Developmental Trajectories of Daily Activities in Children and Adolescents With Cerebral Palsy

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KEY WORDS: cerebral palsy, longitudinal study, developmental outcomes, children and adolescents, young adults

ABBREVIATIONS: CP—cerebral palsy GmFCS—Gross Motor Function Classification System PERRIN—Pediatric Rehabilitation Research In the Netherlands VABS—Vineland Adaptive Behavior Scales

Ms Vos conceptualized the study, prepared the database for analysis, carried out the initial analyses, and drafted the initial manuscript; Dr Becher conceptualized and designed the study, interpreted the results of the analysis for clinical relevance, and critically revised the content of the manuscript; Ms Ketelaar conceptualized and designed the study and critically revised the content of the manuscript; Mr Smits collected data on the school-age children, prepared the database for analysis, interpreted the results of the analysis for clinical relevance, and critically revised the content of the manuscript; Dr Voormann collected data on the adolescents, interpreted the results of the analysis for clinical relevance, and critically revised the content of the manuscript; Ms Tan prepared the database for analysis, interpreted the results of the analysis for clinical relevance, and critically revised the content of the manuscript; Ms Reinders-Messelinck conceptualized and designed the study and critically revised the content of the manuscript; Ms Dallmeijer conceptualized, designed, and guided the study, discussed statistical analysis, interpreted the results of the analysis for clinical relevance, and critically revised the content of the manuscript; and all authors approved the final manuscript as submitted.

WHAT’S KNOWN ON THIS SUBJECT: Rehabilitation of people with cerebral palsy aims to achieve and maintain optimal performance in mobility and daily activities. Although insight into the developmental trajectories of activities from childhood into adulthood is important, little is known about long-term development.

WHAT THIS STUDY ADDS: The gross motor function of children with cerebral palsy determines the developmental trajectories of mobility performance but not of daily activities, where intellectual disability was shown to be the determining factor.

OBJECTIVES: To describe the developmental trajectories of mobility performance and daily activities in children and young adults with cerebral palsy (CP). To explore the influence of gross motor function and intellectual disability on these trajectories.

METHODS: Four hundred and twenty-four Dutch participants with CP (aged 1–20 years at study onset) were followed yearly over a period of 2 to 4 years. Developmental trajectories (from ages 1–16 years) were described for mobility performance and performance of daily activities, assessed by using the Vineland Adaptive Behavior Scale for gross motor function (classified by the Gross Motor Function Classification System) and intellectual disability (by IQ or school type). A subanalysis was done for performance of daily activities in a subgroup of participants without intellectual disability (aged 1–24 years).

RESULTS: The developmental trajectories of mobility performance differed according to levels of gross motor function but not levels of intellectual disability. Intellectual disability affected the performance of daily activities, with lower overall trajectory levels for participants with intellectual disabilities. For participants without intellectual disability, high-level developmental trajectories were found, with values similar to those of typically developing children despite differences in gross motor function level.

CONCLUSIONS: Mobility performance is determined mainly by levels of gross motor function. For performance of daily activities, intellectual disability was a more important determinant. Participants without intellectual disability showed developmental trajectories approaching values for typically developing participants. These estimated trajectories can guide rehabilitation interventions and future expectations for children and young adults with CP. Pediatrics 2013;132:1–9

CONTINUATION....

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Cerebral palsy (CP) is the most common cause of functional disability in children, with a prevalence in Europe of ∼2.0 in every 1000 live-born children. CP is defined as “a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.”

The severity of the functional disability caused by CP is often classified by using the Gross Motor Function Classification System (GMFCS), which ranges from “can generally walk without restrictions” (level I) to “generally very limited in their motor ability” (level V). The goal of rehabilitation for people with CP is to achieve and maintain optimal participation and independence in daily life, throughout the life span. To achieve this goal, and to define a rehabilitation plan, it is important to understand the developmental trajectories of activity domains in people with a range of GMFCS levels. This information will help people with CP and their families in setting meaningful goals and maintain realistic expectations.

Activity is defined as the execution of a task or action. Based on the contextual difference, a distinction is made in the International Classification of Functioning, Disability and Health framework between 2 qualifiers: capacity and performance. Capacity reflects what someone can do in a standardized environment, whereas performance reflects what someone actually does do in his or her daily environment. Recently a third, intermediate qualifier was introduced: capability. Capability reflects what someone can do in his or her daily environment. In the current study, activity is described as performance, in terms of mobility performance and performance of daily activities.

Currently, developmental trajectories from childhood to adulthood are available only for mobility capacity. Different developmental trajectories have been distinguished for different GMFCS levels, and peak levels decline with increasing severity of gross motor limitation. No such developmental trajectories have been described for mobility in terms of performance of activities, and present knowledge is based on cross-sectional studies or on longitudinal studies that included only a few years of follow-up and were restricted to a small age range.

One longitudinal study in adolescents with CP found an effect of GMFCS level on mobility performance (better mobility performance for less gross motor limitation) but no significant change over the course of 1 year. Another study in adolescents with CP found changes in mobility performance over the course of 3 years and differences in course between GMFCS levels, with a less favorable course for those with more severe gross motor limitation over 3 years.

Insight into the developmental trajectory of performance of daily activities is, like that of mobility performance, limited to cross-sectional studies or longitudinal studies with a small age range and few years of follow-up. The available longitudinal data on performance of daily activities represent the results of school-aged children (aged 5–9 years) over a period of 2 years. In this study, the increase over time was significantly higher in the 5-year-olds than in children aged 7 years. In addition to age and gross motor function level, variability between and within individuals over time was related to intellectual disability.

For parents and children with CP, it is important to gain insight into the development of mobility performance and the performance of daily activities over a longer period, including the potential level of independence that may be reached later in life. Therefore, the aim of this study was to describe the developmental trajectories of mobility performance and performance of daily activities in children and young adults with CP and to explore the influence of the level of gross motor function and intellectual disability on these trajectories.

METHODS

Design and Subjects

This study was performed as part of the prospective longitudinal research program PEdiatric Rehabilitation Research In the Netherlands (PERRIN), which started in 2000 as a collaboration of 4 university medical centers and several rehabilitation centers in the Netherlands. For the current study, data on 424 children and young adults with CP were combined from 4 age cohort studies in the PERRIN research program: PERRIN 0 to 5 (aged 1 and 2 years at baseline; n = 97), PERRIN 5 to 9 (aged 5 and 7 years at baseline; n = 116), PERRIN 9 to 16 (aged 9, 11, and 13 years at baseline; n = 108), and PERRIN 16 to 24 (aged 16–20 years at baseline; n = 103). The recruitment process of these studies has been described in detail elsewhere (Fig 1). In short, eligible patients had a clinical diagnosis of CP. Patients were excluded when they were diagnosed with additional diseases or disorders affecting motor functioning and when they or their caregiver lacked a basic knowledge of the Dutch language. Young adults with an intellectual disability (IQ <70) also were excluded.

The young adult cohort study aimed to determine the course and determinants of daily activities and participation from the perspective of the young adults themselves. The instruments that were used were not suitable for people with intellectual disability, who were therefore excluded from the study. Informed consent was obtained from each patient and/or his or her parents or formal caregiver. Ethical approval for the study was granted by the Medical Ethics Committee of the University of Nijmegen.
obtained from the medical ethics committees of each participating center. Within each age cohort, data were collected over the course of 2 years (PERRIN 5–9), 3 years (PERRIN 0–5, PERRIN 9–16), or 4 years (PERRIN 16–24). Of the 424 participants included in the current study, complete data sets were available for 80 toddlers (83%), 97 children (84%), 89 adolescents (82%), and 75 young adults (73%). One measurement occasion was missed by 17 toddlers, 12 children, 10 adolescents, and 11 young adults. Two or more measurement occasions were missed by none of the toddlers, 7 children, 9 adolescents, and 17 young adults.

Measures

Mobility Performance and Performance of Daily Activities

Mobility performance and performance of daily activities were determined by using the Dutch translation of the Vineland Adaptive Behavior Scale (VABS) survey.14 The VABS survey is a reliable and validated instrument15–17 constructed to assess performance of children aged 0 to 18 years, 11 months, with or without disability.17 The VABS survey measures the child’s performance by means of a semistructured interview with the parents or caregivers, within 4 domains that include mobility performance (36 activities) and performance of daily activities (92 activities). Activities are listed by developmental order, with specific starting points at specific ages (based on typically developing children), and answers are categorized as 0 (never performed), 1 (sometimes or partially performed), or 2 (usually or habitually performed). Raw mobility performance scores ranged from 0 to 72, and raw scores of performance of daily activities ranged from 0 to 184. For the toddlers, the Dutch translation of the VABS screener was used, including only the relevant items for this age group.18 For young adults only performance of daily activities was assessed. The raw domain scores of patients with CP were compared with the VABS reference values, derived from 3000 typically developing children in the United States.

CP Characteristics

The condition of patients with a clinical diagnosis of CP was described based on their GMFCS,2 type of motor impairment (ie, spastic, dyskinetic, ataxic, or mixed CP), and, within the spastic CP group, limb distribution (ie, unilateral CP or bilateral CP).19

Intellectual Disability

Intellectual disability was based on either IQ scores (Snijders–Oomen Nonverbal Intelligence Test for toddlers20 and Raven’s Colored Progressive Matrices for children21) or school type (adolescents). In the young adults, “intellectual disability” was an exclusion criterion. A lack of intellectual disability was defined as an IQ ≥70 or following a regular educational program (in a regular school or in a school providing special education for physically disabled children). Intellectual disability was defined as IQ <70 or following a special education program in special schools for children with intellectual disability (with or without physical disabilities).

Statistics

Descriptive statistics were computed for CP characteristics using SPSS software (version 17; IBM, Armonk, NY). Multilevel analyses were performed by using MLwiN (version 2.21; Centre for Multilevel Modelling, Bristol University, Bristol, UK) to analyze the developmental trajectories of mobility performance and performance of daily
activities over age. Because mobility performance was not assessed in young adults, the developmental trajectories of this domain were available only for ages 1 to 16 years. Furthermore, because young adults with intellectual disability were excluded from this study, the developmental trajectories of performance of daily activities were modeled separately for participants with (age range 1–16 years) and without intellectual disability (age range 1–24 years). To take into account that data from 4 age cohorts were combined, with repeated measures within the same patient, multilevel analyses were used with 3 levels: observations (level 3) were clustered within patients (level 2), and patients were clustered within age cohorts (level 1).

Two models were used to study the developmental trajectory of the outcome measures by GMFCS level and analyze the impact of intellectual disability on these trajectories. First, the developmental trajectories of the outcome measures were modeled by age and GMFCS level (basic model). Age was included in the model as an independent continuous variable as both a linear (age) and quadratic function of age (age²), GMFCS level as 4 dummy variables (functioning at GMFCS level I as reference variable), and the interaction of age (both functions) and GMFCS level. To determine differences between the developmental trajectories of the consecutive GMFCS levels, the reference category was alternated. The possible influence of intellectual disability on the developmental trajectories of the outcome measures was examined by including intellectual disability in the model as a dichotomous variable (with “no intellectual disability” as a reference category) and the interaction of age (both linear and quadratic function) and intellectual disability. The ratio likelihood test was used to evaluate whether a random regression coefficient for age had to be considered in the models. The Wald statistic was used to evaluate the significance of the relationship between the outcome measures and determinants. The results are presented as regression coefficients and 95% confidence intervals.

RESULTS

The complete data set included 1346 observations of 424 participants, classified by GMFCS: 50% level I, 13% level II, 14% level III, 13% level IV, and 10% level V. Spastic CP was the most common subtype (87%; 38% unilateral and 49% bilateral), followed by dystonic (6%) and ataxic (2%). The mixed subtype was present in 5% of participants (Supplemental Appendix 1). The regression coefficients of the final models of the developmental trajectories of mobility performance and performance of daily activities are shown in Table 1.

Mobility Performance

An inclining trajectory for mobility performance was found in participants functioning at GMFCS I to IV, with values leveling off at 12 to 13 years of age. As expected, the trajectories for mobility performance were highest for participants functioning at GMFCS I and gradually decreased with increasing GMFCS level. The peak trajectory level of mobility performance of participants functioning at GMFCS I to II was very close to the maximum domain score (ie, close to values for typically developing people) (Fig 2). Trajectories differed significantly between participants functioning at GMFCS I and III (Wald statistics $P < .05$) and between participants functioning at GMFCS I or II or III compared with GMFCS IV or V (based on the interaction Age*GMFCS and Age²*GMFCS; Table 1). Although the developmental trajectory of mobility performance of participants functioning at GMFCS V was much lower overall, reaching only 18% of the performance level of those functioning at GMFCS I, the trajectory continued to improve. There was no significant influence of intellectual disability on the developmental trajectory of mobility performance within GMFCS levels.

Performance of Daily Activities

For performance of daily activities, an inclining trajectory for all GMFCS levels was found over the entire age range, without reaching a plateau during adolescence. The trajectory for performance of daily activity was highest for participants functioning at GMFCS I and gradually decreased with increasing GMFCS level.

Intellectual disability had a significant influence on the developmental trajectory of performance of daily activities (Wald statistics $P < .001$), with lower levels found for participants with intellectual disability (Fig 3). The subanalyses of the developmental trajectories of participants without intellectual disability showed inclining trajectories for GMFCS I to IV until around 22 years of age. The trajectory levels of GMFCS I to IV functioning in participants without intellectual disability were very close to each other and reached levels very close to the maximum domain score (values for typically developing people). Significant differences between the trajectories were found only when participants functioning at GMFCS I functioning were compared with those at GMFCS IV (Table 1). Much lower levels were found for participants with intellectual disability, also showing significantly different trajectories between participants functioning at GMFCS I versus III to V.
### TABLE 1 Final Model Regression Coefficients of Developmental Trajectory of Mobility Performance and Performance of Daily Activities by GMFCS

<table>
<thead>
<tr>
<th>Associated Factors</th>
<th>Mobility Performance</th>
<th>Performance of Daily Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GMFCS I–V, 1–16 y</td>
<td>GMFCS I–V, 1–16 y</td>
</tr>
<tr>
<td>Constant</td>
<td>11.98 (0.41)</td>
<td>5.95 (0.47)</td>
</tr>
<tr>
<td>Age</td>
<td>9.51 (0.41)</td>
<td>18.35 (0.89)</td>
</tr>
<tr>
<td>Age^2</td>
<td>-0.39 (0.02)</td>
<td>-0.56 (0.05)</td>
</tr>
<tr>
<td>GMFCS I</td>
<td>0 ref</td>
<td>0 ref</td>
</tr>
<tr>
<td>GMFCS II</td>
<td>-2.02 (3.52)</td>
<td>3.32 (7.22)</td>
</tr>
<tr>
<td>GMFCS III</td>
<td>-7.63 (3.02)</td>
<td>1.74 (6.84)</td>
</tr>
<tr>
<td>GMFCS IV</td>
<td>-7.01 (3.10)</td>
<td>2.60 (7.30)</td>
</tr>
<tr>
<td>GMFCS V</td>
<td>-7.16 (3.90)</td>
<td>3.76 (9.50)</td>
</tr>
<tr>
<td>Age*GMFCS I</td>
<td>0 ref</td>
<td>0 ref</td>
</tr>
<tr>
<td>Age*GMFCS II</td>
<td>-1.43 (0.79)</td>
<td>-3.03 (1.68)</td>
</tr>
<tr>
<td>Age*GMFCS III</td>
<td>-2.28 (0.79)</td>
<td>-5.76 (1.69)</td>
</tr>
<tr>
<td>Age*GMFCS IV</td>
<td>-5.20 (0.77)</td>
<td>-5.36 (1.69)</td>
</tr>
<tr>
<td>Age*GMFCS V</td>
<td>-9.39 (0.84)</td>
<td>-8.81 (2.15)</td>
</tr>
<tr>
<td>Age^2*GMFCS I</td>
<td>0 ref</td>
<td>0 ref</td>
</tr>
<tr>
<td>Age^2*GMFCS II</td>
<td>0.08 (0.04)</td>
<td>0.18 (0.09)</td>
</tr>
<tr>
<td>Age^2*GMFCS III</td>
<td>0.11 (0.05)</td>
<td>0.16 (0.10)</td>
</tr>
<tr>
<td>Age^2*GMFCS IV</td>
<td>0.22 (0.04)</td>
<td>0.16 (0.11)</td>
</tr>
<tr>
<td>Age^2*GMFCS V</td>
<td>0.41 (0.04)</td>
<td>0.24 (0.12)</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>14.63 (5.73)</td>
<td>14.63 (5.73)</td>
</tr>
<tr>
<td>Age*Intellectual disability</td>
<td>-9.44 (1.44)</td>
<td>-9.44 (1.44)</td>
</tr>
<tr>
<td>Age^2*Intellectual disability</td>
<td>0.33 (0.09)</td>
<td>0.33 (0.09)</td>
</tr>
</tbody>
</table>

5% CI, 95% confidence interval.
In the current study, estimates are provided for the developmental trajectories of mobility performance and performance of daily activities by level of gross motor function in Dutch children and young adults with CP. Results show that the developmental trajectories of mobility performance differed by GMFCS level, whereas intellectual disability had no influence. For the developmental trajectory of performance of daily activities, intellectual disability was distinctive and GMFCS level less so.

In this study, we determined the developmental trajectory of mobility performance over a large age range (1–16 years), and we found an incline in development up to 12 or 13 years. The slight decline in trajectories seen thereafter was model driven and the result of small number of observations for participants aged 15 to 16 years. No evidence of decline is seen in the observed data (Supplemental Appendix 2).

**DISCUSSION**

In the current study, estimates are provided for the developmental trajectories of mobility performance and performance of daily activities by level of gross motor function in Dutch children and young adults with CP. Results show that the developmental trajectories of mobility performance differed by GMFCS level, whereas intellectual disability had no influence. For the developmental trajectory of performance of daily activities, intellectual disability was distinctive and GMFCS level less so.

In this study, we determined the developmental trajectory of mobility performance over a large age range (1–16 years), and we found an incline in development up to 12 or 13 years. The slight decline in trajectories seen thereafter was model driven and the result of the small number of observations of participants aged 15 to 16 years, because no mobility performance data for young adults were available. No evidence of decline in these participants was seen in the observed data (Supplemental Appendix 2).

Our result differs from findings on the developmental trajectories of mobility capacity reported in the same population (GMFCS I–V aged 1–22 or 24 years) in which inclining development peaked much earlier, at age 7 to 9 years (depending on the GMFCS level). Apparently, development in mobility performance occurs after maximum capacity level is reached. The contextual difference between measures of capacity and performance might explain this finding. For mobility performance, not only is the capacity to execute a motor task in a standardized environment important, but even more important is the motivation to actually carry out the motor task in the daily environment.

We found no influence of intellectual disability on the developmental trajectory of mobility performance. It has been shown in cross-sectional studies that intellectual disability in children (2–7 years) with CP was related to the level of mobility performance. However, the explained variance was only 1% to 6%, and no longitudinal data were available. Longitudinal data for mobility capability showed no influence of intellectual disability on the 2-year follow-up in the PERRIN 5 to 9 cohort, but it did influence the 3-year follow-up of mobility capacity in the PERRIN 9 to 16 cohort. We therefore speculate that intellectual disability seems to have little impact on mobility performance at a young age but might become more important during adolescence and adulthood. This finding should be confirmed in future studies.

GMFCS level and intellectual disability have been found to be good predictors of the performance of daily activities, in both cross-sectional studies and in the longitudinal data of the PERRIN 5 to 9 cohort. We therefore expected, and found, a significant influence of intellectual disability on the complete developmental trajectory of performance of daily activities. Looking at the participants without intellectual disability, there is a remarkable similarity in the trajectories of those functioning at GMFCS level I to IV. Even participants functioning at GMFCS level III or IV performed daily activities (eg, self-care and housing) at a level that was close to or only slightly lower than reference values (based on typically developing children, aged 18 years, in the United States). It appears that people with CP need more time to learn or acquire daily living skills than typically developing children, but they catch up during young adulthood. Because the performance of daily activities involves a sequence of actions that must be planned beforehand, these may not be based solely on the ability to physically execute an activity but may also involve the intellectual ability to anticipate a (changing) environment. This could explain the lower level of performance for participants with intellectual disability.

When we interpret the results of this study, some limitations should be considered. The described developmental trajectories are based on a combined database with an average
of 2.5 observations per participant, measured over a period of 2 to 4 years, thus providing only general estimates of the trajectories. Ideally, the developmental trajectories would be based on a longer follow-up period within the same people. In addition, mobility performance was available only until age 16 years, and we had no information about young adults with intellectual disability. Also, the different measures of intellectual disability between the 4 age cohorts should be kept in mind. Finally, it is likely that differences in health care organization influence the level of performance reached. Thus, caution is needed when generalizing these results to people with CP in other countries or to regions with different health care systems.

CONCLUSIONS

Inclining developmental trajectories of mobility performance are seen up to the ages of 12 to 13 years, which is related to GMFCS level and not to intellectual disability. This continuing incline suggests that when mobility capacity levels off after childhood, it is important to continue rehabilitation that focuses on valuable and meaningful activities in the context of the person’s daily life. Where strategy and planning of activities become more important for performance of daily activities, intellectual disability becomes more prominent, with lower overall values for participants with intellectual disability. Participants without intellectual disability were able to reach surprisingly high levels of development and close to values for typically developing peers, despite differences in GMFCS level. The focus of rehabilitation interventions should be on the functional and intellectual abilities of...
people with CP in context of the personal challenges faced in their daily lives.

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