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Understanding participation of children with cerebral palsy in family and recreational activities

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ABSTRACT

Aims: The primary aim of this study was to determine the effect of age, sex, gross motor, manual ability, and communication functions on the frequency and enjoyment of children's participation in family and recreational activities. The secondary aim was to determine the relationships between motor and communication functions and participation.

Methods: Participants were 694 children, 1.5–12 years old, with cerebral palsy (CP) and their parents across the US and Canada. Parents rated children's frequency and enjoyment of participation using the Child Engagement in Daily Life measure. Parents and therapists identified children's level of function using Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), and Communication Function Classification System (CFCS).

Results: Differences in frequency and enjoyment of participation were found based on children's GMFCS, MACS, and CFCS levels but not age or sex. Children with higher gross motor, manual, and communication functions had higher frequency and enjoyment of participation, compared to children with lower functions. Frequency of participation was associated with GMFCS and CFCS levels whereas enjoyment of participation was only associated with CFCS level.

Implications: Knowledge of child's gross motor, manual ability, and communication functions of children with CP is important when setting goals and planning interventions for participation.

1. Introduction

In the past two decades, there has been an increasing interest in understanding and promoting participation of children with cerebral palsy (CP). Although the World Health Organization (WHO) has broadly defined participation as “involvement in life situations” (WHO, 2007), conceptual clarity of the WHO’s definition is still open to debate in the pediatric participation literature. Recently, Imms et al. (2016) conducted a systematic review to explore variations in the language used to describe participation and they found two key terms that describe the participation construct, attendance and involvement. The authors further described attendance as the physical presence of the child in the activity, whereas involvement represents the “in-moment experience” of participation and includes elements of affect, motivation, and social connection (Imms et al., 2016). Chiarello, in press, however, suggests that involvement includes “affective, cognitive, and behavioral elements: how the person is feeling, thinking, and behaving”. Nevertheless, there is a general consensus among researchers that participation is a multidimensional construct that can be influenced by a wide range of child, family, and environmental factors (Chiarello et al., 2016; Imms et al., 2016; King et al., 2006; Palisano et al.,

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2011).

An important outcome of rehabilitation services is to optimize children's participation in different life situations such as home, school, and in the community (Palisano et al., 2012). Participation in family and recreational activities provides avenues for children to play, learn skills, make friendships, and develop self-confidence and belonging (Chiarello et al., 2014; King et al., 2006; King, Petrenchik, Law, & Hurley, 2009; Majnemer et al., 2008). Several child-related attributes influence participation of children with disabilities in family and recreational activities including age, sex, adaptive behavior, functional abilities, and impairments in body functions and structures (Chiarello et al., 2016; Imms, Reilly, Carlin, & Dodd, 2009; King et al., 2006; Palisano et al., 2011; Shikako-Thomas, Majnemer, Law, & Lach, 2008). Previous studies have focused primarily on measuring the diversity (range of activities) and frequency (how often) of participation and investigating its relationship with child-related attributes. However, less attention has been given to understand enjoyment of participation and child-related factors influencing it. Enjoyment of participation can be perceived as part of the emotional (affective) experience of participation (Chiarello, 2017; King et al., 2009) as well as a proxy for the developmental and psychological benefits emerging from the participation experience (King et al., 2009).

Inconsistent findings have been found for the effect of child's age on the frequency and enjoyment of participation in family and recreational activities. Among children with CP (17 months to 6 years), children 3.5–4 years and older participated more often in activities compared to younger children (Chiarello et al., 2012, 2014; Law, King, Petrenchik, Kertoy, & Anaby, 2012). Law et al. (2006) reported no age related differences in the total diversity and frequency of participation in recreational and leisure activities for children with physical disabilities 6–11 years; however, children 12–14 years participated in less number of activities and less frequently compared to children 6–11 years. Palisano et al. (2011) reported that among children with CP aged 6–12 years, younger age was associated with a higher frequency of participation. In regard to the enjoyment of participation, Chiarello et al. (2014) found that although children with CP 3.5–5 years of age enjoyed participation more than children 17 months to 2.5 years of age; on average parents reported that children across all age groups enjoyed their participation "very much" (Chiarello et al., 2014). For children with CP 6–12 years of age, Majnemer et al. (2008) found that younger age was associated with more enjoyment of participation in informal activities.

In general, similarities in the frequency and enjoyment of participation between boys and girls with CP are more common than differences (Chiarello et al., 2012; Law et al., 2006; Palisano et al., 2011). Two studies reported that the total frequency of participation in family and recreational activities for children with CP 3–12 years of age did not differ by the child's sex (Chiarello et al., 2012; Palisano et al., 2011). However, other studies have found that girls with disabilities including CP, 2–14 years of age, participated in a greater number of activities (Law et al., 2006, 2012) and with higher frequency (Law et al., 2012) than boys. In addition, these studies also reported sex-related differences in the frequency of participation for specific dimensions of leisure and recreational activities (Law et al., 2006, 2012). With regard to the enjoyment of participation, Majnemer et al. (2008) reported that for children with CP (6–12 years), female sex was associated with greater enjoyment of participation in formal and informal activities.

Several studies of children with CP have found that children with higher gross motor function participate in a greater diversity of leisure and recreational activities and do such activities more frequently compared with children with lower gross motor function (Chiarello et al., 2014, 2012, 2016; Imms, Reilly, Carlin, & Dodd, 2008; Law et al., 2012; Palisano et al., 2011; Shikako-Thomas et al., 2008). However, Imms et al. (2008) found that diversity and frequency of participation for children with CP, 11–12 years of age, was similar across Gross Motor Function Classification System (GMFCS) levels except for children in level V who had a significantly lower diversity and frequency of participation. For enjoyment of participation, Chiarello et al. (2016) reported that gross motor function of children with CP (1.5–5 years) was not associated with enjoyment of participation.

Less attention has been given to understand the influence of children's manual ability on the frequency and enjoyment of participation. Chiarello et al. (2012) reported that scores on the Upper Extremity and Physical Function subscale of the Pediatrics Outcomes Data Collection Instrument (PODCI) were moderately correlated with frequency of participation for children with CP, 3–6 years old. In another study, the diversity of formal and informal participation were associated with Manual Ability Classification System (MACS) level for children with CP 11–12 years of age (Imms et al., 2009). In a related study, the diversity and frequency of participation did not differ for children in MACS levels I–IV but was lower for children in level V (Imms et al., 2008). The three studies provide some evidence that manual ability has influence on the diversity and frequency of participation for children with CP; however, further investigation over a wider and more inclusive age range is warranted.

Several studies have reported the relationship between communication function and the diversity and frequency of participation of children with CP (Clarke et al., 2012; Imms et al., 2009; King et al., 2006; Palisano et al., 2011) but not enjoyment. These studies used different measures of communication and speech functions and found that higher communication/speech function is associated with a higher diversity and frequency of participation (Clarke et al., 2012; Imms et al., 2009; King et al., 2006; Palisano et al., 2011). The Communication Function Classification System (CFCS), validated in 2011 (Hidecker et al.), is now available to classify communication function of children with CP.

Based on the research appraised, there are several areas where further research is needed. First, the effect of age and sex on a wide age range of children with CP has not been determined. Second, research is needed to understand the effect of manual ability on frequency and enjoyment of participation as well as the effect of gross motor function on enjoyment of participation. Third, we did not identify any studies that examined the effect of communication function on the frequency and enjoyment of participation in family and recreational activities. The primary purpose of this study, therefore, was to determine the effect of age, sex, gross motor, manual ability, and communication function levels on the frequency and enjoyment of participation in family and recreational activities for children with CP, 1.5–12 years of age. The secondary purpose was to determine the association between children's level of function in gross motor, manual ability, and communication function classification systems and participation frequency and enjoyment. Knowledge of the effect of children's age, sex, gross motor, manual ability, and communication functions on frequency