



Frequency of participation and association with functioning in adolescents born extremely preterm – Findings from a population-based cohort in northern Germany



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ABSTRACT

Background: Outcomes after extremely preterm birth (< 28 weeks gestation) have been studied intensely, and follow-up into adulthood is well-established. Following the introduction of the *International Classification of Functioning, Disability and Health*, participation has been recognized to be a relevant outcome in rehabilitation research. During adolescence, participation is crucial to adapting to new social roles. The aim of our study was to investigate participation in the domains *Autonomy*, *Relationships* and *Community Recreation*.

Methods: Participation was assessed as part of a cross-sectional, population-based study in a German federal state examining all adolescents born between January 1997 and December 1999 at under 27 weeks gestation. Of the surviving 90 adolescents, 72 (80%) were followed-up at age 14 to 17. Frequency of participation was assessed using the short form of the *Questionnaire of Young People's Participation* and compared to matched peers. Associations with physical, cognitive, and psychological functioning and contextual factors were examined using multivariate regression.

Results: Frequency of participation in *Autonomy*, *Relationships*, and *Community Recreation* in adolescents born extremely preterm was significantly lower than that of matched peers from the general population ($p < 0,001$). Lower frequency of participation in *Autonomy* and *Relationships* was associated with severe physical and cognitive impairment, and psychological problems. Fifty-seven percent of the adjusted variance in *Autonomy* and 31% of the adjusted variance in *Relationships* was explained by our regression models.

Conclusion: Further research is warranted to investigate additional factors associated with the restricted frequency of participation of adolescents born preterm to design suitable interventions for improving participation.

1. Introduction

Recent decades have shown increased survival rates in individuals born extremely preterm (< 28 weeks gestation), whilst the high rates of cerebral palsy (CP), neuromotor and cognitive impairment remained constant and were inversely correlated with gestational age [1–3]. During adolescence, psychological problems, learning deficits and intellectual disability were identified to further impede a successful transition to adulthood [4–7]. Increased rates of social-emotional problems, attention deficit disorders and autism spectrum disorders have been reported [8,9]. Young adults born preterm finished school less often, had lower grades on their school diplomas, and were less likely to obtain a college education [10,11].

Participation has become a relevant research objective from the societal perspective of health and disability. The *International Classification of Functioning, Disability, and Health* (ICF) constitutes the conceptual framework for participation and its standardized assessment. Participation is understood as “involvement in life situations” [12] and is conceptualized within a biopsychosocial model of health. Participation, activities, body functions and health conditions interact with environmental and personal factors and influence one another multidirectionally, resulting in an individual's health status [12].

During transitional periods, such as adolescence, participation is understood to be essential for the satisfactory adoption of new social roles [13]. Autonomy has been argued to be both a requirement for and a major component of participation [14,15]. Participation among

Abbreviations: ICF, International Classification of Functioning, Disability and Health; QYPP-SF, short form of the Questionnaire of Young People's Participation; CP, cerebral palsy; SPARCLE, Study of Participation of Children with Cerebral Palsy living in Europe; SDQ, Strengths and Difficulties Questionnaire; M-ABC-2, Movement Assessment Battery for Children – Second Edition; GMFCS, Gross Motor Function Classification System

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adolescents with disabilities, particularly cerebral palsy, has been examined in various studies [16–20]. The importance of participation and relationships for young adults born preterm has been recognized [21].

This study aimed to investigate the frequency of participation in three domains, *Autonomy*, *Relationships*, and *Community recreation*, using an ICF-based instrument among adolescents born extremely preterm in comparison to a matched reference cohort from the general population. Additionally, the participation of the extremely preterm cohort was examined with respect to physical and cognitive functioning, psychological problems, age, gender and socio-economic status.

2. Methods

2.1. Study population

The frequency of participation of adolescents born extremely preterm was assessed in a regional population-based cohort in Schleswig-Holstein, the northernmost federal state in Germany. Individuals born extremely preterm (at under 27 weeks gestation) in one of the state's eight neonatal units between January 1st, 1997 and December 31st, 1999 were included in the study. Ninety of the 154 children in this cohort survived until the assessment at 14 to 17 years of age.

2.2. Assessment of participation

The short form of the *Questionnaire of Young People's Participation* (QYPP-SF) was used to examine participation. It constitutes a preliminary version of the *Questionnaire of Young People's Participation* (QYPP [15]) and measures frequency of participation of youth with and without disabilities by means of 31 ICF-based items [20]. Most answer categories are ordinal and comprise frequencies ranging from “every day” to “never”. Thirteen items make up the three domains of the QYPP-SF: *Autonomy*, *Relationships*, and *Community recreation* (Table 1). In this article, participation was assessed only with regard to these three domains.

2.3. Assessment of functioning and contextual factors

Adolescents born extremely preterm were examined by two paediatrically trained researchers at the paediatric outpatient clinic of the University of Luebeck between 11/2013 and 4/2014. In a few cases,

Table 1
Domains and items of the QYPP-SF with corresponding ICF domains.

Domains and items of the QYPP-SF	ICF domains
Autonomy - I decide how to organize my daily routine. - I decide how to spend my money. - I choose with whom I spend my spare time. - I have discussions about when I might leave home to live independently.	No ICF domain
Relationships - Combined item: I use the phone to communicate. - I use online communication. - I spend time with my friends on my own without my parents, carers or other adults present. - I spend leisure time with a boyfriend/girlfriend (romantic relationship). - I spend time on my own with a boyfriend/girlfriend without other people present.	Communication; interpersonal interactions and relationships
Community recreation - I go shopping for pleasure. - I eat meals out in cafés or restaurants. - I go to live music events. - I go on holiday with my family.	Community, social and civic life; mobility

home visits were scheduled to include families who were otherwise unable to participate in the study. Motor function was assessed by a clinical examination using the subtests “balance” and “manual dexterity” of the *Movement Assessment Battery for Children*, 2nd Edition (M-ABC-2 [22]). If cerebral palsy was diagnosed, severity was classified according to the *Gross Motor Function Classification System* (GMFCS [23]). The neurosensory status included the assessment of motor function and auditory and visual impairments. Adolescents were then categorized into the following four groups: no, mild, moderate and severe dysfunction of neurosensory status (refer to [24] for detailed methodological information).

Psychological problems were documented using the total difficulties score of the *Strengths and Difficulties Questionnaire* (“SDQ score” [25,26]). The German version of the *Wechsler Intelligence Scale for Children* was used to examine cognitive function (WISC IV, 4. Edition [27]). Contextual factors, including age and gender, were investigated by means of a parental survey. The *Family Affluence Scale* was used to assess familial socio-economic status (SES) by asking adolescents about the number of consumer goods and vehicles in their homes and family vacations [28]. The instrument's internal consistency and correlation with macroeconomic indicators have been demonstrated [29].

2.4. Reference population

Data from a regional reference cohort were available for the QYPP-SF and suitable for comparison with our cohort (data from SPARCLE 2: *Study of Participation of Children with Cerebral Palsy living in Europe* [20]). Students aged 12 to 18 ($N = 972$) in 12 public secondary schools in Schleswig-Holstein had completed the QYPP-SF in 2009 and 2010 and reported age, gender, and familial affluence.

2.5. Matching

The reference group from the general population showed a distribution of age, gender, and SES that differed markedly from the preterm cohort. To prevent bias, we conducted a 1:3 matching and paired up each adolescent from the preterm cohort with three adolescents from the general population that matched them on these parameters.

2.6. Statistics

An analysis of the domains was conducted in a procedure paralleling the work in the SPARCLE 2 study [20]. The items “using the phone” and “online communication” were combined. Variables were treated as continuous and were normalized to cope with differing distributions of answers. Domain scores were generated by calculating the raw mean of all four z-transformed item scores or three items scores in case of missing answers, applying a missing data tolerance of 25% per domain. Higher domain scores indicated a higher frequency of participation.

Group characteristics were reported using descriptive statistics. *t*-tests were carried out for comparison of means. Boxplot graphs were utilized for visualization of domain scores according to functional status. For analysis of variance of the preterm cohort, three sequential linear regression models were calculated for *Autonomy*, *Relationships* and *Community recreation*. Age, gender, familial affluence, neurosensory status, intelligence quotient, and the SDQ score were included as independent variables (refer to Table 4 for order of entry). Neurosensory status served as a marker of physical functioning, intelligence quotient served as a marker of cognitive functioning, and the SDQ score represented psychological problems. The strength of associations among variable pairs included in regression models was determined by means of Spearman correlations (Table 3).

Prior to regression modelling, an evaluation of normality required the following transformation of two variables: *Community recreation* was inverted, and a square root transformation of the SDQ score was

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