



## Child and environmental factors associated with leisure participation in adolescents born extremely preterm



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### ABSTRACT

**Background:** Developmental impairments persist among adolescents born extremely preterm, and these individuals are at an increased risk for chronic disease later in life. Participating in active and positive leisure activities may act as a buffer against negative outcomes, but involvement in active-physical and skill-based activities is low in youth born preterm.

**Aims:** To explore the child and environmental determinants of leisure participation among adolescents born extremely preterm.

**Study design:** Cross-sectional study.

**Subjects:** Participants were recruited from the hospital's Neonatal Follow-Up Program and included 128 adolescents born preterm (mean gestational age: 26.5 weeks).

**Outcome measures:** Leisure participation was assessed using the Children's Assessment of Participation and Enjoyment. Potential determinants were assessed using standardized tests and questionnaires. Selected factors were entered into five separate multivariable regression models.

**Results:** Child and environmental factors contributed between 21% (skill-based) and 52% (active physical) of the adjusted variance for participation intensity. Lower gestational age was associated with greater participation in recreational activities. Male sex, higher maternal education and better motor competence were associated with involvement in active-physical activities. Being older and feeling socially accepted were associated with participation in social activities. Families oriented to hobbies and higher maternal education were associated with participation in skill-based activities. Preference was the strongest determinant of participation in all five leisure activities.

**Conclusions:** Activities should be adapted to individual skill level, include family and peers, foster social acceptance and be driven by the adolescent's preferences. Although certain factors cannot be modified, they can be used to identify adolescents at risk for low participation.

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**Abbreviations:** CAPE, Children's Assessment of Participation and Enjoyment; CASE, Child and Adolescent Scale of Environment; DAILY, Determinants of Active Involvement in Leisure for Youth; DMQ, Dimensions for Mastery Questionnaire; FES-4th edition, Family Environment Scale – 4th edition; ICF-CY, International Classification of Functioning, Disability and Health, Children & Youth Version; MABC-2, Movement Assessment Battery for Children, 2nd version; MUHC, McGill University Health Centre; NNFU, Neonatal Follow-up Program; PAC, Preferences for Activities of Children; SDQ, Strengths and Difficulties Questionnaire; SPP, Self-Perception Profile; SSS, Social Support Scale; Vineland-II, Vineland Adaptive Behavior Scale, Second edition.

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### 1. Introduction

Traditionally, the consequences of disease were portrayed as causing either morbidity or mortality [1] with the focus of service provision being specifically impairment-based, and rarely included participation-based goals which families tend to prioritize. The World Health Organization has recognized participation as a key concept in its International Classification of Functioning, Disability and Health-Child and Youth version in 2007 (ICF-CY) [2]. This bio-psycho-social model illustrates how functioning with its components *Body Functions, Body Structures and Activities and Participation* is seen in relation to a child's health condition, as well as *Personal and Environmental Contextual Factors* (Fig. 1). Using such a framework in pediatric health care may

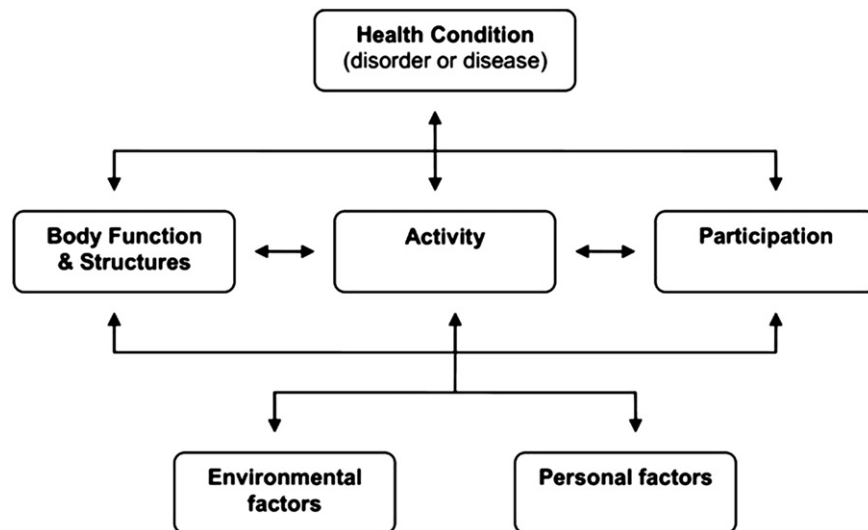


Fig. 1. International Classification of Functioning, Disability and Health (2).

promote client-centered care, identify the factors enhancing or impeding participation, and support the development of tailored programs to remove potential barriers to participation. The role of the family and social environment (e.g. home, schools, recreation settings) in defining participation from early childhood to adolescence is acknowledged in the ICF-CY. Leisure refers to the positive ways individuals fill their free time, and encompasses sedentary, passive activities such as watching TV, active pursuits such as sports, or activities focusing on skill-building and competencies such as playing a musical instrument. Leisure also includes hobbies or activities related to socialization, chores and employment. Additionally, an important aspect of leisure is that of free choice. Adolescence is a time of growing autonomy, peer interactions and increased opportunities to make decisions [3].

Participation in preferred and selected leisure pursuits is experienced positively and may contribute to adolescent development. Leisure provides constructive opportunities for adolescents, with benefits ranging from better physical, social and emotional health [4] to educational successes [5]. Evidence has shown that participation in leisure activities, particularly physical activity, declines during adolescence [6] and into adulthood [7]. Adolescence is an important time when a child gradually takes on new life roles and becomes increasingly independent, preparing for successful transition to adulthood. Maintaining participation levels at this time is therefore essential for maximizing health and ensuring optimal integration into society. Being at risk for or having a disability may add an additional barrier to engaging in leisure, as participation levels in children and youth with physical and other developmental disabilities are known to be lower than in typically developing peers [8,9].

Preterm birth is a global problem, affecting families worldwide [10]. Complex neurodevelopmental problems in preterm survivors have been shown to persist into adolescence [11] and adulthood [12], which may limit activities and restrict participation in the home, at school and in the community. Minor motor incoordination often persists in adolescents born preterm [13] and may co-exist with cognitive deficits [14] and behavioral problems [15]. Furthermore, children born very preterm have higher rates of social withdrawal and peer victimization than term-born peers [16]. Leisure participation may be critical in fostering independence and fitness, promoting psychosocial well-being and preventing chronic health conditions in the preterm population, especially as they transition from adolescence into adulthood. Motor development, cognitive skills and other child-related factors are associated with participation levels of children and youth with physical disabilities [17,18], but have yet to be validated in

adolescents born preterm who may have a wide range of severity of impairments. Furthermore, preferences for activities is a strong determinant of leisure participation in adolescents with cerebral palsy [17]. Family functioning, socio-economic background and environmental factors are also found to influence leisure opportunities and participation in children with disabilities [17], yet quantitative studies on the contextual factors which positively or negatively influence leisure participation in adolescents born preterm are lacking [19]. Reasons for engaging in leisure may be multiple and complex, but gaining a better understanding of the factors that are associated with leisure participation in adolescents born preterm will enable the design of responsive and effective intervention programs and health promotion initiatives aimed at increasing participation. Currently, there is no evidence on the determinants of leisure participation in adolescents born preterm. Therefore, specific child and environmental factors were included in this study based on clinical relevance and on a conceptual model of leisure determinants in children with disabilities [20] which was validated in adolescents with cerebral palsy [17]. The purpose of this study was to identify the child and environmental factors associated with leisure participation in adolescents born extremely preterm.

## 2. Methods

### 2.1. Procedures

Ethical approval was obtained from the Montreal Children's Hospital Research Ethics Board. This cross-sectional study is part of a broader study entitled "Determinants of Active Involvement in Leisure for Youth – DAILY living with disability" which includes adolescents born extremely preterm as well as adolescents born with a congenital heart defect. This paper reports on adolescents born extremely preterm and included youth between 12 and 20 years of age who were born at  $\leq 29$  weeks of gestational age and eligible at birth for the Neonatal Follow-up Program were recruited. Exclusion criteria included documented genetic syndrome or chromosomal anomaly. Details on recruitment have been described previously [21]. Informed consent was obtained from the primary caregiver as well as assent from able adolescents. Standardized assessments, self-report and parent-report questionnaires on leisure participation and potential child and environmental determinants were completed during a three-hour visit at the hospital or at the participant's home. All questionnaires have been translated to French using forward and back translation.

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