



# The influence of participation in leisure activities on quality of life in Spanish children and adolescents with Cerebral Palsy



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## ABSTRACT

Participation is an important modifiable quality of life (QOL) determinant and a key outcome measure. The aim of this study was to confirm if participation in leisure activities affects the QOL domains in children and adolescents with Cerebral Palsy (CP) in Spain. A total of 206 children and adolescents with CP (and their parents), 115 boys and 91 girls, mean age of 11.96 years (SD=3.00; range 8–18 years) participated in the study. Distribution according to the Gross Motor Function Classification System (GMFCS) was 24.3% Level I, 18% Level II, 18% Level III, 12.6% Level IV, and 27.2% Level V. Participation in leisure activities was assessed using the Spanish version of Children's Assessment of Participation and Enjoyment (CAPE) and QOL using the KIDSCREEN parents' version. Diversity, intensity and enjoyment of participation explained the levels of QOL in the Physical well-being, Psychological well-being, Autonomy, Parent relation & home life and Social support & peers domains, independently of gender, age and level of impairment (motor and intellectual). We also found that intensity and enjoyment of participation in informal activities had more influence on the different QOL domains. The most influenced domain by the enjoyment of participation in all domains and types of CAPE activities was Psychological well-being. The participation in leisure activities had a positive effect on the QOL of the Spanish children and adolescents with CP.

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## 1. Introduction

Children with disabilities have the same aspirations as all children, hoping for health, security, respect, opportunities to learn skills, meaningful occupation and the possibility of contributing to the lives of others (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006). In this sense, the UN Convention on the Rights of the People with Disabilities declares the obligation of states to ensure their full participation in the community and their full enjoyment of all human rights and fundamental freedoms on an equal basis with the rest of the children (United Nations, 2006). The content of this statement cover two elements considered essential in the current perspective of caring for children and adolescents with disabilities: objective information of what the child does, i.e. participation, and what child feels about their life, i.e. quality of life (QOL).

Participation is defined by the International Classification of Functioning, Disability and Health – Children & Youth Version (ICF-CY) (World Health Organization, 2007) as involvement in life situations. Typical examples of life roles that

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children participate in include social relationships with family and friends, domestic chores, learning at school, and leisure and recreational activities at home and in the community (Majnemer et al., 2010). Adolescents with physical disabilities have described participation as having fun, feeling successful, doing and being with others and doing things by themselves, highlighting both subjective and objective components of participation as key to their experiences (Heah, Case, McGuire, & Law, 2007). Participation leads to life satisfaction as well as a sense of competence and is essential for psychological and emotional well-being and skill development (Engel-Yeger, Jarus, Anaby, & Law, 2009). Involvement in a variety of activities, especially leisure activities of their own choosing, has been emphasized by adolescents with Cerebral Palsy (CP) as contributing to a good QOL (Shikako-Thomas et al., 2009).

QOL is a multidimensional construct, which incorporates objective and subjective accounts of personal feelings, social relationships, local environment, societal values, political institutions, economic conditions, and international relations (Bjornson & McLaughlin, 2001; Colver, 2009). Rosenbaum (2008) reported that to the extent that people are able to do the things that are important to them, to participate in whatever ways enable “engagement”, their quality of life is probably better than were they thwarted in “participating”.

Even considering the idea that participation may be an important determinant or component of QOL, there is a paucity of studies on quality of life and participation in leisure activities in children and adolescents with CP. The literature attributes the relationship between leisure and well-being to several aspects including that leisure decreases the effects of negative events and enhances well-being by acting as a protective factor by providing social support, feelings of competency and relaxation (Caldwell, 2005; Dickinson et al., 2007; Poulsen, Ziviani, Johnson, & Cuskelly, 2008; Tedeschi & Calhoun, 2004). One of the few studies presently available found that participation affects QOL domains Physical well-being, Social support and peers and Mood and emotions (McManus, Corcoran, & Perry, 2008). However, the authors of this study have assessed only the frequency of participation. Important aspects like the type of activity (diversity) and the level of enjoyment not been investigated, remaining unclear whether these factors also affect QOL of children with CP.

Moreover, one revision recently published aiming to understand the influence of participation in leisure and social activities on the different dimensions of QOL has shown that the participation in physical and everyday activities enhance physical well-being (Dahan-Oliel, Mazer, & Majnemer, 2012). Also, that the participation in leisure activities has an effect on self-perception, can promote emotional and social QOL, and may contribute to happiness and enjoyment, and at least, that participating in chosen, preferred activities, promotes overall well-being. However, the review also highlighted some negative impacts of involvement leisure activities on QOL, mostly mediated by environmental constraints related to accessibility or lack of adaptations.

Because of scarce of information, we were interested in to investigate if the participation in leisure activities outside school influence QOL in children and adolescents with CP, considering objective (diversity and intensity) and subjective (enjoyment) aspects of the participation construct. Specifically, the aims of this study were (i) to investigate if the participation in leisure activities affect QOL after adjusting for age, gender and severity of impairment (motor and intellectual) and (ii) to study the contribution of participation on QOL, according to the different type of activities (formal, informal, recreational, active physical social, skill-based and self-improvement activities).

## 2. Methods

### 2.1. Participants

This paper used data from one large sample of CP children and adolescents from across Spain collected in the study on participation in leisure activities. Children and adolescents with CP were recruited from Associations Caring for People with Cerebral Palsy and Related Disabilities (ASPACE), between December 2008 and June 2010.

In order to achieve a heterogeneous and representative sample of the population of children and adolescents with CP, all ASPACE centers were invited to participate in this study. The 68 ASPACE centers are found in 17 regions in Spain, offering multi-disciplinary assessment services for 8400 people with CP. 23 representatives of these centers were informed of this research in a workshop held at the ASPACE headquarters and, finally, a total of 16 centers agreed to participate in the study.

Children and adolescents with CP, aged between 8 and 18 years, receiving services were eligible if they did not have a concomitant illness or health condition that might affect participation and QOL.

### 2.2. Measures

Participation was measured using the Spanish version of Children's Assessment of Participation and Enjoyment (CAPE) (Longo, Badia, Orgaz, & Verdugo, 2012), which assess the children's and adolescents' participation in leisure and recreation activities outside of mandated school activities. The CAPE is designed to measure if and how children and youths aged between 6 and 21 participate in 55 informal and formal activities that measure participation in five dimensions: diversity, intensity, with whom, where and enjoyment. However, for the purpose of the present study the diversity, intensity and enjoyment CAPE scores were used. The Spanish version has demonstrated good psychometric properties (construct and discriminant validity, and test–retest reliability).

QOL was measured using KIDSCREEN, a 52-item generic health-related quality of life measure applicable to healthy and chronically ill children and adolescents aged 8–18 years and designed for child or parent report. The KIDSCREEN instrument

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