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Picture me playing—A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy

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ABSTRACT

In recent years attention has been paid to the participation levels of children and youth with Cerebral Palsy (CP), particularly the extent to which they have the opportunity to be involved in and enjoy leisure activities. The objective of this study is to describe the level of participation and enjoyment in leisure activities among adolescents with CP and to identify potential differences in participation patterns related to sociodemographic attributes. A cross-sectional design was used. Participants were 175 adolescents 12–20 years old ($M = 15.3$; ± 2.2), GMFCS I = 55/II = 43/III = 13/IV = 18/V = 39 who completed the Children's Assessment of Participation and Enjoyment (CAPE). The types of activities participants engaged in most frequently were social and recreational activities, whereas self-improvement and skill-based activities were least frequent. Social activities were the activities they enjoyed most. In general, participation decreases, as youth grow older. Girls engaged in more self-improvement activities than boys. Adolescents who study in special segregated schools experienced a lower diversity and intensity of engagement in all leisure activity domains. Adolescents who were not ambulatory and those presenting with more severe manual ability limitations participated less in all activity types except skill-based activities. Adolescents with CP place a high value on the ability to engage in activities of their own choosing and on interacting with friends. Engagement in a variety of leisure activities is important for a healthy development. Understanding the leisure patterns and preferences of this population, in addition to the contextual factors, may help in the elaboration of interventions and programs to promote a healthy development for this population.

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1. Introduction

Cerebral Palsy (CP) is the most common type of physical disability affecting children in developed countries (Stanley, Blair, & Alberman, 2000). The focus of rehabilitation interventions within this population is often limited to minimizing impairments and addressing functional aspects of the condition, such as activities of daily living and motor function. In recent years, however, attention has been paid to this population's participation levels, particularly the extent to which they have the opportunity to be involved in and enjoy leisure activities at home and in the community (Adamson, 2003; Specht, King, Brown, & Foris, 2002).

Participation is defined by the World Health Organization (WHO) as involvement in a life situation or sharing an activity. Different areas, such as communication, mobility, domestic life and social relationships, comprise some of the elements of participation. These activities show how an individual functions in his/her environment in different life roles. One important participation domain not often considered is participation in leisure (King et al., 2003; Law, 2002; WHO, 2001).

Studies on child development reinforce the important role that play, leisure and recreation have on health and well-being and it is known that engagement in recreational activities is a key element to the development of children (Larson & Verma, 1999; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). Recent studies have identified determinants of participation in leisure and recreation in children and youth with disabilities, such as motor functioning, age, family environment, motivation and behaviour (Law et al., 2006; Majnemer et al., 2008; Palisano et al., 2011a, 2011b; Rosenbaum, 1998). Knowledge of these determinants is important to guide intervention strategies to promote participation. In particular, there is a lack of information on participation in leisure and recreation in adolescents with disabilities. Although adolescence is one of the most critical periods of development, little is known about specific characteristics of this stage for individuals with developmental disabilities (Adamson, 2003; Majnemer & Mazer, 2004).

Engagement in leisure activities decreases as children with disabilities grow older (Law et al., 2006). Studies have shown that participation in leisure may be crucial for a perceived good quality of life for this population (Aitchison, 2003; Dahan-Oliel et al., 2012; Law, 2002; Shikako-Thomas et al., 2009); however, few studies have characterized the actual participation patterns of adolescents with CP. Evidence is needed on the participation levels and preferences among youth with CP so that effective and targeted health promotion strategies can be developed to enhance enjoyment and community integration for this high-risk population.

The objective of this study is to describe the level of participation and enjoyment in leisure activities among adolescents with CP. We were also interested in identifying potential differences in participation patterns that are related to sociodemographic attributes to better characterize participation in this population.

2. Methods

Ethical approval for this study was obtained from the Montreal Children's Hospital Ethics Review Board, the Centre for Research on Interdisciplinary Rehabilitation (CRIR) and the Agence de la santé et des services sociaux de Montréal (ASSS), the local health and social service authority on the island of Montreal.

2.1. Population

Adolescents 12–20 years of age with a diagnosis of CP were recruited for a study describing factors influencing their leisure participation and quality of life (QUALA study). A sample of children (6–12 years) who had participated in a previous study describing quality of life and participation in school-age children with CP (Majnemer et al., 2008) was contacted for participation in the adolescents' study. An additional sample was recruited from specialty clinics, school, community and transition programs across the province of Quebec, Canada. These recruitment methods ensured a regional, geographically representative sample of adolescents with CP.

2.2. Procedures

A cross-sectional design was used. The current findings are part of a larger study on determinants of participation and quality of life in adolescents with CP. Clinicians and/or program managers received a pamphlet containing a short description of the study to be given to the families of potential participants. Families were approached by a professional from the centre who provided information about the study and passed on the family's contact information (name of the child, name of the parents and telephone number) to the research coordinator upon family's consent. The research coordinator then contacted the family and provided further clarification regarding the study procedures.

Once consent (parental) and assent (adolescent, when feasible) were obtained, an appointment was made with the participant and parent (mother or father) to complete evaluations at the Montreal Children's Hospital Childhood Disability Laboratory, at the Madeleine Bergeron school in Quebec City or as a home visit, when participants were not able to come to one of the assessment sites. For children living in foster care, consent was obtained both from the legal guardian or the public curator and from the foster parent. Participants were formally evaluated by either an occupational therapist (OT) or physical therapist (PT) who completed the Gross Motor Function Classification System (GMFCS; Palisano et al., 1997). The Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004) was applied by a trained occupational therapist or