



Universidade de Lisboa
Faculdade de Motricidade Humana



Leisure Participation of Portuguese Children with Cerebral Palsy

Fábio Augusto Silva Vila Nova

Orientador: Prof^a. Doutora Rita Cordovil Matos

Co-orientador: Prof^o. Doutor Raul Alexandre Nunes da Silva Oliveira

Tese especialmente elaborada com vista à obtenção do grau de
Doutor em Motricidade Humana na especialidade Comportamento Motor

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2020

Deus quer, o homem sonha, a obra nasce.

Fernando Pessoa

*This thesis is dedicated to my parents (in memoriam) and my wife who encouraged
and supported me in every single day of this journey.*

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ABSTRACT

Participation in leisure activities contributes to the child development, health and wellbeing. Nowadays, participation is a major pediatric rehabilitation goal according to the biopsychosocial model of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). However, studies and measures about leisure participation for Portuguese-speaking children with cerebral palsy (CP) are lacking. This research aimed to (i) translate and validate a tool for evaluating participation for children and adolescents with typical development (TD) and CP, (ii) describe the participation and analyze factors that influence the participation of children and adolescents with CP in leisure activities and (iii) identify differences in participation in physical leisure activities among children with TD and CP. The *first study* assessed validity and reliability of the Portuguese (European) version of the Children's Assessment of Participation and Enjoyment (CAPE). Our results show that CAPE Portuguese version showed satisfactory content and construct validity and test-retest reliability to assess children with CP and TD aged between 8 and 18 years. In the *second study* we described patterns and assessed the influence of child and family factors on leisure participation of 69 children with CP. Children with CP were involved in 21 leisure activities. While social and recreational activities were most reported, participation in physical and skill-based activities was low. Overall children with CP experience high enjoyment while engaging in leisure activities. Collectively, factors of age, cognitive function, gross motor function, and mother's education level predicted 33% of diversity and 30% of participation frequency. In the *third study* we focus on differences in participation in 16 leisure physical activities between CP (n=69) and TD children (n=101). Both groups reported high prevalence of participation in four informal physical activities. However, TD children participate more frequently in team sports ($p=0.026$), individual physical activities ($p=0.018$) and bicycling ($p=0.001$) than CP peers (gross motor function level II-V), which participation in horseback riding was higher ($p=0.031$). This research provides preliminary evidence for use CAPE to assess leisure participation in children with CP and TD. We concluded that, despite the limitations, children with CP show diverse leisure participation and high enjoyment, but with low engagement in physical activities. Child and family factors play an important role on

overall participation. Rehabilitation support toward participation promotion could help to improve engagement in leisure activities in children with CP.

Keywords: cerebral palsy, leisure; physical activity; children; participation.

RESUMO

A participação em atividades de lazer contribui para o desenvolvimento, a saúde e o bem-estar da criança com e sem deficiências. Atualmente, a participação é objectivo primário na reabilitação pediátrica de acordo com o modelo biopsicossocial da Classificação Internacional da Funcionalidade, Incapacidade e Saúde para Crianças e Jovens (CIF-CJ). No entanto, estudos e medidas de avaliação da participação de crianças portuguesas com paralisia cerebral (PC) em atividades de lazer ainda são escassos na literatura. Esta pesquisa teve como objectivos: i) traduzir e validar um instrumento de avaliação da participação para crianças e adolescentes com desenvolvimento típico (DT) e PC, ii) descrever a participação e analisar fatores que influenciam a participação de crianças com PC em atividades de lazer e (iii) identificar diferenças na participação em atividades físicas de lazer entre crianças com DT e PC. O *primeiro estudo* avaliou a validade e fiabilidade da versão portuguesa do questionário *Children's Assessment of Participation and Enjoyment (CAPE)*. Os resultados mostram que a versão portuguesa do CAPE detém validade de conteúdo e constructo, e fiabilidade teste-reteste satisfatórios para avaliar crianças com PC e DT com idade entre os 8 e os 18 anos. No *segundo estudo* descrevemos o padrão de participação no lazer e examinámos a influência de fatores da criança da família na participação de 69 crianças com PC. As crianças com PC participaram em média em 21 atividades de lazer. Enquanto as atividades sociais e recreativas foram as mais reportadas, a participação em atividades físicas e baseadas em habilidades foi baixa. Em geral as crianças com PC experimentam um elevado nível de satisfação quando participam nas atividades. Colectivamente, os factores idade, função cognitiva, função motora grossa e nível de educação da mãe previram 33% da diversidade e 30% da frequência de participação nestas atividades. No *terceiro estudo* centramo-nos nas diferenças de participação em 16 atividades físicas de lazer entre as crianças com PC (n=69) e DT (n=101). Ambos os grupos referiram uma elevada prevalência de participação em quatro atividades físicas informais. No entanto, as crianças com DT participam mais frequentemente em desportos de equipa (p=0,026), atividades físicas individuais (p=0,018) e bicicleta (p=0,001) do que os pares com PC (nível de função motora grossa II-V), cuja participação em equitação foi significativamente mais elevada (p=0,031). Esta investigação fornece evidências para a utilização do CAPE na avaliação da participação em atividades

de lazer de crianças com e sem PC, com idade entre 8 e 18 anos. Concluimos que, apesar das limitações, as crianças com PC apresentam uma participação diversa no lazer e uma elevada fruição, mas com baixo envolvimento em atividades físicas. Os fatores individuais e familiares identificados neste estudo desempenham um papel importante na participação e devem ser considerados. Os resultados deste estudo podem ajudar aos profissionais envolvidos na reabilitação a potenciar o envolvimento de crianças e adolescentes com PC em atividades recreativas e de lazer.

Palavras-chave: paralisia cerebral; lazer; atividade física; criança; participação.

LIST OF ABBREVIATIONS

CP – Cerebral palsy

CAPE – Children’s Assessment of Participation and Enjoyment

ICF – International Classification of Functioning, Disability and Health

ICF-CY - International Classification of Functioning, Disability and Health - Children and Youth version

SCPE – Surveillance Cerebral Palsy in Europe

TD – Typical development

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LIST OF PUBLICATIONS AND COMMUNICATIONS

Research papers in international peer-reviewed journals

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CHAPTER I- GENERAL INTRODUCTION

Introduction

Cerebral Palsy (CP) is a lifelong health condition, considered the most common physical disability affecting children in developed countries (Odding, Roebroek, & Stam, 2006), with an estimated prevalence in Portugal of 1.55% in 1,000 live births (Virella et al., 2017). CP describes a group of permanent movement and posture developmental disorders, which cause activity limitation, attributed to a nonprogressive disorder in the developing fetal or infant brain (Bax et al., 2005). Even though the primary lesion is static, the clinical pattern of presentation may change with time due to growth and developmental plasticity and maturation of the central nervous system (Sankar & Mundkur, 2005). Motor disorders are often accompanied by neurosensory, cognition, musculoskeletal problems and other impairments (Rosenbaum et al., 2007).

Children with CP face different limitations in activity and participation that manifest in different ways throughout life, such as mobility, self-care, school participation, and engagement in leisure activities, when compared to their peers without disabilities (Rosenbaum & Rosenbloom, 2012; Schreuer, Sachs, & Rosenblum, 2014; Tonkin, Ogilvie, Greenwood, Law, & Anaby, 2014). Decreased participation in active physical activities is also important for CP population, since physical inactivity can lead to a deconditioning cycle, resulting in deterioration of motor function and increased risk of secondary health complications such as diabetes, hypertension and overweight (Maher, Williams, Olds, & Lane, 2007; Ryan et al., 2014).

In 2007, the World Health Organization's International Classification of Functioning, Disability and Health Children and Youth version (WHO; ICF-CY) proposes a change of perspective on the most relevant aspects in the context of the health of children with and without disabilities (WHO, 2007). The ICF-CY biopsychosocial model uses three levels to classify human functioning, providing a dynamic view of the connections between human biomedical components (body functions and structures), 'the execution of a task or action' (activity), 'the involvement in life situations (participation), and personal and environmental factors (WHO, 2007).

According to ICF-CY, communication, mobility, education, home life, leisure and social relations comprise some of the participation areas, and are indicators of the degree of interaction of children in their environment (WHO, 2007). In the core sets for CP children and youth, the participation in recreation and leisure activities encompasses recreational playing games, sport, culture, hobbies and social activities (Schiariti, Selb, Cieza, & O'Donnell, 2015).

In the perspective of children and adolescents with disabilities, leisure activities include extracurricular activities, occupations for which freedom of choice, fun, pleasure and discovery are primary objectives (Powrie, Kolehmainen, Turpin, Ziviani, & Copley, 2015). Leisure participation contributes to children's physical, psychological and social well-being; and to the quality of life in children with neurodevelopmental disabilities (Badia, Longo, Orgaz, & Gomez-Vela, 2013; Caldwell, 2005; Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012).

Different variables can affect the participation in leisure activities of children and young people with physical disabilities, which result from the interaction of child, family

and environmental characteristics (Ghaffari, Kalantari, Rezaee, & Akbarzadeh Baghban, 2020; King et al., 2003; Shikako-Thomas, Majnemer, Law, & Lach, 2009). Differences in patterns of participation in leisure activities of children with disabilities were identified in European countries (Michelsen et al., 2009), with influencing factors related to differences in culture, country legislation and public policies on information and social support, transport systems, health, education and the promotion of leisure and recreation (Hammal, Jarvis, & Colver, 2004; King et al., 2013; Michelsen et al., 2009; Ullenhag et al., 2012).

The program of National Surveillance of CP at 5 years of age in Portugal describes information on the prevalence and functional characteristics of CP in cooperation with Surveillance Cerebral Palsy in Europe (SCPE)(Virella et al., 2017). However, it includes information of school inclusion, but not participation in leisure activities. In addition, studies and valid measures that directly assess the leisure participation of people with PC in the Portuguese population are lacking. Research in this field could contribute to the interdisciplinary intervention in children with CP in Portugal (Rosenbaum & Stewart, 2004).

Relevance of the study

The relevance of this study is based on the following premises:

- 1) the right to participation and inclusion of people with disabilities in everyday activities, including recreation, sports and leisure;
- 2) CP is a frequent clinical condition in health and education services in Portugal, and implies in important limitations to the activity and participation of children from the early stages of development;

- 3) the benefits of participation in leisure activities for the quality of life, neuromotor, cognitive and psychosocial development of children with CP;
- 4) greater attention has been given to participation in clinical practice, considered an important outcome in pediatric neurorehabilitation programs;
- 5) the possibility of producing knowledge in a transversal area among the different disciplines that assist people with CP in hospitals, rehabilitation centers, regular and special schools, sports clubs, associations and government agencies;
- 6) the scarcity of measures and studies in the Portuguese population with CP that address participation in leisure and recreation.

Objectives of the study

General Objective:

To investigate the participation of children and adolescents aged 8 to 18 years with CP in recreational and leisure activities.

Specific objectives:

- i) To translate, adapt and validate into Portuguese language (Portuguese of Portugal) an instrument that measures participation in leisure activities, named "*Children's Assessment of Participation and Enjoyment*" (CAPE), in a sample of children with and without CP, aged between 8 and 18 years;

ii) To describe participation of children with CP in leisure activities and to identify child and family factors that influences the diversity and frequency of participation in these activities;

iii) To describe and compare the participation of children with and without CP in leisure physical activities.

In addition to the objectives described in this work, we intend to broaden the discussion on the importance of leisure participation for children and adolescents with CP, in order to support for clinical practice, future research and service provision.

Design and Ethics

This cross-sectional study was authorized by the Ethics Committee for Human Research of Faculty of Human Kinetics of University of Lisbon. All procedures performed in studies involving human participants were followed the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Written informed consent was obtained, by parents and children, prior to enrollment in this research.

Structure of the Thesis

This thesis is organized in six chapters. The **first chapter** describes conceptual theoretical framework of the research, the relevance and aims of the study, and the thesis structure. The **second chapter** presents the first study, which describes the process of translation, adaptation and validation of the instrument "*Children's Assessment of*

Participation and Enjoyment", used in this research. The sample and data obtained with this study provided information for the followed studies. The **third chapter** presents the second study, referring to the description of the participation in leisure activities of children with CP, and the identification of the child and family factors of that influence participation in leisure. In the **fourth chapter**, we present the third study that assesses differences in leisure physical activities among children with CP and typical development (TD). Finally, an overview of the findings is highlighted, with limitations and directions for future research in the **fifth chapter**.

CHAPTER II - CROSS-CULTURAL VALIDATION OF CHILDREN'S ASSESSMENT OF PARTICIPATION AND ENJOYMENT PORTUGUESE VERSION

Abstract

Participation is a major pediatric rehabilitation goal according to The International Classification of Functioning, Disability and Health Children and Youth version (ICF-CY). ICF-based leisure participation measures for Portuguese-speaking children with cerebral palsy are currently not available. The aim of this study is to assess validity and reliability of the Portuguese (European) version of the Children's Assessment of Participation and Enjoyment (CAPE). CAPE Portuguese version was applied to 170 children with cerebral palsy (n = 69) and typical development (n = 101) aged between 8 and 18 years (mean = 12.5 years; SD = 2.91). Construct validity was assessed by using the know-groups method and the correlation between participation and quality of life. Reliability was determined by internal consistency and test-retest. CAPE discriminates between participation scores of children with cerebral palsy and typical development. A positive correlation was found between participation frequency and physical well-being. Internal consistency was not entirely satisfactory but comparable with that from the original CAPE study. Test-retest reliability was considered good. Conclusions: CAPE Portuguese (European) version showed satisfactory validity and test-retest reliability to assess leisure participation in children with cerebral palsy and typical development aged between 8 and 18 years.

Keywords: Participation; Leisure; Children; CAPE; Measure; Validation; Cerebral Palsy.

Vila-Nova, F., Oliveira, R., & Cordovil, R. (2019). Cross-Cultural Validation of Children's Assessment of Participation and Enjoyment Portuguese Version. *Frontiers in Pediatrics*, 7, 33. doi:10.3389/fped.2019.00033

Introduction

Participation in everyday activities contributes to the development of children with and without disabilities. In the *International Classification of Functioning, Disability and Health* model (ICF), participation is a key element and is considered the result of the interaction between body functions and structures, activity, personal, and environmental factors (Figure 1). Participation is defined as the “*involvement in life situations*” and reflects a social perspective of functioning (WHO, 2001). In the *Children and Youth ICF* version, the activities (ability to execute a task or action in a standard environment) and participation (what an individual does in his/her current environment) domain comprise a full range of life areas, such as general tasks and demands, communication, mobility, self-care, interpersonal relations, domestic life, learning and applying knowledge, major life areas and community, social and civic life, including leisure (WHO, 2007).

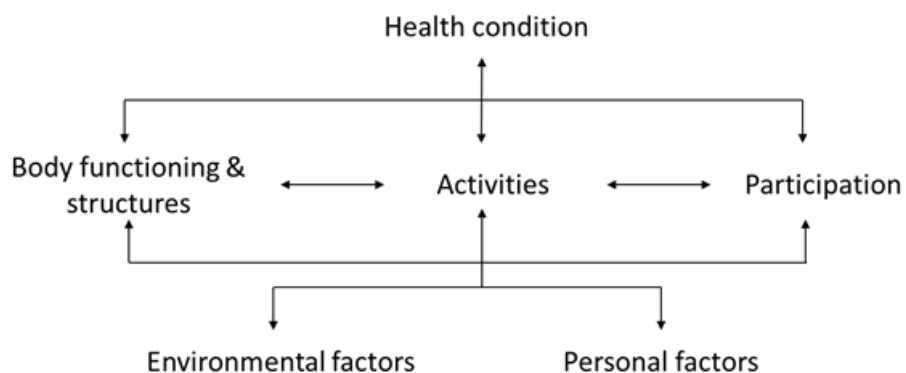


Figure 1. ICF biopsychosocial model(WHO, 2001)

Participation in leisure has increasingly become an area of interest for research and intervention in pediatric neurological rehabilitation (Novak, 2013; Palisano et al., 2012). Leisure represents a significant part of a child's daily life (Larson & Verma, 1999), and may refer to the involvement in formal and informal extracurricular activities, such as play, sport, entertainment, learning, and religious expression . Through leisure, children can learn and develop skills, interact socially, have fun, achieve and fulfill a meaning for life (Powrie et al., 2015). Participating in leisure activities improves their physical, psychological, emotional health and well-being (Caldwell, 2005; Dahan-Oliel et al., 2012; Mc Manus, Corcoran, & Perry, 2008). The relationship between leisure participation and quality of life has been highlighted by a previous systematic review (Dahan-Oliel et al., 2012).

Cerebral palsy (CP) is a chronic health condition caused by injuries in the developing brain. The impairments in neuromotor function caused by these brain injuries may be associated with cognition, communication, and neurosensory system disorders, ultimately impacting on participation (Beckung & Hagberg, 2002). Previous research shows that children with CP are at risk of restricted leisure participation. Indeed, although children with CP may participate in diverse activities and achieve high enjoyment, the frequency of participation is low. Specifically, the frequency of interactions outside the family circle is low, as these children mostly participate in activities carried out at home or at a relative's house, when compared with children without disabilities (Brown & Gordon, 1987; Engel-Yeger, Jarus, Anaby, & Law, 2009; Majnemer et al., 2008b; Schreuer et al., 2014; Shikako-Thomas, Shevell, Lach, Law, Schmitz, Poulin, Majnemer, et al., 2013). Decreased participation is also noticed during the transition from childhood to adolescence (Imms & Adair, 2017). Furthermore, restriction in physical activities is observed in children with CP (Carlon, Taylor, Dodd, & Shields, 2013), which may negatively influence

motor function and physical condition as the child grows (Damiano, 2006; Hanna et al., 2009).

Age, gender, functional ability, and family interests have been identified as determinants of leisure participation (Ghaffari et al., 2020; Shikako-Thomas, Majnemer, Law, & Lach, 2008). Furthermore, a number of studies reveal that significant differences in leisure participation may exist between countries. Ullenhag et al. (2012) found variations in diversity and frequency of leisure participation between Sweden, Norway, and the Netherlands in children with disabilities, and the country of residence was the strongest predictor of variance in all the examined activities practiced on a regular basis. Michelsen et al. (2009) also identified differences in participation among school-aged children with CP from nine regions within seven countries in a multi-center European study. National policies and legislation, support and health services, assistive technology, and the physical environment are likely to cause these differences (Fauconnier et al., 2009).

Since participation is a multidimensional construct, a variety of instruments based on the ICF framework have been developed to measure participation in children and adolescents with disabilities (Phillips, Olds, Boshoff, & Lane, 2013). The *Children's Assessment of Participation and Enjoyment* (CAPE) has been used to measure participation in recreation and leisure activities in children with and without disabilities, aged between 6 and 21 years (Imms, 2008). CAPE was developed in a longitudinal study in Canada with children with physical disabilities, particularly CP (King et al., 2007), and is a child-friendly self-report instrument that records the behavioral (diversity and intensity of participation), contextual (with whom and where activities are done) and affective (enjoyment) aspects of participation, based on information collected directly from the child

(King et al., 2004). CAPE covers core participation constructs, such as objective (*'being there'*) and subjective (*'in the moment'*) elements of experience (Imms et al., 2016). CAPE content validity was obtained by comprehensive literature review, consulting with experts, and pilot testing (King et al., 2004). Reliability and validity were established using data from a longitudinal study with children with physical disabilities (Imms, 2008). Supportive evidence for the construct validity was obtained from prediction correlation with child and family variables (Bult et al., 2010; King et al., 2007), and quality of life domains (Longo, Badia, Orgaz, & Verdugo, 2014). Test-retest reliability was satisfactory (Bult et al., 2010; Fink, Gebhard, Erdwiens, Haddenhorst, & Nowak, 2016; Longo et al., 2014). A systematic review showed that the CAPE is a valid participation measure for CP children (Rozkalne & Bertule, 2014). Translated and adapted versions have been validated (Anastasiadi & Tzetis, 2013; Bult et al., 2010; Colon, Rodriguez, Ito, & Reed, 2008; Fink et al., 2016; Longo et al., 2014), thereby allowing comparisons between countries (King et al., 2013; Ullenhag et al., 2012).

Although the prevalence of CP in Portugal is decreasing, it is still the most common physical disability in children (Sellier, Platt, Andersen, Krageloh-Mann, De La Cruz, & Cans, 2016; Virella et al., 2017). A validated Portuguese version of the CAPE would be instrumental in identifying the patterns of leisure participation in this population, in order to design strategies to promote participation and thereby improve child care. Additionally, this information would be instrumental in providing information for health and education professionals, community services, and public policies.

The aim of the present study is to assess the validity and reliability of the CAPE Portuguese (European) version in children with and without CP, aged between 8 and 18 years. Translated versions require analysis to ensure an adequate cultural adaptation and equivalence (Beaton, Bombardier, Guillemin, & Ferraz, 2002). Thus, construct validity was determined by assessing (i) whether CAPE identifies know-groups differences between children with and without CP, and (ii) there is a significant correlation between participation (diversity, frequency, and enjoyment) and quality of life domains. To assess construct validity, we followed a previous validation study procedure (Longo et al., 2014), small to moderate correlations between quality of life and participation measured by CAPE are expected. Reliability was assessed by internal consistency, and test-retest reliability, with the hypothesis that our results are similar to the original study and translated versions.

Methods

Participants

After initial invitation sent to 263 children (Fig. 1), a convenience sample of 170 children and adolescents (mean age = 12.5 years; SD = 2.91; range 8-18 years) with CP (n = 69) or typical development (TD, n = 101) participated in the study (Table 1).

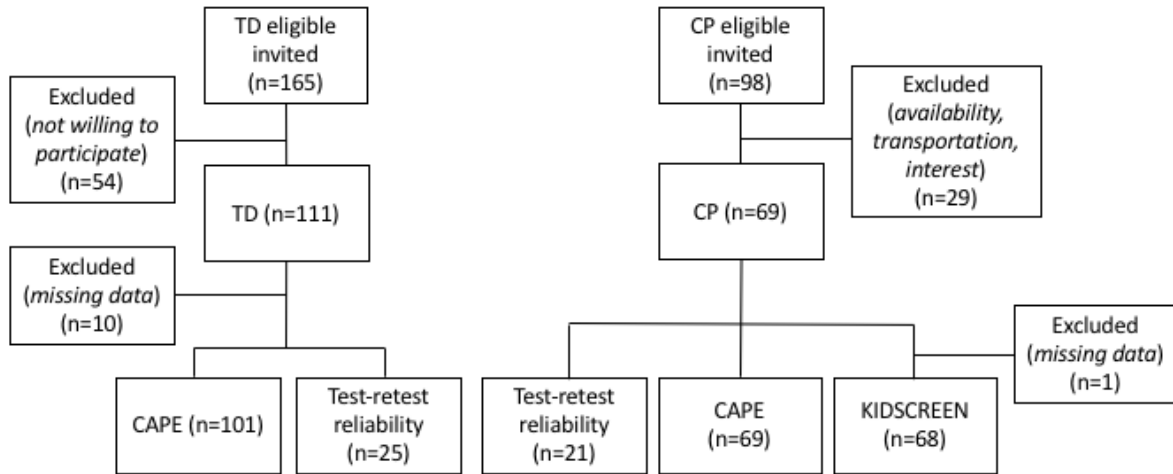


Figure 2 - Flow chart of the recruitment for the study

Participants with CP were identified and contacted by the rehabilitation services of five pediatric rehabilitation centers in the Lisbon area and South of Portugal. Parents of children with CP were invited by telephone or directly at the rehabilitation service, and the objectives and procedures of the study were explained. For those who agreed to participate, an interview was scheduled according to the availability of the family. Participants were given the opportunity to choose the assessment site, either at home or at the rehabilitation service, to reduce interference with the family routine to a minimum. The inclusion criterion was having a medical diagnosis of cerebral palsy. Exclusion criteria were having a severe intellectual disability, a botulinum toxin injection in the last six months, or orthopedic surgical intervention in the last twelve months. The group means age was 12.75 years (SD = 2.95) and included 45 males and 24 females with different levels in the Gross Motor Function Classification System (GMFCS) (level I: 33; level II-III: 23; level IV-V: 13).

Table 1. Sample characteristics

		Children with CP (n = 69) n (%)	Children with TD (n = 101) n (%)	All sample (n = 170) n (%)	<i>p-value</i>
Gender	Male	45 (65.2)	50 (49.5)	95 (55.9)	<i>p</i> = 0.041
	Female	24 (34.8)	51 (50.5)	75 (44.1)	
Age (years)		Mean = 12.75 (SD = 2.95)	Mean = 12.44 (SD = 2.89)	Mean = 12.5 (SD = 2.91)	<i>p</i> = 0.468
	8-12	31 (44.9)	51 (50.5)	82 (48.2)	
	13-18	38 (55.1)	50 (49.5)	88 (51.8)	
Intellectual Disability	None	14 (20.3)	-	-	
	Mild	31 (44.9)	-	-	
	Moderate	24 (34.8)	-	-	
GMFCS	Level I	33 (47.8)	-	-	
	Level II	11 (15.9)	-	-	
	Level III	12 (17.4)	-	-	
	Level IV	7 (10.1)	-	-	
	Level V	6 (8.7)	-	-	

Note. CP: Cerebral palsy; TD: Typical development; GMFCS: Gross Motor Function System.

Participants with TD were recruited from three regular public schools in the Center of Portugal. Parents received an invitation letter with the study explanation and consent form. The inclusion criteria were the absence of disability and orthopedic surgical intervention in the last twelve months. Eligible participants were identified by the teacher. In this group, the mean age was 12.44 (SD = 2.89) and included 50 males and 51 females.

Instruments

Children's Assessment of Participation and Enjoyment (CAPE)

CAPE is a self-report measure of participation in 55 recreation and leisure activities, to assess children and youth between 6 and 21 years with and without disabilities. CAPE can be administered in questionnaire or assisted-interview formats, either with or without parental assistance (Imms, 2008).

CAPE provides information on five dimensions of participation over the previous four months: *Diversity* (Have you done this activity in the past four months? 1 “yes”/0 “no”), if yes, the participant answers the following questions about *Intensity* (How often have you done this activity? from 1 – “one time in the past four months” to 7 – “one time a day or more”), *With Whom* (With whom have you done this activity most often? from 1 – “alone” to 7 – “with others – i.e., coaches, teachers, tutors”), *Where* (Where have you done this activity most often? from 1 – “at home” to 6 – “beyond your community”), *Enjoyment* (How much do you like or enjoy doing this activity? from 1 – “not at all” to 5 – “love it”)(Imms, 2008).

Each of these five dimensions offers three levels of scoring: (I) overall participation score (55 items); (II) domain scores: formal (structured activities that involve rules or goals, typically conducted by a coach or instructor, 15 items), and informal (activities with little or no prior planning often initiated by the child, 40 items); (III) activity type scores: recreational (12 items: e.g., playing board or card games, watching tv), physical (13 items: e.g., bicycling, doing team sports), social (10 items: e.g., going to a party, visiting friends), skill-based (10 items: e.g., learning to sing, playing a musical instrument), and self-improvement (10 items: e.g., doing a religious activity, reading) (King et al., 2004).

KIDSCREEN-52 parent version

The *KIDSCREEN* is a 52-item generic health-related quality of life measure to healthy and chronically ill children and adolescents aged 8–18 years and is designed as a child or parent report. This cross-cultural and standardized instrument was developed based on literature review, expert consultation, and focus groups across Europe (Ravens-Sieberer & Kidscreen Group, 2006). *KIDSCREEN-52* has shown satisfactory psychometric properties (Gaspar & Matos, 2008; Ravens-Sieberer et al., 2008).

KIDSCREEN assesses ten domains of quality of life: physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parental relations, financial resources, social support and peers, school environment, and social acceptance. For each domain, the relevant items are summed and scaled to yield a score in the range 0-100 with higher scores indicating a higher quality of life.

Gross Motor Classification Function System (GMFCS)

GMFCS is a valid and reliable 5-level classification system that describes the gross motor function of children CP based on their self-initiated movement. Emphasis is on usual performance in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). The general heading are: level I (walks without limitations); level II (walks with limitations); level III (walks using a hand-held mobility device); level IV (self-mobility with limitations; may use powered mobility; and level V (transported in a manual wheelchair) (Palisano, Rosenbaum, Bartlett, & Livingston, 2008).

Socio-demographic profile

Information on gender, age, and intellectual disability was recorded according to the participant's clinical information. For intellectual disability, none or mild ($IQ \geq 70$) and moderate ($50 > IQ < 70$) were considered.

Procedures

Translation

The permission to translate and use of the CAPE instrument was initially obtained from the publisher Pearson Corporation. The translation and cultural adaptation were performed in five stages (Beaton et al., 2002; Van de Vijver & Hambleton, 1996).

The original version was translated by three Portuguese-native translators. A synthesis of the translations was carried out by the research team, including an expert in the Portuguese language. The pre-version was reverse-translated by two professional English native translators.

An expert panel comprised by eight researchers with complementary expertise (validation of scales, rehabilitation, and special education) and a parent of a child with CP assessed the content validity by evaluating semantic, idiomatic, experimental, and conceptual adequacy. The experts were instructed to express disagreement with item description and to evaluate the suitability of the construct. Participants scored each item according to relevance using a 4-point Likert scale ranging from "highly relevant" (score 4), "quite relevant" (score 3), "somewhat relevant" (score 2), to "not relevant" (score 1).

We calculated whether CAPE Portuguese version has an appropriate sample of items for the construct by using the overall Content Validity Index (S-CVI/Ave) and the Individual Item Content Validity Index (I-CVI). For this calculation, the number of ratings on relevant scores (scores 3 and 4) was summed and divided by the number of evaluators for each item (I-CVI). For S-CVI/Ave, the I-CVI average of all scale items was calculated. Reference values for excellent content validity index were S-CVI/Ave (>0.90) e I-CVI (>0.78) (Polit & Beck, 2006).

After discussion, the S-CVI/Ave calculated for the CAPE Portuguese version was 0.93. One item ("doing a paid job") received a low I-CVI score (0.63) and generated a discussion regarding its suitability for the study's proposed age group. The item was maintained in the Portuguese version not only because youth engagement in occasional

paid jobs is sometimes observed, but also because consistency with the other CAPE versions is necessary to allow cross-culture comparisons.

A convenience sample (n = 16) was formed to carry out the pre-test of the CAPE Portuguese version (8 CP children; 8 TD children; 8-18 years). The CP group included children with different levels of gross motor function (level I: 3; level II-III: 2; level IV-V: 3), including a child using an augmentative and alternative communication device (computer with vocalizer). Participants reported understanding the guidelines, items, and response options. No activity had to be added or excluded. The final version was accepted by CAPE copyright holders.

Assessment

After consent form assignment, parents of children with CP answered the *KIDSCREEN*. Participants with CP responded to the CAPE by assisted-interview accompanied by a parent. Assisted-interview was the chosen method because it is more enjoyable for the participant, and minimizes the influence of physical impairments on manual completion assessment. Following manual instructions, parents were asked to allow the answers to be given by the children, assisting them if necessary but not answering for them (King et al., 2004). In all situations the child was encouraged to answer independently. The assessments were conducted by the first author (FVN). Gross motor function, intellectual disability and socio-demographic information were obtained from the clinical data available in the rehabilitation services. Participants with TD answered the questionnaire in class, after guidance on the questionnaire items and response options. To perform retest, 46 participants (21 with CP; 25 with TD) responded to the CAPE twice within a two-week interval at the same conditions.

Statistical analysis

Descriptive statistics were used to characterize the sample, diversity, and intensity scores. Diversity refers to the number of different activities and intensity to the frequency of activities carried out. For the CAPE, mean scores were calculated when at least 80% of the items were completed (King et al., 2004).

The known-groups method was used to support Portuguese CAPE construct validity by determining whether the test scores discriminate across groups that are theoretically known to differ. To assess differences in diversity and frequency scores between children with and without CP, independent sample t-tests were performed. After the Bonferroni adjustment, the significance level for the t tests was set at $p < 0.004$. The Pearson-product moment was used to assess the correlation between overall diversity, frequency and enjoyment scores, and *KIDSCREEN* domains in the group of children with CP. The magnitude of the correlations will be assessed according to the effect size proposed by Cohen (Cohen, 1988), small ($r = 0.1$), moderate ($r = 0.3$) and large ($r = 0.5$), with $p < 0.01$. *KIDSCREEN* scores were analyzed when missing data did not exceed one item in each domain (Ravens-Sieberer & Kidscreen Group, 2006).

The internal consistency of the overall, formal and informal, and activity types frequency scores were examined by Cronbach's alpha for the entire sample. Alpha coefficients between 0.70 and 0.95 were considered good (Terwee et al., 2007).

Test-retest reliability was expressed by Intraclass Correlation Coefficients (ICC; two-way mixed effects model; absolute agreement) as a ratio between 0 and 1. Good reliability was considered for ICC values equal or higher than 0.70 (Terwee et al., 2007).

Standard Error of Measurement (SEM) and Smallest Detectable Change (SDC) were also calculated. SEM equals the square root of the error variance, and SDC reflects the smallest within-person change in the score which, with $p < 0.05$, can be interpreted as a real change above measurement error ($SDC = 1.96 \times \sqrt{2} \times SEM$) (de Vet, Terwee, Knol, & Bouter, 2006). Statistical analyses were performed using the SPSS 24.0 version software program.

Results

One hundred and eighty children participated in the study. However, 10 CAPE questionnaires were excluded due to missing data. Thus, 170 children, 69 with CP (40,6%) and 101 with TD (59,4%), were included in the analysis.

Table 2 shows the means of participation diversity by formal and informal domains and activity type. Children with CP have low participation diversity in all activity types, with statistical significance in recreational ($t(168) = 3.54, p = 0.001$), active physical ($t(168) = 3.23, p = 0.001$), social ($t(168) = 2.94, p = 0.002$), and self-improvement activities ($t(168) = 8.13, p < 0.001$). Although there were differences in skill-based activities score means, they were not statistically significant ($t(168) = 0.54, p = 0.586$). Low participation diversity in the CP group was also identified in formal ($t(167) = 3.03, p = 0.003$) and informal domains ($t(168) = 5.66, p < 0.001$).

Table 3 shows the mean of participation frequency on formal and informal domains and activity type. Children with CP have low participation frequency in all activity types, with statistical significance in active physical ($t(168) = 3.64, p < 0.001$); social ($t(168) = 3.71, p < 0.001$); and self-improvement activities ($t(168) = 7.63, p < 0.001$). Recreational ($t(160) = 1.25, p = 0.215$) and skill-based activities ($t(167) = 0.81, p = 0.418$) intensity

scores differences did not show statistical significance. The CP group also presented low participation frequency in formal ($t(165) = 3.46, p = 0.001$) and informal domains ($t(168) = 5.07, p < 0.001$).

Table 2. Comparison of CAPE diversity scores between CP and TD children.

	Children with CP (N = 69) M (SD)	Children with TD (N = 101) M (SD)	<i>T-test</i>	<i>p-value</i>
Formal domain (0-15)	1.9 (1.3)	2.6 (2.0)	-3.036	$p = 0.003$
Informal domain (0–40)	19.0 (4.9)	23.7 (5.6)	-5.661	$p < 0.001$
Recreational activities (0-12)	6.5 (2.0)	7.7 (2.4)	-3.548	$p = 0.001$
Active physical activities (0-13)	2.3 (1.6)	3.1 (1.7)	-3.233	$p = 0.001$
Social activities (0-10)	6.9 (1.6)	7.6 (1.6)	-2.943	$p = 0.002$
Skill-based activities (0-10)	1.8 (1.0)	1.9 (1.6)	-.545	$p = 0.586$
Self-improvement activities (0-10)	3.4 (2.0)	6.0 (2.0)	-8.134	$p < 0.001$

Note. Bonferroni adjustment of the significance level was set at $p < .004$. TD: Typical development; CP: Cerebral palsy.

Table 3. Comparison of CAPE frequency scores between CP and TD children

Domains and activity types (range 0-7)	Children with CP (N = 69) M (SD)	Children with TD (N = 101) M (SD)	T-test	p-value
Formal domain	0.6 (0.4)	0.9 (0.7)	-3.036	$p = 0.001$
Informal domain	2.2 (0.5)	2.7 (0.7)	-5.073	$p < 0.001$
Recreational activities	2.8 (0.9)	3.0 (1.0)	-1.245	$p = 0.215$
Active physical activities	0.8 (0.6)	1.1 (0.7)	-3.642	$p < 0.001$
Social activities	2.9 (0.7)	3.4 (0.9)	-3.708	$p < 0.001$
Skill-based activities	0.8 (0.5)	0.9 (0.8)	-.812	$p = 0.418$
Self-improvement activities	1.6 (1.0)	2.8 (1.0)	-7.630	$p < 0.001$

Note. Bonferroni adjustment of the significance level was set at $p < .004$. TD: Typical development; CP: Cerebral palsy.

One *KIDSCREEN* questionnaire had missing data and was therefore excluded. Small to moderate correlations were found between physical well-being and diversity ($r(66) = 0.289$, $p = 0.017$); psychological well-being and frequency ($r(66) = 0.280$, $p = 0.021$) and enjoyment ($r(66) = 0.264$; $p = 0.030$); and diversity and the school domain ($r(66) = -0.249$, $p = 0.040$) (Table 4). The correlation between physical well-being and frequency of participation was statistically significant ($r(66) = 0.336$, $p = 0.005$).

Table 4. Correlation coefficients between CAPE and KIDSCREEN-52 domains

<i>Children with CP (n = 68)</i>			
<i>KIDSCREEN domains/ CAPE dimensions</i>	<i>Diversity</i>	<i>Frequency</i>	<i>Enjoyment</i>
Physical well-being	0.289*	0.336**	0.019
Psychological well-being	0.209	0.280*	0.264*
Mood and emotions	-0.120	-0.042	0.028
Self-perception	-0.014	0.092	-0.058
Autonomy	0.055	0.111	-0.057
Parent relations and home life	-0.152	-0.059	-0.065
Financial resources	0.218	0.176	-0.180
Social support and peers	0.007	0.053	-0.064
School environment	-0.249*	-0.160	0.130
Social acceptance	-0.196	-0.074	-0.021

Note. *p < 0,05; **p < 0,01. CP: Cerebral Palsy.

Reliability analysis was performed on the overall scale, formal and informal domains, and activity type frequency scores. Alpha values showed good internal consistency for the overall scale (0.79) and formal domains (0.75). The alpha values were low for the informal domain (0.46) and activity types: recreational (0.50), social (0.47), active physical (0.48), skill based (0.40) and self-improvement (0.65).

Test-retest reliability correlation coefficients were good, ranging between 0.74 and 0.83 in the CP group and between 0.82 and 0.91 in the TD group (Table 5). The SDCs ranged between 1.27 and 2.75 in the CP group, and between 1.55 and 3.06 in the TD group.

Table 5 - Test-retest reliability of CAPE frequency scores

	Children with CP (n = 21)				Children with TD (n = 25)			
	CI				CI			
	ICC	CI (95%)	SEM	SDC	ICC	CI (95%)	SEM	SDC
Formal	0.91	0.79-0.96	0.46	1.32	0.93	0.86-0.95	0.62	1.72
Informal	0.86	0.68-0.94	0.56	1.55	0.90	0.83-0.94	0.65	1.81
Recreational	0.80	0.58-0.91	0.99	2.75	0.86	0.77-0.92	1.10	3.06
Physical	0.79	0.55-0.90	0.60	1.67	0.83	0.71-0.90	0.66	1.84
Social	0.74	0.44-0.88	0.76	2.09	0.82	0.70-0.90	0.76	2.11
Skill-based	0.83	0.63-0.93	0.55	1.52	0.91	0.84-0.95	0.72	2.00
Self-improvement	0.81	0.59-0.92	0.77	2.13	0.89	0.81-0.94	1.00	2.77

Note. Two-way mixed effects model; absolute agreement; ICC: Intraclass correlation coefficient; CI: Confidence interval; SEM: Standard error of measurement; SDC: Smallest detectable change.

Discussion

The aim of this study was to assess validity and reliability of the CAPE Portuguese version. The assessment of participation is critical for follow-up monitoring and intervention in children with CP, as participation is an important outcome in pediatric rehabilitation (King et al., 2002; Palisano et al., 2010). Leisure provides opportunities for child development and for improving physical and psychosocial well-being (Shikako-Thomas, Shevell, Lach, Law, Schmitz, Poulin, Majnemer, et al., 2013). The validation of a measure conceptually grounded on ICF provides relevant information about the

involvement of children in everyday life situations, allowing discussion and comparison of results between different countries (WHO, 2001).

Construct validation

To further investigate CAPE construct validity, we tested the hypothesis that there are significant differences between the participation scores of children with and without disabilities. Our data revealed that Portuguese children with CP have lower diversity and frequency of leisure participation than children with typical development (TD). Participation diversity was low in formal (structured, planned activities) and informal (non-structured, self-initiated activities) domains, and recreational, active physical, social, and self-improvement activities. Furthermore, children with CP showed a low frequency of participation in formal and informal domains, and active physical, social, and self-improvement activities.

In agreement with our study, differences in participation between groups of children with and without disabilities were observed in CAPE studies conducted in other countries. A study with 398 Spanish children with and without CP (Longo et al., 2014) identified lower diversity for the CP group in both formal and informal domains, recreational, active physical and self-improvement activities. Bult et al. (2010) also found significant differences between Dutch children with TD and those with physical disabilities, including CP, in the frequency of participation in physical, social, self-improvement and recreational activities. These findings are consistent with previous research (Engel-Yeger et al., 2009; Mc Manus et al., 2008; Michelsen et al., 2009; Schreuer et al., 2014).

Our findings showing a positive correlation between leisure participation and quality of life in children with CP also support construct validity. We found that frequency of participation in leisure activities is positively related to quality of life in the physical well-being domain in children with CP, which is in agreement with previous research (McManus et al., 2008; Shikako-Thomas et al., 2012). Dahan-Oliel et al. (Dahan-Oliel et al., 2012) identified a relationship between participation in leisure activities and different dimensions of quality of life in children with neuro-disabilities.

Furthermore, McManus et al. (2008) showed that overall participation in everyday activities has a significant effect on the quality of life of Irish school-aged children with CP. In that study, a one-unit increase in participation frequency was associated with a 7.8 units increase in the quality of life related to physical well-being. Shikako-Thomas et al. (2012) suggests that children who participate in more leisure activities may experience better quality of life than children who participate in fewer or less frequent activities. The authors also argue that the direction of causality may be reverse, such that children who experience a higher sense of physical and psychosocial well-being may engage in more leisure activities.

Interestingly, Longo et al. (2014) also found positive correlations between leisure participation and other domains of quality of life, such as psychological well-being, financial resources, autonomy, and social support and peers. The differences between the present study and Longo's study may be due to differences between samples. Some participants were children with CP with severe intellectual disability, whereas in our study participants with severe intellectual disability were not included. Indeed, Arnaud et al. (2008), based on parental reports, found that the severity of intellectual impairment in

children with CP was strongly associated with low quality of life in physical well-being, autonomy, and social support domains, suggesting that these children are less able of creating social time or maintaining relationships with their peers.

Reliability

Reliability of CAPE was not entirely satisfactory. The internal consistency of the CAPE Portuguese version is considered good (0.80) for the overall scale. The results for formal (0.46) and informal domain (0.75), and activity types (0.40 to 0.65) are similar to those identified in the original study, where formal and informal alpha values were 0.42 and 0.76, respectively, and activity types ranged from 0.32 to 0.62 (King et al., 2004). The authors argued that low alpha values are expected since frequency scores are determined by various environmental, family, and child factors. Thus, our results are in agreement with the findings of other versions (Anastasiadi & Tzetzis, 2013; Colon et al., 2008; Fink et al., 2016). Regarding the test-retest analysis, our ICC results were adequate, superior to 0.74 in the group with CP, and 0.82 in the TD group, in formal and informal domains, and activity types. SDC values indicate that in both groups, changes would have to be significant for recreational activities to be considered beyond the measurement error.

This study has limitations, such as the use of a sample of children with CP, which excluded children with severe intellectual impairment, and those who underwent interventions that temporarily influenced activity and family routine. Another limitation might be that parental assistance was available, if necessary, only to the participants with CP. Correlations between quality of life and participation were found in previous studies with children with neurodisabilities (Dahan-Oliel et al., 2012; Mc Manus et al., 2008).

However, future studies including children without disabilities, may reinforce the relationship between these constructs. In the present study, children's preference was not assessed, but its relationship with participation has been previously established (Anastasiadi & Tzetzis, 2013; Fink et al., 2016), and could be explored in the future in a Portuguese sample. Quality of life was assessed only from the parents' perspective, although differences between the child's and parent's reports could be expected. Although participation refers to the interaction between person and environment in everyday life situations, we did not analyze how environmental factors influence leisure participation, being also an important approach for future studies. Finally, this study still does not provide normative data of CAPE for Portuguese children. Future studies with larger samples should address this issue.

Conclusion

CAPE is a comprehensive measure that enables identification of leisure participation patterns for clinical and research purposes, covering subjective and objective elements of experience. Also, it can provide relevant information for health and education professionals who assist children with CP. Our results show that the CAPE Portuguese (European) version has adequate construct validity and test-retest reliability to assess children with and without CP aged from 8 to 18 years.

**CHAPTER III - PARTICIPATION IN LEISURE ACTIVITIES BY PORTUGUESE CHILDREN
WITH CEREBRAL PALSY**

Abstract

Leisure participation contributes to the health and wellbeing of children with and without physical disabilities. In the present cross-sectional study, we aimed to assess the influence of child and family factors on leisure activity participation of children with cerebral palsy (CP) aged 8-18 years. A convenience sample of 69 participants with CP (M age = 12.75 years, SD = 2.95; 45 males) responded to the Children's Assessment of Participation and Enjoyment questionnaire to report participation diversity, frequency, companies, environment and enjoyment in leisure activities. From these questionnaires, we used descriptive statistics to summarize overall participation, two activity domains (formal and informal) and five activity types (recreational, social, active physical, skill-based, and self-improvement). Regression analysis assessed child and family factors' influence on participation. On average, children with CP were involved in 21 leisure activities in the last four months. Within activity types, social and recreational activities were the most reported. Participation in physical and skill-based activities was low. Overall children with CP experience high enjoyment with engagement in leisure activities. Collectively, factors of age, cognitive function, gross motor function, and mother's education level predicted 33% of activity diversity and 30% of activity frequency. We concluded that children with CP show diverse leisure activity participation and high leisure activity enjoyment. Health, education and sports professionals should consider the child's functional profile and family context when promoting participation.

Keywords: cerebral palsy; child factors; family factors; leisure; recreation; participation.

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Introduction

Cerebral palsy (CP) describes a group of permanent movement and posture disorders resulting from a developing brain injury. Children with CP show changes in brain structure and function that affect motor development and behavior and that may be associated with impairments in cognition, communication, neurosensory ability, and musculoskeletal impairments (Rosenbaum et al., 2007). Recent updates have estimated CP prevalence in Europe at 1.77/1,000 children, making it the most common childhood physical disability (Sellier, Platt, Andersen, Krageloh-Mann, De La Cruz, Cans, et al., 2016).

The International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY) has proposed a biopsychosocial perspective of functioning and disability for assessment, treatment, and treatment evaluation in the rehabilitation of children with chronic health conditions (WHO, 2007). In this model, participation is a primary goal for rehabilitation and represents the higher level of child's functioning, describing the performance of tasks in the child current environment (WHO, 2007). Participation is a multidimensional construct defined as the involvement in life situations, with such essential elements as *attendance* related to a child's range and frequency of activities, and *involvement* related to the affect, motivation or social connection experienced while in attendance (Imms et al., 2016).

In core ICF considerations for children with CP, participation in recreation and leisure, are described as part of major life activities in community and civic life domains (Schiariti et al., 2015). These activities provide opportunities for experiencing and learning

motor, cognitive, and social skills, and for forming interpersonal relationships in multiple environments (King et al., 2003; Shikako-Thomas, Kolehmainen, Ketelaar, Bult, & Law, 2014). Among children with CP, engagement in leisure activity contributes to quality of life domains, such as physical and psychological well-being, autonomy, social support, and parent relation (Badia et al., 2013). For children with physical disabilities, experiencing fun, freedom, friendship, and fulfillment have emerged as central benefits to engagement in leisure-time activities (Powrie et al., 2015).

Since the publication of the ICF-CY biopsychosocial perspective, there has been increased research attention on leisure activity participation by children with disabilities (Michelsen et al., 2009; Tonkin et al., 2014). To date, studies on leisure activity participation among children with disabilities suggest that these children are involved in less diverse activities and are less frequently engaged in leisure activities than are peers without disabilities; additionally, they are often involved in informal activities, often performed within family environments, either alone or with family members (Engel-Yeger et al., 2009; Law et al., 2006; Tonkin et al., 2014). Individual, family, and environmental factors have been identified as determinants of children's involvement in activities outside of school (King et al., 2003; Shikako-Thomas et al., 2009).

Differences in participation among children with disabilities were identified between different European countries (Michelsen et al., 2009; Ullenhag et al., 2012). In a study with 278 children with disabilities from Norway, Netherlands, and Sweden, Ullenhag et al. (2012) found national differences in patterns of participation in leisure activities, both with regard to diversity and frequency. The country of residence was the strongest predictor of variance in all types of regularly performed activity. Michelsen et al. (2009)

argued that some countries seem to better facilitate participation than others. Influencing factors, varying across countries, include cultural differences, legislation, public policies, health, education and rehabilitation services, accessibility and transportation, and community service provision (King et al., 2013; Michelsen et al., 2009; Ullenhag et al., 2012). Despite growing interest in assessing involvement in everyday activities among children with disabilities, there has been little research regarding leisure activity participation among children with CP in Portugal. The identification of participation patterns, in addition to influencing factors, may support rehabilitation intervention planning, favoring the promotion of health and well-being in these children.

Thus, we aimed in the present study to: (i) describe patterns of participation in extracurricular recreation and leisure activities by Portuguese children and adolescents (aged 8-18 years) with CP; and (ii) identify child and family factors influencing the diversity and frequency of leisure activity participation by these children and adolescents.

Methods

Participants

We recruited a convenience sample of children and adolescents aged 8-18 years with a medical diagnosis of CP from rehabilitation centers in the metropolitan area of Lisbon and the South of Portugal. Exclusion criteria were (a) severe cognitive impairment (IQ < 50), (b) a history of botulinum toxin injection in the last six months, and/or (c) orthopedic surgical intervention in the previous 12 months.

Rehabilitation and health professionals provided participant clinical information regarding age, gender, CP type, motor and cognitive function. For cognitive function a psychologist reported the level of impairment as none or mild ($\text{IQ} \geq 70$) or moderate ($50 < \text{IQ} < 70$). The *Gross Motor Function Classification System* (GMFCS) was used by the physical therapist to describe the participants' gross motor function, based on the child's self-initiated movement. The general headings of this functional classification system range from level I (walks without limitations) to level V (transported in a manual wheelchair) (Palisano et al., 2008).

Parents completed a socio-demographic data form that included such information as mother's education level, family type (single parent; two parents), number of siblings, presence or absence of neurosensory impairments (epilepsy, visual and auditive impairment), and school inclusion.

Participation assessment

The assessment was performed with the *Children's Assessment of Participation and Enjoyment* (CAPE), a valid self-report participation measure for of children with CP (Rozkalne & Bertule, 2014) . It provides information on participation core (attendance and involvement) and related (environment) constructs (Adair et al., 2018) in 55 leisure activities. Validity and reliability of CAPE were obtained in a study with children with CP and other physical disabilities (King et al., 2007). CAPE Portuguese version shows adequate test-reliability and construct validity to assess Portuguese children with CP aged from 8 to 18 years (Vila-Nova, Oliveira, & Cordovil, 2019).

The CAPE provides information on five dimensions of participation over the previous four months. Diversity score is the sum of the number of activities a child does, where higher scores reflect a wide range of participation in a group of activities. Frequency score reflects the average amount of time a child spends participating in activities based on the maximum opportunities for engagement, where higher scores indicate a greater extent of time participating. With whom score reflects the people with whom the child participates in activities most often, low scores indicate more individual and high scores more social engagement. Where score suggests the type of environment in which participation is taking place most of the time, low scores indicate more home-based involvement, and high scores indicate that activities are more community-based. Enjoyment score indicates the average enjoyment rating for all the items the child participates in, where higher scores can be interpreted as pleasure experienced from participation (King et al., 2004).

Each of these five dimensions offers three levels of scoring: (I) overall participation score (55 items); (II) domain scores: formal (15 items), or informal (40 items); (III) activity types: recreational (12 items), physical (13 items), social (10 items), skill-based (10), and self-improvement (10 items) (King et al., 2004). Formal activities refer to structured activities that involve rules or goals with a formally designated leader or instructor (e.g., music or art lessons, organized sports). Informal activities have little or no prior planning and are often, but not always, initiated by the child (e.g., reading, playing games). Activity and score descriptions are attached as supplemental material. Participants responded to the CAPE by assisted-interview, at home, or the health center, accompanied by a parent. The first author conducted the assessments.

Statistical Analysis

Descriptive statistics were used to characterize diversity, frequency, with whom and enjoyment scores, for overall, formal and informal domains and activity types. Frequency analysis was used to describe the activities in which most children participated.

We run a regression analysis to identify influencing factors on diversity and frequency scores. A hierarchical linear regression was performed to verify how child factors (first stage), and family factors (second stage) could explain variances on overall diversity and frequency of participation, defined as dependent variables (DVs). Initially, the independent variables (IVs) related to the child (age, gender, motor function, cognitive function), and to the family (mother education level and family type) were selected according to research and theoretical constructs (King et al., 2003; Shikako-Thomas et al., 2009). Afterwards, a correlation analysis was performed between DV and IVs to identify the variables with potential to contribute to the model, considering eligible for inclusion those with an $r \geq .3$. In this sense, gender ($r_{div} = -.086$, $p = .483$; $r_{freq} = -.099$, $p = .417$) and family type ($r_{div} = -.047$, $p = .702$; $r_{freq} = -.055$, $p = .655$) were not included. All remaining variables were included in the analysis.

Statistical assumptions for regression analysis were checked (Cohen & Cohen, 2003). Akaike information criterion was used to identify the best model for diversity and frequency of participation. The software SPSS 23 was used for statistical analysis.

Results

The sample consisted of 69 participants with CP, with a mean age of 12.75 (± 2.95) years, 45 males (65.2%), and 24 females (34.8%), mostly from spastic type (88.4%). Epilepsy and visual impairment were present in almost half of the sample, which also included 3 participants with auditive impairment (4.3%). Participants with different levels of gross motor function (level I: 33; level II: 11; level III: 12; level IV: 7; level V: 6), and cognitive impairment (none: 14; mild: 31; moderate: 24) were included. All participants were in school, regular (69.5%), or special education (30.4%). Regarding family characteristics, 69.6% have a two-parent family type, 56% of mothers have secondary or higher education, and 85% of the participants have one or more siblings (Table 6).

The table 7 shows ten activities that children most participated in informal and formal domains. In the informal domain, recreational activities were most reported, such as watching TV (98.6%), listening to music (94.2%), and playing video/computer games (92.8%). They were followed by social activities, talking to the phone and visiting (87%), hanging out (84.1%), entertaining others (79.7%), and going to a party (73.9%). Playing games (72.5%) was the most reported informal physical activity. In the formal domain, swimming was the most reported activity, performed by less than half the sample (42%). Involvement in other structured physical activities had low reports, horseback riding (15.9%), doing martial arts (10.1%), learning to dance (7.2%), doing team sports (5.8%), and racing or track and field (2.9%).

Table 6. Sample profile (n=69)

Variable		N (%)
Age	Mean: 12.75 years; SD: 2.95	
	8-12 y	31 (44.9)
	13-18 y	38 (55.1)
Sex	Male	45 (65.2)
	Female	24 (34.8)
CP type	Spastic	61 (88.4)
	Dyskinetic	7 (10.1)
	Ataxic	1 (1.4)
Epilepsy	Yes	34 (49.3)
	No	35 (50.7)
Visual impairment	Yes	35 (50.7)
	No	34 (49.3)
Auditive impairment	Yes	3 (4.3)
	No	66 (95.7)
Intellectual disability	None	14 (20.3)
	Mild	31 (44.9)
	Moderate	24 (34.8)

Table 6.Cont.

Gross motor function	Level I	33 (47.8)
	Level II	11 (15.9)
	Level III	12 (17.4)
	Level IV	7 (10.1)
	Level V	6 (8.7)
School participation	Regular school without support	15 (21.7)
	Regular school with support	33 (47.8)
	Special unit in a regular school	19 (27.5)
	Special school	2 (2.9)
Mother education level	Higher education	20 (29.0)
	Secondary education (12th grade)	19 (27.5)
	Elementary education (9th grade)	22 (31.9)
	Basic literacy	8 (11.6)
Family type	Two-parent	48 (69.6)
	Single-parent	21 (30.4)
Siblings	None	8 (11.6)
	1	32 (46.4)
	2	17 (24.6)
	3+	12 (14.7)

Table 7. Ten activities that children with CP (n=69) most participated in by domain

Rank	Informal	(%)	Formal	(%)
1	Watching TV or rented movie	98.6	Swimming	42.0
2	Listening to music	94.2	Doing a religious activity	36.2
3	Playing computer or video games	92.8	Getting extra help for schoolwork from a tutor	23.2
4	Talking to the phone	87.0	Playing a musical instrument	23.2
5	Visiting	87.0	Horseback riding	15.9
6	Hanging out	84.1	Doing martial arts	10.1
7	Entertaining others	79.7	Taking music lessons	8.7
8	Going to a party	73.9	Learning to dance	7.2
9	Playing games	72.5	Doing team sports	5.8
10	Dancing	68.1	Racing or track and field	2.9

In the table 8, we provide description of overall, domains and activity type participation patterns in leisure activities. Overall scores of children with CP showed that the participants were involved in 37.8% of the 55 possible activities ($M: 20.8$; $SD: 5.7$), with low frequency (1.8 in a total of 7.0) and high enjoyment scores (4.2 in a total of 5).

Within activity types (table 8), participants reported greater frequency of participation in social and recreational activities. Active physical and skill-based activities were performed less frequently. With whom and were scores indicates higher social engagement in active physical, social, and skill-based activities.

Table 8. Means (standard deviations) of CAPE scores (n=69)

	% of activities performed	Diversity¹	Frequency (0-7)	With Whom (0-5)	Where (0-6)	Enjoyment (0-5)
Overall	37.8%	20.8(5.7)	1.8(0.4)	2.5(0.3)	2.5(0.5)	4.2(0.5)
Formal domain	12.5%	1.9(1.3)	0.6(0.4)	3.5(1.8)	3.2(1.7)	3.6(1.8)
Informal domain	47.4%	19.0(4.9)	2.2(0.5)	2.4(0.3)	2.3(0.5)	4.2(0.5)
Recreational activities	54.1%	6.5(2.0)	2.8(0.9)	1.9(0.4)	1.8(0.5)	4.3(0.6)
Active Physical activities	17.6%	2.3(1.6)	0.8(0.6)	2.9(1.4)	2.9(1.5)	3.9(1.6)
Social activities	68.4%	6.9(1.6)	2.9(0.7)	2.7(0.4)	2.8(0.7)	4.3(0.5)
Skill-based activities	17.5%	1.8(1.0)	0.8(0.5)	3.1(1.5)	2.8(1.6)	4.0(1.3)
Self-Improvement activities	34.5%	3.4(2.0)	1.6(1.0)	2.0(0.8)	2.0(1.0)	3.3(1.3)

Note: ¹Range: Overall (0-55); Formal (0-15); Informal (0-40); Recreational (0-12); Active physical (0-13); Social (0-10); Skill-based (0-10); Self-improvement (0-10)

The hierarchical regression analysis revealed in the stage one, age, motor, and cognitive function together accounted for 28% of the variance in diversity scores, $F(3, 65) = 9.727$, $p < .001$ (table 9). Cognitive function unique contribution was statistically

significant ($p < .001$) and accounted for 47% of the variation when the other variables remain controlled.

After adding the family variable (mother education level) in stage two, all four independent variables explained 33% of the variation, and this change in R^2 was significant, $F(4, 64) = 9.466$, $p < .001$. With all independent variables in the model, neither age nor motor functions were significant predictors of diversity. The most important variables influencing diversity were cognitive function ($p = .01$) and mother education level ($p = .015$), which uniquely explained 33% and 28% of the variation, respectively. The regression equation for diversity was $Y_{div} = 24.61 - 0.23 \text{ age} + 1.37 \text{ gross motor function} + 3.82 \text{ cognitive function} + 3.48 \text{ mother education level}$.

Table 9. Summary of the hierarchical regression models for diversity scores

Variables	B	SE B	β	t	R^2	Adjusted R^2	Akaike IC
<i>Block 1</i>					.310	.278	220.410
Age	-.24	.21	-.13	-1.16			
Motor function	1.22	1.34	.10	.91			
Cognitive function	5.42	1.34	.46***	4.06			
<i>Block 2</i>					.372	.332	215.930
Age	-.23	.20	-.12	-1.17			
Motor function	1.37	1.29	.18	1.07			
Cognitive function	3.82	1.44	.33**	2.67			
Mother education level	3.48	1.39	.28*	2.51			

Note. * $p < .05$; ** $p \leq .01$; *** $p < .001$. Motor function (GMFCS I- II = 1; GMFCS III-IV = 0); Cognitive function (IQ $\geq 70 = 1$; IQ $< 70 = 0$); Mother education level (secondary/higher education = 1; basic/elementary = 0).

For the frequency scores (table 10), the hierarchical regression analysis showed that at stage one, age, motor, and cognitive function together accounted for 28% of the variance, $F(3,65) = 9.727, p < .001$. The unique contribution of age and cognitive function ($p < .001$) were statistically significant and accounted respectively for 23% and 42% of the variance in scores. The inclusion of the family variable (mother education level) in stage two resulted in a small contribution to the model, $F(4,64) = 8.197, p < .001$.

In the final model, the four independent variables together accounted for 30% of the variance in frequency. Age ($p = .035$) and cognitive function ($p = .01$) remained as predictors, with a unique contribution of 23% and 33%, respectively. The regression equation for frequency was $Y_{\text{freq}} = 2.312 - 0.4 \text{ age} + 0.08 \text{ gross motor function} + 0.31 \text{ cognitive function} + 0.18 \text{ mother education level}$.

Table 10. Summary of the hierarchical regression model for frequency scores

Variables	B	SE B	β	t	R ²	Adjusted R ²	Akaike IC
<i>Block 1</i>					.313	.281	-128.467
Age	-.04	.02	-.23*	-2.15			
Motor function	.07	.11	.07	.64			
Cognitive function	.40	.11	.42***	3.71			
<i>Block 2</i>					.339	.297	-129.092
Age	-.04	.16	-.23*	-2.15			
Motor function	.08	.11	.08	.72			
Cognitive function	.31	.12	.33**	2.67			
Mother education level	.18	.11	.18	1.58			

Note. * $p < .05$; ** $p \leq .01$; *** $p < .001$. Motor function (GMFCS I- II = 1; GMFCS III-IV = 0); Cognitive function (IQ $\geq 70 = 1$; IQ $< 70 = 0$); Mother education level (secondary/higher education = 1; basic/elementary = 0).

Discussion

This study aimed to assess patterns and factors influencing participation in leisure activities of children and adolescents with CP. To our knowledge, this is the first study regarding leisure participation in children with CP (aged 8 to 18 years) in Portugal.

The results showed that children with CP participate in an average of 21 leisure activities in the last 4 months with high overall enjoyment. Social and recreational were the most reported activities performed. Participation in physical and skill-based activities was low. Our findings are in line with previous reports, where children with disabilities present a diverse pattern of participation, with greater diversity and frequency in social and recreational activities (King et al., 2013; Longo, Badia, & Orgaz, 2013; Ullenhag et al., 2012) and high overall enjoyment (Imms, Reilly, Carlin, & Dodd, 2008; Law et al., 2006; Majnemer et al., 2008a; Shikako-Thomas, Shevell, Lach, Law, Schmitz, Poulin, & Majnemer, 2013; Tonkin et al., 2014).

Similar to others countries (King et al., 2013; Longo et al., 2013; Ullenhag et al., 2012), we identified low participation of children with CP in physical activities. Since CP is a lifelong condition that has in primary impairment a disorder in motor activity and behavior, physical activity participation is a main goal for rehabilitation (Shikako-Thomas et al., 2014). Gross motor function impairments can range from a slight incoordination to walk and perform motor skills such as running and jumping, to a dependence of physical assistance and devices to mobility and antigravity head and trunk postures (Palisano et al., 2008).

In this population, physical activity can improve health-related quality of life (Badia et al., 2013) and is critical to minimize the cardiometabolic risk (Ryan, Hensey, McLoughlin, Lyons, & Gormley, 2015) and the effects of deconditioning resulting from activity limitation (Damiano, 2006). For these reasons, the assessment of pain, fatigue, accessibility of activities and locations should be considered when supporting children with CP to become and remain physically active (Lauruschkus, Nordmark, & Hallstrom, 2015; Shields & Synnot, 2016). Rehabilitation professionals and service providers should also notice the child's perspective on the importance of having fun with family and friends, and the enjoyment of the sensation of speed when engaging in physical activities (Lauruschkus et al., 2015).

Our results show that child and family factors influence on overall diversity and frequency of participation in leisure activities in children with CP. Together, age, motor function, cognitive function, and mother's education level explained 33% of the variation on diversity and 30% on the frequency of participation. These findings are supported by previous reports (Longo et al., 2013; Shikako-Thomas et al., 2009; Shikako-Thomas, Shevell, Lach, Law, Schmitz, Poulin, & Majnemer, 2013).

In a study with Spanish children with CP, aged 8 to 18 years, with none to severe intellectual disability, Longo et al. (2013) found children with better motor and cognitive functioning participate in a wider range of activities and with a higher frequency. However, unlike our study, family variables were not significant predictors, while the environmental variable (type of school) influenced the final model along with the child's variables, 27% in diversity, and 24% in frequency scores (Longo et al., 2013).

We found that cognitive function significantly influenced both diversity and frequency of participation in leisure activities in children with CP. Cognitive impairment is a frequent comorbidity in children with CP (Novak, Hines, Goldsmith, & Barclay, 2012). In Portugal, epidemiological surveillance of CP at age 5 indicates that 59.1% (95%CI: 56.27–62.42) of children have intellectual disability ($IQ < 70$) (Virella et al., 2017).

Cerebral lesions represent a biological constraint that affects the typical developmental trajectory of different cognitive functions. Learning difficulties, information processing, attentional and executive dysfunctions, visual-perceptual deficits, memory impairments are seen to influence child activity and development (Bottcher, 2010). Children with cognitive impairment may require more support from family or others, and activity and environmental adaptations to get involved in those activities (Lawlor, Mihaylov, Welsh, Jarvis, & Colver, 2006). Family plays an essential role in the child's development. Opportunities for parental and social interaction through play and recreation should be prioritized from an early age to foster child growth and development, considering family and context (Frost, 1998).

In our study the increase in age was also identified as determinant on decline of frequency of participation in leisure activities in children with CP, as previously found in children with typical development and disabilities (King et al., 2003; Shikako-Thomas et al., 2009). Developmental and environmental changes associated with diminished involvement in child-related recreational activities, such as play with toys or pretend play, and also physical activities, were reported (Majnemer, Shikako-Thomas, Schmitz, Shevell, & Lach, 2015). Although a decline in participation with the transition to adolescence could be expected, adolescents with CP present low participation patterns when compared with

peers, placing them at higher risk of reduced participation and social isolation (Engel-Yeger et al., 2009; Tonkin et al., 2014). Attention should be given in monitoring participation during the transition from childhood to adolescence (Imms & Adair, 2017), especially if accompanied by changes in school, health, and rehabilitation services.

Access to leisure, engagement in play and recreational activities, and participation in cultural life is a fundamental right for children with and without disabilities (UN, 1989, 2007). The Convention on the Rights of Persons with Disabilities (UN, 2007) emphasizes appropriate measures to ensure that children with disabilities have equal access to participation in play, recreation, leisure, and sporting activities. The results of this study could contribute to the discussion about participation of children with CP in Portugal, since rehabilitation goals might be attained when supporting and raising awareness of families and community on the importance of participation in leisure activities for health and well-being (Shikako-Thomas et al., 2014).

This study had limitations. Our sample was relatively small and restricted in that the CP spastic type was most prevalent, and we did not include participants from all regions of Portugal and those with severe cognitive impairment; thus limiting the generalization of our results to broad populations of these children. Results on Diversity scores should be viewed with caution, due to seasonality and because the Portuguese school curriculum includes activities that could not be scored for the CAPE, such as full-day outings, sports, and other activities in the community. Also, a child might have participated in a few activities but with a high frequency and enjoyment. It is important to individually assess the extent to which and how low diversity scores influenced children's well-being, taking into account the context in which they live. Even though we identified various factors'

influences on involvement in leisure activities, further research with larger and less restricted samples are needed (Tonkin et al., 2014) and pain (Fauconnier et al., 2009), and other family factors, such as financial resources, orientation, and stress (Arakelyan, Maciver, Rush, O'hare, & Forsyth, 2019) might be studied. Future studies identifying environmental barriers (attitudes, physical environment, transportation, policies and support from staff) and facilitators (social support of family and friends) (Anaby et al., 2013), may also provide a better understanding of leisure activity participation by Portuguese children with CP.

Conclusion

The results of this study provide information for multidisciplinary intervention in CP rehabilitation. The identification of child and family profile and inclusion of children's perspective could contribute to the development of tailored strategies to promote engagement in leisure participation and inclusion of children with CP throughout development. Health, education and sports professionals can use these findings in proposing inclusive strategies to foster participation in leisure activities in this population.

CHAPTER IV - DIFFERENCES IN LEISURE PHYSICAL ACTIVITY PARTICIPATION IN CHILDREN WITH TYPICAL DEVELOPMENT AND CEREBRAL PALSY

Abstract

The aim of this study is describe diversity and compare frequency and enjoyment of participation in leisure physical activities in children with typical development (TD) and cerebral palsy (CP). We assessed 170 children aged 8 to 18 years with TD (n=101) and CP (n=69) regarding participation, frequency, and enjoyment in 16 extracurricular physical activities. Non-parametric statistics were used to assess differences between groups. TD and CP children reported high prevalence of participation in four informal physical activities. Children with TD participated more frequently in individual physical activities (p=0.018), team sports (p=0.026), and bicycling (p=0.001), and less in horseback riding (p=0.031) than children with CP in GMFCS II-V. The differences between children with TD and CP in GMFCS I and within the CP group were not statistically significant. All children expressed high enjoyment with participation, without differences between groups. Conclusion: Children with CP in GMFCS II-V tend to participate less in leisure physical activities that require higher motor and perceptual skills. Support in the adaptation of physical recreation and sports may help improve participation.

Keywords: recreation; leisure; physical activity, cerebral palsy: participation

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Introduction

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing brain (Rosenbaum et al., 2007). CP influences the motor function and development and can be clinically classified based on the predominant type of tone or movement abnormality. Spastic CP type has increased tone and pathological reflexes, e.g., hyper-reflexia, clonus, or pyramidal signs. Dyskinetic type includes dystonic and choreoathetotic subgroups, presenting tone fluctuating, involuntary, uncontrolled, recurring, and occasionally stereotyped movements. Ataxic cases present loss of orderly muscular coordination, with movements performed with abnormal force, rhythm, and accuracy (SCPE, 2000). The neuromotor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy and by secondary musculoskeletal problems (Rosenbaum et al., 2007).

The changes in body structures and functions may lead children with CP to develop a variety of musculoskeletal problems during growth and development, such as weakness, muscle/tendon contractures, bony torsion, hip displacement, spinal deformity (Rosenbaum et al., 2007), impacting motor function and physical activity participation. Children with CP are at risk of an inactive lifestyle when compared to peers without disabilities (Carlson et al., 2013). Physical inactivity in CP may be associated with increased sedentary behavior and reduced habitual physical activity, potentiating the deconditioning cycle resulting from motor impairments (Carlson et al., 2013; Maher et al., 2007).

Physical activity is defined as ‘any bodily movement produced by skeletal muscles that result in energy expenditure’, and refers to occupational, leisure-time, household tasks, and other activities (Caspersen, Powell, & Christenson, 1985). Participation in leisure-time physical activity encompasses engagement in formal, structured (e.g., team sports, swimming, dance class) and informal, unstructured (e.g., playing games, doing physical activities, dancing) extracurricular activities. Participation in physical activities is a primary goal for CP pediatric rehabilitation (Schiariti et al., 2015) since it could improve motor function (Damiano, 2006), decrease metabolic risk in children with CP (Ryan et al., 2015), and prevent secondary problems in adult life (Ryan et al., 2014), such as osteoporosis, sarcopenia, hypertension, myocardial infarction, and others non-communicable diseases (Whitney et al., 2018). Furthermore, a positive association between physical activity, quality of life, and happiness were found in young people with CP (Maher, Toohey, & Ferguson, 2016).

Recent research in the USA compared the physical activity engagement and sports participation across disability groups for children (n = 20,867, 6–11 years) and adolescents (n = 28,651, 12–17 years) (Ross et al., 2020). Young children with disabilities had significantly lower odds of being sufficiently active compared with peers without disabilities (adjusted odds ratio = 0.75; 95% confidence interval, 0.60–0.94). A significantly lower percentage of children (33.74%) and adolescents (40.76%) with disabilities were reported to be participating in sports teams or lessons, compared with peers without disabilities (49.89% and 59.94%, respectively). Sport participation in the last year was lowest for those with mobility (26.33%) impairments, compared with those with

function (34.28%), cognitive (38.39%), or sensory (42.12%) impairments (Ross et al., 2020).

Studies have described a low participation frequency in leisure physical activities in children with CP and in comparisons with peers without disabilities (Engel-Yeger et al., 2009; Law et al., 2006; Longo et al., 2013; Majnemer et al., 2015; Ullenhag et al., 2012). A comparative study on participation in physical recreation in Australia found significant differences between children with and without disabilities (physical, intellectual, multiple, others) aged 7 to 17 years (Woodmansee, Hahne, Imms, & Shields, 2016). In that study, participants with CP were included in the group of children with physical disabilities (n=47) with other physical conditions (muscular dystrophy and spina bifida) and showed significant lower participation than peers without disabilities in team and water sports, bicycling, and playing games. Participation may differ between countries due to cultural aspects, legislation, and service provision (King et al., 2013; Michelsen et al., 2009), and can be influenced by child, familial, and environmental factors (Ghaffari et al., 2020; Longo et al., 2013).

The importance of fitness promotion to managing function through fun activities with family and friends is critical for pediatric neurorehabilitation interventions (Rosenbaum & Gorter, 2012). For physical therapy, therapeutic recreation, and sports professionals, participation assessment could provide information for planning and intervention according to the clinical condition, child experiences, and activity-related skills. This could contribute to raise the awareness of the importance of timely involvement in physical activities for child motor development since the stabilization and decline in gross motor function could be clinically significant, especially for children with CP with

greater motor disability (Hanna et al., 2009). Additionally, this study can provide a better understanding of participation in leisure physical activities in Portuguese children with CP so that comparisons with other countries could be made.

This study aims i) to describe the diversity of participation in recreational and leisure physical activities of children with typical development (TD) and CP aged 8 to 18 years; ii) to assess differences in participation frequency and enjoyment in these activities between TD and CP groups. We hypothesized that significant difference in participation in physical activities that require higher perceptual and motor skills would be found between groups, favoring TD children, but not in participation enjoyment.

Materials and Methods

Participants

A convenience sample of participants with TD was recruited from public schools in Lisbon, Portugal. Children aged 8-18 years, without disability, and with no history of orthopedic surgical intervention in the last 12 months were included in this group. The teachers identified eligible participants; parents and children were invited by letter and received the consent form before the assessment. Participants with CP from pediatric rehabilitation centers were invited to collaborate in the study. The inclusion criteria were having a medical diagnosis of CP and age between 8 and 18 years. Exclusion criteria were severe intellectual disability and having undergone interventions that influence physical activity and participation, such as botulinum toxin injection, in the last six months, or surgery in the previous 12 months. Five rehabilitation centers from Lisbon (3), Beja (1), and Faro (1) agreed to collaborate. Families were invited by telephone or directly at the rehabilitation

service. After consent and explanation of study procedures, the assessment was scheduled with the family.

Participation measure

Information on leisure physical activity participation was obtained using Children's Assessment of Participation and Enjoyment (CAPE), a previously validated measure of leisure activity participation for children with and without disabilities (King et al., 2004; Vila-Nova et al., 2019), including physical activities (Capio, Sit, Abernethy, & Rotor, 2010). CAPE is a self-reported measure, which can be answered with or without parental assistance. In this study, we assessed core participation constructs (Imms et al., 2016), related to the extent (diversity and frequency) and experience (enjoyment) of engagement in active recreation, exercise, and sports in the last four months. Data from participation in 16 extracurricular physical activities (Table 11) were extracted according to previous research which also used CAPE as a measuring instrument (Woodmansee et al., 2016).

Diversity scores were assessed, asking children if they had performed the activity in the last four months (0: no; 1: yes). High diversity scores indicate that more children participated in the activity. Frequency scores identify attendance in the last four months (0: not participated to 7: once a day or more). High frequency scores indicate that children performed the activity more often. Enjoyment scores record in a 5 item Likert scale the level of enjoyment while participating (1: not at all to 5: love it). High enjoyment scores indicate that children express more pleasure when performing activity (King et al., 2004).

Table 11. CAPE recreational physical activities

<i>Formal domain</i>	<i>Informal domain</i>
Martial arts	Dancing
Swimming	Going for a walk/hike
Gymnastics	Bicycling
Horseback riding	Water sports
Athletics	Snow sports
Team sports	Playing on equipments
Learning to dance	Playing games
	Individual physical activities
	Non-team sports

Demographic profile

Parents of children with CP filled a form with information about age, gender, and habitual mobility in a community environment (ambulant, ambulant with assistive devices, uses a wheelchair). Rehabilitation services provided clinical information on CP type as well as motor and cognitive function. The Gross Motor Function Classification System (GMFCS) was used to classify the severity of functional limitations in CP children on a five-level scale with an emphasis on movement initiation, sitting control, and walking (Bodkin, Robinson, & Perales, 2003). GMFCS I represents the highest gross motor function, where children presents balance and perform gross motor skills such as walking, running and jumping significantly higher than the others levels (Clutterbuck, Auld, & Johnston, 2019; Pavao, Barbosa, Sato Tde, & Rocha, 2014). Children in level II (with limitations in walking and performance of gross motor skills) to level V (with limitations in mobility, neck, and trunk control) require adaptations to enable participation in physical activities and sports, including physical assistance and self-propelling an assistive device to

walk, a manual wheelchair or powered mobility (Palisano et al., 2008). For a description of cognitive function profile, none or mild ($IQ > 70$) and moderate intellectual disability ($70 < IQ < 50$) were referred according to participant clinical information. Parents of children with TD indicated age and gender before assessment.

Assessment

Prior to the evaluation, all participants were informed about the purpose of the questionnaire and instructed on how to answer the questions. The guidelines of the CAPE manual were followed. Children with TD answered the questionnaire at school while children with CP answered the CAPE questionnaire through an assisted interview, accompanied by the caregiver, at home or at the rehabilitation center. In the assisted interview, figures from the activities and response options were used according to the child's needs. In this case, the caregiver was oriented to allow the children to express their answers, helping them remember the participation in the activities when necessary, in order to capture the perspective of the child. The assessments were performed by the first author.

Statistical analysis

Descriptive statistics were used to characterize the sample (percentage), diversity (percentage), frequency (mean rank), and enjoyment scores (mean and standard deviations). The Kruskal-Wallis H test was used to determine if there were differences in frequency scores between the three groups of participants in formal and informal physical activities, according to the level of severity of motor function: none (children with TD), GMFCS I

(children with CP in level I), and GMFCS II-V (children with CP in levels II-V). A post-hoc test for pairwise comparisons was performed using Dunn's multiple comparison test with a Bonferroni correction. Adjusted p-values are presented. The Mann-Whitney U test compared enjoyment scores between the CP and TD groups. The analysis was performed with SPSS 24.0 version software (IBM Corp., Armonk, NY), with the significance level set at $p < 0.05$.

Results

Participants

The final sample included 170 children (Table 12), 69 with CP (40.6%; mean age 12.75 years, SD 2.95), and 101 with TD (59.4%, mean age 12.44 years, SD 2.98). The group of children with CP was composed mostly of boys (65.2%), with spastic CP as the most common form (88.7%). Community mobility ranged from participants who used a wheelchair (36.2%) to those who walked with an assistive device (4.4%) or walked independently (59.4%). The majority of children with CP (82.6%) and TD (100%) were from the region of Lisbon and Vale do Tejo.

Table 12. Sample characteristics

		Children with CP (n = 69) <i>n (%)</i>	Children with TD (n = 101) <i>n (%)</i>
Gender	Male	45 (65.2)	50 (49.5)
	Female	24 (34.8)	51 (50.5)
Age		Mean = 12.75 (SD: 2.95)	Mean = 12.44 (SD: 2.89)
	8-12y	31 (44.9)	51 (50.5)
	13-18y	38 (55.1)	50 (49.5)
CP type	Spastic	61 (88.4)	-
	Dyskinetic	7 (10.1)	-
	Ataxic	1 (1.4)	-
Motor function	Level I	33 (47.8)	-
	Level II	11 (15.9)	-
	Level III	12 (17.4)	-
	Level IV	7 (10.1)	-
	Level V	6 (8.7)	-
Intellectual disability	None or mild	35 (65.2)	-
	Moderate	24 (34.8)	-
Community mobility	Use wheelchair	25 (36.2)	-
	Walk independent	41 (59.4)	-
	Walk assistive device	3 (4.4)	-

Note. CP: Cerebral palsy; TD: Typical development; GMFCS: Gross Motor Function System.

Leisure physical activity participation

Informal physical activities

Table 13 shows the scores for diversity, frequency, and enjoyment in informal physical activities.

Table 13. Informal physical activity participation comparisons between CP and TD children.

Activities ^a	Diversity		Frequency ^b			Enjoyment	
	CP (n=69)	TD (n=101)	CP GMFCS I (n=33)	CP GMFCS II-V (n=36)	TD (n=101)	CP (n=69)	TD (n=101)
	%	%	Mean rank	Mean rank	Mean rank	M(SD)	M(SD)
Playing games	72.5	76.2	89.24	73.47	88.56	4.48(0.76)	4.52(0.72)
Dancing	68.1	61.4	87.67	85.64	84.74	4.17(1.05)	4.32(0.83)
Walking/Hiking	68.1	83.2	68.38	84.40	91.49	3.96(1.30)	4.05(0.86)
Playing on equipments	52.2	59.4	91.35	72.69	88.15	3.94(1.22)	3.98(0.98)
Individual physical activity	31.9	51.5	79.82	69.40	93.09*	3.68(1.32)	4.13(0.86)
Non-team sports	29.0	27.7	84.09	88.67	84.83	4.55(0.83)	4.21(1.13)
Water sports	27.5	24.8	94.92	77.08	85.42	4.26(0.87)	4.12(1.20)
Bicycling	26.1	61.4	79.09	55.92	98.14***	4.56(0.86)	4.35(0.83)
Snow sports	1.4	4.0	83.00	85.42	86.35	5.00(0)	5.00(0)

Notes. ^aActivities rank with CP group as reference. ^bIn bold significant differences in pairwise comparisons after Bonferroni correction, *p<0.05, ***p<0.001. GMFCS: Gross Motor Function Classification System.

Diversity

In the group of children with CP, the most reported activities were playing games (72.5%), dancing (68.1%), walking/hiking (68.1%), and playing on equipment (52.2%). Approximately a quarter of the children with CP reported participation in bicycling (26.1%). The lowest participation in this group was in snow sports (1.4%).

In the group of children with TD, the pattern was similar, except that participation in bicycling was far more frequent in this group (Table 13). The most reported activities were walking/hiking (83.2%), followed by playing games (76.2%), dancing (61.4%), bicycling (61.4%), and playing on equipment (59.4%). The participation in snow sports (4.0%) was also low in this group (Table 13).

Frequency

We found statistically significant differences between groups in the frequency of participation in two informal activities (Table 13). The distributions were statistically significantly different between groups in individual physical activity, $\chi^2(2) = 8.217$, $p=0.016$, and cycling, $\chi^2(2) = 23.818$, $p < 0.001$.

The post hoc analysis revealed statistically significant differences in frequency scores in individual physical activities between the children in GMFCS II-V (mean rank=69.40) and TD children (mean rank=93.09) ($p=0.018$), but not between children in GMFCS I (mean rank=79.82) and any other group. The differences between frequency distribution in bicycling was also significant only between children in GMFCS II-V (mean rank=55.92) and those without motor impairment (mean rank=98.14) ($p=0.001$).

Enjoyment

Enjoyment with participation was high (≥ 4 in a total of 5) for both the CP and TD groups in almost all activities (Table 13). For children with CP, the lowest enjoyment score was in individual physical activities ($M=3.68$; $SD=1.32$), while for TD children the lowest

enjoyment was found for playing on equipments (M=3.98; SD=0.98). We did not find significant differences between groups.

Formal physical activity

Table 14 shows the scores for diversity, frequency, and enjoyment in formal physical activity.

Table 14. *Formal physical activity participation comparisons between CP and TD children.*

Activities ^a	Diversity		Frequency ^b			Enjoyment	
	CP (n=69)	TD (n=101)	CP GMFCS I (n=33)	CP GMFCS II-V (n=36)	TD (n=101)	CP (n=69)	TD (n=101)
	%	%	Mean rank	Mean rank	Mean rank	M(SD)	M(SD)
Swimming	42.0	24.8	96.06	90.49	80.27	4.21(0.98)	4.32(0.90)
Horseback riding	15.9	3.0	91.91	92.57*	80.89	4.36(1.03)	5.00(0)
Martial arts	10.1	8.9	87.85	84.13	85.22	4.43(0.79)	4.78(0.44)
Learning to dance	7.2	13.9	83.68	80.94	87.72	4.20(1.30)	4.79(0.43)
Team sports	5.8	16.8	85.24	75.00	89.33*	5.0(0)	4.65(0.49)
Athletics	2.9	6.9	81.00	85.60	86.94	5.0(0)	4.57(0.54)
Gymnastics	1.4	9.9	82.59	80.00	88.41	5.00(0)	4.80(0.42)

Notes. ^aActivities rank with CP group as reference. ^bIn bold significant differences in pairwise comparisons after Bonferroni correction, *p<0.05, ***p<0.001. GMFCS: Gross Motor Function Classification System.

Diversity

The results showed swimming was the most performed formal physical activity for both the CP (42%) and TD (24.8%) groups, it was followed by horseback riding (15.9%) and martial arts (10.1%) in the CP group and by team sports (16.8%) and dance lessons (13.9%) in the TD group.

Frequency

We found statistically significant differences in the frequency of participation in two formal activities in the comparisons between groups (Table 14). The distributions were statistically significantly different between motor function groups in horseback riding, $\chi^2(2) = 9.638$, $p=0.008$, and team sports, $\chi^2(2) = 6.899$, $p < 0.032$.

The post hoc analysis revealed statistically significant differences in frequency scores in horseback riding between children in GMFCS II-V (mean rank =92.57) and TD children (mean rank=80.89) ($p=0.031$), but not between the group of children in GMFCS I (mean rank=91.91) and any other group. The differences between frequency distribution in team sports was also significant only between children in GMFCS II-V impairment (mean rank=75.00) and those without motor impairment (mean rank=89.33) ($p=0.026$).

Enjoyment

Enjoyment with participation in formal physical activities was high (≥ 4 in a total of 5) for both CP and TD groups in almost all activities. We did not find significant differences between groups (table 14).

Discussion

This study aimed to describe and assess leisure physical activity participation differences between Portuguese children with TD and CP aged 8 to 18 years. Participation in physical activity is a main goal for rehabilitation interventions aimed to improve motor function and health in children with CP (Damiano, 2006; Schiariti et al., 2015).

We found a higher prevalence of participation in four informal (dancing, playing in equipment, walking/hiking, playing games), and one formal physical activity (swimming) in both groups. The comparison analysis revealed that children with CP in GMFCS II-V participate less frequently in cycling, individual physical activities, and team sports than peers without motor impairments. In contrast, participation in horseback riding was significantly higher for children in GMFCS II-V compared with children with TD. We did not find statistically significant differences between children with TD and children in GMFCS I or in enjoyment between the CP and TD groups.

Our results are similar to previous reports on the participation of children with CP in physical activity (Carlon et al., 2013; King et al., 2013; Lauruschkus, Westbom, Hallstrom, Wagner, & Nordmark, 2013; Longo et al., 2013; Maher et al., 2007). In a multi-center, population-based study in children with (n=813) and without CP (n=2,939), Michelsen et al. (2009) found that more than half of the children played nonsporting games at least weekly. However, 66% of children in the general population played formal sports at least twice a week, compared with 33% of children with CP. Additionally, 24% of children with CP never rode a bicycle for fun, compared with 5% in the general population (Michelsen et al., 2009). Palisano, Copeland, and Galuppi (2007) argued that the performance of physical

activity could differ based on the GMFCS level, with most of the adolescents with CP in the level I performing physical activities by themselves all the time, comparable to what is seen in children without musculoskeletal impairments aged 5 to 15 years. Adolescents in levels II through V suggest the need for physical assistance at times throughout the day in different daily and recreational physical activity (Palisano et al., 2007).

In our study, participation in formal team sports was significantly lower for children in GMFCS II-V. These findings are consistent with studies with children with disabilities in US (Ross et al., 2020), across Europe (Michelsen et al., 2009) and Australia (Woodmansee et al., 2016). In a study with 156 adolescents with CP (11-17 years) (Palisano et al., 2007), 43% of adolescents in GMFCS level I, 67% of the adolescents in levels II and III, and 91% of the adolescents in levels IV and V reported having played team sports in competitive leagues “none of the time” in the previous week. Between 16% and 43% of adolescents reported that they had no opportunity to play team sports with other classmates or in competitive leagues. Formal team sports demand higher motor and perceptual motor skills when playing with implements and in interactions with others and the environment (Fajen, Riley, & Turvey, 2008). Several adaptations to activities, rules, and participation of children with CP could be necessary for inclusion in regular sports when adapted sports are not available.

In line with previous research (Lauruschkus et al., 2013), we found a significantly higher participation in horseback riding in children with CP than in TD peers. Horseback riding is a usual intervention for people with CP, and it includes therapeutic horseback riding (THR) and hippotherapy. Typically, THR is provided by a trained riding instructor who teaches basic riding skills, and hippotherapy is provided by a therapist who uses

equine movements to improve balance, posture, and motor skills (Zadnikar & Kastrin, 2011). Research supports the efficacy of this activity to improve balance and postural control, but not gross motor function (Novak et al., 2020; Tseng, Chen, & Tam, 2013; Zadnikar & Kastrin, 2011). Another potential benefit of improving physical activity and fitness level was identified during riding in children with CP who use wheelchair, who showed higher median and peak heart rate in comparison with those ambulant (Dirienzo, Dirienzo, & Baceski, 2007).

Similarly to Woodmansee et al. (2016), our study found that children with TD participated more in cycling than their peers with CP. The ability to ride a bike requires adequate child skills, environmental context, and task-specific characteristics, which could pose a challenge for children with CP (Sugden, 2017). A survey study with parents of 114 children with CP and 87 children with TD aged 6 to 15 years indicated that the skill development to ride a two-wheeled bicycle was delayed in children with CP compared to their TD peers (Toovey, Reid, Rawicki, Harvey, & Watt, 2017). The authors identified age, gross motor function, and the importance placed on bicycle riding by parents as the most influential factors in the ability to achieve riding a two-wheeled bicycle.

Family and child support may optimize participation and enjoyment of cycling as a recreational activity. Despite the initial negative and overprotective attitudes, the pleasure related to the cycling experience is highlighted by children with CP (Pickering, Horrocks, Visser, & Todd, 2013). Having access to a facility with adapted bicycles, a physiotherapy assessment for a suitable bike and safe adapted cycling conditions were pointed as essential for a successful experience (Pickering et al., 2013). A recent systematic review (Armstrong et al., 2019) found preliminary evidence for cycling interventions to improve components

of gross motor function in non-ambulant children with CP. Encouraging families to provide early opportunities to experience riding a bike with adaptations while ensuring safety and supervision could improve participation in this activity.

Our findings revealed that participation in individual physical activity was significantly lower in children with CP. In CAPE, this group of activities includes jogging, strength, and other exercises (King et al., 2007). The intervention aimed to improve motor function, and physical activity is a central goal in pediatric physical therapy. Supportive evidence was found for exercise, strength, treadmill, task, and goal-oriented training as motor interventions in people with CP (Novak et al., 2020). However, while children with mild motor impairments could participate in most general exercise programs, strategies to break sedentary behavior and physical inactivity aiming to achieve physical activity guidelines could be a challenge for those with more significant motor impairments (Verschuren, Darrah, Novak, Ketelaar, & Wiart, 2014).

Verschuren, Peterson, Balemans, and Hurvitz (2016) emphasize that exercise participation can be performed with a high level of safety by individuals with CP. These authors suggest that healthcare professionals should provide specific counseling to assist with accessibility strategies as well as suggestions for activity and exercise prescription. Also, it is important to note that family and environmental factors play an important role as facilitators of adherence to an exercise program, and the stages of change in physical activity behavior should be considered when supporting families of children with CP (Verschuren, Wiart, & Ketelaar, 2013). Wright, Roberts, Bowman, and Crettenden (2019) reinforce that clinicians should determine both parent and child commitment to a physical

activity program before enrolment, since commitment is likely to facilitate participation and the intervention can then focus on other practical aspects of increasing involvement.

The results of this study contribute to the discussion on the participation of Portuguese children with CP in recreational and leisure physical activity. There has been an increasing discussion on the importance of promoting participation in physical activities in children with CP. The potential benefits on motor, cognitive, and social skills development by engaging in these activities are similar to those for peers without disability and should be encouraged from an early age. Moreover, improved health and quality of life can be achieved by adopting an active lifestyle in children with CP.

Although a greater involvement in informal activities was expected, it is worth mentioning that children benefit from structured physical activities, such as organized sports. The enjoyment was reported only by the children who participated and in the activities with low reports the high scores may reflect appropriate inclusion; it is relevant to stimulate participation and monitor this affective aspect to adjust it according to the child's experience.

Service providers, physical education professionals, and sports coaches can use the results of this study to develop inclusive sports and physical recreation classes in community settings. Providing information about the benefits of regular physical activity and exercise for health could help raise awareness towards an active lifestyle in parents of young people with CP.

This study has some limitations. Most participants included in this study had the spastic form of CP; it is therefore important to include more participants with dyskinetic

and ataxic clinical presentations in future studies. The groups matched for age, but not for gender; being a limitation since participation in physical activities are expected to differ between boys and girls with and without physical disabilities (Law et al., 2006; Seabra, Mendonca, Thomis, Malina, & Maia, 2007; Ullenhag et al., 2012). Although the level of severity of gross motor function may indirectly indicate the degree of cognitive impairment (Himmelmann, Beckung, Hagberg, & Uvebrant, 2006), we were not able to evaluate this aspect directly in the whole sample, being appropriate to address this point and assess children with severe cognitive impairment by proxy. It is also relevant to assess the participation of those with severe intellectual disability and the role of the family in the child involvement in recreational physical activity (Ghaffari et al., 2020). We grouped participants with GMFCS II with those on levels III-V which may be a limitation to consider in future studies that include larger samples of participants with moderate to severe motor impairment. In this study, we evaluated participation through a subjective measure; future research that associates subjective and objective measures could provide a comprehensive view of leisure physical activity in children with CP (Capio et al., 2010), including curricular physical activity, which is not assessed by CAPE. Several personal and environmental factors interact with impairments in body structures and function; it is relevant to take these aspects into account when designing an intervention (Ghaffari et al., 2020). Including the children's activity preferences could include the children's desires regarding involvement in leisure physical activities; the discrepancies between what children do and what they would like to do could then be assessed.

Conclusion

The results of this study showed high enjoyment but significantly lower participation in specific leisure physical activities in children with CP when compared with TD peers. In children with CP in GMFCS II-V, we identified low participation in bicycling, individual physical activity, and team sports when compared with peers without disabilities. Regarding clinical practice, our findings indicate that the promotion of leisure physical activity should be incorporated into rehabilitation programs for children with CP. Healthcare professionals should assess participation patterns, as well as the family perspective regarding physical activity, aiming to encourage early participation in active play and recreation. Rehabilitation support in the adaptation of physical recreation and sports in children with CP in GMFCS II-V could help promote an active and healthy lifestyle.

CHAPTER V. CONCLUSION

Participation in leisure activities contributes to the health, well-being and development of children with disabilities. The participation assessment is critical in pediatric rehabilitation; however, there was a lack of ICF-based measures and research on leisure participation by Portuguese children and adolescents with CP. Despite the challenges and limitations inherent in this type of research, this study aimed to contribute to the participation research in pediatric CP population in Portugal.

Research and Clinical Implications

In order to address these questions, the validation of a measure of participation and enjoyment in leisure activities in children and adolescents with and without CP was performed in this study. The use of a reliable participation measure may help rehabilitation professionals to properly assess children with CP and their families. For research purposes, it allows cross-sectional and longitudinal assessment, broadening the opportunity for intervention and developmental studies in children with CP. CAPE has features that allow a greater interaction with the child/adolescent during the assessment, but may require training and experience in interviewing children with developmental disabilities. It is important to note that the participation construct is multidimensional, and the CAPE focuses only on assessment of extracurricular activities, companies, environment and enjoyment. Researchers should consider whether this measure meets the research purpose, or whether to choose other participation valid measures that include a range of participation domains, such as mobility or school participation. Further measure validation studies for both young children (< 8 years) and adults could provide a whole picture of leisure participation in this population.

The identification of patterns presents a transversal perspective of engagement in leisure activities, providing information of activity, social interactions and environments in which they usually take place. Concerns with social isolation and the secondary complications of physical inactivity are relevant aspects in CP rehabilitation. This research found that despite the differences with peers, Portuguese children with CP reported high participation in social activities in their free time, which may indicate the result of efforts for inclusion and participation in Portugal. The enjoyment expressed for these children could increase intrinsic motivation and strengthen the positive cycle towards participation. In this sense, this assessment can enable a better understanding of the child's perspective on how much they enjoy participating in a particular activity or group of activities. On the other side, the low participation in physical activities identified, alerts to the importance of interventions aimed to improve the engagement in active play, recreation and sport in the family and community contexts. Also, it's important to take in consideration the child and family perspectives, since we revealed the influence of these aspects in participation diversity and frequency.

In CP rehabilitation, the concern with motor function and physical activity takes into account the fact that this health condition implies in limitations on neuromotor activity, balance, mobility and motor skills throughout the development. The benefits to health and well-being of physical activity are numerous, as well as the negative implications of physical inactivity. Regular physical activity can play a determining role in maintaining and minimizing the decline in gross function in children with CP, especially for those with greater motor impairment. Active recreation, play and sports should be available for all children, from early stages of development. Seeking physical recreational activities beyond

those traditionally developed in CP rehabilitation, such as swimming and horseback riding, could allow new and rewarding experiences for children regarding physical activity. The results contribute to highlight the importance of future studies on preferences and perceived barriers to participation in extracurricular physical activity in Portuguese children with PC. Also, research with qualitative design with children, parents, education, rehabilitation, recreation and sports professionals could help to understand, from different perspectives, the barriers to participation experienced for children with CP in leisure activities.

Summary of findings

- The Portuguese version of CAPE have validity and reliability to assess leisure participation of children aged 8-18 years, with CP and TD;
- Children and adolescents with CP have a diverse pattern of participation in leisure with high enjoyment. Participation in social and recreational activities were most reported and performed frequently than skill-based and physical activities;
- Child and family variables influence participation in children with CP. Age, mother education level, motor and cognitive function collectively influence both diversity and frequency of participation in leisure in this population.
- CP and TD children participate with more frequency in four informal leisure physical activities. Differences between groups were significant in individual physical activities, team sports and bicycling, with higher participation on behalf of TD children. Children with CP participate more frequently in horseback riding than TD peers.

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