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Stability of leisure participation from school-age to adolescence in individuals with cerebral palsy



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ABSTRACT

With increasing age, youth with disabilities are at risk for decreased participation in leisure activities, a key component for physical and mental health. This prospective study describes changes in leisure participation and leisure preferences from school-age to adolescence in children with cerebral palsy (CP). Participants were recruited at school-age (6–12 years) for a study on participation and reassessed for a second study on adolescents (12–19 years) if >12 years. Thirty-eight children (24 males) with CP who could actively participate in the completion of the Children's Assessment of Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC) comprised the sample. Average time between assessments was 5.0 ± 1.3 years. Most children were ambulatory (32/38 Gross Motor Function Classification System I–II). In addition to the CAPE and PAC, children were evaluated using the Gross Motor Function Measure-66 and parents completed a socio-demographic questionnaire. Paired *t*-tests revealed a significant decline in leisure participation diversity and intensity (CAPE) for recreation ($p < .0001$), skill-based ($p < .0001$) and self-improvement ($p < .05$) activities, whereas social participation remained stable ($p > .05$). Diversity of active-physical activities increased modestly ($p = .06$) although intensity of participation in this activity domain decreased ($p = .003$). There was also a decline in enjoyment of leisure activities. Preferences for these leisure activities remained unchanged between school-age and adolescence, except for recreational activities. Gender, maternal education, family income and gross motor ability were not related to differences in CAPE/PAC scores with increasing age. Findings suggest that over time, children with CP's participation in leisure activities diminishes, which is of concern to their functioning and well-being. Parents may be more involved in early childhood in facilitating participation whereas in adolescence, youth may be faced with more environmental barriers and a greater awareness of challenges to participation. Adolescents demonstrated a persisting desire to do these activities, challenging rehabilitation specialists to prioritize strategies to promote greater participation as children transition to adolescence.

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1. Introduction

Leisure participation is vital to the growth and development of children and youth, as these activities promote development of skill competencies, peer interactions, personal interests, and greater independence (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012; Ginsburg, 2007). Leisure activities may be structured, organized activities such as music lessons or playing on a sports team, or can be more informal and spontaneous such playing a computer game or going to a movie with friends. Participation in leisure activities of one's choosing can promote self-determination and autonomy, particularly as children grow older and their parents no longer choose their extra-curricular activities for them (Coster & Khetani, 2008; Dahan-Oliel et al., 2012). Engagement in active physical and other recreational activities can promote physical health, and minimize the risk for long term chronic health conditions such as cardiovascular disease, obesity, diabetes and osteoporosis (Waxman & World Health Assembly, 2004; World Health Organization, 2007). Furthermore, participation in social, skill-based and other leisure pursuits can enhance mental health and well-being, which includes relieving stress and anxiety (emotional well-being), enabling identity formation, fostering creative expression and achievement motivation (self-worth, self-efficacy), and providing opportunities to build social connections with family, friends, community (social well-being) (Caldwell & Witt, 2011; Dahan-Oliel et al., 2012). Indeed, leisure was identified as one of nine key domains that health professionals should target when working with children with disabilities (Janssens, Williams, Tomlinson, Logan, & Morris, 2014).

The United Nations Convention on the Rights of the Child (CRC) is aimed at promoting the health and well-being of all children. Within this universal convention, about 20% of the rights enumerated relate to participation in activities (UN General Assembly, 1989). For example, Article 31 of the CRC focuses on the right to play and rest. The World Health Organization has elaborated on the concept of participation in all meaningful and age-appropriate life situations in the International Classification of Functioning, Disability and Health-Child and Youth Version or ICF-CY (World Health Organization, 2007). One of the domains within the Activities and Participation classification is "community, social and civic life" which includes leisure such as the participation in clubs, sports or community groups and home-based recreation activities.

Over the past decade, numerous studies have demonstrated that children and youth with cerebral palsy (CP) have a diminished participation in leisure activities when compared to same age-peers, and tend to pursue more passive, home-based leisure activities (Law et al., 2006; Majnemer et al., 2008; Shikako-Thomas et al., 2013a). Cross-sectional studies have also associated lower participation levels with increasing age (Law et al., 2006). Recent studies also show different patterns in the personal preferences for certain type of leisure activities at different age groups. One study indicated that school-age (6–12 years) children with CP most preferred social and recreational activities whereas adolescents (12–19 years) with CP most wanted to do active-physical and social activities; social activities being common to all age groups (Majnemer et al., 2010; Shikako-Thomas et al., 2013c). Of concern, the desire to participate (i.e. preference for certain activities) in particular leisure activities were not closely correlated with actual involvement in these activities in all age groups (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; Majnemer et al., 2010; Shikako-Thomas et al., 2013c). Studies to date on leisure participation in this high-risk population have been cross-sectional in nature, providing only a snapshot in time. Only one study has reported on the changes in leisure engagement over time. Specifically, King et al. (2009) evaluated the involvement in leisure activities of children 6–15 years of age with a range of physical disabilities on three occasions over a three-year period using the Children's Assessment of Participation and Enjoyment (CAPE). The focus of this report was on the predictors of change, but not the evolution of participation as children transition from one developmental period to another. In their study, there was a decline in participation in recreational, active-physical and social activities with no change in self-improvement in skill-based activities. Age and sex were important determinants of change, however preferences for leisure activities over time were not examined (King et al., 2009).

Therapeutic strategies and health promotion strategies should build citizenship and address the barriers to participation in a range of activities throughout developmental stages. A better understanding of the current evolution of participation from childhood to adolescence is needed. Furthermore, appreciation of personal preferences for engagement is also required, to ensure that approaches used are client-centred and meaningful. Therefore, the objective of this study was to describe changes in leisure participation and leisure preferences from school-age (6–12 years) to adolescence (12–19 years) in individuals with CP. This study also explored individual and environmental factors that may be associated with any changes in participation over time.

2. Methods

2.1. Participants

Individuals in this study were participants in a study on participation and quality of life in school-age children with CP (Majnemer et al., 2008, 2010) who were also recruited several years later to a separate study on leisure participation in adolescents with CP (Shikako-Thomas et al., 2013a, 2013c). In this prospective study, 95 children were initially recruited from a database of all children diagnosed with CP by a child neurologist, who were 6–12 years of age at the time of initial recruitment. Parents who could not read English or French were excluded. The study was approved by the Montreal Children

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