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Determinants of Developmental Gain in Daily Activities in Young Children with Cerebral Palsy

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ABSTRACT. The aim of this study was to examine which child and family characteristics at the child's age of 2 years are determinants of development of self-care and mobility activities over a period of 2 years in young children with cerebral palsy (CP). Longitudinal data of 92 children, representing all levels of the Gross Motor Function Classification System (GMFCS), were analyzed. Children's self-care and mobility activities were assessed with the Functional Skills Scale of the Pediatric Evaluation of Disability Inventory. Development of self-care and mobility activities was related to several child determinants but no family determinants. GMFCS, type of CP, intellectual capacity, and epilepsy were related to the development of self-care and mobility activities, while manual ability and spasticity were related to development of mobility activities. Multivariate analysis indicated that GMFCS and intellectual capacity were the strongest determinants of development of self-care activities, and GMFCS was the strongest determinant of development of mobility activities. The change in self-care and mobility activities was less favorable in severely affected children with severe disability. Knowledge of GMFCS level and intellectual capacity is important in anticipating change over time and goal setting in young children with CP.

KEYWORDS. Cerebral palsy, child, determinants, development, family, mobility, self-care

The most common physical disability in childhood is cerebral palsy (CP) (Oskoui et al., 2013). Children with CP may experience limitations of self-care and mobility

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activities (Ketelaar et al., 2014; Østensjø et al., 2003; Østensjø et al., 2004; Smits et al., 2011; Vos et al., 2013). Well-accepted interventions to promote daily functioning in young children with CP are physical therapy and occupational therapy, although the evidence for the efficacy and working mechanisms of these therapies is inconclusive (Ketelaar et al., 2010; Law et al., 2011; Novak et al., 2013). A significant gap in our knowledge is our understanding of the variables that are related to the developmental gain in self-care and mobility activities in the first years of life of these children, and thus what to focus on in therapy.

Current knowledge about determinants of self-care and mobility activities of young children with CP is mainly based on cross-sectional studies with relatively wide age ranges. For example, Østensjø and colleagues (2003, 2004) studied children aged 2–7 years and Öhrvall and colleagues (2010) studied children aged 3–15 years. Results of these studies indicate that the level of self-care and mobility activities of young children with CP is related to the following *child-related* characteristics: severity of CP according to the Gross Motor Function Classification System (GMFCS; Palisano et al., 1997; Öhrvall et al., 2010; Østensjø et al., 2003), subtype of CP based on type and distribution of the motor impairment (Østensjø et al., 2004), manual ability (Öhrvall et al., 2010), intellectual capacity (Østensjø et al., 2003; Østensjø et al., 2004), and gross motor capacity (Østensjø et al., 2004). A retrospective longitudinal study in children aged 0–19 years found that the combination of the GMFCS level and the level of manual ability best predicted the levels of self-care activities and mobility activities (Phipps & Roberts, 2012). Although all of the above studies have provided valuable information on daily activities of young children and the associated factors, there is still a gap in our knowledge on early determinants at age 2 years that would help understand the *course* of development of daily activities over time in young children with CP.

Developmental gain in mobility and self-care activities and its determinants in young children are best investigated in studies with a prospective longitudinal design. For example, we have learned from a prospective longitudinal study in school-aged (5–9 years) children with CP that GMFCS level and intellectual capacity best predicted the development of self-care activities, whereas the development of mobility activities was best predicted by GMFCS level alone (Smits et al., 2011).

Because early childhood (2–4 years) is a period of particularly rapid developmental gain in skills such as mobility and self-care, knowing the rate of change as well as the determinants at age 2 that are related to the rate of change in these activities over time is pivotal. Based on GMFCS level, five distinct trajectories in the rate of developmental gain in self-care and mobility activities have been described for preschool children with CP (Ketelaar et al., 2014); children with a better gross motor function more rapidly acquired self-care and mobility activities. Nonetheless, large inter-individual differences were noted within GMFCS subgroups, reflected in wide confidence intervals around estimated change in mobility and self-care capability per month of age by GMFCS level (see Ketelaar et al., 2014). Insight into variables in addition to GMFCS that might be related to the variation between and within distinct developmental trajectories at this young age may provide

professionals and parents with knowledge to support realistic goal setting and to target physical therapy, occupational therapy, and other rehabilitation interventions.

Although there is still only a limited understanding of how contextual factors relate to the development of self-care and mobility activities, family ecology is thought to influence development and children's activities and participation in daily life (Bronfenbrenner, 1986; Laforme Fiss et al., 2013). More importantly, variables that relate to the child's functioning, together with variables that relate to family ecology, such as parental stress (Ketelaar et al., 2008), coping (Rentinck et al., 2007), reaction to diagnosis (Marvin & Pianta 1996), and perceived support (Rentinck et al., 2007), need to be investigated for a better understanding of the determinants of self-care and mobility activities over time in young children with CP.

The aim of this longitudinal study was to examine determinants of developmental gain in self-care and mobility activities in young children with CP (2–4 years of age). Selection of determinants was based on the literature as well as *our experience and perspectives*. We categorized the selection of determinants into: (i) determinants related to the child's functioning, and (ii) determinants related to the family's functioning.

METHODS

Design

This study is part of Pediatric Rehabilitation Research in the Netherlands (PER-RIN) CP 0–5, a prospective longitudinal cohort study on the course and determinants of daily functioning in children aged 0–5 years with CP. Data were collected during yearly assessments until the age of 4.5 years.

Participants

Parents of 100 children were recruited from five participating University Medical Centers and six rehabilitation centers to participate in our longitudinal study. Written informed consent was obtained from all participating parents on behalf of their child. Children were eligible when they had a confirmed diagnosis of CP, and were aged 1.5 years (± 2 months, age corrected for prematurity if applicable) or 2.5 years (± 1 month) at study entry. Of these 100 children (58 boys, 42 girls), 63 were included at 1.5 years of age and 37 at 2.5 years of age. Children were excluded when diagnosed with additional diseases and disorders affecting their motor functioning, other than CP, or if parents were uncomfortable about or unable to respond in Dutch. See Ketelaar et al. (2014) for a more detailed description of the participant selection. Details of participant characteristics are provided in the results section, as they are part of the independent variables under investigation. Ethical approval for the study was obtained from the committee for Medical Ethics of the University Medical Centre Utrecht, and the medical ethics committees of all participating centers in the study.

Measures

Self-Care and Mobility Activities

For the purpose of the present study, children's self-care and mobility activities were assessed with the self-care and mobility domain of the Functional Skills Scale of the Pediatric Evaluation of Disability Inventory (PEDI-FSS; Haley et al., 1992). The PEDI is a standardized assessment instrument using parental reports through structured interview in the self-care, mobility, and social function domains. The PEDI-FSS assesses what a child can do in his/her daily environment (Haley et al., 1992). The present study used the Dutch adapted and translated version of the PEDI, the PEDI-NL (Wassenberg-Severijnen & Custers, 2005), which has shown good reliability (Wassenberg-Severijnen et al., 2003) and content validity (Custers et al., 2002). Independent scale scores can be calculated for each domain.

Determinants Related to the Child

Determinants related to the child's functioning were defined by level of gross motor function, level of manual ability, type of CP, level of spasticity, intellectual capacity, and epilepsy.

The level of gross motor function was classified according to the GMFCS (Palisano et al., 1997). The system consists of a five-level ordinal scale, which describes differences in level of mobility abilities. Level I represents the best gross motor function, level V the lowest. The present study used the Dutch version of the GMFCS, which has good inter- and intra-rater reliability (Gorter et al., 2005).

The level of manual ability was classified according to the Manual Ability Classification System (MACS; Eliasson et al., 2006). This system consists of five levels, from level I "Handles objects easily and successfully" to level V "Does not handle objects and has severely limited ability to perform even simple actions." The MACS has shown good inter-observer reliability for children 2–5 years of age (Plasschaert et al., 2009). Validity of the MACS was shown for children 4–18 years of age (Eliasson et al., 2006).

Type of CP was classified according to the Surveillance of Cerebral Palsy in Europe (SCPE) – guideline (Surveillance of Cerebral Palsy in Europe, 2000). This guideline classifies CP into the subtypes of spastic, dyskinetic, and ataxic. In addition, topographical distribution in children with spastic CP is classified as unilateral involvement versus bilateral involvement. For the purpose of this study, we reduced the scores of the type of CP to three groups: bilateral spastic involvement, unilateral spastic involvement, and "other" (i.e., dyskinetic, ataxic, or mixed). The SCPE-guidelines has shown good inter-rater reliability (Sellier et al., 2012).

The child's level of spasticity was determined using the Spasticity Total Score (Gorter et al., 2009). The Spasticity Total Score is an ordinal scale assessing the level of spasticity in the muscle groups that are most relevant for gross motor function of the lower extremities (adductor muscles; hamstrings; gastrocnemius muscle). The total score is computed by adding scores (no spasticity, score 0; probable spasticity, score 1; definite presence of spasticity, score 2) of each muscle group for the right as well as the left side, with total scores ranging from 0 to 12. Assessment of spasticity is generally difficult. Valid and reliable assessment of spasticity in young children is often a challenge, and spasticity scales like the Spasticity Total

Score should be interpreted with caution (Gorter et al., 2009). However, this test is based on the reliable Tardieu Scale (Scholtes et al. 2006) and the measurement error is comparable to that of the Modified Tardieu Scale.

The intellectual capacity of the child was measured by the Bayley Scales of Infant Development- Second edition (BSID-II) – Mental Scale (Bayley, 1993). The mental scale can be used to assess a child's level of cognitive, language, and personal-social capacities. The mental scale consists of 187 items on sensation and perception, object constancy, memory and learning, verbal abilities, higher-order thinking, language, and computation. The BSID-II-Mental Scale has good psychometric properties (Bayley, 1993). In the present study we used the Dutch version of the BSID-II, which has sufficient intra-rater reliability and good inter-rater reliability, and validity (Van der Meulen et al., 2002).

Epilepsy was defined as having had more than one seizure during the previous two years based on parental report.

Determinants Related to the Family

Determinants related to the family's functioning were defined by level of stress, coping style, reaction to diagnosis, and perceived practical and financial support. Since mothers were the primary caregivers in most cases, we chose to focus on them.

Mothers' stress in relation to raising their child was measured by the Nijmeegse Ouderlijke Stress Index – Kort (NOSI-K; de Brock et al., 1992). The 25-item NOSI-K is the short version of the NOSI, which is a Dutch adaptation of the Parenting Stress Index (PSI). It measures parents' perceptions of stress in raising a child in terms of four parent domains (competence; attachment; depression; health) and six child domains (adjustment; mood; differentiability; entitlement; positive reinforcement; acceptance). The NOSI-K has shown good reliability and criterion validity (de Brock et al., 1992). For the purpose of this study, we reduced the norm scores of the NOSI-K to three groups: low, average, and high stress.

Coping style of the mothers was measured by the Utrechtse Copinglijst (UCL), a Dutch 47-item questionnaire to determine how parents handle problems and events in daily life, with satisfactory psychometric properties (Schreurs et al., 1988). The present study used two scales: the active confronting coping scale and the passive reactions coping scale of the UCL, since these differentiate between focus (problem vs. emotion) and approach (active vs. passive) (Wolters et al., 2010). Both the active confronting scale and the passive reaction scale have satisfactory reliability and validity (Schreurs et al., 1988).

Resolution of diagnosis was examined using the Reaction to Diagnosis Interview (RDI; Marvin & Pianta, 1996). The RDI is a semi-structured 10- to 20-min interview consisting of nine open-ended questions about parents' beliefs, memories, and emotional reactions, to assess parental resolution of a child's diagnosis. Coding of the RDI is done according to the guidelines of the Reaction to Diagnosis Classification System, which describes elements of resolution and lack of resolution, and rules for identifying these elements and weighing their relevance. In accordance with the guideline, parents were classified, based on their responses, as "resolved" or "unresolved" regarding their child's diagnosis. The RDI has shown to be reliable and valid (Marvin & Pianta, 1996). The present study used the Dutch translation

of the RDI, as described before by Schuengel and colleagues (2009) and Rentinck and colleagues (2010).

In order to limit the extent of the measurement instruments parents had to complete, perceived support was determined briefly by two self-developed questions. For the purpose of this study we assessed the amount (much, little, or no support) of practical support and financial support the parents experienced from their social network in raising their child with CP, by asking “Are you experiencing practical support from your own social network in raising your child?” and “Are you experiencing financial support from your own social network in raising your child?”

Procedure

All participating children and their parents visited the pediatric rehabilitation department of the medical center or rehabilitation center yearly. During these visits, trained research assistants administered the measurements. All research assistants had passed criterion tests for the measures for reliability after training. The PEDI-FSS was administered at each of 3 visits in a face-to-face interview with the parent (mostly the mother) or by telephone in case this could not take place during the visit. To examine which of the early determinants was related to the development of self-care and mobility activities over time, the data of the assessment at 2.5 years for all children and parents was used to relate the child and family determinants to the yearly PEDI-FSS data from age 2.5–4.5 years.

Data Analysis

Data of 92 children were used for analyses, since three of the 100 participating children recruited for the PERRIN 0–5 study no longer met the inclusion criteria of a diagnosis of CP at the 4.5-year assessment, and another five children only had one PEDI-FSS assessment. For all determinants, descriptive statistics including frequencies, means, and standard deviations were computed for age 2.5.

To analyze which determinants were related to development of self-care and mobility activities, we used random coefficient analysis, also known as multilevel analysis (*MLwiN version 2.25*). This analysis method considers the dependency of repeated measures within the same person by allowing the regression coefficients to differ between subjects. In addition, random coefficient analysis allows the number of observations per person to vary, so children with a missing assessment did not have to be excluded from the analysis. The ordinal-scale determinants GMFCS level, MACS level, type of CP, level of stress, and perceived support were analyzed as categorical determinants as represented by dummy variables. The determinants presence of epilepsy (yes/no) and reaction to diagnosis (resolved/unresolved) were analyzed as dichotomous determinants. Intellectual capacity, level of spasticity, and coping style of the mother were analyzed as continuous determinants. Time was expressed as the age in years at which the measurements took place (i.e., ages 2, 3, and 4 years).

Distinct models, including child or family determinants, were separately computed for the child’s development in terms of self-care and mobility scores on the PEDI-FSS. First, time effects were analyzed, and each of the determinants and their interaction terms with time was entered into the model separately. Thereafter, a multivariate model was built using a forward stepwise procedure, beginning

with the strongest related determinant. Subsequently, the other determinants were added one by one to the model as a single factor and were removed if not significant ($p > .05$). This was followed by adding the interaction terms with time to the model one by one, and these were also removed from the model if not significant ($p > .05$). We used a Chi Square test ($p < .05$) to determine statistical significance for the determinants and their interactions terms. To analyze whether the fit of the multivariate model improved by adding a determinant the likelihood ratio test was used. The log likelihood value can be used to compare the fit of two models, when comparing models of which one model is an extension of the other model.

RESULTS

Child and family characteristics (i.e., the determinants) of all subjects in this study at age 2.5 are presented in Table 1. PEDI-FSS scores at age 2.5 years were available for 86 children, at 3.5 years for 86 children, and at 4.5 years for 72 children. The main reason for missing data was the burden of the assessment for the child or the family.

PEDI-FSS self-care and mobility scores increased over time ($p < .001$). In the *development of self-care activities* there were significant differences (i.e., significant interaction with time) for GMFCS level, type of CP, intellectual capacity, and epilepsy. Parents of children with in GMFCS levels I and II, children with higher intellectual capacity, children with unilateral CP, and children without repeated seizures in the previous two years reported greater increase in PEDI-FSS self-care scores of their child during the study period (Table 2).

In the *development of mobility activities*, there were significant differences (i.e., significant interaction with time) for GMFCS level, MACS level, type of CP, level of spasticity, intellectual capacity, and epilepsy. Parents of children in GMFCS and MACS levels I, II, and III, children with unilateral CP, children with lower levels of spasticity, children with higher intellectual capacity, and children without repeated seizures in the previous two years reported greater increase in PEDI-FSS mobility scores of their child during the study period (Table 3). The development of both self-care and mobility activities was not related to any of the family determinants (Tables 2 & 3).

Multivariate Models for the Development of Self-Care and Mobility Activities

The results of the multivariate analysis of the development of self-care and mobility activities are presented in Table 4. The final model for the development of self-care activities contains GMFCS level, intellectual capacity, epilepsy, GMFCS level by time, and intellectual capacity by time. The significant interactions of both GMFCS level and intellectual capacity with time, as presented in Table 4, indicate that GMFCS level and intellectual capacity, are the strongest related determinants of the *developmental gain* in self-care activities. The final model for the development of mobility activities contains GMFCS level and GMFCS level by time. The significant interaction of GMFCS level and time, as presented in Table 4, indicate that GMFCS level is the strongest related determinant of the *developmental gain* in mobility activities. Since none of the family determinants we studied was significantly related to the development of self-care or mobility activities, no multivariate models could be constructed with the family determinants.

TABLE 1. Characteristics of the Children with Cerebral Palsy at 2.5 Years of Age and Families

Determinants			
Child Characteristics			
Age, years, mean (SD)		30.8	(1.1)
Gender, <i>n</i> (%)	Boy	54	(59)
	Girl	38	(41)
GMFCS, <i>n</i> (%)	Level I	28	(30)
	Level II	12	(13)
	Level III	23	(25)
	Level IV	20	(22)
	Level V	9	(10)
MACS, <i>n</i> (%)	Level I	23	(26)
	Level II	39	(42)
	Level III	15	(17)
	Level IV	5	(6)
	Level V	8	(9)
	<i>Unknown:</i>	2	
Type of CP, <i>n</i> (%)	Spastic bilateral	49	(53)
	Spastic unilateral	40	(44)
	Other	3	(3)
Spasticity total score, mean (SD)		2.06	(2.12)
Cognitive capacity, mean (SD)		83.5	21.9
Epilepsy, <i>n</i> (%)	Yes	23	(25)
	No	68	(75)
	<i>Unknown:</i>	1	
Family characteristics			
NOSI-K, <i>n</i> (%)	Low	27	(34)
	Average	25	(32)
	High	27	(34)
	<i>Unknown:</i>	13	
UCL-active coping, mean (SD)		18.60	(3.97)
UCL-passive coping, mean (SD)		11.26	(2.88)
RDI, <i>n</i> (%)	Resolved	33	(90)
	Unresolved	4	(10)
	<i>Unknown:</i>	55	
Social support practical, <i>n</i> (%)	None	4	(5)
	Little	39	(48)
	Much	38	(47)
	<i>Unknown:</i>	11	
Social support financial, <i>n</i> (%)	None	49	(61)
	Little	23	(28)
	Much	9	(11)
	<i>Unknown:</i>	11	

Abbreviations: SD, standard deviation; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System, CP, Cerebral Palsy; BSID-II-Mental Scale, Bayley Scales of Infant Development- Second edition-Mental Scale; NOSI-K, Nijmeegse Ouderlijke Stress Index – Kort; UCL, Utrechtse Copinglijst; RDI, Reaction to Diagnosis Interview.

DISCUSSION

The aim of this prospective longitudinal study was to examine which child and family determinants are related to the change in self-care and mobility activities in young children with CP. We found none of the family determinants we studied to be related to the developmental gain in self-care or mobility activities. For all significant determinants related to the child, the results showed the same pattern of change in self-care and mobility activities, with a less favorable trajectory in

TABLE 2. Results of Random Coefficient Analyses, Showing the Relationship Between Child and Family Determinants and the Development of Self-Care Activities

		Determinants Regression coefficient (SE)	Determinants * time Regression coefficient (SE)
Child related determinants			
GMFCS	I	0 (ref)	0 (ref)
	II	-0.62 (3.54)	-2.00 (1.08)
	III	0.14 (2.80)	-3.65 (0.87)**
	IV	-6.99 (2.94)	-4.40 (0.90)**
	V	-18.27 (4.06)	-5.53 (1.31)**
MACS	I	0 (ref)	0 (ref)
	II	3.77 (2.52)	-1.67 (0.88)
	III	-7.23 (3.22)	-2.38 (1.16)
	IV	-11.00 (4.51)	-3.59 (1.57)
	V	-11.61 (4.89)	-4.70 (1.58)
Type of CP	Bilateral	0 (ref)	0 (ref)
	Unilateral	5.01 (2.41)	2.06 (0.76)**
	Other	3.35 (7.45)	-1.31 (2.18)
Spasticity total score		-0.48 (0.68)	-0.30 (0.22)
Cognitive capacity		0.13 (0.06)	0.09 (0.02)**
Epilepsy	Yes	0 (ref)	0 (ref)
	No	-6.43 (2.71)	-2.95 (0.83)**
Family related determinants			
NOSI-K	Low	0 (ref)	0 (ref)
	Average	-1.12 (2.86)	-1.95 (1.01)
	High	-4.93 (2.79)	-1.09 (0.97)
UCL-active coping		0.19 (0.29)	-0.01 (0.10)
UCL-passive coping		0.05 (0.39)	-0.02 (0.13)
RDI	Resolved	0 (ref)	0 (ref)
	Un resolved	2.16 (8.25)	0.64 (1.41)
Social support – Practical	None	0 (ref)	0 (ref)
	Little	-8.58 (6.19)	-1.49 (2.00)
	Much	-5.17 (6.18)	-2.38 (1.99)
Social support – Financial	None	0 (ref)	0 (ref)
	Little	1.14 (3.00)	-0.57 (0.91)
	Much	3.17 (4.16)	-1.68 (1.25)

Abbreviations: SE, standard error; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System, GMFM-66, Gross Motor Function Measure-66 items; NOSI-K, Nijmeegse Ouderlijke Stress Index – Kort; UCL, Utrechtse Copinglijst; RDI, Reaction to Diagnosis Interview.

** $p < .05$.

children with severe limitations in motor ability and intellectual capacity. The multivariate analysis showed that GMFCS level and intellectual capacity were the most important determinants of the development of self-care activities, and GMFCS level was the most important determinant of the development of mobility activities.

The importance of the GMFCS level in predicting change in self-care and mobility activity scores in young children with CP as measured by the PEDI-FSS is consistent with findings of previous studies, including two cross-sectional studies in children aged 2–7 years (Østensjø et al., 2003) and in children and adolescents aged 3–15 years (Öhrvall et al., 2010), a retrospective longitudinal study in children aged 1–19 years (Phipps & Roberts, 2012), and a prospective longitudinal study on developmental trajectories of daily activities in children and adolescents aged 1–20 (Vos et al., 2013). In contrast to the last of these studies, our study of young

TABLE 3. Results of Random Coefficient Analyses, Showing the Relationship Between Child and Family Determinants and the Development of Mobility Activities

		Determinants Regression coefficient (SE)	Determinants * time Regression coefficient (SE)
Child related determinants			
GMFCS	I	0 (ref)	0 (ref)
	II	-9.99 (4.52)	-0.53 (1.45)
	III	-17.38 (3.56)	-1.66 (1.56)
	IV	-23.45 (3.74)	-4.81 (1.20)**
	V	-29.71 (5.20)	-7.90 (1.75)**
MACS	I	0 (ref)	0 (ref)
	II	2.55 (3.91)	-1.39 (1.09)
	III	-9.90 (4.98)	-2.37 (1.42)
	IV	-16.69 (7.11)	-7.17 (1.91)**
	V	-15.83 (6.80)	-7.18 (1.98)**
Type of CP	Bilateral	0 (ref)	0 (ref)
	Unilateral	13.60 (3.29)	3.06 (0.98)**
	Other	5.61 (10.21)	-1.36 (2.84)
Spasticity total score		-1.91 (0.94)	-0.54 (0.27)**
Cognitive capacity		0.38 (0.07)	0.07 (0.02)**
Epilepsy	Yes	0 (ref)	0 (ref)
	No	-10.77 (3.90)	-2.33 (1.14)**
Family related determinants			
NOSI-K	Low	0 (ref)	0 (ref)
	Average	-9.41 (4.36)	-0.94 (1.35)
	High	-12.98 (4.26)	-0.07 (1.30)
UCL-active coping		0.44 (0.47)	-0.10 (0.14)
UCL-passive coping		-0.52 (0.64)	0.04 (0.18)
RDI	Resolved	0 (ref)	0 (ref)
	Un resolved	8.47 (8.54)	-1.57 (2.48)
Social support – Practical	None	0 (ref)	0 (ref)
	Little	-11.09 (9.05)	-1.24 (2.68)
	Much	-9.58(9.04)	2.25 (2.68)
Social support – Financial	None	0 (ref)	0 (ref)
	Little	-0.47 (4.37)	-1.16 (1.22)
	Much	-1.69 (6.09)	-0.84 (1.67)

Abbreviations: SE, standard error; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System, GMFM-66, Gross Motor Function Measure-66 items; NOSI-K, Nijmeegse Ouderlijke Stress Index – Kort; UCL, Utrechtse Copinglijst; RDI, Reaction to Diagnosis Interview.

** $p < .05$.

children with CP found a relation between intellectual capacity and the development of both self-care and mobility activities, whereas Vos et al. suggest a stronger relationship between intellectual capacity and daily activities in adolescents and young adults but not in younger children. A possible explanation for this difference is that we studied capability of self-care and mobility activities, i.e. what a child can do in a daily environment, whereas Vos et al. studied performance of self-care and mobility activities, i.e., what a child actually does in a daily environment, which are different constructs of activities (Holsbeeke et al., 2009).

To our knowledge, ours is the first study to investigate the relationship between family determinants and change in self-care and mobility activities in young children with CP. We did not find statistically significant relations between our outcomes of interest and the specific family determinants available for this analysis,

TABLE 4. Results of the Random Coefficient Analyses, Showing the Multivariable Models

		PEDI-FSS Self-care Regression coefficient (SE)	PEDI-FSS Mobility Regression coefficient (SE)
Constant		37.39 (8.20)	43.18 (2.37)
Time		4.50 (2.11)	8.88 (0.77)
GMFCS	I	0 (ref)	0 (ref)
	II	3.70 (4.30)	-9.99 (4.52)
	III	3.10 (3.58)	-17.38 (3.56)**
	IV	-4.47 (4.33)	-23.45 (3.74)**
	V	-13.82 (5.48)	-29.71 (5.20)**
GMFCS* Time	I	0 (ref)	
	II	-2.73 (1.15)	-0.53 (1.45)
	III	-3.44 (0.95)**	-1.66 (1.16)
	IV	-3.63 (1.14)**	-4.81 (1.20)**
	V	-5.36 (1.49)**	-7.90 (1.75)**
Cognitive capacity		-0.02 (0.08)	
Cognitive capacity *Time		0.05 (0.02)**	
Epilepsy	Yes	0 (ref)	
	No	-5.84 (2.21)**	

Abbreviations: PEDI-FSS, Pediatric Evaluation of Disability Inventory-Functional Skills Scale; SE, standard error; GMFCS, Gross Motor Function Classification System

** $p < .05$.

including mother's reaction to diagnosis, parental coping style, the level of stress or perceived practical and financial support. A notable finding was that, 90% of the parents were classified as "resolved" based on the RDI measure when their child was aged 2.5 years (Rentinck et al., 2010), which might explain why no statistically significant relation between this determinant and the development of self-care and mobility activities was found.

The fact that we did not find a relation with parental coping style, however, is in accordance with a longitudinal study in school-aged children with CP (Smits et al., 2011). Even though it is assumed by therapists that the support that parents receive might be a determinant of motor change (Bartlett & Palisano, 2002), we found no relationship between perceived practical and financial support and the development of self-care or mobility activities over time in our young children with CP. A standardized measure would have provided more detailed information on perceived support. Since the concept of family ecology is broader than the family determinants we have studied, we suggest including a wider range of variables of family ecology in future studies of the development of activities in children with CP.

The complexity of understanding variability between young children with CP in their development is acknowledged in the literature (Bartlett et al., 2014; Wright et al., 2008). Bartlett and colleagues (2014) studied child, family, and service determinants together in order to explain changes in gross motor function in children with CP over a 1-year period. Their multivariate model did not explain much more variance than a preliminary analysis based on GMFCS level and age alone (Bartlett et al., 2014). The authors argued that this might be due to the non-linearity of development and that instead of predicting change, it would be more sensible to predict future function. Since development has been studied with outcome measures such as the Gross Motor Function Measure (GMFM; Russell et al., 2002) and the PEDI,

which may have limitations in detecting change that is relevant to the individual child, we suggest to explore the use of individual outcome measures, for example the Canadian Occupational Performance Measure (COPM; Law et al., 1998). Future research with a longitudinal design is needed to explore this.

Some methodological issues should be considered when interpreting the results. The sample size study limited the number of determinants that could be analyzed. In addition, the number of children allocated to subgroups was low for some of the determinants. For example, only 5 children were classified as MACS level IV and 8 children as level V. Although it should be noted that the distribution of children over the groups of the MACS corresponds with that in the population seen in rehabilitation practice (Shevell et al., 2013), these small numbers may have influenced the outcome of the data analyses. Furthermore, we based the determinants related to the family's functioning on the responses of the primary caregivers, in most cases mothers. Responses from fathers, might have led to different results. Finally, in generalizing our findings to other countries or health care systems, one should realize that all children in our study received regular care, which for children with CP under age of 4 in the Netherlands means that they usually had physical and occupational therapy 1–3 times a week.

Our findings show that it is important for service providers and clinicians to take both a child's GMFCS level and their intellectual capacity, as measured by the mental scale of the BSID-II, into account in the process of shared goal setting with parents. Early assessment of a child's potential and an interdisciplinary approach are recommended in the support of young children with CP and their families.

CONCLUSIONS

The results of this prospective longitudinal study of 92 children with CP, and their families showed that the development in self-care and mobility activities, as measured with the PEDI, was less favorable in children with severe limitations in motor ability and intellectual capacity. The results of multivariate analysis indicate that the children's GMFCS level and intellectual capacity and GMFCS level alone were the strongest related determinants of the rate of change in developmental gain in self-care and mobility activities, respectively. Assessing GMFCS level and intellectual capacity of young children with CP is recommended when goal setting and planning interventions for young children with CP.

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