabilitation medicine (University Medical Center Utrecht, Rehabilitation Center De Hoogstraat, VU University Medical Center) and special education (Utrecht University and VU University Amsterdam). As such it concerned a collaboration project of pediatric rehabilitation in Utrecht and Amsterdam. A total of 116 children, aged 5 or 7 years at study entry and having a confirmed diagnosis of CP, participated with their parents. All were invited for a baseline assessment (T0), followed by an assessment 1 year (T1) and 2 years (T2) later. Children and their parents visited Rehabilitation Center De Hoogstraat or the department of Rehabilitation Medicine of the VU University Medical Center. During these visits children were tested (among others for body functions, motor capacity and cognitive capacity) and parents were interviewed (among others with the PEDI). Assessments started in May 2006 and finished in October 2009.

## Learning and teaching of daily activities

Knowledge about the development (course and determinants) of daily activities in children with CP may help answering questions of children and parents, establishing realistic treatment goals, and improving children's daily activities. However, for actually improving a specific activity of an individual child with CP, such knowledge alone might not be sufficient. It has been suggested that a key element in this respect would be increased knowledge about learning and teaching of daily activities in children with CP.[44-46]

Knowledge about learning and teaching of daily activities is available in the literature, covering topics such as feedback, mental practice, and environmental constraints.[47] Learning is understood as a set of processes associated with practice and experience leading to relatively permanent change in capabilities for performance, while teaching is the facilitation of these processes.[48] Learning leads to capabilities and may thus lead to performance of daily activities. Performance itself, however, is the result of a complex interaction among many variables, only one of which is learning.[49] In physiological terms, learning can be seen as a continuum from *short-term changes in the efficiency or strength of synaptic connections to long-term structural changes in the organization and number of synaptic connections*,[49] a principle that is also known as 'synaptic pruning'.[50] There are many forms of learning (e.g., associative learning, conditioning, procedural and declarative learning) and, as a consequence, there are many theories of learning and strategies for teaching. The challenge in practice is which forms, theories, and strategies to choose for which individual. The individual's preference for the process of learning, i.e., his or her learning style,[51] can be one guide.

Taking individual learning styles into account when teaching daily activities to children with CP could make the process of learning more pleasant for the children and more efficient for the teachers as well as the parents and therapists. However, knowledge about learning styles of children with CP is not available yet. Since this is a new topic in CP care and research, explorative studies are needed addressing both quantitative and qualitative aspects of learning styles.

## The PROMOVE-CP study

In 2008, a separate study was initiated to explore the topic of learning styles and teaching strategies for motor activities in children and adolescents with CP. This study was named PROMOVE-CP (*Praktijk Onderzoek Motorische Vaardigheden Educatie bij CP*). PROMOVE-CP was initiated as an 'action research',[52] which aimed at active involvement in generating knowledge by professionals teaching motor activities in children and adolescents with CP.

The PROMOVE-CP study was incorporated in the research program 'Pediatric Rehabilitation' of the Center of Excellence for Rehabilitation Medicine in Rehabilitation Center De Hoogstraat in Utrecht and in the research theme 'Function' of NetChild (Network for Childhood Disability Research in the Netherlands). The study consisted of two parts: a theoretical exploration followed by a practical exploration. The theoretical exploration concerned the concept of learning styles and its possible tools in the field of (pediatric) rehabilitation. The practical exploration concerned professionals' perceptions of classifying learning styles in children and adolescents with CP as well as trying out available tools. The latter was designed as a mixed-methods study. The PROMOVE-CP study was performed between June 2008 and December 2009.

## Outline of this thesis

The main aim of this thesis was to gain knowledge about daily activities and its multiple influences in children with CP. Two topics were explored. One topic related to the development of daily activities. The second topic concerned learning and teaching of daily activities.

Chapters 2, 3, 4, and 5 report on the development of daily activities, focusing both on possible determinants and on the course of daily activities. **Chapter 2** describes two instruments for measuring selective motor control in children with CP. Selective motor control is considered an important body function determining daily activities in children with CP. Since little is known about standardized measurement of selective motor control in children with CP, we examined two available instruments for their reliability. **Chapter 3** focuses on the relationship between gross motor capacity and mobility in daily life in children with CP. Gross motor capacity is also considered an important determinant for daily activities in children with CP. We were specifically interested whether the relationship between gross motor capacity and daily-life mobility is moderated by the severity of CP. **Chapter 4** investigates a third potential determinant for daily activities in children with CP: children's intellectual capacity. We were interested in the development of non-verbal intellectual capacity of children with CP and examined whether this development is associated with the severity of CP. **Chapter 5** describes the development of daily activities in the domains of self-care, mobility, and social function. In this chapter, we investigated multiple determinants for the course of daily activities in three domains. Next to the influence of severity of CP, selective motor control, children's gross motor capacity, and children's intellectual capacity, we were also interested in influences of family-characteristics.

Chapters 6 and 7 deal with learning and teaching of daily activities. The purpose of **chapter 6** was to introduce the concept of learning styles in rehabilitation. The purpose of **chapter 7** was to explore professionals' perceptions of classifying learning styles in pediatric rehabilitation and specifically with respect to children and adolescents with CP. We were interested if classifying learning styles is perceived as an important basis for optimizing motor activities in daily life of children and adolescents with CP.

The thesis concludes with a general discussion (**chapter 8**), describing the main findings, clinical implications, unanswered questions, and methodological considerations. Subsequently, a conceptual model is outlined and directions for future research are proposed.

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# 2

# Selective motor control of the lower extremities in children with cerebral palsy: inter-rater reliability of two tests

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# Abstract

**Purpose:** The purpose of this study was to examine the inter-rater reliability of two tests measuring selective motor control (SMC) of the lower extremities in children with cerebral palsy (CP).

**Methods:** Two testers independently assessed 21 children (13 boys, 8 girls; mean age 6 years 5 months, SD 12 months) with spastic CP (14 unilateral and 7 bilateral) using the Boyd and Graham SMC test (with an existing protocol) and the modified Trost SMC test (with a newly developed protocol). Inter-rater reliability was analyzed using Cohen's Kappa.

**Results:** For the Boyd and Graham SMC test for ankle dorsiflexion, Kappa was 0.55 (95% CI 0.36–0.74). For the modified Trost SMC test for ankle dorsiflexion, knee extension, hip abduction, and hip flexion, Kappas were 0.65 (0.47–0.84), 0.69 (0.49–0.88), 0.57 (0.37–0.78), and 0.71 (0.51–0.91), respectively.

**Conclusion:** The SMC tests showed moderate (Boyd and Graham SMC test) to good (modified Trost SMC test) inter-rater reliability.


## INTRODUCTION

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations, which are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.[1] Very common in CP are neuromuscular impairments such as spasticity, muscle weakness, and loss of selective motor control.[2] Although most research on neuromuscular impairments in children with CP has been focused on spasticity and muscle weakness,[3,4] several studies have also started to explore the importance of selective motor control (SMC).[5-10]

Based on previous studies and for the purpose of the present study, SMC can be clinically defined as 'the ability to move an individual joint voluntarily and independently from posture and other joints in the same limb'. Loss of SMC is neurophysiologically explained by lesions in the corticospinal tracts.[11] On a functional level, SMC is assumed to be one of the most important impairments influencing gross motor activities in children with CP,[12,13] for instance crawling and walking. Furthermore, SMC has shown to be an important guide in clinical interventions like botulinum toxin treatment[14,15] and selective dorsal rhizotomy (SDR).[16] Therefore, clinical assessment of SMC – in particular SMC of the lower extremities – is very useful during the early stage of childhood for children with CP.

So far, two instruments have been used for clinical assessment of SMC in children with CP: the SMC test by Boyd and Graham[17] and the SMC test by Trost.[18] Boyd and Graham developed one test to assess the selective dorsiflexion of the ankle. Their test has been used in four published studies.[8,13-15] The concept behind this test was to observe a child's ability to activate the muscles involved in dorsiflexion of the ankle. Trost developed another test to assess SMC for movements of the ankle, knee, and hip. The Trost SMC test has been used in two published studies.[5,12] The concept behind this SMC test was to observe a child's ability to move an individual joint independently from other joints. According to this concept, loss of SMC manifests clinically through synergistic movement patterns – defined as 'the tendency for two or more joints of a limb to simultaneously move in flexion or extension' – which are also known as 'mass flexion or extension patterns'. In a mass extension pattern for instance, knee extension is associated with hip extension and ankle plantar flexion.[19]

With respect to SMC influencing gross motor activities of children with CP, it is of particular interest that SMC tests are valid, reliable, and feasible for use at an early age. Currently, however, none of these properties have been reported for the Boyd and Graham SMC test and the Trost SMC test in children with CP.

The objective of this study was to examine the inter-rater reliability of the Boyd and Graham SMC test and the Trost SMC test in children with CP aged 5–7 years. In this study, we used the existing protocol for the Boyd and Graham SMC test and a newly developed protocol for the Trost SMC test.

## METHODS

This study was performed as part of PERRIN (Pediatric Rehabilitation Research in the Netherlands), a prospective longitudinal cohort study on the course and determinants of daily functioning in children with CP. The present study on reliability of SMC tests was part of the first (baseline) assessment of a cohort of children born between 1998–2002.

### Participants

Between October 2006 and March 2007, 21 consecutive children from PERRIN participated in the reliability study. The participants were all children aged between 5–7 years with a confirmed diagnosis of spastic CP and were recruited at Rehabilitation Center De Hoogstraat and the pediatric rehabilitation department of the University Medical Center Utrecht (UMCU) in the Netherlands. Children diagnosed with additional diseases and disorders besides CP affecting motor functioning were excluded. Informed consent was obtained from all parents. Ethical approval for the study was given by the Committee for Medical Ethics of Rehabilitation Center De Hoogstraat and the UMCU.

## Instruments

***Boyd and Graham SMC test.*** The Boyd and Graham SMC test has a five-point scale to assess the selective dorsiflexion of the ankle: score 0, no movement when asked to dorsiflex the foot; score 1, limited dorsiflexion using mainly extensor hallucis longus and/or extensor digitorum longus; score 2, dorsiflexion using extensor hallucis longus, extensor digitorum longus and some tibialis anterior activity; score 3, dorsiflexion achieved using mainly tibialis anterior activity but accompanied by hip and/or knee flexion; and score 4, isolated selective dorsiflexion achieved, through available range, using a balance of tibialis anterior activity without hip and knee flexion. The description of the test protocol is: 'The child sits with hips flexed and knees comfortably extended, able to see its feet. The child is requested to dorsiflex each foot individually to a target. The limb is in vision and the balance of muscle activity is observed' (p. S26).[17] The Boyd and Graham SMC test scale and protocol are presented in **Appendix 2.1**.

***Trost SMC test.*** The Trost SMC test originally has a three-point scale: score 0, no ability to isolate movement; score 1, partially isolated movement; and score 2, complete isolation of movement.[18] To date however, neither a specification of the movements nor a test protocol has been published. For the purpose of this study, the authors therefore composed a standardized protocol for the Trost SMC test, including comprehensive descriptions of the selective movement, the synergistic movement patterns, and the scoring method. The protocol was developed for the leg movements that are considered to be most important for walking: ankle dorsiflexion, knee extension, hip flexion, and hip abduction. Furthermore, the three-point scale was changed to a four-point scale, by adding one extra score indicating a child's inability to execute the SMC test. Thus, the Trost SMC test in this study is further referred to as 'modified Trost SMC test'. Both the original and the modified Trost SMC tests (scale and protocol) are presented in **Appendix 2.2**.

## Procedure

Testers were one physical therapist (DWS) and one medical doctor (ACG). Before data collection, they carefully studied the administration of both the Boyd and Graham SMC test and the modified Trost SMC test, and assessed five children with CP in a practice session. During data collection, the two testers independently assessed children's SMC, each using the Boyd and Graham SMC test and the modified Trost SMC test successively. Between the assessment by the first tester and the one by the second tester, a 1-hour time interval was maintained in which a child's gross motor function was tested as part of PERRIN. To neutralize possible effects of children's fatigue, motivation, or learning, the order of the testers was randomly assigned. Each assessment consisted of four movements – i.e. ankle dorsiflexion (for the Boyd and Graham SMC test and the modified Trost SMC test), knee extension, hip abduction, and hip flexion (only for the modified Trost SMC test) – which were observed separately for the left and the right legs for both children with bilateral and unilateral spastic CP (the latter group thus being assessed on the affected side and on the presumed non-affected side of their body). Each movement was explained and also demonstrated to the children, and children were given verbal feedback on their performance as well. For both the Boyd and Graham SMC test and the modified Trost SMC test, the best of three performances was administered for analyses.

### Statistical analyses

Children's characteristics were analysed using SPSS version 16.0 (SPSS Inc, Chicago, IL, USA). For the inter-rater reliability, Cohen's Kappa values with 95% confidence intervals (95% CI) were calculated using the Kappa Calculator by Lowry.[20] All SMC scores – including the 'inability' score added to the Trost SMC test in this study – were adopted as categorical data. For interpretation of the Kappa values, the following guidelines by Altman[21] were used: lower than 0.20 is 'poor agreement'; between 0.21–0.40 is 'fair agreement'; between 0.41–0.60 is 'moderate agreement'; between 0.61–0.80 is 'good agreement'; and above 0.80 is 'very good agreement'.

## RESULTS

Children's characteristics in terms of age, sex, limb distribution (unilateral versus bilateral), and level on the Gross Motor Function Classification System (GMFCS)[22] are summarized in **Table 2.1**.

**Table 2.1** Characteristics of the participating children (*n* = 21)

| | |
|---|---|
| Age (years; months) | |
| Range | 4;11–7;7 |
| Mean (SD) | 6;5 (1;0) |
| Sex, *n* | |
| Boys | 13 |
| Girls | 8 |
| Limb distribution, *n* | |
| Unilateral | 14 |
| Bilateral | 7 |
| GMFCS, *n* | |
| I | 13 |
| II | 3 |
| III | 2 |
| IV | 1 |
| V | 2 |

GMFCS, Gross Motor Function Classification System; *n*, number of children; SD, standard deviation.

**Table 2.2** Inter-rater reliability statistics of the Boyd and Graham SMC test (*n* = 42)

| | Cohen's Kappa | 95% CI |
|---|---|---|
| Ankle dorsiflexion | 0.55 | 0.36–0.74 |

SMC, Selective Motor Control; *n*, number of limbs; CI, confidence interval.

**Table 2.3** Inter-rater reliability statistics of the modified Trost SMC test (*n* = 42)

| | Cohen's Kappa | 95% CI |
|---|---|---|
| Ankle dorsiflexion | 0.65 | 0.47–0.84 |
| Knee extension | 0.69 | 0.49–0.88 |
| Hip flexion | 0.71 | 0.51–0.91 |
| Hip abduction | 0.57 | 0.37–0.78 |

SMC, Selective Motor Control; *n*, number of limbs; CI, confidence interval.

In 21 children, a total of 42 legs were assessed with both the Boyd and Graham SMC test and the modified Trost SMC test. For the Boyd and Graham SMC test for ankle dorsiflexion, Kappa was 0.55 (**Table 2.2**). For the modified Trost SMC test for ankle dorsiflexion, knee extension, hip abduction, and hip flexion, Kappas were 0.65, 0.69, 0.57, and 0.71, respectively (**Table 2.3**).

## DISCUSSION

In this study, the inter-rater reliability of two tests measuring SMC of the lower extremities in children with CP was examined. The inter-rater reliability of the Boyd and Graham SMC test for ankle dorsiflexion was 'moderate'. The inter-rater reliability of the modified Trost SMC test was 'moderate' for hip abduction and was 'good' for ankle dorsiflexion, knee extension, and hip flexion.

These findings are in line with two recent studies showing moderate to good inter-rater reliability for SMC tests in children with CP. One study used the Boyd and Graham SMC test[8] and the other used the Selective Control Assessment of the Lower Extremity (SCALE).[7] The SCALE is a new instrument – unpublished at the time this study was performed – which resembles the present study's modified Trost SMC test in terms of concept, protocol, and scale. As distinct from these recent studies, the present study did not use just one but two available SMC tests and besides focused on younger children. One of the main benefits of this study was the possibility to compare two different SMC tests in children with CP aged 5–7 years. In this respect, the modified Trost SMC test appeared to have higher Kappa values than the Boyd and Graham

SMC test. This may be attributable to the raters' perception that the joint movements observed in the Trost SMC test are easier to score than muscle activation as required in the Boyd and Graham SMC test.

Systematic examination of the feasibility of both SMC tests was originally not an objective of the present study. However, while conducting the tests, the testers encountered several important issues concerning the feasibility in relation to both the protocol and the scale of both SMC tests.

In relation to the protocols, it is first worth mentioning that both SMC tests were generally easy to administer, were non-threatening for the children, were inexpensive, and required little material. The Boyd and Graham SMC test and the modified Trost SMC test can be administered within 5 and 15 minutes, respectively. Nevertheless, the testers experienced some difficulty when assessing the SMC in children with poorer functional abilities (GMFCS level III, IV, and V). These children often suffer from severe muscle shortening and/or spasticity of the limbs, resulting in limited range of motion. The testers realized the importance of the instruction, provided with the modified Trost SMC test, to check the range of motion prior to initiating testing. This prevented limited range of motion interfering with the scoring of SMC. According to the testers, this procedure needs to be added to the Boyd and Graham SMC protocol. It is further important to mention that all but two children were able to follow the instructions for both tests. These two children were not only physically, but also severely cognitively impaired (both GMFCS level V), and were not able to move an individual joint voluntarily. There is a need for future research with a larger number of children across all GMFCS levels to get a better understanding of SMC testing in children with cognitive impairments.

In relation to the scales, the testers reported some difficulties with the Boyd and Graham SMC test. It was not clear how to allocate scores to children who were unable to follow the instructions or did not have enough strength to perform a selective movement. According to the Boyd and Graham SMC test, these children were given score 0, i.e. 'no movement when asked to dorsiflex the foot', whereas the modified Trost SMC test had an option for scoring the 'inability to execute the test', which included that voluntary movement is not possible due to lack of strength or understanding. The testers recommended adapting the Boyd and Graham scale accordingly. Further, it was unclear whether the criterion for score 3 of the Boyd and Graham SMC test ('some movement of the hip and knee') always excluded score 1 ('limited dorsiflexion using mainly EHL and/or EDL') and score 2 ('dorsiflexion using EHL, EDL, and some TA activity'). The testers felt that this criterion should be included in the descriptions for scores 1 and 2 as well, and therefore recommend extending the protocol description for scores 1 and 2 by 'often accompanied by hip and/or knee flexion'.

A limitation of this study concerns the validity of the SMC tests. This study introduced a clinically useful definition of SMC and examined the inter-rater reliability of two SMC tests. It did, however, not examine (e.g., through using a gold standard) to what extent these tests really represent the concept of SMC. There are several factors that might have interfered with the assessments. For instance, as stated above, limited range of motion of the joint, possibly caused by muscle shortening and/or spasticity, could have had consequences for the SMC assessment. Furthermore, gravity and the length of lever arms could have had unintended effects on children's SMC performance, as these factors differed in ideal starting positions compared to synergistic starting positions (see the protocol for the modified Trost SMC test, **Appendix 2.2**).

Overall, the Boyd and Graham SMC test and the modified Trost SMC test are both reliable instruments for assessing SMC in children with CP aged 5–7. In addition, both SMC tests are believed to be feasible for children with CP, provided that they are not severely cognitively impaired. In view of the somewhat higher inter-rater reliability values and smaller confidence intervals of the modified Trost SMC test, and the fact that this test corresponds most closely to the introduced definition of SMC, the authors recommend the modified Trost SMC test when assessing SMC in young children with CP.

### Acknowledgements

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# APPENDIX 2.1

**The Boyd and Graham Selective Motor Control test – test scale (movement: dorsiflexion)[17]**

| Definition | Grade |
|---|---|
| No movement when asked to dorsiflex the foot | 0 |
| Limited dorsiflexion using mainly EHL and/or EDL | 1 |
| Dorsiflexion using EHL, EDL and some TA activity | 2 |
| Dorsiflexion achieved using mainly TA activity but accompanied by hip and / or knee flexion | 3 |
| Isolated selective dorsiflexion achieved, through available range, using a balance of TA activity without hip and knee flexion | 4 |

EHL, extensor hallucis longus; EDL, extensor digitorum longus; TA, tibialis anterior.

**The Boyd and Graham Selective Motor Control test – test protocol (movement: dorsiflexion)**

| Description |
|---|
| The child sits with hips flexed and knees comfortably extended, able to see their feet. The child is requested to dorsiflex each foot individually to a target. The limb is in vision and the balance of muscle activity is observed. |

# APPENDIX 2.2

**The Trost Selective Motor Control test – *original* test scale (protocol: not available) (movements: not specified)[18]**

| Definition | Grade |
|---|---|
| No ability to isolate movement | 0 |
| Partially isolated movement | 1 |
| Complete isolation of movement | 2 |

**The Trost Selective Motor Control test – *modified* test scale (movements: hip flexion, hip abduction, knee extension and ankle dorsiflexion)**

| Definition | | Grade |
|---|---|---|
| Unable | Voluntary movement is not possible due to lack of strength or understanding. | Unable |
| No ability to isolate movement (total synergy) | Movement is in mass pattern of flexion or extension. | 0 |
| Partially isolated movement observed (partial synergy) | Selective movement is only possible at initial movement; at the end range of motion the movement continues in pattern. | 1 |
| Completely isolated movement observed (no synergy) | Selective movement is possible in the available range of motion. | 2 |

*Appendix 2.2 continues on next page.*

**The *Modified* Trost Selective Motor Control test – test protocol (movements: hip flexion, hip abduction, knee extension and ankle dorsiflexion)**

| Description | |
|---|---|
| **Preparations:** The child is tested without trousers, socks, or shoes. | |
| **Materials required:** An examination table, a pillow (head support), a cushion (stabilizing the back), a knee wedge (in case of knee contracture) and a toy (used as a target point). | |
| **Time required:** The test can be administered within 15 minutes. | |
| **Instructions:** The test is explained by verbal instructions and passively and/or actively demonstrated to the child. If necessary, the test is demonstrated by the testers themselves. During the test, the child is encouraged and continuously reminded of the instructions and is provided with verbal feedback on his/her performance. The four consecutive tests (hip flexion, hip abduction, knee extension and ankle dorsiflexion) are comprehensively described below. | |
| ***Hip flexion*** | |
| Starting position of child | Supine position, on the examination table with hips and knees in anatomical position, or in maximally extended position in the case of a flexion contracture. A pillow behind the child's head and a wedge underneath the knee (in the case of knee flexion contracture) are allowed. The arms are resting on the examination table, along the body. |
| Position of tester | Next to the child, on the side being tested. |
| Maximum passive range of motion | The maximum passive ROM for hip flexion from the starting position is determined in advance by the tester. Relevance: to determine over what range of motion SMC can be scored. The ROM may be limited by hamstring shortening, requiring knee flexion to increase the ROM at the end range. |
| Instruction to the child | *'Lift your whole leg straight up from the table, like a stiff stick, from here to there'* (indicating the range of motion the child has to make). |
| Performance and scoring | The child is asked to flex the hip actively. The arms are not allowed to facilitate the selective motor movements. Determine, during active hip flexion, *if* and *when* synergistic knee flexion takes place in the available ROM. Contralateral movements are allowed during the performance. The best of three performances is scored. The test is scored separately for the right and left legs. |
| Synergistic starting position of child | If voluntary movement is not possible from the original starting position, the movement can be performed in a facilitated position, in this case the starting position but with the knee flexed. Relevance: to allow differentation between 'unable' and 'total synergy (0)' scores. |
| ***Hip abduction*** | |
| Starting position of child | Side-lying on the examination table. The upper leg is in anatomical position with respect to hip and knee or in maximally extended position in the case of a flexion contracture. The lower leg is in hip and knee flexion to stabilize the body. A pillow behind the child's head is allowed. One arm is resting under the child's head, the other on the leg, along the body. |
| Position of tester | In front of the child. |

*Appendix 2.2 continues on next page.*

*Appendix 2.2 – Continued.*

| Description | |
|---|---|
| Maximum passive range of motion | The maximum passive ROM for hip abduction from the starting position is determined in advance by the tester. Relevance: to determine over what range of motion SMC can be scored. The ROM may be limited by shortening of the m. gracilis, requiring knee flexion to increase the ROM at the end range. |
| Instruction to the child | *'Lift your upper leg straight up from the other leg, like a stiff stick, from here to there'* (indicating the range of motion the child has to make). |
| Performance and scoring | The child is asked to abduct the hip actively. The arms are not allowed to facilitate the selective motor movements. Determine, during active hip abduction, *if* and *when* synergistic knee flexion takes place in the available ROM. Contralateral movements are allowed during the performance. The best of three performances is scored. The test is scored separately for the right and left legs. |
| Synergistic starting position of child | If voluntary movement is not possible from the original starting position, the movement can be performed in a facilitated position, in this case the starting position, but with the knee of the upper leg flexed. Relevance: to allow differentiation between 'unable' and 'total synergy (0)' scores. |
| ***Knee extension*** | |
| Starting position of child | Upright short-sitting position, with legs hanging over the edge of the examination table. The arms are resting in the lap or are placed on the knees. The tester is allowed to provide mild support to the child's upper back, to stabilize the body. |
| Position of tester | Next to the child, on the side being tested. |
| Maximum passive range of motion | The maximum passive ROM for knee extension from the starting position is determined in advance by the tester. Relevance: to determine over what range of motion SMC can be scored. The ROM may be limited by hamstring shortening, requiring hip extension to increase the ROM at the end range. |
| Instruction to the child | *'Sit up tall, straighten your leg, from here to there* (indicating the range of motion the child has to make) *and try to hold your back as straight as you can'.* |
| Performance and scoring | The child is asked to extend the knee actively. The arms are not allowed to facilitate the selective motor movements. Determine, during active knee extension, if and when synergistic hip extension takes place in the available ROM. Contralateral movements are allowed during the performance. The best of three performances is scored. The test is scored separately for the right and left legs. |
| Synergistic starting position of child | If voluntary movement is not possible from the original starting position, the movement can be performed in a facilitated position, in this case the starting position, but with the hip extended (the tester can provide support to the child's extended back). Relevance: to allow differentation between 'unable' and 'total synergy (0)' scores. |

*Appendix 2.2 continues on next page.*

*Appendix 2.2 – Continued.*

| Description | |
|---|---|
| ***Ankle dorsiflexion*** | |
| Starting position of child | Long-sitting position on the examination table, with hips flexed at 60/ (a cushion can be placed behind the back for stabilization) and knees extended, able to see the feet. A wedge behind the knee (in the case of knee flexion contracture) is allowed. The ankles are just hanging over the edge of the examination table (feet free of support). The arms are resting in the lap or on the examination table, alongside the body. |
| Position of tester | Next to the child, on the side being tested. |
| Maximum passive range of motion | The maximum passive ROM for ankle dorsiflexion from the starting position is determined in advance by the tester. Relevance: to determine over what range of motion SMC can be scored. The ROM may be limited by shortening of the m. gastrocnemicus, requiring knee flexion to increase the ROM at the end range. |
| Instruction to the child | *'Move your foot/toes towards the toy/yourself, from here to there* (indicating the range of motion the child has to make)*, without raising your knee'.* |
| Performance and scoring | The child is asked to dorsiflex the ankle actively. The arms are not allowed to facilitate the selective motor movements. Determine, during active ankle dorsiflexion, *if* and *when* synergistic knee flexion takes place in the available ROM. Contralateral movements are allowed during the performance. The best of three performances is scored. The test is scored separately for the right and left legs. |
| Synergistic starting position of child | If voluntary movement is not possible from the original starting position, the movement can be performed in a facilitated position, in this case in supine position with legs hanging over the edge of the examination table (knees flexed). Relevance: to allow differentation between 'unable' and 'total synergy (0)' scores. |

3

# Relationship between gross motor capacity and daily-life mobility in children with cerebral palsy

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## Abstract

**Aim:** The aim of this study was to examine the relationship between gross motor capacity and daily-life mobility in children with Cerebral Palsy (CP) and to explore the moderation of this relationship by the severity of CP.

**Method:** Cross-sectional analysis in a cohort study with a clinic-based sample of children with CP (*n* = 116; 76 males, 40 females; mean age 6y 3mo, SD 12mo, range 4y 8mo–7y 7mo). Gross motor capacity was assessed by the Gross Motor Function Measure (GMFM-66). Daily-life mobility was assessed by the Pediatric Evaluation of Disability Inventory (PEDI): Functional Skills Scale (FSS-mobility) and Caregiver Assistance Scale (CAS-mobility). Severity of CP was classified by the Gross Motor Function Classification System (48% Level I, 17% Level II, 15% Level III, 8% Level IV, 12% Level V), type of motor impairment (85% spastic, 12% dyskinetic, 3% ataxic), and limb distribution (36% unilateral, 49% bilateral spastic).

**Results:** Scores on the GMFM-66 explained respectively 90% and 84% of the variance of scores on PEDI-FSS mobility and PEDI-CAS mobility. Limb distribution moderated the relationship between scores on the GMFM-66 and the PEDI-FSS mobility, revealing a weaker relationship in children with unilateral spastic CP (24% explained variance) than in children with bilateral spastic CP (91% explained variance).

**Interpretation:** In children aged 4-7 years with unilateral spastic CP, dissociation between gross motor capacity and daily-life mobility can be observed, just as in typically developing peers.


## INTRODUCTION

Gross motor capacity is the ability to use large groups of muscles to keep one's balance and change positions, e.g., sitting, standing, walking, running, and jumping. In typically developing children, this ability is well established by the age of five years.[1] In children with cerebral palsy (CP), which is the most common motor disorder in childhood with a prevalence of two per 1000 live births,[2] this ability is not fully established,[3] even in children over five years of age with the best functional characteristics.[4] In general, gross motor capacity can be considered an important basis for movement activities of daily living, or daily-life mobility. In typical development, children's daily-life mobility gradually dissociates from their gross motor capacity as it becomes increasingly determined by other intrinsic (cognitive and personal) and extrinsic (contextual) factors.[1]

Both the concept of gross motor capacity and the concept of daily-life mobility are found within the *activities* domain of the International Classification of Functioning, Disability and Health (ICF).[5] Although the two concepts can be distinguished by qualifying them, respectively, as 'capacity' and 'performance', various qualifiers are frequently used interchangeably, causing confusion even within the domain of activities. In the field of motor control, the ambiguity of qualifiers like 'ability', 'capacity', 'capability', 'skill', and 'performance' has been criticized.[6] In unravelling the complex relationships in the development of movement activities, the terms 'capacity', 'capability', and 'performance' seem the clearest and most helpful ones.[7] Capacity refers to an underlying ability, that is what a person *can do* in a *standardized environment*. Capability and performance both refer to activities of daily life: capability describes what a person potentially *can do* in his or her *daily environment*, whereas performance describes what a person actually *does do* in his or her *daily environment*. These three constructs provide a clear framework for studying relationships concerning the development of movement activities.

The relationship between gross motor capacity and daily-life mobility is a clinically relevant topic for children with CP. Physical therapy has traditionally focused on improving gross motor capacity, and by this, on improving a child's daily-life mobility in terms of capability and performance.[8] The underlying assumption is that a higher level of gross motor capacity leads to a higher level of capability and performance.[9] Several cross-sectional studies have investigated the relationship between gross motor capacity and daily-life mobility in children with CP.[7,10-12] These studies found highly diverse relationships, ranging from weak to very strong. Unfortunately, they did not use the same constructs and the same measurement instruments, and did not distinguish any subgroups of CP, allowing no uniform conclusions to be drawn regarding the relationship between gross motor capacity and daily-life mobility in children with CP.

Children with CP comprise a very heterogeneous group. Depending on the purpose, the severity of the disorder can be classified at the activity level by the Gross Motor Function Classification System (GMFCS), but also at the impairment level by the predominant type of motor impairment (spastic, dyskinetic, or ataxic) and by limb distribution in the case of spastic CP (unilateral or bilateral).[13,14] Severity, classified by the GMFCS and limb distribution, has previously been shown to influence gross motor capacity in children with CP.[4,15] It is important to gain insight into severity moderating the relationship between gross motor capacity and daily-life mobility in children with CP, especially after the age of four years.

The objective of the present study was to examine the relationship between gross motor capacity and daily-life mobility in children aged 4 to 7 years with CP, and to explore the moderation of the relationship by severity of CP. Daily-life mobility was studied in terms of both capability and performance. Severity of CP was studied at both the activity level and the impairment level.

## METHODS

This study was performed as part of Pediatric Rehabilitation Research in the Netherlands (PERRIN), a prospective longitudinal cohort study on the course and determinants of daily functioning in children with CP. The present study had a cross-sectional design and concerned the first (baseline) assessment of a cohort of children born between 1998 and 2002.

### Participants

The participants of the present study were all children with CP aged from 4 to 7 years at study entry. The children were recruited between May 2006 and October 2007, at the pediatric rehabilitation departments of two university medical centers (University Medical Center Utrecht; VU University Medical Center Amsterdam) and four rehabilitation centers (Rehabilitation Center De Hoogstraat, Utrecht; Rehabilitation Center Amsterdam; Rehabilitation Center De Trappenberg, Huizen; and Rehabilitation Center Breda) in the Netherlands. Children with a confirmed diagnosis of CP according to the latest definition were eligible to participate.[16] Children diagnosed with additional diseases and disorders besides CP affecting motor functioning, and children whose parents lacked a basic knowledge of Dutch were excluded. Informed consent was obtained from all parents. Ethical approval for the study was given by the Committees for Medical Ethics of the two university medical centers and the participating rehabilitation centers.

### Measurements

The main concepts to be operationalized were gross motor capacity and daily-life mobility, the latter in terms of both capability and performance (**Table 3.1**).

**Table 3.1** Constructs of capacity, capability, and performance: description and operationalization on the motor domain

| **Construct** | Capacity | Capability | Performance |
|---|---|---|---|
| **Description** | Can do<br>in standardized environment | Can do<br>in daily environment | Does do<br>in daily environment |
| **Measure** | GMFM-66<br>• Capacity for motor activities | PEDI-FSS mobility<br>• Capability of motor activities | PEDI-CAS mobility<br>• Given assistance in motor activities (less assistance = higher performance) |
| | • Ordinal items (0-3)<br>• Scaled total (0-100) | • Dichotomous items (0/1)<br>• Scaled total (0-100) | • Ordinal items (0-5)<br>• Scaled total (0-100) |

GMFM, Gross Motor Function Measure; PEDI-FSS, Pediatric Evaluation of Disability Inventory Functional Skills Scale; PEDI-CAS, Pediatric Evaluation of Disability Inventory Caregiver Assistance Scale.

Gross motor capacity was assessed by the Gross Motor Function Measure (GMFM-66). The GMFM is a standardized observational instrument designed to measure gross motor function in children with CP in a specific test situation, without the use of mobility aids or orthoses.[3] The data were analyzed with the Gross Motor Ability Estimator to obtain a GMFM-66 interval score for each child, ranging from 0 (lowest motor function) to 100 (highest motor function).[17] This GMFM-66 score represents a child's overall level of gross motor capacity. The present study used the Dutch version of the GMFM, which has good psychometric properties.[18]

We defined daily-life mobility as mobility in 'home environments', as assessed by the Pediatric Evaluation of Disability Inventory (PEDI). The PEDI is a standardized assessment instrument using parental reports in a structured interview. The PEDI measures activities in everyday situations in three domains – self-care, mobility, and social function – focusing on children's capability as well as performance. Capability is measured by the PEDI Functional Skills Scale (PEDI-FSS), which relates to the activities a child can do in his/her daily environment. Performance is measured by the PEDI Caregiver Assistance Scale (PEDI-CAS), which relates to what extent assistance is provided by the caregiver.[19] In view of the objective of this study, only the mobility domains were used: the mobility domain of the PEDI-FSS was used to operationalize daily-life mobility capability, while the mobility domain of the PEDI-CAS was used to operationalize daily-life mobility performance. The mobility domain of the PEDI-FSS consists of 65 items, each item being scored as positive (score 1) or negative (score 0). A positive score is given when the child is capable of accomplishing the activity. The mobility domain of the PEDI-CAS consists of seven items, and each item is scored on a 6-point ordinal scale. A score of 5 refers to full independence (no assistance) and a score of 0 to full dependence (total assistance). Mobility sum scores were calculated for both PEDI-FSS and PEDI-CAS, and transformed to interval-scaled scores (0-100) according to the Dutch PEDI manual. The present study used the Dutch version of the PEDI (the PEDI-NL), which has good psychometric properties.[20]

Severity of CP was classified at two levels. At the activity level, severity of CP was classified by means of the GMFCS. The GMFCS is a 5-level classification system of age-specific gross motor activity, based on functional limitations, need for assistive devices and, to a lesser extent, quality of movement.[21] Level I represents the highest level of gross motor function, level V the lowest. We used the Dutch version of the GMFCS, which has good psychometric properties.[22] At the impairment level, type of motor impairment (i.e., spastic, dyskinetic, or ataxic) and topographical distribution (i.e., unilateral spastic CP [USCP] or bilateral spastic CP [BSCP]) were classified according to the Surveillance of Cerebral Palsy in Europe guidelines.[13]

### Procedure

All children visited the pediatric rehabilitation department of the medical center or rehabilitation center with their parent(s). During these visits, one of two trained researchers (DWS / PVS) classified the children according to the GMFCS, type of motor impairment, and limb distribution, and administered the GMFM. Both researchers had passed the GMFM criterion test for reliability after training. The PEDI was administered by one of three trained researchers, either in a face-to-face interview with a parent during the same visit or by telephone within one month.

### Statistical analysis

Analyses were performed with SPSS version 16.0 (SPSS Inc, Chicago, IL, USA), using a 0.05 level of significance for all statistical tests. The analyses considered only participants with complete data for both the GMFM-66 and the two PEDI scales. Descriptive statistics were used to describe these three variables for the total group, for GMFCS levels, for type of motor impairment, and for limb distribution.

The relationship between gross motor capacity and daily-life mobility – in terms of both capability and performance – was calculated as the percentage of explained variance of each PEDI scale by the GMFM-66 using univariate regression analysis.

To explore the moderation of the relationship by severity of CP, we performed multivariate regression analyses. PEDI-FSS mobility and PEDI-CAS mobility were successively the dependent variables. GMFM-66 and its interaction with separate GMFCS levels were the independent variables. Each GMFCS level was added as a dummy variable, and was in turn set as reference category. Thus, all GMFCS levels were tested for mutual differences in effecting the relationships. Similarly, moderation by type of motor impairment and by limb distribution was tested.

## RESULTS

Of the 199 parents of children with CP we contacted, 116 (58%) agreed to participate (child age 4y 8mo–7y 7mo; mean 6y 3mo), whereas 83 (42%) did not agree to participate (child age 4y 6mo–7y 6mo; mean 6y 3mo). The main reasons for non-participation were children being overburdened due to therapy and school, parents' lack of time, children's and parents' participation in other studies, and parents being unreachable by phone or mail. The characteristics of participants and non-participants were equal for many items, although participants were statistically significantly less involved in special education and slightly less impaired than non-participants (**Table 3.2**). GMFM-66 and/or PEDI data were incomplete for six participating children – distributed across

**Table 3.2** Characteristics of participants and non-participants

| Characteristics | | | Participants (*n* = 116) | Non-participants (*n* = 83) | *p* |
|---|---|---|---|---|---|
| Age (years, months) | | | | | 0.49 |
| Range | | | 4y 8mo–7y 7mo | 4y 6mo–7y 6mo | |
| Mean (SD) | | | 6y 3mo (12mo) | 6y 3mo (12mo) | |
| Sex, *n* (%) | | | | | 0.52 |
| Boys | | | 76 (66) | 58 (70) | |
| Girls | | | 40 (34) | 25 (30) | |
| GMFCS, *n* (%) | | | | | 0.09 |
| I | | | 56 (48) | 31 (39) | |
| II | | | 20 (17) | 10 (13) | |
| III | | | 17 (15) | 12 (15) | |
| IV | | | 9 (8) | 14 (18) | |
| V | | | 14 (12) | 12 (15) | |
| | | | | Unknown: 4 | |
| Typology, *n* (%) | | | | | 0.74 |
| Spastic | | | 98 (85) | 71 (86) | |
| | Distribution | Unilateral | 42 (36) | 25 (30) | |
| | | Bilateral | 56 (49) | 46 (56) | |
| Dyskinetic / mixed | | | 14 (12) | 8 (10) | |
| Ataxic | | | 4 (3) | 3 (4) | |
| | | | | Unknown: 1 | |
| Type of education, *n* (%) | | | | | 0.02 |
| Mainstream education | | | 55 (47) | 24 (30) | |
| Special education / day care | | | 61 (53) | 56 (70) | |
| | | | | Unknown: 3 | |

Y, years; mo, months; SD, standard deviation; GMFCS, Gross Motor Function Classification System.

various GMFCS levels – either because the child became overburdened or because an assessment took much longer than expected and there was insufficient time to finish it with the full cooperation of the child or parents. As a result, data of 110 children were used in the present study.

Scores for GMFM-66, PEDI-FSS mobility, and PEDI-CAS mobility differed significantly (using analysis of variance) among the five GMFCS levels, among the three types of motor impairments, and between USCP and BSCP (except for GMFCS level II vs GMFCS level III in relation to PEDI-CAS mobility scores, for dyskinetic vs ataxic CP in relation to GMFM-66 scores, and for spastic vs ataxic CP in relation to all three variables; **Table 3.3**).

In the total group, the GMFM-66 scores explained 90% of the variance of the PEDI-FSS mobility and 84% of the variance of the PEDI-CAS mobility.

**Table 3.3** Mean scores, standard deviation, and range for GMFM-66, PEDI-FSS mobility, and PEDI-CAS mobility

| | | GMFM-66 | | | PEDI-FSS mobility | | | PEDI-CAS mobility | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | *n* | Mean | SD | Range | Mean | SD | Range | Mean | SD | Range |
| Total | 110 | 64.4 | 21.5 | 8–96 | 67.6 | 24.8 | 0–100 | 68.5 | 28.7 | 0–100 |
| GMFCS I | 52 | 81.4 | 7.1 | 60–96 | 85.1 | 9.1 | 68–100 | 87.0 | 12.2 | 65–100 |
| GMFCS II | 19 | 66.8 | 5.4 | 56–78 | 73.7 | 9.6 | 59–100 | 75.7 | 12.4 | 53–100 |
| GMFCS III | 16 | 55.7 | 6.0 | 45–65 | 60.7 | 6.1 | 48–70 | 64.6 | 12.6 | 50–100 |
| GMFCS IV | 9 | 44.2 | 6.1 | 35–54 | 46.0 | 5.9 | 37–58 | 46.9 | 7.6 | 41–66 |
| GMFCS V | 14 | 21.2 | 6.7 | 8–37 | 15.9 | 10.3 | 0–33 | 8.0 | 13.3 | 0–33 |
| Spastic | 93 | 67.5 | 19.9 | 8–96 | 70.9 | 22.3 | 0–100 | 72.4 | 25.6 | 0–100 |
| Unilateral | 38 | 81.1 | 7.6 | 60–96 | 86.5 | 8.7 | 68–100 | 87.4 | 12.4 | 65–100 |
| Bilateral | 55 | 58.1 | 20.4 | 8–92 | 60.2 | 22.4 | 0–94 | 62.1 | 27.2 | 0–100 |
| Dyskinetic | 13 | 41.1 | 22.6 | 18–88 | 39.8 | 27.8 | 0–90 | 35.4 | 32.5 | 0–91 |
| Ataxic | 4 | 68.3 | 5.3 | 64–75 | 80.1 | 14.0 | 67–100 | 84.1 | 13.7 | 71–100 |

GMFM, Gross Motor Function Measure; PEDI-FSS, Pediatric Evaluation of Disability Inventory Functional Skills Scale; PEDI-CAS, Pediatric Evaluation of Disability Inventory Caregiver Assistance Scale; GMFCS, Gross Motor Function Classification System.

Moderations of these relationships by GMFCS level, by type of motor impairment, and by limb distribution are presented in **Table 3.4**.

No significant moderation by GMFCS level or by type of motor impairment was found for the relationship between GMFM-66 and either PEDI-FSS mobility or PEDI-CAS mobility. However, a significant moderation ($p = 0.003$) by limb distribution was found for the relationship between GMFM-66 and PEDI-FSS mobility. The moderation of the relationship between GMFM-66 and PEDI-FSS mobility using limb distribution is shown in a scatterplot (**Figure 3.1**).

GMFM-66 scores showed a weaker relationship with PEDI-FSS mobility scores in children with USCP than in children with BSCP. Additional univariate regression analysis within groups revealed that GMFM-66 scores explained only 24% of the variance of PEDI-FSS mobility scores in children with USCP, compared with 91% in children with BSCP.

## DISCUSSION

This study shows that daily-life mobility is closely related to gross motor capacity in children with CP aged 4 to 7 years, explaining 90% and 84% of the variance of their capability and performance, respectively. Moderation of this relationship by GMFCS level or by type of motor impairment did not appear to be statistically significant.

**Table 3.4** Regression analyses including two PEDI scales as successive dependent variables, GMFM as independent variable (univariate analysis), and interaction terms of GMFM-66 with GMFCS levels, type of motor impairment, and limb distribution as successive independent variables (multivariate analyses for moderation)

| | PEDI-FSS mobility | | | PEDI-CAS mobility | | |
|---|---|---|---|---|---|---|
| | $\beta$ | SE ($\beta$) | *p*-value | $\beta$ | SE ($\beta$) | *p*-value |
| GMFM-66 | 1.09 | 0.04 | <0.0005 | 1.23 | 0.05 | <0.0005 |
| GMFM-66 * GMFCS I (ref. cat.) | 0 | | | 0 | | |
| GMFM-66 * GMFCS II | 0.50 | 0.36 | 0.165 | 0.35 | 0.51 | 0.500 |
| GMFM-66 * GMFCS III | 0.18 | 0.35 | 0.609 | 0.73 | 0.50 | 0.146 |
| GMFM-66 * GMFCS IV | -0.05 | 0.45 | 0.920 | -0.10 | 0.65 | 0.880 |
| GMFM-66 * GMFCS V | 0.06 | 0.34 | 0.856 | -0.25 | 0.48 | 0.600 |
| GMFM-66 * spastic CP (ref. cat.) | 0 | | | 0 | | |
| GMFM-66 * dyskinetic CP | 0.14 | 0.11 | 0.184 | 0.21 | 0.25 | 0.166 |
| GMFM-66 * ataxic CP | -0.40 | 0.86 | 0.640 | -1.62 | 1.22 | 0.186 |
| GMFM-66 * unilateral spastic CP (ref. cat.) | 0 | | | 0 | | |
| GMFM-66 * bilateral spastic CP | 0.49 | 0.16 | 0.003 | 0.47 | 0.25 | 0.062 |

PEDI-FSS, Pediatric Evaluation of Disability Inventory Functional Skills Scale; PEDI-CAS, Pediatric Evaluation of Disability Inventory Caregiver Assistance Scale; GMFM, Gross Motor Function Measure; GMFCS, Gross Motor Function Classification System; ref. cat., reference category; $\beta$, slope; SE ($\beta$), standard error of slope.

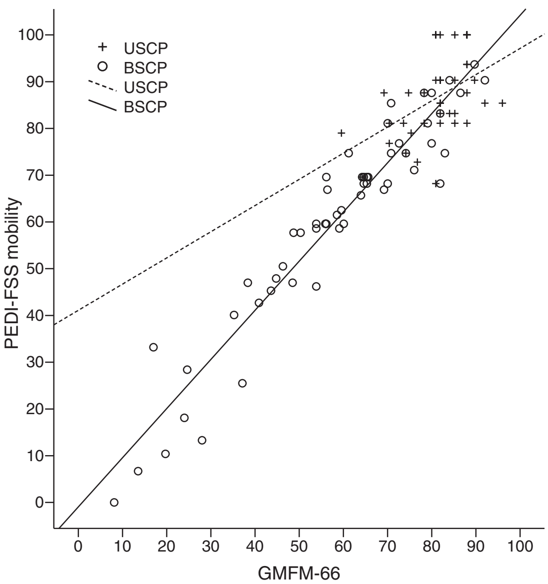


**Figure 3.1** Scatterplot of the relationship between GMFM-66 and PEDI-FSS mobility modified by limb distribution (USCP versus BSCP). GMFM, Gross Motor Function Measure; PEDI FSS, Pediatric Evaluation of Disability Inventory Functional Skills Scale; USCP, unilateral spastic CP; BSCP, bilateral spastic CP.

However, limb distribution did significantly modify this relationship, the relationship being weaker in children with unilateral spastic CP (USCP) than in those with bilateral spastic CP (BSCP).

Previous studies have found both strong and weak relationships between gross motor capacity and daily-life mobility in children with CP. Strong relationships have been reported in younger children (age range 2–7 years)[7,11] and weaker relationships in older children (age range 5–15 years).[10,12] In the present study, however, we examined more explicitly the moderation of the relationship between gross motor capacity and daily-life mobility according to severity – at both the activity level and at the impairment level – among children aged 4 to 7 years with CP. Another benefit of our study was that it explored two different constructs of daily-life mobility (capability and performance), which were not distinguished in most previous studies.

In our study, we differentiated between USCP and BSCP, but we did not further subdivide BSCP into 'diplegia' and 'quadriplegia'. The value of further differentiation is controversial in terms of reliability[23] and its relevance to gross motor activities.[14] We found a statistically significant difference between BSCP and USCP for the relationship between 'capacity' and 'capability' ($p = 0.003$), but not for the relationship between 'capacity' and 'performance' ($p = 0.062$). Apparently, limb distribution, as an impairment measure, has a greater effect on the capacity-capability relationship than on the capacity-performance relationship. The overall strong relationships in BSCP were found at all capacity levels (lower and higher ends of GMFM-66), whereas the weaker relationships in USCP were found only at the higher capacity levels. Post-hoc analyses with more similar ranges in capacity levels (GMFM-66) for both USCP and BSCP did not result in any changes in the distinctive findings for both groups. Thus, our analyses with limb distribution indicate that, for USCP, gross motor capacity does not seem to be the prominent factor determining daily-life mobility.

We found no evidence for moderation of the relationship between gross motor capacity and daily-life mobility using separate GMFCS levels. However, post-hoc analyses involving grouping of GMFCS levels showed that daily-life mobility was relatively weakly related to gross motor capacity at GMFCS levels I-II (explaining 46% and 36% of the variance of capability and performance, respectively), but strongly at GMFCS levels III to V (explaining 90% and 86% of the variance of capability and performance, respectively). Controlling for limb distribution did not change these distinctive findings in either GMFCS group. Thus, as with the analyses with limb distribution, these analyses indicate that, for children with less severe CP, gross motor capacity seems to be less important in determining daily-life mobility.

Several limitations of our study should be noted. First, although the two researchers were trained in classifying children with CP, the classification of typology and limb distribution has yet not been demonstrated to be reliable,[23] and is, therefore, a possible cause of noise. In case a child showed a mix of spastic, dyskinetic, or ataxic features, the predominant motor impairment subtype was chosen, according to the Surveillance of Cerebral Palsy in Europe framework. In the event of uncertainty about the classification, the cases were reviewed by the projectleaders of the PERRIN study and consensus was reached. Second, larger sample sizes, especially for GMFCS levels IV and V, and for dyskinetic and ataxic subtypes, might have yielded more specific information about the actual moderation using GMFCS level and typology. Third, we would like to point out that there is good reason to omit children with GMFCS level V from the analysis because of difficulties in interpreting their mobility performance and, consequently, the floor effect of the measure (PEDI-CAS mobility). When excluding children classified as GMFCS level V, the differences found in the GMFCS post-hoc analyses remain prominent but are somewhat smaller. Fourth, the utility of the PEDI-CAS as a direct measure for performance is open to question as it measures a child's performance in terms of the extent of caregiver's assistance (see **Table 3.1**). Moreover, the PEDI-CAS exhibited floor and ceiling effects, possibly because of the limited number of items. It appears that performance was not easy to capture by the PEDI-CAS, not only confounding its relationship to gross motor capacity, but also making it difficult to distinguish it properly from capability. Fifth, in our study we deliberately chose to focus on the relationship between gross motor capacity and daily-life mobility, with severity according to the GMFCS level, type of motor impairment, and limb distribution as moderating factors. Including other factors in the regression analysis – such as manual, intellectual, and communicative functioning – might have changed the explained variance of PEDI scores, as these factors have been previously shown to be associated with a child's activity level, level of mobility, and self care as measured by the Activity Scale for Kids (ASK).[24]

Regarding the concepts in our study, we strongly believe that capability and performance should be considered distinctive constructs within the International Classification of Functioning, Disability and Health domain of activities and should preferably be measured separately. The first basically relates to the skills a person has developed by practice in a particular physical environment, the second to the actual application of these skills, which is influenced not only by physical environment but also by personal and social factors.[6,7] With the PEDI, an instrument is available to measure both constructs with one method (i.e., a structured interview with parents regarding their child's motor functioning in the context of the home environment). It should be noted, however, that the two PEDI scales differ in the number of items (65 vs 7) and in scoring (2-point scale vs 6-point scale). It would be even better to use an instrument which contains three scales – one for capacity, one for capability, and one for performance – with the same items and with mutually corresponding interval scores. An alternative to the PEDI that approaches this objective is the ASK. According to our definitions, however, this self-report instrument does not capture a person's capacity – only a person's capability and performance – nor does it separate the domains of mobility and self-care.[25] A recent opinion paper by Morris[26] makes a strong plea for distinguishing capability from capacity and performance. He defines capacity as *functioning in an ideal 'standardised' environment*, capability as *a range of possible functionings* (adding 'lived environment' to capacity), and performance as *achieved functioning in the lived environment* (adding 'opportunity and freedom to choose' to capability). Like us, this author recognizes that the distinctions between the three may not be immediately apparent. Morris supports the need to develop methods to assess capability alongside assessments of capacity and performance, and the need for research to understand the relationships between these three constructs.

Overall, our results imply that, among children aged 4 to 7 years diagnosed with CP, gross motor capacity is not the sole factor contributing to mobility in daily life. In particular, in children with USCP, just as in their typically developing peers, dissociation between gross motor capacity and daily-life mobility can be observed. On the other hand, in children of the same age who have more severe CP at the impairment level (BSCP) and also at the activity level (GMFCS levels III, IV, and V), as in typically developing younger children, gross motor capacity can be considered the most important factor determining daily-life mobility.

These findings may have implications for therapy and research aimed at improving the capability and performance of children with CP in terms of mobility in daily life situations. Although focusing on gross motor capacity enhancement would work best for children with BSCP or those classified as GMFCS levels III, IV, or V, children with USCP or classified as GMFCS levels I and II might benefit more from treatment focusing on other intrinsic (e.g., cognitive and personal) or extrinsic (contextual) factors – in addition to further maximization of their gross motor capacity. This general conclusion is in agreement with a recent study on this topic by Tieman et al.[27]

We have gained some insight into moderation of the relationship between gross motor capacity and daily-life mobility in children with CP. This insight, however, reveals nothing yet about change in gross motor capacity leading to change in capability and performance. From a developmental perspective, it is therefore necessary to investigate the relationship over time, which requires a longitudinal study. Further, although we found that gross motor capacity alone can not explain daily-life mobility in many children with CP, we have not fully uncovered what additional factors might also be explanatory. That is why future research should investigate the influence of other factors that moderate the relationship between gross motor capacity daily-life mobility in children with CP. Disturbances of sensation, perception, cognition, communication, and behavior, as well as epilepsy and secondary musculoskeletal problems are part of the definition of CP and should be looked at. Moreover, potential modifiable factors such as personal choices, and environmental influences should also be taken into account. Finally, we recommend continued and more extensive research with a proper and uniform operationalization of daily-life mobility in terms of capability and performance.

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# 4

# Development of non-verbal intellectual capacity in school-age children with cerebral palsy

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## Abstract

**Background:** Children with cerebral palsy (CP) are at greater risk for a limited intellectual development than typically developing children. Little information is available which children with CP are most at risk. This study aimed to describe the development of non-verbal intellectual capacity of school-age children with CP and to examine the association between the development of non-verbal intellectual capacity and the severity of CP.

**Method:** A longitudinal analysis in a cohort study was performed with a clinic-based sample of children with CP. Forty-two children were assessed at 5, 6, and 7 years of age, and 49 children were assessed at 7, 8, and 9 years of age. Non-verbal intellectual capacity was assessed by Raven's Coloured Progressive Matrices (RCPM). Severity of CP was classified by the Gross Motor Function Classification System, type of motor impairment, and limb distribution. MANOVA for repeated measurements was used to analyze time effects and time x group effects on both RCPM raw scores and RCPM IQ scores.

**Results:** The development of non-verbal intellectual capacity was characterized by a statistically significant increase in RCPM raw scores but no significant change in RCPM IQ scores. The development of RCPM raw scores was significantly associated with the severity of CP. Children with higher levels of gross motor functioning and children with spastic CP showed greater increase in raw scores than children with lower levels of gross motor functioning and children with dyskinetic CP.

**Conclusions:** Children with CP aged between 5 and 9 years show different developmental trajectories for non-verbal intellectual capacity, which are associated with the severity of CP. The development of non-verbal intellectual capacity in children with less severe CP seems to resemble that of typically developing children, while children with more severe CP show a limited intellectual development compared to typically developing children.


## INTRODUCTION

Cerebral palsy (CP) describes a group of permanent motor disorders causing activity limitations due to non-progressive disturbances that occurred in the developing fetal or infant brain.[1] The prevalence of CP is around 2 per 1000 live-born children[2] and is reported to be stable over the past two decades in western countries.[3] An aspect of CP that has attracted growing interest is the children's intellectual capacity, defined as the general mental ability to adapt to the environment, including logical reasoning, problem solving, and abstract thinking.[4,5] Whereas the level of intellectual capacity of 50 to 80% of children with CP is comparable to that of typically developing children,[2,6,7] the level is commonly lower for those with more severe CP.[8-13]

Several studies have demonstrated the importance of the level of intellectual capacity for daily-life functioning of children with CP. Intellectual capacity has, for instance, been found to predict the acquisition of phonological awareness,[14] verbal working memory skills,[15] arithmetic skills,[16] literacy skills[17] and functional skills in the domains of mobility, self-care, and social functioning.[10,18,19] Intellectual capacity is positively associated with participation at school,[10,20,21] participation in daily-life situations,[22] health status,[23] quality of life,[24] and – particularly among children with severe CP – life expectancy.[25] Intellectual capacity is also positively associated with functional benefits following clinical interventions like botulinum toxin treatment[26] and selective dorsal rhizotomy.[27]

Although knowledge is currently available about the level of intellectual capacity and its association with daily-life functioning, there is little information about the development of intellectual capacity in children with CP, that is, if and how intellectual capacity changes in childhood. Studying intellectual development in children with CP must be based on certain principles of typical intellectual development. For instance, an absolute increase is expected during school age, especially in non-verbal or fluid intellectual capacity, which has a strong neurobiological basis and relates to general reasoning ability.[28-30] Relative stability is expected in terms of intelligence quotient (IQ), which refers to the age-dependent rank within a normal population.[31-33] These absolute and normative developmental trajectories may differ between children with CP and typically developing children. In this respect, it has been theorized that early brain injuries leave less brain tissue for later synaptic pruning (i.e., 'weeding out' weaker synapses) and thus limit the intellectual development during school age.[34,35]

So far, the development of non-verbal intellectual capacity of children with CP has been investigated in four longitudinal studies with relatively small sample sizes.[17,35-37] Muter et al. included 38 children aged 3 to 5 years with unilateral CP, who underwent a baseline assessment with one follow-up assessment after 2 years.[36] Levine et al. included 15 children aged 4 to 6 years with unilateral CP, who were given a baseline assessment with one follow-up assessment after 1½ to 15 years.[35] Dahlgren et al. included 6 children aged 5 to 7 years with bilateral or dyskinetic CP, who underwent a baseline assessment with one follow-up assessment after 3 years and a second one after 6 years.[17] Gonzalez-Monge et al. included 32 children aged 3 to 5 years with unilateral CP, who were given a baseline assessment with one follow-up assessment after 3 years and a second one after 7 years.[37] All studies found a decline in normative scores for non-verbal intellectual capacity. However, no studies have reported on changes in absolute scores, no studies have examined the association with severity of CP, and only one study[17] explicitly controlled for motor interference using Raven's Coloured Progressive Matrices.

To summarize, children with CP are at greater risk for limited intellectual development than typically developing children, but previous research has insufficiently examined which children with CP are most at risk. Longitudinal research is needed in which the development of non-verbal intellectual capacity is described in association with severity of CP, using a 'motor-free' test and revealing both normative and absolute developmental trajectories. Therefore, this study aimed (1) to describe the development of non-verbal intellectual capacity of school-age children with CP (5 to 9 years old) using Raven's Coloured Progressive Matrices and focusing on both age-dependent IQ scores and age-independent raw scores, and (2) to examine if the development of non-verbal intellectual capacity is associated with the severity of CP.

# METHODS

## Design

This study is part of Pediatric Rehabilitation Research in the Netherlands (PERRIN) CP 5-9, a prospective longitudinal cohort study on the course and determinants of daily functioning in children aged 5 to 9 years with CP. Data were collected during a baseline assessment (T0), a follow-up assessment after one year (T1) and a second follow-up assessment after two years (T2).

## Participants

Children were recruited between May 2006 and October 2007 at the pediatric rehabilitation departments of two university medical centers (University Medical Center Utrecht and VU University Medical Center Amsterdam) and four rehabilitation centers (Rehabilitation Center De Hoogstraat, Utrecht; Rehabilitation Center Amsterdam; Rehabilitation Center De Trappenberg, Huizen; and Rehabilitation Center Breda), all in the Netherlands.

Eligible were children aged 5 years (i.e., 60 ± 6 months) or 7 years (i.e., 84 ± 6 months) at study entry, with a confirmed diagnosis of CP.[1] Children diagnosed with additional diseases and disorders affecting motor functioning, other than CP, and children whose parents lacked a basic knowledge of Dutch, were excluded. Informed consent was obtained from all parents. Ethical approval for the study was obtained from the medical ethics committees of all participating centers.

Of the 199 parents contacted, 116 agreed to participate with their child (see for details Smits et al.[38]). As longitudinal data on non-verbal intellectual capacity were incomplete for 25 children – due to missing follow-ups or technical problems – data for 91 children were used in the analyses of the present study (**Figure 4.1**). Forty-two children were about 5 years of age and 49 children were about 7 years of age at study entry, referred to below as 'age cohort 5' (born between January 2001 and December 2002) and 'age cohort 7' (born between January 1999 and December 2000), respectively. Children with complete longitudinal data ($n = 91$) did not differ statistically from children with

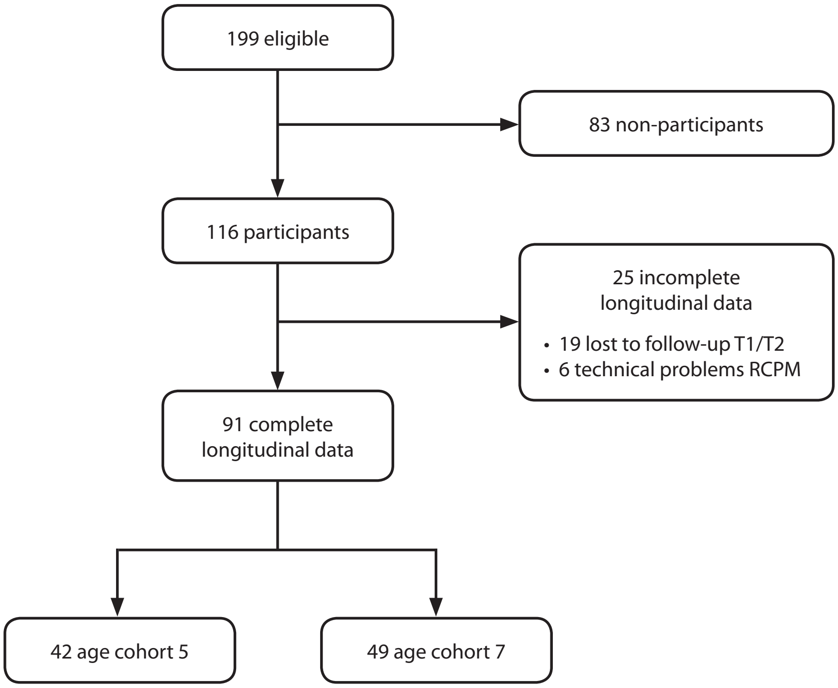


**Figure 4.1** Flow of data through the study.

incomplete longitudinal data (*n* = 25) in terms of age, gender, severity of CP or type of education. Within the group of children with complete data, age cohort 5 (*n* = 42) did not differ statistically from age cohort 7 (*n* = 49) in terms of gender and severity of CP, but did differ in type of education (**Table 4.1**).

## Measures

### *Non-verbal intellectual capacity*

Non-verbal intellectual capacity was measured by Raven's Coloured Progressive Matrices (RCPM). The RCPM is a standardized test designed to measure non-verbal intellectual capacity – especially logical reasoning – in children from the age of 5 years onwards and in children with an intellectual disability. It needs little verbal instruction.[39] The RCPM can be used for children with CP despite severe motor and speech disorders.[40] Scores on the RCPM correlate highly with scores on tests of general intellectual capacity.[41] The RCPM consists of 36 items, presented in three sets of 12, which become progressively more difficult. Each item contains a pattern problem with one part removed and six pictured inserts, one of which contains the correct pattern. The number of correct

**Table 4.1** Baseline characteristics

| | Complete longitudinal data | | | Incomplete longitudinal data | |
|---|---|---|---|---|---|
| | Age cohort 5 ($n = 42$) | Age cohort 7 ($n = 49$) | $p^a$ | Age cohort 5 and 7 ($n = 25$) | $p^b$ |
| Age (years months) | | | .000 | | .40 |
| Range | 4y 8mo – 5y 8mo | 6y 8mo – 7y 7mo | | 4y 10m – 7y 5mo | |
| Mean (SD) | 5y 3mo (3mo) | 7y 2mo (3mo) | | 6y 3mo (12mo) | |
| Gender, *n* (%) | | | .53 | | .26 |
| Boys | 30 (71) | 32 (65) | | 14 (56) | |
| Girls | 12 (29) | 17 (35) | | 11 (44) | |
| GMFCS level, *n* (%) | | | .37 | | .30 |
| I | 23 (55) | 22 (45) | | 11 (44) | |
| II | 5 (12) | 8 (16) | | 7 (28) | |
| III | 8 (19) | 6 (12) | | 3 (12) | |
| IV | 3 (7) | 3 (6) | | 3 (12) | |
| V | 3 (7) | 10 (21) | | 1 (4) | |
| Typology, *n* (%) | | | .23 | | .10 |
| Spastic | 34 (80) | 41 (84) | | 23 (92) | |
| Unilateral | 17 (40) | 14 (29) | | 11 (44) | |
| Bilateral | 17 (40) | 27 (55) | | 12 (48) | |
| Dyskinetic | 8 (20) | 6 (12) | | 0 | |
| Ataxic | 0 | 2 (4) | | 2 (8) | |
| Type of education, *n* (%) | | | .03 | | .33 |
| Mainstream education | 24 (57) | 17 (35) | | 14 (56) | |
| Special education or day care | 18 (43) | 32 (65) | | 11 (44) | |

*n*, number of children; SD, standard deviation; y, years; mo, months; GMFCS, Gross Motor Function Classification System; $p^a$, *p*-value for difference between children with complete longitudinal data in age cohort 5 vs age cohort 7; $p^b$, *p*-value for difference between children with complete vs incomplete longitudinal data.

answers is added up to form a total raw score (0-36) and transformed to an IQ score based on age-dependent normative data provided in the manual. The present study used a computer version of the RCPM, including Dutch norms.[42] The RCPM has good psychometric properties, including satisfactory test-retest reliability.[43,44]

### *Severity of CP*

Subgroups of CP severity were classified in terms of both activities and impairments.[45] In terms of activities, the Gross Motor Function Classification System (GMFCS) was used. The GMFCS is a five-level classification system for age-specific gross motor activity, based on functional limitations, the need for assistive devices and, to a lesser extent, quality of movement.[46] Level I represents the highest level of gross motor function, i.e., the child walks without restrictions, and level V the lowest, i.e., the child is transported in a manual wheelchair (**Appendix 4.1**). The GMFCS has good psychometric properties, including stability over time.[47,48] The present study used the Dutch version of the GMFCS.[49] As regards impairments, the type of motor impairment (i.e., spastic, dyskinetic, or ataxic CP) and – within spastic CP – limb distribution (i.e., unilateral spastic CP [USCP] or bilateral spastic CP [BSCP]) were classified according to the Surveillance of Cerebral Palsy in Europe guidelines.[50]

## Procedure

All children visited the pediatric rehabilitation department of a medical center or rehabilitation center with their parent(s) for three yearly measurements. The children of age cohort 5 had their T0, T1, and T2 assessments at the ages of 5 years (mean 5y 3mo, SD 3mo), 6 years (mean 6y 3mo, SD 3mo), and 7 years (mean 7y 4mo, SD 3mo), respectively. The children of age cohort 7 had their T0, T1, and T2 assessments at the ages of 7 years (mean 7y 2mo, SD 3mo), 8 years (mean 8y 3mo, SD 3mo), and 9 years (mean 9y 3mo, SD 4mo), respectively.

During the first visit, one of two trained researchers (DWS / PS) classified the children according to GMFCS level, type of motor impairment and limb distribution. In case of doubt, video recordings were examined with the project leaders (JB / JWG). During all three visits, the RCPM was administered by one of three trained researchers (DWS / PS / MW) in an individual test situation, preceded by short and simple instructions as provided in the manual. If a child did not comprehend the instructions or did not answer the first three practice items correctly, the test was cancelled.[42] In this case, the researcher recorded a total raw score of '0' and subsequently classified the child as 'not testable' (i.e., no IQ score possible) by RCPM.

## Statistical analyses

Analyses were performed with SPSS version 16.0 (SPSS Inc, Chicago, IL, USA) using a 0.05 level of significance for all statistical tests. Descriptive statistics were computed per age cohort and per CP severity subgroup, for each of the three measurements, both for number of testable children, for RCPM raw scores, and for RCPM IQ scores. To determine whether the data of the two age cohorts could be pooled, the number of testable children, the RCPM raw scores and the RCPM IQ scores of the two cohorts were compared for the age of 7 years (i.e., at T2 for age cohort 5 and at T0 for age cohort 7). Next, the development of non-verbal intellectual capacity was examined by analyzing time effects on RCPM raw scores and on RCPM IQ scores, using the 'one-within' design of the MANOVA for repeated measurements ('univariate' approach) with Bonferroni testing for post-hoc time comparisons. The association of the development of non-verbal intellectual capacity with the severity of CP was then examined by analyzing time x group effects on RCPM raw scores and on RCPM IQ scores, using the 'one-within, one-between' design of the MANOVA for repeated measurements ('univariate' approach) with Bonferroni testing for post-hoc time x group comparisons.[51]

# RESULTS

## RCPM scores in two age cohorts

Descriptive statistics of the RCPM are presented in **Table 4.2** for the number of testable children, in **Table 4.3** for mean raw scores (including not-testable children, whose raw scores were '0') and in **Table 4.4** for mean IQ scores (excluding not-testable children, for whom no IQ scores were available) for each age cohort. There was no marked difference in the number of testable children between the two cohorts at the age of 7 years. However, age cohort 5 appeared to have considerably higher raw scores ($t$ = 1.92, $p = 0.06$) and statistically significantly higher IQ scores ($t = 2.24$, $p = 0.03$) at T2, compared to age cohort 7 at T0. In view of these differences, we decided not to pool the data but instead to continue the separate analyses for each age cohort.

**Table 4.2** Number of RCPM testable and not-testable children per year in two age cohorts, according to GMFCS level, type of motor impairment and limb distribution

| | Age cohort 5 | | | | | | Age cohort 7 | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | T0 | | T1 | | T2 | | T0 | | T1 | | T2 | |
| | Testable | | Testable | | Testable | | Testable | | Testable | | Testable | |
| | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No |
| GMFCS I | 21 | 2 | 22 | 1 | 23 | 0 | 22 | 0 | 22 | 0 | 22 | 0 |
| GMFCS II | 5 | 0 | 5 | 0 | 5 | 0 | 8 | 0 | 8 | 0 | 8 | 0 |
| GMFCS III | 6 | 2 | 6 | 2 | 6 | 2 | 5 | 1 | 5 | 1 | 5 | 1 |
| GMFCS IV | 1 | 2 | 1 | 2 | 2 | 1 | 3 | 0 | 3 | 0 | 3 | 0 |
| GMFCS V | 0 | 3 | 0 | 3 | 0 | 3 | 2 | 8 | 1 | 9 | 1 | 9 |
| Spastic | 29 | 5 | 30 | 4 | 32 | 2 | 37 | 4 | 36 | 5 | 36 | 5 |
| USCP | 16 | 1 | 17 | 0 | 17 | 0 | 14 | 0 | 14 | 0 | 14 | 0 |
| BSCP | 13 | 4 | 13 | 4 | 15 | 2 | 23 | 4 | 22 | 5 | 22 | 5 |
| Dyskinetic | 4 | 4 | 4 | 4 | 4 | 4 | 2 | 4 | 2 | 4 | 2 | 4 |
| Ataxic | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 1 | 1 | 1 | 1 |
| Total | 33 | 9 | 34 | 8 | 36 | 6 | 40 | 9 | 39 | 10 | 39 | 10 |

RCPM, Raven's Coloured Progressive Matrices; GMFCS, Gross Motor Function Classification System; USCP, unilateral spastic cerebral palsy; BSCP, bilateral spastic cerebral palsy; T0, baseline measurement; T1, measurement after one year; T2, measurement after two years.

**Table 4.3** Mean RCPM raw scores per year in two age cohorts, according to GMFCS level, type of motor impairment and limb distribution

| | Age cohort 5 | | | | Age cohort 7 | | | |
|---|---|---|---|---|---|---|---|---|
| | | T0 | T1 | T2 | | T0 | T1 | T2 |
| | *n* | Mean (SD) | Mean (SD) | Mean (SD) | *n* | Mean (SD) | Mean (SD) | Mean (SD) |
| GMFCS I | 23 | 15.87 (6.81) | 19.78 (7.65) | 23.70 (7.14) | 22 | 19.09 (5.76) | 24.05 (6.69) | 25.41 (7.10) |
| GMFCS II | 5 | 13.60 (5.03) | 17.40 (2.41) | 23.00 (8.22) | 8 | 20.25 (6.09) | 22.50 (6.78) | 25.38 (6.50) |
| GMFCS III | 8 | 8.25 (5.52) | 10.13 (6.49) | 12.88 (8.13) | 6 | 15.00 (8.44) | 15.83 (8.84) | 18.00 (9.63) |
| GMFCS IV | 3 | 6.00 (10.39) | 5.67 (9.82) | 10.00 (11.14) | 3 | 15.67 (4.04) | 11.67 (4.73) | 15.00 (7.81) |
| GMFCS V | 3 | 0 | 0 | 0 | 10 | 1.70 (3.77) | 1.0 (3.16) | 1.20 (3.80) |
| Spastic | 34 | 13.53 (7.47) | 16.97 (8.24) | 21.06 (8.63) | 41 | 16.98 (7.81) | 19.56 (9.90) | 21.44 (10.36) |
| USCP | 17 | 16.12 (6.75) | 19.88 (6.37) | 24.41 (6.25) | 14 | 19.57 (4.45) | 22.86 (6.30) | 24.57 (6.72) |
| BSCP | 17 | 10.94 (7.43) | 14.06 (9.03) | 17.71 (9.52) | 27 | 15.63 (8.85) | 17.85 (11.05) | 19.81 (11.60) |
| Dyskinetic | 8 | 7.13 (8.03) | 7.88 (9.99) | 9.63 (12.02) | 6 | 5.50 (8.98) | 5.83 (10.21) | 6.17 (10.67) |
| Ataxic | 0 | - | - | - | 2 | 3.50 (4.95) | 6.00 (8.49) | 5.50 (7.78) |
| Total | 42 | 12.31 (7.90) | 15.24 (9.21) | 18.88 (10.26) | 49 | 15.02 (8.94) | 17.33 (10.96) | 18.92 (11.65) |

RCPM, Raven's Coloured Progressive Matrices; GMFCS, Gross Motor Function Classification System; USCP, unilateral spastic cerebral palsy; BSCP, bilateral spastic cerebral palsy; *n*, number of children; SD, standard deviation; T0, baseline measurement; T1, measurement after one year; T2, measurement after two years.

**Table 4.4** Mean RCPM IQ scores per year in two age cohorts, according to GMFCS level, type of motor impairment and limb distribution

| | Age cohort 5 | | | | | | Age cohort 7 | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | T0 | | T1 | | T2 | | T0 | | T1 | | T2 | |
| | *n* | Mean (SD) | *n* | Mean (SD) | *n* | Mean (SD) | *n* | Mean (SD) | *n* | Mean (SD) | *n* | Mean (SD) |
| GMFCS I | 21 | 102 (17) | 22 | 101 (21) | 23 | 101 (22) | 22 | 87 (15) | 22 | 96 (21) | 22 | 95 (20) |
| GMFCS II | 5 | 89 (21) | 5 | 90 (7) | 5 | 99 (23) | 8 | 95 (17) | 8 | 90 (20) | 8 | 96 (22) |
| GMFCS III | 6 | 79 (8) | 6 | 77 (7) | 6 | 80 (8) | 5 | 83 (13) | 5 | 83 (13) | 5 | 80 (15) |
| GMFCS IV | 1 | 100 (-) | 1 | 90 (-) | 2 | 78 (18) | 3 | 77 (13) | 3 | 68 (6) | 3 | 73 (14) |
| GMFCS V | 0 | - | 0 | - | 0 | - | 2 | 65 (0) | 1 | 65 (-) | 1 | 65 (-) |
| Spastic | 29 | 96 (19) | 30 | 96 (19) | 32 | 98 (21) | 37 | 87 (15) | 36 | 91 (20) | 36 | 92 (20) |
| USCP | 16 | 100 (19) | 17 | 98 (21) | 17 | 104 (20) | 14 | 88 (14) | 14 | 92 (20) | 14 | 92 (20) |
| BSCP | 13 | 90 (18) | 13 | 93 (15) | 15 | 91 (20) | 23 | 87 (17) | 22 | 91 (21) | 22 | 92 (21) |
| Dyskinetic | 4 | 93 (14) | 4 | 85 (27) | 4 | 84 (28) | 2 | 83 (25) | 2 | 83 (25) | 2 | 83 (25) |
| Ataxic | 0 | - | 0 | - | 0 | - | 1 | 65 (-) | 1 | 65 (-) | 1 | 65 (-) |
| Total | 33 | 96 (18) | 34 | 95 (20) | 36 | 96 (22) | 40 | 86 (16) | 39 | 90 (20) | 39 | 91 (20) |

RCPM, Raven's Coloured Progressive Matrices; GMFCS, Gross Motor Function Classification System; USCP, unilateral spastic cerebral palsy; BSCP, bilateral spastic cerebral palsy; *n*, number of children; SD, standard deviation; T0, baseline measurement; T1, measurement after one year; T2, measurement after two years.

## Development of RCPM raw scores

Within each age cohort and averaged over all subgroups of CP severity, RCPM raw scores increased over time (**Table 4.3**). This time effect was significant for age cohort 5 ($F = 42.02$, $p < 0.001$) and age cohort 7 ($F = 22.92$, $p < 0.001$). Within each cohort, post-hoc testing revealed significantly higher raw scores at T1 compared to T0, at T2 compared to T1, and at T2 compared to T0.

## Development of RCPM IQ scores

Only slight changes in RCPM IQ scores over time were observed (**Table 4.4**). Time effects were not significant, neither for age cohort 5 nor for age cohort 7.

## Development of RCPM raw scores in relation to severity of CP

Within each age cohort, there were differences between severity subgroups in the increase in RCPM raw scores (depicted in **Figures 4.2** and **4.3**). These time x group effects were significant for age cohort 5 as regards type of motor impairment ($F = 4.07$, $p < 0.05$) and for age cohort 7 as regards GMFCS level ($F = 5.88$, $p < 0.001$).

Within age cohort 5, post-hoc testing revealed a significantly steeper increase in raw scores between T0 and T2 for children with spastic CP compared to children with dyskinetic CP ($F = 6.63$, $p < 0.05$).

Within age cohort 7, post-hoc testing revealed a significantly steeper increase in raw scores in children classified as GMFCS level I compared to children classified as GMFCS level III between T0 and T1 ($F = 26.00$, $p < 0.05$), as well as to children classified as GMFCS level IV between T0 and T1 ($F = 15.86$, $p < 0.001$) and T0 and T2 ($F = 5.26$, $p < 0.05$), and to children classified as GMFCS level V between T0 and T1 ($F = 20.28$, $p < 0.001$) and T0 and T2 ($F = 17.21$, $p < 0.001$). Furthermore, children classified as GMFCS level II showed a significantly steeper increase in raw scores compared to children classified as GMFCS level IV between T0 and T1 ($F = 10.16$, $p < 0.05$) and to children classified as GMFCS level V between T0 and T1 ($F = 6.61$, $p < 0.05$), T1 and T2 ($F = 6.83$, $p < 0.05$), and T0 and T2 ($F = 14.12$, $p < 0.05$). A steeper increase in raw scores was also observed for children classified as GMFCS level III compared to children classified as GMFCS level IV between T0 and T1 ($F = 9.96$, $p < 0.05$) and to children classified as GMFCS level V between T1 and T2 ($F = 5.90$, $p < 0.05$) and T0 and T2 ($F = 11.80$, $p < 0.05$). Finally, children classified as GMFCS level IV showed a significantly steeper increase in raw scores compared to children classified as GMFCS level V between T1 and T2 ($F = 10.27$, $p < 0.05$).

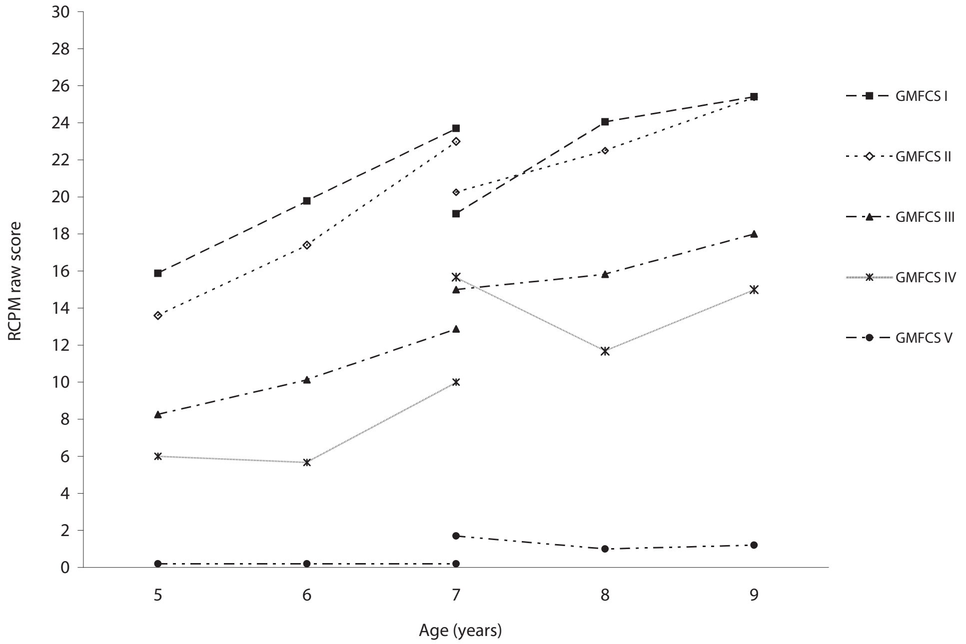


**Figure 4.2** RCPM raw scores per year in two age cohorts, according to GMFCS level.

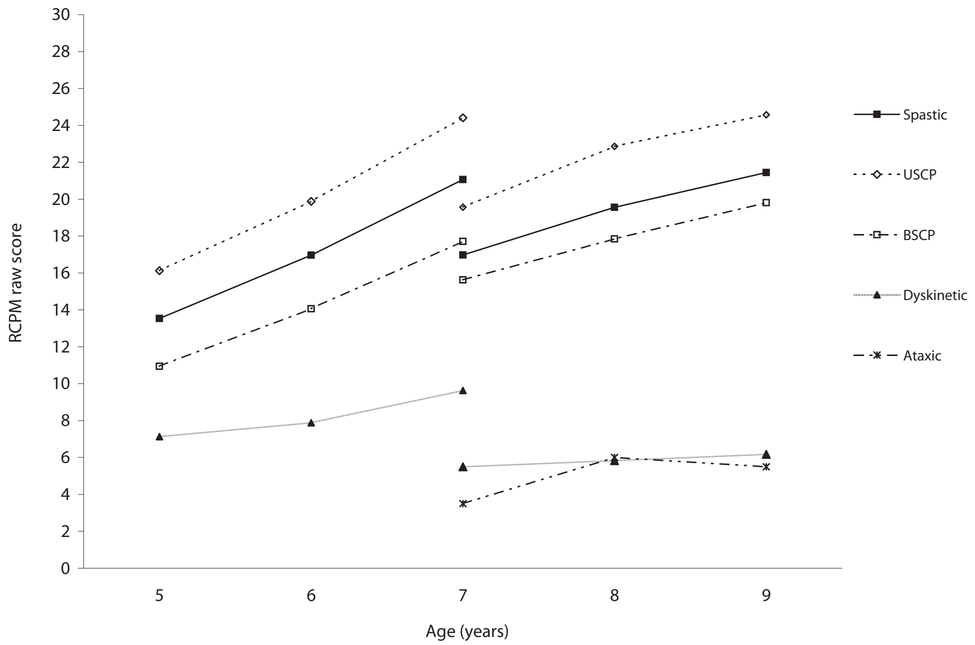


**Figure 4.3** RCPM raw scores per year in two age cohorts, according to type of motor impairment and limb distribution.

### Development of RCPM IQ scores in relation to severity of CP

There were no significant time x group effects on RCPM IQ scores, neither within age cohort 5 nor within age cohort 7.

## DISCUSSION

The first aim of this study was to describe the development of non-verbal intellectual capacity of school-age children with CP (aged 5 to 9 years) in terms of both RCPM raw scores and RCPM IQ scores. The results showed an increase of RCPM raw scores but no change in RCPM IQ scores over time. The second aim was to examine if the development of non-verbal intellectual capacity is associated with the severity of CP. Results showed that the development of RCPM raw scores was associated with the severity of CP, in particular with the GMFCS level (i.e., level of gross motor functioning) and the type of motor impairment.

The development of non-verbal intellectual capacity resembles the trajectory of typical development, which is characterized by an absolute increase and normative stabilization. However, analyses of subgroups of severity revealed that no absolute increase occurred among children with dyskinetic CP (age cohort 5) nor among children classified as GMFCS level IV or level V (age cohort 7). Analyses also revealed relatively low levels of non-verbal intellectual capacity in children with dyskinetic CP and in children with GMFCS level III, IV, or V. Taken together, this suggests that, between the age of 5 to 9 years, non-verbal intellectual capacity develops typically in children with less severe CP, while children with more severe CP show a limited development compared to typically developing children.

Our findings on the development of non-verbal intellectual capacity differ from those reported in previous longitudinal studies of children with CP, which have mainly shown a decline in terms of IQ scores.[17,35-37] The present study included a much larger sample, covering the whole severity spectrum of CP, was performed among children within a relatively large age range (5 to 9 years), and focused both on raw scores and IQ scores. The findings for levels of intellectual capacity in subgroups of severity did not differ from those of previous studies, which have cross-sectionally shown higher scores for intelligence in children with less severe CP.[8-13] Interestingly, the RCPM raw scores obtained by the children with GMFCS level I or level II at the ages of 5, 6, 7, 8, and 9 years strongly correspond to those of typically developing children as found in several earlier cross-sectional studies in various countries.[43,44,52] Since the data from the present longitudinal study and the previous cross-sectional studies cannot be compared statistically, we can only speculate that children with GMFCS level I or level II show the same average levels and developmental trajectories as their typically developing peers.

This study had several strengths. First, our sample represented the heterogeneous population of children with CP that is seen in clinical practice at rehabilitation departments of hospitals and rehabilitation centers. Second, our prospective longitudinal study had a very strict design with follow-up assessments after one year and two years, leaving a margin of only one month for each child. Third, we administered the RCPM as an easy and quick measure independent of motor performance, which makes it an appropriate and encouraging intelligence test for children with CP of various ages and levels of severity. In addition, the RCPM is known as an international, 'culture-free' test[17,53] and is also considered one of the best measures of general intelligence.[54] Fourth, both RCPM raw scores and IQ scores were analyzed, enabling more detailed examination of developmental trajectories than previously reported.

Some methodological issues should be considered when interpreting the results. Based on the observation that, at age 7, both RCPM raw scores and RCPM IQ scores differed between children from age cohort 5 and age cohort 7, we decided not to pool the RCPM data but to perform separate analyses for each of the two age cohorts. This weakened the statistical power, especially concerning the association with subgroups of severity. For instance, the sample sizes for GMFCS level IV and ataxic CP became very small, which may have distorted some results. There is no definite answer to the question why the two age cohorts appeared so different in terms of RCPM scores at the age of 7 years. Of all the variables we used to compare the two age cohorts – gender, level of GMFCS, type of motor impairment, limb distribution, and type of education – only type of education differed between the age cohorts, indicating that children from age cohort 7 were more likely to attend schools for special education or day care centers. However, this variable would rather reflect than explain the difference in RCPM scores. Alternatively, a selection effect may have occurred by which more children with intellectual disabilities were included at 7 years than at 5 years of age. A third possible explanation is that, despite the satisfactory test-retest reliability reported for the RCPM,[43,44] there was a RCPM test effect or a general assessment effect, through which many children in age cohort 5 – but particularly children with GMFCS levels I and II – had higher scores at the age of 7 years than those in age cohort 7.

The major finding of the present study is the contrast in developmental trajectories for intellectual capacity within the population of children with CP. There was a group showing very limited development in comparison to typically developing children, but also a group showing typical development. What mechanisms could explain these findings? Previously, prevention of synaptic pruning has been theorized to be one important explanation for limited intellectual development in school-age children with CP:[34,35] 'Infants are born with far more synapses, both excitatory and inhibitory, than adults end up with. In a process called pruning, synapses that are inactive during development disappear while active ones proliferate. A cerebral lesion (with less remaining brain tissue) occurring early in brain development would prevent the pruning of excess synapses necessary for intellectual development'.[37] Since our study revealed that intellectual development was not limited for all school-age children with CP, we propose a further differentiation of this theory. Following Muter et al.,[36] we suggest that the onset, extent, and localization of the brain lesion, as well as the presence of seizures, may be important elements for such a differentiation. Unfortunately, no adequate instruments to classify brain lesion and epilepsy were available for the present study. It is also possible that the typical intellectual development revealed in our study specifically applies to a certain age period (e.g., 5 to 9 years) and that a true decline in intellectual development actually occurs later (after the age of 9 years). Knowledge about the intellectual development of adolescents and young adults with CP is not available yet.

The present findings have practical implications. Professionals and parents generally need to know that there are different developmental trajectories for intellectual capacity in children with CP. Within these trajectories, large individual changes are not to be expected during school age. As such, intellectual capacity can be considered a stable characteristic of a child with CP. More specifically, therapists and educators should know about the different levels and developmental trajectories of intellectual capacity in different children with CP. Applying activity-focused interventions or working in mainstream or special education, this knowledge could enable them to tailor their instructions and strategies better.

This study has offered unique insights into the development of non-verbal intellectual capacity in children with CP between the ages of 5 and 9 years, based on a relatively large sample size. The main insight is that intellectual development is not always affected in children with CP – as had long been assumed – but is rather dependent on the severity of CP. This does not yet reveal, however, how intellectual capacity might influence the development of daily-life functioning in children with CP (e.g., toileting tasks, crossing a street, playing with peers). This knowledge could be helpful to develop therapeutic and educational programmes focussing on daily-life functioning in children with CP.

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**Appendix 4.1** Summary account of gross motor function by GMFCS level at ages 6 to 12 years[46]

| Level | Description |
|---|---|
| I | Walks without restrictions; limitations in more advanced gross motor skills |
| II | Walks without assistive devices; limitations walking outdoors and in the community |
| III | Walks with assistive mobility devices; limitations walking outdoors and in the community |
| IV | Self-mobility with limitations; children are transported or use power mobility outdoors and in the community |
| V | Self-mobility is severely limited even with the use of assistive technology |

# 5

# Development of daily activities in school-age children with cerebral palsy

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## Abstract

The purpose of this study was to describe the course of capabilities in self-care, mobility, and social function in school-age children with cerebral palsy (CP) and to investigate associations with CP-, child-, and family-characteristics. A clinic-based sample of children with CP ($n$ = 116; 76 males, 40 females; mean age 6y 3mo, SD 12mo) was followed longitudinally in three yearly measurements. Children's capabilities were assessed with the Pediatric Evaluation of Disability Inventory Functional Skills Scale (PEDI-FSS). Averaged for the total group, significant increases over time were shown in PEDI-FSS scores in all three domains. For self-care, the course was best predicted by a model including level of gross motor function (measured by the Gross Motor Function Classification System) and intellectual capacity (measured by Raven's Coloured Progressive Matrices). For mobility, the course was best predicted by a model containing only level of gross motor function. For social function, the course was best predicted by a model comprising level of bimanual function (measured by the Manual Ability Classification System) and paternal educational level. Generally, the increase in capabilities was greater if level of functioning was higher, except for level of paternal education. The findings indicate that there are different sets of determinants for the course of different domains of daily activities. Such different sets of determinants may help to set realistic expectations and to create appropriate treatment plans for different domains of daily activities in school-age children with CP.


## INTRODUCTION

Cerebral palsy (CP) is recognized as one of the most common developmental disabilities in childhood. The prevalence is around 2 per 1000 life births in Europe.[1,2] CP is defined as a group of permanent disorders of the development of movement and posture, causing activity limitation, which are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.[3] Without underestimating the motor impairments in CP, the focus in care and research is shifting towards the impact on children's daily activities.[4-6] Daily activities are those activities that people undertake routinely in their everyday life including personal care, functional mobility, and social tasks.[7] This is in line with the three meaningful domains that have been identified in the early 1990's by Coster and Haley when they conceptualized disablement in children.[8] Little is known, however, about the development in these three daily activity domains for children with CP. Therefore, longitudinal studies are needed with special attention for the heterogeneity of the CP population and both the course of daily activities and its determinants.

So far, we have learned about daily activities of children with CP from studies with a cross-sectional design[6,9-14] or from longitudinal studies looking at adolescents and young adults with CP.[15-17] These studies demonstrated large variability in the level of daily activities. Variability between individuals was mostly explained by their age and by the level of severity of CP. In addition, variability within individuals was observed for different domains of functioning, e.g., self-care, mobility, and social function,[6,10,11] and for different environments, e.g., home, community, and school environment.[12,14] Furthermore, it was found to be helpful to differentiate the concept of activities in the constructs of capacity (what a child can do in a standardized environment), capability (what a child can do in a daily environment), and performance (what a child does do in a daily environment).[9,13,16] In the present longitudinal study, the focus will be on the course and its determinants of children's capabilities (what they can do) in the home environment in the domains of self-care, mobility, and social function.

The school-age period is particularly of interest for investigating development of children's capabilities. For typically developing children, this age period is characterized by a major expansion of a child's world and by an increase of a child's tasks in everyday life.[18] Although many parents and professionals will have comparable expectations for children with CP, we don't know if they develop along similar lines in their capabilities as typically developing peers. We do know that in this age period the gross motor capacity of children with CP stabilizes or even declines in specific subgroups.[19,20] Possibly, this influences the course of capabilities of children with CP, for instance by stabilizing or declining capabilities in mobility. However, we have learned in a cross-sectional study that gross motor capacity alone is only moderately associated with capability in mobility at this age.[13] To conclude, in the school-age period there might be multiple determinants for the course of capability in mobility, and likewise in self-care and social function.

To investigate determinants for the course of capabilities, we will use the framework of the International Classification of Functioning, Disability and Health - Child and Youth version (ICF-CY). The advantage of the ICF-CY is that multiple health components can be considered in conjunction, including characteristics of CP (the health condition), characteristics of the child (the body functions, the capacities, and the personal factors), and characteristics of the family (the environmental factors).[21] Characteristics of CP concern the most commonly used subtypes and functional levels of CP, i.e., the predominant type of motor impairment (spastic, dyskinetic, ataxic), limb distribution (unilateral or bilateral), level of self-mobility by the Gross Motor Function Classification System (GMFCS), and level of manual ability by the Manual Ability Classification System (MACS).[22] For children's body functions, selective motor control (SMC) has recently gained much interest as a relevant factor[23,24] – more than, for instance, traditional impairments such as spasticity which explain only little of development in functioning.[25] Children's capacities and personal factors concern their gross motor capacity, intellectual capacity, and adaptive behavior.[3] Characteristics of the family, although less explicitly studied, concern parental coping, parental education, and presence of siblings. For all these characteristics, associations with capabilities have been demonstrated, mainly in cross-sectional studies (see **Appendix 5.1** for an overview).

The present study describes the course of capability in self-care, mobility, and social function over a two year period in school-age children with CP (5-9 years) and investigates associations between this course and CP-, child-, and family-characteristics. Models with CP-characteristics were chosen as the starting points (basic models), which were extended with relevant child- and family-characteristics (extended models). Information from multivariate models is thought to be valuable for better prediction of daily activities of school-age children with CP. This information could help children, parents, and families to set realistic expectations, and professionals to identify children developing 'less than expected' and to create treatment plans for optimizing children's daily activities.

# METHODS

## Design

This study is part of Pediatric Rehabilitation Research in the Netherlands (PERRIN) CP 5-9, a prospective longitudinal cohort study on the course and determinants of daily functioning in children aged 5 to 9 years with CP. Data were collected during a baseline assessment (T0), a follow-up assessment after one year (T1), and a second follow-up assessment after two years (T2).

## Participants

Children were recruited between May 2006 and October 2007 at the pediatric rehabilitation departments of two university medical centers (University Medical Center Utrecht and VU University Medical Center Amsterdam) and four rehabilitation centers (Rehabilitation Center De Hoogstraat, Utrecht; Rehabilitation Center Amsterdam; Rehabilitation Center De Trappenberg, Huizen; and Rehabilitation Center Breda), all in the Netherlands.

Eligible were children aged 5 years (i.e., 60 ± 6 months) or 7 years (i.e., 84 ± 6 months) at study entry, with a confirmed diagnosis of CP.[3] Children diagnosed with additional diseases and disorders affecting motor functioning, other than CP, and children whose parents lacked a basic knowledge of Dutch, were excluded. Informed consent was obtained from all parents. Ethical approval for the study was obtained from the medical ethics committees of all participating centers.

Of the 199 parents of children with CP that were invited, 116 agreed to participate (see for details Smits et al.[13]). At study entry, 56 children were about 5 years of age (age range 4y 8mo–5y 8mo) and 60 children were about 7 years of age (age range 6y

8mo–7y 7mo), referred to below as 'age cohort 5' (born between January 2001 and December 2002) and 'age cohort 7' (born between January 1999 and December 2000), respectively. Age cohort 5 did not differ statistically from age cohort 7 for CP-, child-, and family-characteristics (**Table 5.1**).

## Measures

### *Capabilities*

Children's capabilities were assessed with the Pediatric Evaluation of Disability Inventory (PEDI). The PEDI is a standardized assessment instrument using parental report in a structured interview. The PEDI measures activities in everyday situations in three domains: self-care, mobility, and social function.[26] In this study, the Dutch version of the PEDI (PEDI-NL) was used, which is a cross-cultural adaptation of the USA version and has good psychometric properties.[27] From the PEDI, the Functional Skills Scale (PEDI-FSS) was used, which specifically asks for children's capabilities (what they can do in a daily environment). The PEDI-FSS consists of 74 items for self-care, 65 items for mobility, and 66 items for social function. Each item is scored as positive (score 1) or negative (score 0). A positive score is given when the child is capable of accomplishing the activity. Per domain, sum scores were calculated and transformed to interval-scaled scores (0–100) according to the PEDI-NL manual.[27]

### *CP-characteristics*

CP-characteristics were classified in terms of both 'functional levels' and 'subtypes'. In terms of functional levels, the GMFCS and the MACS were used. The GMFCS is a five-level classification system for gross motor activity, based on functional limitations, the need for assistive devices, and, to a lesser extent, quality of movement.[28] Level I represents the highest level of gross motor function (the child walks without limitations) and level V the lowest (the child is transported in a manual wheelchair). The present study used the Dutch translation of the GMFCS.[29] The MACS is a five-level classification system for fine motor activity, reflecting the child's typical bimanual performance in daily activities.[30] Level I represents the highest level of bimanual performance (the child handles objects easily and successfully) and level V the lowest (the child requires total assistance). In this study, the Dutch translation of the MACS (available online at www.macs.nu) was used. In terms of subtypes, type of motor impairment (i.e., spastic, dyskinetic, or ataxic CP) and – within spastic CP – limb distribution (i.e., unilateral spastic CP [USCP] or bilateral spastic CP [BSCP]) were classified according to the SCPE guidelines.[31]

**Table 5.1** Baseline characteristics

| | | | Age cohort 5, *n* = 56 | Age cohort 7, *n* = 60 | *p* |
|---|---|---|---|---|---|
| Age, mean (SD) | Years months | | 5y 3mo (3mo) | 7y 2mo (3mo) | <.001 |
| Gender, *n* (%) | Boys | | 35 (63) | 41 (68) | .51 |
| | Girls | | 21 (37) | 19 (32) | |
| **CP-characteristics** | | | | | |
| GMFCS, *n* (%) | Level I | | 28 (50) | 28 (47) | .26 |
| | Level II | | 11 (20) | 9 (15) | |
| | Level III | | 10 (18) | 7 (12) | |
| | Level IV | | 4 (7) | 5 (8) | |
| | Level V | | 3 (5) | 11 (18) | |
| MACS, *n* (%) | Level I | | 9 (34) | 24 (40) | .16 |
| | Level II | | 24 (43) | 16 (27) | |
| | Level III | | 8 (14) | 6 (10) | |
| | Level IV | | 2 (4) | 6 (10) | |
| | Level V | | 3 (5) | 8 (13) | |
| Subtype, *n* (%) | Spastic | | 46 (82) | 52 (87) | .71 |
| | Unilateral | | 22 (39) | 20 (33) | |
| | Bilateral | | 24 (43) | 32 (54) | |
| | Dyskinetic | | 8 (14) | 6 (10) | |
| | Ataxic | | 2 (4) | 2 (3) | |
| **Child-characteristcs** | | | | | |
| SMC scale, *n* (%) | Good | | 25 (47) | 30 (55) | .61 |
| | Moderate | | 11 (21) | 7 (13) | |
| | Poor | | 10 (19) | 8 (15) | |
| | Unable | | 7 (13) | 9 (17) | |
| | | | Unknown: 3 | Unknown: 6 | |
| GMFM-66, mean (SD) | Scaled score (0-100) | | 65.74 (16.86) | 63.78 (24.88) | .62 |
| RCPM, mean (SD) | IQ score (55-125) | | 86.62 (20.91) | 81.42 (18.06) | .16 |
| CBCL, *n* (%) | Externalizing problems | | 12 (24) | 13 (22) | .99 |
| | No externalizing problems | | 38 (76) | 41 (78) | |
| | Internalizing problems | | 14 (28) | 24 (40) | .08 |
| | No internalizing problems | | 36 (72) | 30 (60) | |
| | | | Unknown: 6 | Unknown: 6 | |
| **Family-characteristics** | | | | | |
| UCL parents, *n* (%) | Active coping | Below | 8 (16) | 13 (25) | .81 |
| | | Average | 24 (49) | 24 (44) | |
| | | Above | 17 (35) | 16 (31) | |
| | Passive coping | Below | 12 (25) | 14 (26) | .14 |
| | | Average | 25 (50) | 16 (30) | |
| | | Above | 12 (25) | 23 (43) | |
| | | | Unknown: 7 | Unknown: 7 | |
| Education parents, *n* (%) | Level father | Lower | 31 (57) | 33 (58) | .96 |
| | | Higher | 23 (43) | 24 (42) | |
| | | | Unknown: 2 | Unknown: 3 | |
| | Level mother | Lower | 34 (62) | 41 (71) | .32 |
| | | Higher | 21 (38) | 17 (29) | |
| | | | Unknown: 1 | Unknown: 2 | |
| Siblings, *n* (%) | Yes | | 45 (80) | 46 (77) | .63 |
| | No | | 11 (20) | 14 (23) | |

*n*, number; SD, standard deviation; y, years; mo, months; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System; SMC, Selective Motor Control; GMFM, Gross Motor Function Measure; RCPM, Raven's Coloured Progressive Matrices; CBCL, Child Behavior Checklist; UCL, Utrecht Coping List.

## Child-characteristics

Children's selective motor control (SMC) was assessed with the Trost SMC test. The Trost SMC test is a standardized instrument to assess the ability to move an individual joint voluntarily and independently from other joints in the same leg.[32] A modified version of the Trost SMC test was used, which has shown good inter-rater reliability.[33] Scores for dorsiflexion of the ankle and extension of the knee for the two sides were added up to a total score (ranging from 0 to 8) and subdivided into three categories: poor SMC (i.e., total score 0, 1, 2), moderate SMC (3, 4, 5), and good SMC (6, 7, 8).[24]

Children's gross motor capacity was measured by the Gross Motor Function Measure (GMFM-66). The GMFM-66 is a standardized observational instrument designed to measure gross motor function in children with CP in a specific test situation without the use of mobility aids or orthoses.[34] Data were analyzed with the Gross Motor Ability Estimator to obtain a GMFM-66 interval score for each child, ranging from 0 (lowest motor function) to 100 (highest motor function).[35] The present study used the Dutch translation of the GMFM,[36] which has good psychometric properties.[37]

Children's intellectual capacity was measured by Raven's Coloured Progressive Matrices (RCPM). The RCPM is a standardized test consisting of 36 pattern problems designed to measure non-verbal intellectual capacity.[38] Based on age-dependent norm tables, IQ scores were obtained ranging from 55 (lowest intellectual capacity, including 'not testable') to 125 (highest intellectual capacity). The present study used a computer-version of the RCPM,[39] which can be administered in most children with CP.[40,41] The RCPM has good psychometric properties.[42,43]

Children's behavior was measured by the Child Behavior Checklist (CBCL) Parent Form for children aged 4-18 years. The CBCL is a questionnaire containing 113 items about childhood behavior problems.[44] Based on age- and gender-dependent norm tables, the presence of externalizing problem behavior (delinquency, aggression) and internalizing problem behavior (depression, withdrawal, somatization) was assessed. The present study used the Dutch translation of the CBCL, which has good psychometric properties,[45] also in children with developmental delays.[46]

## Family-characteristics

Parental coping styles were assessed by the Utrecht Coping List (UCL). The UCL is a questionnaire containing 47 items about coping with stressful situations in general.[47] The items are grouped into seven subscales, which assess problem-focused coping (active confronting) and emotion-focused coping (palliative reactions, seeking social support, passive reactions, avoiding, expressing emotions, and reassuring thoughts).

The present study only used the active confronting coping scale and the passive reactions coping scale, since these differentiate both focus (problem vs. emotion) and approach (active vs. passive).[48] The active confronting scale represents active problem-focused coping, e.g., tackling a problem at once. The passive reactions scale represents passive emotion-focused coping, e.g., worrying about the past. Based on age- and gender-dependent norm tables, individual scores were categorized into three classes according to the UCL-manual: below average, average, and above average. Both the active confronting scale and the passive reaction scale have satisfactory psychometric properties.[47] In addition, parental level of education was operationalized as lower level (vocational education) or higher level (higher education) and presence of siblings was operationalized as yes or no.

## Procedure

All children visited the pediatric rehabilitation department of a medical center or rehabilitation center with their parent(s) for three yearly measurements. The children of age cohort 5 had their T0, T1, and T2 assessments at the ages of 5 years (mean 5y 3mo, SD 3mo), 6 years (mean 6y 3mo, SD 4mo), and 7 years (mean 7y 4mo, SD 3mo), respectively. The children of age cohort 7 had their T0, T1, and T2 assessments at the ages of 7 years (mean 7y 2mo, SD 3mo), 8 years (mean 8y 3mo, SD 3mo), and 9 years (mean 9y 3mo, SD 3mo), respectively.

Preceding the first visit, parents (mostly mothers) completed the CBCL and the UCL. During the first visit, one of two trained researchers (DWS / PS) administered the GMFCS, the MACS, subtype of CP, the Trost SMC scale, the GMFM-66, and the RCPM. During all three visits, one of six trained researchers administered the PEDI in a face-to-face interview with a parent (mostly a mother). In case the PEDI could not be administered during the visit (e.g., due to time limits) it was done by telephone within one month.

## Statistical analyses

Analyses were performed with SPSS version 16.0. Descriptive statistics were computed per age cohort and per GMFCS level, for each of the three measurements, for the PEDI-FSS domains of self-care, mobility, and social function.

To describe the course of capabilities, time effects on PEDI-FSS scores were analyzed using the Linear Mixed Models (LMM) procedure.[49] This analysis method considers the dependency of repeated measures within the same person by allowing the regression coefficients – for intercepts and slopes – to differ between subjects. As such, the 'best fitting model' was determined for each of the PEDI-FSS domains and potential determinants, using likelihood ratio tests. In addition, the number of observations per person are allowed to vary in this analysis (i.e., subjects with missing data can be analyzed).

To investigate associations between the course of capabilities and CP-, child-, and family-characteristics at baseline, univariate time-interaction effects on PEDI-FSS scores were analyzed using LMM ($p < 0.05$). Subsequently, those time-interactions with p-values lower than 0.15 in the univariate analyses were candidates for multivariate analyses. Multivariate models were formed for each of the three PEDI-FSS domains using backward stepwise procedures ($p < 0.05$). First, basic models were made, just including CP-characteristics. Then, extended models were made, including CP-characteristics (i.e., only the significant ones in the basic model) together with child- and family-characteristics. To get an impression of the robustness of the fit of the final models, the percentages of explained variance were calculated using multivariate regression analysis.

## RESULTS

Mean scores on the PEDI-FSS are depicted in **Figure 5.1**. Of the 56 children involved in age cohort 5, PEDI-FSS scores were available for 54 at T0 (i.e., 5 years), for 48 at T1 (i.e., 6 years), and for 50 at T2 (i.e., 7 years). Of the 60 children involved in age cohort 7, PEDI-FSS scores were available for 58 at T0 (i.e., 7 years), for 55 at T1 (i.e., 8 years), and for 54 at T2 (i.e., 9 years). In total, 6 children were drop-outs after T0. In addition, 17 children had intermittent missing scores on the PEDI-FSS ($n = 4$ at T0, $n = 7$ at T1, and $n = 6$ at T2). Drop-outs and intermittent missing scores were distributed proportionally over the two age cohorts and over the five GMFCS levels.

### Course of capabilities

The time effects are presented in **Table 5.2**. Within the total group, PEDI-FSS scores increased over time for all domains. Within the separate age cohorts 5 and 7, PEDI-FSS scores also increased over time for all domains, except for the domain of mobility in age cohort 7. Post-hoc testing revealed no significant differences between age cohort 5 and age cohort 7 in the course of mobility and social function. In the domain of self-care, however, a significantly greater increase in scores was revealed for children in age cohort 5 compared to children in age cohort 7 ($t = 2.45$, $p = 0.02$).

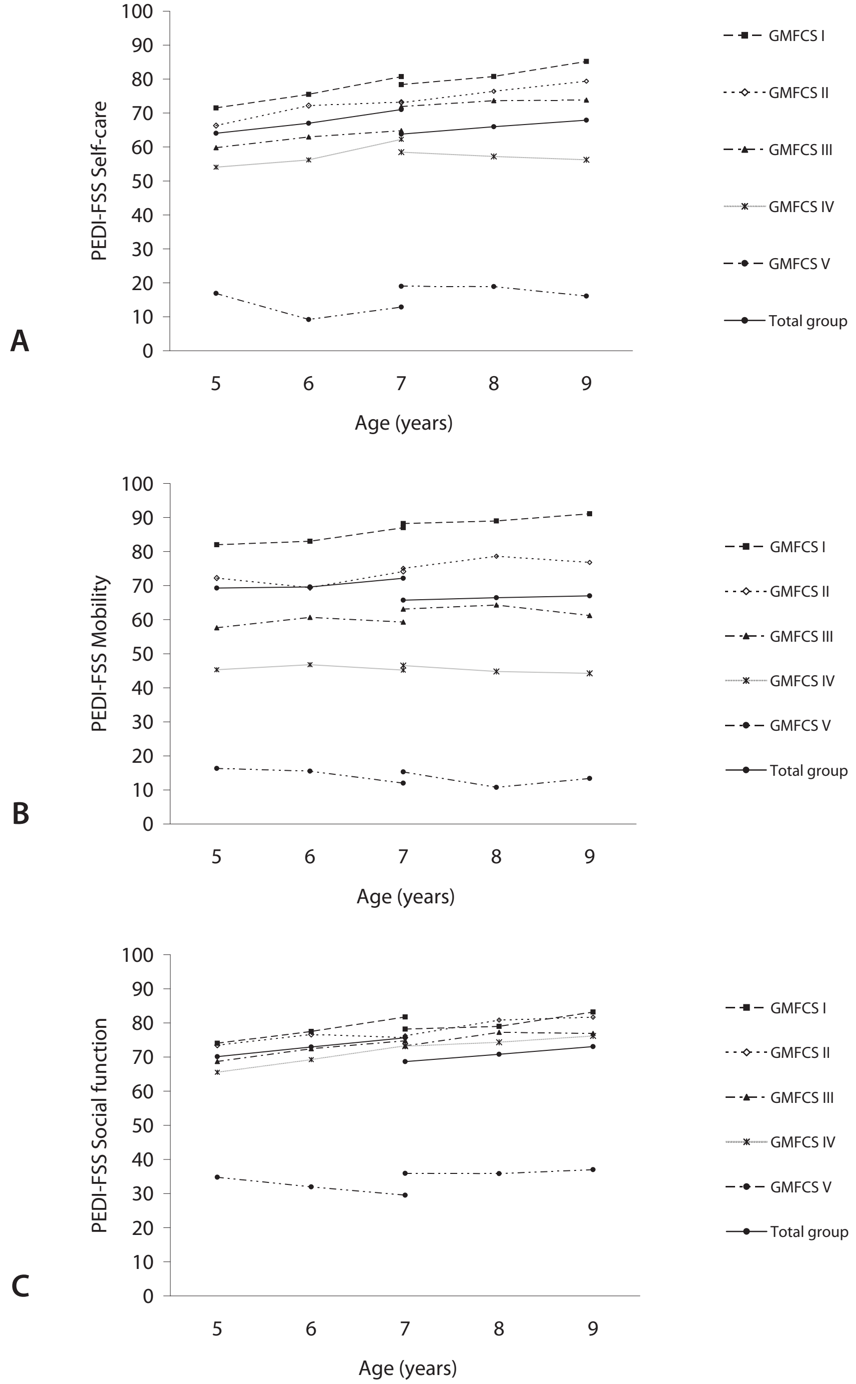


**Figure 5.1** Mean scores per age cohort and per GMFCS level, for each yearly measurement, for the PEDI-FSS domains of self-care (**A**), mobility (**B**) and social function (**C**).

**Table 5.2** Time effects on PEDI-FSS scores

| | PEDI-FSS Self-care | | | PEDI-FSS Mobility | | | PEDI-FSS Social function | | |
|---|---|---|---|---|---|---|---|---|---|
| | Beta | SE | *p*-value | Beta | SE | *p*-value | Beta | SE | *p*-value |
| Total (*n* = 116) | | | | | | | | | |
| Constant | 64.09 | 1.86 | | 68.00 | 2.30 | | 69.50 | 1.44 | |
| Time (T0-T1-T2) | 2.72 | 0.33 | < 0.001 | 0.83 | 0.39 | 0.04 | 2.46 | 0.31 | < 0.001 |
| Age cohort 5 (*n* = 56) | | | | | | | | | |
| Constant | 64.09 | 2.07 | | 69.81 | 2.56 | | 70.13 | 1.54 | |
| Time (T0-T1-T2) | 3.55 | 0.46 | < 0.001 | 1.21 | 0.59 | 0.04 | 2.78 | 0.48 | < 0.001 |
| Age cohort 7 (*n* = 60) | | | | | | | | | |
| Constant | 64.07 | 3.06 | | 66.34 | 3.89 | | 68.91 | 2.49 | |
| Time (T0-T1-T2) | 1.96 | 0.45 | < 0.001 | 0.48 | 0.51 | 0.35 | 2.18 | 0.42 | < 0.001 |

PEDI-FSS; Pediatric Evaluation of Disability Inventory Functional Skills Scale; Beta, regression coefficient; SE, standard error; *n*, number of children; T0, baseline measurement; T1, measurement after one year; T2, measurement after two years.

## Course of capabilities in relation to CP-, child-, and family-characteristics

Univariate analyses within the total group showed that time effects on PEDI-FSS scores were associated ($p < 0.05$) with specific CP-characteristics (**Table 5.3**) and with specific child- and family-characteristics (**Table 5.4**). For the domain of self-care, the course was associated with GMFCS level and MACS level (i.e., more increase in higher levels of functioning), with SMC grade, GMFM-66 score, and RCPM IQ score (i.e., more increase in higher grades or scores), and also with subtype (i.e., more increase in children with USCP and ataxic CP compared to BSCP and dyskinetic CP). For the domain of mobility, the course was associated with GMFCS level (i.e., more increase in higher levels of functioning) and with GMFM-66 score (i.e., more increase in higher scores). For the domain of social function, the course was associated with GMFCS level and MACS level (i.e., more increase in higher levels of functioning), with GMFM-66 score and RCPM IQ score (i.e., more increase in higher scores), and also with of education of the father (i.e., more increase in children whose father had a lower educational level).

## Multivariate models for the course of capabilities

**Table 5.5** presents the results of the multivariate analyses. For the basic self-care model, GMFCS level, MACS level, and subtype were entered as candidate predictors (i.e., $p < 0.15$ in univariate analyses). A model containing only GMFCS level appeared to fit the data for the course of self-care the best, explaining 68% of the variance in PEDI-FSS self-care scores. For the extended self-care model, GMFCS level, SMC grade, GMFM-66

**Table 5.3** Associations between the course of capabilities and CP-characteristics (univariate analyses)

| | PEDI-FSS Self-care | | | PEDI-FSS Mobility | | | PEDI-FSS Social function | | |
|---|---|---|---|---|---|---|---|---|---|
| | Beta | SE | *p*-value | Beta | SE | *p*-value | Beta | SE | *p*-value |
| GMFCS level | | | | | | | | | |
| I * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| II * time | 0.01 | 0.76 | 0.99 | -1.14 | 0.99 | 0.25 | -1.03 | 0.89 | 0.25 |
| III * time | -2.09 | 0.77 | < 0.01 | -1.79 | 1.00 | 0.08 | -0.60 | 0.89 | 0.50 |
| IV * time | -3.25 | 1.07 | < 0.01 | -2.16 | 1.39 | 0.12 | -1.41 | 1.22 | 0.25 |
| V * time | -5.31 | 0.85 | < 0.001 | -3.19 | 1.11 | 0.01 | -2.69 | 0.99 | < 0.01 |
| MACS level | | | | | | | | | |
| I * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| II * time | -0.56 | 0.66 | 0.40 | 1.08 | 1.22 | 0.21 | -1.18 | 0.74 | 0.11 |
| III * time | -1.18 | 0.88 | 0.18 | -1.73 | 1.12 | 0.12 | -0.90 | 0.97 | 0.36 |
| IV * time | -2.68 | 1.15 | 0.02 | -1.15 | 1.46 | 0.43 | -2.13 | 1.28 | 0.10 |
| V * time | -5.48 | 0.96 | < 0.001 | -2.14 | 1.33 | 0.08 | -3.12 | 1.07 | < 0.01 |
| Subtype | | | | | | | | | |
| USCP * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| BSCP * time | -1.90 | 0.71 | < 0.01 | -1.40 | 0.87 | 0.11 | -0.29 | 0.70 | 0.68 |
| Dyskinetic* time | -2.63 | 1.03 | 0.01 | -0.99 | 1.26 | 0.43 | -0.72 | 1.01 | 0.48 |
| Ataxic* time | -0.15 | 1.94 | 0.94 | -2.26 | 2.38 | 0.35 | -2.90 | 1.93 | 0.13 |

PEDI-FSS; Pediatric Evaluation of Disability Inventory Functional Skills Scale; Beta, regression coefficient; SE, standard error; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System; USCP, unilateral spastic cerebral palsy; BSCP, bilateral spastic cerebral palsy.

score, RCPM IQ score, and CBCL externalizing behavior were entered as candidates. A model with GMFCS level and RCPM IQ fitted the data the best, explaining 73% of the variance in PEDI-FSS self-care scores. Regarding this model, post-hoc testing revealed significant more increase in children with GMFCS level I compared to children with GMFCS level IV ($t$ = 2.37, $p$ = 0.02) and to children with GMFCS level V ($t$ = 3.14, $p$ < 0.01); in children with GMFCS level II compared to children with GMFCS level IV ($t$ = 2.36, $p$ = 0.02) and to children with GMFCS level V ($t$ = 3.09, $p$ < 0.01); and in children with higher RCPM IQ scores compared to children with lower RCPM IQ scores ($t$ = 3.42, $p$ < 0.01).

For the basic mobility model, GMFCS level, MACS level, and subtype were entered as candidate predictors. A model including only GMFCS level was the best fit for the data for the course of mobility, explaining 86% of the variance in PEDI-FSS mobility scores. For the extended mobility model, GMFCS level and GMFM-66 score were entered as candidates. GMFM-66 did however not add to the basic model which contained GMFCS level. Regarding this model, post-hoc testing revealed significant more increase only in children with GMFCS level I compared to children with GMFCS level V ($t$ = 2.89, $p$ < 0.01).

**Table 5.4** Associations between the course of capabilities and child- and family-characteristics (univariate analyses)

| | PEDI-FSS Self-care | | | PEDI-FSS Mobility | | | PEDI-FSS Social function | | |
|---|---|---|---|---|---|---|---|---|---|
| | Beta | SE | *p*-value | Beta | SE | *p*-value | Beta | SE | *p*-value |
| SMC | | | | | | | | | |
| Good * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| Moderate * time | -1.24 | 0.80 | 0.12 | 0.93 | 1.05 | 0.38 | -0.60 | 0.78 | 0.44 |
| Poor * time | -2.50 | 0.83 | < 0.01 | -0.08 | 1.08 | 0.94 | -0.51 | 0.80 | 0.52 |
| GMFM-66 * time | 0.08 | 0.01 | < 0.001 | 0.04 | 0.02 | < 0.01 | 0.03 | 0.01 | 0.02 |
| RCPM IQ * time | 0.09 | 0.01 | < 0.001 | 0.03 | 0.02 | 0.17 | 0.03 | 0.02 | 0.04 |
| CBCL Externalizing | | | | | | | | | |
| No problem * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| Problem * time | 1.23 | 0.82 | 0.14 | 0.32 | 0.99 | 0.75 | -0.17 | 0.81 | 0.83 |
| CBCL Internalizing | | | | | | | | | |
| No problem * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| Problem * time | 0.67 | 0.73 | 0.36 | -0.76 | 0.86 | 0.39 | 0.69 | 0.70 | 0.33 |
| UCL Active confronting | | | | | | | | | |
| Above | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| Average | -0.27 | 0.83 | 0.74 | 0.37 | 0.93 | 0.69 | 1.02 | 0.78 | 0.19 |
| Below | -1.17 | 0.99 | 0.24 | -0.83 | 1.14 | 0.47 | 1.55 | 0.95 | 0.11 |
| UCL Passive reactions | | | | | | | | | |
| Above | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| Average | 0.85 | 0.93 | 0.31 | 0.61 | 0.94 | 0.52 | -0.16 | 0.80 | 0.84 |
| Below | 0.13 | 0.93 | 0.89 | 0.13 | 1.06 | 0.90 | -0.13 | 0.89 | 0.89 |
| Educational level father | | | | | | | | | |
| Higher * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| Lower * time | -0.37 | 0.68 | 0.59 | 0.44 | 0.79 | 0.58 | 1.39 | 0.63 | 0.03 |
| Educational level mother | | | | | | | | | |
| Higher * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| Lower * time | 0.10 | 0.69 | 0.89 | 0.47 | 0.82 | 0.57 | 0.72 | 0.66 | 0.28 |
| Siblings | | | | | | | | | |
| Yes * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | |
| No * time | 0.33 | 0.82 | 0.69 | 1.06 | 0.97 | 0.28 | -0.08 | 0.78 | 0.92 |

PEDI-FSS; Pediatric Evaluation of Disability Inventory Functional Skills Scale; Beta, regression coefficient; SE, standard error; SMC, selective motor control; GMFM, Gross Motor Function Measure; RCPM, Raven's Coloured Progressive Matrices; CBCL, Child Behavior Checklist; UCL, Utrecht Coping List.

For the basic social function model, GMFCS level, MACS level, and subtype were again entered as candidate predictors. A model with only MACS level fitted the data for the course the best, explaining 56% of the variance in PEDI-FSS self-care scores. For the extended social function model, MACS level, GMFM-66 score, RCPM IQ score, UCL active confronting level, and educational level of the father were entered.

**Table 5.5** Multivariate models for the course and determinants of capabilities

| | Self-care Basic model ($R^2$: 68%) | | | Self-care Extended model ($R^2$: 73%) | | | Mobility Basic model ($R^2$: 86%) | | | Social function Basic model ($R^2$: 56%) | | | Social function Extended model ($R^2$:56%) | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Beta | SE | *p*-value | Beta | SE | *p*-value | Beta | SE | *p*-value | Beta | SE | *p*-value | Beta | SE | *p*-value |
| Constant | 77.56 | 1.49 | | 61.92 | 4.96 | | 85.06 | 1.13 | | 76.16 | 1.26 | | 75.56 | 1.53 | |
| Time | 3.96 | 0.39 | < 0.001 | -1.37 | 1.60 | 0.40 | 1.90 | 0.51 | < 0.001 | 3.44 | 0.51 | < 0.001 | 4.08 | 0.52 | < 0.001 |
| GMFCS level | | | | | | | | | | | | | | | |
| I | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | | | | | | | |
| II | -5.13 | 2.42 | 0.04 | -4.54 | 2.25 | 0.05 | -11.45 | 2.20 | < 0.001 | | | | | | |
| III | -8.95 | 2.55 | < 0.01 | -6.31 | 2.51 | 0.01 | -24.53 | 2.31 | < 0.001 | | | | | | |
| IV | -18.77 | 3.31 | < 0.001 | -16.03 | 3.18 | < 0.001 | -39.25 | 3.00 | < 0.001 | | | | | | |
| V | -57.78 | 2.79 | < 0.001 | -51.91 | 3.16 | < 0.001 | -70.32 | 2.49 | < 0.001 | | | | | | |
| I * time | 0 (ref) | | | 0 (ref) | | | 0 (ref) | | | | | | | | |
| II * time | 0.01 | 0.76 | 0.99 | 0.24 | 0.75 | 0.53 | -1.14 | 0.99 | 0.25 | | | | | | |
| III * time | -2.09 | 0.77 | < 0.01 | -1.18 | 0.79 | 0.18 | -1.79 | 1.00 | 0.08 | | | | | | |
| IV * time | -3.25 | 1.07 | < 0.01 | -2.52 | 1.06 | 0.02 | -2.16 | 1.39 | 0.12 | | | | | | |
| V * time | -5.31 | 0.85 | < 0.001 | -3.22 | 1.03 | < 0.01 | -3.19 | 1.11 | < 0.01 | | | | | | |
| MACS level | | | | | | | | | | | | | | | |
| I | | | | | | | | | | 0 (ref) | | | | | |
| II | | | | | | | | | | -2.93 | 1.81 | 0.11 | -2.61 | 1.97 | 0.19 |
| III | | | | | | | | | | -4.60 | 2.52 | 0.07 | -4.68 | 2.70 | 0.09 |
| IV | | | | | | | | | | -9.55 | 3.16 | < 0.01 | -9.54 | 3.36 | 0.01 |
| V | | | | | | | | | | -46.38 | 2.76 | < 0.001 | -46.22 | 2.94 | < 0.001 |
| I * time | | | | | | | | | | 0 (ref) | | | 0 (ref) | | |
| II * time | | | | | | | | | | -1.18 | 0.74 | 0.11 | -1.25 | 0.67 | 0.06 |
| III * time | | | | | | | | | | -0.90 | 0.97 | 0.36 | -0.70 | 0.87 | 0.42 |
| IV * time | | | | | | | | | | -2.13 | 1.28 | 0.10 | -1.93 | 1.13 | 0.09 |
| V * time | | | | | | | | | | -3.12 | 1.07 | < 0.01 | -3.21 | 0.95 | < 0.01 |
| RCPM IQ | | | | 0.17 | 1.06 | < 0.01 | | | | | | | | | |
| RCPM IQ * time | | | | 0.06 | 0.02 | < 0.01 | | | | | | | | | |
| Education father | | | | | | | | | | | | | | | |
| Higher | | | | | | | | | | | | | 0 (ref) | | |
| Lower | | | | | | | | | | | | | -1.17 | 1.68 | 0.49 |
| Higher * time | | | | | | | | | | | | | 0 (ref) | | |
| Lower * time | | | | | | | | | | | | | 1.46 | 0.56 | 0.01 |

$R^2$, explained variance; Beta, regression coefficient; SE, standard error; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System; RCPM, Raven's Coloured Progressive Matrices.

MACS level of the child and educational level of the father were the best predictors in this model, still explaining 56% of the variance in PEDI-FSS social function scores. Regarding this model, post-hoc testing revealed significant more increase in children with MACS level I compared to children with MACS level V ($t = 3.41$, $p < 0.01$); in children with MACS level II compared to children with MACS level V ($t = 2.07$, $p = 0.04$); in children with MACS level III compared to children with MACS level V ($t = 2.61$, $p = 0.01$); and in children whose father had a lower educational level compared to children whose father had a higher educational level ($t = 2.61$, $p = 0.01$).

## DISCUSSION

The aim of this study was to describe the course of capabilities in self-care, mobility, and social function over a two year period in school-age children with CP (5-9 years) and to investigate associations with CP-, child-, and family-characteristics. Averaged for the total group, the results showed significant increases over time in the PEDI-FSS domains of self-care, social function, and, to a lesser extent, mobility. For self-care, the course was best predicted by a model including GMFCS level (i.e., level of gross motor function) and intellectual capacity. For mobility, the course was best predicted by a model containing only GMFCS level. For social function, the course was best predicted by a model comprising MACS level (i.e., level of bimanual function) and educational level of the father. Thus, three models were developed in this study, each having its own set of determinants. It is important to note that such different sets of determinants can help to understand the development of daily activities in different domains in school-age children with CP.

The present study is the first longitudinal description of daily activities in school-age children with CP. It extends existing knowledge about daily activities of children with CP by revealing specific patterns of development in the early primary school-age period. Firstly, patterns of age-related development were revealed using time-effect analyses. In this respect, it was particularly informative that the greatest increase was in the domain of self-care between 5 and 7 years, while there was no increase in the domain of mobility between 7 and 9 years. Secondly, patterns of determinants were revealed using multivariate analyses. Here, it was enlightening that explaining the course of capabilities was not exclusively allocated to CP-characteristics, but to other characteristics as well.

Our findings concerning multiple determinants for the course of capabilities are partly consolidated by previous findings from large cross-sectional studies that, through multiple regression, also analyzed determinants for capabilities in school-age children with CP. To begin with, the finding that GMFCS level is the strongest predictor in the domain of mobility matches the results of four previous studies.[6,50-52] Also, the finding that GMFCS level is the strongest predictor and that intellectual capacity is an important additional predictor in the domain of self-care matches the results reported by two of these studies,[6,51] but not a third one showing that MACS level is a stronger predictor regarding self-care.[52] For the finding that MACS level is the strongest predictor in the domain of social function, there is no known match, nor for the finding that paternal education level is an important additional predictor in this domain. It is worth mentioning that, unlike the previous studies, our focus was on the course instead of the level of daily activities and, besides, our focus was on much more candidate predictors.

The multiple dependent and independent variables in the present study were intentionally chosen. The different dependent variables (i.e., self-care, mobility, and social functioning) were based on the conceptualization of disablement by Coster and Haley.[8] The different independent variables were based on the ICF-CY components that are linked to daily activities (i.e., the health condition, the body functions, the capacities, the personal and environmental factors);[21] per component one or more potentially important variables were selected. This holistic approach provided a comprehensive outset for studying a complex phenomenon like the development of daily activities in children with CP. Using a reductionist approach here, with only a few variables to be studied, would probably not have been adequate. Recently, this type of research has been called for[53] and has been described as 'comprehensive rehabilitation outcomes research'.[54] Furthermore, with respect to the dependent variables, we intentionally chose for one specific construct within the concept of daily activities: capability. Focusing primarily on 'capability' (can do in a daily environment) provides clarity with regard to the outcome, i.e., it prevents confusion with 'performance' (does do in a daily environment). Although performance may in fact be the ultimate outcome, it is still much more difficult to capture in research.[13]

Some methodological issues should be considered when interpreting the results. First, the present study had relatively small sample sizes considering the heterogeneity of the population. This limits the statistical power, especially regarding GMFCS levels IV and V, MACS levels III, IV and V, and dyskinetic and ataxic subtypes. Nevertheless, the distribution of functional levels and subtypes of CP was in proportion to the CP-population in clinical practice at rehabilitation departments of hospitals and rehabilitation centers, as known from previous descriptive studies.[55,56] Secondly, several measures were parent-reported (PEDI, CBCL, and UCL) and involved variation in which parents predominantly reported, i.e., mother (mostly) or father (rarely). In addition, it should be noted that the parental coping styles in this study were mainly those of mothers. Thirdly, although the instruments used in this study have adequate psychometric properties, this is still subject for research with respect to SMC testing,[23] especially in younger children and children with lower levels of intelligence.[33]

One major finding of the present study is the relatively strong increase in self-care between the age 5 of and 7 years. Apparently, children with CP below the age of 7 years can make more progress in this domain compared to the domains of mobility and social function and also compared with children above the age of 7 years. One explanation of this developmental pattern is the typical expansion of a child's world, e.g., going to primary school (whether regular or special), at the age of approximately 5 years. This development in self-care can be considered in concordance with developmental patterns of typically developing children. Another explanation is that children with CP reach their ceiling earlier in the domain of mobility than in the domain of self-care, which could partly be related to differences in item-complexity of these PEDI-FSS domains. A second major finding concerns the strong association between the course of capabilities and both GMFCS levels and MACS levels. This is not surprising, as the construct of these two classification systems is the child's performance (does do in a daily environment), which can be expected to reflect their capabilities (can do in a daily environment).

In addition to GMFCS level and MACS level, children's intellectual level and paternal education level were found as determinants for the course of capabilities. Children with higher IQ scores showed more increase in self-care. Here, it can be speculated that children with a higher IQ have a greater ability for adaptation and are therefore better able to acquire certain skills. Children with lower paternal education level showed more increase in social function. One suggestion in this respect is that children whose fathers have a lower level of education catch up in various domains, among which social function, once they enter school. Post-hoc analyses indeed showed a lower mean self-care score at baseline for children with lower paternal education level.

In the present study, three models were developed for the course of daily activities. These models provide clinically relevant information that can be used to advise children with CP, their parents and professionals. For instance, the findings about the strong increase in self-care capabilities and its association with levels of GMFCS and children's intelligence can help parents and therapists to set realistic expectations and create appropriate treatment plans. Such insights also help monitoring children over time and checking whether they develop as expected, above expected level or below expected level.

This study offered first insights in developmental patterns of daily activities in school-age children with CP. We recommend further adjustment of the presented models, firstly, by more extensively examining the impact of various child- and family-characteristics and, secondly, by expanding research in younger and older age groups.

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**Appendix 5.1** Overview of associations ($p < 0.05$; positive [+] and negative [-]) between capabilities (in self-care, mobility, and social function) and health components (in terms of CP-, child-, and family-characteristics) in children with CP

| | Outcomes: capabilities | | | |
|---|---|---|---|---|
| Determinants: health components | self-care | mobility | social | Studies |
| **CP-characteristics** | | | | |
| Type (spastic, ataxic, dyskinetic) | + | + | + | Østensjø et al. (2004)[57] |
| Limb distribution | - | - | - | Østensjø et al. (2004),[57] Wong et al. (2004)[58] |
| | - | - | | Wichers et al. (2009)[59] |
| | - | | | Voorman et al. (2006)[60] |
| GMFCS level | - | - | - | Østensjø et al. (2003),[6] Morris et al. (2006),[51] Donkervoort et al. (2007),[61] Gunel et al. (2009)[62] |
| | - | - | | Voorman et al. (2006),[60] Wichers et al. (2009),[59] Ohrvall et al (2010)[52] |
| | | - | | Kennes et al. (2002),[10] Beckung & Hagberg (2002)[50] |
| | | | - | Voorman et al. (2010)[17] |
| MACS level | - | - | - | Morris et al. (2006),[51] Gunel et al. (2009)[62] |
| | - | - | | Wichers et al. (2009),[59] Ohrvall et al. (2010)[52] |
| | - | | | Van Eck et al. (2010)[63] |
| **Child-characteristics** | | | | |
| Selective motor control | + | + | + | Østensjø et al. (2004)[57] |
| Gross motor capacity | + | + | + | Østensjø et al. (2004)[57] |
| | + | + | | Wright et al. (2008)[64] |
| | | + | | Van Eck et al. (2009),[16] Holsbeeke et al. (2009),[9] Smits et al. (2010)[13] |
| Intellectual capacity | + | + | + | Østensjø et al. (2003, 2004),[6,57] Morris et al. (2006)[51] |
| | | + | | Beckung & Hagberg (2002)[50] |
| | | | + | Voorman et al. (2006)[60] |
| Behavior problems | | | - | Voorman et al. (2010)[17] |
| **Family-characteristics** | | | | |
| Parental coping | | | + | Voorman et al. (2010)[17] |
| Parental education level | | | + | Voorman et al. (2010)[17] |
| Presence of siblings | + | + | | Craft et al. (1990)[65] |
| | | | + | Voorman et al. (2010)[17] |

# 6

# Introducing the concept of learning styles to rehabilitation

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## Abstract

A major focus of rehabilitation is that of optimizing patients' activities. Learning and teaching are key elements in this respect, but raise important questions: what do rehabilitation professionals know with respect to learning and teaching, what do they do, and what do they need? This paper discusses the issue of learning and teaching in rehabilitation practice, and introduces the concept of learning styles. This concept, new in the field of rehabilitation, but well-known in other areas, is presumed to benefit both patients and professionals, as it allows teaching strategies to be matched to individual patients. As a consequence, the process of learning may be more efficient and optimizing activities may be more effective.


## INTRODUCTION

*Imagine a patient with a central neurological disorder standing at the top of the stairs, and you, a rehabilitation professional, standing at the bottom of the stairs. You intend to get this patient to come downstairs independently for the first time.*

A situation like this is very common in rehabilitation practice. The focus is on optimizing the patient's *activities*, i.e., the patient's execution of his or her actions.[1] Key elements here are *learning* by the patient and *teaching* by the professional. Learning is defined as the process by which the underlying abilities to execute actions are acquired, re-acquired, enhanced, or changed consistently, through practice and experience.[2,3] Teaching, in addition, can be defined as the facilitation of this process. However, as many patients in rehabilitation have cognitive impairments, learning often occurs problematic and teaching often requires special effort. Thus, when focusing on activities in rehabilitation, learning and teaching are essential but challenging matters.

This paper first discusses the issue of learning and teaching of activities in rehabilitation, then introduces a new concept to the field of rehabilitation that might be beneficial to both patients and professionals: the concept of learning styles.

## LEARNING AND TEACHING OF ACTIVITIES IN REHABILITATION

*The patient at the top of the stairs has already shown some ability to step downwards during a recent therapy session. The present situation with real stairs is, however, a new experience for both of you. To get the patient to come downstairs independently, what do you know, what do you do, and what do you need?*

These questions can be placed in a broader perspective to assess how rehabilitation professionals deal with learning and teaching of activities. First of all, *what do we know?* Knowledge about learning and teaching of activities has grown in recent decades, with relevant knowledge for rehabilitation being generated especially in the fields of educational psychology and sports psychology.[2,4] Knowledge is, for instance, available on matters as feedback, mental practice, environmental constraints, and goal-directed training.[5,6]

*What do we do?* Applying available knowledge to individual patients in rehabilitation practice appears to be difficult. In the case of our imaginary patient for example, should you choose to facilitate mental practice or environmental constraints? Choosing an appropriate teaching strategy is a rather complex dilemma.[7] Consequently, what is done in rehabilitation practice with respect to learning and teaching occurs implicitly, i.e., by the professional's intuition, rather than explicitly.[8] There are probably as many strategies to get the imaginary patient to come downstairs independently as there are professionals.

*What is needed?* In order to choose and use appropriate teaching strategies in daily clinical practice, rehabilitation professionals may need some tools, one of which might be the concept of learning styles. This concept may make the complex dilemma of 'which strategy to select for which patient' to be more accessible and explicit.

## THE CONCEPT OF LEARNING STYLES

Learning styles are individuals' preferences for the process of learning.[9] These preferences may change slightly from situation to situation, but are generally considered to be stable over time, providing the learner with confidence and routine. Some people, for instance, always translate information to concrete examples while others are always concerned with abstract concepts in order to learn.

The concept of learning styles emerged in the second half of the 20th century. In recent years, interest in this concept has revived for several reasons. First, the concept does not concentrate on weaknesses or limitations, but on strengths and talents. Secondly, it does not merely involve information processing within an individual, but also person-environment interaction. And thirdly, it does not relate to average persons and large populations, but to individuals.

Various instruments have been developed to assess learning styles.[10] One example is Kolb's Learning Style Inventory (LSI). This self-report questionnaire contains dimensions of 'task' (concrete vs abstract) and 'process' (active vs reflective) in order to classify an individual's learning style as one of four combinations: reflector (concrete-reflective), theorist (abstract-reflective), pragmatist (abstract-active), and activist (concrete-active).[11,12] **Table 6.1** describes the characteristics of each of these styles.

In the field of education, instruments such as Kolb's LSI have been used for tailoring teaching strategies to individuals. Central in this is the 'match' of a certain teaching

**Table 6.1** Characteristics of learning styles according to Kolb's Learning Style Inventory

| Learning styles* | Main characteristics | Teaching strategies |
|---|---|---|
| Reflector | 'Concrete-reflective'<br>• Likes to imagine<br>• Views concrete situations from many perspectives<br>• Interested in people and tends to be feeling-oriented | 'Focus on meaning'<br>• Learning by imagination<br>• Reflection on experience<br>• Personal feedback |
| Theorist | 'Abstract-reflective'<br>• Likes to reason<br>• Thinks theories must be logical rather than practical<br>• Is more concerned with concepts than with people | 'Focus on intellect'<br>• Learning by analysis<br>• Observation and writing<br>• Own opinion |
| Pragmatist | 'Abstract-active'<br>• Likes to solve problems<br>• Does best in situations like conventional intelligence tests<br>• Prefers technical problems rather than interpersonal issues | 'Focus on application'<br>• Learning by information<br>• One answer is correct<br>• Teacher-driven |
| Activist | 'Concrete-active'<br>• Likes to do things<br>• Good at adapting to changing circumstances<br>• At ease with people, but sometimes impatient and 'pushy' | 'Focus on experience'<br>• Learning by doing<br>• Real life cases<br>• Skills-driven |

*Nomenclature from Honey and Mumford.[12]

strategy to a certain learning style. By matching teaching strategies to learning styles, selection of teaching strategies can be more appropriate and explicit. Besides, matching can make the process of learning more efficient and the outcomes of the learning process more effective.[13,14]

## USING LEARNING STYLES IN REHABILITATION

*The patient is still at the top of the stairs. Prior to the current therapy session, you have identified your patient's learning style according to Kolb's LSI. Now, one of the following four scenarios seems possible for teaching.*

*Scenario 1: The patient shows a preference for concrete tasks combined with reflective processes, and thus appears to be a 'reflector'. Matched to this learning style, you choose to let your patient imagine the activity in advance and reflect on the actual experience after the activity. A possible instruction could be: 'Can you imagine yourself coming downstairs?'.*

*Scenario 2: The patient shows a preference for abstract tasks combined with reflective processes, and thus appears to be a 'theorist'. Matched to this learning style, you choose to analyze the activity together with your patient and enable the patient to practice mentally. A possible instruction could be: 'How would you come downstairs?'.*

*Scenario 3: The patient shows a preference for abstract tasks combined with active processes, and thus appears to be a 'pragmatist'. Matched to this learning style, you choose to give your patient technical information. A possible instruction could be: 'Coming downstairs, your good leg must do the heavy work'.*

*Scenario 4: The patient shows a preference for concrete tasks combined with active processes, and thus appears to be an 'activist'. Matched to this learning style, you choose to let your patient do the activity with little information in advance and enable the patient to learn from occurring errors. A possible instruction could be: 'Please come downstairs'.*

In fact, using the concept of learning styles like this seems logical but is new in the field of rehabilitation. In view of its potential to match strategies to individuals, it is worth considering its use in rehabilitation practice. The learning style concept can be approached as one important basis for optimizing activities in rehabilitation. An outline of such an approach is shown in **Figure 6.1**. Using learning styles in rehabilitation practice is very likely to make the learning process more efficient, and, ultimately, possibly more effective as well.

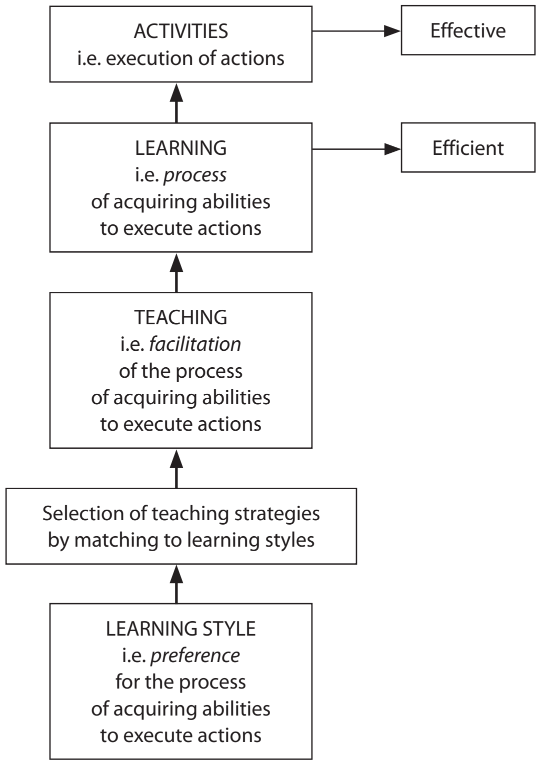


**Figure 6.1** The concept of learning styles as a basis for optimizing patients' activities in rehabilitation

## DISCUSSION

The concept of learning styles is an important example of how rehabilitation professionals can explicitly choose and use appropriate teaching strategies. In addition, it is likely that matching teaching strategies to patients' learning styles makes the process of learning more efficient and the outcomes more effective. Hence, we are convinced that this concept provides opportunities to optimize a patient's activities in rehabilitation.

We would like to note, however, that it is still early for a satisfactory assessment of learning styles in rehabilitation practice. In this paper, Kolb's LSI was used as a first example, and may not be the most useful instrument for patients in rehabilitation. The next challenge, therefore, is to determine the feasibility, reliability, and validity of learning style instruments in various patient populations.

In conclusion, we hope to have shown the importance and usefulness of the concept of learning styles in rehabilitation practice. This introduction should still be followed by further efforts in research, including establishing adequate instruments. But then, how else can we optimize patients' activities if we do not know how they learn?

### Acknowledgements

We would like to thank Eline Lindeman, MD PhD, and Jan Willem Gorter, MD PhD, for supporting and stimulating the topic of this paper. We also would like to thank the Dr. W.M. Phelps Foundation for their financial support.

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7

# Classifying learning styles for motor activities in children and adolescents with cerebral palsy: an explorative study

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## Abstract

The purpose of this study was to explore professionals' perceptions of classifying learning styles for motor activities in children and adolescents with cerebral palsy (CP). The participants were twenty-one pediatric physical therapists (PPTs) and seven physical educators (PEs). Participants took part in written surveys and tried out two established learning style instruments in brief versions. A majority of the PPTs and PEs were positive about classifying learning styles, giving three main reasons: individual approach, professional communication, and treatment awareness. Trying out brief versions of Kolb's Learning Style Inventory and Myers-Briggs Type Indicator in children and adolescents with CP resulted in poor feasibility and inter-rater agreement. Professionals teaching motor activities in children and adolescents with CP perceive classifying learning styles as clinically relevant, but established instruments do not provide a useful basis. It is therefore recommended that a new learning style classification instrument be developed for children and adolescents with CP.


## INTRODUCTION

Optimizing motor activities of daily life has become an important focus of interventions for children with neurodevelopmental disorders. Key elements in this respect are motor learning and teaching.[1-3] Motor learning is a set of processes associated with practice and experience leading to relatively permanent change in capabilities for performance, while teaching is the facilitation of these processes.[4] Knowledge about motor learning and teaching is available in the literature, covering aspects like feedback, mental practice, environmental constraints, and goal-directed training.[5] At a clinical level, however, there is an urgent need to apply this knowledge in interventions, enabling more effective outcomes.[6-9]

To promote the application of knowledge about motor learning and teaching in activity-focused interventions, professionals require some tools. One tool that may promote the application of motor learning and teaching is the concept of learning styles.[10-12] Learning styles describe the preferred way in which an individual approaches a learning situation.[13] Some people, for instance, prefer concrete experiences in a learning situation, while others prefer abstract conceptualizations.

The concept of learning styles offers a theoretical basis for optimizing activities. It allows a teaching strategy to be matched to an individual patient. By matching teaching strategies to patients' learning styles, selection of teaching strategies can be more appropriate and explicit.[11] In addition, studies in the field of education have shown that classifying learning styles and matching teaching strategies to classified learning styles can make the process of learning more efficient and the outcomes of the learning process more effective.[14,15]

Competing perspectives on learning have led to a variety of instruments measuring learning styles. The literature shows that Kolb's Learning Style Inventory (LSI) and

Myers-Briggs Type Indicator (MBTI) are currently two of the most influential learning style instruments.[16] Kolb's LSI describes distinctive classes of styles from an information processing perspective (e.g. 'active style' versus 'reflective style'), while the MBTI describes distinctive classes of styles from a personality perspective (e.g. 'artisan type' versus 'rational type'). Moreover, in relation to their classes of learning styles, both instruments yield practical insights for distinctive teaching strategies (e.g. focus on 'doing' or 'imaging' [Kolb's LSI] and on 'experiencing' or 'reasoning' [MBTI]).[17]

In clinical settings, the relevance of learning styles has been reported for adults with neurological conditions,[18-20] but no reports have been published yet for children and adolescents with neurodevelopmental disorders. For this group, studying learning styles could start off with cerebral palsy (CP), as this neurodevelopmental disorder is relatively common in childhood. CP concerns a permanent motor disorder causing activity limitation, due to nonprogressive disturbances that occurred in the developing fetal or infant brain. The motor disorder is often accompanied by disturbances of sensation, perception, cognition, communication, and behavior.[21] Consequently, it is likely that there are substantial differences in the way children with CP learn motor activities, not only in comparison with typically developing peers but also in comparison with each other. This is challenging for the children and adolescents themselves, for their parents, and for experts like pediatric physical therapists (PPTs) and physical educators (PEs) as well. It therefore seems advantageous to classify learning styles of children and adolescents with CP, allowing relevant teaching strategies to be matched to their learning styles.

For PPTs and PEs, a brief classification system of learning styles for motor activities could be helpful in treating and educating children with CP. They could use it in intradisciplinary or interdisciplinary practice. However, it is unknown to what extent PPTs and PEs regard it as relevant to classify learning styles for motor activities in children and adolescents with CP. Nor is it known to what extent descriptions from established learning style instruments – like Kolb's LSI and the MBTI – could provide a useful basis for a classification system for children and adolescents with CP. A first step in studying learning styles in children and adolescents with CP is exploring the clinical relevance for PPTs and PEs. A second step concerns a further exploration regarding the basis for a brief classification system.

The research questions for this study were:

1. What are pediatric physical therapists' and physical educators' general perceptions of classifying learning styles of children and adolescents with CP?
2. Can descriptions taken from two established instruments – Kolb's LSI and the MBTI – provide a useful basis for a brief classification system of learning styles for children and adolescents with CP?

# METHODS

## Design

This study had a mixed-methods design. More specifically, it concerned a multistrand mixed model research.[22] For the primary research question ('the general perceptions of classifying learning styles'), qualitative aspects dominated. For the secondary research question ('the usefulness of established instruments'), inter-rater agreement and feasibility were analyzed, and therefore quantitative aspects dominated. Approval for the study was obtained from the local ethics committees of three institutions involved (see Acknowledgements).

## Participants

Between October 2008 and February 2009, a sample consisting of all the PPTs and PEs from three schools for special education in the Netherlands was invited to participate. Based on their formal education and their professional experience, these PPTs and PEs were considered clinical experts on the field of motor learning in children. To be included, the clinical experts had to be treating or educating children with CP aged 5 to 17 years at level I, II, or III on the Gross Motor Function Classification System (GMFCS) i.e. children who are capable of walking with or without assistive devices.[23]

## Procedure and outcome measures

Prior to data collection, one-hour introductory meetings were organized to familiarize the clinical experts with the concept of learning styles and with two classification systems. The meetings were led by one investigator (DWS). At the end of these meetings, the clinical experts individually decided whether to actually participate in data collection.

Data collection started by conducting individual written surveys, including the following questions: 'What is your general perception of classifying learning styles of children with CP (positive, doubtful, or negative)?' and 'Why are you positive, doubtful, or negative about classifying learning styles of children with CP?' These surveys were conducted among the clinical experts until no new information – i.e. data saturation[24] – was obtained.

All clinical experts were then requested to classify the learning styles of three children with CP from their case load, using Kolb's LSI and the MBTI, and keeping a therapeutic or educational situation in mind. Both Kolb's LSI[25] and the MBTI[26] are originally self-report questionnaires, with 12 and 93 items respectively, and with adequate levels of reliability for adults without disabilities. Since only brief proxy versions would be easy to use for PPTs and PEs working in a clinical setting with children and adolescents with CP, we only provided the clinical experts with the key descriptions from Kolb's LSI and the MBTI (see **Appendices 7.1** and **7.2**).

Using the key descriptions from Kolb's LSI and the MBTI as two brief classification systems, one PPT ('Expert A') and one PE or a second PPT familiar with the child ('Expert B') independently classified the same child. Thus, each child was assessed by a pair of independent classifiers, producing data for inter-rater agreement.

To examine feasibility, all clinical experts were asked the question: 'Did you generally find it easy or difficult to administer the classification system?' This question was answered by means of a 10-cm Visual Analogue Scale (VAS) with 'difficult' at one end and 'easy' at the other. On the same form, the clinical experts were also asked to report in their own words their experiences in administrating the two brief classification systems.

After one month, one-hour meetings were organized in which one of the investigators (DWS) gave feedback about the first results and the clinical experts about their experiences. This final meeting was used to draw up recommendations for classifying learning styles in the future.

## Data analysis

The clinical experts' perceptions were explored by first calculating the frequencies of positive, doubtful, or negative perceptions. Next, the reasons behind these perceptions were analyzed qualitatively by means of coding. In this coding, three investigators (DWS, OV, and AK) independently clustered the data, reached consensus about the main clusters, and together provided each cluster with a brief descriptive label.

The agreement on both brief classification systems among pairs of independent classifiers was examined by analyzing frequencies in cross-tabulations ('Experts A' vs 'Experts B'), after which the proportion of agreement and Cohen's Kappa were calculated, both with 95% confidence intervals (CI). To examine the feasibility of the two brief classification systems, the VAS answers were transformed to scores ranging from 0 (most difficult) to 10 (most easy), and mean scores were calculated.

The reported experiences with administrating the brief classification systems, as well as the recommendations, were described qualitatively by means of coding, again performed by three investigators (DWS, OV, and AK). All quantitative analyses were performed with SPSS version 16.0 (SPSS Inc, Chicago, IL, USA).

## RESULTS

Thirty-one clinical experts met the inclusion criteria and took part in the introductory meetings. After the introductory meetings, three PEs doubted the relevance for their practice and dropped out. As a result, 28 clinical experts participated in data collection. See **Table 7.1** for their characteristics. The surveys on perceptions involved 14 clinical experts. With this contribution data saturation was reached regarding experts' perceptions. The classification of children's learning styles and the response to feasibility questions involved all 28 clinical experts. All classified three children, resulting in 168 classifications: 84 'LSI classifications' and 84 'MBTI classifications'. Since we had formed pairs of independent classifiers for each child, the 84 classifications related to a total of 42 children. As data for four children were incomplete, the agreement analyses were performed using data of 38 children (mean age 10y 7mo, SD 3y 6mo; 21 boys, 17 girls; 12 GMFCS level I, 9 level II, and 17 level III). See **Figure 7.1** for the flow of data through our study.

### Perceptions of classifying learning styles

Ten clinical experts (seven PPTs and three PEs) were generally positive about classifying learning styles, while two expressed doubts (both PPTs), and two were negative (one PPT and one PE). Three main reasons for being positive about classifying learning styles were identified: individual approach towards a child; communication with professionals and parents; and therapists' own awareness of treatments. The following reasons for being doubtful or negative were identified: uncertainty about feasibility; other factors are also important; and no added value for practice. **Table 7.2** lists these reasons with a selection of quotes from the clinical experts.

**Table 7.1** Characteristics of participating clinical experts

| | PPTs (*n* = 21) | PEs (*n* = 7) | Total (*n* = 28) |
|---|---|---|---|
| Gender, *n* (%) | | | |
| Male | 6 (29) | 0 (0) | 6 (21) |
| Female | 15 (71) | 7 (100) | 22 (79) |
| Age in years | | | |
| Mean (SD) | 35 (9) | 37 (7) | 35 (9) |
| Experience as PPT / PE in years | | | |
| Mean (SD) | 9 (9) | 8 (3) | 9 (7) |

PPTs, pediatric physical therapists; PEs, physical educators; *n*, number of clinical experts; SD, standard deviation.

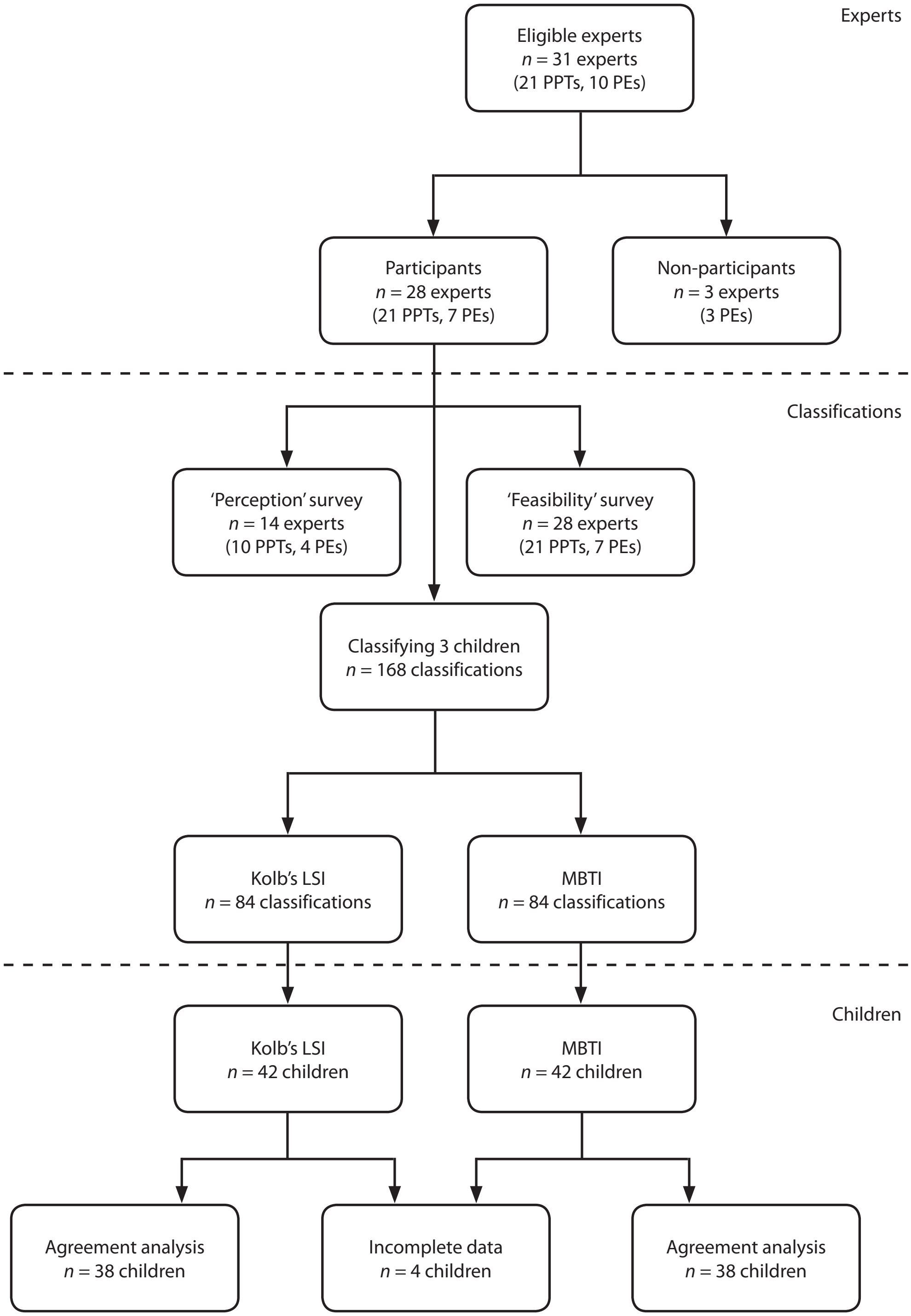


**Figure 7.1** Flow of data through the study.

**Table 7.2** Clinical experts' reasons for being positive, doubtful, or negative about classifying learning styles

| Perception | Reason | Illustrative quote |
|---|---|---|
| Positive | 'Individual approach' | *'It's a good idea to study the way a child learns, so you can tailor your therapy to this when you want to teach them something, to find out the best approach.'* |
| | | *'We can imagine that this could help us use an individual approach. Since our teaching must always be tailored to the diversity among our pupils, this could improve the quality of our teaching.'* |
| | 'Awareness' | *'This could allow you to make a more conscious choice of methods, or to take certain key aspects into consideration. I think we're already doing that, but at a subconscious level.'* |
| | | *'If I identify the child I'm treating as a thinker, I will now design a treatment plan together with the child, and write it down. This helps me become conscious of the differences between children.'* |
| | 'Communication' | *'If you have identified a particular learning style, you could use it in communication with colleagues or parents.'* |
| | | *'If all of my colleagues recognize the various learning styles, this could make communication more efficient.'* |
| Doubt | 'Feasibility' and 'more factors important' | *'I'm not so sure whether this is feasible, and what added value it would provide.' … 'I think I look at a lot of other aspects besides learning style. And I also think that as a physical therapist, you have more than one way to teach a particular motor skill. Depending on your own learning style, you may try out a particular approach, and if that doesn't work, you try something else.'* |
| Negative | 'No added value' | *'I don't think it adds anything to the quality of my teaching. I think I'm professional enough to tailor my teaching to the children's specific needs.'* |

## Agreement and feasibility of the classification systems

Results of the administration of the brief classification systems are presented in **Table 7.3** (classification system based on Kolb's LSI) and **Table 7.4** (classification system based on the MBTI). The majority of the children were classified as either 'activist' (LSI) or 'artisan' (MBTI), while only few children were classified as 'pragmatist' (LSI) or 'rational' (MBTI). The proportions of agreement were 0.53 (95% CI 0.36 to 0.69) and 0.29 (95% CI 0.16 to 0.46) for LSI and MBTI, respectively. Cohen's Kappas were 0.28 (95% CI 0.04 to 0.52) and -0.05 (95% CI -0.26 to 0.16) for LSI and MBTI, respectively.

The initial feasibility question asked the respondents to estimate the general difficulty of administration. On the VAS scale, the brief classification system based on Kolb's

**Table 7.3** Cross-tabulation by pairs of clinical experts ('Experts A' vs 'Experts B') using a classification system based on Kolb's LSI

| | | Experts A | | | | |
|---|---|---|---|---|---|---|
| | | Reflector | Theorist | Pragmatist | Activist | Total (%) |
| Experts B | Reflector | 4 | 1 | 0 | 3 | 8 (21) |
| | Theorist | 2 | 4 | 1 | 1 | 8 (21) |
| | Pragmatist | 1 | 0 | 0 | 0 | 1 (3) |
| | Activist | 7 | 0 | 2 | 12 | 21 (55) |
| Total (%) | | 14 (37) | 5 (13) | 3 (8) | 16 (42) | 38 (100) |

Proportion of agreement is 0.53 (95% CI 0.36 to 0.69) and Cohen's Kappa is 0.28 (95% CI 0.04 to 0.52).

**Table 7.4** Cross-tabulation by pairs of clinical experts ('Experts A' vs 'Experts B') using a classification system based on the MBTI

| | | Experts A | | | | |
|---|---|---|---|---|---|---|
| | | Artisan | Guardian | Rational | Idealist | Total (%) |
| Experts B | Artisan | 7 | 6 | 0 | 4 | 17 (45) |
| | Guardian | 6 | 3 | 1 | 2 | 12 (32) |
| | Rational | 1 | 2 | 1 | 0 | 4 (10) |
| | Idealist | 1 | 3 | 1 | 0 | 5 (13) |
| Total (%) | | 15 (39) | 14 (37) | 3 (8) | 6 (16) | 38 (100) |

Proportion of agreement is 0.29 (95% CI 0.16 to 0.46) and Cohen's Kappa is -.05 (95% CI -0.26 to 0.16).

LSI and the one based on the MBTI were given mean scores of 4.3 (SD = 2.1 and 2.5, respectively; range = 0.1–9.2 and 0.3–9.1, respectively; scores lower than 6 = 73% and 81%, respectively), indicating that both were rather difficult to administer. The clinical experts' qualitative reports confirmed the estimated difficulty of administration. Overall, four themes were identified: the brief classification systems were not suitable for young children; the systems were not suitable for children with low levels of cognition; the systems needed clearer descriptions about the 'test' situation; and the systems needed more distinctive descriptions for each style.

## Clinical experts' recommendations

Recommendations for future administration were identified for three themes: specification of the target group (illustrative quote: *'I definitely see the advantages, but I think it should be limited to children with normal cognitive abilities.'*); adjustment of the classification system (quote: '*The methods we have tried so far are not very useful to me. I think there should be an adjusted version or a completely new classification, which therapists could apply correctly, and which would be easy to use.*'); and an alternative method of data collection (quote: *'I think the classifications are not clear enough. I do think the system might be useful, but I do think one should use self-reports to classify the children, rather than "estimating the child's learning style", as we found this to be highly subjective.*').

## DISCUSSION

In this study, a majority of the participating PPTs and PEs were generally positive about classifying learning styles of children and adolescents with CP. The descriptions from Kolb's LSI and the MBTI, however, provided no useful basis for a brief classification system of learning styles for these children and adolescents.

Our study explored the topic of learning styles with the help of clinical experts, using a mixed-methods design in which qualitative data provided valuable insights that were complementary to quantitative data. Some methodological issues should be considered when interpreting the results. First, our findings about perceptions were only based on a sample size of 14. Still, we considered this size to be sufficient, as data saturation was reached in the qualitative analyses; after ten experts (eight PPTs and two PEs) no new information was obtained. Second, we included both PPTs and PEs as experts on teaching motor activities to children, representing different professions with different backgrounds and work situations. This variety was mostly enriching for perceptions, but may have been confounding in relation to the inter-rater agreement. Third, our choice of Kolb's LSI and the MBTI is debatable, since these instruments were originally developed for older students and adults. Versions for children would have been preferred. Although a few of such versions exist – e.g. the Student Styles Questionnaire[27] and the Murphy-Meisgeier Type Indicator for Children[28] – these were not available in brief proxy formats and were therefore not suitable for the clinical setting on which our study focused.

In our study, the PPTs were generally positive about classifying learning styles, perceiving benefits in terms of individual approach, professional communication, and treatment awareness. PEs were generally less positive (there was one negative report in the survey but also three PEs who declined to participate), perceiving disadvantages in terms of lack of added value for their practice and – as was found in a personal communication with the non-participants – too much unnecessary work and undesirable labeling. It appears that PPTs and PEs have different perceptions of classifying learning styles – presumably caused by the different natures of the professions (e.g. teaching in one on one settings versus group settings) – and that classifying learning styles suits PPTs better than PEs.

The inter-rater agreement was reported to be low for both brief classification systems. Post-hoc analyses controlling for the effect of profession (i.e. PPT versus PE) did not explain this poor agreement. However, post-hoc analyses specifying for one-dimensional contrasts did show some extra insights in the agreement results. For Kolb's LSI, the dimension of 'abstract versus concrete' revealed more agreement (Cohen's Kappa 0.43) than the dimension of 'active versus reflective' (Cohen's Kappa 0.31). For the MBTI, differences were even more remarkable: the additional dimension of 'extravert versus introvert' revealed far more agreement (Cohen's Kappa 0.55) than those of 'thinking versus feeling' (Cohen's Kappa 0.27), 'judging versus perceiving' (Cohen's Kappa 0.07), and 'sensing versus intuition' (Cohen's Kappa -0.06). Although it might seem that some dimensions are more useful than others, the relevance of a one-dimensional approach is questionable in regard of teaching strategies.

The feasibility was reported to be poor not only due to children's age and level of cognition, but also due to the lack of clarity about the 'test' situation and about the distinction between styles. Given the fact that our brief classifications were based on styles for mainly cognitive learning in adults, they do not really lend themselves to capture learning styles for motor activities in children with CP.

The reported recommendations – specifying the target group, adjusting the classification system, and trying other measurement methods – should therefore be adopted. We support the need to develop a new learning style classification system for children and adolescents with CP that meets the requirements of feasibility and agreement. Research to develop such a new instrument should also involve parents, as they are experts on their child's learning in daily-life situations.

Provided there is an adequate instrument, classification of learning styles should be viewed as one important tool for choosing applicable teaching strategies for children and adolescents with CP – and other patient populations – in activity-focused interventions. Central to this is the 'match' between a particular teaching strategy and a particular learning style.[11] Through matching of teaching strategies to learning styles, it might become easier in the future to apply knowledge about motor learning and teaching in interventions.

This study demonstrated that classifying learning styles is considered to be relevant, particularly by PPTs and to a lesser extent by PEs, for teaching motor activities to children and adolescents with CP. These experts did, however, call for classification instruments that are suitable for clinical practice. As a first study to explore classification of learning styles in children and adolescents with neurodevelopmental disorders, the findings represent a starting point for future research in investigating the teaching of motor activities in daily life.

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This study was approved by the local ethics committees of the schools for special education 'Ariane de Ranitz' in Utrecht, 'De Schalm' in Breda, and 'Mytylschool Tilburg' in Tilburg.


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**Appendix 7.1** Key descriptions and main characteristics of learning styles according to Kolb's LSI

| Classification* | Key descriptions | Main characteristics |
|---|---|---|
| Reflector (concrete-reflective) | Learns from concrete experiences and reflective observations | • Likes to imagine<br>• Views concrete situations from many perspectives<br>• Is interested in people and tends to be feeling-oriented |
| Theorist (abstract-reflective) | Learns from abstract conceptualisation and reflective observation | • Likes to reason<br>• Thinks theories must be logical rather than practical<br>• Is more concerned with concepts than with people |
| Pragmatist (abstract-active) | Learns from abstract conceptualisation and active experimentation | • Likes to solve problems<br>• Does best in situations like conventional intelligence tests<br>• Prefers technical problems, rather than interpersonal issues |
| Activist (concrete-active) | Learns from concrete experience and active experimentation | • Likes to do things<br>• Good at adapting to changing circumstances<br>• Is at ease with people, but sometimes impatient |

* Nomenclature from Honey and Mumford (2000).

**Appendix 7.2** Key descriptions and main characteristics of learning styles according to the MBTI

| Classification* | Key descriptions | Main characteristics |
|---|---|---|
| Artisan (sensing-perceiving) | Prefers to acquire applicable information by the five senses, and prefers to perceive the environment | • Is action seeking, practical, and flexible<br>• Lives in the moment and assesses situations quickly |
| Guardian (sensing-judging) | Prefers to acquire applicable information by the five senses, and prefers to judge the environment | • Is duty seeking, responsible, and precise<br>• Prepares according approved methods |
| Rational (intuition-thinking) | Prefers to acquire meaningful information by intuition, and prefers to make decisions on logic analysis | • Is knowledge seeking, systematic, and perfectionistic<br>• Searches for ever increasing insights |
| Idealist (intuition-feeling) | Prefers to acquire meaningful information by intuition, and prefers to make decisions on social appreciation | • Is ideal seeking, creative, and imaginitive<br>• Focuses on personal growth and development |

* Nomenclature from Keirsey (1998).

# 8

## General discussion

The aim of this thesis was to gain knowledge about daily activities of children with cerebral palsy (CP). Although there is increasing knowledge about the impact of CP on children's daily activities, little information exists about the development of daily activities in this group of children. Furthermore, little is known about the way children with CP learn daily activities. Therefore, these two topics – development and learning – were the key elements of this thesis. The topic of development was investigated in the PERRIN CP 5-9 study, a longitudinal study in school-age children (aged 5-9 years) with CP, whereas the topic of learning was investigated in the PROMOVE-CP study, an action research with professionals teaching activities to children with CP. The present chapter starts with recapitulating the main findings. Subsequently, the clinical implications, unanswered questions, and methodological considerations are discussed. In addition, a conceptual model is outlined for optimizing daily activities of children with CP. Finally, directions for future research are presented.

## Main findings

In **chapter 2**, we examined the inter-rater reliability of two available tests measuring selective motor control (SMC) of the lower extremities in children with CP. SMC is the ability to move an individual joint voluntarily without moving other joints. Data for this study were gathered as part of the baseline assessment (T0) of PERRIN CP 5-9. It was shown that SMC can be measured with moderate to good inter-rater reliability, both using the Boyd and Graham SMC test with an existing protocol, and using the modified Trost SMC test, with a newly developed protocol. This finding was in line with simultaneous studies by Löwing et al.[1] applying the Boyd and Graham SMC test and by Fowler et al.[2] applying a test that largely corresponded with the modified Trost SMC test. Based on our work, we recommend the modified Trost SMC test since it has the highest inter-rater reliability values in our study population. In **chapter 3**, we examined the relationship between gross motor capacity and daily-life mobility in children with CP and we explored the moderation of this relationship by severity of CP. Daily-life mobility was studied both as capability (i.e., can do in a daily environment) and as performance (i.e., does do in a daily environment). Data for this study were also gathered as part of the baseline assessment (T0) of PERRIN CP 5-9. A strong relationship was found between gross motor capacity and daily-life mobility, but this relationship appeared to be moderated by severity of CP in terms of limb distribution. The relationship between gross motor capacity and daily-life mobility was weaker in children with unilateral spastic CP than in those with bilateral spastic CP. Compared to previous studies focusing on the relationship between gross motor capacity and daily life mobility in children with CP,[3-5] the major contribution of our study was not only that we specified for severity of CP in terms of limb distribution, but also that we used two separate constructs – capability and performance – for daily-life mobility. In **chapter 4**, we described the development of non-verbal intellectual capacity (as measured by Raven's Progressive Coloured Matrices [RCPM]) and we examined the association between the development of non-verbal intellectual capacity and severity of CP. Data for this study were gathered during the baseline assessment (T0) and two follow-up assessments (T1 and T2) of PERRIN CP 5-9. The results showed an increase over time in non-verbal intellectual capacity for the total group, and at the same time a diversity in developmental trajectories associated with severity of CP in terms of gross motor function (i.e., level of the Gross Motor Function Classification System [GMFCS]). Children with higher levels of gross motor function (GMFCS level I and II) showed a greater increase in non-verbal intellectual capacity than children with lower levels of gross motor function (GMFCS level III, IV, and V). These findings differed from previous longitudinal findings on non-verbal intellectual capacity in children with CP,[6-9] which generally showed a decline. In contrast to these studies, our study covered the whole severity spectrum of CP and focused not only on normative RCPM scores but also on raw RCPM scores. In **chapter 5**, we described the course of children's capabilities in the domains of self-care, mobility, and social function over a two year period, between the age of 5 to 9 years, and we investigated associations between this course and various CP-, child-, and family-characteristics. As in chapter 4, data for this study were gathered during the baseline assessment (T0) and two follow-up assessments (T1 and T2) of PERRIN CP 5-9. Firstly, averaged for the total group, an increase over time was shown in all three capability domains. Most increase was revealed in the domain of self-care between the age of 5 and 7 years. Secondly, different sets of determinants were revealed for the course of different capability domains. For self-care, the course was best predicted by a model including level of severity in terms of gross motor function (i.e., GMFCS level) and intellectual capacity (i.e., RCPM IQ). For mobility, the course was best predicted by a model containing only GMFCS level. For social function, the course was best predicted by a model comprising level of severity in terms of bimanual function (i.e., level of the Manual Ability Classification System [MACS]) and paternal educational level. With these findings, a first longitudinal and multivariate description is now available for daily activities of school-age children with CP.

**To summarize, what were the main findings of the PERRIN CP 5-9 study?**

- We found reliable tools for assessing selective motor control
- There is a moderate relationship between gross motor capacity and mobility in daily life
- Developmental trajectories for non-verbal intellectual capacity differ
- There are increases in three domains of daily activities between the age of 5 and 9 years
- Determinants were found for the course of daily activities, including level of gross motor function, level of bimanual function, and level non-verbal intellectual capacity

In **chapter 6**, we introduced the concept of learning styles. This conceptualization was developed as part of PROMOVE-CP and provided an outline for studying learning styles in pediatric rehabilitation. Based on literature and our clinical insights, we advocate that the use of learning styles will benefit both patients and professionals, as it allows teaching strategies to be matched to individual patients. In **chapter 7**, we explored pediatric physical therapists' and physical educators' perceptions of classifying learning styles for motor activities in children and adolescents with CP. This part of PROMOVE-CP revealed that pediatric physical therapists and, to a lesser extent, physical educators were positive about classifying learning styles of children with CP, giving three main reasons: individual approach, professional communication, and treatment awareness. Also in chapter 7, the feasibility and inter-rater reliability were explored regarding brief versions of Kolb's Learning Style Inventory and Myers-Briggs Type Indicator for use in children and adolescents with CP. The feasibility and inter-rater reliability were shown to be poor, which indicated the need to develop a more suitable instrument for children and adolescents with CP.

**To summarize, what were the main findings of the PROMOVE-CP study?**

- We developed a conceptual basis for learning and teaching of daily activities in rehabilitation
- We found clinical relevance for the use of learning styles in pediatric physical therapy
- We gained first insights in developing a learning style classification for children with CP

## Clinical implications

One of the major topics in this thesis concerned the *development of daily activities* in children with CP. The findings from PERRIN CP 5-9 suggest that many children with CP make satisfactory progress in daily activities between the age of 5 and 9 years. Apparently, the age period between 5 and 9 years is an age period involving expansion of the world for a large group of children with CP, which is comparable to most non-disabled peers.[10] However, this expansion has not been demonstrated in all children with CP and, besides, it has not been demonstrated to the same extent in all domains of daily activities. So, what are the patterns of development for daily activities in the heterogeneous group of children with CP and what are the implications for the children themselves, their parents, and professionals?

A first pattern is that the less severe the CP is, the more beneficial the course of daily activities. In this, the level of severity relates to the level of gross motor function (as expressed by the GMFCS), to the level of bimanual function (as expressed by the MACS), and also to the level of intellectual function (as expressed by the RCPM). Second, based on the severity levels, differences in the course of daily activities are most prominent in the domain of self-care and less prominent in the domains of social function and mobility. Here, it is important to note that children with the most severe CP (i.e., GMFCS level V, MACS level V, and RCPM IQ < 55) show the least beneficial courses in all three domains. Third, severity of CP is an important determinant for the course of daily activities, but not the only one. Indeed, in the domains of self-care and mobility, severity shows most explanation (ca. 70 and 90%, respectively) in relation to the course. However, in the domain of social function, severity shows much less explanation (ca. 50%) in relation to the course. This indicates that, for instance, personal and environmental factors can be of much more importance here. Fourth, considering different domains of daily activities, the set of determinants is likely to differ among subgroups of severity of CP. At least in the domain of mobility, gross motor capacity seems to be less important in children with less severe CP (GMFCS I and II) than in those with more severe CP (GMFCS III-V). These patterns – regarding the course, the domains, and the determinants – can be added to existing insights in daily activities of children with CP aged between 5 and 9 years, which, thus far, only concerned the 'status at a certain moment' and not the 'development over time'.[11-13]

Based on the developmental patterns, *children* with CP, their *parents*, and other *family members* (including siblings and grandparents) can be given more detailed information about activities in a child's daily life, now and in the near future, at home and possibly at school. Thus, families can be helped in communicating and sharing expectations. For instance, it is expected that a boy with CP, aged 5 years classified at GMFCS level I, is capable of dressing himself to a large extent and will refine this capability in the near future, while a child classified at GMFCS level IV or V cannot be expected to be largely capable in this activity and can at best be expected to have only little refinement over time. At the same time however, a child classified at GMFCS level IV has a good chance for a similar beneficial development ('rate' and 'level') in social function as a child classified at GMFCS level I. For professionals such as *physical therapists* and *teachers*, the developmental patterns can help in adjusting treatment and teaching plans. Regarding daily activities as outcome, one important consideration is when to focus on a child's capacities (i.e., what a child can do in a standardized environment) – e.g., gross motor capacity and intellectual capacity – and when to focus on environmental and personal factors. It seems that, in particular children with more severe CP, for instance classified at GMFCS level III, can have great benefits by focusing firstly on enhancement of their capacities, while children with less severe CP, for instance classified at GMFCS level I, can have their greatest benefits by focusing on environmental and personal factors. Furthermore, the developmental patterns can be used by professionals to monitor and evaluate children's daily activities over time. Checking whether children develop as expected, above expected level or below expected level can contribute to timely offering support.

The second major topic in this thesis concerned *learning and teaching of daily activities* in children with CP. From PROMOVE-CP, we can presently infer that classifying learning styles of children with CP is considered promising with respect to optimizing children's daily activities. Both researchers and clinicians in pediatric rehabilitation (including pediatric physical therapists) and special education (including physical educators) have become enthusiastic by this action research. I believe that the future can bring more concrete clinical implications for professionals regarding the practical use of learning styles in children with CP, but also for the children themselves, their parents, and their families. For that to happen, it is now necessary to carry forward this research along new avenues.

## Unanswered questions

Although studying patterns of development of daily activities in children with CP has answered some important questions, several questions remained unanswered and new questions arose. One of the questions that has not been answered is whether school-age children with CP develop along similar lines in their daily activities as their non-disabled peers do. It seems that children with CP with the best functional abilities show developmental courses that resemble those of non-disabled peers. However, since we did not study the course of development of non-disabled, age- and gender-matched peers simultaneously to those of the children with CP, we are unable to make such a claim with absolute certainty. A second major issue that remained unanswered is the development of daily activities in terms of performance (i.e., does do in a daily environment). Although performance of daily life activities can be considered the ultimate outcome in practice, we discovered in one of the cross-sectional studies of PERRIN CP 5-9 (see chapter 3) that this construct is more difficult to capture in research than capability (i.e., can do in a daily environment). Therefore, regarding the development of daily activities, we chose to pursue our research efforts on the construct of capabilities. Possibly, when more insights about capturing performance will be gained in the future, we can shift our concentration to development in terms of performance. A third major issue that is still unanswered relates to the search for treatable and modifiable aspects in order to optimize daily activities. Selective motor control might be a treatable body function, but we don't know whether and how it can be influenced and, moreover, whether better selective motor control will lead to improvements in daily activities. With gross motor capacity we seem to have a treatable aspect, but for many ambulatory children with CP classified at GMFCS level I or II it is questionable to what extent a change in gross motor capacity will help them in optimizing their daily activities. Non-verbal intellectual capacity is an important cognitive function, especially when it comes to self-care activities, but little information is yet available to what extent non-verbal intellectual capacity is modifiable in school-age children with CP. In this respect, our study gave rise to questions about other cognitive functions – such as working-memory and attention – that have suggested to be influential in adjacent populations.[14-16] In addition, environmental characteristics might be modifiable and relevant in relation to daily activities. We chose to include several family aspects, but instruments with a much broader scope on environmental characteristics (e.g., the Craig Hospital Inventory of Environmental Factors[17]) are currently being developed and interesting to consider when measuring determinants for daily activities.

Studying individual learning of daily activities in children with CP and best-practice teaching strategies of professionals involved in the care for children with CP has only just begun. Here, the ultimate goal would be to match teaching strategies with children's learning styles.[18,19] Presently, it is still unknown to what extent this could affect the capability and performance of daily activities in children with CP. Furthermore, many basic questions remained unsolved, for example about the best way to classify learning styles, about the diversity in distinctive learning styles, and about the contents of distinctive learning styles in children with CP. For answering these questions, we might use recent insights in the distinction between declarative and procedural learning in children with CP.[15]

## Methodological considerations

Both the PERRIN CP 5-9 study and the PROMOVE-CP study generated knowledge with the rationale to ultimately optimize daily activities of children with CP. The first had a developmental perspective, the latter a learning perspective. As such, I consider the two studies as complementary. Due to their different perspectives, the studies differed in their methodological characteristics and exhibited their own strengths and weaknesses.

### *Study population*

The children studied in PERRIN CP 5-9 were recruited from the caseload in rehabilitation centers and in the rehabilitation departments of university hospitals in the Netherlands. The study population was, therefore, not representative for the total CP population but rather for the Dutch CP population depending on secondary and tertiary health care. Besides, it is worth mentioning that of the 199 parents we contacted, 116 agreed to participate. Reasons for non-participation varied (e.g., overburdened by therapy, participation in other research, lack of time by parents). It is not unthinkable that the study population comprised a selective group, for instance regarding parents' and children's coping. Nonetheless, the study population covered the whole severity spectrum of CP (in terms of GMFCS level) in proportion to the CP population as known from previous descriptive studies.[20,21] As a consequence, however, the sample sizes for some subgroups of severity were small, limiting the statistical power in several analyses. It should further be noted that, during our follow-up assessments many children participated in regular therapies (such as botulinum toxin therapy, physical therapy, occupational therapy, and speech therapy). Although these therapies might have influenced the natural course concerning daily activities, this must presently be considered the most realistic situation in which to describe the development of daily activities.[22] In addition, after the baseline assessment there was a 'drop-out' of nine children for various reasons (e.g., overburdened and moved away). These children were, however, equally divided over severity levels (in terms of GMFCS levels). Overall, I think that our results concerning developmental patterns can be generalized to the clinically-based Dutch CP population.

The professionals participating in the PROMOVE-CP study were recruited from three schools for special education in the Netherlands. The study population was not representative for all professionals working with children with CP but rather for pediatric physical therapists (PPTs) and physical educators (PEs) working in a special education setting. The sample size ($n = 28$ in quantitative analysis; $n = 14$ in qualitative analysis) was considered to be sufficient with regard to the purpose of our study, in which statistical power was of less importance than active participation and exchange of information. I think that the findings concerning PPTs' and PEs' perceptions are a valid impression of how a considerable part of professionals involved in teaching motor activities to children with CP encounter the topic of learning and teaching in children with CP.

### *Design and analyses*

PERRIN CP 5-9 used a longitudinal design with three yearly measurements. Through repeated observations in relation to individual subjects, it was possible to provide large amounts of reliable quantitative data. Moreover, in respect of the embedding of PERRIN CP 5-9 in the larger PERRIN program, the results found consolidation by cohort studies looking at younger (PERRIN CP 0-5) and older children with CP (PERRIN CP 9-16), in particular regarding the construct validity and the prognostic value of the GMFCS.[23-25] PROMOVE-CP used a mixed-methods design in which qualitative aspects dominated. Through in-depth exploration, it was possible to stimulate professionals' thinking (and likely their acting as well). As such, the analyses concerned singular expert opinions with little a priori knowledge, mainly setting a starting point for further research.

### *Implementation*

Clinical implementation of knowledge played an important role in both studies. In PERRIN CP 5-9, this was already recognizable at the start of the study when many of the measurement tools were chosen in relation to their expected clinical usefulness (e.g., GMFCS and PEDI). Furthermore, considering the length and the broad scope of the study, we undertook additional efforts in reporting results timely to a diverse public. Examples in this respect are the distribution of newsletters to both parents and professionals, the organization of national symposia together with the other PERRIN studies, and the PERRIN knowledge brokers project.[26] In PROMOVE-CP, the exchange of information between researchers and clinicians was an integral part of the study. Through such exchange, an important foundation has been created for implementation of future results.

### *A comprehensive perspective*

The two studies not only concerned different types of research but were also in different stages within the research process. Whereas the PERRIN CP 5-9 study was largely built on existing knowledge (e.g., about concepts, instruments, and associations), the PROMOVE-CP study comprised a nearly new exploration (e.g., about concepts and instruments). For PROMOVE-CP, I think that modesty is appropriate; empirical data have not been collected yet with respect to learning and teaching in children with CP. For PERRIN CP 5-9, some important building blocks have been established regarding development of daily activities in children with CP. Still, modesty is also appropriate for PERRIN CP 5-9, but then in the light of clinical implications and interventions. Together, the two studies can be understood as a brief example of 'comprehensive rehabilitation outcomes research'.[27,28] In this perspective on research, a complex phenomenon in rehabilitation practice (here: optimizing daily activities in children with CP) is studied in a holistic way by making use of multiple sources of variation (here: aspects of development and aspects of learning).

On reflection, what should have been done differently? Firstly, I discovered that it would have been an added value if we had standardized instruments to measure various environmental and personal factors in PERRIN CP 5-9. Currently, these components of the ICF framework are still under-exposed. Secondly, I realized that we missed a chance in further exploration of professionals' reasoning and arguments during classifying learning styles. This could have provided more information in addition to their perceptions, and, moreover, could have given more specific directions for future instrument development. Finally, I regret that we did not find a linkage in data sets between the two studies. For PERRIN CP 5-9, it would have been interesting having an extra personal factor (children's learning styles). For PROMOVE-CP, it would have been valuable to look at learning styles over time, for instance, to study the test-retest reliability of classification instruments.

## Optimizing daily activities: *a conceptual model*

In my opinion, it is important to create a conceptual model that guides us in optimizing daily activities of children with CP. For this end, input is needed from different types of research methods (quantitative and qualitative) and from different parties involved in practice (e.g., children, parents, and professionals). Pioneering efforts have already been taken to create such conceptual models. I believe that some of the work in this thesis can be connected to previous models.

Previous models guiding optimization of daily activities in children with CP have been outlined by Bartlett & Palisano,[29,30] Ketelaar et al.,[31] and Valvano.[32] Key elements in these models are child-characteristics (e.g., primary and secondary impairments, motor capacity, and personality), environmental characteristics (e.g., family expectations and support to families), task-characteristics (e.g., self-care activities and peer-interaction activities), goal setting-characteristics (e.g., meaningful short-term and long-term goals), and learning-characteristics (e.g., active problem solving, procedural and declarative learning). Some of the elements are not modifiable; they can, for instance, be used for realistic goal setting. Other elements are modifiable and are considered targets for interventions.[27] In this line, so-called 'activity-focused interventions' have recently been designed and studied.[33-35]

Based on the work presented in this thesis, I think that current models for optimizing daily activities in children with CP could be extended in several ways. First of all, the central outcome – daily activities – needs differentiation by the constructs of capability and performance. Secondly, severity of CP in terms of gross motor function (as measured by the GMFCS) is one of the most important determinants for realistic goal setting in daily activities of children with CP and must therefore be given a prominent position. Thirdly, children's intellectual capacity is, in addition to severity of CP in terms of gross motor function, an important determinant for the improvement of self-care activities. Finally, children's learning style is one important aspect, that may provide a useful basis when optimizing daily activities.

Looking at up-coming activity-focused interventions for children with CP, I advocate realizing – and discussing – whether the focus is on improving either children's capabilities (can do in a daily environment) or their performance (does do in a daily environment), or perhaps both. This matters since improving capabilities requires another set of strategies than improving performance. Improving capabilities asks particularly for knowledge about an individual's capacities and the physical environment, whereas improving performance rather demands knowledge about a person's motivation and the social environment. In addition, I advocate using learning styles to further tailor the set of strategies to individual preferences for the process of learning. I have the impression that these accents are currently indispensible in various settings dealing professionally and systematically with optimizing individuals' activities, for instance in education, sports, management, and in the future presumably also in rehabilitation.

## Directions for future research

Considering the conceptual model for optimizing daily activities of children with CP, it seems to me that research in the future should be directed at creating further building blocks with respect to development and learning.

Large blocks of information about development of daily activities can be obtained by continuation of PERRIN. This continuation might be possible in two ways. One way implies an integration of the PERRIN CP 0-5, PERRIN CP 5-9, PERRIN CP 9-16, and PERRIN CP 16-24 studies. Existing data can be merged to answer new questions. Another way includes assessing the same children again, for instance the PERRIN CP 5-9 sample, after a few years. Thus, the follow-up of the sample can be lengthened and old and new variables can be measured. New variables are, for example, various environmental characteristics. To my opinion, one of the greatest challenges will be to study the development of daily activities in terms of performance.

Furthermore, I think that advanced blocks of information about learning and teaching of daily activities could be obtained, firstly, by continuing the search and development of instruments. Later on, studying the effects of teaching strategies, whether or not matched to learning styles, would be a major step in pediatric rehabilitation research. For such a step, it is in my view important to extend the collaboration between medical and educational sciences that has been built up in our studies in the past years.

## Conclusion

Many children with CP make progress in daily activities between the age of 5 and 9 years. Using functional classifications of CP enables detailed information about the development of daily activities. In addition, learning styles may enable teaching of daily activities to children with CP at an individual level. Knowledge about both development and learning in children with CP can help in creating comprehensive models for optimizing their daily activities.

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# Summary

In care and research, there is increasing interest in the daily lives of children with cerebral palsy (CP). So far, we know that CP can have a limiting impact on daily activities such as locomotion and self-care. What we, however, don't know is how children with CP develop over time in terms of their daily activities. Is there progress, stagnation, or decline, and to what degree, in which activities, in which children? Besides, little is known about how children with CP learn their daily activities. Knowledge about development and learning of daily activities can help to create realistic expectations and goals for children with CP, their parents, and others involved. Moreover, this knowledge may help to optimize the daily activities of children with CP.

This thesis describes the results from studies focusing on development and learning of daily activities in children with CP. The results concerning development in terms of daily activities originate from the research program 'Pediatric Rehabilitation Research in the Netherlands' (PERRIN), and in particular from the project 'PERRIN CP 5-9'. PERRIN CP 5-9 is a longitudinal study among children with CP aged 5 to 9 years. The results concerning learning of daily activities originate from the 'Praktijk Onderzoek Motorische Vaardigheden Educatie' (PROMOVE-CP). PROMOVE-CP is an action research with professionals engaged in learning of motor activities by children with CP.

In **chapter 1**, the central theme of the thesis is introduced: daily activities of children with CP. First, the clinical manifestation of CP is described in terms of subtypes and functional abilities. Subtypes are unilateral spastic CP, bilateral spastic CP, dyskinetic CP and ataxic CP. Functional abilities are classified for gross motor function according to the Gross Motor Function Classification System (GMFCS) and arm-hand function according to the Manual Ability Classification System (MACS). Further, a description is given for the concept of daily activities, defined as those activities that children undertake routinely in their everyday life. Regarding development of daily activities, one can study the change over time but also the factors that determine change (chapters 2, 3, 4 and 5). With regard to learning of daily activities, learning styles can be a practical guide for optimizing daily activities of individual children (chapters 6 and 7).

Selective motor control (SMC) is the ability to move an individual joint voluntarily without moving other joints. SMC is considered an important determinant for daily motor activities in children with CP. In **chapter 2**, two SMC tests are described and studied for the degree of agreement between raters. The Boyd and Graham SMC test with an existing protocol (movement: dorsiflexion ankle) and the Trost SMC test with a newly developed protocol (movements: dorsiflexion ankle, knee flexion, hip extension and hip abduction) are administered by two independent raters in 21 children with spastic CP. The inter-rater agreement of the Boyd and Graham SMC test is moderate. The inter-rater agreement of the SMC Trost test is moderate to good. The Trost SMC test is recommended for use in practice.

The term *capacity* refers to what children can do in a standardized environment, for instance, sitting, standing and walking in a practice situation. The terms *capability* and *performance* refer to what children respectively *can do* and *do do* in their daily environment, for instance, going upstairs at home. It is generally assumed that there is a strong positive correlation between the gross motor capacity of children with CP and their daily motor activities (capability and performance). In **chapter 3**, this relationship is investigated in 116 children with varying severity of CP. To measure the gross motor capacity, the Gross Motor Function Measure (GMFM-66) is used. Measuring daily motor activities is done with the Pediatric Evaluation of Disability Inventory (PEDI) – domain 'ambulation'. The capability in ambulation is measured with the PEDI Functional Skills Scale (PEDI-FSS) and performance of ambulation with the PEDI Caregiver Assistance Scale (PEDI-CAS). For the total group, there is a strong correlation between the gross motor capacity and daily motor activities (in terms of both capability and performance). However, in children with unilateral spastic CP, the correlation between the gross motor capacity and daily motor activities (in terms of capability) is significantly weaker than in children with bilateral spastic CP. It is concluded that – especially in case of unilateral spastic CP – the gross motor capacity is not the only determinant for daily activities.

Another possible determinant for daily activities of children with CP is children's intellectual capacity. Little is known, however, about the development of this capacity in children with CP. In **chapter 4**, the development of non-verbal intellectual capacity – the capacity for logical reasoning – is described in 91 children with varying severity of CP. Non-verbal intellectual capacity is measured with Raven's Coloured Progressive Matrices (RCPM). Averaged for the total group, there is a significant increase in RCPM raw scores, with the RCPM IQ scores showing stability over time. In children with less severe CP (GMFCS level I, II and III), the increase in RCPM raw scores appears to be higher than in children with more severe CP (GMFCS levels IV and V). The conclusion is that children with CP between 5 and 9 years have different developmental trajectories for non-verbal intellectual capacity and that these different trajectories relate to the severity of CP.

In **chapter 5**, the development of daily activities in children with CP ($N$ = 116) is examined between the age of 5 and 9 years in three domains: self-care, ambulation, and social functioning. First, the change over time is described in each of the three domains in terms of capability. Then, each domain is studied for the factors that determine change over time. To measure daily activities, the PEDI-FSS is used. Averaged for the total group, significant increases over time are shown in PEDI-FSS scores on each of the three domains. For self-care, change is best predicted by a model with gross motor function (measured by the GMFCS) and intellectual capacity (measured by the RCPM). For ambulation, change is best predicted by a model with gross motor function. For social functioning, change is best predicted by a model with arm-hand function (measured by MACS) and paternal educational level. It thus appears that there are different sets of determinants for change in different domains of daily activities in children with CP.

In addition to knowledge about development, knowledge about individual learning seems useful in order to optimize daily activities of children with CP. Classifying learning styles, as known in education and sports, could be one guide. Learning styles are individuals' preferences for the process of learning. For example, some people learn best by watching, others learn best by doing. In **chapter 6**, the idea of classifying learning styles is introduced to rehabilitation. Taking learning styles into account, professionals could be helped in selecting and applying specific teaching strategies during therapy.

In **chapter 7**, it is examined whether the idea of classifying learning styles is perceived as relevant by professionals working with children with CP. In this chapter, it is also explored whether there is a useful basis for classifying learning styles in children with CP. Twenty-one pediatric physical therapists and seven physical educators tried out brief versions of two existing learning style instruments (Kolb's Learning Style Inventory and Myers-Briggs Type Indicator) and reported their perceptions. The results show that these pediatric physical therapists' and physical educators' perceptions of classifying learning styles of children with CP were mostly positive, giving three main reasons: individual approach, professional communication, and treatment awareness. Additionally, it is shown that brief versions of the two learning style instruments are not useful for children with CP. It is therefore recommended that a new learning style classification instrument be developed for children with CP.

In **chapter 8**, the main findings and implications are presented. Many children with CP make progress in daily activities between the age of 5 and 9 years. For a more detailed prediction of the development of daily activities in children with CP, it is recommended to classify their functional abilities, for instance, with the GMFCS and MACS. For teaching daily activities to individual children with CP, it may also help to classify their learning styles. Knowledge about both development and learning in children with CP can help in creating comprehensive models for optimizing their daily activities.

# Samenvatting
# (Summary in Dutch)

In zorg en onderzoek is steeds meer aandacht voor het dagelijks leven van kinderen met cerebrale parese (CP). We weten dat CP een beperkende invloed kan hebben op dagelijkse activiteiten zoals voortbeweging en zelfverzorging. Wat we echter nog niet weten is hoe kinderen met CP zich in de loop van de tijd ontwikkelen ten aanzien van hun dagelijkse activiteiten. Is er vooruitgang, stilstand of achteruitgang en in welke mate, bij welke activiteiten, bij welke kinderen? Tevens is er nog weinig bekend over de manier waarop kinderen met CP hun dagelijkse activiteiten aanleren. Kennis over ontwikkeling en leren van dagelijkse activiteiten kan helpen om realistische verwachtingen en doelstellingen te scheppen voor kinderen met CP, hun ouders en andere betrokkenen. Bovendien kan deze kennis helpen om de dagelijkse activiteiten van kinderen met CP te optimaliseren.

In dit proefschrift worden resultaten beschreven van onderzoek naar ontwikkeling en leren van dagelijkse activiteiten bij kinderen met CP. De resultaten over ontwikkeling ten aanzien van dagelijkse activiteiten komen voort uit het onderzoeksprogramma 'Pediatric Rehabilitation Research in the Netherlands' (PERRIN) en in het bijzonder uit het project 'PERRIN CP 5-9'. PERRIN CP 5-9 is een longitudinaal onderzoek bij kinderen met CP in de leeftijd van 5 tot 9 jaar. De resultaten over het aanleren van dagelijkse activiteiten komen voort uit het 'Praktijk Onderzoek Motorische Vaardigheden Educatie' (PROMOVE-CP). PROMOVE-CP is een praktijkonderzoek met professionals die zich bezighouden met het leren van motorische activiteiten door kinderen met CP.

In **hoofdstuk 1** wordt het centrale thema van het proefschrift geïntroduceerd: dagelijkse activiteiten van kinderen met CP. Allereerst wordt het klinisch beeld van CP beschreven in termen van subtypen en functionele mogelijkheden. Subtypen zijn unilaterale spastische CP, bilaterale spastische CP, dyskinetische CP en atactische CP. Functionele mogelijkheden worden voor grofmotorisch functioneren ingedeeld volgens de Gross Motor Function Classification System (GMFCS) en voor arm-handfunctioneren volgens de Manual Ability Classification System (MACS). Verder wordt er stilgestaan bij het begrip dagelijkse activiteiten, gedefinieerd als die activiteiten die kinderen routinematig ondernemen in hun alledaagse leven. Met het oog op de ontwikkeling ten aanzien van dagelijkse activiteiten kan gekeken worden naar verandering in de tijd, maar ook naar factoren die bepalend zijn voor verandering (hoofdstuk 2, 3, 4 en 5). Met betrekking tot het aanleren van dagelijkse activiteiten kunnen leerstijlen bovendien een praktische leidraad vormen voor het optimaliseren van dagelijkse activiteiten van individuele kinderen (hoofdstuk 6 en 7).

Selectieve motorische controle (SMC) is het vermogen om vrijwillig een beweging te maken in een gewricht onafhankelijk van beweging in andere gewrichten. SMC wordt beschouwd als een bepalende factor voor dagelijkse motorische activiteiten van kinderen met CP. In **hoofdstuk 2** worden twee SMC testen beschreven en wordt voor beide testen onderzocht wat de mate van overeenstemming is tussen verschillende beoordelaars. De Boyd en Graham SMC test met een bestaand protocol (beweging: dorsaalflexie enkel) en de Trost SMC test met een nieuw ontwikkeld protocol (bewegingen: dorsaalflexie enkel, flexie knie, extensie heup en abductie heup) zijn door twee onafhankelijke beoordelaars afgenomen bij 21 kinderen met spastische CP. De interbeoordelaarsovereenstemming van de Boyd en Graham SMC test is matig. De interbeoordelaarsovereenstemming van de Trost SMC test is matig tot goed. De Trost SMC test wordt daarom aanbevolen voor gebruik in de praktijk.

Het begrip *capacity* (vermogen) verwijst naar wat kinderen kunnen in een gestandaardiseerde omgeving, bijvoorbeeld zitten, staan en lopen in een oefensituatie. De begrippen *capabilit*y en *performance* verwijzen naar wat kinderen respectievelijk kunnen (vaardigheid) en daadwerkelijk doen (uitvoering) in hun dagelijkse omgeving, bijvoorbeeld thuis de trap op gaan. Algemeen wordt verondersteld dat er een sterke positieve correlatie is tussen het grofmotorisch vermogen van kinderen met CP en hun dagelijkse motorische activiteiten (vaardigheid en uitvoering). In **hoofdstuk 3** wordt deze relatie nader onderzocht bij 116 kinderen met een uiteenlopende ernst van CP. Voor het vastleggen van het grofmotorische vermogen is de Gross Motor Function Measure (GMFM-66) gebruikt. Het vastleggen van dagelijkse motorische activiteiten is gedaan met de Pediatric Evaluation of Disability Inventory (PEDI) – domein 'ambulantie'. De ambulantie-vaardigheid is gemeten met de PEDI-Functionele Vaardigheden Schaal (PEDI-FVS) en de ambulantie-uitvoering met de PEDI-Verzorgers Assistentie Schaal (PEDI-VAS). Voor de totale groep blijkt er inderdaad een sterke correlatie te zijn tussen het grofmotorische vermogen en dagelijkse motorische activiteiten (zowel in de zin van vaardigheid als uitvoering). Echter, bij kinderen met unilaterale spastische CP blijkt de correlatie tussen het grofmotorisch vermogen en dagelijkse motorische activiteiten (in de zin van vaardigheid) significant zwakker te zijn dan bij kinderen met bilaterale spastische CP. Er wordt geconcludeerd dat – zeker in geval van unilaterale spastische CP – het grofmotorische vermogen niet de enige bepalende factor is voor dagelijkse activiteiten.

Een andere mogelijk bepalende factor voor dagelijkse activiteiten van kinderen met CP is het intellectuele vermogen. Er is echter nog weinig bekend over de ontwikkeling van dit vermogen bij kinderen met CP. In **hoofdstuk 4** wordt de ontwikkeling van het non-verbale intellectuele vermogen – het vermogen voor logisch redeneren – beschreven voor 91 kinderen met een uiteenlopende ernst van CP. Het non-verbale intellectuele vermogen is gemeten met Raven's Coloured Progressive Matrices (RCPM). Gemiddeld voor de totale groep is er een significante toename in RCPM ruwe scores, waarbij de RCPM IQ-scores gelijk blijven. De toename in RCPM ruwe scores blijkt groter te zijn bij kinderen met minder ernstige CP (GMFCS niveau I, II en III) dan bij kinderen met ernstigere CP (GMFCS niveau IV en V). De conclusie is dat kinderen met CP tussen 5 en 9 jaar verschillende ontwikkelingslijnen laten zien met betrekking tot het non-verbale intellectuele vermogen en dat deze verschillende lijnen samenhangen met de ernst van CP.

In **hoofdstuk 5** wordt de ontwikkeling van dagelijkse activiteiten van kinderen met CP ($N = 116$) tussen 5 en 9 jaar onderzocht op drie domeinen: zelfverzorging, ambulantie en sociaal functioneren. Allereerst is de verandering in de tijd op elk domein beschreven in de zin van *capability* (vaardigheid). Vervolgens is op elk domein bestudeerd welke factoren samen bepalend zijn voor verandering in de tijd. Voor het vastleggen van dagelijkse activiteiten is gebruik gemaakt van de PEDI-FVS. Gemiddeld voor de totale groep blijkt er een significante toename in PEDI-FVS scores op elk van de drie domeinen. Verandering ten aanzien van zelfverzorging wordt het best voorspeld vanuit een model met grofmotorisch functioneren (gemeten met de GMFCS) en intellectueel vermogen (gemeten met de RCPM). Verandering ten aanzien van ambulantie wordt het best voorspeld vanuit een model met alleen grofmotorisch functioneren. Verandering ten aanzien van sociaal functioneren wordt het best voorspeld vanuit een model met arm-handfunctioneren (gemeten met de MACS) en het opleidingsniveau van de vader. Het blijkt dus dat er verschillende combinaties van factoren zijn voor verandering ten aanzien van verschillende domeinen van dagelijkse activiteiten bij kinderen met CP.

Naast kennis over ontwikkeling, lijkt ook kennis over individuele leerprocessen zinvol om dagelijkse activiteiten van kinderen met CP te kunnen optimaliseren. Het classificeren van leerstijlen, zoals bekend in onder andere onderwijs en sport, zou daarbij een leidraad kunnen zijn. Leerstijlen zijn voorkeursmanieren om iets te leren. Sommige mensen leren bijvoorbeeld het best door te observeren, anderen juist door te doen. In **hoofdstuk 6** wordt het idee om leerstijlen te classificeren geïntroduceerd in de revalidatie. Door rekening te houden met leerstijlen zouden professionals geholpen kunnen worden bij keuze en toepassing van bepaalde leerstrategieën tijdens therapie.

In **hoofdstuk 7** wordt onderzocht of het idee om leerstijlen te classificeren ook daadwerkelijk als relevant wordt ervaren door professionals die werkzaam zijn met kinderen met CP. Tevens wordt onderzocht of er een bruikbare basis is voor het classificeren van leerstijlen bij kinderen met CP. Eenentwintig kinderfysiotherapeuten en 7 bewegingsonderwijzers hebben korte versies van twee bestaande leerstijlinstrumenten (Kolb's Learning Style Inventory en Myers-Briggs Type Indicator) uitgeprobeerd bij kinderen met CP en hebben hun ervaringen gerapporteerd. Het classificeren van leerstijlen is door een meerderheid als positief ervaren met als voornaamste redenen: de individuele benadering, de professionele communicatie en het bewustzijn tijdens therapie of onderwijs. Daarnaast wordt aangetoond dat korte versies van de twee leerstijlinstrumenten niet bruikbaar zijn voor kinderen met CP. Er wordt daarom aanbevolen om een nieuw leerstijlclassificatieinstrument te ontwikkelen dat specifiek geschikt is voor kinderen met CP.

In **hoofdstuk 8** worden de belangrijkste bevindingen en implicaties gegeven. Veel kinderen met CP boeken vooruitgang in hun dagelijkse activiteiten in de leeftijd tussen 5 en 9 jaar. Om de ontwikkeling ten aanzien van dagelijkse activiteiten bij kinderen met CP in te schatten is het aan te raden om hun functionele mogelijkheden te classificeren met bijvoorbeeld de GMFCS en de MACS. Om dagelijkse activiteiten te leren aan individuele kinderen met CP kan het daarnaast helpen om leerstijlen van kinderen te classificeren. Deze kennis kan worden samengebracht in een conceptueel model dat richting geeft aan het optimaliseren van dagelijkse activiteiten van kinderen met CP in de praktijk.

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*"Dankbaarheid is de herinnering van het hart"*
(Jean Baptiste Massieu)

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Wie echt niet vergeten mogen worden in het kader van het PERRIN CP 5-9 onderzoek zijn de kinderen met CP en hun ouders. Jongens, meisjes, vaders en moeders, jullie staan misschien wat verborgen in dit dankwoord, maar jullie zijn voor mij de allerbelangrijksten geweest in het onderzoek! Eén van de leukste bezigheden in de afgelopen vijf jaar vond ik de 'metingen' samen met jullie. Ik hoop dat ik jullie ook heb kunnen vermaken met oefeningen, puzzels, spelletjes en sporten.

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Aansluitend bij het thema leerstijlen wil ik ook Caroline van Heugten en Olaf Verschuren noemen. Caroline, ik herinner me onze interessante brainstormsessies over hoe we het leerstijl-onderwerp kunnen introduceren in de revalidatie. Mede op basis daarvan hebben we een leuk 'andersoortig' artikel geschreven, een conceptstuk zogezegd. Olaf, met jou durfde ik de stap te maken om leerstijlen in de praktijk te brengen. Of het nu onderzoek is of de groep kinderen met CP, jij ziet allereerst mogelijkheden en niet zozeer beperkingen. Dat is een geweldige instelling waarmee je altijd voor een zeer plezierige samenwerking zorgt!

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# About the author

# CURRICULUM VITAE

Dirk-Wouter Smits werd op 23 mei 1977 geboren te Made en Drimmelen. Hij behaalde in 1995 zijn VWO-diploma aan het Newman College in Breda. Van 1995 tot 2000 studeerde hij Pedagogische Wetenschappen (specialisatie Sport, Bewegen en Gezondheid) aan de Universiteit Utrecht. Binnen deze studie nam hij in 1999 deel aan het European Master's Degree in Adapted Physical Activity (EMDAPA) programma aan de Katholieke Universiteit Leuven. Van 2000 tot 2003 volgde hij de (verkorte) opleiding Fysiotherapie aan de Hogeschool Utrecht.

In 2003 werkte Dirk-Wouter enkele korte periodes als fysiotherapeut. Daarna was hij een jaar werkzaam bij de opleiding Fysiotherapiewetenschap aan de Universiteit Utrecht en vervolgens een jaar bij de opleiding Fysiotherapie aan de Hogeschool Utrecht. Bij beide opleidingen was hij medewerker in het ontwikkelen van wetenschappelijk onderwijs en was hij tevens betrokken bij onderzoek en onderwijs rond het thema 'motorisch leren'. Vanaf 2004 combineerde hij zijn werk in het onderwijs met een functie als onderzoeksassistent in het Kenniscentrum van Revalidatiecentrum De Hoogstraat in Utrecht. In deze functie heeft hij zich gedurende een jaar gericht op het plannen en uitvoeren van metingen in het kader van het Pediatric Rehabilitation Research in the Netherlands (PERRIN) CP 0-5 project, een longitudinale studie naar het beloop en determinanten van het dagelijks functioneren van kinderen met CP van 0 tot 5 jaar.

Vanaf de zomer van 2005 werd het PERRIN CP 5-9 project opgestart en begon Dirk-Wouter zijn werk als junior-onderzoeker op dit project. In het PERRIN CP 5-9 project lag voor hem de kans promotieonderzoek te doen. In 2007 schreef hij een subsidieaanvraag voor een onderzoek naar leerstijlen voor het leren van motorische vaardigheden bij kinderen met CP: het Praktijkonderzoek Motorische Vaardigheden Educatie bij CP (PROMOVE-CP). Vanaf 2008 kon hij zich – naast het PERRIN CP 5-9 project – dus ook richten op het PROMOVE-CP project. Hiermee ging een wens van hem in vervulling om zich als onderzoeker te kunnen verdiepen in het thema motorisch leren bij kinderen.

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