



# Factors contributing to the longitudinal development of social participation in individuals with cerebral palsy



Siok Swan Tan<sup>a,b,\*</sup>, Wilma M.A. van der Slot<sup>a,c</sup>, Marjolijn Ketelaar<sup>d,e</sup>,  
Jules G. Becher<sup>f</sup>, Annet J. Dallmeijer<sup>f</sup>, Dirk-Wouter Smits<sup>d,e</sup>,  
Marij E. Roebroek<sup>a,c</sup>, on behalf of the PERRIN+ study group<sup>1</sup>

<sup>a</sup> Erasmus MC University Medical Center, Department of Rehabilitation Medicine, Rotterdam, The Netherlands

<sup>b</sup> Erasmus University Rotterdam, Institute for Medical Technology Assessment, Rotterdam, The Netherlands

<sup>c</sup> Rijndam Rehabilitation Institute, Rotterdam, The Netherlands

<sup>d</sup> Brain Center Rudolf Magnus and Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, The Netherlands

<sup>e</sup> Partner of NetChild, Network for Childhood Disability Research, The Netherlands

<sup>f</sup> VU University Medical Center, department of Rehabilitation Medicine, Amsterdam, The Netherlands

## ARTICLE INFO

### Article history:

Received 4 May 2015

Received in revised form 23 March 2016

Accepted 29 March 2016

Available online 14 July 2016

### Keywords:

Cerebral palsy

Social participation

Associated factors

Longitudinal development

Social functioning

Lifespan expectations

## ABSTRACT

**Aims:** We aimed to determine factors associated with the longitudinal development of social participation in a Dutch population of individuals with Cerebral Palsy (CP) aged 1–24 years. **Methods and procedures:** For this multicentre prospective longitudinal study, 424 individuals with CP aged 1–24 years were recruited from various rehabilitation centers in The Netherlands. Social participation was measured with the Vineland Adaptive Behavior Scales. We assessed associations with age, intellectual impairment, level of gross motor function, gender, type of CP, manual ability, epilepsy, hearing-, visual-, speech impairment and pain, internalizing- and externalizing behavioral problems, type of education and parental level of education. Each individual was measured 3 or 4 times. The time between measurements was 1 or 2 years.

**Outcomes and results:** Epilepsy and speech impairment were each independently associated with the longitudinal development of social participation. The effects were rather small and did not change with age. Also, a trend was found that children attending special education develop less favorably in social participation.

**Conclusions and implications:** Our results might provide parents and caregivers with starting points to further develop tailored support for individuals with epilepsy, with speech impairment and/or attending special education at risk for suboptimal social participation.

© 2016 Published by Elsevier Ltd.

## 1. What this paper adds

This is the first study using a large dataset of individuals with Cerebral Palsy (CP) aged 1–24 years that longitudinally identified a number of risk factors for an unfavorable development of social participation over a broad timespan.

\* Corresponding author at: P.O. Box 2040, 3000 CA Rotterdam, The Netherlands.

E-mail address: [s.s.tan@erasmusmc.nl](mailto:s.s.tan@erasmusmc.nl) (S.S. Tan).

<sup>1</sup> Members of the PERRIN+ study group are listed in the Acknowledgements.

In addition to intellectual impairment and level of gross motor function, epilepsy and speech impairment are risk factors for an unfavorable development regarding social participation for individuals with CP in the long term. Also, a trend was found that children attending special education develop less favorably in social participation.

Timely identification of children with CP who are at an increased risk for suboptimal social participation may assist parents and caregivers in tailoring guidance and support to achieve better outcomes later in life.

## 2. Introduction

With a prevalence of about 2 per 1000 live-births, cerebral palsy (CP) is one of the most common childhood-onset disabilities (Odding, Roebroeck, & Stam, 2006). CP has historically been studied in relation to the pathology and etiology of the impairments. The publication of the International Classification of Functioning, Disability and Health, Child and Youth version (ICF-CY), however, incentivized research interest in the consequences for activities and participation. Participation is a multidimensional construct addressing, among others, social participation which is related to the aspects of social connection, social inclusion and membership and personal and societal responsibilities (Hammel et al., 2008). In the present paper, we focus specifically on these aspects, which are best covered by the ICF domains of Interpersonal interactions and relationship (D7) and Recreation and leisure (D920) (World Health Organisation (WHO) & International classification of functioning, disability and health, 2001).

Knowledge about long-term outcomes may support individuals with CP and their families in setting realistic expectations and support practitioners in optimizing interventions at an early age (Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009). Except for gross motor function, data on long-term outcomes for individuals with CP were not yet available. Therefore, the longitudinal Pediatric Rehabilitation Research in The Netherlands (PERRIN) program ([www.perrin.nl](http://www.perrin.nl)) recently determined the developmental trajectories of different outcome measures (Smits et al., 2013; Tan, Wiegerink et al., 2014; Tan, van Meeteren et al., 2014; Vos et al., 2013, 2014), including social participation (Tan, Wiegerink et al., 2014; Tan, van Meeteren et al., 2014). Age, intellectual impairment and level of gross motor function were observed to be the *primary factors* of the longitudinal development of social participation in individuals with CP aged 1–24 years. For individuals without intellectual impairment, the level of social participation increases with age and stabilizes at about 18 years. On the average, these individuals reach social participation levels similar to typically developing individuals. The trajectories are significantly less favorable for individuals with intellectual impairment and for individuals with the lowest level of gross motor function (Tan, Wiegerink et al., 2014; Tan, van Meeteren et al., 2014).

The longitudinal development of social participation may vary considerably between individuals with CP (Dang et al., 2014; Michelsen et al., 2009; van der Slot et al., 2010). Insight into the factors associated with the longitudinal development of social participation is essential to understand this observed variability. If factors can modify the relationship between the social participation of young adults and their corresponding scores earlier in life, they may help children and adolescents with unfavorable levels of participation to achieve better outcomes later in life. Modifiable factors may thus improve social participation for specific subgroups of individuals with CP, as they provide starting points to tailor interventions according to specific risk factors.

In addition to the *primary factors* age, intellectual impairment and level of gross motor function, previous studies have examined the association of social participation with several additional factors. However, these studies have been cross-sectional or have focused on a small age range, and have often employed a broader definition of social participation. For example, the Dutch PERRIN program investigated associated factors of several domains of participation for three age cohorts of individuals with CP within small age ranges: children (5–9 years), adolescents (9–16 years) and young adults (16–24 years). For children, social participation was assessed with the domain of social functioning of the Pediatric Evaluation of Disability Inventory Functional Skills Scale (PEDI-FSS) which is best covered by the ICF domains of Learning and applying knowledge (D1), Communication (D3), Doing Housework (D640), Interpersonal interactions and relationship (D7) and Recreation and leisure (D920). Social functioning was best predicted by manual ability and parental level of education (Smits et al., 2011). For adolescents, social participation was measured with the domain of socialization of the Vineland Adaptive Behavior Scales (VABS) survey which is best covered by the ICF domains of Interpersonal interactions and relationship (D7) and Recreation and leisure (D920). Epilepsy, speech impairment, externalizing behavior problems, parental level of education and parental stress were associated with greater restrictions in socialization (Voorman, Dallmeijer, Van Eck, Schuengel, & Becher, 2010). For young adults, social participation was assessed with the dimension of social roles of the Life Habits questionnaire which is best covered by the ICF domains of Interpersonal interactions and relationship (D7), Major life areas (D8) and Community, social and civic life (D9). Manual ability and general self-efficacy proved to be important factors (Donkervoort et al., 2007; van Meeteren et al., 2008; van der Slot et al., 2010).

Another study examining associated factors of social participation for individuals with CP is the European Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE). The cross-sectional SPARCLE study was carried out with 818 children with CP aged 8–12 years across 9 European regions and also used the dimension of social roles of the Life Habits questionnaire to measure social participation (ICF domains D7–D9). Significant associations were observed between both the difficulty and frequency of social participation and manual ability, speech impairment and pain (Fauconnier et al., 2009; Michelsen et al., 2009). Gender was associated with different frequency (Michelsen et al., 2009), whereas type of CP, visual impairment and the physical, social and attitudinal environment were additionally associated with greater difficulty of social participation (Colver et al., 2012; Fauconnier et al., 2009). Following up these children at the age of 13–17 years

Download English Version:

<https://daneshyari.com/en/article/371010>

Download Persian Version:

<https://daneshyari.com/article/371010>

[Daneshyari.com](https://daneshyari.com)