



Do environmental barriers affect the parent-reported quality of life of children and adolescents with cerebral palsy?



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ABSTRACT

Physical, social, and attitudinal environment may affect the quality of life (QoL) of children and adolescents with cerebral palsy (CP). Participants in this study included parents of 206 children and adolescents with CP (55.8% males) aged 8–18 years ($M = 11.96$, $SD = 3$). 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. Environmental barriers were assessed with the Spanish version of the European Child Environment Questionnaire (ECEQ), and QoL was assessed with the KIDSCREEN parents' version. The results of the correlation analysis revealed that GMFCS level, IQ, and type of schooling are significantly correlated with QoL. Barriers were also associated with QoL. A series of hierarchical regression analyses indicated that, after controlling for the effect of child and parent's variables, barriers at home and at school significantly contribute to QoL. These findings underscore the importance of providing interventions to produce environmental changes that contribute to the improvement of QoL.

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What this paper adds

- Environment has currently become a focus of interest because, as it is considered a potentially modifiable factor, its negative (barriers) and positive (facilitators) aspects that may influence QoL can be identified. This study provides relevant information about how the barriers perceived by parents influence QoL. The results showed that barriers, understood as factors of the physical, social, and attitudinal environment that limit the functioning of children with CP, are related to lower parent-reported QoL. The availability of a wide range of physical environmental facilitators (home, school, and public spaces), the adequacy of the services according to the children's needs, and, especially, the positive attitudes of the family and the school are aspects that determine the QoL of children and adolescents with CP.

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1. Introduction

The International Classification of Functioning, Disability and Health (ICF) (World Health Organization [WHO], 2001) defines disability as the result of a interaction between personal health conditions and contextual factors. The ICF introduces environmental factors that make up the physical, social, and attitudinal environment in which people live. As the environment is a potentially modifiable variable, it has become prominent in research on disability (Fougeyrollas et al., 1998; Jönsson, Ekholm, & Schult, 2008; Whiteneck et al., 2004). In addition, the achievement of environmental changes favoring people with disabilities is one of the guidelines established by the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), which, in article 31, specifies states' obligation to identify and eliminate the barriers faced by people with disabilities in the exercise of their rights.

QoL has become a key outcome of intervention procedures in children with CP (Colver, 2006; Dickinson et al., 2007; Rosenbaum, 2008). The WHO defines QoL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (The WHOQOL Group, 1995: 1045). QoL is a multidimensional construct that includes subjective and objective components (Bjornson & McLaughlin, 2001; Waters, Maher, Salmon, Reddihough, & Boyd, 2005) and that is influenced by environmental factors (Schalock et al., 2002; Verdugo, Schalock, Keith, & Stancliffe, 2005). Although self-report questionnaires are regarded as the primary method of assessing QoL, it is proposed that, because of children's cognitive immaturity, limited social experience, and continued dependency, parents may be more able to report some aspects of their child's QoL (Arnaud et al., 2008; Davis et al., 2007; Waters et al., 2007). Currently implementation of this construct serves as a guide for professional practice in order to improve the QoL of children with CP (Colver, 2006; Majnemer & Mazer, 2004).

In recent years, there has been increasing interest in the study of the QoL of children with CP (Arnaud et al., 2008; Davis et al., 2007; Dickinson et al., 2007; Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007; White-Koning et al., 2007). Some research indicates that the QoL reported by parents of children with CP is low (Beckung et al., 2008; Law et al., 2014; Liptak et al., 2001; Longo-Araújo-de-Melo et al., 2012; Majnemer et al., 2007; Vargus-Adams, 2009; Wake, Salmon, & Reddihough, 2003). However, the study carried out by the SPARCLE group, in which six European countries participated, has shown that self-reports of QoL in children with CP are similar to those of children from the general population, and children with CP even obtained better results in the school setting domain (Dickinson et al., 2007). Therefore, children and parents perceive QoL differently, confirming that parents tend to underestimate their children's QoL in most domains (Davis et al., 2007; White-Koning et al., 2007).

Studies have shown that participation in leisure activities may be crucial for a perceived good QoL for this population (Badia, Longo, Orgaz, & Gómez-Vela, 2013; Dahan-Oliel, Mazer, & Majnemer, 2012; McManus, Corcoran, & Perry, 2008; Shikako-Thomas et al., 2012). Badia et al. (2013) found that diversity, intensity, and enjoyment of participation explained levels of QoL in physical well-being, psychological well-being, autonomy, parent relations and home life, and social support and peer domains. However, Dahan-Oliel et al. (2012) pointed out some negative impacts of involvement in leisure activities on QoL, mostly mediated by environmental constraints related to accessibility or lack of adaptations.

Several studies have shown that some environmental factors such as lack of physical and emotional support, inaccessibility of the physical environment, and negative attitudes affect participation of children with CP (Colver et al., 2012; Forsyth, Colver, Alvanides, Woolley, & Lowe, 2007; Mihaylov, Jarvis, Colver, & Beresford, 2004; Vargus-Adams & Martin, 2011; Vogts, Mackey, Ameratunga, & Stott, 2010). Colver et al. (2012) also found that the physical, social, and attitudinal environment influences participation of children with CP, understood as their involvement in diverse life areas.

Other studies have focused on analyzing the factors that determine QoL, participation, and the environment (Forsyth et al., 2007; Law, Petrenchik, King, & Hurley, 2007; Mihaylov et al., 2004; Shikako-Thomas et al., 2013; Verschuren, Wiart, Hermans, & Ketelaar, 2012). It has also been shown that children with CP with a major motor impairment, presence of pain, and intellectual disabilities obtain lower QoL (Arnaud et al., 2008; Badia, Riquelme, Orgaz, Acevedo, Longo, & Montoya, 2014; Dickinson et al., 2007; Riquelme, Cifre, & Montoya, 2011; Swiggum, Hamilton, Gleeson, & Roddey, 2010) and that these factors interfere with their participation in daily activities and the fulfillment of social roles (McKearnan, Kieckhefer, Engel, Jensen, & Labyak, 2004; Penner, Xie, Binopal, Switzer, & Fehlings, 2013). Finally, it has been found that high participation is associated with the availability of a better environment (Colver et al., 2012) and that a supportive, accessible environment is also a predictor of better QoL (Law et al., 2014).

Although the ICF includes environmental factors as a component of the biopsychosocial model of disability, little is known about how environmental factors influence the QoL of children and adolescents with CP. The goal of this study is to test the hypothesis that establishes that the QoL of Spanish children and adolescents with CP is influenced by environmental factors. More specifically, the following hypotheses are proposed in this study: (1) the QoL of children and adolescents with CP informed by their parents is related to the child's factors, (2) low QoL is associated with the perception by parents of physical, social, and attitudinal barriers, and (3) barriers explain QoL after controlling for the child and parents' factors.

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