Developmental Trajectories of Mobility and Self-Care Capabilities in Young Children with Cerebral Palsy

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Objective To describe development of mobility and self-care capabilities in young children (aged 1-4 years) with cerebral palsy, and to examine whether the development of mobility and self-care capabilities differs by cerebral palsy severity in terms of 5 distinct Gross Motor Function Classification System (GMFCS) levels.

Study design This prospective longitudinal cohort study included 100 children with cerebral palsy (aged 1.5 or 2.5 years at baseline) and their parents. Mobility and self-care capabilities were assessed by the Pediatric Evaluation of Disability Inventory during yearly assessments from inclusion up to age 4.5 years. Longitudinal data for 92 children were available for analysis. Repeated-measures analyses with random coefficient analysis were performed using linear mixed models.

Results Despite large variations among individuals in the development of mobility and self-care capabilities in young children with cerebral palsy, distinct developmental trajectories were found for children in different GMFCS levels. The estimated change per month differed significantly by GMFCS level for both outcomes.

Conclusions This longitudinal study provides an evidence base for prognosis in daily mobility and self-care skills in young children with cerebral palsy. The developmental trajectories for GMFCS levels can be helpful in communication between professionals and also in discussions of expectations and goal setting with families regarding mobility and self-care in the daily life of young children with cerebral palsy in neonatal follow-up and pediatric practice. *(J Pediatr 2014;164:769-74)*.

With a prevalence varying from 2.0 to 3.6 cases per 1000 live births,[1-3] cerebral palsy is the most common physical disability of childhood. Cerebral palsy is not a single, homogeneous health condition or disorder, but rather encompasses a wide variety of permanent disorders of development of movement and posture, attributed to nonprogressive disturbances occurring in the developing fetal or infant brain.[4] The motor disorder is often accompanied by disturbances in sensation, perception, cognition, communication, and behavior; epilepsy; and secondary musculoskeletal problems.[4,5] Thus, cerebral palsy can affect the development of children's everyday function, with a wide range of effects. In neonatal follow-up clinic or pediatric practice, parents often ask what their child's future will hold, including the prognosis for daily activities, such as walking and self-care.[6]

The Gross Motor Function Classification System (GMFCS) has become the international standard for describing subgroups of children with cerebral palsy across the severity spectrum.[7,8] It provides a 5-level classification of severity, ranging from walking without limitations (level I) to being transported in a wheelchair (level V).[7] Classification with the GMFCS after age 2 years is reliable and valid and can be used to predict later gross motor functioning.[9,10] The GMFCS facilitates communication between health professionals and families about developmental implications of cerebral palsy.[6,11]

Five distinct motor development curves based on the GMFCS have been described, identifying clinically relevant and statistically significant differences in the rates and limits of gross motor development in children and adolescents with cerebral palsy.[12,13] In these curves, the Gross Motor Function Measure, 66-item version[14] served as the outcome measure, used to assess gross motor capacity in a standardized environment (ie, therapy setting). A child's capacity reflects what he or she can do in a standardized environment, and capability represents what he or she can do at home, at school, and in the community.[15] For prognosis, it is important to create capability trajectories for mobility and self-care to enhance the Gross Motor Function Measure, 66-item version motor curves.

Little is known about the development of mobility and self-care capabilities of children with cerebral palsy.[16,17] In both studies, the GMFCS was found to be a

GMFCS	Gross Motor Function Classification System
PEDI	Pediatric Evaluation of Disability Inventory
PEDI-CAT	Pediatric Evaluation of Disability Inventory, computer adaptive testing
PEDI-FSS	Pediatric Evaluation of Disability Inventory, Functional Skills Scale

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This study is part of the PERRIN (Pediatric Rehabilitation Research in the Netherlands) research program, which is supported by the Netherlands Organization for Health Research and Development (1435.0011). The authors declare no conflicts of interest.

 http://dx.doi.org/10.1016/j.jpeds.2013.11.070

significant predictor of both mobility and self-care capabilities. To be able to inform parents and professionals early about a child's prognosis and facilitate communication in neonatal follow-up and pediatric clinical practice, more knowledge is needed regarding early development of children with cerebral palsy. The present study examined the development of mobility and self-care capabilities in young children (aged 1-4 years) with cerebral palsy, and evaluated whether the development of mobility and self-care capabilities differs for distinct GMFCS levels.

Methods

This study is part of the Pediatric Rehabilitation Research in the Netherlands Cerebral Palsy 0-5 study, a prospective longitudinal cohort study on the course and determinants of daily function in children aged 0 to 5 years with cerebral palsy. Data were collected at yearly assessments from inclusion at age 1.5 or 2.5 years up to age 4.5 years.

One hundred children and their parents were recruited at 5 university medical centers and 6 rehabilitation centers in The Netherlands. Parents were invited to participate in the study by the child's pediatrician, child neurologist, or rehabilitation physician. Children aged 1 year, 6 months (±2 months, corrected age for prematurity if applicable) or 2 years, 6 months (±1 month) at study entry with a confirmed diagnosis of cerebral palsy[4] were eligible. Children diagnosed with additional diseases and disorders affecting motor functioning and children whose parents lacked a basic knowledge of Dutch were excluded. All children participating in this study received regular care covered by the standard Dutch healthcare insurance, including rehabilitation services, such as physical and occupational therapy. The Medical Ethics Committee of University Medical Centre Utrecht and the Medical Ethics Committees of all participating centers approved the study, and all parents of participating children gave informed consent.

Mobility and self-care capabilities were assessed using the Pediatric Evaluation of Disability Inventory (PEDI), Functional Skills Scale (PEDI-FSS). The PEDI is a standardized instrument using parental reports in a structured interview.[18] Trained research assistants administered the PEDI in a face-to-face interview with a parent (usually the mother).

The mobility and self-care domains of the PEDI-FSS consist of 65 and 74 items, respectively, with each item scored as positive (1) or negative (0). A score of 1 is given when the child is capable of accomplishing the activity. The mobility domain samples transfer and indoor and outdoor mobility skills. The self-care domain samples eating, grooming, dressing, bathing, and toileting skills. Mobility and self-care sum scores were transformed to interval-scaled scores (0-100), reflecting an increasing level of functioning.

Severity of cerebral palsy was classified with the GMFCS.[7,19] The 5-level scale uses separate descriptions for different age groups and has shown to be stable over time.[9,10,20] In this study, all participating children were classified at age 2.5 years using the GMFCS descriptions for age 2 up to age 4 (**Table I**; available at www.jpeds.com).[7] For descriptive purposes, the child's type of motor impairment (ie, spastic, dyskinetic, or ataxic cerebral palsy) and, within spastic cerebral palsy, limb distribution (ie, unilateral or bilateral) were classified according to the guidelines for the Surveillance of Cerebral Palsy in Europe.[21]

Repeated-measures analysis with random coefficient analysis was performed using linear mixed models.[22] This method considers the dependency of repeated measures within the same individual by allowing the regression coefficients for intercepts and slopes to differ among subjects. The number and timing of observations per person are free to vary. In effect, average trajectories are estimated while predicting how each child's development differs from the average. First, the developmental trajectories of the outcome measures were modeled by age. The intercepts were treated as random effects to capture the variability in the data. Second, GMFCS was added to the model. The ratio likelihood test was used to compare models and to evaluate whether or not a random regression coefficient for age had to be considered in the models. Third, to test whether the development of mobility and self-care capabilities differed for distinct GMFCS levels, the interaction between age and GMFCS level was included. Finally, age^2 was added to the model to test quadratic trajectories.

Results

Out of 100 participants, 63 children were recruited at age 1 year, 6 months, and 37 were recruited at age 2 years, 6 months. Data from 8 children were excluded after baseline, including 3 children who were deemed ineligible because they did not fulfill the criteria for the diagnosis of cerebral palsy and 5 children who declined further participation. Thus, data for 92 children (**Table II**) were available for analysis. PEDI data for 52 children (56%) were available at age 1.5 years, for 86 children (92%) at age 2.5 years, for 86 children (92%) at age 3.5 years, and for 72 children (77%) at age 4.5 years. The main reason for dropout and missing data was the burden of the assessment on the child or family.

For both PEDI-FSS domains, mean scores increased with increasing age. Children with the most severe cerebral palsy had the lowest PEDI-FSS scores. Individual children showed wide variations in the development of motor capability and self-care capability (**Figures 1** and **2**; available at www.jpeds.com).

Repeated-measures analysis for both domains revealed a linear increase in all GMFCS levels between 1.5 and 4.5 years of age, with different baseline scores for the GMFCS levels. No significant random effect for age was found for either mobility or self-care, indicating no evidence of heterogeneity in the rate of change. Including fixed effects for GMFCS and the interaction between age and GMFCS in the models significantly improved the model fit ($P < .001$ for both models), indicating that children in different GMFCS level develop