Participation in leisure activities among adolescents with cerebral palsy: Description, preferences and determinants

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ABSTRACT

Cerebral Palsy (CP) is the most common cause of physical disabilities in children. It is a broad term that describes a set of conditions that is associated with major physical impairments and other developmental deficits and arises in the early stages of brain development. Regardless of the non-progressive nature of the condition, the clinical manifestation and severity of impairments may change as the child develops. As a consequence, limitations in everyday activities in different life situations may be experienced, with possible impact to the individual's health and social participation.

Participation in leisure activities is an important aspect of health, as described by the International Classification of Functioning, Disability and Health (ICF). Engagement in leisure activities is essential for the development of a series of competencies such as the understanding of societal rules, the development of self-esteem, and the achievement and maintenance of cardio-vascular health and therefore is crucial across the life span for a healthy development.

Adolescence is a period of rapidly occurring transformations. Adolescents with disabilities may experience particular and unique challenges with regards to changes in their health condition, acceptance by peers and engagement in a variety of life roles, which may collectively have an impact on long-term outcomes. Children with disabilities are known to have a lower level of participation as compared to children without disabilities. They also engage in more passive and home-based activities as opposed to participating in activities with their peers and outside the home environment.

Recently, studies have found factors related to participation in children with physical disabilities. However, information is lacking with regards to participation of adolescents, particularly what types of leisure activities are preferred by this population and predictors of participation in different type of leisure activities. Understanding of factors associated with participation in leisure activities may

contribute to the development of rehabilitation and community programs and policies.

The primary objective of this study is to quantify the level (intensity and diversity) of participation in leisure activities of adolescents (12-19 years of age) with cerebral palsy (CP), and to estimate the potential influence of both intrinsic child characteristics and extrinsic environmental factors as determinants of leisure participation.

The secondary objective of this study is to determine factors associated with preferences for specific leisure activities in this population of interest.

A cross sectional design was used. A total of 185 adolescents (12-20 years old) completed the study. Participation was measured with the Children's Assessment of Participation and Enjoyment (CAPE) and preferences for activities was measured with the Preferences for Activities of Children (PAC).

Results demonstrate that adolescents with CP participated in a variety of out-of-school leisure activities. Similar to studies on younger children with disabilities, adolescents participated in a greater number of informal activities than formal activities, and with greater frequency. Adolescents engaged in a variety of recreational and social activities, but not in many self-improvement activities. Participation in skill-based activities was the least frequent type of activity done, but diversity and frequency of participation in physical activities was also limited.

In terms of preferences for activities, social and physical activities were most preferred, and self-improvement activities were least preferred. Family factors, personal factors and functional abilities influenced leisure preferences. High preference for certain activities was not always associated with actual involvement in these activities.

Models of determinants of intensity of participation in five leisure activity domains demonstrated that leisure is a multifaceted construct that appears to be

associated with a variety of factors related to the adolescents' functional characteristics and attitudes, the family environment and socioeconomic status and other contextual factors such as school type. Aspects of the adolescent's mastery motivation and behavior were also associated with participation in different activity domains. The adolescent's perception of self in relation to competence in different life skills and physical appearance was also associated with participation in certain types of leisure activities.

Rehabilitation interventions should consider adolescents' preferences and family dynamics to minimize barriers to leisure participation, such as low motivation or environmental obstacles, so as to promote engagement in leisure activities. Expanding the scope of rehabilitation interventions to support the creation of programs in the community and advocate for policies that may facilitate participation in a variety of activities is needed, to promote a healthy development and well-being for this at-risk population.

RÉSUMÉ

La paralysie cérébrale est la cause de handicap physique la plus importante chez les enfants. La paralysie cérébrale est un ensemble de conditions associées à des déficiences majeures et à des déficits au niveau du développement qui se forment lors des premiers stades de développement du cerveau. Même si la nature de cette condition est considérée comme non évolutive, les manifestations cliniques et la sévérité des handicaps peuvent changer au fur et à mesure que l'enfant se développe. En conséquence, l'individu peut être limité dans ses activités de tous les jours, ce qui peut avoir un impact sur sa santé et sa participation à la vie en société. La participation à des activités de loisir est un aspect important de la santé, selon la Classification Internationale du Fonctionnement, du Handicap et de la Santé (CIF). Participer à des activités de loisir est essentiel pour le développement d'une série de compétences comme la compréhension des règles de vie en société, le développement de l'estime de soi ainsi que l'atteinte et le maintien de la santé cardio-vasculaire. Il est donc crucial que l'individu prenne part à ces activités pour que son développement soit sain. L'adolescence est une période qui comporte de nombreuses transformations rapides. Les adolescents handicapés font souvent face à des défis particuliers et uniques en ce qui a trait à leur santé, l'acceptation par les pairs et leur engagement dans une variété de rôles qui, collectivement, peuvent avoir un impact à long terme. De façon générale, les enfants handicapés ont un taux plus bas de participation à des activités de loisir comparé à des enfants non handicapés. Ils participent davantage à des activités passives et centrées sur le domicile familial plutôt que des activités avec des pairs ou hors de l'environnement familial. Récemment, des études ont démontré des facteurs liés à la participation chez des enfants souffrant de handicaps physiques. Par contre, la documentation concernant la participation d'adolescents, particulièrement les types d'activités de loisirs préférés par cette population et les prédicteurs de la participation dans différents types d'activités de loisir, est incomplète. Comprendre les facteurs associés à la participation à des activités de loisir pourrait contribuer au développement de programmes et de politiques

communautaires et de réhabilitation.

L'objectif principal de cette étude est de quantifier le niveau, l'intensité et la diversité de la participation des adolescents (de 12 à 19 ans) souffrant de paralysie cérébrale (PC) à des activités de loisir et d'estimer l'influence potentielle des caractéristiques intrinsèques de l'enfant et les facteurs environnementaux extrinsèques en tant que déterminants de la participation à l'activité de loisir.

Le second objectif de cette étude est de déterminer les facteurs associés aux préférences pour des activités de loisirs spécifiques chez cette population.

Notre étude, de type transversale, a été complétée par 185 adolescents entre 12 et 20 ans. La participation a été mesurée avec le "Children's Assessment of Participation and Enjoyment" (CAPE), et les préférences pour les activités ont été mesurées avec le "Preferences for Activities of Children" (PAC).

Les résultats démontrent que les adolescents souffrant de PC participent à une variété d'activités parascolaires. De façon similaire aux jeunes enfants handicapés, les adolescents participent à un plus grand nombre d'activités récréatives et sociales, et de façon plus fréquente.
Les adolescents participent à une variété d'activités récréatives et sociales, mais à très peu d'activités de croissance personnelle. La participation à des activités basées sur les compétences était le type d'activité le moins populaire, mais la diversité et la fréquence de la participation à des activités physiques était également limitée.

En ce qui a trait à la préférence pour certaines activités, les activités sociales et physiques étaient les plus populaires, et les activités de croissance personnelle étaient les moins populaires. Des facteurs familiaux et personnels ainsi que les habiletés fonctionnelles influençaient les préférences en matière de loisir. Une préférence élevée pour certaines activités n'était pas toujours associée à la

participation à ces activités.

Des modèles déterminant l'intensité de la participation à cinq domaines d'activités ont démontré que le concept de loisir comporte de nombreuses facettes qui sont associées à une variété de facteurs reliés aux caractéristiques fonctionnelles et aux attitudes des adolescents, à l'environnement familial, au statut socio-économique et à divers facteurs contextuels comme le type d'école fréquenté. La motivation et le comportement étaient aussi associés à la participation dans différents domaines d'activité. La perception de soi de l'adolescent en relation avec la maîtrise des différentes compétences de base et l'apparence physique étaient également associées à la participation à certains types d'activités de loisir.

Les interventions visant la réhabilitation devraient considérer les préférences des adolescents et les dynamiques familiales afin de minimiser les obstacles à la participation à des activités de loisir, comme le manque de motivation ou les obstacles environnementaux, afin de promouvoir la participation aux activités de loisir. Il est nécessaire de développer la portée des interventions de réhabilitation afin de supporter la création de programmes dans la communauté et de plaider en faveur de politiques qui faciliteront la participation à une variété d'activités. Ceci permettrait de promouvoir le développement sain ainsi que le bien-être de cette population à risque.

CONTRIBUTIONS OF CO-AUTHORS

The following manuscripts are included in this thesis:

Manuscript #1	Shikako-Thomas, K., Majnemer, A., Law, M., & Lach, L. (2008). Determinants of Participation in Leisure Activities in Children and Youth with Cerebral Palsy: Systematic Review. *Physical & Occupational Therapy in Pediatrics*, *28*(2), 155-169. doi:10.1080/01942630802031834
Manuscript #2	Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the *QUALA group*. Picture me playing - A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy. Submitted to Journal of Adolescence.
Manuscript #3	Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the *QUALA group*. Are you doing what you want to do? Leisure preferences of adolescents with cerebral palsy. Submitted to Developmental Medicine and Child Neurology.
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The PhD candidate, Keiko Shikako-Thomas, coordinated all elements of the work contributing to this thesis. The original research proposal was part of a project entitled : Determinants of quality of life and participation in leisure activities in adolescents with CP (Annette Majnemer, PI). This project was funded by the Canadian Institute of Health Research (CIHR) previously to the candidate graduate studies began. The candidate then contributed to ethical approval at the

Montreal Children's Hospital and leaded ethical approval procedures for the other sites (CRIR, CSSS). The candidate coordinated all aspects of recruitment in the different sites. Organization of participants' evaluations and coordination of professionals involved in participants' assessments, as well as data entry was coordinated by the candidate with the help of the research assistants Nick Hall and Anna Radzioch. The research assistants Joey Waknin and Christopher Saunders contributed with technical support and data entry. Statistical analysis was conducted by the candidate, with the direct consultation of Dr. Norbert Schmitz and Dr. Mourad Dahhou. All manuscripts were written by the PhD candidate. The co-authors of the papers, Dr Michael Shevell, Dr Lucy Lach, Dr. Mary Law, Dr. Chantal Poulin and Dr. Norbert Schmitz contributed to the study design and interpretation of data and provided critical review of the manuscripts submitted for publication. In addition to critically reviewing the manuscripts, Dr Mary Law and Dr Lucy Lach contributed as members of the research committee providing feedback on the other elements of the thesis. Dr Richard Cooper from the McGill University writing center proof-read two manuscripts. All the efforts were conducted under the close supervision of Dr. Annette Majnemer.

STATEMENT OF ORIGINALITY

The material in this thesis is original and has not been published elsewhere unless specified. Feedback and guidance for the development of this work was provided by the student's supervisor. Although the project was initially conceived by Dr. Majnemer and colleagues in the CIHR project, the PhD candidate has taken the lead to the develop the aspects related to participation in leisure activities. This topic had not been explored when this project started and has since gained interest in the literature. The unique contribution of this project is to provide an understanding of preferences for participation in adolescents with CP and also to establish models of determinants of participation in specific domains of leisure. This project was supported by and integrated with a parallel qualitative study coordinated by the PhD candidate. The study explored aspects of quality of life for adolescents with CP and their parents. No studies have clearly established the relationship between participation in leisure activities and quality of life for children and youth with disability.

DEDICATION

To my beloved husband, Johnny for always being there for me.

For Zack and Nina, for the best smiles on earth.

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If it takes a village to raise a child, it also takes one to raise a PhD.
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ABBREVIATIONS

ASSS	Agence de la Santé et des Services Sociaux de Montréal
CAPE	Children's Assessment of Participation and Enjoyment
CCHCSP	Canadian Child Health Clinician Scientist Program
CRIR	Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal
CP	Cerebral Palsy
CSSS	Centre de Service Sociaux et Santé du Québec
DMQ	Dimensions for Mastery Questionnaire
ECEQ	European Child Environment Questionnaire
FES	Family Environment Scale
FRSQ	Fonds de la Recherche en Santé du Québec
GMFCS	Gross Motor Classification System
GMFM – 66	Gross Motor Function Measure
ICC	Intraclass Correlation coefficient
ICF	International Classification of functioning, Disability and Health
MACS	Manual Ability Classification System
OT	Occupational Therapist
PAC	Preferences for Activities of Children
PT	Physical Therapist
QUALA	determinants of QUality of life And participation in Leisure activities in Adolescents with cerebral palsy
SDQ	Strengths and Difficulties Questionnaire
SPPA	Self-perception Profile for Adolescents
VABS	Vineland Adaptive Behavior Scale
VABS-II	Vineland Adaptive Behavior Scale 2nd edition
WHO	World Health Organization

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CHAPTER 1: INTRODUCTION

Preface:

This thesis is being presented as a requirement of my doctoral studies. It will be presented in manuscript-based format, as approved by the Faculty of Graduate Studies at McGill University.

Thesis overview:

The introductory chapter will present the field of research, define terms, and provide background information and rationale for the present study. Additionally, the objectives of the study and the hypotheses will be described.

The second chapter will describe the methodology of the study, although methodology will also be succinctly described in each manuscript.

Four manuscripts will be presented in the main body of this thesis:

- Chapter 3 (manuscript #1) consists of a systematic review that was published in 2008 and will be followed by a complementary structured review of the literature on determinants of participation in leisure activities for adolescents with cerebral palsy.
- Chapter 4 (manuscript #2) will address the first objective of the study: to describe the patterns of participation in the population of interest, which is the main outcome of the study.
- Chapter 5 (manuscript #3) will focus on the secondary objective of the thesis: to describe adolescents'preferences for leisure activities and their determinants.
- Chapter 6 (manuscript #4) will then provide models of determinants of participation in five leisure domains, which was the primary aim of this research study.

Finally, a discussion chapter will summarize the main conclusions of the study as a whole, establish links with the published literature as well as other research studies in which the candidate has been involved and discuss implications for clinical practice and future directions for research.

Relevant tables are presented throughout the body of each chapter and references lists are also presented by chapter.

1.1. Cerebral Palsy: Definition and epidemiology

Cerebral Palsy (CP) is a broad term that describes a set of conditions that is associated with major physical impairments and other developmental deficits and arises in the early stages of brain development. A consensus statement from the 'Executive Committee for the Definition of Cerebral Palsy' presents the following definition of CP:

> *"Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non- progressive disturbances that occurred in the develop in fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and bebavior; by epilepsy, and by secondary musculoskeletal problems."* (Rosenbaum et al., 2007, p.09).

The consensus definition reflects the heterogeneity of the condition and the variety of organ systems involved, which may be reflected by the variety of limitations and challenges that a child with CP may face in everyday life.

Prevalence of CP is high, estimated at 2.0 to 2.5/1000 children in developed countries (Missiuna et al., 2001; Odding et al., 2006). Despite advances in prenatal and neonatal medical care, the incidence of CP has remained stable over the past decades (Odding et al., 2006). In addition, regardless of the non-progressive nature of the condition, the nature and severity of impairment may change as the child develops. As a consequence, limitations in everyday activities in different life situations may be experienced, with possible impact to the individual's health and well-being (Shevell & Bodensteiner, 2004; Majnemer & Mazer, 2004; Odding et al., 2006).

1.2. Participation in leisure activities: Defining the terms

Leisure is defined as *"freedom provided by the cessation of activities; especially time free from work or duties"* ("Leisure", n.d.). It is also defined as the time that is spent doing what one enjoys while not working or studying (Sally, W. ed., 2000 in Oxford

advanced learner's dictionary). Leisure is a concept that has been defined in different fields of study, however the definitions of leisure somewhat agree on a component of freedom and choice that must be inherent to leisure activites (Voss & Caroll, 1967; Samdahl, 2009).

For children and youth, leisure activities can be considered the out-of-school activities, those that are not mandatory. While engaging in leisure activities, children should be able to experience a suspension from reality. Social interactions and self-expression are key elements of leisure and may define the objective and subjective components that characterize the leisure experiences of children (Samdahl, 2009; Colver, 2009).

Participation is broadly defined as involvement in a life situation. It is a concept reinforced by the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (WHO, 2001). The ICF emphasizes the level of an individual's health rather than disability level and presents participation as one of the main areas of a person's functioning, along with body structure, function and activities. Different areas such as communication, mobility, domestic life and social relationships compose some of the elements of participation. These activities reflect how an individual functions within his or her environment in different life roles (WHO, 2006; Law, 2002, King et al., 2003). Leisure is a component of participation, and constitutes one of the elements of occupational performance that is often neglected, but is a crucial element of health.

1.2.1. Participation in leisure activities: Why is it important?

Engagement in leisure activities has several known benefits for the development of children and youth. Through leisure and play, children can experiment and explore new abilities; they have the opportunity to understand and assimilate societal rules and to develop different skills (Ginsburg, 2007).

For children and youth with and without disabilities, participation in leisure activities has been associated with benefits for self-concept and self-esteem, social relationships and integration, as well improvement of life satisfaction and overall well-being (Cassidy,

1996; Harrison & Narayan, 2003; Specht et al., 2002). Engagement in physical activities and sports enhances physical health and functioning (McManus et al., 2008). Children and youth with disabilities benefit from an enhanced adjustment to living with a disability when they are engaged in leisure activities (Specht et al., 2002). Indeed, the level of participation and enjoyment in leisure activities likely has an important influence on the quality of life and the overall development of individuals with disabilities such as CP (Aitchison, 2003; Law, 2002; Shikako-Thomas et al., 2009).

There is an increasing interest in participation as an important outcome for health promotion. It is often assumed that more participation in leisure will directly contribute to a better quality of life. However, participation and quality of life are two different constructs (Colver, 2009). In a recent review, we investigated the relationships that are established in the literature between participation in leisure and quality of life for children with neurodevelopmental disabilities (Dahan-Oliel et al., 2012). We found that engagement in leisure activities is associated with a better physical, emotional and social well-being and also with an increased sense of functioning that contributes to an overall positive regard for life. We also found that participation may have an impact on the perception of well-being for children with developmental disabilities, however the negative emotions associated with leisure participation are often mediated by barriers and constraints in the environment.

The importance of promoting leisure activities for children with disabilities therefore relies heavily on the need to promote health and well-being, which is also supported by the concept of the human rights of every child to participate in leisure as established by the United Nations High Commission for Human Rights (Office of the United Nations High Commissioner for Human Rights, 1989).

1.3. Patterns of participation in leisure activities for children and youth with physical disabilities

Participation in leisure activities for children and youth with disabilities has gained increased attention in the past decade. Studies have shown that children and youth with

disabilities enjoy participating in leisure activities and believe this is a key element for their overall well-being (Majnemer et al., 2008; Law et al., 2004; Shikako-Thomas et al., 2009). Neverthless, children and youth with disabilities participate in less activities, engage more in informal rather than formal activities, spend more time with their families than with friends and participate in more passive, home-based activities when compared to peers without disabilities (Margalit, 1981; Engel-Yager et al., 2009; King et al., 2010a)

Participation restrictions can be understood as challenges that an individual may face with regards to involvement in life situations (Beckung & Hagberg, 2002), where personal factors along with environmental factors (physical, social and attitudinal) may collectively influence health and functioning, either positively or negatively (WHO, 2006). These restrictions may be seen in different activities and roles throughout the life span and may limit the acquisition of skills and competences. Furthermore, they may limit the learning process that enables children to evaluate situations, and to formulate goals, values and priorities. Participation restrictions may also negatively affect the socialization process and the internalization of societal rules and expectations, and comprehension of cultural values (Brown & Gordon, 1987; Law et al., 2006).

Recent studies show that participation varies according to different groups. Gender is one factor that is associated with participation in leisure. Girls and boys engage in different types of activities. Girls usually participate in more activities than boys in most activity domains, except for physical activities (Law et al., 2006; Majnemer et al, 2008; King et al., 2010a). Participation in leisure activities tends to decrease as children grow older (King et al., 2010a, 2010b). Functional aspects such as better gross and fine motor function, better communication and socialization skills have also been associated with increased participation. Other intrinsic, personal aspects that have been associated with participation are motivation, behavior, preferences for activities and enjoyment; however these variables are explored in very few studies (Shikako-Thomas et al., 2008; Imms et al., 2009; Bult et al., 2011).

Within the intrinsic personal factors that are associated with participation, preferences for activities and enjoyment in doing these activities appear to be important factors that are

not often considered (Majnemer et al., 2010; King et al., 2009; Palisano et al., 2011a, 2011b). Although it is known that participation is essential for an appropriate development, there are no optimal levels for participation and it should rather be evaluated according to preferences and priorities of children and their families (Murphy et al., 2008; King et al., 2009).

Contextual or environmental aspects that are related to participation are mainly family dynamics and environmental constraints or barriers. Namely, families who are more inclined to engage in leisure will also facilitate their children's involvement. Socioeconomic factors that may be to some extent associated with leisure include ethnic origin and parents' educational level. School environment (regular/inclusive versus special /adapted) and presence of attitudinal barriers in the environment and lack of peer support have also been suggested as being associated with levels of participation in children with disabilities (Shikako-Thomas et al., 2008; Imms et al., 2009; Bult et al., 2011). Chapter 4 presents a complete literature review of factors associated with leisure participation).

1.4. Participation as an outcome in rehabilitation

Individuals with CP have been an important target population needing rehabilitation services. The focus of rehabilitation interventions within this population is often focused on minimizing impairments and addressing functional aspects limited by the condition such as activities of daily living and mobility (Kibele, 1989; Saleh et al., 2008). It is only very recently that attention has been paid to the quality of life and participation of this population as a main outcome of rehabilitation interventions, particularly the extent to which these individuals have the opportunity to be involved and enjoy leisure activities at home and in the community (Specht et al., 2002; Adamsom, 2003; Poulsen & Ziviani, 2004).

1.5. Participation in adolescents with disabilities

Adolescence is one of the most critical periods of development. The substantial biologic, psychological, social and life role changes that occur during this life stage are highly

influential for future outcomes in adult life (Lerner & Casterllino, 2002). Adolescence may be even more critical for youth with physical disabilities because of other issues such as transition of health care and deterioration of the motor condition (Roebroeck et al., 2009). Nevertheless, this phase of development within the population of youth with physical disabilities has been somewhat neglected in outcomes research (Adamson, 2003; Majnemer & Mazer, 2004).

Research on adolescents with disabilities has identified engagement in leisure as one critical intervention area for adolescents with CP (Livingston et al., 2011). However, similar to younger children, research and rehabilitation intervention for adolescents often focus on impairments in body function and functional limitations with a lack of evidence supporting the generalization of therapeutic benefits to enhancing participation in leisure and recreational activities (Rosenbaum & Stewart, 2004). This aspect may become more critical as services are likely to decrease as a child grows older, and emphasis tends to be given to addressing 'must do' activities (e.g. self-care, mobility) and providing necessary adaptations in the home, but not to leisure participation (Majnemer et al., submitted, Darrah et al., 2002).

It is known that participation patterns change with age and stage of development and that ongoing participation throughout childhood and adolescence is important to ensure a healthy transition into adult life (King et al., 2000; Simeonsson et al., 2001; King et al., 2002). Limitations that are experienced by children with CP may be reinforced during adolescence, when opportunities for participation in leisure activities are likely to decrease. Furthermore, parents are less involved in facilitating integration and participation opportunities during adolescence.

Some studies have demonstrated that adolescents with spina bifida and CP have very few out-of-school relationships with friends, and little participation in organized social activities (Blum et al., 1991; Kang et al., 2010). It is important to understand that participation may be highly motivated by personal interests and one cannot infer that higher levels of participation are necessarily better. However, studies have revealed that although youth with physical disabilities place a strong value on leisure activities,

participation is relatively low when compared to peers without disabilities (Solish et al., 2010; Enger-Yager et al., 2009; King et al., 2009). As with children of school age with disabilities, adolescents with disabilities participate more in informal than formal leisure activities; there is less variety in the types of activities that they engage in, and these are more passive and home-based and tend to be carried out alone or with parents rather than with friends (Aitchison, 2003; Margalit, 1984; Specht et al., 2002). A study on adolescents without disabilities (Shannon, 2006) revealed that formal leisure activities tend to be more important than informal activities for the development of social skills and skill competencies. Thus, if adolescents with disabilities participate predominantly or exclusively in informal activities, this should present a major concern for rehabilitation specialists.

Other differences between adolescents with and without disabilities exist in areas that influence and are influenced by opportunities to engage in leisure activities. For instance, self-perception of attributes such as romantic appeal and social, athletic and academic competence are known to be different in adolescents with disabilities, and these factors may influence the establishment of social relationships (King et al., 1993). Lack of opportunities to develop healthy peer relationships may in turn influence important developmental aspects such as identity formation, friendships and independence; all important characteristics that can affect the quality of life of adolescents and young adults with disabilities (Margalit, 1984; Shikako-Thomas et al., submitted). Leisure for youth with disabilities may be more influenced by the social interaction than by the type of activities available or other environmental aspects (Aitchison, 2003). Moreover, the demand for social activities increases in adolescence, and therefore, the lack of those attributes may also negatively influence levels of participation (Law et al., 2006; Magill-Evans et al., 2001).

Although peers begin to exert a greater impact on leisure activities and choices during adolescence, parents are still significant in orienting the use of leisure time (Shannon, 2006). Family expectations and preferences, higher levels of family cohesion, higher incomes, better family coping and lower levels of family stress are also believed to be

important facilitators of engagement in leisure for adolescents with or without disabilities (Shannon, 2006; Wilhite, 1999).

In addition to family-related aspects, transportation, societal attitudes, availability of rehabilitation services and physical barriers may hinder participation in different leisure activities by adolescents with physical disabilities (McMeeking & Purkayastha, 1995; Shannon, 2006). It is conceivable that decreased participation in formal activities may be due to the fact that informal activities are less likely to be affected by environmental barriers such as transport and accessibility (Law et al., 2006). Indeed, the need for community supports may increase during adolescence; nevertheless there is a shortage of services and resources offered to this population in the transition from childhood to adulthood, which may contribute to less participation opportunities (Stevenson et al., 1997).

1.6. Conclusion

It is increasingly appreciated that multiple factors may lead to a decrease in participation for adolescents with a disability, which may impact the individual's quality of life. The lack of emphasis on leisure and recreation in rehabilitation intervention may be in part due to a priority given to other areas of development (Aitchison, 2003), but also due to a paucity of information on what factors may promote participation in this occupational performance domain. Evidence is needed regarding the intrinsic and extrinsic factors that can promote participation in youth with CP, so that health promotion strategies may be developed to enhance enjoyment and community integration for this high-risk population.

1.7. Rationale

Participation is an important element of health, functioning and disability as framed by the ICF-CY. Nevertheless, there is little information on participation as it relates to youth with disabilities. Studies (Law et al., 2005; Majnemer et al., 2008) are beginning to describe level of participation and enjoyment in children with CP and other physical disabilities, and identify factors associated with greater participation in leisure and recreation. However, to date, no studies have explored the associations between a series

of intrinsic and extrinsic factors and the level of involvement in different types of leisure activities (beyond formal/informal) in adolescents (12-19 years) with CP. Moreover, evidence in children with disabilities reinforces the importance of preferences for activities on the participation levels, however, there is no evidence describing the leisure preferences of adolescents with CP and the factors that appear to influence the preferences for certain types of activities.

Elucidation of potentially modifiable factors predicting participation and preferences for leisure activities may guide intervention strategies and promote health and well-being within this at-risk population.

1.8. Objectives and hypotheses:

1.8.1. Objectives

The primary objective of this study is to quantify the level (intensity and diversity) and enjoyment of participation in leisure activities of adolescents (12-19 years of age) with CP, and to estimate the potential influence of both intrinsic characteristics and extrinsic environmental factors as determinants of leisure participation.

The secondary objective of this study is to determine factors associated with preferences for specific leisure activities in this population of interest.

1.8.2. Hypotheses

We hypothesize that personal and environmental factors (i.e., contextual factors as framed by the International Classification of Functioning, Disability and Health) such as the adolescent's motivation, family functioning and environmental resources will be more strongly associated with levels of participation for adolescents with CP than the severity of activity limitations.

A higher level of participation (diversity and intensity) in leisure activities is expected to be associated with:

a. higher family functioning (family expressiveness, independence and recreational activity orientation)
b. greater environmental resources (e.g. accessibility, transportation and services)
c. greater mastery motivation (persistence and expressive elements)
d. greater self-worth (social acceptance, athletic competence, physical appearance, close friendships, job competence and global self-worth)
e. better behavioral conduct
f. higher motor performance
g. fewer activity limitations (socialization, communication and daily living skills), and
h. younger age.

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CHAPTER 2: METHODS

2.1. Study Design

This study aimed to find determinants for participation in leisure activities. A cross-sectional design was used to describe the variables and associations between exposures and the primary outcome.

2.2. Study Population

A study was completed (Majnemer et al., 2008) describing quality of life and participation in school-aged (6-12 years) children with CP. Children recruited for this study were a consecutive sample of children with CP seen by a single neurologist over a 10-year period (1991-2001) in a variety of settings (private office, hospital, neonatal clinic, suburban private clinic). Participants previously investigated in this first study who were 12-19 years at the time of recruitment were recruited for re-assessment of participation in leisure activities. In addition, participants were recruited from specialty clinics, school and transition programs at the Mackay Rehabilitation Centre, at the Centre de Readaptation Marie-Enfant, at the Shriner's Hospital, at the Centre Monterégien de Réadaptation, at the Centre Bouclier de Réadaptation, at the Centre de Réadaptation lEstrie, and at the Institut de Réadaptation en Déficience Physique de Québec and Viomax. Once consent was obtained, appointments were made to evaluate the adolescents and their families at either the Montreal Children's Hospital, or at the Institut de Réadaptation en Déficience Physique de Québec's department in the Madeleine Bergeron School in Quebec City or as a home visit.

2.2.1. Inclusion Criteria

- Adolescents (12-19 years at the time of recruitment) diagnosed with CP.
- Adolescents able to understand English or French, and a parent who can read English or French in order to complete questionnaires (with the help of an interpreter if needed).

2.2.2. Exclusion Criteria

- Adolescents with other neurological conditions not consistent with diagnosis of CP (as per Badawi et al., 1998).

2.3. Procedures

Families who accepted to participate were scheduled for an evaluation at their convenience at one of the assessment locations. Caregivers provided consent and adolescents provided assent to participate in the study when feasible. For participants who were in foster care, consent to participate in the study was obtained from biological families or the public curator when needed. The parent-completed questionnaires were completed by the caregiver who spent the most time with the adolescents, as judged by biological parents. Ability to complete adolescent-completed questionnaires was judged by the research coordinators in agreement with caregivers at the time of the visit. For families whose first language was not English or French and as judged necessary, a translator was requested to help parents in the completion of questionnaires and interviews.

Participants were tested by a neurologist to ascertain their diagnosis of cerebral palsy. The neurologist also performed a brief neurological exam. A psychologist or occupational therapist completed the Vineland Adaptive Behavior-II with the caregiver either during the visit or by phone and completed the Children's Assessment of Participation and Enjoyment with the adolescent with proxy help when needed and the Preferences for Activities of Children with the adolescent when feasible. An occupational therapist or physical therapist completed the Gross Motor Function Measure, the Gross Motor Function Classification System and the Manual Ability Classification System. Caregivers completed a socio-demographic information questionnaire and a series of questionnaires described below. Adolescents completed a series of questionnaires when feasible, as described below. Testers were blind to the medical history of the participants and to each others' test findings.

Assessment of the adolescent (CAPE – Children's Assessment of Participation and Enjoyment/PAC – Preferences for Activities of Children, GMFM – Gross Motor Function Measure) took approximately one hour to complete. The caregiver interview took approximately 1 hour and completion of forms by parents and adolescents usually another hour, for a total of 2-3 hours of assessment. Families were reimbursed for their travel expenses, snacks were offered and activities for siblings were provided when necessary.

Table 2.1 presents the constructs measured for the variables of interest and the respective assessment tools selected.

Table 2.1 Description of contructs and procedures

Construct	**Measure**	**Procedure**
Intrinsic (independent variables)		
Activity limitations (daily living skills, communication and socialization)	Vineland Adaptive Behavior Scale (VABS-II)	Interview with caregiver
Motor function	Gross Motor Function Measure (GMFM -66) and Gross Motor Classification System (GMFCS) Manual Ability Classification System (MACS)	Assessment with adolescent
Mastery motivation	Dimensions of Mastery Questionnaire (DMQ – adolescent and parent questionnaires)	Self-completed by adolescent and proxy-report by caregiver
Self- worth	Self-perception Profile for Adolescents (SPPA)	Self-completed by adolescent
Behaviour	Strengths and Difficulties Questionnaire (SDQ)	Self-completed by caregiver
Extrinsic (independent variables)		
Family function	Family Environment Scale (FES)	Self-completed by caregiver
Environmental resources and supports	European Child Environment Questionnaire (ECEQ)	Self-completed by caregiver
Outcome		
Participation in leisure activities	Children's Assessment of Participation and Enjoyment (CAPE	Interview with adolescent and caregiver if necessary

2.4. Variables and Measurement

2.4.1. Exposures

- Motor function: Gross Motor Function Measure (GMFM – 66; Russell et al., 2002).

GMFM- 66 is a continuous scale that measures changes in gross motor function in children with CP. The measure is criterion-referenced and validated for children with CP from 5 months to 16 years of age. Each item is scored by a trained evaluator on a four - point system from 0 (does not initiate the movement) to 4 (satisfactory movement). Test-retest reliability was demonstrated through a high intraclass correlation coefficient (ICC = .99) and agreement between estimates (r = .97). Acceptable validity and responsiveness was demonstrated through studies (Russell et al., 2000).

- Manual ability: Manual Ability Classification System (MACS; Eliasson et al., 2006) classifies typical self-initiated manual hand function in everyday activities, and the need for assistance or adaptations. This measure has very good construct validity and inter-rater reliability (kappa=.62). Participants are rated by an evaluator in agreement with a parent or proxy who knows the child typical performance using a 5-point ordinal scale (e.g. level I: handles objects easily and successfully with some limitations in speed and accuracy; level V: does not handle objects and requires total assistance to perform simple hand functions).
- Activity limitations: Vineland Adaptive Behavior Scale (VABS-II; Sparrow et al., 2005).

The Vineland Adaptive Behavior Scales measures functioning in daily activities in three different domains: Communication (receptive, expressive and written), daily living skills (personal, domestic and community), socialization (interpersonal relationships, play and leisure, coping skills) and motor function (gross and fine). It uses a discrete ordinal scale from 0 (never shows that behavior) to 2 (yes, usually) with 2 other scoring options: N (no opportunity to observe that behavior) and DK (don't know) to measure adaptive behavior (i.e. the performance of the daily activities required for personal and social functioning). The information is collected by a semi-structured interview format. Final scores per

domain are represented as continuous standard scores. Internal consistency reliability coefficient for the adaptive behavior total score range from .89 to .98 (median .94), which is considered excellent. Test-retest reliability coefficient is 0.88 and inter-rater reliability is .74. The instrument is widely used and appropriate for this age group (motor function domain excluded for that age group) as it is used to assess individuals from birth through 90 years.

- Mastery motivation: Dimension of Mastery Questionnaire (DMQ; Morgan et al., 2000).

The DMQ is a 45-item questionnaire that evaluates mastery motivation, a multidimensional psychological construct that relates to an individual's persistence in mastering a skill. The adolescent and/or a parent completes the questionnaire on level of: persistence, which has seven dimensions (object-oriented persistence, gross motor persistence, social persistence with adults, social persistence with children, mastery pleasure, general competence, and negative reaction to failure). In addition, two summary scores are calculated (i.e. total persistence and total mastery motivation). Items are rated on a five-point scale (1= not at all typical, 5 = very typical). The DMQ has good internal consistency for parent's rating (Cronbach alpha = .84), child's rating (.69) and teacher's rating (.89) (elementary school children). Total persistence and total mastery motivation alpha range from .85 to .96. It is also age-appropriate as it was validated with children ranging in age from 6 months to 19 years.

- Self-worth: Self-Perception Profile for Adolescents (SPPA; Harter, 1988).

The SPPA is a measure of how adolescents view themselves in regards to eight different domains: scholastic competence, social acceptance, athletic competence, physical appearance, job competence, romantic appeal, behavioral conduct and close friendship. In addition, it has a global self-worth domain, a direct account of their own value as an individual. Cronbach's alpha for the different subscales vary from .74 to .93. The instrument is adequate for use with this population.

- Behavior: Strengths and Difficulties Questionnaire (SDQ; Goodman, 2001).

The SDQ is a behavioral screening questionnaire to identify psychological adjustment. The questionnaire was completed by the parent or other proxy responder. The SDQ has overall satisfactory reliability and validity, with a mean internal consistency of .70. The prosocial scale (the extent to which the adolescent manifests positive behaviors towards others) and impact scale (the extent to which behavior has a negative consequence) were used in the multivariate models.

- Family environment: Family Environment Scale (FES; Moos & Moos, 1989).

This measure assesses three dimensions of family environment: relationship, personal growth and system maintenance, across 10 subdomains (cohesion, expressiveness, conflict, independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation, moral-religious emphasis, organization and control). It evaluates family functioning and its relations with the social environment. Internal consistency for each subdomain varies from .69 to .78 and test-retest reliability ranges from .68 to .85. It has been used for research with different populations, including adolescents with developmental disabilities.

- Environmental resources and supports: European Child Environment Questionnaire (ECEQ ; Colver and the SPARCLE group, 2006).

The ECEQ is a recently developed instrument that assesses the extent to which environment facilitates or hinders participation (Colver and the SPARCLE group, 2006). The questionnaire has 60 items that assess the physical, social and attitudinal environment of the child. Parents are asked to complete the questionnaire. Items are rated in a yes or no format with a subdivision for frequency (e.g. how often does the item have an effect in daily life?). A summary score is derived for environmental needs and for availability if needed items per domain. Very few measures evaluating environmental factors are available and appropriate for use with this study population. Psychometric properties of the ECEQ are still being compiled, but it has been used in a large study in Europe and one of its authors is providing consultation for analysis and use of the measure. Moreover, the measure was developed based on qualitative studies and an

extensive literature review that ensure content validity (Mihaylov et al., 2004; Lawlor et al., 2006).

2.4.2. Outcome

- Participation in leisure activities: Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004).

The CAPE is a questionnaire for children and adolescents between 6-21 years of age and meant to be completed by the child, together with a parent/guardian if needed. Activities are illustrated and rated as yes or no if they have been performed in the past 4 months. If performed, there is a numbered scale for frequency, from 1 (1 time in the past 4 months) to 7 (once a day or more). Activities are grouped in five domains (recreational, active-physical, social, skill-based and self-improvement). Scores may be derived for intensity (how often), diversity (number of different activities) and enjoyment (from 1 – not at all, to 5 – love it) for each domain or summary scores for formal (structured, preplanned) and informal (spontaneous) activities. Final scores are given on a continuous scale. Test-retest reliability ranges from .65 to .75 on overall participation, and face validity is assured by extensive literature review and on the basis of the ICF as a framework.

- Preferences for Activities of Children (PAC; King et al., 2004):

The PAC is a questionnaire for children and adolescents between 6-21 years of age that measures preferences for leisure activities. The questionnaire is completed by the child or adolescent, with proxy- help if needed. The same 55 leisure activities that are part of the CAPE are illustrated and rated by the child on a 3-point scale according to the level of preference as stated: "if you could do anything in the world, how much would you like to be doing this specific activity: (1) Would not like to do it at all; (2) Would sort of like to do it; (3) Would love to do it. Leisure activities are grouped into 5 subdomains (recreational, social, active-physical, skill-based and self-improvement) for which continuous mean scores are derived. A higher PAC mean score indicates a higher preference for the activity type. Reliability has been tested, cronbach's alpha range from .67-.77 for the five subdomain scales for internal consistency.

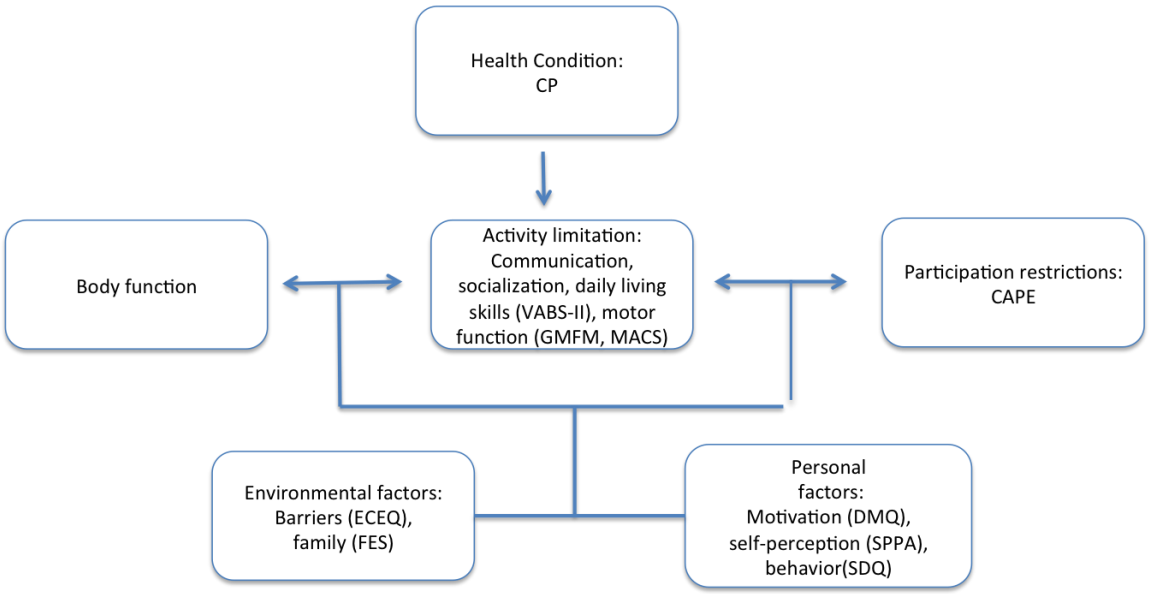
2.4.3. Confounders

One potential confounder for this study is socioeconomic status, as it can strongly account for the level of participation due to greater opportunities and financial resources. This variable will be assessed by classifying the total annual income of families participating in the study. Another variable that may be a confounder is gender, as some studies support that boys tend to participate more in active leisure activities than girls.

2.5. Theoretical Framework

Participation is understood according to the conceptual framework proposed by the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF). Understanding participation within this framework will help us to estimate the potential influence of both intrinsic characteristics and extrinsic environmental factors as determinants of leisure participation.

Figure 2.1 - Constructs in the ICF



2.6. Analysis

Statistical analyses performed to address each research question is described in detail in the manuscripts.

2.6.1. Sample Size Considerations

Based on Cohen's model (Cohen and Cohen, 1983), a sample of 50 subjects would provide a 80% power, with alpha = 0.05 to detect a correlation (r of 0.5) between the exposure and outcome variables in a linear regression model (model equation: N= $\lambda(1-R^2)/R^2$). The rationale for an r of 0.5 was based on preliminary data from previous research on this sample and clinical significance.

For multiple linear regression models, using the principle of 5-10 subjects per independent variable, a sample of 80 adolescents would be adequate. Our sample consisted of 187 participants.

2.7. Ethical considerations

Participation in the study was voluntary. Parents who agreed to have their children participate in the study were required to sign a consent form and adolescents provided written assent when feasible. All of the subjects' data are being kept strictly confidential. Documents are kept in a locked room and database is password protected. Each subject has a code; names are not included and will not be used in publications or presentations.

Ethical approval was obtained from the Montreal Children's Hospital, the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR) and the Agence de la santé et des services sociaux de Montréal (ASSS).

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CHAPTER 3: LITERATURE REVIEW

Chapter 3 is composed by the first manuscript of this thesis, which consists of a systematic review of the literature on determinants of participation in leisure activities in adolescents with CP.

3.1. Introduction to literature review

The first manuscript is a systematic review of the literature (Shikako-Thomas et al, 2008 manuscript copy attached). We performed a second structured review (focusing specifically on new studies since the published review) to examine key personal and environmental factors that may promote or limit participation and was concluded in December, 2008. The topic has encountered increasing interest in research in the past decade. Another review on the broader area of participation (not specific leisure participation) in children with cerebral palsy has been published (Imms, 2007) and a more recent review in children with physical disabilities has also been published (Bult et al., 2011). This chapter will therefore present the published systematic review and a current overview of the literature to date.

Manuscript 1: Determinants of Participation in Leisure Activities in Children and Youth with Cerebral Palsy: A Systematic Review

This manuscript was published in 2008. Permission was granted from Informa HealthCare to include a copy of the published article in this thesis.

Shikako-Thomas, K., Majnemer, A., Law, M., & Lach, L. (2008). Determinants of participation in leisure activities in children and youth with cerebral palsy: Systematic Review. *Physical & Occupational Therapy in Pediatrics*, *28*(2), 155-169. doi:10.1080/01942630802031834

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Determinants of Participation in Leisure Activities in Children and Youth with Cerebral Palsy: A Systematic Review

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3.2.1. Abstract

Children and youth with cerebral palsy experience difficulties in their ability to move, problem solve, socialize and communicate; associated with limitations in activities in all environments. They are at risk for lower participation in social and recreational activities critical in fostering friendships, developing interests and promoting well-being. Little is known about involvement in leisure activities and their determinants. This systematic review aims to identify personal and environmental factors that influence participation. The following databases were reviewed: CINAHL, Medline, Cochrane, Web of Science, OTSeeker and Rehabdata (1980 onwards), using the keywords: participation, cerebral palsy, leisure and recreation**.** The literature to date suggests that children with physical disabilities are less involved in leisure activities than their peers; activities are more passive, home-based and lack variety. Several factors influence participation in leisure activities, and include activity limitations, family preferences and coping, motivation, age, gender and environmental resources and support.

Keywords: CP, Participation, Leisure

3.2.2. Introduction

Participation is a relatively new concept in rehabilitation science, recently reinforced by the World Health Organization (WHO), in their International Classification of Functioning Disability and Health (ICF http://www.who.int/research/en/). The ICF emphasizes the level of an individual's health status at different levels as opposed to focusing on an individual's deficits at the impairment, disability and handicap level. Furthermore, it presents participation as one of the main areas of a person's functioning, along with body structure, body function and activities. The ICF also recognizes that environmental and personal factors may collectively influence health and functioning (Rosenbaum & Stewart, 2004), either positively or negatively.

Participation is defined by the WHO as involvement in life situations or being involved in everyday activities. Different areas such as communication, mobility, education, domestic life, leisure and social relationships comprise some of the elements of participation. These activities are indicators of the extent to which an individual functions in his/her environment in different life roles (WHO, 2006; Law, 2002).

Although play is frequently used as a modality in therapeutic interventions for children with disabilities (Poulsen & Ziviani, 2004), rehabilitation interventions typically place greater emphasis on the other two occupational performance domains, addressing functional aspects of self-care and productivity. A recent study by Saleh et al. (2008) revealed that occupational therapy practioners in paediatrics settings focus predominantly on impairment and basic functions while the enhancement of play and recreation as a primary goal of intervention is less evident in practice. It is only very recently that attention has been paid to quality of life and social participation in this population, particularly the extent to which children and adolescents with physical disabilities have the opportunity to be involved in and enjoy leisure activities at home and in the community (Majnemer, Shevell, Law, Rosenbaum, Poulin, 2006(a); Specht, King, Brown, Carey, 2002; Adamsom, 2003).

Cerebral Palsy (CP) is a broad term that describes a set of conditions that is associated with major physical impairments as well as other associated developmental deficits, and arises in the early stages of brain development. CP is the most common type of physical disability affecting children in developed countries (Stanley, Blair, & Alberman, 2000), with an estimated prevalence of 2.0 to 2.5/1000 children (Missiuna et al., 2001; Boyle et al., 1996; Robertson et al., 1998).

Individuals with CP are an important target population who have ongoing needs and require intermittent rehabilitation services. As with other children with chronic health conditions, they experience physical and social issues that can manifest in different ways over their life course, such as a lower participation in recreational activities when compared to peers (Cadman et al., 1987).

It is increasingly appreciated that multiple factors may lead to decreased participation in children and youth with disabilities, which may have an impact on the individual's health and life satisfaction (Law et al., 2006). Recent studies are beginning to identify the determinants of participation in leisure and recreation in children and youth with disabilities (Law et al., 2006; Law et al., 2005a; Rosenbaum, 1998). In addition, a recent model was proposed to include a number of different child and family factors that may directly or indirectly influence participation in children with physical disabilities to include CP (King et al., 2003). This model has recently been tested in a large population of children (ages 6-14 years) with different physical disabilities (King et al., 2006). The group of determinants identified are described below.

However, evidence is still needed regarding the intrinsic and extrinsic factors that can be targeted to promote participation among children and youth with CP using health promotion strategies that enhance enjoyment and community integration for this population that is at risk for lower participation and social isolation.

It remains to be determined if children with CP exhibit factors that are similar to children with other disabilities, or whether there are some unique attributes with the child or in the environment that exert and important influence on involvement and enjoyment in recreational activities.

The objective of this review was to summarize the existing evidence on participation in leisure activities in children and adolescents with cerebral palsy.

3.2.3. Methodology

The literature to date (1980 onwards) was reviewed to describe existing evidence regarding participation in leisure and recreation and to identify factors that predict participation in these activities in children and youth with CP. The following databases were searched: CINHAL, Medline, Cochrane, Web of Science, OTSeeker and Rehabdata using the following keywords: participation, Cerebral Palsy, leisure and recreation, as well as combinations of these terms (Table 3.1).

Table 3.1 Number of articles retrieved on combined searches from the respective databases (March/2007)

Database	Participation and CP	Leisure And CP	Recreation CP and
CINHAL	76	15	6
Medline	64	2	2
Cochrane	1	0	0
Web of Science	65	7	3
OtSeeker	5	137	96
Rehabdata	28	13	40

Very few studies to date describe participation in leisure activities in children or adolescents with CP. Given the paucity of evidence for this population of interest; studies on children and youth with physical disabilities that included individuals with CP were also included in this review. Abstracts were reviewed and selected based on sample characteristics (children and youth with physical disabilities, including CP) and an indication that the study focused on participation in leisure and/or recreational activities. Those studies are summarized in Table 3.2. There were 551 studies identified in the different databases in the first combined searches (cp and participation/ cp and leisure/ cp and recreation). Every article title was verified and those not related to the paediatric population or participation in leisure were first excluded. Remaining articles' abstracts were reviewed and those that did not match inclusion criteria were omitted, resulting in 13 studies that were reviewed. Furthermore, for every paper reviewed, their reference list was also reviewed for possible additional reference sources.

Existing literature was organized to identify any determinants of leisure participation under the categories of child, family and environmental factors, the outcome measures that were used to identify those factors and their primary findings

Table 3.2 Overview of studies on participation in leisure activities in children and youth with physical disabilities

Author / year	Sample size/ Age/ Diagnosis	Outcome Measures	Primary Findings
Heah et al, 2007	8 families/ 6-15 years/ Physical disabilities	Semi-structured interview (child's activity preferences, meaning ascribed to activity, level of satisfaction)	- Successful participation means having fun, feeling successful, being with others and doing things independently - Environmental barriers or support to participation: community program design, parents' values and preferences, parent vigilance, social and physical support - Personal supports and barriers: keeping up with peers.
Braun et al, 2006	614 young adults / 21-25 years/ Developmental disabilities	Structured Questionnaire	- Presence of disabilities does not prevent participation in leisure activities - Participation is similar for informal social and individual activities - Activity limitations are associated with lower frequency of leisure activities - No difference in number of activities between young adults without disabilities and adults with CP only - Participation in activities specially designed for individuals with disabilities are associated with higher level of participation.

Author / year	Sample size/ Age/	Outcome Measures	Primary Findings
Colver & the SPARCLE Group, 2006	818 children / 8-12 years CP	KIDSCREEN; Assessment of Life Habits; Strength and Difficulties Questionnaire; Parenting Stress Index	- Results not yet available
King et al, 2006	427 families and children / 6-12 years / Physical functional limitations	Children's Assessment of Participation and Enjoyment	- Child's functional ability, child activity preferences and family participation in social and recreational activities were the major predictors for formal and informal activities. - Children's preferences and family preferences are important predictors even when adjusting for child's functional ability - Indirect paths for participation were related mainly to family cohesion
Law et al, 2006	427 children / 6-14 years/ Health and Development Problems (50.8%	Children's Assessment of Participation and Enjoyment	- Higher participation intensity in informal than formal activities - Participation differs for age groups and sex - Family income, parents education and single-parent family as determinants for diversity

Author / year	Sample size/ Age/ Diagnosis	Outcome Measures	Primary Findings
Lawlor et al, 2006	13 families/ 4-17 years/ Cerebral Palsy	In-depth interviews (topics: physical independence, mobility, participation in health care, educational participation, financial and economic participation, and social and leisure participation)	- Mobility, transport, support to and by parents and attitudes of individuals and institutions towards the children were the four main themes - Transport perceived as vital for participation in leisure - Supervision of leisure activities is more required than for non-disabled child - Financial constraints reduce participation (high cost of equipments, etc)
McManus et al, 2006	Parents of 28 children/ 5-14 years/ Cerebral Palsy	Discussion Groups (topics: Home, school, transport, health services, free-time and finances	- Same obstacles within the environment as in Lawlor et al (2006), and in addition: bureaucracy and access to information as barriers

Author / year	Sample size/ Age/	Outcome Measures	Primary Findings
Voorman et al, 2006	110 children / 9-13 years/ Cerebral Palsy	Pediatric Evaluation of Disability Inventory; Vineland Adaptive Behaviour Scale; Gross Motor Function Measure	- Ability to move independently is important for social function - Severity of impairment affects social skills development initially but is similar to peers at older ages.
Welsh et al, 2006	443 children/ 5 years/ Cerebral Palsy	Lifestyle Assessment Questionnaire	- Environmental obstacles to participation: Lack of money and personal assistance, attitudes of strangers, presence of stairs and lack of transport.
Beckung & Hagberg, 2002	176 children/ 5-8 years/ Cerebral Palsy	Gross Motor Function Measure, Bimanual Fine Motor Function	- Gross and fine motor function associated with greater restrictions in mobility, education and social relationships.
Mactavish & Schleien, 1997	16 families / (mean age 9.33 years) / Developmental disabilities	In-depth interviews(topics: - Who participates in family recreation? -Where does family recreation transpire?)	- Small group activities (one of the parents and child) tend to dominate in family recreation - Most families believe that most recreational activities occur with equal frequency in home and community settings.

Author / year	Sample size/ Age/	Outcome Measures	Primary Findings
Margalit, 1984	40 children/ not presented 20 Learning disabled and 20 Controls	Liker type scale questionnaire (Subscales: passivity, loneliness, dependency on parents, spending time with friends)	- Children with learning disabilities tend to spend more time in passive and solitary activities compared to peers - Activities are more controlled by parents when compared to peers.
Margalit, 1981	70 children / 9 – 17 y/ 51 children with Cerebral Palsy and 20 controls	Semi-structured interview (describe their free-time activities)	- Leisure activities of children with CP are limited in range and variety, more passive, home-based and adult-controlled (parents, specially) when compared to peers.

3.2.4. Participation in Leisure Activities

Leisure activities encompass those outside of mandated school hours (Law et al., 2005b, and include occupations for which freedom of choice and enjoyment are the primary motives (Jacobs & Jacobs, 2001). Participation in leisure activities is important for the healthy development of numerous social, physical and psychological competencies (Law et al., 2006; Haggard & Williams, 1992; Margalit, 1984). Leisure activities can be divided into formal (structured, preplanned) and informal (spontaneous, unstructured) activities, and both are fundamental to child development (King et al., 2003). However, studies demonstrate that children with disabilities participate predominantly in informal activities, particularly those that are carried out within the home and family environment and are organized by adults. These children experience less diversity of activities and social engagements than their peers, spending more time in isolated activities such as watching TV and using the computer (Law et al., 2006; Aitchison, 2003; Margalit, 1981, 1984).

Studies on inclusive leisure experiences, in which children and youth with and without disabilities interact, reveal that children and youth with physical disabilities place a strong value on these types of activities, and indeed prefer environments in which they can interact with peers without disabilities. However, frequency of participation is relatively low when compared to their peers without disabilities. More typically, children with disabilities carry out leisure activities on their own or with parents rather than with friends, which may in part explain reports of boredom and perhaps a more passive lifestyle (Aitchison, 2003).

3.2.5. Factors Influencing Participation in Leisure Activities (Table 3.3)

3.2.5.1. Child Factors

Recent evidence suggests that intrinsic factors such as activity limitations, motor function, mastery motivation and other personality traits, lifestyle preferences, age and gender may affect social participation and participation in leisure activities (Beckung & Hagberg, 2002, Alisson et al., 2005; Law et al., 2005; Majnemer et al., 2006; Voorman et

al., 2006; Braun et al., 2006). Increasing age was shown to be an important determinant of decreasing level of participation in leisure, particularly with respect to informal activities (Law et al., 2006).

Furthermore, gender is likely to influence the choice of activities. Studies on children with and without disabilities demonstrate that girls tend to participate more in arts and social activities, while boys participate more in group activities involving physical activity and sports (Law et al., 2006; Alison et al., 2004; McMeeking & Purkayastha, 1995).

A greater limitation in motor function is associated with greater dependency on adults and restricts access to formal and informal leisure activities (Majnemer et al., 2006a; Margalit, 1984). Restricted mobility is viewed by parents as a key barrier to participation for their child with a physical disability (Welsh et al., 2006).

3.2.5.2. Family Functioning

The family environment should be considered in all studies on children and youth, as it is a fundamental context of their lives. Indeed, it is within the family environment that most leisure activities take place.

Few studies describe the role that the family may play in influencing involvement in leisure and recreational activities for children with a physical disability. It has been demonstrated that for these families, involvement in leisure activities may reduce family stress and help maintain a healthy family environment (Mactavish & Schleien, 1997). However, families of children and youth with physical disabilities often experience time constraints, financial burden and a lack of supportive mechanisms (i.e. babysitting, school environment) that reduce leisure opportunities (Margalit, 1981).

As a child grows older, there is a need to gain more independence in daily living skills, but also in social and recreational activities (McMeeking & Purkayastha, 1995). However, for children and youth with CP, leisure time is spent predominantly with family, rather than with peers, thus promoting ongoing dependency. Therefore, parents coping and

attitudes are of great importance in influencing their children's participation. It is conceivable that parenting behaviours and attitudes that involve setting limits to the extent in which their child or adolescent is allowed to engage in leisure activities may also inadvertently contribute to creating a more deprived social environment, but this requires validation. Evidence in recent studies (Heah et al., 2007, Law et al., www.canchild.ca, 2006; King et al., 2006; Majnemer et al., 2006b; Mactavish & Schleien, 1997) suggest that particular family expectations and recreational preferences, higher levels of family cohesion, higher incomes, better family-coping, and lower levels of stress may be important facilitators of participation for children who have a physical disability.

3.2.5.3 Environmental Factors

Participation in leisure can be facilitated or complicated by several environmental factors. In a socio-political model, disabilities are viewed as a problem in the individual's relationship with the environment, not as a problem within the child or youth (Law & Dunn, 1993). Perhaps for this reason, there is growing interest in identifying the environmental factors that may act either as barriers or facilitators to participation in leisure activities.

Environmental barriers directly affect participation in leisure as they may limit access to activities and spaces**.** Specifically, physical design as well as cultural and social attitudes are factors that contribute to the leisure profile and experiences of children and youth with disabilities (Aitchison, 2003; Wilhite, 1999). Characteristics of community programs that may or may not accommodate the needs of these children are also identified as an important factor for participation (Heah et al., 2007).

Although the diversity and frequency of leisure may be influenced by the social environment, studies concur that physical restrictions such as transportation and physical barriers (e.g., uneven surfaces, stairs) greatly impede the full participation by children and youth with disabilities in various leisure activities. Possibly, these restrictions are responsible for the extent to which these children participate in informal rather than in

formal activities, as the latter are more likely to be impeded by physical and institutional barriers (Majnemer, 2006a; McMeeking & Purkayastha, 1995; Shannon, 2006).

Attitudes towards children or youth with physical disabilities constitute an important barrier for participation in recreational activities. Specifically, bullying by peers, need for adult assistance, staring by others, policy segregation, segregation within schools, and lack of information are dominant factors within the attitudinal and social environment that have been identified as negatively influencing participation in leisure for children with CP (Mihaylov et al., 2004). Children and youth with physical disabilities most prefer segregated environments involving activities with children with disabilities so as to avoid physical and attitudinal obstacles in the community at large, and thus participate more easily (Braun et al., 2006; Heah et al., 2007).

Table 3.3 - Primary determinants of participation identified in the literature

	Determinants	Relationships
Child	Age	Increasing age contributes to less participation
	Gender	Influences the choice of activities
	Motor Function	Greater limitations are associated with less participation
	Interests and Preferences	Affect the choice of activities and level of participation
Environment	Physical	Lack of equipment and structural barriers affect participation in formal activities
	Social	Policies; segregation; lack of information and organization; peer support
	Attitudinal	Bullying; staring; dependence on adults
Family	Socioeconomic Status	Lower family income and lower parental education associated with lower participation
	Parents' Educational Level	
	Family Functioning	Leisure preferences and level of social support

3.2.6. Conclusions

Very few studies on children with physical disabilities describe determinants specific to participation in leisure; most are on participation in general, and may or may not include a specific description of leisure activities. The studies include different populations that combine children and adolescents who have CP with others who have different developmental disabilities. However, some studies analyzing characteristics and determinants suggest that similar aspects may influence participation across populations of children and youth with disabilities. Therefore we might utilize data from other populations to generate hypotheses regarding those with CP. This remains to be validated in studies that compare determinants across disability groups. It is possible that several factors are universal or generic; however there may be additional "disability-specific" attributes that either directly or indirectly influence level of participation.

While many studies focus on productivity and self-care, there is a paucity of information on leisure and recreational activities among children with CP, in spite of the importance of this sphere of occupational performance. Participation in recreational activities may play a fundamental role in the quality of life of children and youth with CP.

Studies highlight the importance that contextual factors such as personal lifestyle preferences, demographic characteristics, family function and environmental attributes may play in influencing level of participation in leisure. Greater priority should be given by health services providers to the identification of a child's personal interests in the area of leisure/recreation and to their satisfaction with that important life area. This area is currently overlooked by rehabilitation specialists. Intervention strategies can focus on minimizing barriers to participation in older age groups to include addressing behaviour problems and poor social skills. Therapists can work in partnership with families to identify and address resource needs, and enhance family coping, so as to facilitate participation of their children. Furthermore, rehabilitation specialists can play an important role to advocate at the policy level to ensure that adequate resources and supports are available to maximize participation and inclusion at the community level.

Further studies are required to identify and test the role that potentially modifiable attributes across the lifespan play in promoting participation in leisure activities among individuals with CP, and that enable these individuals to achieve life satisfaction, health and well-being. This information will assist health-care providers to target their intervention/prevention efforts and provide a basis for the practice of evidence-based care.

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3.3. Systematic review update

Participation is a novel area of research and new evidence is becoming rapidly available as increased interest in biopsychosocial factors is emerging in the health and rehabilitation fields.

3.3.1. Characteristics of studies

Table 3.4 summarizes the studies reviewed after the publication of the systematic review of determinants of participation in leisure activities in adolescents with CP. Studies included in this new review were all studies published after the previous review that measured the influence of environmental resources and personal characteristics in leisure participation of children and youth with CP. Different outcome measures were used to assess participation. The CAPE and the Leisure Activities Questionnaire (LAQ)- CP measure specific participation in leisure activities and were used in four studies. Other measures used in these studies assess participation in different areas, some of which include the specific sub-domain for leisure participation and others have items within broader domains that relate to leisure activities. Two studies used questionnaires developed by researchers covering different topics related to participation, including leisure.

Several predictor variables were analysed by different authors, but the only common independent variables across studies was motor function (gross motor function as measured by GMFM or GMFCS). Age and gender were personal factors used to build models of factors influencing participation in some studies, however, only three studies accounted for other personal factors such as motivation and behaviour. Other contextual factors accounted for in the studies included immigration status, socioeconomic deprivation in geographical area, parental stress, parental educational level and service utilization.

Table 3.4 - Description of constructs measured in the recent studies

01	Morris et al., 2006	Cross sectional (postal survey)	- Gross motor function - Manual function - Age - Gender - Deprivation in family area	Activity Scale for Kids (ASK) And Leisure Activities Questionnaire – CP version (LAQ CP)
02	Donkervoort et al., 2007	Cross sectional	- Gross Motor Function - Level of parental education - Age - Gender	Life - Habits
03	Maher et al., 2007	Cross sectional (survey)	- Self-reported gross motor function	Physical Activity Questionnaire for Adolescents (PAQ – A)
04	Imms et al., 2008	Population-based survey	- Gross motor function - Manual Ability	Children's Assessment of Participation and Enjoyment (CAPE)
05	McManus et al., 2008	Cross sectional	- Gross motor function - Manual function - Intelligence quotient - Age - Gender	Frequency of participation questionnaire (FPQ)
06	Wright et al., 2008	Before and after study (baseline, 2 months and 6 months post botulin toxin type A injections)	- Gross motor function - Walking ability - Activity limitations - Spasticity	Pediatric Outcomes Data Collection Instrument (PODCI)
07	Majnemer et al., 2008	Cross sectional	- Activity limitations - Gross motor function - Cognitive status - Mastery motivation - Behavioral difficulties - Parental stress - School type - Rehabilitation services - Parent education/income	CAPE
08	Fauconnier et al., 2009	Cross sectional	- Gross and fine motor function - Intellectual ability - Vision, hearing, seizures, feeding, communication - Sociodemographic characteristics	Life-Habits

				- Age - Sex - School type - Disability of any siblings	
09	Kang et al., 2010	Prospective study	cohort	- Age - Sex - Gross motor function - Enjoyment of participation - Coping - Primary caregiver education - Family structure and relationships - Family activity orientation - Processes of services - Services available	CAPE
10 **11**	Palisano et al., 2011 (a and b)	Prospective study	cohort	- Age - Sex - Gross motor function - Physical activity - Enjoyment of participation - Primary caregiver education - Family structure and relationships - Family activity orientation - Health services	CAPE

Table 3.4 presents main sample characteristics for each study reviewed after the first publication. All studies used gross motor function as a determinant of participation in leisure. A variety of environmental or family-related factors were described, but few studies included personal factors in their models. The most used outcome measure was the CAPE.

Most studies reported their response rate and had samples that were representative of a large geographical area or from registries and included participants in the five levels of

gross motor function severity. Table 3.5 presents key quality indicators and main results for each study reviewed.

Table 3.5 - Sample characteristics of studies reviewed

		1	2	3	4	5	6	7
Sample size		129	103	112	114	98	35	67
Response rate		41%	56%	51%	52%	82%	NR	74%
Recruited from		4 countries (database)	8 Rehabilitation centers	Community based service provider	CP registry	CP registry	Convenience sample BoNT-A clinic	Community sample
GMFCS (N)	I	25	78	42	26	37	11	39
	II	43	7	27	41	22	12	15
	III	15	5	10	12	11	12	13
	IV	14	12	17	10	12	-	
	V	23	1	15	25	16	-	
Gender #male (%)		72 (56)	62 (60)	76 (67.9)	65 (57.1)	53 (54.1)	19 (54.2)	42 (63)
Age Mean (SD)		9y9m (1y9m)	17y9m (1y4m)	13y11m (23m)	11y9m (6m)	8-9y(n=40) 10y(n=20) 11y(n=15) 12+y(n=23)	5y6m (2y2m)	9y7m (2y1m)
Country		United Kingdom	Netherlands	South Australia	Australia	Ireland	Canada	Canada

y=years/m=months

Table 3.5 - Sample characteristics of studies reviewed (Continued)

		8	9	10	11
Sample size		818	209	209	288
Response rate		97%	NR	NR	NR
Recruited from		CP registries of 6 countries	6 Shriner's hospitals	6 Shriner's hospitals	6 Shriner's hospitals
GMFCS (N)	I	257	54	54	74
	II	164	57	57	68
	III	139	33	33	61
	IV	113	26	26	45
	V	145	39	39	40
Gender #male (%)		286 (52)	108 (52)	108 (52)	166 (57)
Age Range		8-12y	13-20y	13-20y	6-12y
Country		Six European countries	United States	United States	United States

y=years/m=month

Table 3.6 - Key findings of recent studies on determinants of participation in leisure in children and youth with physical disabilities

ID	Sample	Outcome measure (Reliability, validity)	Key findings
1	Population-based sample	No psychometric properties described	- Gross motor function, manual function, age, sex and deprivation in family were associated with participation on univariate analysis. - Age, gross motor function, manual ability, cognitive ability and presence of seizures accounted for 89% of variation in participation in leisure.
2	Population-based sample assessed on a volunteer basis	Good reliability and validity although not specific to leisure participation	- Gross motor function and level of education were important determinants of participation in leisure and community activities.
3	Population-based sample	- PAQ has fair reliability and good validity (quotients not provided) - Screen time report not standardized	- Individual characteristics accounted for 36% of variation in physical activities (PA). - Gross motor function associated with higher PA level. - Older age associated with lower PA. - Gender (male) associated with higher "screen time" (time spent watching TV or playing videogame). - Adolescents with CP had lower PA level when compared to same age controls without disabilities. - CP population and non-CP have same sedentary activity level.
4	Population-based sample	The CAPE has high reliability and validity	- Children with CP participated in less formal activities than informal activities. - Children with quadriplegic CP had lower diversity and intensity participation in informal activities than children with diplegic or hemiplegic CP. - Children with more severe motor impairment (GMFCS V) had lower participation in informal activities when compared to other levels. - Children with CP participated in more organized sports than children without CP and report more frequency, however children without CP participated in more activities (diversity). Both groups reported same intensity of TV watching and reading.
5	Population-based sample	Instrument derived from a QoL instrument; Face validity, but no reliability	- Level of motor impairment was associated with participation in most leisure activities. - Age and gender were not associated with participation, unless if combined with severity of impairment.
6	Convenience sample; power analysis provided and adequate	PODCI discriminant and construct validity is reported as good; no information of reliability	- Activity limitations and participation in leisure activities were related at base-line, but not at 2 and 6 months. - Spasticity and body function accounted for 50% of variation in PODCI, PEDI and GMFM together. - Gross motor function not associated with participation in leisure activities.
7	Convenience sample; representative of community sample (CP registry)	The CAPE has good reliability and validity	- Lower communication ability and hyperactivity associated with lower diversity of participation in formal activities. - Conduct problems, female sex and no hyperactivity predicted enjoyment of formal activities while lower IQ, lower parental stress, female gender, and younger age predicted enjoyment of informal activities.

			- Conduct problems, mastery motivation, level of independence in everyday activities, parental distress associated with higher frequency of participation in leisure activities.
8	Population-based sample from registry	Life-H is a valid and reliable instrument measuring participation in life situations (not specific to leisure)	- Walking abilities, intellectual ability and communication were related to participation in recreational activities. - Participation levels differed by geographical region.
9	Convenience sample	CAPE	- Lower gross motor function, higher upper extremity function, higher adaptive behaviour, less communication and learning problems affecting daily activities were associated with more participation with others. - More family conflict and organization, higher parental education, more availability of resources in the community and presence of rehabilitation services in the school setting were related to more engagement in activities with others. - Higher physical and sports function and less communication and learning problems affecting daily living skills, and studying in a regular school was related to more participation in activities with friends. - Presence of desired community services, attending regular school was related to more participation in activities with friends.
10	Convenience sample	CAPE	- Higher physical ability, more enjoyment of participation, younger age, female sex and higher family activity orientation were associated with higher intensity of participation in leisure activities (for youth with CP).
11	Convenience sample	CAPE	- Higher gross motor function, more adaptive behavior, higher enjoyment, younger age, and higher family activity orientation are associated with higher intensity of participation in leisure activities (for childen with CP).

PODCI= Pediatric Outcomes Data Collection Instrument; CAPE= Children's Assessment of Participation and Enjoyment; LAQ CP=Leisure Activities Questionnaire – CP version

3.3.2. Determinants of participation identified in the literature

A series of child, family and environmental factors may collectively affect participation in leisure activities. Table 3.6 summarizes the associations of predictor variables and leisure participation reported since our published systematic review.

3.3.2.1. Body Function

One study (Fauconnier et al., 2009) described pain and visual impairment as factors related to diminished participation. Three studies (Fauconnier et al., 2009; McManus et al.2008; Majnemer et al., 2008a) found that children with higher intellectual abilities participate more in social and community-based activities.

3.3.2.2. Activity Limitation

Several studies investigated the associations between activity limitations and participation in leisure. All studies included in this updated review applied measures of motor function as potential predictors of participation in leisure activities. Most studies found that higher gross motor function and higher manual ability were both independently associated with increased participation in leisure activities; however Kang et al. (2010) reported that lower gross motor function was associated with higher levels of leisure participation and Wright et al. (2008) found no association between gross motor function and participation in general leisure activities. Of note, models that accounted for a variety of other personal and environmental factors found a smaller influence of motor function on level of participation.

Wright et al. (2008) reported that more mobility predicted more participation in sports activities whereas Majnemer et al. (2008a) found that increased communication ability was associated with higher intensity and diversity of self-improvement leisure activities. Fauconnier et al. (2009) found that children with lower communication ability participated less in recreational activities.

3.3.2.3. Personal Factors

Four studies reported age as a predictor for leisure participation. Majnemer et al. (2008a) and and Morris et al. (2006) reported higher participation in self-improvement activities and community-based activities with increasing age. Age was associated with less participation in physical activities in a sample of young adolescents (mean age 13 years old) in Maher et al. (2007).

Gender was a factor considered in two studies. In one study, female gender was related to an overall higher enjoyment of participation (Majnmer et al., 2008a) whilst in another study (Maher at al., 2007), male gender was reported as predicting more time on computer and watching television.

One study found that a higher level of education was associated with more participation in leisure in young adults with CP (Donkervoort et al., 2007). An increased sense of mastery and motivation and behaviour problems were reported to be associated with more participation in recreational activities in school-aged children with CP (Majnemer et al., 2008a). Self-perceived competence and social interaction skills were important for participation in activities with other people for children and youth with disabilities (Majnemer et al., 2008a; Kang et al., 2010).

3.3.2.4. Environmental Factors

A number of studies investigated the impact of environmental factors on leisure participation. Majnemer et al. (2008a) reported a negative association between increased parental distress and participation intensity and diversity in self-improvement and recreational activities respectively. Kang et al. (2010) reported that the presence of desired community services and attending a regular school was associated with more involvement in activities with friends for adolescents with CP. Palisano et al (2011b) reported that family recreational orientation was one of the main factors associated with intensity of participation.

Two studies reported no significant association between socioeconomic status and leisure participation and one multi-country study pointed at geographical region as an important determinant of participation in different domains, including recreational activities (Fauconnier et al., 2009). Authors in this last study attributed differences in participation levels to the offer of services and programs favouring participation in certain regions more than others.

3.3.3. Main conclusions

Few studies included adolescents (12 -18 years of age) in their sample (Donkervoort et al., 2007; Maher et al., 2007; Kang et al., 2010; Palisano et al., 2011). While participation is one of the most important long-term outcomes for individuals with disabilities (King et al., 2002), it is also a variable that changes with age and one's stage of development (Simeonsson et al., 2001). Limitations that are experienced by children with CP may be reinforced during adolescence, when opportunities for participation in leisure activities are likely to decrease. Factors that are associated with participation are different for children and youth and also for different participation domains (King et al., 2009). Clearly, ongoing participation throughout childhood and adolescence is important to ensure a healthy transition into adult life (King et al., 2000); however, there is a lack of information related to the concept of ongoing participation and how it affects individuals with CP.

Quality of studies is a concern for this area of research. Measuring participation in leisure according to the ICF is a challenge. Participation is an objective outcome as it relates to what the individual actually does; however, many factors such as personal aspects (preferences, age and gender), frequency, and environmental factors (socio-economic status, accessibility and family orientation towards leisure) play a role in and have an influence on the actual level of participation (Law et al., 2004; Majnemer et al., 2008a). Proxy accounts, which are often used to measure different outcomes in children with disabilities may not reflect the actual participation level of children, though the severity of the disability may not allow the child to respond by himself (Majnemer et al., 2008b), and recall biases may also be a factor.

To date, the CAPE (King et al., 2004) is the only measure that captures participation in discretionary leisure activities exclusively and has sound psychometric properties. Many studies developed their own questionnaires and the other measures used may present a questionable reliability and validity. The use of sub-domains of other measures (e.g. Life-Habits) to assess participation may not be the best method either as construct validity for specific sub-domains may not be established for children with disabilities. These measurement issues limit interpretation of findings. Nonetheless the various factors obtained provide a preliminary overview of participation in this population.

The designs and statistical methods used for the respective studies are also an issue undermining the quality of information obtained thus far. However, the study of participation is very recent to rehabilitation research and therefore, these initial exploratory methods may be appropriate. As the level of knowledge increases, study designs should become more rigorous.

Very few personal and environmental factors were included in most of the studies. While motor function may explain part of the variance in participation, there is an array of other predictors such as motivation, self-perception and environmental barriers that are reported in the literature as being important potentially modifiable issues for this population and therefore, should be investigated. These predictors are meaningful for clinical practice yet evidence is needed to elaborate evidence-based goals and programs.

3.3.4 Summary

An update to our published systematic review was performed to further explore the factors identified that influence participation in leisure activities in adolescents. Results demonstrated that children and youth with CP engage in a variety of leisure activities. Personal and environmental factors may act as barriers or facilitators influencing their level of participation in leisure activities. These factors should be considered in the elaboration of rehabilitation interventions for this population. Findings from these combined reviews may also guide future research in participation in children and youth with cerebral palsy, especially, attention must be given to methodological and

measurement aspects of study designs in order to improve the quality of information provided and contribute to evidence-based practice in the field.

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CHAPTER 4

Chapter 3 presented a comprehensive literature review of factors that are associated with leisure participation in children with physical disabilities and especially cerebral palsy The literature to date highlights a series of factors that are related to the participation of children and youth with disabilities in leisure activities and suggests the need to identify factors that may influence participation in leisure activities for adolescents with cerebral palsy.

In order to plan interventions and strategies to promote participation, we need to better understand the participation patterns of this high-risk population of interest. No published studies to date have described the participation patterns of adolescents with CP. Chapter 4 therefore provides a detailed depiction of the participation of adolescents with CP in five different leisure activity domains and compares these patterns according to key socio-demographic characteristics.

Manuscript 2: Picture me playing - A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy

Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the *QUALA group**

** The QUALA group includes the following collaborators: Michele Gardiner, Danielle Guimond, Celine Lepage, France Martineau, Kathleen Montpetit and Sylvie Thibault. These individuals assisted with recruitment of participants and were asked to provide feedback on the research proposal and the manuscript submitted for publication.*

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Keywords: Participation, Leisure, Adolescent, Cerebral Palsy

4.1. Abstract

Introduction: In recent years attention has been paid to the participation levels of children and youth with Cerebral Palsy (CP), particularly the extent to which they have the opportunity to be involved in and enjoy leisure activities. The objective of this study is to describe the level of participation and enjoyment in leisure activities among adolescents with CP and to identify potential differences in participation patterns related to sociodemographic attributes. Methods: Cross-sectional design. Participants completed the Children's Assessment of Participation and Enjoyment (CAPE).

Results: Participants were one hundred seventy-five adolescents 12-20 years old 15.3 (±2.2), GMFCS I = 55/ II= 43/III = 13/ IV = 18/V = 39. The types of activities participants engaged in most frequently were social and recreational activities, whereas self-improvement and skill-based activities were least frequent. Social activities were the activities they enjoyed most. In general, participation decreases as youth grow older. Girls engaged in more self-improvement activities than boys. Adolescents who study in special segregated schools experienced a lower diversity and intensity of engagement in all leisure activity domains. Adolescents who were not ambulatory and those presenting with more severe manual ability limitations participated less in all activity types except skill-based activities.

Discussion: Adolescents with CP place value on the ability to engage in activities of their own choosing and on interacting with friends. Engagement in a variety of leisure activities is important for a healthy development. Understanding the leisure patterns and preferences of this population, in addition to the contextual factors, may help in the elaboration of interventions and programs to promote a healthy development for this populatio

4.2. Introduction

Cerebral Palsy (CP) is the most common type of physical disability affecting children in developed countries (Stanley et al., 2000). The focus of rehabilitation interventions within this population is often limited to minimizing impairments and addressing functional aspects of the condition such as activities of daily living and motor function. In recent years, however, attention has been paid to this population's participation levels, particularly the extent to which they have the opportunity to be involved in and enjoy leisure activities at home and in the community (Specht et al., 2002; Adamsom, 2003).

Participation is defined by the World Health Organization (WHO) as involvement in a life situation or sharing an activity. Different areas such as communication, mobility, domestic life and social relationships comprise some of the elements of participation. These activities show how an individual functions in his/her environment in different life roles. One important participation domain not often considered is participation in leisure (WHO, 2001; Law, 2002; King et al., 2003).

Studies on child development reinforce the important role that play, leisure and recreation have on health and well-being. Recent studies have identified determinants of participation in leisure and recreation in children and youth with disabilities such as motor functioning, age, family environment, motivation and behavior (Palisano et al., 2011a, 2011b; Majnemer et al., 2008; Law et al., 2006; Rosenbaum, 1998). Knowledge of these determinants is important to guide intervention strategies to promote participation. In particular, there is a lack of information on participation in leisure and recreation in adolescents with disabilities. Although adolescence is one of the most critical periods of development, little is known about specific characteristics of this stage for individuals with developmental disabilities (Adamson, 2003; Majnemer & Mazer, 2004).

It is increasingly appreciated that there is a decrease in participation among adolescents with a disability (Law et al., 2006) . Studies have shown that participation in leisure may be crucial for a good perceived quality of life for this population (Shikako-Thomas et al.,

2009; Dahan-Oliel et al., 2012; Aitchison, 2003; Law, 2002); however, few studies have characterized the actual participation patterns of adolescents with CP. Evidence is needed on the participation levels and preferences among youth with CP so that effective and targeted health promotion strategies can be developed to enhance enjoyment and community integration for this high-risk population.

The objective of this study is to describe the level of participation and enjoyment in leisure activities among adolescents with CP. We were also interested in identifying potential differences in participation patterns that are related to sociodemographic attributes to better characterize participation in this population.

4.3. Methods

Ethical approval for this study was obtained from the Montreal Children's Hospital Ethics Review Board, the Centre for Research on Interdisciplinary Rehabilitation (CRIR) and the Agence de la santé et des services sociaux de Montréal (ASSS), the local health and social service authority on the island of Montreal.

4.3.1. Population

Adolescents 12-20 years of age with a diagnosis of CP were recruited for a study describing factors influencing their leisure participation and quality of life (QUALA study). A sample of children (6-12 years) who had participated in a previous study describing quality of life and participation in school-age children with CP (Majnemer et al., 2008) was contacted for participation in the adolescents' study. An additional sample was recruited from specialty clinics, school, community and transition programs across the province of Quebec. These recruitment methods ensured a regional, geographically representative sample of adolescents with CP.

4.3.2. Procedures

A cross-sectional design was used. The current findings are part of a larger study on determinants of participation and quality of life in adolescents with CP. Clinicians and/or

program managers received a pamphlet containing a short description of the study to be given to the families of potential participants. Families were approached by a professional from the center who provided information about the study and passed on the family's contact information (name of the child, name of the parents and telephone number) to the research coordinator upon family's consent. The research coordinator then contacted the family and provided further clarification regarding the study procedures.

Once consent (parental) and assent (adolescent, when feasible) were obtained, an appointment was made with the participant and parent (mother or father) to complete evaluations at the Montreal Children's Hospital Childhood Disability Laboratory, at the Madeleine Bergeron school in Quebec City or as a home visit, when participants were not able to come to one of the assessment sites. For children living in foster care, consent was obtained both from the legal guardian or the public curator and from the foster parent. Participants were formally evaluated by either an occupational therapist (OT) or physical therapist (PT) who completed the Gross Motor Function Classification System (GMFCS; Palisano et al., 1997; Palisano et al., 2008). The Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004) was applied by a trained occupational therapist or psychologist through an interview either with the adolescents alone, with an adolescent and proxy help or with a proxy alone, according to the cognitive ability of the child or feasibility issues. Children were tested by a neurologist to confirm the CP diagnosis and classify the CP distribution. All evaluators were blinded to medical history, CP classification subtypes and the results of other testers' evaluations. Assessment of an adolescent took approximately two hours to complete. Families were reimbursed for their travel expenses and snacks were offered. The adolescents received a gift certificate (CAD$20 for either movie tickets or retail store) upon completion of the study.

4.3.3. Measures

Demographic information was collected through a questionnaire completed by a parent or legal guardian to ascertain, among other information, the subject's medical history, the family's socio-economic status and the adolescent's school setting.

As part of these evaluations, the OT/PT completed the Manual Ability Classification System (MACS; Eliasson et al., 2006) and Gross Motor Function Classification System (GMFCS; Palisano et al., 1997; Palisano et al., 2008), with parental input. The GMFCS is a widely used classification system for children with CP that measures gross motor function. A classification is made on a five-point scale based on gross motor function with particular emphasis on mobility. The GMFCS has shown evidence of reliability and validity. The MACS classifies typical self-initiated bimanual hand function when handling objects during everyday activities and the extent to which the individual requires assistance or adaptations on usual performance in home, school or community. The MACS has very good construct validity and reliability (kappa=0.62). The MACS is a 5-point ordinal scale (e.g. level 1: handles objects easily and successfully with some limitations in speed and accuracy; level 5: does not handle objects and requires total assistance to perform simple hand functions). The participant is classified on the basis of the observations of the evaluator and the proxy's input concerning the typical performance of the child.

The Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004) is a questionnaire for children and adolescents between 6-21 years of age. It is a measure meant to be completed by the child, together with a parent/guardian if needed. Activities are illustrated and rated as yes or no if they have been performed in the past 4 months. If performed, there is a numbered scale for frequency of participation, from 1 (1 time in the past 4 months) to 7 (once a day or more). Activities are grouped into five domains (recreational, active physical, social, skill-based and self-improvement). Scores may be derived for intensity (how often), diversity (number of different activities) and enjoyment (from 1: not at all, to 5: love it) for each domain, or summary scores for formal (structured, pre-planned) and informal (spontaneous) activities. Summary scores can also be derived for "with whom" the child performs the activity and "where" the activity is performed (higher scores indicate that activities are done with other people and that are more distant from the family/home context). Final scores are expressed on a continuous scale. Test-retest reliability ranges from .65 to .75 on overall participation, and face

validity is assured by extensive literature review and on the basis of the International Classification of Functioning, Disability and Health (ICF) as a framework.

4.3.4. Analysis

Descriptive statistics were calculated to characterize leisure participation of adolescents with CP. Scores of diversity, intensity and enjoyment in the five different domains (recreational, active physical, social, skill-based and self-improvement) and also in the formal and informal activity domains were obtained. Pearson product moment correlations were used to determine associations between age and leisure participation. T-tests were performed to compare mean differences between groups for dichotomous independent variables (gender, younger and older adolescents, regular and special school, ambulatory or non-ambulatory, mild or severe manual ability limitation).

4.4. Results

Participants in the study were 179 adolescents and one or both of the parents or caregivers who completed the CAPE. Twenty-eight percent of the participants answered the CAPE by themselves while 18% completed it with proxy help; 47% of the questionnaires were completed by parents without child input because of the adolescent's cognitive or language limitations in self-reporting or because of feasibility issues. Participants' characteristics are reported in table 4.1. Approximately 2/3 of the sample were ambulatory with or without assistive devices (GMFCS I-III) and approximately 3/4 had mild limitations in manual ability (MACS I-III).

Table 4.1- Description of the sample

Variable	N = 175	
Gender	Male = 110 (59%)	
Age	Mean =15.3 (±2.2)	
School type (N=173)	Special = 74 (42.8%) Regular = 57 (32.9%) Regular with special resources = 40 (23.1%) Other = 2 (1.2%)	
CP Distribution (N=153)	Spastic quadriplegia = 64 (41.8%) Spastic diplegia = 25 (16.3%) Spastic hemiplegia = 41 (26.8%) Other = 23 (15%)	
Motor function	**GMFCS (N=171)** I = 55 (32.2%) II= 45 (26.3%) III = 13 (7.6%) IV = 19 (11.1%) V = 39 (21.3%)	**MACS (N=172)** I = 50 (29.1%) II = 44 (25.6%) III = 31 (18%) IV = 17 (9.9%) V = 30 (17.4%)
Family SES	**Income before tax** 0-$19,999 = 12% $20,000-$39,999= 19% $40,000-$59,999= 12% $60,000-$79,999= 14.6% $80,000 + = 42.4%	**Maternal education** High school inc = 6.7% High school com = 25.6% College/Cegep = 32.9% University degree = 29.9% Graduate degree = 4.9%

4.4.1. Overview of participation

Adolescents with CP participated in a variety of out-of-school activities. Considering the formal (structured, preplanned) and informal (spontaneous) domain scores, adolescents participated more in informal activities (diversity M= 18.58, SD= 6.67 – out of 45 possible activities) than formal activities (diversity M= 2.01, SD= 1.58 – out of 10 possible activities). Frequency of participation was also higher for informal (M= 2.17, SD= .79) than formal activities (M= .60, SD= .49). When considering the activity domains by category (recreational, active physical, social, skill-based and self-improvement) adolescents engaged in a variety of recreational and social activities, but in fewer self-improvement activities. Participation in physical activities was lower than the other domains but was especially limited in the skill-based domain. The distribution of leisure participation for each domain is depicted in Figure 4.1 (diversity) and Figure 4.2 (intensity).

Figure 4.1 CAPE Diversity per activity domain

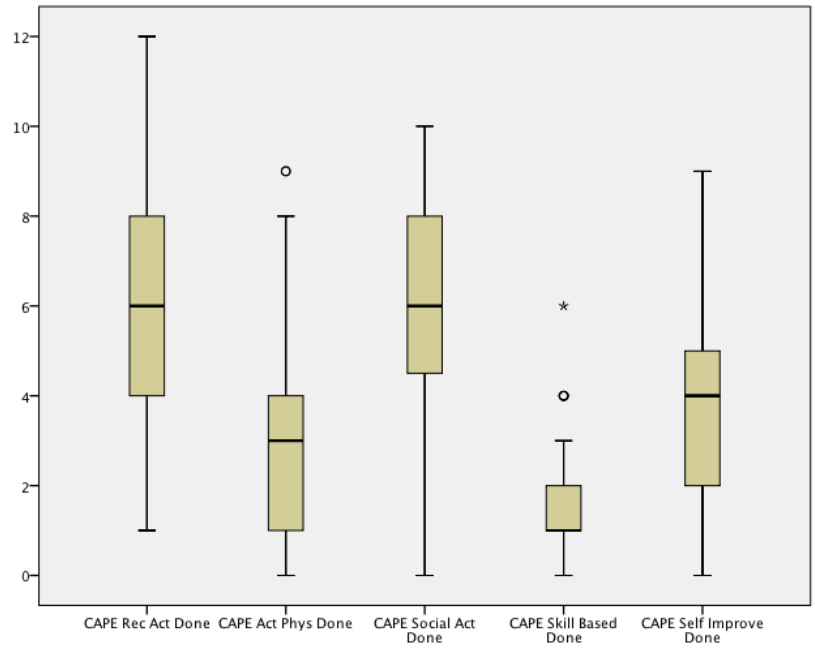
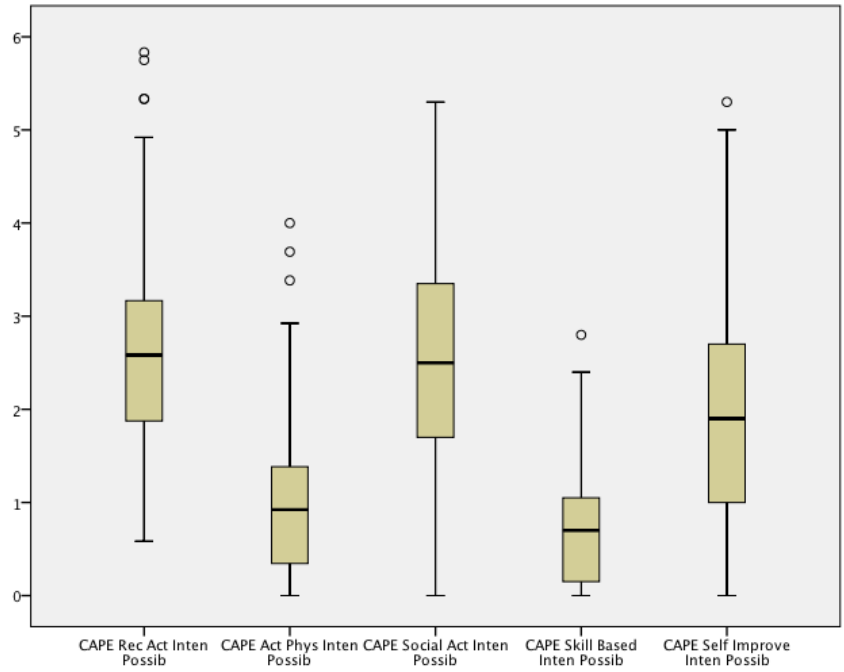


Figure 4.2 - CAPE Intensity per activity domain



Watching TV or a rented movie and listening to music were the most frequent activities performed every day (88 % and 84%, respectively participated once a day or more). For the activities that were commonly done once a week, like most skill-based activities, which require classes or special set up (e.g. swimming, doing gymnastics) or activities that are likely not done on school days; walking or hiking was done by 68% of the adolescents (37% did once a week or more). Swimming and team sports were both done by 29% of the sample; however 18% of adolescents swam every week or more while 21% did team sports. Other types of activities in a variety of domains were commonly done with less frequency since they required more planning and were not usually done during school days, such as going to a live event or going on a full day's outing. Of these activities, visiting and going to a party were the most frequent, with 65% and 61%, respectively who did it at least once in the past four months. Table 4.2 shows the percentages of the most frequent activities performed by adolescent (divided by activities that were commonly done daily, weekly, monthly and/or less often).

Table 4.2 – Most frequent activities done daily, weekly or monthly

Activities commonly done daily	N (% once a day or more)
Watching TV or rented movie	160 (62)
Listening to music	152 (59)
Computer or videogame	133 (42)
Playing with pets	100 (33)
Doing homework	101 (25)
Reading	107 (24)
Talking on the phone	125 (24)
Playing with things or toys	72 (18)
Activities commonly done weekly	N (%once a week or more)
Playing board games	117 (71)
Doing a chore	97(44)
Walking or hiking	124 (37)
Making food	87 (24)
Playing an instrument	43 (13)
Activities commonly done less frequently	N (% once a month or more)
Shopping	137 (65)
Visiting	117 (53)
Going to the movies	109 (34)
Going a full day out	78 (17)
Going to a live event	72 (12)

4.4.2. With whom, where and level of enjoyment

Adolescents with CP engaged in activities with a variety of people (Table 4.3). Social activities, naturally, were typically done with other people ($\bar{x}$ = 2.83, SD = .62), followed by active physical ($\bar{x}$ = 2.56, SD = 1.42) and skill-based activities ($\bar{x}$ = 2.55, SD = 1.75). Self-improvement activities were done mostly alone or with close family members ($\bar{x}$ = 1.89, SD = .85). Hanging out, entertaining others and visiting were the three activities that most adolescents did with friends (52%, 26% and 33% respectively), while going for a walk or hike, playing board games and making food were the top three activities done with family (46%, 37% and 34% of the sample did these activities with family).

Leisure activities were carried out in different settings and environments (Table 4.3). Higher scores on the "where" domain indicate that adolescents did activities that are more community-based as opposed to home-based. Social and active-physical activities were done mostly outside the household ($\bar{x}$ = 2.96, SD = .97 / $\bar{x}$ = 2.81, SD = 1.66). Recreational activities tend to occur more frequently at home, and that is reflected in this sample ($\bar{x}$ = 1.72, SD = .67).

Adolescents felt average to high enjoyment from engaging in leisure activities (Table 4.3). On a scale from 0 (do not like at all) to 5 (love it), the highest enjoyment was experienced in social activities ($\bar{x}$ = 3.86, SD = 1.11) and lowest in self-improvement activities ($\bar{x}$ = 2.87, SD = 1.33).

Table 4.3 – With whom, where and enjoymet per domain

Domain 0-5 scale scores	**With whom** Range (mean, SD)	**Where** Range (mean, SD)	**Enjoyment** Range (mean, SD)
Recreational	0.8 - 4.5 (2.18; .69)	0.3 - 3.7 (1.72; .67)	0.0 – 5.0 (3.68; .99)
Active Physical	0.0 - 5.0 (2.56; 1.42)	0.0 – 6.0 (2.81; 1.66)	0.0 – 5.0 (3.27; 1.69)
Social	0.0 – 4.7 (2.83; .62)	0.0 – 6.0 (2.96; .97)	0.0 – 5.0 (3.86; 1.11)
Skill-based	0.0 – 5.0 (2.55; 1.75)	0.0 – 6.0 (2.44; 1.91)	0.0 – 5.0 (3.15; 1.94)
Self-Improvement	0.0 – 5.0 (1.89; .85)	0.0 – 6.0 (2.39; 1.14)	0.0 – 5.0 (2.87; 1.33)

4.4.3. Differences in participation pattern across groups

Boys and girls did not differ in the quantity of recreational activities they performed. However, older adolescents (≥ 16 years of age) engaged in fewer recreational activities and completed them less often. Moreover, differences in gender were found in the

diversity (Table 4.4) and intensity (Table 4.5) of self-improvement activities, in which the girls participated more than the boys, with no significant difference between younger and older adolescents. No other gender differences were noted. Participation enjoyment did not differ across the age groups. Diversity and intensity of social activities were not significantly different as the adolescents grew older. Considering age as a continuum, the intensity of skill-based ($r = -.16$, $p = .02$), active physical ($r = -.15$, $p = .04$) and recreational ($r = -.22$, $p = .00$) activity diminished as the adolescents increased in age. The mean difference, however, is significant for recreational activities only if the group is divided into younger and older adolescents. Enjoyment of participation does not change across age groups.

For the purpose of this study, regular schools with special resources were considered within the regular school group, whereas special schools were those exclusively for children with disabilities. Adolescents in the special schools engaged in less (i.e. diversity) recreational, active physical, social and self-improvement activities than children in the regular schools ($p<.001$). Intensity of participation was also lower in active physical, social and self-improvement activities for adolescents in the special schools ($p = .001$).

Table 4.4 - Participation diversity/number of activities done (gender, age, and school type difference)

Activity domain	Total sample (n=175) Range Mean (SD)	Gender		Age groups		School type	
		Boys n=109	Girls n=70	12-15 n=111	≥ 16 n=62	Special n=71	Regular n=97
Recreational (12 items)	.82 – 12 (6.16; 2.31)	6.03 (2.28)	6.28 (2.35)	6.57** (2.28)	5.46** (2.20)	5.54** (2.52)	6.48** (2.05)
Active Physical (13 items)	.00 – 9.00 (2.9; 2.07)	6.06 (2.29)	6.37 (2.05)	3.04 (2.09)	2.58 (2.04)	2.09*** (1.91)	3.36** (2.02)
Social (10 items)	.00 – 10 (6.22; 2.18)	6.37 (2.05)	6.06 (2.29)	6.18 (2.20)	6.25 (2.26)	5.22*** (2.26)	6.86*** (1.87)
Skill-based (10 items)	.00 - 6.00 (1.49; 1.12)	1.42 (1.16)	1.6 (1.05)	1.60 (1.09)	1.30 (1.18)	1.46 (1.11)	1.15 (1.14)
Self-improvement (10 items)	.00 – 9.00 (3.94; 2.26)	3.72* (2.18)	4.41* (2.36)	4.14 (2.23)	3.82 (2.40)	2.90*** (2.02)	4.81*** (2.14)

* Pair of means are significantly different at the $p<0.05$ level.

** Pair of means are significantly different at the $p<0.01$ level.

*** Pair of means are significantly different at the $p<0.001$ level.

Table 4.5 - Participation intensity/ frequency of participation (gender, age and school type differences)

Activity domain	Total sample (n=175) Range Mean (SD)	Gender		Age group		School type	
		Boys n=109	Girls n=70	12-15 n=111	≥ 16 n=62	Special n=71	Regular n=97
Recreational (12 items)	.58 - 5.83 (2.65; 1.01)	2.58 (0.97)	2.70 (1.09)	2.87** (1.03)	2.25** (0.84)	2.43 (1.11)	2.27 (0.92)
Active Physical (13 items)	.00 – 4.00 (.98; .00)	1.02 (0.80)	0.87 (0.73)	1.05 (0.79)	0.85 (0.75)	0.69*** (0.71)	1.12*** (0.75)
Social (10 items)	.00 – 5.3 (2.58; 1.03)	2.48 (1.06)	2.69 (0.99)	2.56 (1.03)	2.64 (1.04)	2.03*** (0.98)	2.92*** (0.89)
Skill-based (10 items)	.00 -2.8 (.66; .53)	0.64 (0.57)	0.68 (0.47)	0.72 (0.53)	0.56 (0.54)	0.65 (0.53)	0.69 (0.54)
Self-improvement (10 items)	.00 – 5.3 (1.94; 1.18)	1.79* (1.14)	2.15* (1.24)	2.03 (1.18)	1.81 (1.24)	1.37*** (1.03)	2.35*** (1.15)

* Pair of means are significantly different at p=0.05.

** Pair of means are significantly different at the p<0.01.

*** Pair of means are significantly different at the p<0.001 level.

The last aspect considered in the description of the sample was motor functioning. Following analysis of histograms and scatterplots, we detected a trend in the relationship between motor functioning (as measured by the GMFCS and MACS) and participation level. We then divided participants into two groups according to their gross motor and manual functions: adolescents in GMFCS levels 1 to 3 (ambulatory) or 4-5 (non-ambulatory) and adolescents in MACS levels 1-3 (minimal to moderate manual ability limitations) or 4-5 (severe manual ability limitation). Table 4.6 depicts the mean scores across levels. Adolescents who were ambulatory (approximately 2/3 of the sample) participated consistently in more activities and at higher frequency in all activity types (p<.001) except for skill-based activities, for which differences between severity groups was not significant (p =.86 – diversity/p =.49 – intensity). Adolescents who do not ambulate engaged in noticeably fewer active-physical activities (ambulatory diversity M

= 3.57 ± 1.92/non-ambulatory diversity M = 1.48 ± 1.60) and self-improvement activities (ambulatory diversity M = 4.84 ± 1.16/non-ambulatory diversity M = 1.16 ± 1.03). Seventy-five percent of participants in the non-ambulatory group also had severe manual ability limitations. A similar pattern of participation was therefore noticed in this later group when comparing them to adolescents with lesser manual ability limitations; adolescents with more severe manual limitations presented less diversity and intensity of participation in all domains ($p < 0.001$), with the exception of the skill-based activities.

Table 4.6 - Differences in participation by motor function

	Ambulatory Mean (SD)		Manual ability limitations Mean (SD)	
	Yes (n=113)	No (n=58)	Mild (n=124)	Severe (n=47)
Recreational diversity	6.84 (2.12)*	4.91 (1.15)*	6.28 (2.11)*	4.53 (2.00) *
Recreational intensity	2.91 (1.02)	2.11 (0.81)	2.88 (1.00) *	2.00 (0.78) *
Active physical diversity	3.57 (1.92)*	1.48 (1.60)*	3.45 (1.96) *	1.31 (1.44) *
Active physical intensity	1.21 (0.75)*	0.47 (0.51)*	1.16 (0.76) *	0.44 (0.50) *
Social diversity	6.77 (1.96)*	5.22 (2.27)*	6.78 (1.97) *	4.85 (2.14) *
Social intensity	2.81 (0.99)*	2.11 (0.96)*	2.78 (0.98) *	2.05 (0.97) *
Skill based diversity	1.53 (1.07)	1.50 (1.23)	1.57 (1.06)	1.38 (1.27)
Skill based intensity	0.69 (0.54)	0.63 (0.52)	0.70 (0.53)	0.60 (0.54
Self-improvement diversity	4.84 (1.86)*	1.16 (1.03)*	5.02 (1.82)*	2.89 (2.17)*
Self-improvement intensity	2.38 (1.02)*	2.55 (2.18)*	2.48 (1.01)*	1.34 (1.05)

*Pair of means are significantly different at the $p<0.001$ level.

4.5. Discussion

This study demonstratedd that adolescents with CP participate in a broad range of out-of-school activities, especially informal activities. The types of activities they engaged in most frequently were social and recreational activities, whereas self-improvement and

skill-based activities were least frequent. Social activities were the activities they enjoyed most. In general, participation decreases as youth grow older, but this difference was only significant for recreational activities when dichotomizing age groups. Girls engaged in more self-improvement activities than boys. Adolescents who study in special segregated schools experienced a lower diversity and intensity of engagement in all leisure activity domains. Adolescents who were not ambulatory and those presenting with more severe manual ability limitations participateed less in all activity types except skill-based activities.

These findings contribute to our understanding of participation patterns in adolescents with CP, and that understanding can elicit critical thinking about the needs of this population when establishing programs and interventions to promote participation in out-of-school activities. Overall, we noticed that the adolescents with CP surveyed enjoyed participating in a variety of activities; however, participation was limited, especially in skill-based and self-improvement activities.

This study confirms the results from previous studies describing participation patterns of school-age children with disabilities. Children with disabilities participate more in informal than in formal activities. There is less variety, activities are more passive and home-based and they tend to be done alone or with parents rather than with friends; moreover, participation in leisure is more restricted for children with more severe impairments (Margalit, 1984; Specht et al., 2002; Fauconnier et al., 2009). Nevertheless, comparing the adolescents' mean participation scores per leisure domain in the current study with those found in other studies that used the CAPE measure with younger children and adolescents (Law et al., 2006; Majnemer et al., 2008; Imms et al., 2008; Orlin et al., 2010), we can see that our adolescent sample presented consistently lower mean scores in all domains of participation, especially in recreational and self-improvement activities. Despite sample differences, we can understand that adolescents as a matter of course grow out of some recreational activities measured by the CAPE (e.g. doing puzzles, crafts, pretend or imaginary play) and shift towards more social activities (Garton & Pratt, 1991), as was also demonstrated by Orlin et al. (2010) when comparing children and adolescents with CP. In this comparison, the latter study showed decreased

participation in skill-based activities among adolescents. A longitudinal comparison within the same sample would produce a better understanding of changes in participation patterns as children grow older.

A few recent studies have specifically investigated leisure participation patterns of adolescents with CP. In a qualitative study exploring leisure participation of youth with CP (11-15 years of age), Aitchison (2003) found patterns of participation similar to those in our sample. Participation was captured through adolescents' diaries of daily leisure activities that recorded a high prevalence of passive and home-based activities. A study comparing typically developing adolescents and those with CP (Engel-Yeger et al., 2009) found that adolescents with CP participated in more activities alone than do their peers without disabilities, while adolescents in both groups experienced equal enjoyment in all activity domains except self-improvement (higher for CP group). Within the CP group, they found no gender difference in activity intensity and diversity but found that girls with CP had higher enjoyment than boys with CP in self-improvement activities, whereas in our study we found gender differences in the diversity and intensity scores for this domain. Their study however had a small sample of adolescents with CP (n=22), and its main objective was to describe the differences between adolescents with and without CP, but not to characterize participation in the CP sample. Regardless of the lack of a comparison group in our study, our results improve the understanding of important characteristics of leisure participation in this understudied population of adolescents with CP. It is also important to consider that levels of participation are not necessarily comparable across samples, meaning more participation is not necessarily better, because participation is a complex construct that may vary according to contextual and personal factors (King et al., 2003).

The adolescents with CP took part in activities that were less structured and required fewer or no adaptations or environmental modifications and were mostly done in their home, such as recreational activities (e.g. playing computer or video games, watching TV). These activities are also often more sedentary and passive, demonstrating that adolescents with CP have limited involvement in active physical activities, with the most frequent activities performed on a daily basis being passive (except for doing a chore,

which may be active but is probably not vigorous). In a study exploring passive versus physical activity levels, adolescents with CP were less physically active than adolescents in the control group (Maher et al., 2007). Despite the non-progressive nature of the neurological condition in CP, several studies have illustrated the cycle of deconditioning that occurs as children with CP grow older (Rimmer et al., 2012). That cycle is likely to be reinforced if adolescents do not have the opportunity to regularly engage in active physical activities as they mature, which in turn may contribute to greater deconditioning and less participation, as suggested by studies comparing increasing age with motor function and physical activities (Donkervoort et al., 2007; Orlin et al., 2010).

Studies of typically developing adolescents show that involvement in formal leisure activities tend to be more important than informal activities for the development of social skills and competencies (Shannon, 2006). Engaging in predominantly unstructured social leisure activities such as 'hanging out' with friends as opposed to more structured, formal activities such as taking extra-curricular lessons is related to negative outcomes for adolescents (Jacbos et al., 2004). Blum et al. (1991) demonstrated that adolescents with spina bifida and CP have very few out-of-school relationships with friends and little participation in organized social activities. Adolescents in our sample had high involvement in social activities (as compared to the other activity domains), but overall less involvement in formal activities when compared to informal activities. Thus, we may assume that these adolescents are missing out on important developmental social opportunities, and that this issue should be addressed in interventions.

Contextual environmental factors may contribute to explaining the very low diversity and intensity scores in skill-based activities, which were probably due to a lack of organized programs available for adolescents with disabilities. The need for environmental adaptations and specialized programs may also explain the diminished engagement in active-physical activities when motor abilities are limited. The presence of environmental barriers as a limiting factor for participation, especially for children with more severe motor limitations, has been reported for younger children and adults with physical disabilities (Kirchner et al., 2008; Law et al., 2007, Dickinson et al., 2011). However, other factors are likely to interact with environmental barriers to limit participation in

skill-based and self-improvement activities, such as increased self-awareness and cognizance of limitations, less parental involvement and "push" to do specific activities and a growing need for autonomy that may force adolescents to gravitate towards activities that are less demanding or that naturally present with fewer barriers and challenges (Jacobs et al., 2004).

Recently, efforts have been directed at exploring determinants and promoting participation in active physical activities for children and youth with disabilities (McBurney et al., 2003; Verschuren et al., 2007; Kolehmainen et al., 2011). Engaging in physical activities is a key component for health promotion, but this kind of activity is also one for which intervention strategies are more logical and clearer than for interventions required to promote participation in other domains, such as self-improvement and skill-based activities. Furthermore, in times when many social interactions may actually occur in virtual environments (i.e. social media, the internet), which may be especially accommodating to the needs of adolescents with disabilities, it is important to investigate further the quality and nature of such social activities reported by adolescents. Attention to these other areas of leisure participation is imperative to promote a more holistic healthy development (Aitchison, 2003).

4.6. Conclusion

Adolescents with CP place a high value on the ability to engage in activities of their own choosing and on interacting with friends (Shikako-Thomas et al., 2009; Livingston et al., 2011). A systems view of adolescent development as proposed by contemporary theories suggests that a healthy development for adolescents is only possible through the interaction between multiple levels that range from biological characteristics to policies and services (Lerner & Castellino, 2002). Healthcare professionals should actively participate in promoting healthy development for adolescents with CP. Understanding the leisure patterns and preferences of this population, in addition to the contextual factors, may help in the elaboration of interventions and programs to promote a healthy development for this population.

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CHAPTER 5

Chapter 4 provided a description of participation patterns of adolescents with CP in our sample. The importance of understanding what adolescents do and what type of activities they engage in was emphasized, so as to plan interventions aimed at promoting leisure participation.

It is known that adolescents are more likely to engage in leisure activities of their own choosing. Therefore, we also needed to understand their preferences for particular types of leisure activities and the factors that appear to influence these preferences in order to support the elaboration of intervention plans and programs according to the adolescent's preferences and priorities, which may contribute to higher levels of engagement.

Chapter 5 therefore describes the leisure activity preferences of adolescents with CP in our sample in five leisure activity domains and also presents multivariate models of determinants of preferences. This aims to provide a better clinical understanding of the intrinsic and extrinsic factors that are related to preferences. Understanding these factors may contribute to clinical reasoning and program planning that takes advantage of the adolescent's preferences so as to enhance engagement in social, recreational and other leisure activities of their choosing.

Manuscript 3: Are you doing what you want to do? Leisure preferences of adolescents with cerebral palsy.

Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer, and the *QUALA group**

** The QUALA group includes the following collaborators: Michele Gardiner, Danielle Guimond, Celine Lepage, France Martineau, Kathleen Montpetit and Sylvie Thibault. These individuals assisted with recruitment of participants and were asked to provide feedback on the research proposal and the manuscript submitted for publication.*

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Are you doing what you want to do?

Leisure preferences of adolescents with cerebral palsy.

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Keywords: Leisure, preferences, cerebral palsy, adolescence

5.1. Abstract

Introduction: Adolescents with cerebral palsy (CP) may experience decreased participation in leisure activities. Engagement in leisure may be easier when adolescents can engage in activities of their choosing. Greater appreciation of adolescents' leisure preferences may influence goals and interventions in rehabilitation in order to promote health and well-being.

Objectives: To describe leisure activity preferences of adolescents with CP and their relationship to participation and to identify factors associated with greater interest in particular leisure activities.

Methods: This cross-sectional study included 127 adolescents (59.5% male; mean 15.3 + - 2.01 years) with CP (GMFCS levels: I 40%, lII 33%, III–IV 26%) who could complete the Preferences for Activities of Children (PAC) and other self-report questionnaires.

Results: Social and physical activities were most preferred, and self-improvement activities were least preferred. A decreased self-worth was related to greater preference for skill-based activities. Higher functioning level was related to less preferences in recreational skill-based and self-improvement activities. Preference for certain activities was not necessarily associated with actual involvement in these activities. In multivariate models, family activity orientation (families that tend to engage in or value recreational and intellectual/cultural activities) and family expressiveness (the extent to which members of the family can express their feelings) and adolescent's motivation were not significant individually, but contributed to the total explained variance in the models. In general, our models explained 15% of the variance in preferences for social activities, but explained up to 37% of the variance in preferences for self-improvement activities.

Discussion: Family factors, personal factors and functional abilities influence leisure preferences. Rehabilitation interventions should consider adolescents' preferences and family dynamics to minimize barriers to leisure participation, such as low motivation or environmental obstacles, so as to promote engagement in leisure activities.

5.2. Introduction

Participation in leisure activities by children with disabilities is a concept that has received growing interest, particularly since it has been brought to the forefront by the World Health Organization (WHO) in their International Classification of Functioning, Disability and Health (ICF; WHO, 2001).

Involvement in certain activities and preferences for those activities are likely to be related, however literature shows that they are distinct concepts (Garton & Pratt,1991; King et al., 2004). The ability to partake in leisure activities of one's choosing or preference may have an influence on an individual's overall quality of life, especially during adolescence when exploring and asserting one's individual interests is developmentally very important (Jacobs et al., 2004; Zaff et al., 2003; Dahan-Oliel et al., 2012).

Within the larger population of children with physical disabilities, a majority of studies on participation focus on children with cerebral palsy (CP) (Bult et al., 2011). This interest may be due to the high prevalence of the condition that has been stable over time (2-2.5/1000 children, Odding et al., 2006; Missiuna et al., 2001), the large variety of developmental characteristics that are likely to contribute to activity limitations and participation restrictions and the potential interaction of these characteristics with environmental factors surrounding the child (Shevell & Bodensteiner, 2004; Shikako-Thomas et al., 2008).

Studies to date on participation have largely focused on school-age children with CP (Majnemer et al., 2008; Law et al., 2006) with few studies examining specific participation characteristics of adolescents (Palisano et al., 2011b; King et al., 2010). Studies to date reveal that adolescents with CP may experience decreased participation in leisure activities; however, existing evidence has not focused on specific leisure preferences and the characteristics that may define these preferences.

The objective of this study was to describe leisure activity preferences of adolescents with CP and their relationship to actual levels of participation and to identify factors

associated with greater interest in particular leisure activities.

5.3. Methods

Ethical approval for this study was obtained from the Montreal Children's Hospital Ethics Review Board, the Centre for Research on Interdisciplinary Rehabilitation (CRIR) and the Agence de la santé et des services sociaux de Montréal (ASSS), the regional health and social service authority in the city of Montreal.

5.3.1. Population

Adolescents 12-20 years of age with a diagnosis of CP were recruited for a study describing factors influencing their leisure participation and quality of life (QUALA study). A sample of children (6-12 years) who had participated in a previous study describing quality of life and participation in school-age children with CP (Majnemer et al., 2008) was contacted for participation in the adolescents' study. An additional sample was recruited from specialty clinics - schools, rehabilitation centers, and community and transition programs across the province of Quebec who were initially identified and contacted by a health care professional.

5.3.2. Procedures

A cross-sectional design was used in this study. Once consent (parent) and assent (adolescent) were obtained, an appointment was made with the participant and parent (mother or father) to complete evaluations at the Montreal Children's Hospital Childhood Disability Laboratory, at the Madeleine Bergeron school (for participants in Quebec City) or as a home visit, whenever participants were not able to come to one of the assessment sites. The adolescents who were able to complete the Preferences for Activities of Children (PAC - King et al., 2004) were interviewed by an occupational therapist or psychologist. Parents were invited to help adolescents respond if necessary. The evaluator also administered the Children's Assessment of Participation and Enjoyment with the adolescent and proxy help if necessary (CAPE; King et al., 2004) and the Vineland Adaptive Behavior Scale (VABS; Sparrow et al., 2005) with parents. Parents completed a

demographic information questionnaire, the Family Environment Scale (FES; Moos & Moos, 1989), Strengths and Difficulties Questionnaire (behavior: SDQ; Goodman, 2001). Adolescents completed the Dimensions of Mastery Questionnaire (mastery motivation: DMQ; Morgan et al., 2000) and the Self-Perception profile for Adolescents (SPPA; Harter, 1988).

An occupational therapist (OT) or physical therapist (PT) completed the Gross Motor Function Classification System (GMFCS; Palisano et al., 1997) and the Manual Ability Classification System (MACS; Elisasson et al., 2006) and a neurologist confirmed the CP diagnosis and assigned a subtype of motor impairment.

5.3.3. Measures

Parents completed a questionnaire with information about the participant's medical history, the family's socio-economic status and the adolescent's rehabilitation services and school setting (Majnemer et al., submitted).

5.3.3.1. Activity limitations

The GMFCS is a widely used classification system for children and youth with CP. A five-point scale defines gross motor function classification with particular emphasis on mobility. The GMFCS has shown evidence of reliability and validity (interrater reliability =.93; Wood & Rosenbaum, 2000)**.**The MACS is a 5-point ordinal scale (e.g. level 1: handles objects easily and successfully with some limitations in speed and accuracy; level 5: does not handle objects and requires total assistance to perform simple hand functions). It classifies typical self-initiated manual hand function when handling objects during everyday activities and the extent to which the individual requires assistance or adaptations on usual performance in the home, school or community settings. The MACS has very good construct validity and interrater reliability (kappa=0.62; Eliasson et al., 2006). The VABS–II measures adaptive behavior (i.e. the performance of the daily activities required for personal and social sufficiency) in three domains: Communication (receptive, expressive and written), daily living skills (personal, domestic and community) and socialization (interpersonal relationships, play and leisure, coping

skills). Internal consistency reliability coefficient for the adaptive behavior total is considered excellent (0.89 to 0.98). Test-retest reliability coefficient is 0.88 and inter-rater reliability is 0.74. The instrument is widely used and appropriate for this age group as it is used to assess individuals from birth through 18 years.

5.3.3.2. Personal factors

The Dimensions of Mastery Questionnaire (DMQ; Morgan et al., 2000) is a 45-item questionnaire that evaluates mastery motivation (individual's persistence in mastering a skill) on a five-point scale (1= not at all typical, 5 = very typical). Adolescents (when feasible) and caregivers completed the questionnaire on level of persistence in seven dimensions (object-oriented persistence, gross motor persistence, social persistence with adults, social persistence with children, mastery pleasure, general competence, and negative reaction to failure). The DMQ has good internal consistency for parent's rating (Cronbach alpha = 0.84), child's rating (0.69). It is also age-appropriate as it was validated with children ranging in age from 6 months to 19 years.

The Self-Perception Profile for Adolescents (SPPA; Harter, 1988) is a measure of how adolescents view themselves in regards to eight different domains: scholastic competence, social acceptance, athletic competence, physical appearance, job competence, romantic appeal, behavioral conduct and close friendship. In addition, it has a global self-worth domain, a direct account of their own value as an individual. Cronbach's alpha for the different subscales vary from 0.74 to 0.93. The instrument is adequate for use with this population.

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 2001) is a 25-item behavioral screening questionnaire that measures the psychological adjustment of children and adolescents. Parents were asked to complete items divided into 5 domains: Emotional Symptoms, conduct problems, hyperactivity-inattention, peer problems, and prosocial behaviour. This questionnaire has overall satisfactory reliability and validity.

5.3.3.3. Environmental factors

The Family Environment Scale (FES; Moos & Moos, 1989) assesses three dimensions of family environment: relationship, personal growth and system maintenance, across 10 subdomains (cohesion, expressiveness, conflict, independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation, moral-religious emphasis, organization and control). Internal consistency for each subdomain varies from 0.69 to 0.78 and test-retest reliability ranges from 0.68 to 0.85. It has been used for research with different populations, including adolescents with developmental disabilities.

5.3.3.4. Outcome measures

The PAC is a questionnaire for children and adolescents between 6-21 years of age that measures preferences for leisure activities. It is meant to be completed by the child, with proxy- help if needed. Fifty-five leisure activities are illustrated and rated by the child on a 3-point scale according to the prompt: "if you could do anything in the world, how much would you like to be doing this specific activity: (1) Would not like to do it at all; (2) Would sort of like to do it; (3) Would love to do it. Activities are grouped into 5 subdomains (recreational, social, active-physical, skill-based and self-improvement) for which continuous mean scores are derived. A higher PAC mean score indicates a higher preference for the activity type. Reliability has been tested, cronbach's alpha range from .67-.77 for the five subdomain scales for internal consistency.

The CAPE contains the same 55 leisure activities, that are then rated as yes or no if they have been performed in the past 4 months. If performed, there is a numbered scale for intensity of participation, from 1 (1 time in the past 4 months) to 7 (once a day or more). For the purposes of this study scores were derived for intensity (how often) for each of the five domains. Final scores are expressed on a continuous scale. Test-retest reliability ranges from .65 to .75 on overall participation, and face validity is assured by extensive literature review and on the basis of the ICF.

5.3.4. Analysis

Descriptive statistics were conducted to characterize leisure preferences of adolescents with CP, and participants' personal and environmental characteristics. Scores of preferences in the five different domains (recreational, active-physical, social, skill-based and self-improvement) were obtained. Pearson product moment correlations were used to determine associations between preferences for activities (PAC) and intensity of participation (CAPE) in the five domains. Student's T-test were carried out to compare gender and age differences in the PAC. Chi-square tests were performed to test the differences between preferences for activity and intensity of involvement in each activity (recoded into 3 categories: 1: once a month, 2-3 times in the past 4 months or once in the past 4 months, 2: every two weeks or once a week, and 3: 2-3 times a week or once a day or more). Simple and multiple linear regressions were carried out to identify models of predictors of leisure preferences in each of the five participation subdomains.

We established a conceptual model of preferences for activities based on previous studies on preferences for younger children with physical disabilities (Law et al., 2004; Majnemer et al., 2008) and preferences for activities in adolescents without disabilities (Garton & Pratt, 1991). Evidence shows a large number of potential predictors for preferences and the importance of previously unstudied variables were also considered. Therefore, we initially used a hierarchical regression approach and compared the best predictive models generated in this approach to those generated in our initial conceptual modeling. Based on both methods, we then tested four different models: (1) A reference model that included explanatory variables that had a theoretical reasoning (activity limitations and demographic variables); (2) A model that included the reference model and child-related personal variables; (3) A model including the reference variables and extrinsic, environment and family-related variables; (4) A model including the reference variables and both intrinsic and extrinsic independent variables. The model that explained the highest proportion of variance (r^2) for each outcome was selected.

Residual plots were inspected to verify linearity, normality, and homoscedasticity assumptions for all regression models. Collinearity was assessed based on tolerance

variation of inflation. Only participants who completed the PAC were included in the analysis. There were no significant differences between main demographic characteristics (age and gender) of adolescents who completed the PAC (n=128) and those who did not (n=44) although naturally, adolescents who were able to complete the PAC were those with higher motor and cognitive abilities. Missing values on independent variables were deleted list-wise in the multiple regression models as they were missing at random.

5.4. Results

5.4.1. Participants' characteristics

A total of 128 participants completed the PAC. Mean age was 15.4 years (±2.1) and 59% were male. Children who were able to complete the PAC were primarily ambulatory, with 72% in GMFCS levels I or II and had good manual function (67% MACS I and II). Although adolescents in the sample may have better motor function as compared to general population-based sample, 50% presented with difficulties in activities of daily leaving, 37% had difficulties in communication and 31% in socialization domains as measured by the Vineland Adaptive Behavior Scale-II (abnormal scores < 78) and 60% were in special schools or in special resource classes within regular schools. The sociodemographic characteristics of participants and comparison between participants and non-participants are presented in Table 5.1. The first seven participants in the study had completed a previous version of the PAC that had a few different activities and therefore they were excluded from analysis.

Table 5.1 - Participant's characteristics

	PAC completed (n=128)	PAC not completed (n=44)
Age (mean; SD)	15.3 (2.1)	15.5 (2.7)
Gender	60% male	64% male
VABS (% Abnormal)		
Communication	37%	97%
Socialization	31%	95%
Daily living skills	50%	97%
GMFCS		
I	40%	3%
II	32%	10%
III	7%	10%
IV	11%	10%
V	10%	67%
MACS		
I	37%	3%
II	30%	10%
III	19%	13%
IV	10%	10%
V	4%	64%
School type		
Special	32%	70%
Regular with special resources	28%	7%
Regular	40%	11%

5.4.2. Description of preferences

Social and active-physical activities were most preferred (social mean score= 2.53; SD = .38; active physical mean score= 2.10; SD = .42), and self-improvement activities were the least preferred (self-improvement mean score = 1.93; SD= .49). Adolescents presented a very low level of participation in skill-based activities regardless of high preferences in this activity domain (skill-base mean score= 2.04; SD = .51). Playing computer or videogame (recreational), going to the movies (social), doing snow sports (active-physical), playing a musical instrument (skill-based) and shopping (self-improvement) were the top preferred activities in each of the five domains. Table 5.2 shows the five most preferred activities in each domain.

Table 5.2 - Top 5 activity preferences per domain

Activity	"I would love to do it" (%)
Recreational	
Computer or videogame	81
Watching TV or rented movie	74
Listening to music	70
Taking care of a pet	52
Playing board or card games	45
Social	
Going to the movies	78
Hanging out	74
Going to a live event	65
Going to a party	64
Making food	56
Active-physical	
Snow sports	64
Doing a paid job	63
Water sports	63
Doing team sports	58
Playing games	54
Skill-based	
Playing a musical instrument	56
Swimming	53
Dancing	48
Taking music lessons	45
Horseback riding	42
Self-improvement	
Shopping	60
Reading	48
Doing a volunteer work	38
Going to the public library	37
Getting extra help for schoolwork from a tutor	35
Writing letters(or email)	35

Girls and boys had different preferences. Girls would prefer to do more skill-based and self-improvement activities, but contrary to gender expectations, the difference was not statistically significant for the active-physical activity subdomain (Table 5.3). There were no significant differences in activity preferences between younger (15 years and younger) and older adolescents (16 years and older).

Table 5.3 - Differences in gender

Girls = 52 Boys = 76	**PAC (mean , SD)**	**t (df), sig**
Recreational	Girls (2.22, ± .39) Boys (2.04, ± .39)	2.58 (129), p <0.05
Active Physical	Girls (2.11, ± .44) Boys (2.12, ± .39)	-.16 (129), p=0.90
Social	Girls (2.62, ± .34) Boys (2.47, ± .39)	2.3 (129), p<0.05
Skill Based	Girls (2.23, ± .43) Boys (1.91, ± .50)	3.73 (129), p<0.001
Self-improvement	Girls (2.11, ± .42) Boys (1.80, ± .51)	3.54 (129), p<0.001

5.4.3. Univariate relationships

A low positive relationship between age and preferences was noted only for social activities (r=.18; p<0.05). Mastery motivation, as rated by parents was positively associated with interest in recreational (r=.25) and active-physical (r=.31) activities. However, correlations with adolescent-completed DMQ questionnaires showed a significant relationship between the adolescents' total persistence and all the five PAC leisure domains. Different aspects of self-perception were related to participation: feeling good about performance in sport activities was related to high preferences for social activities (r=.29) and romantic appeal was related to preferences for self-improvement activities. Interestingly, a higher general sense of self-worth was negatively related to preferences for skill-based activities (-.24). Family active-recreational orientation was related to preference for active-physical (r= .21) and self-improvement (r=.20) activities. Higher functioning levels (VABS-II) was related to less preferences in recreational (r=-.37), skill-based (r=-.26) and self-improvement (r=-.37) activities. The impact (distress and social impairment) of negative behaviour (SDQ) had a fair positive association with preferences in recreational (r=31), skill-based (r=.18) and self-improvement (r=.21) activities. Table 5.4 summarizes the univariate analysis results.

Table 5.4 - Correlations between participation preferences, participation and intrinsic and extrinsic factors

Preferences (PAC)	Participation (CAPE): Intensity Enjoyment	Self-perception	Motivation		Behavior	Family Environment
			Parent-report	Self-report		
Recreational	.58 .24		Total motivation (.22)	Total persistence (.24)	Impact of behavior (.31)	
Active-Physical	.35 .27	Athletic competence (.29)	Total motivation (.27) Negative reaction to failure (.19)	Total persistence (.19)* Negative reaction to failure (.21)*		Family active-recreational orientation (.21)
Social	.29 .26		Negative reaction to failure (.20)	Total persistence (.38)		Family moral-religious orientation (-.26)
Skill-based	.24 .29	Romantic appeal (.25)*		Total persistence (.24)* Negative reaction to failure (.21)*	Impact of behavior (.18)*	
Recreational	.27 .60	Global self-worth (-.24)*	Negative reaction to failure (.24)	Total persistence (.19)*	Impact of behavior (.21)*	Family active-creational orientation (.19)

* Correlations significant at the ≤.05 level
All other correlations reported were significant at the ≤.01 level

5.4.4. Multivariate models

Table 5.5 shows the best predictive models for leisure activities preferences. When controlling for activity limitations, boys had less preference for skill-based and self-improvement activities. A higher sense of mastery motivation, as perceived by the adolescents, accounted for more preferences for active-physical and self-improvement activities. Other family and environmental characteristics such as family activity

orientation (families that tend to engage in or value recreational and intellectual/cultural activities) and family expressiveness (the extent to which members of the family can express their feelings) were not significant individually, but contributed to the total explained variance in the models. In general, our models explained 14% of the variance in preferences for social activities, but explained up to 40% of the variance in preferences for self-improvement activities. Collinearity was not an issue in the multivariate models.

Table 5.5 - Best predictive models of preferences for leisure participation

	Outcome (n=88)									
	Recreational		Physical		Social		Skill-based		Self-improvement	
	β	p-value	β	p-value	β	p-value	β	p-value	β	p-value
Model R^2 *; p-value	.26; .04		.20; .20		.14; .58		.26; .04		.40; <.001	
Gender	-.08	.39	.07	.47	-.04	.68	**-.25**	**.04**	**-.31**	**.00**
Total motivation	.14	.07	**.22**	**.01**	.05	.49	.08	.39	**.18**	**.03**
Negative reaction to failure	-.01	.84	-.06	.31	-.05	.40	.02	.79	-.06	.35
Prosocial behavior	.02	.31	-.03	.16	.00	.74	-.00	.74	-.02	.26
Family activity orientation	.00	.68	.00	.17	-.00	.52	.00	.11	.00	.06
Family Expresiviness	.00	.41	.00	.50	.00	.33	-.00	.62	-.00	.89
Family income	-.08	.34	-.00	.92	.04	.61	-.19	.09	-.00	.94
School type	-.10	.33	-.22	.04	-.20	.07	-.13	.32	-.17	.14

DMQ (C/P) – Dimensions of Mastery Questionnaire Child/Parent; FES – Family Environment Scale;
GMFM-66 – Gross Motor Function Measure;
MACS – Manual Ability Classification System; VABS – Vineland Adaptive Behavior Scale.
* Models included GMFM-66, MACS, VABS (communication, socialization), Age

5.4.5. Relationship between preferences and actual involvement in leisure activities

The level of participation in leisure activities and the preferences for those activities were modestly correlated for the five participation sub-domains (Table 5.4). Comparing the frequency (how often) of participation and preference for each of the fifty-five activities, we could see that adolescents engage more often (once a week or more) in activities they prefer when these activities are more home-based and less structured such as listening to

music and watching TV or a rented movie (i.e. 82% and 79% of adolescents who did it once a week or more also rated these activity as " I would love to do it"). Conversely, activities that are not necessarily freely chosen but yet happen in higher frequencies such as doing chores and homework were rated as "would not like to do it at all" by 42% and 52% respectively of adolescents who engaged in these activities at least once a week. Activities that commonly require more structure, planning or people out of the family circle such as going to a party or going to the movies were performed rarely regardless of higher preference for them (i.e. 87% and 78% of adolescents "would love to" go to the movies or to go to a party), but did it less than once a month. The differences between leisure preferences and actual involvement (chi-square test) for activities are presented in Table 5.6 (a,b,c).

Table 5.6a - Activities performed once a week or more and "I would love to do"

Activity	Total number who performed once a week or more and would love to do it (total n who did this activity)	**p-value (chi-square)**
Bicycling	13(44)	0.33
Computer or videogame	**82 (116 – 70.7%)**	**0.00**
Crafts	21 (69)	0.78
Hanging out	34 (88)	2.45
Individual phys. act	**15 (39 – 38.5%)**	**0.01**
Non-team sports	7 (21)	0.08
Paid job	8 (28)	0.90
Talking on the phone	34 (97)	0.18
Playing games	**27 (77 – 35.0%)**	**0.04**
Playing with pets	**45(76 – 59.2%)**	**0.00**
Pretend or imaginary play	7 (35)	0.79
Reading	**43(81 – 53.0%)**	**0.00**
School club	5 (21)	0.84

Taking care pet	19 (53)	0.46
Watching TV	**81 (120 – 67.5%)**	**0.00**
Writing letters	15 (59)	0.10
Writing stories	11 (28)	0.91
Listening to music	**75 (108 – 69.4%)**	**0.00**

Table 5.6b - Activities done once a week or more and "I would not like to do it at all"

Activity	Total number who participated once a week or more and would not like to do it at all (total n who did this activity)	**p-value (chi-square)**
Doing a chore	22 (90)	0.21
Participating in community organizations	9 (29)	0.44
Doing homework	38 (92)	0.36
Playing a musical instrument	10 (31)	0.40

Table 5.6c - Activities done once a month or less and " I would really like to do it"

Activity	Total number who participated once a month or less and would really like to do it (total n who did this activity)	**p-value (chi-square)**
Fishing	7(13)	0.59
Full day out	32(60)	0.28
Gardening	5 (16)	0.64
Live event	35(57)	0.78
Going to the movies	61(92)	0.82
Going to a party	**55(86 – 63.9%)**	**0.05**

5.5. Discussion

This study described the preferences for leisure activities of adolescents with CP. It demonstrated that adolescents with CP have preferences for a variety of activities in five

different domains: recreational, social, active-physical, skill-based and self-improvement activities, but especially in the social and active-physical domain. Girls had more preferences than boys in all activity domains, except in active-physical activities. There were no differences for preferences between younger and older adolescents. Adolescents' persistence in completing a challenging task, negative reaction to failure, negative behaviour and different aspects of self-perception such as athletic competence and romantic appeal were adolescent-related factors that contributed to preferences for certain types of activities. Family orientation towards leisure and moral-religious orientation were the family factors that predicted preference for activities. Preferences for certain activities and actual engagement and enjoyment in these activities were modestly correlated.

Few studies have looked at adolescents' interests in leisure activities and no studies to our knowledge have explored predictors of preferences for adolescents with disabilities. The PAC reflects what an adolescent would like to do in an "ideal" situation, representing a situation with absence of constraints of all kinds, to include environmental barriers, lack of resources and disability itself. Some parents who helped our participants to respond the PAC referred to "ideal" as a disability-related concept "imagine if you could do anything, if you were like me, let's say…". Previous qualitative studies completed by our group showed however that in contrast to their parents, adolescents do not perceive disability as a barrier to participation; one of the main barriers perceived is the lack of opportunities to make individual choices (Shikako-Thomas et al., 2009). Intensity of participation in each of the five domains was only modestly correlated with preferences, except for recreational activities, showing that there is a discrepancy between what an adolescent would like to do and what they actually do in real life. However, if we look at the activities that have higher discrepancies, we can conclude that activities that adolescents would really like to partake in, but do so with least frequency, are the ones that may present with the greatest physical, attitudinal or socioeconomic (i.e. environmental) barriers such as going to the movies, going to a party or participating in a full-day outing. Conversely, most activities that are done with higher intensity and are highly preferred, are passive and home-based in nature, naturally present with few or no barriers to

participation, such as listening to music, playing computer or videogames and watching TV. These findings resonate with a previous study that found as children grew older, they tend to spend more time at home and less in the community (King et al., 2010). Not surprisingly, discrepancies are also perceived in self-improvement activities such as doing a chore or homework, that are done with higher intensity in spite of low preferences.

While we could logically attribute much of these discrepancies between preferences and participation to disability-related aspects, similar findings were reported by Garton and Pratt (1991) in describing leisure preferences of typically developing adolescents. Recent studies reported differences in levels of participation between adolescents with and without disabilities (King et al., 2010; Engel-Yeger et al., 2009), with less participation being consistently attributed to adolescents with physical disabilities, however these studies did not report participants' preferences. In Garton and Pratt's study, social activities were most preferred by typically developing adolescents, and the most common reasons cited for not engaging in preferred activities were the lack of facilities for that activity, regardless of the activity type, lack of time and opportunities or feelings of poor physical ability to engage in the activity. Their conclusion was that personal interest precedes participation, which may lead to a belief that in the absence of ability and environmental barriers, adolescents would participate in activities of their choosing. Similarly, recent studies of predictors of participation of youth with disabilities have demonstrated that enjoyment of activities is a predictor for involvement in these activities (Imms et al., 2009; Palisano et al., 2011a, 2011b) as well as availability of environmental resources that facilitate the engagement in preferred activities (Kang et al., 2010). While this study approximates the preferences of adolescents with and without disabilities, it also proposes a challenge for clinicians and researchers, that is to understand what influences preferences for certain activities. For instance, are activities (e.g. recreational; passive) preferred because they are easier to be done and can be accomplished with relatively no effort? In contrast, are self-improvement, and skill-based activities that require an instructor or a special set-up not preferred because there are too many barriers to be overcome for both adolescents and families? Or rather, are preferences for certain

types of activities only a product of developmental stage?

Studies have reported a trend for decreased participation as children with disabilities grow older (Majnemer et al., 2008; Law et al., 2006; Imms et al., 2009; King et al., 2010). However, no studies have compared the development of preferences in this population during adolescence. Our group has previously reported preferences for leisure activities in school-age children (6-12 years) with CP (Majnemer et al., 2010). Mean scores of preference in the five domains were consistently lower than this age group for adolescents, although not dramatically different. However, if we compare the correlations between preferences and enjoyment of participation we can conclude that adolescent's enjoyment of participation and preferences for recreational activities and self-improvement activities are significantly less related (School-age/Adolescents enjoyment vs. preferences r: recreational .46/.24; self-improvement .82/.60). The differences between school-age children and adolescents in the relationship between intensity of participation and preferences varied per domain and were especially different for active-physical activities, in which adolescents preference and engagement was higher (school-age/ adolescents r=.20/ .35), contrary to skill-based activities in which adolescent's preferences and engagement was smaller than the relationship for school-age children (school-age/ adolescents r=.44/.24). This preliminary comparison suggests preference changes, as children grow older. Adolescents may not enjoy engaging in activities that they previously enjoyed, in spite of their ongoing involvement and they may be participating in less skill-based activities such as swimming or horseback-riding , in spite of higher preferences for these activities. Nonetheless, the higher correlation between preference for active-physical activities and actual involvement in this type of activity may be a good indicator of the importance of maintaining programs and opportunities for this type of activity, in spite of the general higher preferences in the adolescent groups for passive, electronic and computer-based activities. Girls demonstrated more preferences for almost all types of activities. However, contrary to previous studies (Garton & Pratt, 1991; King et al., 2010), our study showed no significant differences across gender for active-physical activities, indicating that gender-specific preferences may be evolving over time.

Consideration of the adolescent-related factors that predicted preferences for certain types of activities is important in the development of intervention strategies and programs. While a simple question to be included in intervention plans, goal setting and programs is: what would you like to do? - a more complex question is what are the factors that may shape your preferences and more specifically, how to support personal choices that promote physical and psychosocial health and well-being. Interventions could be developed targeting aspects of mastery motivation such as negative reaction to failure and strategies that will facilitate the ability to persist in tasks that are challenging or difficult. Behavior problems tend to persist as children grow older (Brossard-Racine et al., submitted). Behavioral interventions such as promoting social skills that may facilitate social interactions and decrease negative, disrupting behaviors may help adolescents to expand their preferences and choices for social and other leisure activities, especially skill-based and self-improvement activities that are done less frequently. Aspects of self-perception that may influence preferences for certain activities must be also integrated into interventions. Interestingly, feeling competent in sports activities was associated with interest in social activities which contributes to our understanding of secondary benefits that adolescents may experience when engaging in active-physical activities. This may be explained by the fact that physical activities include team sports and other opportunities for social interaction, which has also been observed in studies of adolescents without disabilities (Donaldson & Ronan, 2006). The way an adolescent experiences success or failure in romantic attempts had an influence on the preferences for self-improvement activities. This relationship may possibly be explained by the shared types of abilities that are necessary to thrive in romantic attempts and self-improvement activities.

Family activity orientation demonstrated importance in explaining preferences for different types of leisure activities. Although one may think that adolescents' preferences may be predominantly dictated by peers, it is acknowledged that family has an important influence on the decision-making and activities chosen by adolescents with or without disabilities (Brown & Mann, 1991; Shikako-Thomas et al., 2009; Kang et al., 2010). Moreover, family activity orientation has an influence on the actual levels of involvement in leisure for adolescents with disabilities, who are more likely to partake in activities

with their family than with their peers (King et al., 2010; Palisano et al., 2011b; Shikako-Thomas et al., submitted). This issue raises two main concerns: First, interventions targeted at improving participation for this population should consider a family-centred approach where families' values, expectations and preferences are taken into consideration, in addition to that of the adolescent. Secondly, it is important to note that differentiating from their parents and acquiring personal autonomy in decision-making are important developmental competencies that should be acquired during adolescence. The fact that families appear to influence adolescents' preferences may indicate a need to develop services for children and parents focusing on the strategies and tools to help adolescents to develop their own personal identity and promote opportunities to develop social competencies outside the family context. Moreover, the similarities in needs, preferences and barriers for leisure participation for adolescents with and without disabilities may point to the need for community programs that are universally accessible and available, promoting the benefits of leisure for all adolescents. In addition to the benefits of integration of adolescents with different abilities, this would allow adolescents with disabilities to circulate in the public spaces and participate with more autonomy from their families (Pegg & Comptom, 2003).

This study is the first to our knowledge to explore preferences for leisure activities for adolescents with CP. One limitation of this study however is the inclusion of only adolescents who could self-report or required minimal parental help to indicate their leisure preferences. Although the participants represented adolescents across all the spectrum of CP severity as classified by the GMFCS and MACS, as expected, these adolescents had higher levels of language and cognitive functioning than those who did not complete the PAC. It is a constant challenge trying to understand the most subjective needs of adolescents who present with very low speech, motor and cognitive abilities. Moreover, multivariate models did not explain a large percentage of the variance in preferences in some activity domains, showing this is a complex construct likely influenced by other variables that were not accounted in our models. Considering the importance of leisure participation to overall development, regardless of functional ability, it would be important to understand the preferences of this population as well, and

to reflect on the different elements that may shape preferences of the population as whole, perhaps in light of family preferences and other environmental variables.

5.6. Conclusion

Participation is an important construct and preferences for activities are an important predictor of actual participation. Family factors, personal factors and functional abilities influence leisure preferences. Rehabilitation interventions should consider adolescents' preferences and family dynamics, target mastery motivation and address behavioral and self-perception difficulties to help adolescents shape their preferences and engage in leisure activities of their choosing. Health promotion programs for adolescents with disabilities should also be extended to the community in order to promote accessibility and facilitate the pursuit of their interests and preferences and therefore promote more fulfilling and healthier life styles.

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5.7. References

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CHAPTER 6

Chapter 5 described the preferences for activities of adolescents with CP in our sample and also outlined models of preferences for activities.

We have thus far described the participation patterns of adolescents with CP and understood their preferences for particular activities. The next chapter explores the intrinsic and extrinsic factors that may either hinder or promote participation in leisure activities in five different domains. This is the final manuscript addressing this study's primary objective. We expect to provide a comprehensive picture of the important components that influence participation in leisure activities for adolescents with CP in order to support health promotion strategies that will promote participation in leisure and its expected benefits for health and well-being for this at-risk population.

Manuscript 4: Determinants of participation in leisure activities among adolescents with cerebral palsy.

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Determinants of participation in leisure activities among adolescents with cerebral palsy.

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Keywords: Leisure, determinants, cerebral palsy, adolescence

6.1. Abstract

Background: Engagement in meaningful leisure activities has health benefits for adolescents. Studies have identified restrictions in leisure activities as an important issue for adolescents with disabilities and their families. Participation is a complex construct and likely influenced by a variety of factors, especially during adolescence. These potential determinants have not yet been sufficiently been explored in the population of adolescents with cerebral palsy (CP). Knowledge of these determinants will be important to guide intervention strategies to promote participation.

Objectives: The primary objective of this study is to estimate the potential influence of both intrinsic adolescent characteristics and extrinsic environmental factors as determinants of participation in different types of leisure activities for adolescents with CP.

Results: A total of 185 adolescents with CP (12-20 years old) completed the study. Participation was measured with the Children's Assessment of Participation (CAPE) and Enjoyment. Participants were distributed across all gross motor classification levels (58% level I-II, 50% level III-V). Intrinsic and extrinsic factors were measured and models of intensity of participation in leisure revealed that leisure is a multifaceted construct that appears to be associated with a range of factors related to the adolescents' functional characteristics and attitudes, the family environment, socioeconomic status, and contextual factors such as school type. Aspects of the adolescent's mastery motivation and behavior were also associated with participation in different activity domains. The adolescent's perception of self in relation to competence in different life skills and physical appearance was also associated with participation in certain types of leisure activities.

Discussion: Engagement in different types of leisure activities may have different contributions to adolescents' development and well-being. Therefore it would be important to develop interventions that focus on participation more holistically. Clinicians should consider individual adolescents' and families' characteristics, but also

expand the scope of potential interventions to support the creation of programs in the community and advocate for policies that will facilitate participation in a variety of activities.

6.2. Introdution

Cerebral Palsy (CP) is the most common type of physical disability affecting children in developed countries (Stanley et al., 2000). The focus of health interventions within this population is often focused on minimizing impairments and addressing functional aspects of the condition such as activities of daily living and motor function. However, with the endorsement of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) over the past decade, attention has been directed at other subjective and objective aspects that may contribute to a more holistic understanding of health. This includes participation in different life situations, particularly the extent to which individuals have the opportunity to be involved and enjoy leisure activities at home and in the community (Specht et al., 2002; Adamsom, 2003).

It is known that engagement in meaningful leisure activities has several long term physical and mental health benefits for adolescents (Zaff et al., 2003). Studies have identified restrictions in leisure activities as an important issue for adolescents with disabilities and their families (Livingston et al., 2011). Different determinants of participation in leisure and recreation in children and youth with disabilities are being explored. These determinants include for instance activities limitations, family-related factors and service provision (Law et al., 2006; Rosenbaum, 1998; King et al., 2010; Palisano et al., 2011). However, participation is a complex construct and likely influenced by a variety of factors. During adolescence a series of additional personal and environmental elements are likely to impact participation levels. Individual characteristics and attitudes as well as contextual factors may become more critical. These potential determinants have not been adequately explored in adolescent populations to date. Knowledge of these determinants will be important to guide effective intervention strategies to promote participation.

In summary, few studies have described determinants of leisure participation in adolescents with CP (King et al.,2010; Kang et al., 2010; Palisano et al., 2011); furthermore, studies reported to date have focused on predictors of formal/informal or activities as a whole, but have not identified key intrinsic and extrinsic factors that are associate with greater involvement in different leisure activities types such as social, skill-based and self-improvement activities.

The primary objective of this study was to estimate the potential influence of both intrinsic adolescents characteristics and extrinsic environmental factors as determinants of participation in different types leisure activities for adolescents with CP.

6.3. Methods

6.3.1. Procedures

Ethical approval for this study was obtained from the Montreal Children's Hospital Ethics Review Board, the Center for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR) and the Centre de Service Sociaux et Santé du Québec (CSSS). Participants for this study were recruited from rehabilitation centers, community leisure programs for youth with disabilities and pediatric hospitals across the province of Quebec. Participants were contacted by their health care providers and consent to transmit their contact information to the research team was granted. Families of children who had previously participated in a study about quality of life and participation of school-age children with CP (Majnemer et al., 2008, 2010) were also invited to participate in the adolescents' study. Once consent was obtained, appointments for all participants were made at one of the testing locations or for a home visits.

Inclusion criteria were adolescents 12-19 years of age with a primary diagnosis of CP. Adolescents with a degenerative condition or other diagnosis not consistent with the consensus definition of CP (Rosenbaum et al., 2007) were excluded. A neurologist validated the diagnosis of CP as well as other neurologic characteristics. Medical records were reviewed to retrieve the neurological information of participants who were not directly examined by a neurologist during the study.

Developmental assessments performed with the adolescents included the The Gross Motor Function Measure (GMFM)/Gross Motor Functional Classification System (GMFCS; Russell et al., 2000) and the Manual Ability Classification System (MACS; Eliasson et al., 2006) conducted by an occupational therapist or physical therapist. Adolescents also responded to a series of self-completed questionnaires when feasible and completed the Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activity of Children (PAC; King et al., 2004) with proxy-assistance when required. A parent or legal guardian completed a series of questionnaires and were also interviewed by a psychologist or occupational therapist to answer the Vineland Adaptive Behavior Scale 2nd edition (VABS – II; Sparrow et al., 2005).

6.3.2. Measure

6.3.2.1. Independent variables

Standardized assessments:

The Gross Motor Function Measure (GMFM-66) is a criterion-referenced measure for children and youth with CP. The measure is widely used in research and clinical practice. Each item is scored by a trained evaluator on a three - point system. Test-retest reliability has been demonstrated (ICC = .99) and agreement between estimates (r= .97). Acceptable validity and responsiveness has been demonstrated (Russell et al., 2000). The GMFCS is a widely used 5-level ordinal classification of gross motor function. It categorizes movement ability with a focus on ambulation and the need for assistive devices and mobility aids (e.g. level I: walks without limitations; level V: transported in a manual wheelchair). Its psychometric properties are well supported (kappa=.75) (Palisano et al., 1997; Wood & Rosenbaum, 2000).

The Manual Ability Classification System (MACS) classifies typical self-initiated bi-manual hand function in everyday activities, and the need for assistance or adaptations. This measure has very good construct validity and inter-rater reliability (kappa=.62). Participants are rated by an evaluator in agreement with a parent or proxy who knows the child typical performance using a 5-point ordinal scale (e.g. level I: handles objects easily

and successfully with some limitations in speed and accuracy; level V: does not handle objects and requires total assistance to perform simple hand functions) (Eliasson et al., 2006).

The Vineland Adaptive Behavior Scale - II (VABS-II) measures functioning in daily activities in three different domains: Communication, daily living skills, socialization. The information is collected by a semi-structured interview format. Final scores per domain are represented as continuous standard scores. Internal consistency reliability coefficient for the adaptive behavior total score range from .89 to .98 (median 0.94). Test-Retest reliability coefficient is .88 and inter-rater reliability is .74. The instrument is widely used and appropriate for this age group (Sparrow et al., 2005).

Questionnaires:

Parents completed a questionnaire with information about their child's medical history, schooling, and family sociodemographic information.

The Self-Perception Profile for Adolescents (SPPA; Harter, 1988) was completed by adolescents, when feasible. It is a measure of how adolescents view themselves in regards to eight different domains: scholastic competence, social acceptance, athletic competence, physical appearance, job competence, romantic appeal, behavioral conduct and close friendships. In addition, it has a global self-worth domain, a direct account of their own value as an individual. Cronbach's alpha for the different subscales vary from .74 to .93.

The Dimensions of Mastery Questionnaire (DMQ; Morgan et al., 2000) evaluates mastery motivation (the individual's persistence in mastering skills that are challenging). Adolescents (when feasible) and parents independently completed questionnaires covering the following subdomains: persistence (object-oriented persistence, gross motor persistence, social persistence with adults, social persistence with children), mastery pleasure, general competence, and negative reaction to failure. In addition, two summary scores are calculated (i.e. total persistence and total mastery motivation). The DMQ has

good internal consistency for parent's rating (Cronbach alpha = .84), and child's rating (.69). Total persistence and total mastery motivation alpha range from .85 to .96.

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 2001) is a behavioral screening questionnaire to identify psychological adjustment. The questionnaire was completed by the parent or proxy. The SDQ has overall satisfactory reliability and validity, with a mean internal consistency of .70. The prosocial scale (the extent to which the adolescent manifests positive behaviors towards others) and impact scale (the extent to which behavior has a negative consequence) were used in the multivariate models.

The Family Environment Scale (FES; Moos & Moos, 1989) assesses dimensions of family environment across 10 subdomains (cohesion, expressiveness, conflict, independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation, moral-religious emphasis, organization and control). Internal consistency for each subdomain varies from .69 to .78 and test-retest reliability ranges from .68 to .85. It has been used for research with different populations, including adolescents with developmental disabilities.

The European Child Environment Questionnaire (ECEQ; Colver and the SPARCLE group, 2006) is a recently developed instrument that assesses the presence of physical and attitudinal barriers in the community, family and school environment (Colver et al., 2011; Dickinson et al., 2011). Parents completed the questionnaire indicating the presence or absence of specific barriers and facilitators and indicating their child's need for this particular resource. Psychometric properties of the ECEQ are still being compiled, but it has been used in a large multicenter study in Europe. Moreover, the measure was developed based on qualitative studies and an extensive literature review ensuring content validity (Mihaylov et al., 2004; Lawlor et al., 2006; Dickinson et al., 2011). For the purpose of multivariate models, the total number of barriers was used as an indicator of barriers in the environment.

6.3.2.2. Outcome variable

The Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004) is a questionnaire for children and adolescents between 6-21 years of age and meant to be completed by the child with proxy help if needed. Activities are illustrated and rated as 'yes' or 'no' if they have been performed in the past 4 months. If performed, a scale from 1 (1 time in the past 4 months) to 7 (once a day or more) indicates frequency of participation in this activity, characterizing intensity of involvement. Activities are grouped in five domains (recreational, active-physical, social, skill-based and self-improvement). Scores may be derived for intensity (how often), diversity (number of different activities) and enjoyment (from 1 – not at all, to 5 – love it) for each domain. Final continuous scores are derived. The CAPE has been extensively used to measure participation in leisure for children with a variety of disabilities. Test-retest reliability ranges from .65 to .75 on overall participation, and content validity is assured by extensive literature review. The primary outcome was intensity of participation in leisure activities in the five different leisure domains.

6.3.4. Analysis

Pearson correlations were carried out for continuous variables, (significance levels were set at $p < .05$). Multiple linear regressions were performed to define the best predictive models for the outcome variables. Collinearity in the multiple regression models was verified (correlation matrix for the independent variables and variation inflation factor >4; O'brien, 2007). Simplified models were tested eliminating variables that were highly correlated.

6.3.4.1. Modeling approach

The modeling strategy used was designed to test a theoretical concept of determinants of participation in leisure activities in adolescents with CP. Based on current evidence, function and activity limitations are known predictors of participation in leisure activities. Our theoretical conceptualization and based on some evidence we suggested that adolescent intrinsic characteristics and extrinsic factors such as family environment and

environmental barriers were associated with participation in leisure, and collectively could contribute to determine participation. We tested four different models for each of the outcomes:

1.Reference model: including only activity limitations as explanatory variables: hand function (MACS levels I, II-III, IV-V), gross motor ability (GMFM-66), socialization, communication and daily living skills (VABS-II), age and sex as predictors.

2.Reference model plus intrinsic, adolescent-related variables (motivation - DMQ and behavioral profile - SDQ)

3. Reference model plus extrinsic variables (family environment - FES, number of barriers in the environment - ECEQ, family sociodemographic characteristics) as predictors.

4. Joint model including reference model, extrinsic and intrinsic variables.

The focus of analysis was to determine if there is a better fit when new variables were added to the reference model. The model that provided the better fit (i.e. higher r^2) was considered as the "best" model to support the theoretical model of determinants of leisure participation initially proposed (Figure 1).

Out of the 185 participants, 7 had completed an older version of the CAPE and because there were discrepancies in subdomains and a few items, these participants were excluded from multivariate models. The dataset was evaluated with respect to missing data and main characteristics of participants with missing data in specific domains of the CAPE were compared to the rest of the sample for each outcome to ascertain there were no systematic errors. Only parent-completed measures were used as exposures in the multivariate models in order to minimize missing data related to severity of disability. Therefore adolescents who could not self-report were also included in the analysis. For this reason, preferences for activities, as measure by the PAC were not included in the final models. However, we also performed separate regression analysis including this

variable for all the best predictive models and presented the respective r^2 and parameter estimate for the PAC as we believed that this was a clinically significant predictor.

6.4. Results

A total of 185 adolescents completed the study and 153/185 were classified by a neurologist or by chart review for cerebral palsy subtype of motor impairment. The proportion of children with spastic quadriplegia was 42% (n=64), with spastic diplegia 16% (n=25), with spastic hemiplegia 27% (n=41), and 15% had other type of motor impairments (n=23). Fifty-three percent of the participants were born prematurely. Table 6.1 presents summary characteristics of adolescents and families in the study.

Table 6.1 - Adolescents' and Families' characteristics (n=185)

Characteristics Age 12-20 years old (M=15.4; SD=2.2)	N	%
Adolescents' characteristics		
Sex		
Female	75	40.5
Male	110	59.5%
Gross motor function level (n=171)		
I. Walks without limitations	55	32.2
II. Walks with limitations	45	26.3
III. Walks hand-held mobility device	13	7.6
IV. Self-mobility with limitations; may use powered mobility	19	11.1
V. Transported in a manual wheelchair	39	22.8
Manual ability level (n=172)		
I. Handles objects without limitations	50	29.1
II. Handles most objects with few limitations	44	25.6
III. Handles objects with difficulty	31	18
IV. Handles few objects; needs adaptations	17	9.9
V. Does not handle objects; severe limitations	30	17.4
Family characteristics		
Family income (n=156)		
a. CAN$0-19,999	19	12.2
b. CAN$20,000 - $39,999	30	19.2
c. CAN$40,000 - $59,000	19	12.2
d. CAN$60,000 - $79,000	23	14.7
e. CAN$80,000+	65	41.7
Ethnic origins (n=166)		
a. Canadian	73	44
b. French-canadian	44	26.5
c. Latin american	11	6.6
d. Other	35	32.9

Mother education (n=162) / Father education (n=154)		
a. High school incomplete	41/20	6/13
b. High school	41/42	25/27
c. Cegep/College	54/44	33/28
d. University degree	49/38	30/24
e. Graduate degree	7/9	4/5
Environment characteristics		
Received rehabilitation services in the past 6 months (n=168)		
a. Yes	113	67.3
b. No	55	32.7
School setting		
a. Regular school	57	33.3
b. Special school	72	42.1
c. Regular with special resources	40	23.4
d. Other	2	1.2

6.4.1. Participation overview

Adolescents with CP participate in a variety of leisure activities, especially in social and recreational activities. However, they do not necessarily engage in activities that they would prefer such as active-physical and skill-based activities. A detailed report of participation patterns are described elsewhere (Shikako-Thomas et al., submitted).

The bivariate correlations for CAPE intensity and the different continuous explanatory variables are presented in Table 6.2. Higher intensity of participation in all activities domains, except for skill-based activities, was fairly to moderately associated with better gross motor function (r ranged from .35 - .54, $p < .05$) and better socialization, communication and daily living skills (r ranged from .21 - .58, $p < .05$).

Table 6.2 - Performance in continuous independent variables

Instrument Construct	Sample size	Minimum-maximum value	Mean (SD)
VABS-II			
Daily living skills	178	20-129	66.2 (28.6)
Communication	177	20-134	71.7 (27.2)
Socialization	178	20-130	76.5 (25.3)
SDQ			
Prosocial behavior	161	0-10	7.6 (2.6)
Impact of behavior	158	0-15	3.6 (3.8)
DMQ			
Gross motor persistence	151	1-4.8	2.6 (.89)
Total persistence	151	1-4.8	2.9 (.64)
Total mastery motivation	151	1.4-4.8	3.1 (.61)
Negative reaction to failure	151	1-4.8	2.7 (.88)
FES			
Family expressiveness	167	22-71	54.67 (9.4)
Family conflict	167	33-80	45.81 (9.4)
Family independence	168	5-70	50.4 (10.7)
Family intellectual/cultural orientation	169	25-69	49.5 (11.1)
Family active-recreational orientation	169	23-69	48.5 (12.2)
Family moral-religious emphasis	168	27-71	47.4 (10.9)
Family control	168	27-70	50.7 (9.2)

6.4.2. Intrinsic factors

Aspects of self-perception that were associated with participation were job competence and athletic competence for active-physical activities and perception of a positive physical appearance was associated with more participation in skill-based activities.

Different aspects of mastery motivation were associated with more involvement in all activities domains, except for skill-based activities. Specifically, according to parents' report, persistence and mastery pleasure had a fair association with participation in all activities types. Gross motor persistence was associated only with participation in active-physical activities for both parent-report and adolescent-report. According to adolescents' reports object-oriented persistence (persistence in tasks that are cognitively challenging) and total mastery motivation were also related to participation in recreational and active-

physical activities, but not with the other activity domains. Interestingly, negative reaction to failure as reported by parents and by adolescents was positively associated with intensity of participation in recreational activities as was a higher impact of difficult behavior in the adolescent. A positive, prosocial behavior was also positively associated with participation in all but the skill-based domain. Table 6.3 shows the bivariate correlations for the intrinsic and extrinsic factors.

6.4.3. Extrinsic factors

Family independence (the extent to which each member of the family has the opportunity to experience a certain degree of independence) was positively associated with intensity of recreational activities, while family expressiveness (the extent to which each member of the family has the opportunity to express their own opinions) was associated with participation in social activities. Family inclination towards different activities (both recreational and intellectual) was related to the intensity of engagement in active-physical activities and self-improvement activities.

There were no significant associations between the total number of barriers in the physical environment and participation in leisure activities.

Table 6.3 - Significant correlations (p< .05) between CAPE intensity and continuous variables

Variables	Recreational	Active-physical	Social	Skill-based	Self-improvement
Activities limitations					
GMFM	.38**	.54**	.35**	.	.51**
VABS					
Socialization	.29**	.46**	.42**	.	.56**
Communication	.21**	.44**	.46**	.	.58**
Daily living	27**	.48**	.41**	.	.53**
Self-perception (SPP)					
Job competence	.	.21*	.	.	.
Athletic competence	.	.36**	.	.	.
Physical appearance	.	.	.	.30**	.
Motivation (DMQ - Parent)					
Object-oriented persistence	.	.31**	.22**	.	.40**
Social persistence with adults	.27**	.18*	.17*	.	.32**

Social persistence with children	.24*	.29*	.26**	.	.27*
Gross motor persistence	.	.49**	.	.	.24**
Mastery pleasure	.21**	.	.18*	.	.27*
Negative reaction to failure	.27**	.17*	.	.	.27*
Total mastery motivation	.22**	.38**	.25**	.	.38*
Motivation (DMQ - Adolescent)					
Object-oriented persistence	.21*	.22*	.	.	.
Social persistence with children	.28**	.27**	.	.	.
Gross motor persistence	.	.44**	.	.	.
Total mastery motivation	.24*	.35**	.	.	.
Behavior (SDQ)					
Prosocial scale score	.30**	.24**	.29**	.	.49**
Impact scale score	.28**	.	.	.	.
Total problems	.	.25**	.	.	.
Family Environment (FES)					
Independence	.18*	.	.	.	.
Active-recreational orientation	.	.16*	.	.	.24**
Intellectual/cultural orientation	.	.	.28**	.	. 24**

VABS – Vineland Adaptive Behaviour Scale/DMQ – Dimensions of Mastery Questionnaire (C = Child / P=Parent)/SDQ – Strenghts and difficulties questionnaire/SPP – Self-perception profile for Adolescents/FES – Family Environment Scale/GMFM – Gross Motor Function Measure/ CAPE – Children Assessment of Participation and Enjoyment (*p<.05; **p<.01)

6.5. Multivariate models

Multiple regression analysis was performed for participation diversity and participation intensity in each of the five domains of the CAPE.

6.5.1. Recreational activities

The best predictive model of participation in recreational activities included activity limitations, intrinsic factors: motivation, behavior and extrinsic: family characteristics and family environment. This model explained 30% and 33% of the variance in diversity and intensity of participation in leisure activities (Table 6.4). Higher gross motor functioning was a significant predictor of a higher diversity and intensity of recreational activities. Lower bi-manual ability was predictive of greater participation in recreational

activities and family independence predicted greater intensity of participation in recreational activities.

When including preferences (PAC) for recreational activities in the model, the explained variance increased by 22% for diversity and 18% for intensity of participation in recreational activities. Preference for recreational activities alone accounted for an increase of 3.38 in diversity and 1.31 in recreational activities when accounting for the other variables in the model (maximum number of activities =12).

Table 6.4 - Best predictive model: Recreational activities

Predictors	Diversity (n=115) r^2 (% variance) .35 p-value (model) <.0001		Intensity (n=115) r^2 (% variance) .33 p-value (model) <.001	
	Parameter estimate (β)	p(variable)	Parameter estimate (β)	p(variable)
Activities limitations				
GMFM	***.03***	***<.001***	***.01***	***<.001***
MACS (ref. level 1: levels 4 and 5)	1.09	.10	***.77***	***.008***
Communication (VABS)	-.02	.09	-.01	.19
Socialization (VABS)	.01	.25	.002	.76
Environmental factors				
Family activity orientation (FES)	.02	.19	.01	.32
Family independence (FES)	.02	.21	***.01***	***.04***
Family control (FES)	-.02	.35	-.004	.62
Family income	.07	.85	.03	.86
Maternal (low) and paternal (high) education (ref. low and low)	-.70	.40	-.35	.33
Personal factors				
Negative reaction to failure (DMQ)	.36	.17	.09	.40
Total persistence (DMQ)	.01	.96	.14	.45
Prosocial behavior (SDQ)	.19	.06	.08	.07
Confounders				
Age	-.10	.28	-.01	.10
Gender (ref. Female)	-.27	.53	-.18	.33
Model with preferences (PAC)				

Diversity (n=98)	r^2=.57, p< .0001; Preferences for recreational activities β= 3.38, p< .0001
Intensity (n=98)	r^2=.51, p< .0001; Preferences for recreational activities β= 1.31, p< .0001

6.5.2. Active- physical activities

Personal factors (motivation and behaviour difficulties) did not increase the fit of the model for active-physical activities diversity and were therefore excluded from the model. Activity limitations and environmental factors collectively explained 35% of the variance in diversity of active-physical activities. These personal factors did contribute to the model fit for intensity of participation in active-physical activities and with activity limitations and environmental factors explained 40% of the total variance observed (Table 6.5).

Better gross motor function had a small significant estimation for diversity of active-physical activities, but not for intensity of participation in this type of activity. Socialization skills and higher family income also had a statistically significant influence in the estimation of diversity of active-physical activities. A higher family income estimated an increase in diversity of active-physical activities.

Greater persistence in gross motor tasks (mastery motivation) was the single statistically significant parameter noted for intensity of active-physical activities.

Preferences (PAC) for active-physical activities increased the explained variance by only 2% and 3% for diversity and intensity, respectively. Adolescent's preference for active-physical activities alone predicted 1.42 (diversity) and .56 (intensity) increase in this type of activity when accounting for the other variables in the model (maximum number of activities =13).

Table 6.5 - Best predictive model: Active-physical activities

Predictors	Diversity (n=119) r^2 (% variance) .37 p-value (model) <.0001		Intensity (n=106) r^2 (% variance) .39 p-value (model) <.0001	
	Parameter estimate (β)	p(variable)	Parameter estimate (β)	p(variable)
Activities limitations				
GMFM	***.02***	***.01***	.006	.08
MACS (ref. level 1: levels 4 and 5)	-.14	.45	.03	.87
Socialization (VABS)	***.01***	***.03***	.00	.50
Environmental factors				
Family activity orientation (FES)	.01	.26	.00	.74
Family independence (FES)	.01	.45	.00	.14
Family income	***.91***	***.01***	.23	.13
Maternal (high) and paternal (high) education (ref. low and low)	-.23	.64	-.21	.35
Total number of barriers in the environment	-.03	.43	-.02	.22
Personal factors				
Negative reaction to failure (DMQ)	-	-	-.09	.17
Gross motor persistence (DMQ)	-	-	***.32***	***< .001***
Prosocial behavior (SDQ)	-	-	-.00	.93
Impact of behavior (SDQ)	-	-	.01	.33
Confounders				
Age	-.03	.61	-.01	.69
Gender (ref. Female)	.42	.23	.10	.49
Model with preferences (PAC) **Diversity (n=90)** r^2=.39, p< .005; Preferences for active-physical activities β= 1.42, p= .008 **Intensity (n=90)** r^2=.42, p=.001; Preferences for active-physical activities β=.56 , p=.006				

6.5.3. Social activities

Interestingly, personal factors did not contribute to a greater explained variance in intensity and diversity of social activities and therefore were not considered in the final models. Models employed explained approximately 30% of the variance in engagement in social activities (Table 6.6).

Adolescents who studied in a special school (segregated) were more likely to participate in social activities.

Addition of preferences for social activities contributed to only a fair increase in the r^2 for participation in social activities (maximum number of activities =10), and predicted an increase in participation by 1.73 (diversity) and .70 (intensity). When accounting for preferences for social activities, a decrease in prosocial behavior became significant in improving the intensity of participation in social activities.

Table 6.6 - Best predictive model: Social activities

	Diversity (n=138) r^2 (% variance) .33 p-value (model) <.0001		Intensity (n=138) r^2 (% variance) .33 p-value (model) <.001	
Predictors	Parameter estimate (β)	p(variable)	Parameter estimate (β)	p(variable)
Activities limitations				
GMFM	-.00	.83	-.00	.48
MACS (ref. level 1: levels 4 and 5)	-.25	.67	-.32	.25
Socialization (VABS)	.01	.20	.00	.33
Communication (VABS)	.01	.21	.00	.43
Environmental factors				
Family activity orientation (FES)	.01	.44	.00	.39
Family independence (FES)	.02	.13	.00	.36
Family moral-religious orientation (FES)	-.02	.15	-.00	.31
Maternal (low) and paternal (high) education (ref. low and low)	-.46	.49	-.17	.58
School type	.60	.14	***.59***	***<.01***
Confounders				
Age	.05	.47	.07	.06
Gender (ref. Female)	-.23	.50	-.18	.25
Model with preferences (PAC) **Diversity (n=105)** r^2=.39, p< .001; Preferences for active-physical activities β= 1.73, p< .001 **Intensity (n=105)** r^2=.49, p< .0001; Preferences for active-physical activities β=.70 , p< .001				

6.5.4. Self-improvement

The model including environmental factors and activity limitations explained the highest variance (48%) in diversity and intensity of participation in self-improvement activities (total number of activities =10). Better socialization skills contributed to more intensity of participation in self-improvement activities and better communication skills had also a

small significant contribution to more diversity and intensity of participation in this activity domain. A family's higher orientation towards recreational and intellectual activities also contributed to more participation in diversity and intensity of self-improvement activities. Gender was the strongest predictor in the model, demonstrating that male gender predicted participation in a smaller number of self-improvement activities and with less frequency (Table 6.7). Models specifically including preferences for self-improvement activities decreased the explained variance of diversity and intensity of self-improvement activities.

Table 6.7 - Best predictive model: Self-improvement activities

Predictors	Diversity (n=139) r^2 (% variance) .48 p-value (model) <.001		Intensity (n=139) r^2 (% variance) .48 p-value (model) <.001	
	Parameter estimate (β)	p(variable)	Parameter estimate (β)	p(variable)
Activities limitations				
GMFM	.005	.51	.00	.28
MACS (ref. level 1: levels 4 and 5)	-.17	.76	-.27	.35
Socialization (VABS)	.01	.25	***.01***	***.03***
Communication (VABS)	***.03***	***.009***	***.01***	***.04***
Daily living skills (VABS)	-.01	.34	-.01	.10
Environmental factors				
Family activity orientation (FES)	***.03***	***.01***	***.01***	***.01***
Family moral-religious orientation (FES)	-.006	.66	-.00	.75
Maternal (high) and paternal (low) education (ref. low and low)	-.36	.49	-.21	.43
School type	.34	.35	.19	.33
Confounders				
Age	-.04	.53	-.03	.44
Gender (ref. Female)	***-.84***	***.01***	***-.48***	***.00***
Model with preferences (PAC) **Diversity (n=106)** r^2=.32, p<.005; Preferences for self-improvement activities β= 1.19, p< .01 **Intensity (n=106)** r^2=.33, p=.003; Preferences for self-improvement activities β=.58, p< .01				

6.5.5. Skill-based activities

The models of determinants of participation in skill-based activities (maximum number of activities =10) were not significant (Diversity: r^2 ranged from .03 - .17, p > .21; Intensity: r^2 ranged from .06 - .13, p >.21). Including preferences for skill-based activities to not change the significance of the models (Diversity: r^2= .28, p=.08; Intensity : r^2= .29, p=.06). In these models, male gender was a significant predictor of less diversity and intensity of participation in skill-based activities. The combination of a low maternal

education with a high paternal educational level was predictive of more participation in skill-based activities when compared to both parents having a low educational level. More prosocial behaviours predicted less participation in this activity domain (Table 6.8).

Table 6.8 - Best predictive model: Skill-based activities

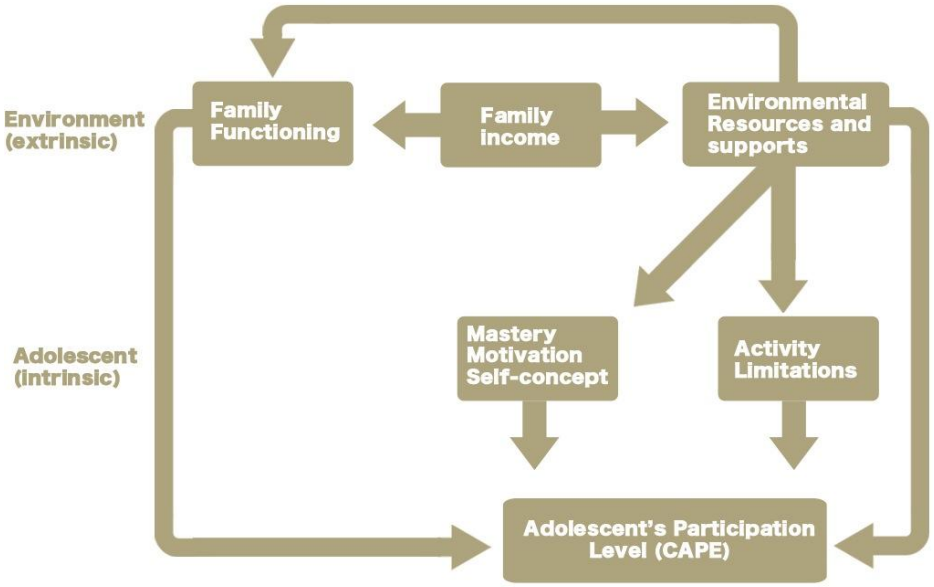
Predictors	Diversity (n=120) r^2 (% variance) .28 p-value (model) .08		Intensity (n=95) r^2 (% variance) .29 p-value (model) .06	
	Parameter estimate (β)	p(variable)	Parameter estimate (β)	p(variable)
Activities limitations				
GMFM	-.00	.45	-.00	.63
MACS (ref. level 1: levels 4 and 5)	.13	.74	-.06	.76
Socialization (VABS)	-.00	.38	-.00	.29
Communication (VABS)	-.00	.77	-.00	.79
Daily living skills (VABS)	.00	.41	.00	.47
Environmental factors				
Family moral-religious emphasis (FES)	-.01	.22	-.00	.28
Family activity orientation (FES)	.01	.16	-.00	.75
Maternal (low) and paternal (high) education (ref. low and low)	-.82	.13	***.65***	***.01***
School type	.30	.31	-.12	.40
Number of barriers (ECEQ)	.00	.91	-.01	.56
Personal factors				
Negative reaction to failure (DMQ)	-.10	.56	-.06	.46
Total persistence (DMQ)	-.09	.70	.02	.84
Prosocial behavior (SDQ)	-.14	.07	***-.09***	***.01***
Preference for skill-based activities (PAC)	.35	.17	.23	.06
Confounders				
Age	-.09	.13	-.05	.07
Gender (ref. Female)	-.62	.03	***-.33***	***.01***

6.6. Discussion

Participation in leisure is a multifaceted construct that appears to be associated with a variety of factors related to the adolescents' functional characteristics and attitudes, the family environment and socioeconomic status and other contextual factors such as school type. Aspects of the adolescent's mastery motivation and behavior were also associated with participation in different activity domains. The adolescent's perception of self in relation to competence in different life skills and physical appearance was also associated with participation in certain types of leisure activities.

We hypothesized that personal and environmental factors (i.e., ICF contextual factors) such as the adolescent's motivation, family functioning and environmental resources would be more strongly associated with levels of participation for adolescents with CP than the actual severity of motor impairments or activity limitations (see Figure 6.1). This hypothesis was not supported by the bivariate correlations, which were stronger between functional limitations and participation than between individual and environmental characteristics and leisure participation. These findings reproduce those in studies of determinants of participation in school age-age children with CP (Majnemer et al., 2008; Law et al., 2004; Imms et al., 2009) and adolescents with CP (King et al., 2010; Palisano et al., 2011). Nevertheless, when accounting for the other intrinsic and extrinsic characteristics, functional abilities individually had only a small predictive value and only for participation in recreational and physical activities, whereas other environmental and individual characteristics were better predictors in the models. Communication ability was one of the functional characteristics that had a significant predictive value for participation in self-improvement activities. Difficulties in communication have been previously demonstrated as an important barrier for participation (Clarke et al., 2012).

Figure 6.1 - Proposed model of determinants of participation in leisure activities



A higher level of participation (diversity and intensity) in leisure activities was expected to be associated with higher family functioning (e.g. family cohesion, adaptability and active-recreational orientation), greater environmental resources (e.g. accessibility, transportation and services), greater mastery motivation (persistence and expressive elements), greater self-worth, higher motor performance, fewer activity limitations (socialization, communication and daily living skills), and younger age. Even though these relationships were confirmed, the associations of personal factors were weak and the influence of these variables in the multivariate models were fair at best for the different activity domains, although the variance explained by our proposed models as a whole for the five activity domains was substantial (r^2 range .30 - .48).

6.6.1. Intrinsic factors

Although personal factors (motivation and behavior) were associated with all activity domains, they were not important predictors for active-physical activities diversity and social activities diversity and intensity and were therefore excluded from these multivariate models. It is conceivable that a family directs most of the social activities

and physical activity choices of adolescents and therefore these activities may be more influenced by the family's environment and contextual characteristics than the adolescent's own drive to do these type of activities. Few studies exploring participation in leisure of youth and adults with disabilities (including CP) have investigated the influence of adolescents' intrinsic characteristics and attitudes such as motivation and behavior. Badia and colleagues (2011) found that personal factors accounted for a small variation of participation in activities done at home and social activities but not in physical activities done by youth and adults with developmental disabilities (< 30% CP). In contrast to our study, the personal factors included in this study were only socioeconomic aspects (e.g. place of residence, education level) that were categorized as extrinsic in our study. Age and severity of disability were the personal factors that were considered in another study of contextual factors affecting participation in leisure of adults with CP (Boucher et al., 2010). It was demonstrated that most participants (mean age = 28 years) still lived with their parents. Participants in this study described that their main life activity was participation in leisure activities. Barriers in the environment such as accessibility and family-related aspects were perceived by these young adults as more important determinants of participation than individual characteristics.

Previous studies have focused on the influence of motor abilities in participation in physical activities (Palisano et al., 2007; Meeteren et al., 2008; Orlin et al., 2010). Interestingly, our study shows that motivation to accomplish a task that is physically challenging may be more important to promote participation than actual motor ability itself. This is an important message for clinicians to direct efforts towards increasing mastery motivation (Majnemer et al., in preparation).

Personal factors such as self-esteem and self-competency were found to be important predictors of involvement in romantic relationships and sexual activities in youth with CP (Wiegerink et al., 2012) and overall participation in activities with peers (Kang et al., 2010). Although self-esteem was not accounted for in the multiple regression models in our study, it was associated with participation in different domains of leisure. Noticeably, a perceived sense of competence and a positive regard towards one's own appearance were associated with greater participation in physical and skill-based activities. A higher

motivation and even higher self-critique that may be expressed through more negative reactions to failure were also associated with participation in all activity domains, including social activities, which are activities that may potentially generate opportunities for engagement in romantic and sexual relationships. Engagement in social activities are important for a healthy development at this age and are activities that are highly valued by adolescents, but done in less frequency as compared to adolescents without disabilities (King et al., 2003; King et al., 2010; Shikako-Thomas et al., 2009).

Similar to other studies, we found that gender was a predictor of participation in leisure activities (Shikako-Thomas et al., 2008; Bult et al.; 2011, Imms et al., 2009). In contrast to previous studies (King et al., 2010; Garton & Pratt, 1991), male gender was a negative predictive factor for participation in all activity domains, including active-physical activities, when controlling for the other factors in the models. Interestingly, the direction of the relationship changed when adding preferences for active physical activities into the model, revealing that boys may prefer to do physical activities, but do not have the opportunity to participate as the influence of the family environment may be more predominant. Male gender significantly predicted less participation in self-improvement activities and skill-based activities, demonstrating that there is a prevalent gender trend for girls to engage more in these types of activities, that is consistent across age groups (King et al., 2010; Garton & Pratt, 1991; Majnemer et al., 2008; Imms et al., 2009).

Personal preferences for leisure activities was an important determinant of both diversity and intensity of participation in all activity domains. Activity preferences are described in detail elsewhere (Shikako-Thomas et al., submitted). It is important to consider that only adolescents who could self-report had their preferences accounted for. This is a reality of clinical practice where it may be challenging for clinicians to obtain the personal opinions, preferences and choices of patients who have severe intellectual disabilities and/or communication challenges. Interestingly, a preference for activities significantly increased the explained variance for recreational activities, but was not as important for social and active-physical activities. This may reflect the nature of recreational activities measured, which are more informal and home-based activities. In this type of activities, even adolescents with greater difficulties may be able to make

choices without the influence of external barriers as may be the case for the other activity types. As for active-physical activities, the small influence of preferences in the model may be due to the fact that family resources largely determine the participation in these activities. The importance of preferences for activities as a determinant of participation has been described in formal and informal activities for children (Imms et al., 2009) and young adolescents (12-24 years old; King et al., 2010). It is important to understand how preferences for specific activity types may be of importance in determining an adolescent's participation, and therefore preferences should be considered in intervention programs.

The impact of negative behaviour was positively associated with more participation in recreational and physical activities in the bivariate correlations. Prosocial (positive) behavior was positively associated with more participation in all activity domains, but was a significant predictor of less participation in skill-based activities in the multivariate models, when accounting for preferences for this type of activity. It seems counterintuitive that adolescents who have behavioral problems would participate more. However, this finding reproduces the findings in younger children with CP (Majnemer et al., 2008) and suggests that engagement in leisure activities may continue to work as an outlet or an escape mechanism for adolescents with hyperactivity and other behavioral difficulties. In adolescents with intellectual disabilities, negative behavior and attitudes predicted less participation in inclusive activities (Buttimer et al., 2005). Behavioral issues tend to be persistent as children with CP develop (Brossard-Racine et al., submitted) and therefore should be addressed in intervention plans and strategies.

6.6.2. Extrinsic factors

Different aspects of the family environment were important for participation in all leisure domains. King and colleagues (2003) had described the theoretical model that includes the family as an important determinant of participation in leisure activities for children with disabilities. Different determinants would be important for the different activity type and found that families who engage in both recreational and intellectual-cultural leisure pursuits, may foster greater participation in self-improvement activities. Furthermore, socioeconomic status such as family income may facilitate engagement in physical activities, likely due to costs of adapted sports programs. Higher maternal education was associated with participation in skill-based activities. Nonetheless, participation in these activities was very limited in our sample, in spite of over 40% of families having a higher income and 30% having higher maternal education levels (Shikako-Thomas et al., submitted). It is likely that mothers are more involved in the planning of children's activities than fathers and more educated mothers may be more likely to engage their adolescents in skill-based activities. Overall, it is evident that family-related factors are more prominent than adolescent-related variables for participation, showing that parents continue to be predominantly responsible for orchestrating adolescents' lives (Palisano et al., 2011; Blum et al., 1991), even for activities that are done with others (Kang et al., 2010). Parents, however, may not be aware of rehabilitation services that are available for their adolescent (Majnemer et al., submitted) and therefore, a better coordination of efforts between health care professionals, educational services, parents and adolescents may contribute to effective interventions to promote leisure participation.

Other contextual factors are likely to influence participation in leisure activities (Law et al., 2007; Fauconnier et al., 2009; Welsh et al., 2006). In the SPARCLE study, Colver and colleagues (2011) have identified several barriers in the physical, family and school environment of the child. In our study we adopted an earlier version of the ECEQ. The psychometric properties of the measure are still in development. Therefore we only used a sum of the numbers of barriers encountered in the physical environment of adolescents. This variable contributed to the explained variance of participation in physical activities, but did not present as a significant predictive value for participation. Parents of children

and adolescents identified a series of constraints in the environment affecting participation (Law et al., 2007; Vogts et al., 2010). Therefore this construct should be explored in more depth in future studies. Findings illustrate that an adapted, segregated school environment was a determinant of greater involvement in social leisure activities, replicating results in a previous study (Law et al., 2007). Special schools may naturally facilitate participation and social interactions by minimizing the number of physical and attitudinal barriers (Almqvist & Granlund, 2005), which highlights the importance for adolescents with CP to be able to circulate in both "adapted" and "regular" environments in order to maximally optimize the quality and range of experiences and interactions, and also to experience the freedom of making choices without environmental constraints (Law et al., 2007; Shikako-Thomas et al., 2009). The social context in which leisure activities occur is especially important for adolescents in terms of identity formation and competency development (Jacobs et al., 2004).

6.6.3. Study limitations

This study has a several limitations. Bivariate correlations reveal associations between child-completed variables and participation domains; however, these associations were not taken into consideration in the multivariate models due to a reduction in sample size and exclusion of those with severe activity limitations.

We had planned to create a structural equation model of participation in leisure activities in five different domains. However, there was a poor fit of models possibly related to the sample's heterogeneity. Low correlations between variables support this statement. It would be interesting to consider more homogenous samples (e.g.. by age or by severity levels), but we did not have the power in our sample for these sub-analyses. Other authors who have used this analytical approach have built models that explained participation by formal and informal activities (King et al., 2006) or total participation intensity (Palisano et al., 2011). Unique to our study, analysis was focused on separate domains as it was expected that predictors would vary for each activity type, which was indeed confirmed. We believe this information, in addition to the previous studies, will contribute to the

understanding of the key effect modifiers of participation in leisure activities for this population of interest.

Collinearity was a concern in the multiple regression models as we used subdomains of specific instruments as explanatory variables. Variation inflation for some of the variables were above the recommended cut-offs (i.e. VIF > 4). We therefore tested different models with a reduced number of predictors, but then maintained the models with more explanatory variables based on clinical significance of these variables and understanding that the inflation of estimates did not affect the interpretation of the suggested models as a whole. The low parameter estimates found in our models may also be explained by the heterogeneity of the sample, as indicated by high standard deviations, emphasizing that participation is a complex outcome construct being measured in a highly heterogeneous sample.

6.7. Conclusion and future directions

The multivariate models will inform clinicians and families with regards to the intrinsic (adolescent) and extrinsic (family and environment) characteristics that contribute to greater participation in leisure activities in adolescents with CP. Individual characteristics such as motivation and behavioural difficulties and environmental factors such as family participation in leisure and number of barriers in the environment are potentially modifiable through therapeutic strategies. Awareness of these factors may also inform policy change and strategic planning for adolescent's health promotion programs and ultimately to promote health and well-being for this at-risk population.

Engagement in a variety of leisure activities has important benefits for the overall health and development of children and youth. Studies over the past decade have identified barriers and facilitators that influence the participation of children, and more recently of adolescents with disabilities. Studies are beginning to test effective interventions to increase participation levels in this population, with a primary emphasis on promoting physical activities. Engagement in different types of leisure activities may have different contributions to adolescents' development and well-being and therefore, it would be

important to develop interventions that focus on participation more holistically. Clinicians should consider adolescents' and families' characteristics, but also expand the scope of considered interventions to more broadly support the creation of programs in the community and advocacy for policies that will facilitate participation in a variety of activities.

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CHAPTER 7: DISCUSSION

7.1. Overview

This study aimed to quantify the level (intensity and diversity) of participation and enjoyment of leisure activities of adolescents with CP, and to estimate the potential influence of both intrinsic characteristics and extrinsic environmental factors as determinants of leisure participation. Moreover, we wanted to determine factors associated with preferences for specific leisure activities in adolescents with CP. A sample of 185 adolescents (12-20 years old) with CP took part in this study.

Adolescents with CP participated in a variety of leisure activities, but with greater quantity and frequency in informal activities (e.g. watching television, talking on the phone) than formal activities (e.g. organized sports, taking art lessons). In addition, they engaged in a variety of recreational and social activities, but not in many self-improvement activities. Participation in physical activities was lower in relation to the other three leisure participation domains, but engagement in skill-based activities was the most limited.

Adolescents in our sample preferred primarily social and physical activities. Self-improvement activities were the least preferred. Family factors, personal factors and functional abilities influenced leisure preferences. More preference for certain activities was not necessarily associated with actual involvement in these activities.

Models of determinants of participation in five leisure activity domains demonstrated that leisure is a multifaceted construct that appears to be associated with a variety of factors related to the adolescents' functional characteristics and attitudes, the family environment and socioeconomic status, and other contextual factors such as school type. Aspects of the adolescents' mastery motivation and behaviour were also associated with participation in different leisure activity domains. Finally, adolescents' perception of self in relation to competence in different life skills and physical appearance was also associated with participation in certain types of leisure activities.

7.2. Hypotheses tested

Our primary hypothesis was that personal and environmental factors (i.e., contextual factors as framed by the International Classification of Functioning, Disability and Health) would be more strongly associated with levels of participation for adolescents with CP than the severity of activity limitations. A higher level of participation (diversity and intensity) in leisure activities was expected to be associated with both intrinsic and extrinsic factors as outlined below:

7.2.1. Extrinsic factors: Higher family functioning and greater environmental resources

7.2.1.1. Family functioning

This study showed how some aspects of family dynamics, such as family orientation towards recreational and intellectual leisure activities, as well as moral-religious orientation, predicted preference for activities. Moreover, family orientation towards leisure activities and independence and socioeconomic characteristics such as parental educational levels and family income contributed to higher levels of participation.

Family factors were also found to be important determinants of participation in other studies that included adolescents with CP (King et al., 2006; Kang et al., 2010; Palisano et al., 2011b).

Although more independence from family is expected during adolescence, it is known that adolescents with disabilities, especially those adolescents with a more severe physical disability, are still highly dependent on families to engage in recreational pursuits (Blum et al., 1991; McMeeking & Purkayashta, 1995). Family characteristics such as cohesion and socioeconomic status and parent-child relationship issues such as adolescent's attachment to parents and parents' decision-making competencies are perceived as important determinants of continuous engagement in leisure for adolescents with and without disabilities (Brown & Mann, 1991; McGee et al., 2006; King et al.,2009). Conversely, it is important to note that family involvement in leisure

contributes to better family functioning, which may contribute to higher levels of participation (Dodd et al., 2009).

Autonomy in leisure pursuits is an important developmental benchmark for adolescents. Indeed, autonomous engagement in leisure may be crucial to fully enjoy leisure benefits (McMeeking & Purkayashta, 1995; Bonhert et al., 2007). If we consider the definition of leisure as freely chosen activities defined by self-expression and a sense of control, we may understand that the lack of autonomy actually may hinder the possibility of adolescents with disabilities to fully experience leisure opportunities (Samdahl, 2009). Moreover, studies have shown that adolescents with disabilities express the need for independence from family and the lack of ability to control and pursue one's own interests as important barriers for their quality of life (Shikako-Thomas et al., 2009; McMeeking & Purkayashta, 1995)

7.2.1.2. Environmental factors

Socioeconomic status and school type were two aspects that contributed to the variation in participation in physical and social activities in our sample. The influence of socioeconomic status is likely related to the costs involved in adapted physical activities such as organized sports. School type, however, is a variable that is heavily related to level of severity of disability, and it is notable that adolescents in special schools participate more in social activities. Similar to young adults living in segregated communities (Ralph & Usher, 1995), adolescents in segregated settings will likely have more opportunities for social encounters when these are restricted to other individuals with disabilities. However, adolescents still manifest an interest and a need to interact with others with and without disabilities and these types of interactions are usually limited (Shikako-Thomas et al., 2009; Stevenson et al., 1997; King et al., 2000; Blum et al., 1991). The creation of support systems to facilitate social interactions between adolescents with and without disabilities within the community at large may be an important measure to promote leisure by fostering accepting, inclusive environments (Ralph & Usher, 1995)

For young adults with disabilities, it was demonstrated that integration into employment opportunities, school attendance and living arrangements are factors that impact levels of participation in leisure activities to a greater degree than activity limitations (Van Naarden et al., 2006).

Limitations with the measure of environmental barriers we adopted precluded more in-depth analysis of this important variable and its influence in multivariate models. Recent studies have described the barriers in the environment for children with physical disabilities (Anaby et al., 2012; Lawlor, 2006; Dickinson, 2011; Colver et al., 2011; Welsh et al., 2006; Hammal, 2004). It is necessary to understand the existing constraints in the environment in order to promote participation. However, limitations in measurement need to be addressed in clinical research. It is conceivable that barriers only exist when a certain type of activity is taking place in this environment and that these constraints are mostly related to the level of physical impairment of the child or youth. However, if we consider the premise of the social model of disability (Race et al., 2005), intervention strategies should facilitate the creation of environments that are universally accessible and that facilitate the participation in leisure activities of adolescents with physical disabilities, eliminating the physical barriers and fostering positive attitudes in both inclusive and segregated leisure opportunities.

Clinical intervention and leisure promotion programs should take into consideration the resources available within families that could support the participation of adolescents (such as families' interests and dynamics) and recognize parents as facilitators for a healthy development through participation in leisure activities (Sciberras & Hutchison, 2003). However, clinicians should also develop strategies that support adolescents' independence and autonomy, and foster their ability to make choices and engage in activities of their choosing independently from families, in order to promote global health and well-being (Wong et al., 2010). Those strategies must include not only collaborative work with the family to promote autonomy, but also the improvement of environmental factors such as access to adapted transportation. Finally, the elaboration and maintenance

of inclusive leisure programs in the community may facilitate access to the desired activities of adolescents and empower them in the choice making process (Jones, 2012; Pegg & Compton, 2003).

7.2.2. Intrinsic factors

7.2.2.1 Higher motor performance, fewer activity limitations, younger age and gender

Previous studies have focused on the influence of motor abilities in participation in physical activities (Palisano et al., 2007; Meeteren et al., 2008; Orlin et al., 2010). Our study confirmed the findings from previous studies that activity limitations do influence participation levels in different leisure activity domains.

Age and severity of disability were factors considered in other studies and confirmed in ours as determinants of participation. Increasing age and more severe disability as measured by gross and fine motor functioning, and activity limitations as measured by diminished ability in communication, socialization and daily living skills are consistently associated with participation restrictions (Shikako-Thomas et al., 2008; Imms et al., 2009; Bult et al., 2011; Palisano et al., 2011a; Palisano et al., 2011b). Boucher and colleagues (2010) described perceptions of young adults with disabilities with respect to the central role of participation in leisure activities in their lives. Barriers in the environment such as accessibility and family-related aspects were perceived by these young adults as more important determinants of participation than individual characteristics. While it is important to consider the impact of activity limitations on participation restrictions, it is also necessary to understand the other personal and environmental factors that relate to participation as proposed by the new models of determinants of participation that were investigated in this study and others (Law et al., 2004).

Similar to other studies, we found that gender was a predictor of participation in leisure activities (Shikako-Thomas et al., 2008; Bult et al., 2011; Imms et al., 2009). In contrast to previous studies (King et al., 2010; Garton & Pratt, 1991), however, male gender was a negative predictive factor for participation in all activity domains, including active-

physical activities. Interestingly, the direction of the relationship changed when adding preferences for active physical activities into the model, revealing that boys may prefer to do physical activities, but do not have the opportunity to participate as the family environment may be a more predominant variable. Male gender significantly predicted less participation in self-improvement activities and skill-based activities, demonstrating that there is a prevalent gender trend for girls to engage more in these types of activities, that is consistent across age groups (King et al., 2010; Garton & Pratt, 1991; Majnemer et al., 2008; Imms et al., 2009).

7.2.2.2. Preferences for activities, greater mastery motivation, greater self-worth, better behavioral conduct

Our study demonstrated that adolescents with CP have preferences for a variety of activities but especially in the social and active-physical domain. Adolescents' persistence in completing a challenging task, negative reaction to failure, negative behavior and different aspects of self-perception such as athletic competence and romantic appeal were intrinsic factors that contributed to preferences for certain types of activities. Motivation and behavior were associated with intensity and diversity of participation in all activity domains; however, they were not important predictors for active-physical activities diversity and social activities diversity and intensity. The different weight that intrinsic factors have in determining preferences, as opposed to determining actual participation levels indicates the need of integrating these personal factors, including preferences for activities, in interventions and program planning. It is known that more motivation contributes to better performance and greater fulfillment in activities (Deci & Ryan, 2008).

Adolescents with physical disabilities adopt a series of coping strategies when faced with stressors or challenging tasks. Those who are more likely to avoid stressful situations also express more negative feelings (Smith et al., 2006). In our study, negative reaction to failure was a factor related to more participation, and the presence of more negative behavior was associated with more participation. Moreover, persistence in motor tasks (a component of mastery motivation) was important for engagement in physical activities

and positive social behavior was associated with more participation in all leisure activity domains. Engagement in leisure has been shown to be a positive coping mechanism that can therefore help adolescents cope with challenges in different areas. These results reproduce the findings in younger children with CP (Majnemer et al., 2008) and suggest that engagement in leisure activities may continue to work as an outlet or a coping strategy for adolescents with hyperactivity and other behavioral difficulties. In adolescents with intellectual disabilities, negative behavior and attitudes predicted less participation in inclusive activities (Buttimer et al., 2005). Behavioural issues such as hyperactivity, peer problems and emotional symptoms persist as children with CP develop (Brossard-Racine et al., submitted) and therefore should be addressed in intervention plans and strategies.

Self-esteem was associated with participation in different domains of leisure. Notably, a perceived sense of competence and positive regard towards one's own appearance were associated with greater participation in physical and skill-based activities. In previous studies, self-esteem and self-competency were found to be important predictors of involvement in romantic relationships and sexual activities in youth with CP (Wiegerink et al., 2012) and overall participation in activities with peers (Kang et al., 2010).

When examining the activities that are preferred with the actual levels of involvement in activities we can see that engagement in preferred activities may be moderated by environmental factors. The activities that are less structured and present no major environmental constraints (i.e. activities done at home and alone, with no need for instructors, peers or transportation, accessibility) are the ones with higher agreement between preferences and actual involvement. This points to the need to understand the interactions between intrinsic and extrinsic factors to fully understand participation patterns and plan interventions. Studies indicate that adolescents with CP believe that engagement in social activities, interactions with peers and social relationships are crucial elements for their quality of life and important determinants of the pleasure experienced in leisure activities (King et al., 2003; King et al., 2010; Shikako-Thomas et al., 2009). Nevertheless, successful participation in these activities may be highly dependent on the opportunities that are available within the environment (Heah et al., 2007).

7.3. Summary of studies in adolescents with CP: what is known, what is new.

Recent studies have explored determinants of participation in leisure activities in adolescents with CP. Palisano and colleagues (Palisano et al., 2011b; Kang et al., 2010) used a theoretical model approach to confirm the relationship of several intrinsic and extrinsic factors as determinants of a total intensity score of participation. Importantly, the process of care and availability of services were included in their models as determinants of participation. They also explored patterns of participation with friends and others who are not family members, which is a very important component of participation for adolescents (Kang et al., 2010). Information from these studies add to our findings in the sense of understanding the interactions between service provision and family factors. However, our study enhances the understanding of determinants that are specific to five different leisure activity domains (recreational, social, active-physical, skill-based, self-improvement), rather than examining formal and informal activities only, and takes into consideration a series of personal factors that are likely modifiable and therefore possible to be targeted in interventions.

Furthermore, Palisano et al. (2011b) found that enjoyment in leisure activities was a determinant of intensity of participation. Our study explored preferences for activities as a determinant that reflects what adolescents would like to do in an ideal situation, as opposed to what they are already doing. Preferences for certain activities may therefore represent a more distinct construct. It is conceivable that if adolescents can actually participate in their preferred activities, they will also enjoy these activities more and increase their intensity as a consequence.

King and Law's group has explored a series of models of determinants of participation cross-sectionally and longitudinally (Law et al., 2004, 2006, 2007; King et al., 2000, 2003, 2006, 2009, 2010). Their group has delineated a theoretical model of determinants of participation in leisure for children with disabilities (King et al., 2003) that has greatly contributed to the conceptualization of our study. King and Law's studies tested models of determinants of participation in formal and informal leisure activities for school age children and young adolescents (12-14 years old) with different physical disabilities.

Participation in leisure is a complex construct that includes a variety of possible activities as framed by the ICF. This variety is reflected in the five domains measured by the Children's Assessment of Participation and Enjoyment (CAPE), the main outcome measure used in all the abovementioned studies and in ours. Our study adds to a better understanding of the determinants of leisure in these five different domains, as opposed to formal and informal activities, which were shown to be very specific for each activity type.

Moreover, leisure patterns are likely to vary as adolescents grow older. Indeed, in a previous qualitative study we noted that older adolescents (16 years and over) and their parents had a completely different perspective of the constraints perceived in relation to when they/their child was younger (Shikako-Thomas et al., 2009; Shikako-Thomas et al., submitted). King et al. (2009) analyzed the predictors of change over time in leisure participation of children and youth with physical disabilities ages 6-15 years over a three-year period. They also found that predictors were different for the five different domains of the CAPE and did vary according to child's age. Therefore, it is important to understand the participation patterns and the determinants of participation in the five different domains and also throughout the adolescent period.

7.4. Limitations

Limitations to this study should be appreciated. We had initially planned to obtain a larger sample that would contribute to more reliability in the models and statistical analysis, including more explanatory variables and better fit of structural equation models as outlined below. Recruitment efforts included the expansion of recruitment sites, to include rehabilitation centers and primary health care centers across the whole province of Quebec (Centre des services sociaux et santé), and community programs such as different adapted summer camps and recreational programs.

Challenges in recruitment are probably the reflection of two main problems. Firstly, there is an absence of adolescents with CP in the health care system. Most rehabilitation programs offer only occasional consultation programs for this age group as the need

arises, and adolescents with CP are not generally regularly services in the primary health care system. It is understandable that the health care system as it is currently organized may impose constraints in the offering of services for this population, however the absence of structured regular services is striking and likely a concern for overall health promotion. Secondly, there is also very little research being conducted in these sites, indicating a need to foment knowledge translation strategies that will likely contribute to more collaboration and reduce sample bias by including children who are not in rehabilitation centres but rather in the general community.

Secondly, parents of adolescents often have other priorities than to participate in research, regardless of our best efforts to accommodate their needs. Possible bias in our sample include the fact that higher functioning adolescents, who could participate independently of parents, sometimes opted for not participating in the study. However the distribution of severity of motor dysfunction is comparable to a population-based sample as per the Quebec CP registry (Shevell, M. & Dagenais, L., personal communication, August 10, 2012) (Table 7.1).

Table 7.1 – GMFCS proportion for Quebec CP registry and QUALA study

GMFCS level	Quebecc registry (n=647)	QUALA Study (n=171)
I	42%	32%
II	16%	26%
III	13%	7%
IV	14%	11%
V	13%	22%

We initially used structural equation modeling (SEM) to determine the relative influence (direct or indirect pathways) of child, family and environmental factors that may collectively predict level of participation. We calculated several goodness-of-fit indices, including the Standardized Root Mean Square Residual (RMSEA), for which values closer to 0 indicate better fit, and the Comparative Fit Index (CFI) for which values closer to 1 indicate better fit. Although there are no strict criteria for evaluating these fit indices, conventional rule of thumb suggests that a CFI of .90 or more indicates adequate fit and .95 or more indicates excellent fit; RMSEA of .08 or lower indicates adequate fit (.06 or lower indicates excellent fit). We compared different structural equation models, but the

model fit was not adequate (maximum CFI was .86 and minimum RMSEA was .22). Therefore, we decided not to use the SEM modeling strategy (Hu &Bentler, 1999).

Additionally, we should emphasize some limitations in measurements. Although validated for children and youth ages 6-21 years old, the CAPE has some activities that are not appropriate for older adolescents, or are not likely to be carried out by older adolescents such as doing pretend or imaginary play or doing puzzles, as noticed in another study (Orlin et al., 2010). The ECEQ is a comprehensive measure on environmental barriers and facilitators developed for children and youth with CP that has a sound face validity (Dickinson et al., 2011). However we adopted the measure in its initial stages of development and therefore there were a few challenges in the use of the measure as a whole, since scoring and further psychometric testing required some modifications in the measure. We used the ECEQ as a checklist for the presence of barriers in the environment. Barriers and facilitators in the environment may be a key determinant of participation in leisure, as indicated by several studies (Welsh et al., 2006; Law et al., 2007). Measuring environmental factors without the need to control for severity of disability or in a comprehensive manner is a challenge. There is a need to develop measures of environmental factors that reflect characteristics of the environment that can be then applied to any type of disability or need in a more universal access approach, and that encompasses all the different aspects of environment as proposed in the ICF.

7.5. Participation, quality of life (QoL) and health promotion: Looking at the big picture

7.5.1. Relationship between participation and QoL

Participation in leisure is a factor that undoubtedly contributes to QoL (Datilo & Schlein, 1994, Van Naarden et al., 2006). Parents and adolescents alike describe engagement in leisure activities of adolescents' s choosing and with the people of their choosing as a key component to enjoying a good QoL (Shikako-Thomas et al., 2009; Shikako-Thomas et al., submitted). A recent review of the literature showed that engagement in leisure is

associated with a series of QoL subdomains (Dahan-Oliel et al., 2011). In school-age children with CP, we found that intensity of participation, but not diversity, in active-physical activities such as team sports, bicycling, water and snow sports, and other individual physical activities was significantly correlated with physical well-being. Intensity and diversity of involvement in skill-based activities, that is, of activities such as dancing, arts, and music classes done with an instructor, were negatively correlated with physical well-being. Intensity of participation in active-physical activities also accounted for better psychosocial well-being (Shikako-Thomas et al., 2012).

7.5.2. Participation as a right

Engagement in meaningful activities can be considered within basic human needs, those that need to be satisfied in order for individuals to achieve optimal outcomes in other life areas and general optimize development (Deci &Ryan, 2009).

Several documents state the different needs and rights of children and youth that must be respected. The United Nations convention on the rights of persons with disabilities articulates the right of children and youth with disabilities to participate in cultural life, leisure and sports on an equal basis with others, ensuring that their needs and expectations are met (WHO, 2007). In order to have this right respected, it is fundamental to understand which are the aspects that influence engagement in leisure activities and how to measure the impact of various personal and environmental aspects on overall levels of participation by individuals in this group.

The expression of health and disability in children and youth has particular characteristics that are presented in the International Classification of Functioning, Disability and Health- Childre and Youth (ICF-CY, WHO, 2007), which has adapted the ICG to the pediatric context. Understanding all the aspects involved in this comprehensive classification system may help health care providers, educators and others involved in the care of children and youth to ensure that children and youths' rights in terms of access to care and meaningful activities are being respected (WHO, 2007).

Considering participation in leisure as a right and its critical relationship with the promotion of quality of life and well-being in children and youth with disabilities, rehabilitation professionals should regard participation as a key outcome in health promotion interventions.

7.6. Implications for clinical practice and future directions

An array of studies has delineated the factors that are associated with participation in leisure activities for children and youth with disabilities. Rehabilitation professionals should consider these factors to expand the scope of interventions aimed at promoting participation in leisure for adolescents. Adolescents with disabilities often receive exclusively consultative services that tend to target specific aspects of self-care and mobility, but not more global aspects of health and well-being such as participation and overall satisfaction with life (Darrah et al., 2002; Saleh et al., 2008; Majnemer, submitted).

Participation in leisure activities may ultimately affect other areas of development that are also part of the ICF such as mobility and activity limitations. However, there is a misconception that achieving good performance in skills such as self-care and mobility, patients will consequentially achieve more participation (Rimmer, 2006). It is important to plan interventions that will continuously promote motor development and physical conditioning, that develop communication abilities, cognitive skills and daily life skills, avoiding deconditioning and function loss, as children grow older. However, it is important to develop interventions that will allow these motor abilities to be transferred to "real life" situations, such as engagement in recreational activities and participation in social interactions. Interventions to improve participation in active-physical activities are being explored in recent studies and can be potentially incorporated into current practice (Verschruen, 2007; Kohleiman, 2011).

Interventions should also include strategies to tackle intrinsic factors that may promote participation in leisure and are potentially modifiable. Aspects of of self-perception that are especially important during adolescence such as close friendships, romantic appeal,

and job competence can be addressed in interventions (Bos et al., 2006). Strategies can be developed to support the development of positive social behavior and teach adolescents to apply it in social interactions with peers, for instance. Motivation to accomplish challenging tasks can be addressed through the offer of realistic goals and with the necessary emotional and strategic support. These skills should then be applied to overcome aspects of skill-based activities that involve learning new skills and self-improvement activities that may be instrumental for adult life – both types of activities that are very limited in this population. Very importantly, therapists should be aware of the role of personal preferences in leisure participation, and ask adolescents about what is important to them, what are the activities that they would like to partake in and what are the perceived barriers, acknowledging the importance of adolescent's values and opinions and giving them empowerment to make choices.

Moreover, extrinsic barriers and facilitators to participation in leisure must be considered in intervention programs. Firstly, we could see the central role of families in the promotion of leisure activities for adolescents. Family preferences should be explored and linked to the necessary resources in the community at the same time that identified barriers are removed. Examination of social and economic disparities alone may contribute to a better understanding of adolescents who are at risk for lower participation (Nardeen et al., 2006). The definition and conception of disability itself is likely to evolve with society and therefore, the definition of meaningful activities that need to be tackled needs to be constantly put into a broader societal context and at the same time understood within the youth's individual needs (Mackenzie et al., 2009; Magill-Evans & Darrah, 2012).

It is necessary to actively promote the creation of accessible leisure programs in the community and to advocate for policies that may facilitate participation in a variety of activities. Leisure is within the interface of health, education and social services. In order to address challenges to participation in leisure and act effectively, we need to think of research and clinical strategies that encompass those three areas.

Moreover, we must consider participation in leisure as part of transition programs for adolescents with disabilities. Fostering participation in leisure in adolescence may contribute to better outcomes in adulthood. Adults with disabilities experience poor social interactions and limited participation in leisure (Ralph & Usher, 1995; Boucher et al., 2010). Engagement in meaningful leisure activities may be considered as a key element for health promotion within a systems view of human development. The relations between multiple levels such as intrinsic characteristics, relationships and societal context are all integrated and in a continuum of development and contribute to positive long-term outcomes beyond the adolescent years (Lerner & Castellino, 2002; Wong et al., 2010).

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Appendix 2: Outcome measure - Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC)

Appendix 3: Demographics Questionnaire