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Participation in leisure and physical activity among children and adolescents with juvenile idiopathic arthritis

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Résumé

Contexte: L'arthrite juvénile idiopathique (AJI) est l'une des maladies chroniques auto-immune les plus répandues chez les enfants et est caractérisée par des enflures articulaires (maladie active), de la douleur, de la fatigue et des raideurs matinales pouvant restreindre leur niveau de participation aux activités quotidiennes (par exemple: les loisirs, l'activité physique, la mobilité et les soins personnels) à la maison comme à l'école. Participer aux activités de loisirs et à l'activité physique a des bienfaits au niveau de la santé et du développement de tous les enfants et démontrent aussi des effets positifs qui réduisent les symptômes des maladies chroniques telle l'AJI. Malgré ces bienfaits la participation aux loisirs chez les jeunes avec l'AJI demeure largement sous-étudiée.

Objectifs: Cette étude vise à évaluer le niveau de participation aux loisirs et à l'activité physique chez les enfants et les adolescents atteints d'AJI, ainsi qu'à identifier les facteurs liés à la maladie, la personne et l'environnement.

Méthodes : L'évaluation du niveau de participation et l'exploration des facteurs associés aux loisirs et à l'activité physique ont été complétés par l'entremise d'une revue systématique de la littérature, l'analyse de données d'un échantillon national représentatif d'enfants canadiens atteints d'arthrite âgés entre 5 et 14 ans ($n_{pondéré}$ = 4350), ainsi que l'analyse standardisée du niveau de participation aux loisirs à l'aide du *Children's Assessment of Participation and Enjoyment* (n=107) et la mesure objective de l'activité physique par accéléromètre (n=76) auprès d'un échantillon d'enfants (âgés entre 8 et 11 ans) et d'adolescents (âgés entre 12 et 17 ans) suivis en clinique de rhumatologie à l'hôpital de Montréal pour enfants, Centre

Universitaire de Santé McGill. Les résultats cliniques ont été comparés à des données normatives, ainsi qu'à un groupe contrôle sans AJI. Nous avons exploré les facteurs associés avec le niveau de participation aux loisirs et à l'activité physique en utilisant les modèles de régression linéaire multiple et l'analyse hiérarchique.

Résultats : Les enfants et les adolescents atteints d'AJI participent à une multitude d'activités de loisirs; cependant ils sont moins souvent impliqués dans des activités physiques et de raffinement en comparaison aux autres types d'activités de loisirs. Ceux avec l'AJI étaient en général moins actifs que leurs pairs sans arthrite et la plupart n'atteignaient pas les recommandations nationales d'activité physique. Les garçons avec l'AJI participent plus souvent à des activités physiques et moins aux activités sociales, de raffinement et de développement de soi en comparaison avec les filles ayant l'AJI. En général, être un garçon, être plus âgé, avoir une meilleure motivation pour participer aux activités de motricité globale, avoir un statut socio-économique plus élevé et être d'origine culturelle canadienne sont associés à un niveau de participation plus élevé aux activités physiques. La préférence pour les activités de raffinement, un niveau d'éducation maternelle plus élevé et être une fille étaient associés à un niveau de participation plus élevé aux activités de raffinement.

Conclusion: La participation aux loisirs et à l'activité physique en AJI est un concept complexe et semble surtout être expliqué par des facteurs personnels et environnementaux. L'identification des facteurs associés aux loisirs et à l'activité physique est très importante en AJI puisqu'elle peut permettre aux professionnels de la santé de développer des interventions significatives basées sur les activités préférées des enfants, améliorer l'observance au traitement et promouvoir des habitudes de vie saine.

Mots-clés : arthrite juvénile idiopathique, participation, loisirs, activité physique, accéléromètre, déterminants intrinsèques et extrinsèques, classification internationale du fonctionnement du handicap et de la santé, étude transversale, analyse de régression hiérarchique

Abstract

Background: Juvenile idiopathic arthritis (JIA), one of the most common chronic childhood autoimmune diseases, is a heterogeneous inflammatory condition characterised by joint inflammation (i.e. active disease), chronic pain, fatigue and morning stiffness, which may interfere with age-appropriate daily activities (i.e. leisure and physical activity, mobility and self-care), both at home and at school. Involvement in leisure and physical activity is beneficial to the health and development of all children and adolescents, and has also shown to help mitigate the effects of disease among those with chronic conditions such as JIA. Despite the benefits of leisure participation this subject remains vastly understudied in JIA.

Objective: The aim of this thesis was to assess participation in leisure and physical activity among children and adolescents with JIA, as well as identify associated disease-related, personal and environmental factors.

Methods: The assessment of patterns and exploration of potential predictors of participation in leisure and physical activity in children and adolescents with JIA was completed through a systematic review of the literature, analysis of survey data from a nationally representative sample of Canadian children with arthritis (age range = 5 to 14 years, $n_{weighted}$ = 4350), as well as the standardized assessment of leisure with the Children's Assessment of Participation and Enjoyment (n=107) and the objective measurement of physical activity with accelerometer (n=76) among a clinical sample of children (age range = 8 to 11 years) and adolescents (age range = 12 to 17 years) with JIA followed at the Rheumatology clinic at the Montreal Children's Hospital, McGill University Health Center. Clinical data were also compared to

normative data and children and adolescents without JIA. We explored factors associated with participation in leisure and physical activity using multiple linear regression models and hierarchical analysis.

Results: Children and adolescents with JIA participated in an array of leisure activities; however involvement was least frequent in active physical and skill-based leisure activities compared to other types of activity. Those with JIA were generally less physically active than healthy peers without JIA, and most with JIA did not meet national recommendations for physical activity. Boys with JIA were more likely to engage in physical activities, and less likely to take part in social, skill-based and self-improvement activities than girls with JIA. In general, being a boy, older age, greater mastery motivation for gross motor skills, higher socio-economic status and being of Canadian cultural background were associated with increased participation in more physical activities. Preference for skill-based activities, higher maternal education and being a girl were associated with increased participation in skill-based activities.

Conclusion: Participation in leisure and physical activity in JIA is a complex concept and is mostly explained by personal and environmental factors. The identification of factors associated with leisure participation and physical activity is of utmost importance in JIA as it may aid health care professionals to tailor meaningful intervention plans based on preferred activities, improve adherence to treatment and help promote healthier lifestyles.

Keywords: juvenile idiopathic arthritis, participation, leisure, physical activity, accelerometer, intrinsic and extrinsic determinants, international classification of functioning disability and health, cross-sectional study, hierarchical regression analysis

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List of abbreviations

ACR: American College of Rheumatology

AJC: Active Joint Count

AJI: Arthrite Juvénile Idiopathique

BMI: Body Mass Index

CAPE: Child Assessment of Participation and Enjoyment

CASE: Child and Adolescent Scale of Environment

CHAQ: Child Health Assessment Questionnaire

CI: Confidence Interval

DMARD: Disease-Modifying Antirheumatic Drugs

DMQ: Dimensions of Mastery Questionnaire

EULAR: European League Against Rheumatism

FES: Family Environment Scale

ICC: Intraclass Correlation Coefficient

ICF: International Classification of Functioning, Disability and Health

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

ILAR: International League of Associations for Rheumatology

JCA: Juvenile Chronic Arthritis

JIA: Juvenile Idiopathic Arthritis

JRA: Juvenile Rheumatoid Arthritis

MEGAPHONE: Montreal Epidemiological and Geographical Analysis of Population Health Outcomes and Neighbourhood Effects

MET: Metabolic Equivalent of a Task

MTX: Methotrexate

MVPA: Moderate to Vigorous Physical Activity

NSAID: NonSteroidal Anti-Inflammatory Drug

OT: Occupational therapy

PA: Physical Activity

PAC: Preference for Activities of Children

PACS: Pediatric Activity Card Sort

PAL: Physical Activity Level

PALS: Participation and Activity Limitations Survey

PIP: Pediatric Interest Profile

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PT: Physical therapy

QUALITY: QUebec Adipose and Lifestyle InvesTigation in Youth

SAS: Statistical Analysis System

SPP: Self-Perception Profile

SPSS: Statistical Package for Social Sciences

SSS: Social Support Scale for children and adolescents

SUDAAN: SUrvey DAta ANalysis

TNF-α: Tumor Necrosis Factor – alpha

VAS: Visual Analog Scale

WHO: World Health Organization

Without ambition one starts nothing. Without work one finishes nothing.

-Ralph Waldo Emerson

To my beloved Matthew for believing in me

and standing by me every step of the way.

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Preamble

It should be stated that data for this thesis was obtained through collaboration with Statistics Canada for post-census population information, as well as through clinical recruitment at the Rheumatology clinic at the Montreal Children's Hospital of the McGill University Health Center. Furthermore, I worked in partnership with Dre. Marie-Ève Mathieu on the analysis of comparator data on physical activity obtained through the QUebec Adipose and Lifestyle InvesTigation in Youth research study.

As the doctoral candidate I was extensively involved in all aspects of this research project. I was responsible for the preparation of the project proposal and subsequent grant application. Under the direction of my thesis supervisors, I drafted and researched the content for the proposal which obtained funding from the Canadian Initiative for Outcomes in Rheumatology Care. I was responsible for obtaining and renewing yearly ethical approval at the Montreal Children's Hospital and the Université de Montréal for our clinical study, as well as with the Research and Development Center of Statistics Canada for our analysis of population-based data. I coordinated all research activities of the clinical study including purchasing equipment, obtaining office space, reviewing medical files of all potential participants with juvenile arthritis (n=350) from the Montreal children's hospital, recruiting and following up with participants with juvenile arthritis (e.g. completed home visits), as well as recruitment and hiring of support staff. Furthermore, I compiled, managed and created databases, as well as completed statistical analysis of study data independently and in consultation with statisticians only when needed. I presented population and clinical results at

various national and international conferences as 5 poster and 2 podiums talks. I have written 5 manuscripts for this project, one of which is published, two are in press, and two more have been submitted for publication.

1. Introduction

Living with a chronic condition such as juvenile idiopathic arthritis (JIA) may have long standing effects on a child's health, which may preclude participation in age-appropriate activities and the development of skills essential to fulfill roles throughout childhood, adolescence, and eventually adulthood. Multi-faceted interventions are needed to manage JIA and these often require an interdisciplinary approach. Among the professionals involved are rehabilitation professionals (mainly occupational therapists and physiotherapists), who traditionally address clinical symptoms of disease and functional limitations. In addition, rehabilitation professionals may be in a unique position to favour a client-centered approach promoting leisure participation and engagement in physical activity, which may be beneficial in ensuring participation in a wide gamut of activities and ultimately promoting healthy living. Rarely do health care professionals address these issues of reduced participation and physical activity and they are even less concerned with overall habitual leisure. Often children are encouraged to limit their participation in preferred sports or physical education during acute phases of the disease, although there is no real evidence to support this and in fact current recommendations support physical activity as tolerated (1).

In the last decade, there has been a move towards understanding participation in recreational and leisure activities among children and adolescents with disabilities (2-8). However this subject remains vastly understudied in JIA. The International Classification of Functioning, Disability and Health (ICF) highlights participation and how it may be

influenced by a wide network of intrinsic (i.e. disease-related, activity limitations, personal) and extrinsic (i.e. environmental) factors (9).

The main purpose of this study was to describe the patterns of participation in leisure and physical activity among children and adolescents with JIA, as well as identify associated factors (barriers and facilitators) related to the disease, the child (personal), the family and the environment. Identifying both restrictive and protective predictors of leisure participation will help inform rehabilitation interventions. It will also aid in the promotion of leisure participation among children and adolescents with JIA through development of initiatives targeting provision of health information and programs to help favour behaviour change and promote healthy lifestyles.

This thesis will document the relevance of the present study (chapter 1) as demonstrated through a thorough review of the literature (chapter 2). The epidemiology and treatment of JIA will be defined. The concepts of participation, leisure and physical activity, the related health benefits, the patterns of engagement and associated factors will be described. Chapter 3 describes the methods used in our studies including the description of recruitment of study participants, data collection methods and statistical analysis. Results will be presented with 5 articles in chapter 4. Finally, parallels between findings across our studies and with the existing literature, strengths and weaknesses of our studies will be discussed in chapter 5, a concluding statement will also be included.

1.1 Relevance of the study

Juvenile idiopathic arthritis (JIA) is one of the most common chronic conditions of childhood affecting approximately 1 in 1000 Canadian children (10). This illness is characterized by intermittent periods of joint swelling, pain, decreased function in mobility, hand use, daily living, school and leisure activities (11-13) and its effects are felt well into adulthood (14,15). In general those with JIA are found to be less physically active (16-23) and engage in fewer social activities with friends (23,24) than their healthy counterparts. Long-term reduction of participation in leisure and physical activity may have negative physical and psychosocial implications on children and adolescents with JIA such as decreased muscle strength, poor range of motion, poor bone mineral density and poor cardiovascular endurance (25-28), as well as decreased opportunities to foster important social contacts with peers leading to greater feelings of isolation and increased risk for depression (24,29,30).

Despite physical limitations brought on by their disease children and adolescents living with JIA have as much right to take part in play, leisure, sports and other physical activities as their healthy peers (31-33). Due in large part to the World Health Organization (WHO) and its endorsement of the International Classification of Functioning, Disability and Health for children and youth (ICF-CY), participation has been recognised as an important outcome of health in children and adolescents with or without disabilities. It is important that children with JIA participate fully in meaningful activities of their choosing.

The benefits of participation in leisure and physical activity on health and well-being in children are well documented (34-42). Additional benefits can be felt among those with a chronic condition such as JIA by reducing physical consequences of illness (i.e. reducing the number of painful joints), as well as improving physical function and quality of life (21,43,44).

Despite the critical role participation in leisure activities plays in a child's development and well-being there is a paucity of information on participation in leisure among children and adolescents with JIA (45). Studying involvement in leisure and physical activity among children and adolescents with JIA across various characteristics such as age, sex, income, and disease activity, will help us discern those at greater risk for poor participation in age-appropriate activities and subsequently tailor treatment interventions and health promotion initiatives targeted to this population. To our knowledge no study to date in JIA has comprehensively examined leisure participation in a multitude of formal and informal activities (i.e. recreational, active physical, social, skill-based and self-improvement) and described these across multiple dimensions (i.e. diversity, frequency and enjoyment).

Research in childhood disability has in the last decade made efforts to identify factors associated with leisure participation (2,6,8,46-51). However there remains a critical gap in our knowledge of the facilitators and barriers to leisure participation among children and adolescents with JIA. To date the assessment of correlates of social and physical activity in JIA has focused on disease-related characteristics such as disease activity, disease duration, disease subtype and disability/function (45). Therefore, existing studies adopted a narrow

medically driven perspective rather than one adopting a 'bio-psychosocial' approach to health, functioning and disability as illustrated by the ICF and ICF-CY models. The shortcomings of using the biomedical model of illness for analysis provided us with the incentive to expand the scope of potential predictors beyond the realm of pathology to include personal, social, family and environmental characteristics.

Measurement of participation, its barriers and facilitators are important components in the development of public health interventions (52).

1.2 Objectives

The general purpose of this study was to describe the patterns of participation in leisure and physical activity among children and adolescents with JIA, as well as identify associated factors (barriers and facilitators) related to the disease, the child (personal), the family and the environment. In order to better describe the patterns of leisure and physical activity among children and teenagers with JIA we first need to ascertain whether children and teenagers with JIA were involved in a variety of activities, how often and if they enjoyed these (Objective 1), and if their participation based on these various characteristics differed from children without JIA (Objective 2). To better understand how patterns of participation may differ between groups it is important to determine what intrinsic and extrinsic characteristics may be responsible for facilitating or hindering participation (Objective 3). Finally, our secondary aim was to determine how these facilitators may interact with each other to provide a

rudimentary conceptual framework of participation in leisure and physical activity in JIA. Specific goals and associated hypotheses are listed below.

Primary objectives

1) To describe the level of participation in leisure activities in terms of diversity, frequency and enjoyment, as well as the activity level and frequency of physical activity among children (8-11 years) and adolescents (12-17 years) with juvenile idiopathic arthritis;

2) To compare participation in leisure and physical activity among children (8-11 years) and adolescents (12-17 years) with juvenile idiopathic arthritis to comparator groups without juvenile idiopathic arthritis and to normative data.

3) To identify potential factors associated with participation in leisure and physical activity among children (8-11 years) and adolescents (12-17 years) with juvenile idiopathic arthritis such as: 1). body functions and structures (pain, disease activity, body mass index); 2). Activity limitations (level of disability/function), 3). Personal (age, sex, child's self-concept, child's mastery motivation, activity preferences, disease duration) and 4). environmental (cultural background, family functioning, family structure, mother's age, socio-economic status, treatment services received, perceived social support, perceived environmental barriers, proximity of local recreation facilities, affordability of activities, season).

Secondary objective

4) To explore moderating effects of disease activity, pain and socio-economic status on the potential effects of age, sex, motivation, athletic competence, physical appearance on involvement in leisure and physical activity.

1.3 Hypotheses

1) Children and adolescents will participate in more informal rather than formal types of activities, as well they will engage less frequently in physical activity in comparison to other leisure pursuits (i.e. recreational, social, self-improvement and skill-based).

2) Children and adolescents with juvenile idiopathic arthritis will participate less in active physical and social activities compared to children and adolescents without juvenile idiopathic arthritis and most (>80%) will not meet established health guidelines for physical activity.

3) Greater participation in leisure and physical activities will be associated with lower perceived pain, greater functional status, increased preference for activities, higher family socio-economic status, strong family functioning, accessible local recreation facilities and availability of affordable activities.

4) Children and adolescents with greater disease activity and of lower socio-economic status will be less motivated and show less preference for leisure and physical activity physical and skill-based leisure activities leading to decreased participation in these activities.

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2. Literature review

2.1 Juvenile Idiopathic Arthritis

In this section, I will describe JIA, its epidemiology and management.

2.1.1 Description and epidemiology

Juvenile idiopathic arthritis (JIA) is a chronic childhood autoimmune disease that has important implications on a child's physical health and psychosocial integration (1). JIA is a heterogeneous inflammatory condition, with periods of unpredictable flare and remission and no known cure (1). The diagnosis of JIA is given when inflammatory episodes persist for at least 6 weeks, with onset between 0 and 16 years of age (1). During periods of joint inflammation (i.e. active disease) children experience increased pain, fatigue, tender joints, and morning stiffness which may interfere with age-appropriate activities (mobility, self-care and leisure), both at home and at school (2,3). There are seven subtypes of JIA, as described by the International League of Associations for Rheumatology (ILAR) (1), these are: oligoarthritis (40-60% of cases), polyarticular rheumatoid factor negative (20-30% of cases), polyarticular rheumatoid factor positive (3% of cases), systemic onset (10-20% of cases), enthesitis related arthritis (2-4% of cases) and psoriatic arthritis (5 % of cases). The seventh category is known as undifferentiated arthritis and is used when the arthritis does not fit into

any of the above mentioned (1). Each of these categories presents with differing age of onset, frequency of symptoms, female to male ratio and joint involvement (type and number) (1).

On average, age at diagnosis is 9.8 years ± 4.6 years with a known female predominance (4). A reported 2:1 ratio of females to males is common among children and adolescents for most subtypes of JIA (1,5). The higher female to male ratio may be explained by a possible link with the level of androgen (hormone that is produced in the testes), where low levels of androgen may contribute to cartilage degradation pathogenesis (1). One third of those diagnosed with JIA will be afflicted with physical limitations, such as difficulties in fine motor tasks (eg. buttoning one's shirt) or gross motor (eg. climbing stairs) (6). Specific physical limitations in terms of muscle strength and fitness have been described. Broström et al. showed that young girls diagnosed with JIA, with active disease and lower-extremity involvement, had weaker plantarflexor and dorsiflexor muscles as compared with their age matched peers (7). In their review, Klepper et al. (2003) described that children with JIA have greater limitations in aerobic fitness and muscle strength when compared with healthy children, presumably caused by decreased physical activity secondary to disease symptoms (8). School age children with JIA (45.5%) and their parents (49.1%) reported the child's decreased participation in physical education classes, difficulties in mobility and decreased attendance in school (9). Longitudinal findings on children and adolescents with arthritis showed that after a median disease duration of 7 years, of those diagnosed with JIA, 30.6% were in remission (i.e. no signs of joint inflammation and without medication for two years or more), 20.2% presented with inactive disease (i.e. no signs of joint inflammation and without medication for less than 2 years), 30.6% had stable disease (i.e. disease well controlled by

medication) and 18.6% suffered from active disease (i.e. despite being on medication they continue to present with an increasing number of active joints) (10). Furthermore Packham et al. (2002) showed that five years following diagnosis, two-thirds of diagnosed cases were left with irreparable joint damage (6). Nearly 40% of cases diagnosed with juvenile rheumatoid arthritis suffer persisting limitations well into adulthood, including joint deformity and destruction, as well as osteopenia, which may result in pain, reduced mobility, difficulty with daily living and depression (6,11). These children and adolescents may also become depressed, experience low self-esteem, poor academic, social and athletic competencies, as well as encounter difficulties fostering peer relationships (12-14). Furthermore, it stands to reason that those living with more severe illness or functional limitations may be at greater risk for psychosocial maladjustment (12,15,16) and decreased participation in developmentally appropriate activities.

The worldwide prevalence of children with JIA varies from 0.02 to 0.40 percent of children and youth and incidence varies from 8 to 54 cases per 100 000 children and youth per year (17). Explanation for this tremendous variation in prevalence and incidence include differences in diagnostic criteria, varying quality of healthcare resources, differences in study design and study sample size (17). In Canada, JIA is among the most common chronic disabling diseases of childhood with a prevalence of 0.12 percent and incidence of 17.8 per 100 000 children and youth per year (17). An American population-based study showed that this disease was more prevalent in children (10 to 17 years) than both diabetes and epilepsy (18). Childhood arthritis was shown to result in greater financial burden than other more prevalent childhood chronic conditions such as asthma (18,19). One study showed that the

total difference in annual average medical costs for children and adolescents with JIA versus those with other chronic conditions (asthma, diabetes, epilepsy) was $1,686 (95% CI $875, $2,500) (19). Higher costs were associated with medication use, regular visits to specialists and allied health care professionals, and diagnostic tests. In addition, indirect costs such as annual parental salary losses averaged $1,241 in those with JIA (95% CI $693, $1,788) versus $404 for those with other chronic conditions (95% CI $192, $615) (19).

2.1.2 Treatment

The management of this disease is complex and involves a multi-disciplinary treatment approach (1). Among the healthcare professionals typically caring for children with JIA are the paediatric rheumatologist, nurse, physiotherapist, occupational therapist, and social worker. Other specialists such as orthopaedic surgeons, ophthalmologists, dentists and psychologists may also be consulted. Medication is often prescribed together with an exercise and/or splinting regimen. Drug therapy for JIA, although not always successful for patients with persistent joint inflammation, may include the prescription of nonsteroidal anti-inflammatory drugs (NSAIDs) such as naproxen, and disease modifying anti-rheumatic drugs (DMARDs) such as Methotrexate, Sulfasalazine, Hydrochloroquine, Leflunomide, Azathioprine, Cyclosporine. More aggressive treatment may involve the use of intra-articular injection of corticosteroids and biologic agents. Biologic agents such as Etanercept are made of genetically engineered proteins derived from human genes designed to inhibit specific components of the immune system responsible for joint inflammation (20). Their prescription may lead to further improvements in outcomes specifically for those with polyarticular

arthritis (20). Current rehabilitation (occupational therapy and physiotherapy) programs for children with JIA focus on improving muscle strength and flexibility through the use of orthotics and exercise regimens. Although physical activity is generally encouraged (21), habitual physical activity has yet to be incorporated into a comprehensive care plan (22). In fact, the goals of rehabilitation within this population need to extend from improving the physical limitations caused by the disease, to favoring functional abilities through daily exercises and adaptive equipment and finally to promoting the child's participation age-appropriate activities necessary for their development and well-being. There has been a shift in the focus of treatment in rehabilitation from treating only the impairment to improving function and participation. However tailored interventions to increasing participation in persons with JIA are limited, partly due to the limited knowledge of associated factors (23). Further research is needed to ascertain which factors related to both the person and their environment can be modified to improve participation.

2.2 Definition of key terms

2.2.1 Participation

Participation is defined by the WHO as 'the nature and the extent of a person's involvement in life situations and includes activities of self-care, mobility, socialization, education, recreation, and community life'(24) (p.123). Participation is an important aspect of health and is included as an integral component of the ICF and the ICF-CY endorsed by the WHO (24). For children participation occurs in their everyday life in activities of varying

difficulty within various social contexts (i.e. home, school, community) (25). Leisure is considered an important part of child participation (26), however has gained little attention in JIA (27).

2.2.2 Leisure

An important aspect of participation among children and adolescents is the involvement in play, extracurricular, recreational and leisure activities (26). Involvement in leisure activities plays an important role in children's development and health and deserves consideration (28). Leisure participation has been defined as the 'involvement in the formal and informal everyday activities of childhood in all types of non-school environments, including environments for play, sport, entertainment, learning, and religious expression'(29) (p.65). Formal or structured leisure activities are organized, supervised by a coach or instructor, impose time restrictions, and focus on skill building (30,31). Engagement in leisure and recreational activities is recognized as an important aspect of participation by those living with a disability, rehabilitation professionals and policy-makers (32). Participation in physical activities has also been shown to be important for health in children with disabilities (33) and will be described in the next section.

2.2.3 Physical activity

Physical activity is defined as: "Any bodily movement produced by skeletal muscles that result in energy expenditure." (34) (p.126), whereas exercise is defined as: "A subset of physical activity that is planned, structured, repetitive and purposeful in the sense that

improvement or maintenance of physical fitness is the objective."(34) (p.128). According to Pettee Gabriel et al.'s (2012) conceptual framework, physical activity can be grouped into four main activity types: 1). Leisure, 2). Occupational and school, 3). Household, domestic and self-care and, 4). Transport (35). Our study will focus on physical activity as it pertains to the level of movement (i.e. activity) throughout the day, therefore all these domains without distinction.

2.3 Benefits of participation in leisure and physical activity

Involvement in leisure and physical activity is beneficial to all children and adolescents including those with chronic health conditions and disabilities.

2.3.1 General benefits of leisure and physical activity

Participation in leisure activities provides enriching experiences, opportunities to develop cognitive and physical abilities, as well as social skills needed to foster relationships with family members, peers and others throughout life (36-38). Leisure offers a child the opportunity to freely explore new, meaningful and challenging activities; the possibility to choose the activity may afford them with a sense of control over their environment, may promote problem-solving, creative thinking (39), self-competence, self-efficacy and overall well-being (40). In general among children and adolescents, participation in organized leisure has been linked with better engagement in and enjoyment of academics (41,42), lower rates of school drop-out (38), stronger academic achievement, more frequent pursuit of post-secondary

education compared to peers less engaged in leisure (43-46) and prosocial behaviour (47). In contrast, it is suggested that pursuit of unstructured and unsupervised activities may result in deleterious behaviour such as drug and alcohol use (48). Despite this risk less formal leisure activities such as hanging out, going to the mall and going to the movies have also been found to help adolescents (aged 11 to 15 years) cope with stress as these activities are perceived as enjoyable. However, less socially engaging activities such as watching television or listening to music in their rooms is related to more avoidance coping behaviour (49). Furthermore, engaging in leisure activities with peers (i.e. on a team or as part of a club) is also associated with better social adjustment, less negative behaviour, less substance abuse and less loneliness (36,43,46,50).

Regular physical activity can help control weight gain (decreasing the risk for obesity), improve muscle strength, cardiovascular endurance and favour healthy bones (decreasing the risk for osteoporosis) in children and adolescents (51-56). In fact, several randomized control trials have shown that participation in weight bearing activities during a healthy child's growth period enhances bone mass, structure and strength (57-60). Similar positive effects on bone health were found among those with JIA (61,62).

2.3.2 Disease-specific benefits of leisure and physical activity

In addition to improving quality of life in terms of physical, social and emotional well-being among those with chronic conditions and disabilities (63,64) leisure and physical activity may also help to lessen the effects of disease symptoms. Physical activity may offer

anti-inflammatory properties against chronic low-grade inflammation found in chronic conditions such as certain cancers (e.g. breast cancer, colon cancer), cardiovascular related health problems and type 2 diabetes by reducing the levels of Tumor necrosis factor-alpha (TNF-α) (65-68). TNF-α is a cytokine involved in the inflammatory process. Moreover, positive effects of physical activity interventions have also been linked with improvement in physical disability and joint range of motion, reduction of the number of swollen joints and pain among children and adolescents with JIA (69-71). Leisure activities specifically geared to those living with JIA such as attending summer camps have resulted in participants' improved overall knowledge about their disease and its management, as well as better overall self-concept (72). Furthermore, some adolescents may also benefit from the social and emotional support provided by others living with arthritis and the opportunity to share their experiences (73,74), which may help them feel less isolated (74). Moreover, habitual participation in age-appropriate leisure activities with peers and family members may help normalize their health situation (75) and provide a healthy escape from their illness (76).

2.4 Methods and measurement tools

In the following sections, I describe methods of measuring participation in children and adolescents. I will address measurement of leisure and physical activity.

2.4.1 Leisure participation among children and adolescents

Studies assessing activity in children with JIA use daily diaries to provide qualitative information on the child's involvement in school, sports and social activities (75). Daily diaries have been used to elucidate the effects of daily pain and other arthritis-related symptoms on the level of participation (77), however these tools are not standardized and do not clearly reflect the construct of leisure participation. Other measures of leisure based on a specific conceptual framework must be explored.

Findings from a review conducted by Chien et al. (2014) demonstrated that a number of questionnaires assess participation in leisure among children and adolescents with or without disabilities (78). Results highlight how the items and activities of the Pediatric Activity Card Sort (PACS), the Pediatric Interest Profile (PIP) and the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children (CAPE/PAC) are most strongly representative of the leisure and recreation category of the ICF-CY (78). All are child self-report. For the most part they demonstrated adequate reliability, however the CAPE demonstrates the strongest validity (i.e. excellent construct validity) across a number of diagnoses (i.e. typically developing, acquired brain injury, cerebral palsy, developmental disorder, spina bifida, musculoskeletal disorder) (79). Moreover the CAPE/PAC has been used frequently in the study of leisure participation in childhood disability (80-88). The CAPE/PAC is designed to measure participation directly and to document what the child does and not how well the child performs activities or the degree of support required to complete

the activity. In addition to diversity and frequency, the CAPE/PAC measures enjoyment and activity preferences which may be helpful in identifying meaningful activities from which rehabilitation professionals may create an intervention plan.

2.4.2 Physical activity among children and adolescents

Although there is no gold standard to measuring habitual physical activity in children and adolescents there are advantages and disadvantages to using either self-report or objective electronic methods.

Traditionally, physical activity in children and adolescents has been assessed using self-report measures due to the ease of administration and low cost (89). Self-reported physical activity may suffer from potential response bias possibly linked with a social desirability bias, as well as recall bias in reliably estimating the frequency and duration of physical activity for children and adolescents (90,91). Research has demonstrated that activity monitors such as accelerometers provide valid and reliable measurement of physical activity behaviour throughout the day and for multiple days, which may therefore be better suited for use in children and adolescents (91-97). Furthermore, these small devices can be worn inconspicuously under clothing, which may be less bothersome to children and adolescents. Moreover, contrary to self-report measures, data collected electronically through accelerometer are not affected by recall bias and may provide a more accurate assessment of physical activity among children and adolescents (93). Nevertheless, these monitors present with certain drawbacks such as high cost, time consuming data download and difficulty in

assessing large numbers of children (98). Also, these devices are not recommended for wear during contact sports and do not accurately measure movement when cycling (99). Furthermore, older models are not waterproof and cannot assess activity when swimming (99,100).

In pediatric rheumatology, physical activity is mostly assessed using self-report or proxy measures (62,71,101-106), and to a lesser extent with motion and activity monitors (62,102-104,107). Furthermore, most of the self-report measures present with weak psychometric properties (12,62,71,77,102-106) and are not in-line with a set conceptual framework.

The next sections address participation in leisure and physical activity in healthy children and adolescents, those with chronic conditions and disabilities, and specifically those with JIA.

2.5 Participation in leisure and physical activity

2.5.1 Among healthy and typically developing children and adolescents

Outside of school, children spend most of their time in discretionary pursuits (108). In general, Canadian children and adolescents adopt sedentary behaviour over more active pursuits (e.g. as active free play, active transportation and organized sports) (109,110). This tendency for less active pursuits has become a public health concern. In fact, in 2014, Active

Healthy Kids Canada report card showed that only 7% of healthy children and youth (5 to 17 years) met current physical activity guidelines of 60 minutes of moderate to vigorous daily physical activity for optimal growth and development released by the Canadian Society for Exercise Physiology on January 24th, 2011 and endorsed by the Public Health Agency of Canada (110).

2.5.2 Among children and adolescents with a chronic condition and/or disability

Research supports that children and adolescents with physical limitations participate in fewer and less varied leisure activities in comparison to their healthy peers, where activities are often more home-based and less social (111-113). Findings from Law et al. (2006) study on leisure participation showed that children living with physical disabilities engaged in an average of only 3 out of 10 active physical activities assessed, these were: playing games, doing water sports and bicycling (82). Moreover they tend to engage in more quiet types of activities and less in socially driven or physically demanding activities (111). Adolescents with cerebral palsy were found to prefer physical activities that were less formal and less physically strenuous such as arts and crafts or playing computer or video games compared to adolescents without disabilities (114).

2.5.3 Among children and adolescents with juvenile idiopathic arthritis

Among children and adolescents suffering from chronic pain and those living with JIA the type, degree and quality of participation in social and recreation activities was found to be

below the normative data for their age level (115). Swimming and cycling were recognized as the most popular activities representing respectively 62% and 74% of participation among children and youth with JIA (116). Children with JIA tend to participate in more passive and less strenuous physical activities compared with their peers unaffected by disease (102,107,117). Younger children with JIA may experience decreased participation in play (28). Moreover, adolescents with JIA report limitations in participating in physical education classes (46.1%) and playing their favourite sport (35.9%) (118).

2.6 Factors associated with leisure and physical activity in children and adolescents

A myriad of factors related to the child, the family and the environment have been studied as possible barriers or facilitators to participation in leisure and physical activity among children and adolescents with and without chronic health conditions or disabilities. These are described in the following sections and are classified into personal factors, environmental factors, and factors related to chronic illness and disability.

2.6.1 Personal factors

Age and sex are often recognised as strong predictors of participation in leisure activities, however their association is dependent on the type of activity (81,82,84,108,119-121). In general, engagement in physical activity such as active play and organised sports

decreases as the child gets older (114,120,122-124), whereas more socially driven behaviour increases with age (123,125). Boys are commonly more physically active than girls (90,125-128), whereas girls take part more in social, skill-based and self-improvement activities than boys (108,120,121,123).

Many other personal barriers to participation in leisure and physical activity have been identified such as: body mass index mostly among boys (129,130), body image (119,129,131), physical and motor competence (90,132), social competence (47), perceived behavioral control (133), intention or motivation to act (81,90,132), self-efficacy (81,90,124,133-135), previous engagement in a given leisure activity (136), preference and enjoyment for the activities (90,137). These factors have yet to be explored in JIA.

2.6.2 Environmental factors

In line with the ICF-CY the child's environment (i.e. family, school, and community) plays an important part in promoting involvement in leisure and physical activity and may also mediate the effects of the child's personal attributes (138,139). A number of family characteristics have been identified as facilitators to participation specifically: higher family socio-economic status (i.e. higher family income, higher parental education) (82,83,119,122,124,129,140), parental support and encouragement for their child's participation in leisure (90,141-143), provision of transportation to and from activities (132), strong parental participation and interest for recreation and leisure (82,83,90,126,129,144). Furthermore, cultural background may influence the type and the frequency of leisure activity

(108,122). Support provided by peers, teachers, and other adults may also positively influence engagement in leisure activities, notably in physical activity (126,132,136,141,145-147). An overprotective style of parenting may lead the caregiver to discourage their child who is living with a chronic condition from participating in more strenuous and potentially more harmful types of physical activities, as seen in children and adolescents with JIA (148) and those with a history of prematurity (149). Structural barriers such as restricted access or lack of activities, the lack of available green spaces (137,150,151), negative attitudes fostered by others (75,132,152,153) and bad weather (137,154) may limit the child's level of participation. Moreover the lack of adapted and limited access to specialized activities may be of particular importance among children with development and physical disabilities possibly leading to feelings of isolation, boredom and fear (63,152,153). Proper provision of rehabilitation services may help towards improving access to adapted and specialized activities (81).

Although many theories support that environmental factors may be more significant determinants of participation than characteristics of the children themselves (29), these have yet to be assessed in JIA (27).

2.6.3 Factors related to chronic illness and disability

Barriers to participation in leisure related to the child's health issues such as injury, illness or other chronic medical condition, as well as fatigue have also been reported (132). Specifically among children and adolescents with physical disabilities greater physical dysfunction is associated with less participation in leisure activities (81,114,116,119). Clinical

manifestations such as chronic wheezing for children living with asthma have also shown to be correlated with decreased physical activity (155).

In JIA, disease related factors identified as barriers to physical activity are: a more recent diagnosis (i.e. often associated with more acute disease), higher number of swollen joints, and lower well-being. Factors hindering engagement in social activities are increased pain, joint stiffness and fatigue (27). Pain is a common and debilitating symptom of JIA and may restrict age-appropriate discretionary activities (77), and the more intense the pain the greater the risk for decreased physical, emotional and social functioning (118,156). A child experiencing pain due to illness may avoid certain activities not to exacerbate symptoms. This type of avoidance behaviour may be explained by a series of negative experiences that result in manifestation of this learned behaviour (157).

2.6.4 Studies on social and physical activity in JIA

Studies assessing involvement in social and physical activity in JIA have focused on exploring the potential influence of age, sex, functional status and disease related factors such as disease duration, active joint count, pain levels, fatigue and overall well-being (71,77,104,105,107). However none considered the potential impact of additional personal factors (e.g. self-perception, mastery motivation, activity preferences) and environmental factors (e.g. family functioning, perceived environmental barriers, socio-economic status, cultural background) on participation on leisure. Most studies completed simple correlation analysis between outcome and potential correlates (71,104,105,107). In fact, only Schanberg

et al. (2003) proposed a multi-level random effects model to assess the association of pain, stiffness and fatigue with social activity (77).

There are multiple factors associated with participation in leisure and physical activity. In the following sections, I will discuss conceptual frameworks that can be used in assessing participation and associated factors.

2.7 Conceptual frameworks used to assess health behaviour including participation in leisure and physical activity

In this section, I have chosen to describe theoretical frameworks that have commonly been used to describe behaviour surrounding participation in physical activity and leisure, and that consider intrinsic and extrinsic factors of potential influence. Generally, health behaviour change theories rooted in psychology have been used to explain health behaviour surrounding the involvement in leisure and physical activity in healthy pediatric populations (154,158-161). Many theories focus on the individual such as the social cognitive theory, the theory of reasoned action and the theory of planned behaviour, the health belief model and the transtheoretical model. Other conceptual frameworks such as the social ecological theory and the hierarchical model of leisure constraints highlight the role of the environment in behaviour change, and explore the interaction between the person and the environment (i.e. social, cultural, physical and institutional aspects) (162,163). These models are described below.

2.7.1 Social cognitive theory

Bandura's social cognitive theory suggests that an individual's behaviour is influenced by reciprocal relationships between the person's self-efficacy, outcome expectation and self-regulation, as well as perceived social and physical environmental barriers and facilitators to action (134,164). Self-efficacy is the person's belief that they can complete activity and achieve their goal (134).

2.7.2 Theory of reasoned action and theory of planned behaviour

The theory of reasoned action supports that the intention to act determines the person's behaviour (165). The intention to act is predicted by the individual's attitude toward the behaviour (i.e. how important and valuable the behaviour is to the person) and subjective norms (i.e. perceived social demands to perform the behaviour or not) (165). The theory of planned behaviour extends the theory of reasoned action by incorporating the concept of perceived behavioural control as a third determinant of intention. The belief that the person can perform the behaviour may reflect the person's given skills, past experiences, opportunities and available resources to engage in the given behaviour (165).

2.7.3 Health belief model

The health belief model postulates that health related behaviour is influenced by many factors such as the perceived susceptibility to developing a health problem, the perceived severity of that health problem, the person's level of confidence to take action (i.e. self-efficacy), the perceived benefits of and barriers to action, the person's level of confidence to take action despite barriers (i.e. self-efficacy), as well as the person's readiness for action (i.e. cues to action based on intrinsic and extrinsic factors) (166).

2.7.4 Transtheoretical model

The transtheoretical model illustrates how behavioural change is dictated by the person's readiness to change and involves the following phases: precontemplation (i.e. no present intent to change behaviour), contemplation (i.e. problem recognised and strong consideration to change behaviour), preparation (i.e. partial diminishment of negative behaviour without reaching effective levels of change), action (i.e. the person has altered their behaviour, experiences and environment to facilitate positive behaviour change) and maintenance (i.e. sustaining behavioural change and avoiding relapses into the negative behaviour) (158,167). According to the transtheoretical model individuals move cyclically through stages until they are able to maintain the healthy behaviour (167).

2.7.5 Socio-ecological model

The socio-ecological framework underlines how determinants of a person's health behaviour may be found at various levels of human ecology, such as at the individual/personal, intra-individual/social, organizational/institutional, community, and policy levels (168). The model recognizes that the social environment may also play a role in altering health behaviour (168). In this thesis, we have used this model to inform our search of potential predictors of leisure and physical activity.

2.7.6 Hierarchical model of leisure constraints

Crawford et al.'s (1991) hierarchical model of leisure constraints illustrates how barriers to leisure appear hierarchically. First, at the intrapersonal level (i.e. stress, depression, anxiety, religious belief, prior participation in the leisure activity, group attitudes, perceived self-skill, perception of the availability and appropriateness of the leisure activities) (163). Then interpersonal constraints may arise when the activity in question requires multiple participants or collaboration with at least one more person (163). Finally, structural obstacles may also hinder participation (i.e. family functioning, family financial resources, time to participate in the leisure activity, availability of leisure activities and attitudes of others (i.e. family, peers, classmates, community members)) (163).

2.7.7 International Classification of Functioning, Disability and Health (ICF)

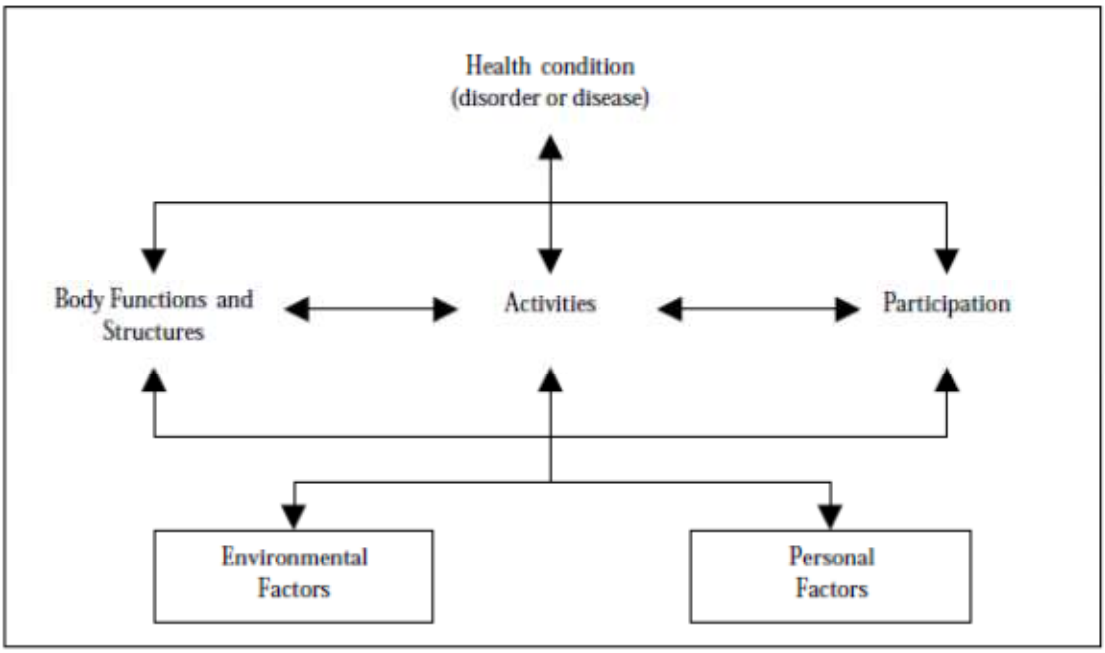
Living with a chronic health condition or disability may further influence engagement in activities. Therefore, considering the biological effects of disease, the person, the family and the environment (i.e. community, school), as well as the potential interactions between these components may better explain participation in leisure and physical activity. The ICF takes account of the social model of disability (169), which regards disability as resulting from the interaction between individuals and their environment.

Participation is a key component of the ICF published by the WHO. The ICF provides a framework whereby we can quantitatively identify not only the contributions of disease-related determinants to the state of the disease, but also underlines personal and environmental factors as important determinants of overall health (24,75). The ICF favours a 'bio-psychosocial' approach to health, functioning and disability to ensure that individual and social perspectives of health, as well as those related to biology are considered (24) (p.28). The ICF model contends that individuals with similar levels of intrinsic impairment will achieve differing levels of participation in different settings.

The three levels in the ICF are body function and structure, performance of personal activities, and participation in communal life, as influenced by environmental factors and personal factors (Figure 1). The ICF recognizes that disability is a universal human experience and shifts the focus from its cause to the impact it has on the lives of people in society. The frequency of participation and the presence of barriers and facilitators are

important components of its measurement specifically in terms of public health intervention (170).

Figure 1: International Classification of Functioning, Disability and Health (24) (p.18).



The international classification of functioning, disability and health for children and youth (ICF-CY) is an extension of the ICF and was created as a child and youth version of the ICF to contend with the various developmental needs of children and youth. It applies to those aged from 0 to 17 years and considers various aspects of children's participation in everyday life as influenced by various contextual factors (138).

2.7.8 Conceptual model of recreation and leisure participation in children with disabilities

King et al. (2003) proposed a multi-level model that extensively describes various determinants of participation in both leisure and physical activity among children with limitations in physical function. The determinants are related to the child (child's self-perception of athletic and scholastic abilities, child's cognitive and physical function, child's ability to communicate, child's activity preferences), the family (time and financial constraints on the family, parent's education and employment, family income, supportive home environment and family preference for recreation) and the environmental (supportive physical and institutional environments, presence of supportive relationships for the child) (29) (p.74-80). Motivation and the family's cultural background are also highlighted in King et al.'s review as potential predictors of leisure participation (29).

Although we were also inspired by other theoretical models to help explain participation in leisure and physical activity the ICF-CY was best suited to our population and our intention of incorporating the health condition, as well as personal and environmental factors. For the present study we chose to include predictors informed by the literature in JIA, King et al's (2003) model of leisure participation and the ICF-CY framework.

As illustrated by the ICF-CY *participation* in leisure and physical activity among children and adolescents with JIA may be associated with the following components: *health*

condition (i.e. JIA), *basic structures and functions* (pain, disease activity, BMI); 2). *activity* (level of function in daily life, mobility, self-care), 3). *personal* factors (self-concept, mastery motivation, activity preferences, disease duration) and 4). *environmental factors* (cultural background, family functioning, family structure, mother's age, socio-economic status, treatment services received, perceived social support, perceived environmental barriers, proximity of local recreation facilities, affordability of activities, season).

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3. Methods

We had three main objectives: 1) to describe the participation in leisure and physical activity among children and adolescents with JIA; 2) to compare participation in leisure and physical activity among children and adolescents with JIA to children and adolescents without arthritis and to normative data, 3) to identify the factors associated with participation in leisure and physical activity in JIA. Before embarking on these, we first undertook a systematic review of the literature to assess the state of knowledge in leisure and physical activity among children and adolescents with JIA. To achieve our study objectives we researched participation in leisure and physical activity through the analysis of population-based survey data from a nationally representative sample of Canadian children with arthritis, as well as the standardized self-report assessment of leisure participation and the objective measurement of physical activity among a clinical sample of children and adolescents with JIA followed at the Rheumatology clinic at the Montreal Children's Hospital, McGill University Health Center. These methods were used to allow for a more complete picture of participation in leisure and physical activity in JIA, and to enable us to gather information on a number of potential predictors across a wide range of activity types. A detailed description follows for each of these components.

3.1 Systematic literature review

We conducted a systematic literature review to determine the current state of knowledge regarding participation in leisure and physical activity among children and adolescents living with JIA.

We systematically searched for key words pertaining to leisure in JIA (Appendix 1) in the following electronic databases: MEDLINE (1946 to Present), CINAHL (1982 to December week 1 2013), Base de Données en Santé Publique (June 2013), ERIC (1965 to April 2013), Health and Psychosocial Instruments (1985 to April 2013), OT Seeker (June 2013), PsycINFO (1806 to May Week 3 2013), EMBASE (1974 to 2013 Week 21), Cochrane Database of Systematic Reviews (2005 to March 2013), ACP Journal Club (1991 to April 2013), Database of Abstracts of Reviews of Effects (2nd Quarter 2013), Cochrane Central Register of Controlled Trials (March 2013) and Cochrane Methodology Register (3rd Quarter 2012). Key term selection was guided by using a PICOS (population, intervention, comparator, outcome, study design) framework (1-3).

Quantitative studies pertaining to participation in habitual leisure activities among youth with JIA and other rheumatic diseases (aged 0 to 21 years) were retained, whereas those reporting exclusively on participation in exercise programs done during school classes or as part of a regimented exercise program in a controlled setting (laboratory) were excluded. All diagnostic classifications provided by the International League of Associations for

Rheumatology (ILAR), the European League Against Rheumatism (EULAR) or the American College of Rheumatism (ACR) were accepted.

Selection of articles based on the inclusion criteria and abstraction of pertinent information were completed independently by two researchers. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement was used to inform reporting of this systematic review (4). These same two researchers together with a third researcher systematically appraised the retained articles using the Quality Assessment Tool for Quantitative Studies (5).

3.2 Study samples

Our study samples include two cohorts of children and adolescents living with juvenile arthritis. The first is a sample of participants gathered through a post-census survey from across Canada and the second is a clinically-based sample. The first cohort allowed us to obtain information on leisure participation in a representative sample of Canadian children with JIA. The clinically-based study allowed us to explore in more detail the patterns and factors associated with leisure participation, as well as engagement in physical activity. It should be noted that both samples have different characteristics (i.e. different age range, proxy-reported diagnosis of arthritis versus diagnosis given by a pediatric rheumatologist). Furthermore, in our clinical study we also collected objective data on physical activity (using an accelerometer), for a subsample of our cohort, which was compared to children and

adolescents without JIA from a different study (QUebec Adipose and Lifestyle InvesTigation in Youth).

3.2.1 Population-based study

3.2.1.1 Sample description

The study sample consisted of children aged 5-14 years living across Canada for whom parents (or caregiver) were interviewed over the telephone to complete the Participation and Activity Limitation Survey (PALS) post-census survey in 2006 and for whom a parent indicated that their child was diagnosed with arthritis. Parents were asked about their child's participation and limitations in leisure activities. All post-census data were collected prior to the start of the doctoral candidate's project. The PALS sample included all persons who reported the presence of a disability (yes, sometimes; yes, often) on one or both of the two 2006 census filter questions regarding disability and activity limitations who were living in private and collective households in the 10 provinces and 3 territories in Canada (excluding persons living in institutions and on First Nations reserves). A subgroup of participants was randomly selected for enrollment following the 2006 census. The study data were then weighted in order to be better representative of the target population (6) (p.146).

3.2.1.2 Study design

We conducted a secondary analysis of the cross-sectional data from the PALS. The data were obtained from databases managed by Statistics Canada, which adopted the following methodology and practices to limit sampling errors: pilot testing to assess survey processes, training interview staff to limit non-responses and exhaustively tested editing rules were applied to assess inconsistencies in data responses (7).

3.2.1.3 Outcomes

Our main outcome is participation in leisure specifically for sedentary, active physical, non-sport skill-based activities, formal and informal activities. Scores for diversity (number of different activities completed) and frequency of participation (how often one participates in the activity) were calculated.

3.2.1.4 Independent Variables

Of the available post-census data we retained information on the following independent variables for our analysis: body functions and structures (i.e. pain), function (i.e. limitations in mobility, limitations in hand use), child's personal characteristics (i.e. age, sex, disease duration) and environmental factors (i.e. annual household income, use of rehabilitation services, medication use, availability of assistance for activities, lack of transport to and from leisure activities, affordability of leisure activities).

3.2.1.5 Analysis

The association between the diversity and frequency of participation in active physical, sedentary and non-sport skill-based, as well as formal and informal types of activities (dependent variables) and the child's age, sex, disease duration, annual family household income before taxes, function (as described by the level of restriction in mobility and in using hands), reported pain, weekly medication use, and use of rehabilitation services were explored using multivariate linear regressions. In order to properly assess the complex survey data, analyses were completed using the SAS-callable SUDAAN for Windows program (release 9.0.0) (8).

3.2.2 Clinically-based study

3.2.2.1 Sample description

Participants for the clinically-based study were recruited during their regular visit at the Rheumatology clinic of the Montreal Children's Hospital, McGill University Health Centre between October 2010 and June 2012. The doctoral candidate was responsible for recruitment, follow-ups with participants and data management.

Inclusion criteria for enrollment of children and adolescents into the study were: 1) were 8 to 17 years (children 8 to 11 years and adolescents 12 to 17 years); 2) had a clear diagnosis of JIA made by a rheumatologist; 3) were actively followed in the rheumatology

clinic at the hospital and seen every 3 to 4 months; and 4) were able to speak and write either English or French. The age range was specified to include those 8 to 17 years of age, as children within this age group are capable of understanding the format and the content of the study questions, have the needed attention span to respond to questions, allowing them to report their own perceptions and opinions accurately with minimal parental involvement (9).

Ethical approval was obtained from the Montreal Children's Hospital's Research Ethics Board, as well as the *Comité d'Éthique de la Recherche en Santé*, *Université de Montréal* (Appendix 2).

3.2.2.2 Study design

We used a cross-sectional design for our clinical study. Patients with JIA and their parents were recruited at their scheduled visit at the Montreal Children's Hospital Pediatric Rheumatology clinic. The study was described to them, and, if they agreed to participate, the patients and their parents signed assent (Appendix 3) and consent (Appendix 4) forms, respectively. Children and adolescents with JIA and their parents were asked to complete a battery of questionnaires. Data were obtained from parental reports, physician evaluations abstracted from the chart, and, self-report from the children and adolescents. Data on the level of participation in leisure and physical activity among children and adolescents were collected through both self-report questionnaires with assistance as needed from the research assistant and objectively with accelerometers. Information on personal and environmental factors was gathered from both children and parents through standardized and validated self-report questionnaires. When possible, we recruited a

sibling without JIA ranging in age from 8 to 17 years with a maximum age difference of 3 years from the JIA patient's age. If the sibling agreed, he or she signed assent forms (Appendix 5) brought home by the parent.

3.2.2.3 Outcome Measures

The main outcomes measured are participation in leisure and physical activity. We used a self-report questionnaire and accelerometer to assess each of these outcomes, respectively. These are described in detail below.

3.2.2.3.1 Children's assessment of participation and enjoyment

Leisure participation was assessed using the self-administered version of the Children's Assessment of Participation and Enjoyment (CAPE) (Appendix 6) with assistance provided by an experienced research assistant (10). The intraclass correlation coefficients (ICC) of the self-administered version and the interview-assisted version which uses activity and category cards, as well as visual response pages are highly correlated (ICC > 0.80) for participation intensity scores (i.e. frequency) (10).

The CAPE is a standardized 55-item questionnaire designed to examine how children and youth ranging in ages from 6 to 21 years, with or without physical disabilities, participate in physical and other more sedentary leisure activities (10). It takes 30 to 45 minutes to complete. Data on the following dimensions of participation in active physical and leisure

activities is collected: diversity (i.e. number of activities done by domain) and intensity (i.e. frequency of participation measured on a 7-point ordinal scale). In addition, the CAPE measures enjoyment of activities. The CAPE has good internal consistency for diversity and intensity scores with Cronbach's alpha scores ranging from 0.67 to 0.84 and good test-retest reliability scores of participation intensity with Cronbach's alpha scores ranging from 0.72 to 0.81 (10,11). The CAPE demonstrates good construct validity (r=0.71), when compared to other measures of leisure participation (10). The CAPE has been administered to children and adolescents with JIA in a previous study as part of a heterogeneous sample for which specific JIA results were not reported (12). One major strength of the CAPE is that it allows for child self-report (10). The CAPE is child friendly in that it can allow the child to express the impact of disease on their participation. Children and youth report (with help from parent/caregiver or research assistant as needed) what activities they have participated in within the last four months and how often. The frequency of participation in activities is measured by the frequency of completing a specific activity, where '1' corresponds to 'once in the past 4 months' and '7' corresponds to '1 time a day or more' divided by the total number of items. A higher score is related to a greater level of participation. There are three levels of scoring for the CAPE: overall participation scores; scores for two domains (formal and informal activities); and scale scores for five types of activities (recreational, active physical, social, skill-based, self-improvement).

3.2.2.3.2 ActiGraph GT3X accelerometer

In addition, physical activity was measured objectively with accelerometers. The ActiGraph GT3X accelerometer (ActiGraph LLC, Florida) was used to measure the activity level, duration and time of day of physical activity performed daily. The ActiGraph GT3X accelerometer is a small device weighing 27 g and measuring 3.8 × 3.7 × 1.8 cm. It can record acceleration in the vertical, horizontal and diagonal planes ranging from ~0.05 to 2G in magnitude. Participants with JIA were asked to wear the device around their waist (held with an elastic belt) over their right hip for seven consecutive days (5 weekdays and 2 consecutive weekend days), as well as complete a log informing on wear and non-wear times specifying reasons for removal. It was only to be removed overnight and when swimming, showering or bathing. Converging findings support that 4 to 7 days of objective physical activity monitoring are required to reliably estimate daily physical activity in children and adolescents (13). The raw accelerometer data registered in the vertical axis were collected over a 7 day period and were expressed as movement counts per minute and uploaded using the ActiLife analysis software program (version 5.8.3 Copyright© ActiGraph 2011). Cut-points based on movement counts per minute used specifically for children were applied to the data to describe the following physical activity levels: sedentary (≤ 100 counts*min^{-1}), light physical activity (>100 counts*min^{-1}), moderate physical activity (≥ 2296 counts*min^{-1}) and vigorous physical activity (≥ 4012 counts*min^{-1}) (14,15). Its output is a 'count' of the accumulated, filtered changes in acceleration (1 count= 0.001664 g, where g= 9.806 m/s^2). Norms for healthy children and adolescents are available (16). Accelerations are converted into movement counts recorded per 5 second intervals or epoch transformed into 60 second epochs. Smaller

epochs are often recommended for the initial recording of physical activity among children and adolescents as activity in this population is often characterised by short, intermittent and unpredictable bouts of movement (17).

The inter-instrument reliability of the ActiGraph GT3X accelerometer is excellent (ICC = 0.96 – 0.99, CI 95%: 0.81 – 0.99) and concurrent validity of the accelerometer count data and VO_2 max is fair to good ($r = 0.67$, $p < 0.001$) when assessing walking in children with cerebral palsy (18). The calibration of the accelerometer was verified before its use with participants by securing the accelerometer to a standard laboratory shaker for 15 minutes each at low, moderate and high speeds (19). Coefficients of variation between accelerometers lower than 10% for all units represent an acceptable variability between measurement devices, which meant that re-calibration was not necessary.

3.2.2.4 Independent study variables

In our clinical study, a series of questionnaires were completed by children with JIA and their parents to gather information on potential predictors of participation in leisure and physical activity, such as mastery motivation, self-concept, activity preference, functional limitations, pain, and perceived social support.

Only the parent was asked to respond to a series of questionnaires informing on the level of family functioning, the impact of physical, social and attitudinal environments on the

child's participation and socio-demographic characteristics (i.e. family income, parental level of education, cultural background, and family structure).

The most recent disease-related information was abstracted from the rheumatologist's report in the medical file. The child's disease severity was assessed and recorded by the pediatric rheumatologist at each visit in terms of active joint count (ajc) and other arthritis related clinical presentations (i.e. rash, arthritis induced fever, enthesitis). Disease was further characterised by sub-type and disease duration. Information on rehabilitation services was also obtained from the child's hospital record.

3.2.2.5 Study questionnaires

3.2.2.5.1 Dimensions of Mastery Questionnaire

The child's and adolescent's mastery motivation behaviours were measured through self and proxy report (parent/caregiver) using the Dimensions of Mastery Questionnaire (DMQ) (Appendix 7). The DMQ is a 45-item, self-report, questionnaire and takes approximately 10 minutes to complete. It measures mastery motivation, which is defined as a psychological force stemming from the child's desire to master tasks for personal satisfaction (intrinsic motivation) rather than for an extrinsic reward (20). This measure evaluates the child's persistence at object-oriented tasks, gross motor tasks, social persistence with adults and with other children, and also measures mastery pleasure and general competence (20). Items are rated on a 5-point scale (parents: "not at all typical" to "very typical"; child: "not at

all like you" to "very much like you"). Ratings are summed to produce the raw scores. There are 7 subscales and 2 summary scores. Norms are available for each subscale. The DMQ has good to very good internal consistency (11) with Cronbach's alpha scores ranging from 0.68 to 0.89 with a median of 0.84 (20). Discriminant and concurrent validity are not reported.

3.2.2.5.2 Self-Perception Profile

The Self-Perception Profile (SPP) for children (age range = 8 to 12 years) and adolescent (age range = 13 to 18 years) uses a core set of 36 self-reported items to measure personal perception of competence (Appendix 8). The domains assessed are those related to personal perceptions of academic and athletic competence, social acceptance, physical appearance and behaviour, as well as overall self-worth. The 45-item adolescent version, for those 13 to 18 years of age, assesses three additional subscales, job competence, romantic appeal and close friendship. In either version, each item consists of two opposite descriptions, for example "Some kids often forget what they have learned" but "Other kids are able to remember all things easily". Children and teens have to choose the description that best fits them and then indicate whether the description is *somewhat true* or *very true* for them. Accordingly, each item is scored on a four-point scale with a higher score reflecting a more positive view of one's self. For each of the self-concept subscales and for the global self-worth scale, a total score is computed by summing relevant items (9,21). This instrument shows good to very good internal consistency with Cronbach's alpha scores ranging from 0.71 to 0.86 and 0.74 to 0.93, respectively for the child and adolescent version (9,21). Factorial validity is supported as all the designated subscales define very separate and discrete factors

with factor loadings no lower than 0.3 and without any overlapping correlation (21). No other results on validity are reported. This test takes 15 to 20 minutes to complete.

3.2.2.5.3 Preferences for Activities of Children

The Preferences for Activities of Children (PAC) was completed by the child to further characterize activity preference (10) (Appendix 9). Participants classify each of the activities on the CAPE as those they would really like to do, sort of like to do, or prefer not to do at all (scores range from 3 to 0). The PAC may enable us to determine whether the activities children and adolescents most prefer are indeed the activities that they participate in. The PAC is reliable with good to very good internal consistency scores: Cronbach's alpha ranging from 0.78 to 0.84 for domain scores (i.e. formal and informal) and 0.67 to 0. 77 for activity type scores (i.e. recreational, active physical, social, skill-based, self-improvement) (10). Content validity has been established (10). This test takes 10-15 minutes to complete.

3.2.2.5.4 Childhood Health Assessment Questionnaire

Data on functional ability in children with arthritis was collected using the Childhood Health Assessment Questionnaire (CHAQ) (22) (Appendix 10). This tool is widely used in JIA and comprises disability and discomfort sub-scales. The CHAQ shows very good internal reliability with Cronbach's alpha = 0.94 and good test-retest reliability ICC=0.8 (23). The construct validity was demonstrated by fair to good correlations of the CHAQ averaged score on all functional areas with Steinbrocker functional class (r = 0.77), number of involved joints

(r= 0.67) and morning stiffness (r = 0.54) (23). The CHAQ comprises 30 items that explore eight domains, where questions are grouped into the following categories: dressing and grooming, arising, eating, walking, hygiene, reach, grip and activities. For each item, there is a four-level scale scored from 0 to 3 representing "no difficulty" to "unable to do" (24). The CHAQ is an appropriate measure of function and may be used in research, as well as in a clinical setting (23). The child's perceived level of pain is rated using a 100 mm visual analog scale (VAS) anchored by 0 (no pain) and 10 (very severe pain) (25). The CHAQ takes approximately 15 to 20 minutes to complete.

3.2.2.5.5 Social Support Scale

Social support from relationships that may facilitate participation in leisure and physical activity was measured using the self-report Social Support Scale for children and adolescents (SSS) (8-18 years) (26) (Appendix 11). This instrument collects data on social support from four sources: parents, teachers, friends and classmates (26). The internal consistency is good to very good with Cronbach's alpha scores ranging from 0.72 to 0.88 (26). Construct and convergent validity were demonstrated (26). It takes approximately 10 to 15 minutes to complete.

3.2.2.5.6 Family Environment Scale

The Family Environment Scale (FES) is a self-report assessment completed by parents (27) (Appendix 12). It collects data on child and family health, formal and informal sources of

support and community involvement within the family environment, as well as family relationships. This measure has ten subscales measuring three dimensions of social environment of the family: relationship, which relates to cohesion and conflicts; personal growth, which relates to self-sufficiency and achievement; and system maintenance, which relates to organization and control. The personal growth domain highlights the level of participation in social and recreational activities, the level of independence and achievement that are encouraged within the family. This questionnaire has been used in JIA research (28,29). The FES has good internal consistency for all 10 subscales with Cronbach's alpha scores ranging from 0.61 to 0.78 (27). Test-retest reliability ranges from fair to very good with scores ranging from r = 0.52 to r = 0.89 (27). Construct and discriminant validity were demonstrated (27). It takes approximately 20 to 30 minutes to complete.

3.2.2.5.7 Child and Adolescent Scale of Environment

The Child and Adolescent Scale of Environment (CASE) is a self-report questionnaire completed by parents/caregivers consisting of 18 items pertaining to the impact (how much of a problem) of physical, social and attitudinal factors in the child's home, school and community, as well as the quality and availability of services (Appendix 13). Problems are rated on a 3-point ordinal scale, where 1 = no problem, 2 = little problem and 3 = big problem. It takes respondents approximately 5 minutes to complete (30). A total score corresponds to the sum of item scores divided by the maximum possible score. Higher scores indicate greater environmental problems. The maximum possible score for the CASE is 54 (30). The CASE has good test retest reliability (ICC = 0.75) and excellent internal consistency (Cronbach's

alpha = 0.91). Construct and discriminant validity were demonstrated (31). It takes 10 to 15 minutes to complete.

3.2.2.6 Analysis

Descriptive data were used to compare characteristics of participants and non-participants. We described leisure participation measured by the CAPE in terms of diversity, frequency (i.e. CAPE intensity scores), and enjoyment of involvement in leisure activities. We described physical activity measured by accelerometer in terms of activity level, frequency and duration. Paired t-tests were conducted to compare leisure participation (CAPE mean scores) between the participant with JIA and their nearest-age matched sibling without JIA. Physical activity in the JIA group was compared to a group of children and adolescents without JIA obtained from a different study (i.e. QUebec Adipose and Lifestyle InvesTigation in Youth) using mixed modeling. We used bivariate analysis to compare these outcomes (i.e. leisure and physical activity) by participant characteristics (i.e. age, sex, disease activity, pain, disease duration, function and BMI). The differences between groups were assessed using t-tests for continuous variables and chi-square analysis for categorical variables.

A series of regression models using hierarchical analysis were used to analyse each group of independent variables associated with the various components of the ICF-CY to explore their association with participation in leisure and physical activity. Leisure and physical activity were modeled as a function of 1) basic structures and functions (pain, disease activity, BMI); 2) activity limitations (level of disability/function), 3) personal factors (age,

sex, child's self-perception, child's mastery motivation, activity preferences, disease duration), and 4) environmental factors (cultural background, family functioning, family structure, mother's age, maternal education, median neighborhood income, number of arthritis medication prescribed, rehabilitation services received, child's perceived social support, parental perceived environmental barriers, season) (Figure 1, Article 4; Figure 1, Article 5).

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4. Results by article

The results for this thesis will be presented with the following 5 articles:

Article 1

Leisure in children and adolescents with juvenile idiopathic arthritis: A systematic review.

Sabrina Cavallo, Karine Toupin April, Viviane Grandpierre MA, Annette Majnemer, Debbie Ehrmann Feldman

Article 2

Participation in leisure activities among Canadian children with arthritis: Results from a national representative sample

Sabrina Cavallo, Annette Majnemer, Barbara Mazer, Gevorg Chilingaryan, Debbie Ehrmann Feldman

Article 3

Participation in leisure activities by children and adolescents with juvenile idiopathic arthritis

Sabrina Cavallo, Annette Majnemer, Ciarán M. Duffy, Debbie Ehrmann Feldman

Article 4

Personal and environmental factors associated with leisure participation among children and adolescents with juvenile idiopathic arthritis

Sabrina Cavallo, Annette Majnemer, Ciarán M. Duffy, Debbie Ehrmann Feldman

Article 5

Physical activity in children and adolescents with juvenile idiopathic arthritis and associated factors

Sabrina Cavallo, Marie-Ève Mathieu, Annette Majnemer, Désirée B. Maltais, Ciarán M. Duffy, Mélanie Henderson, Debbie Ehrmann Feldman

Article 1

Leisure in children and adolescents with juvenile idiopathic arthritis: A systematic review

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Cavallo, S., April, K. T., Grandpierre, V., Majnemer, A., & Feldman, D. E. (2014). Leisure in children and adolescents with juvenile idiopathic arthritis: A systematic review. *PLoS ONE, 9*(10), e104642. doi: 10.1371/journal.pone.0104642

Author contributions: The PhD candidate completed the entire systematic search of the literature, reviewed, selected and appraised all included articles, and wrote the entire manuscript. Dre. Feldman contributed through discussions about study appraisal and provided feedback on several drafts of the manuscripts. Dre. April and Miss Grandpierre contributed to reviewing and appraising the selected studies, as well provided feedback on the final draft of the manuscript. Dre. Majnemer provided feedback on the final draft of the manuscript.

Abstract:

Objectives: The aim of this systematic review is to describe participation in social and physical leisure activities among children and adolescents with JIA, as well as identify potential determinants of leisure participation.

Methods: Electronic databases were systematically searched for articles published up until June 2013 pertaining to participation in leisure activities among youth with JIA and other rheumatic diseases. Studies were included if they measured involvement in either social or physical leisure activities. Selection and quality appraisal of articles were completed independently by two authors.

Results: Eight hundred and ninety-three articles were found through electronic and reference search. One hundred and nine full articles were reviewed to assess for eligibility. Twelve articles met inclusion criteria and findings were reviewed. Most focused on describing participation in physical rather than social activities. Results suggest that youth with JIA participated less in both social and physical leisure activities as compared to healthy peers, and those with JIA did not meet national recommendations for physical activity. Potential determinants of leisure participation were socio-demographic (age, sex), anthropometric (height, weight) and disease-related (JIA subtype, disease duration, pain, number of swollen or painful joints, stiffness, fatigue, well-being) factors.

Conclusion: Characterization of leisure activity remains limited and mostly focused on physical activity in JIA. Assessment of more comprehensive outcome measures is warranted to obtain a better description of leisure in this population. Evidence of the influence of contextual factors as potential determinants of involvement in leisure among children with pediatric rheumatologic diseases is needed.

Introduction

Juvenile idiopathic arthritis (JIA), which includes juvenile rheumatoid arthritis (JRA), is one of the most common chronic conditions of childhood (1). Children and adolescents with JIA are at greater risk for adopting a more sedentary lifestyle compared to their healthy peers in part due to disease related factors such as pain, fatigue, swollen and stiff joints (1,2). In the past decade there has been a growing interest for the study of leisure participation in children with disabilities. However this concept has been vastly understudied in youth with pediatric rheumatologic diseases.

Leisure participation has been defined as the 'involvement in the formal and informal everyday activities of childhood in all types of non-school environments, including environments for play, sport, entertainment, learning, and religious expression' (3) (p.65). Participation in leisure activities is of critical importance in childhood and adolescence to maintain a fit lifestyle, develop friendships, engage in focus-oriented activities, as well as acquire cognitive and social skills important for development (4,5). If participation in leisure activities remains limited on a long-term basis, children and adolescents may not have enough social contacts with peers, may be less able to make friends, experience greater social isolation, and may be at greater risk for depression (6). Furthermore, engagement in active physical activities is important for physical and cardiovascular health.

Participation is a key component of the International Classification of Functioning, Disability and Health (ICF) endorsed by the World Health Organization (WHO) (7). As depicted in the

ICF, a child's participation in leisure may be influenced by various factors to include those related to the health condition (e.g. disease severity), as well as personal (e.g. age, sex) and environmental (e.g. accessibility to services) (7,8). Most of the existing literature in JIA focuses on describing the level of involvement and benefits of exercise or physical activity programs on health outcomes such as quality of life, physical function and fitness, as well as other JIA related disease outcomes (e.g. number of swollen joints and bone mineral density) (9-13), as well as describing the level of involvement. However limited research has been done in the broader area of leisure participation in JIA.

The main purpose of this systematic review was to describe involvement in social (e.g. outings with friends and/or family) and physical (e.g. sports, biking, swimming, etc.) leisure activities among children and adolescents with JIA. It reports on the type and frequency of these activities as compared with either healthy controls, normative data or health guidelines. A secondary objective was to identify potential socio-demographic, disease-related, personal and environmental determinants of leisure activities in children and adolescents with JIA.

Materials and methods

Literature Search

The first author (SC) devised an electronic search strategy (Appendix 1) in collaboration with a librarian. The librarian also assisted in identifying the appropriate key terms for the systematic review and reviewed the final search strategy to ensure correctness. An example of the detailed search strategy formatted for the MEDLINE database with all key words is

provided (Appendix 1). In addition to MEDLINE (1946 to Present), we searched the following electronic databases: CINAHL (1982 to December week 1 2013), Base de Données en Santé Publique (June 2013), ERIC (1965 to April 2013), Health and Psychosocial Instruments (1985 to April 2013), OT Seeker (June 2013), PsycINFO (1806 to May Week 3 2013), EMBASE (1974 to 2013 Week 21), Cochrane Database of Systematic Reviews (2005 to March 2013), ACP Journal Club (1991 to April 2013), Database of Abstracts of Reviews of Effects (2nd Quarter 2013), Cochrane Central Register of Controlled Trials (March 2013) and Cochrane Methodology Register (3rd Quarter 2012). Key term selection was guided by using a PICOS (population, intervention, comparator, outcome, study design) framework (14-16). The search strategy did not restrict on language or design of the study; non pertinent articles were removed by authors after the search was completed. Scientific journals, internet browsers and reference lists of reviewed articles were also consulted for any pertinent information and potential articles.

Inclusion and Exclusion Criteria

We included studies related to participation in physical or social leisure-time activities among children between the ages of 0 and 21 years diagnosed with juvenile idiopathic arthritis, juvenile chronic arthritis, or juvenile rheumatoid arthritis. All diagnostic classifications provided by the International League of Associations for Rheumatology (ILAR), the European League Against Rheumatism (EULAR) or the American College of Rheumatism (ACR) were accepted. As both social and physical activities are considered leisure pursuits we have focused on including a variety of habitual activities performed for the purpose of having fun. Studies reporting findings exclusively on participation in exercise programs done during

school classes or as part of a regimented exercise program in a controlled setting (laboratory) were excluded. Both English and French publications were included in the search. We restricted our search to quantitative studies. Although reviewed for pertinent information and potential references, review papers, abstracts, commentaries or letters to the editor, study protocols, work group or conference proceedings and studies aimed at validating measures were not retained for the systematic review. Results from our search were exported into EndNote X6 and subsequently managed in excel database sheets.

Identification of Studies

After duplicates were removed, two authors from the team (SC and VG) independently screened titles, abstracts and key words for pertinent articles according to the identified eligibility criteria. After initial screening the retained full articles were assessed to ensure that they met inclusion criteria and a list of relevant articles was compiled. A review of these articles was completed by each reviewer who then independently decided which articles met the eligibility criteria and should be included in the systematic review. If consensus could not be reached between reviewers, a third author (KTA) resolved any disagreements.

Data Extraction

Two authors (SC and VG) independently extracted data from the retained articles using a previously pilot-tested extraction table. After thorough review of selected articles information on the studies (study design, geographical location, sample size, participant characteristics [i.e. age and sex distribution, diagnosis], objectives) and the methods of data collection (measure of leisure participation, child or proxy report, psychometric properties) were summarized in a

table, as well as information on potential determinants of leisure participation was reported in a separate table. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement was used to inform reporting of this systematic review (17).

Study appraisal

Studies meeting the inclusion criteria were systematically appraised using the Quality Assessment Tool for Quantitative Studies (18). This tool has been deemed suitable for quality assessment of randomised and non-randomised studies (19). Ratings of strong, moderate or weak were assigned for each of the following six quality components: selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts (20). The tool's test-retest (intra-rater) reliability was assessed for two reviewers and results on agreement were acceptable (Kappa 0.74 and 0.61, respectively for each reviewer) (18). Adequate content and construct validity were also demonstrated (18).

Synthesis of findings

A narrative summary allowed us to analyse our findings by describing content and highlighting strengths and weaknesses of reviewed studies. Due to the heterogeneous characteristics of the included studies (demographic distributions, leisure outcomes, units of measure) it was not feasible to conduct a meta-analysis (21).

Results

The electronic search yielded 884 unique references (i.e. after duplicates were removed). An additional 9 references were obtained through manual review of reference lists from consulted articles and through internet browser search. A total of 893 titles and abstracts were screened. One hundred and nine full articles were reviewed to assess for eligibility. Of these, 12 articles met inclusion criteria and were included in the qualitative synthesis of results (Figure 1).

The identified studies were rated as to their quality. Using the Quality Assessment Tool for Quantitative Studies, none of the studies met all of the quality criteria (18,20). All studies exhibited some level of selection bias. Selected participants were deemed to be at most somewhat likely to represent the studied population, appraisal scores ranged from weak (n = 2) (22,23) to moderate (n = 10) (2,24-32). Retained studies were observational. Half of the studies adequately controlled for important confounders (24,25,29-32), such as age and sex. Only 3 studies collected data on leisure-time activities using outcome measures with known or properly cited validity and reliability (22,27,29). The descriptive characteristics of study participants and information on leisure participation are included in Table I. Studies reporting on potential determinants of leisure participation are described in Table II.

Characteristics of the Studies

Only one study included data from a childhood rheumatic disease database (22), while all others recruited participants from tertiary care centers (hospital and centers). One study included 78 participants with JIA and 17 with other rheumatologic diagnoses (24), whereas all

other studies included only participants with JIA. A range of ages were studied (4 to 18 years); certain authors focused their examination of leisure participation on specific age groups: children (n = 3) (23,26,29) and/or adolescents (n = 3) (24,25,29), whereas other studies reported outcomes for all ages combined (e.g. 4 to 18 years) (n = 5) (2,22,27,30,32). Ten out of the 12 studies used comparison analysis to illustrate differences in leisure participation between groups (within JIA group analysis (n=4), healthy controls (n=9) and controls with other medical conditions (n=1)). Of these, only one study employed matching on age and sex, as well as race and county of residence (30), while others either controlled for covariates such as age, sex and anthropometric factors (weight, height or body mass index) (22,23,25,27,31,32), and others simply reported findings in groups of similar age and sex (24,29).

The main objective of 8 studies hinged on reporting information on the level of participation in leisure activities among those living with JIA, as well as identifying potential determinants and comparing findings on leisure participation between patients with JIA and controls (2,23,24,27-29,31,32). The remaining 4 studies inquired primarily on overall bone health (geometry, density and strength) and participation in leisure-time physical activity as a secondary outcome (22,25,26,30).

Participation in social activities was assessed through self-report and quantified using various scales (e.g. Likert, interval) (2,24,29). Physical activity was evaluated through self-report or proxy activity questionnaires (22,23,25,26,28,30-32) and/or objectively with motion and activity monitors (n=5) (23,25-28). Studies described involvement in physical activities in

terms of exertion level (light, moderate or vigorous), frequency (hr/day or hr/week) (n=6) (23,25-27,30,31), duration (months in a year) (n=3) (23,25,26), energy expenditure (Metabolic equivalent of a task (MET)) (n=2) (22,32) and movement counts (n=4) (23,25-27). Some authors also quantified physical activity using ordinal scales to indicate level of participation (how active) (28,29).

There were 3 studies that focused on social activities (2,24,29), 10 that also reported on physical activities (22,23,25-32), and 5 that explored potential determinants of participation (2,27,28,31,32). These are summarized below.

Participation in social activities

Schanberg et al. conducted a longitudinal study assessing activity reduction among 41 youth with JIA (aged between 8 to 17 years) and found that 66% had restricted participation in social activities at least one day during the 2 month study (2). Billings et al. showed that youth (aged ≥ 10 years) with severe disease reported fewer activities with family members in comparison to those with milder disease, as well as significantly fewer activities with friends compared to healthy controls (24). Although, participants with mild/inactive disease reported fewer activities with friends compared to healthy controls, they took part in more family activities than healthy controls. Huygen et al.'s investigation into the psychological, behavioural and social adjustment of 47 children and adolescents with JIA revealed that there were no differences among adolescents (ages 12 to 16 years) in terms of the frequency of social interactions between those with JIA and healthy controls (29). However, children (ages 7 to

11 years) with JIA did not play or visit as frequently with friends as their healthy peers (1.7 (0.1) versus 2.0 (0.0), p=0.04; 3-point Likert scale) (29).

Participation in physical activities

Results on physical activity measured through self-report in 7 studies were lower in children and adolescents with JIA compared to their healthy controls (22,23,25,29-32). Specifically participants with JIA participated less in moderate to vigorous physical activities compared to healthy peers (23,31), however no differences were found between groups for participation in light physical activity (23,25,26,31). Studies examining participation in sports revealed that both children (range 4.6 to 11.0 years) and adolescents (range 11 to 18 years) with JIA took part in sports less frequently than their peers without JIA (23,25,29,31). Two studies reported fewer weight-bearing physical activities among those with JIA compared to healthy controls (22,30). However Félin et al. reported that only those with systemic JIA (and not those with polyarticular or oligoarticular JIA) were less involved in weight-bearing activities compared to healthy controls (22).

Significant within group differences for participation in physical activity were found in two studies (22,26). When exploring disease subtypes, authors reported that patients with systemic JIA (Mean = 26.0 [95% CI 3.8, 48.2] METs hours/week) were significantly less involved in weight-bearing physical activity compared to patients with oligoarticular (Mean = 45.4 [95% CI 20.9, 70.9] METs hours/week) or polyarticular (Mean = 40.7 [95% CI 23.8, 57.6] METs hours/week) JIA ($p \leq 0.01$) (22). The other study described how duration of involvement in organized sports was significantly greater in children with normal bone mineral density (Mean

= 1.7 [SD = 2.2] months/year) in comparison to those with low bone mineral density (Mean = 0.2 [SD = 0.8] months/year, p=0.03) (26). Only one study compared daily average physical activity between boys and girls in 30 patients with JIA and found no statistically significant differences (31).

When measured objectively through accelerometry, most authors reported no statistically significant differences in average daily physical activity (i.e. movement counts) between JIA and healthy groups (23,25,26). In fact only Maggio et al. found that children and adolescents with JIA participated less in moderate to vigorous physical activity (MVPA) compared to healthy counterparts (JIA, 6.9% of time in MVPA, Mean = 54.1 [SD = 5.7] min/day; healthy controls, 9.1% of time in MVPA, Mean = 71.3 [SD = 4.5] min/day), p = 0.04 (27). Furthermore, two studies indicated that fewer children with JIA met international recommendations of 60 minutes of daily MVPA compared to healthy controls (27,31), and the proportion varied between one-third (23% vs. 66%) to two-thirds (38% vs. 60%) than that of healthy controls (27,31).

Potential determinants of leisure

Potential determinants of leisure participation were assessed in 5 studies (2,27,28,31,32), however only 4 reported statistically significant associations with leisure (2,27,28,31) (Table II). Socio-demographic factors were assessed in two studies (27,28). Results showed that when adjusted for age boys displayed higher physical activity levels than girls (27). Also, the younger the child, the higher the level of physical activity (28). Disease-related factors were assessed in all studies examining potential determinants (2,27,28,31,32). However in only

four studies were disease-related factors associated with lower levels of leisure activity (systemic JRA subtype, lower well-being, pain, larger number of painful joints, stiffness, and fatigue) (2,22,28). Moreover, longer disease duration was associated with more frequent participation in physical activity (31). Anthropometric measures were also considered as potential determinants of physical activity participation in one study (27) and higher height and weight were associated with increased physical activity among children and adolescents living with JIA (27).

Discussion

Our systematic review revealed that participation in social and physical activities during leisure-time may be decreased in children and adolescents living with JIA as compared to their healthy peers and fewer JIA patients met national physical activity recommendations. Studies to date have methodological weaknesses; therefore results should be interpreted with caution. Furthermore, only a few studies empirically explored the association between potential determinants and participation in leisure-time activities. Authors used various self-report and objective outcome measures with differing measurement units and scales and lack of validity and reliability to assess involvement in leisure-time activities making it difficult to generalize results on leisure participation in JIA.

The self-report assessment of leisure participation was for the most part restricted to a handful of activities, specifically social (e.g. taking part in play with friends, seeing friends, going to ball games, being part of a club, participating in sports, going to parties or dances) and

physical (e.g. participating in organized sports or weight-bearing activities), rather than a larger gamut of recreational activities (e.g. playing board games or card games, screen time activities [computer or video games, watching TV], playing with pets), skill-based (e.g. swimming; learning to sing [choir or individual lessons], learning to dance, playing a musical instrument) and self-improvement (e.g. writing a story, reading, doing volunteer work, shopping). A more comprehensive approach to assessment is needed in order to truly capture a complete picture of leisure in this population. Findings would subsequently enable health care professionals to assess the benefits and potential determinants of participation. As our review demonstrates, social and physical activities of children and adolescents with JIA may vary with age, sex, type of activity, social engagement (friends, family) and disease activity/status.

In our review, social participation in young children was characterised as play with friends, whereas for adolescents it included analysis of spontaneous social contacts and going on outings with friends. Among children, social interactions are often fostered through informal play time with friends (4,33). Children with JIA took part in less play than healthy peers possibly due to physical limitations and pain brought on by their disease. Younger children tend to be involved in more active types of play, which may discourage young patients with JIA affected by fluctuating joint pain and swelling to partake in these activities with friends (2,28).

Adolescents with JIA took part in as many spontaneous social interactions as their healthy peers (29), however did not attend as many outings with friends (24). These results parallel

those found among adolescents (12 to 20 years of age) with cerebral palsy, where participants favoured quiet social activities such as hanging out, listening to music and talking on the phone with friends (34) and less in outings (34). The similarities found between adolescents with and without JIA may reflect the natural progression of social leisure participation (4,33); as children get older they become less involved in play and more engaged in socially oriented activities which tend to be less physically straining (35,36).

Social engagement in activities (i.e. with whom they engaged in activities) (37) varied across disease status (24). The more severe the disease activity the less patients participated in activities with friends and family members (24). During periods of more severe arthritis, parents may limit their child's participation in activities to avoid exacerbating disease symptoms. The fear of pain may influence the parents' and the child's willingness to take part in social activities (38,39). This avoidance and the need to monitor their child's health closely may also explain why those even with milder or inactive JIA may be less inclined to participate in social activities with friends and more involved in family activities (24). Similarly, children and adolescents with systemic JIA (a more severe subtype of JIA) were less involved in weight-bearing physical activities compared to those with oligoarticular or polyarticular JIA (22).

The association of age and sex with participation in physical activity is often studied (40). Our findings support that physical activity in JIA tends to decrease with age (28), which parallels results from the general pediatric population (4,33). Boys are often found to be more physically active than girls (36,40-42). Studies included in our review revealed divergent

results. When adjusting for age (Mean = 10.8 [SD = 0.5] years; range 4.8 to 17.9) Maggio et al. (2010) reported that boys with JIA were more physically active than their female counterparts (27). Whereas when comparing physical activity among adolescents with JIA (Mean = 17.0 [SD = 0.6] years) Lelieveld et al. (2008) reported no significant differences across sexes (31). In general, participation in sports and other active pursuits is higher throughout middle childhood and drops during adolescence (33). This may in part explain why no significant differences in physical activity were found among adolescent boys and girls with JIA (31).

Although results varied, most studies showed that children with JIA spent significantly less time pursuing physical activities compared to healthy controls (22,23,25,27,29-32). In addition to disease-related factors (e.g. disease duration, number of painful and swollen joints), poor physical fitness may also contribute to lower levels of physical activity in JIA (28). Children living with polyarticular JIA have been found to be less physically fit than healthy and normally active (non-competitive) controls (43). The lack of physical fitness is not necessarily associated with disease severity but avoidance of exercise by those with JIA is often encouraged by parents and health care professionals to limit exacerbation of disease related symptoms (43).

Osteopenia (or lower than normal bone mineral density) is of particular concern in children and adolescents with JIA as it may lead to decreased bone strength and a subsequent increased risk for fractures (44,45). Those suffering from JIA are at greater risk of bone density anomalies secondary to greater disease severity, treatment by glucocorticoids and decreased

participation in organized sports or other physical activity (25,26). The more children took part in organized sports the better their bone mineral density (26). The study's cross-sectional design restricts inference of causality and one can argue that low bone mineral density (a characteristic of more severe disease (25)) is a potential determinant of participation in sports rather than an outcome.

Self-report measures were a popular means of collecting data on social and physical leisure-time activities. Researchers may appreciate the low cost and convenience of using these tools. Activity monitors were also used albeit less frequently to objectively assess physical activity. Electronic data collection is not affected by recall bias and may be more appropriate for assessing physical activity among children and adolescents (46).

Less than 40% of those with JIA met international recommendations to engage in at least 60 minutes of moderate to vigorous physical activity daily, as compared to 60% of healthy controls (27). Persons with JIA may intentionally avoid more physically strenuous activities to keep from aggravating disease-related symptoms such as swollen joints (28). However, there is no evidence that activity in fact exacerbates symptoms (47) and current evidence supports that physical activity is beneficial in JIA in helping to reduce pain, the number of swollen joints, as well as improving overall aerobic endurance and bone health (10,48). Furthermore, there is a potential for exercise to favor immune function and help reduce chronic inflammation (49-52).

The literature on childhood disability supports that involvement in leisure activities may be influenced by intrinsic and extrinsic factors (3,41). Most studies in pediatric rheumatology explored the effects of disease severity as a function of disease-related factors (e.g. active joint count, pain, fatigue, function/disability), rather than potential effects of contextual factors relating to the child (personal) and his or her environment (family and community). Only one study explored the potential association of anxiety and depression with participation in social activities, however no significant results were found (32). No studies reported on such aspects as self-esteem, motivation, activity preferences, family functioning and environmental barriers.

Future research determining extent of involvement in a range of leisure activities in children with JIA and their determinants may benefit from a well grounded theoretical framework such as the ICF, which considers how participation in activities is influenced by body structure and function associated with the health condition (e.g. active joint count, perceived pain), activity limitations as well as personal (e.g. age, sex, motivation) and environmental (e.g. family functioning, availability of community services) factors (7,8).

Study limitations

Based on the appraisal criteria of the Quality Assessment Tool for Quantitative Studies, (18) no study met all quality criteria. All studies retained for review were observational (19). Most studies recruited children and adolescents with JIA systematically from a convenience sample (i.e. clinic), weakening external validity. Furthermore, sample sizes were all relatively small, which may lead to type 2 errors. We do recognise how challenging recruitment in pediatric

rheumatology is, considering the low prevalence of the disease (range of 0.02 to 0.40 percent of children) (53). Most studies used outcome measures with questionable psychometric properties threatening the quality of data collection (2,23-26,28,30-32)

Conclusion

In general, children and adolescents with JIA display limitations in participation in either social or physical leisure-time activities. Despite the known benefits of leisure participation, no study to date has fully explored the experience of leisure participation in JIA. In order to properly explore leisure participation in JIA, there is a need for high quality observational studies. Future research into the study of leisure participation in pediatric rheumatic diseases may benefit from using a comprehensive, valid and reliable outcome measure exploring a broad range of possible leisure activities from which to draw valid conclusions (54). Moreover, the assessment of contextual factors may provide researchers with compelling information on potential barriers and facilitators to leisure in JIA.

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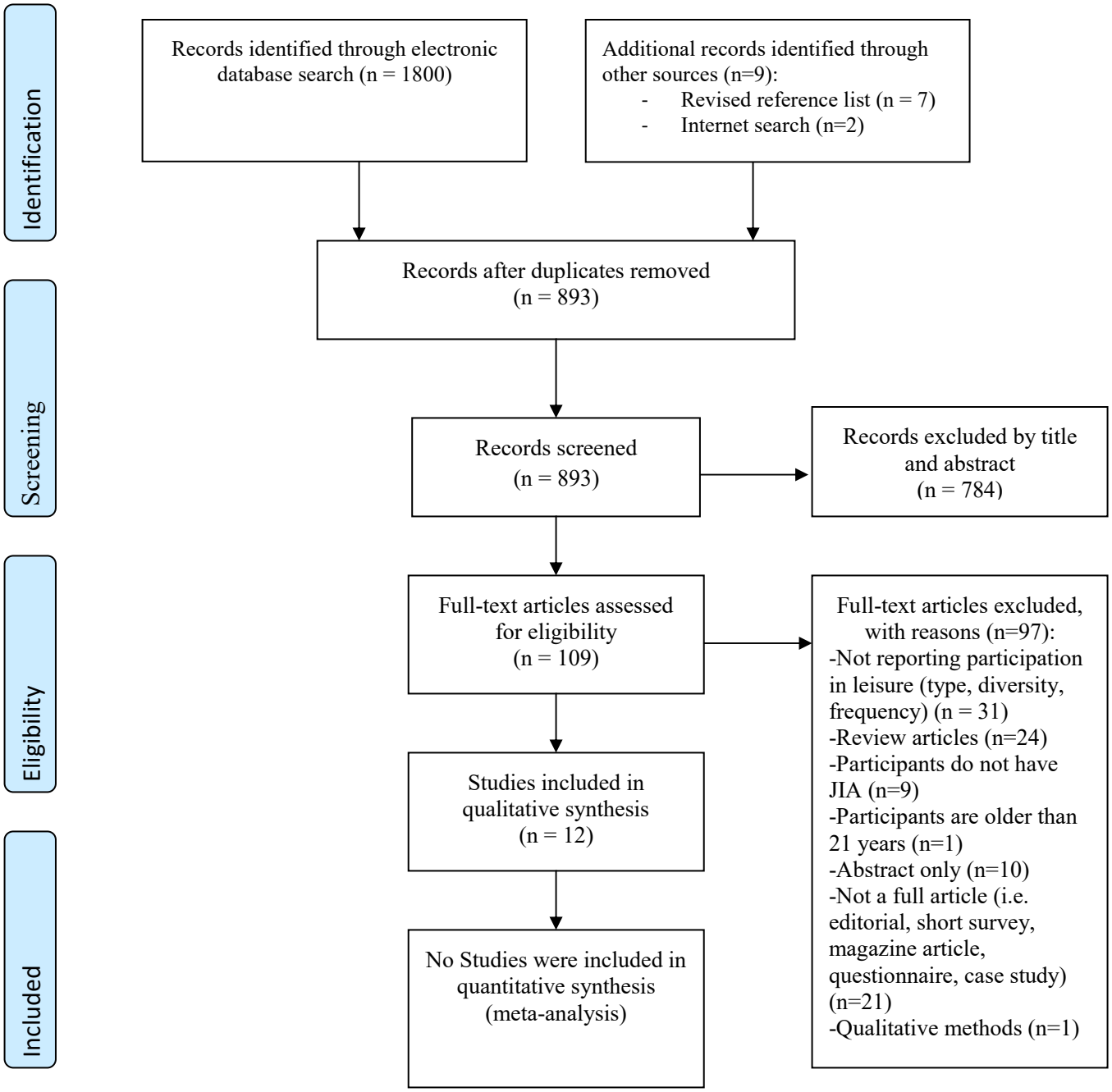
Figure 1. PRISMA flow diagram of articles included in the systematic review as well as the main reasons for rejection



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097. **For more information, visit** www.prisma-statement.org**.**

Table I. Findings from a systematic review on leisure participation in children and adolescents living with JIA

Author, Country (year)	Participants		Study design	Leisure outcome measure	Variable recorded	Findings
	JIA	Comparator groups				
Billings, USA (1987)	56 (37 girls and 19 boys) ; mean age 13.7 years (≥10 years)	Within group comparison and 77 HC	Cross-sectional	Youth Health and Daily living form	# of social activities done with family, friends and at school out of 10	Fewer family activities for severe JIA group compared to those with mild/inactive JIA ($p < 0.05$). Fewer activities with friends for JIA groups compared to HC ($p < 0.05$). More family activities for mild/inactive JIA compared to HC ($p < 0.05$).
Félin, USA (2007)	48, age range 4 -18 years	Within group comparison and 266 HC	Cross-sectional	PA questionnaire on weight-bearing activities	Average METs hr/wk in the last year	Decreased weight bearing PA for systematic JIA group compared to oligoarthritis, polyarthritis JIA or HC groups ($p \leq 0.01$). No significant differences between oligoarthritis or polyarthritis JIA groups and HC.
Henderson, USA (1995)	23 (16 females), mean age 8.1 years (range 5-11 years	23 HC	Cross-sectional	Caltrac accelerometer and UCMS; Parent-report activity record, 3 day; Parent-report questionnaire on organized sports	Average daily movement counts; Daily activities, type (light, strenuous) and intensity (hours/day); Frequency (hours/week) and amount in the last year (months)	No significant differences in daily movement. Decreased time spent in strenuous activities for JIA group ($p<0.01$). No significant differences in low intensity PA between groups. ↓ time spent participating in sports at baseline ($p=0.01$) and in the last year ($p<0.01$) for JIA group.
Henderson, USA (1997)	48 (37 female, 11 male), mean age 8.1±1.9 years (range = 4.6-11.0 years)	Within-group comparisons	Cross-sectional	Caltrac accelerometer and UCMS; Parent-report activity record, 3 day; Parent-report questionnaire on organized sports	Average daily movement counts; Daily PA, type (light, strenuous) and intensity (hours/day); Frequency (hours/week) and amount in the last year (months)	No significant differences in daily movement. No significant differences in daily PA. Decreased time spent in organized sports for JIA group with low TB BMD compared to those with normal TB BMD ($p = 0.03$).
Henderson, USA (2000)	Thirty-six females, mean age 16.0 ± 1.8 years (age range 11 to 18 years)	Within-group comparisons and 51 HC	Cross-sectional	Caltrac accelerometer and UCMS; Self-report activity record, 3 day; Self-report questionnaire on organized sports	Average daily movement counts; Daily PA, type (light, strenuous) and intensity (hours/day); Frequency (hours/week) and amount in the last year (months)	No significant differences in daily movement. No significant differences in daily PA. 50% of JIA patients participated in organized sports compared to 65% of HC ($p = 0.01$). Decreased time spent in organized sports for JIA group compared to HC ($p = 0.005$).

Table I. Continued.

Huygen, Netherlands (2000)	47 (32 girls and 15 boys), age range 7-16 years (child, 7-11 years of age; adolescents, 12-16 years of age)	52 HC	Cross-sectional	Dutch CBCL, parent-report on the child's social functioning; Dutch Youth Self Report , adolescents self-report on social functioning	3-point Likert scale	Decreased participation in play with friends for children with JIA ($p = 0.04$). No significant differences between groups for seeing friends. Decreased participation in sports for adolescents with JIA ($p=0.00$).
Lelieveld, Netherlands (2008)	30 (18 girls, 12 boys), mean age 17.0 ± 0.6 years	106 HC	Cross-sectional	Self-report activity diary, 3 days	Daily average PA (hours/day)	Decreased PA in JIA group ($p < 0.01$). Increased time spent in bed for JIA group. No significant differences in PA between boys and girls among JIA or HC groups. No significant differences in low intensity activities between JIA and HC. Decreased time spent in moderate intensity leisure activities ($p< 0.01$); high intensity leisure activities ($p< 0.05$); and in competitive sports ($p< 0.01$) for JIA group. Only 23% of patients with JIA met public health recommendations to perform ≥1 hour daily MVPA (mean of 87 min/day of MVPA) compared with 66% of HC (mean of 133 min/day of MVPA).
Lien, Norway (2005)	108, age range of 6–18 years	108 HC	Longitudinal	Self-report questionnaire on weight-bearing activities outside of school hours	Frequency (number of times per week), ordinal scale (0.5 = less than once a week, 1= once a week)	Decreased participation in weight-bearing activities at baseline ($p=0.033$) and at the 2 year follow-up ($p= 0.040$).
Maggio, Switzerland (2010)	31, mean age 10.8 ± 0.5 years (range 4.8 to 17.9 years)	85 HC, 45 obese, 48 type 1 diabetes mellitus	Cross-sectional	Uniaxial Actigraph accelerometer, 7 days	Average daily PA (minutes/day)	When adjusted for age, decreased daily PA for JIA group compared to HC ($p < 0.001$) and compared to patients with obesity ($p = 0.002$). Decreased time spent in MVPA for JIA group versus HC ($p = 0.036$). 38.1% of JIA, 38.5% of type 1 diabetes mellitus, 51.6% with obesity and 60.4% of HC met the daily recommended 60 minutes of MVPA.
Schanberg, USA (2003)	41 (59% were girls), mean age 12.3 ± 2.9 years (range 8–17 years)	None	Longitudinal	Self-report diary on daily social activities	Reduction in activities, 4-point Likert scale (anchored by 'not at all' and 'a lot')	No control data available for comparison

Table I. Continued.

Takken, Netherlands (2003)	45 (10 male, 35 female), mean age 8.9 ± 2.2 years	None	Cross-sectional	Caltrac activity monitor measuring daily PA for 4 consecutive days; Parent-report PAL	Average daily motion counts; Child's usual PAL, 5 point Likert scale (1 = inactive to 5 = very active)	No control data available for comparison
Tarakci, Turkey (2011)	52 (33girls, 19 boys), mean age 12.13 ± 2.92 years (range 8-17 years)	48 HC	Cross-sectional	Self-report diary on PAL, 1-day	METs/day	↓ time spent in PA for JIA group (p=0.000)
JIA, Juvenile idiopathic arthritis; UCMS, University of Cincinnati Motion Sensor; HC, Healthy controls; PA, Physical activity; PAL, Physical activity level; TB BMD, Total body bone mineral density; CBCL, Child Behaviour Checklist						

Table II. Potential determinants of participation in leisure-time activities in JIA identified in the systematic review

Potential determinants	Association with leisure
Socio-demographic:	
Age (28)	Older age was associated with ↓ PA
Sex (27)	Male sex was associated with ↑ PA level
Anthropometric:	
Weight (27)	↑ weight was associated with ↑ PA
Height (27)	↑ height was associated with ↑ PA
Disease:	
Disease duration (31)	Longer disease duration was associated with ↑ PA
Pain (2)	↑ perceived pain and the number of painful locations were associated with ↓ social activity
Stiffness (2)	↑ daily stiffness was associated with ↓ social activity
Fatigue (2)	↑ fatigue was associated with ↓ social activity
Swollen joints (28)	↑ number of swollen joints was associated with ↓ PA
Physical fitness** (28)	↑ maximal oxygen consumption (absolute, relative) was associated with ↑ PA
Well-being (31)	↓ perceived well-being was associated with ↓ PA

PA, Physical activity

**The association between physical fitness and physical activity may be bidirectional, i.e. physical fitness can be both a determinant and an outcome of PA (28).

Article 2

Participation in leisure activities among Canadian children with arthritis: Results from a national representative sample

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Author contributions: The PhD candidate contributed to developing the study design, conducted all analyses and drafted the entire manuscript. Dre. Feldman contributed through discussions about study design, analyses and provided feedback on several drafts of the manuscripts. Dre. Majnemer, Dre. Mazer and Dr. Chilingaryan provided feedback on study design, analysis and on the final draft of the manuscript.

Abstract:

Objectives: To describe participation in leisure activities among children and adolescents with arthritis, as well as identifying the socio-demographic (age, sex, family income), disease-related (functional limitations, disease duration, pain, medication use, child's need for assistance) and contextual factors (utilization of rehabilitation services, proximity of local recreation facilities, cost of activities) that may be associated.

Methods: Data from the Participation and Activity Limitation Survey (PALS) 2006 data, a Canadian post-census survey was analyzed. Bivariate and multivariable linear regression analysis was applied to examine the associations between the sample's level of participation in leisure activities, socio-demographic, disease-related and contextual characteristics.

Results: In Canada in 2006, an estimated 4350 children ranging in age from 5 to 14 years were living with arthritis. Fifty-six percent of parents reported that arthritis restricted their child's participation in leisure activities. Bivariate analysis showed that the availability of local recreational facilities, the affordability of activities and the child not requiring any assistance were all associated (modified Bonferroni correction $\alpha < 0.005$) with greater participation in various types of leisure activities. Multiple linear regressions showed that higher family income ($\beta = 0.47$, 95% CI= 0.09, 0.85) and greater perceived pain ($\beta = 0.59$, 95% CI= 0.07, 1.10) were positively associated with involvement in informal leisure.

Conclusion: Our findings underline the importance of considering contextual factors in developing treatment plans aimed at improving participation in leisure activities among children with arthritis. Future longitudinal studies targeting children living with arthritis could provide pertinent information on participation over fluctuations in disease status.

Introduction

In Canada, childhood arthritis is among the most common chronic disabling diseases of childhood with a prevalence of 0.12 percent and a yearly incidence of 17.8 per 100 000 children and youth (1,2). Children affected by arthritis report chronic pain, joint stiffness, fatigue, and limitations in mobility which may restrict their participation in age-appropriate daily activities (e.g. mobility, self-care and leisure), both at home and at school (3-5). One third of those diagnosed with arthritis have physical limitations, such as difficulties in fine motor (e.g. buttoning one's shirt) or gross motor tasks (e.g. climbing stairs), which may persist well into adulthood (6).

The psychosocial implications of living with arthritis (e.g. emotional distress, family functioning, mood, stress, coping with pain) may have an impact on the child's participation in school and social activities (7,8). Participation in leisure activities is of critical importance to maintaining a fit lifestyle, forming friendships and refining life skills needed throughout adulthood, as well as developing social contacts (9). Research suggests that if participation in active leisure activities remains limited on a long-term basis, children and adolescents may not have enough social contact with peers, may be less able to make friends, experience greater social isolation and may be at greater risk for depression (10). Among Dutch children living with chronic juvenile arthritis, global self-esteem and amount of spontaneous social interactions did not differ from their healthy counterparts, however they did report lower competency in athletics, possibly owing to the decreased opportunity to participate in sports (11).

Lower levels of physical activity lead to decreases in muscle mass and function, as well as eventual bone abnormalities (e.g. osteopenia) and possible cardiovascular implications (4,12). Children with arthritis have greater limitations in aerobic fitness and muscle strength when compared with healthy children, presumably caused by decreased involvement in physical activity secondary to disease symptoms (13). Physical activity interventions have been documented in children and youth with arthritis to reduce pain, number of swollen joints and medication use, as well as increase overall aerobic endurance (13-17). However little is known regarding patterns and determinants of leisure activities in children with arthritis.

Involvement in leisure activities plays an important role in children's development and health and deserves consideration (18). Participation is a key component of the International Classification of Functioning, Disability and Health (ICF) and its Child and Youth version (ICF-CY) endorsed by the World Health Organization (WHO) (19,20). The ICF-CY depicts how a child's participation in activities is influenced by the health condition (e.g. disease severity), as well as personal (e.g. age, sex) and environmental (e.g. accessibility to services) factors (19-21). The ICF-CY provides a framework whereby we can quantitatively identify both intrinsic (i.e. related to the person) and extrinsic (i.e. related to the environment) determinants that may impact participation in leisure. The ICF-CY contends that children with similar levels of intrinsic impairment may achieve differing levels of participation across settings.

The aim of this study was to describe the level of participation in leisure among a nationally representative sample of Canadian children aged 5 to 14 years with arthritis in terms of

diversity and frequency, as well as to identify associated socio-demographic, disease-related and contextual factors.

Patients and Methods

Design

The 2006 Participation and Activity Limitation Survey (PALS) was carried out in Canada shortly after the 2006 National Census, specifically in November 2006 and February 2007. The PALS was funded by Human Resources and Social Development Canada (HRSDC). The PALS design was a two-phase stratified design, where the 2006 census was first distributed randomly to approximately every fifth household across Canada and then only participants reporting an activity limitation were approached for the PALS post-census survey (22).

Sample

The PALS sample included all persons living in private and collective households in the 10 provinces and 3 territories in Canada (excluding persons living in institutions and on First Nations reserves) who reported the presence of a disability (yes, sometimes; yes, often) on one or both of the two census filter questions regarding disability and activity limitations. The sample was further restricted with the following questions: Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities? Does a physical condition or mental condition or health problem reduce the amount or the kind of activity this person can do a) at home, b) at work or school or c) in other activities (e.g. transportation or leisure)? Participants who responded yes to the above

filter questions were also asked to identify their specific health diagnosis: Does this person have any of the following long-term conditions which have been diagnosed by a health professional? (23)

A representative sample (n= 8954) of Canadian children with activity limitations was selected from the 2006 census for participation in the 2006 PALS post-census survey. The parent or guardian of the child living with a disability were interviewed over the telephone resulting in a 79.7% response rate. If it was established that the parent or guardian was not available, another adult in the household was asked to respond as a proxy. Data were weighted to ensure that all Canadian children with a disability were represented. Weights were applied as described by Statistics Canada with data adjusted for non-response and child characteristics as reported in the census (province of residence, age, sex and severity of the limitation) (24). Children younger than 5 years were excluded from our analysis as no data on participation and activity limitations were collected for this age group. Over 18 common childhood conditions were identified in the post-census survey, including arthritis and rheumatism. For the purposes of our study we analysed data exclusively from children aged 5 to 14 years for whom a parent reported a diagnosis of arthritis or rheumatism on the PALS in 2006.

Main outcome

Participation in leisure activities, our study's outcome, was described in terms of diversity (number of different activities) and frequency of participation. The physical leisure activities included in the survey questionnaire were grouped as follows: sports with a coach or instructor; lessons or instructions in other organized physical activities with a coach or instructor, such as

dance, gymnastics or martial arts; unorganized sports or physical activities without an instructor. Sedentary leisure activities listed were: watching television; playing computer or video games; talking on the phone with friends; reading alone (by himself/herself) for pleasure; having books read to (him/her); using the internet to participate in newsgroups or chat groups, for personal interest or entertainment and e-mail to stay in touch with friends. Non-sport skill-based activities were: taking lessons or instruction in music, art or other non-sport activities; taking part in clubs, groups or community programs, such as church groups, Girl or Boy Scouts. We further categorised participation in these same activities as formal (led by a coach or instructor) and informal (unstructured or spontaneous) activities. Diversity was defined as the sum of the different activities completed weekly by the child, where 0=not completed and 1=completed. The number of possible leisure activities ranged from: 0 to 11 for overall leisure, 0 to 3 for active physical, 0 to 6 for sedentary, 0 to 2 for non-sport skill-based, 0 to 4 for formal and 0 to 7 for informal activities. We quantified the frequency at which the child participates in each activity as follows: 0= never participating, 1=participating yearly, 2= participating monthly, 3=participating weekly and 4= participating daily. The measures of diversity and frequency were applied to all identified levels of leisure (overall leisure, active physical, sedentary, non-sport skill-based, formal, informal) (24).

Potential determinants

In line with the ICF-CY model (19,20), factors under study and potentially associated with participation in active physical and sedentary leisure activities were age, sex, family income, difficulty walking, difficulty using hands, disease duration, pain, medication use, utilization of rehabilitation services, child's need for assistance, proximity of community services, affordability

of leisure activities. The following questions from the PALS helped to discern limitations in walking and in hand use: 'Because of a condition or health problem, does (….) have any difficulty walking? This means walking on a flat firm surface, such as a sidewalk or floor.**';** 'Because of a condition or health problem, does (….) how much if any the child had using (his/her) hands or fingers to grasp or hold small objects, such as a pencil or scissors?'. Pain was defined as: How would you describe the usual intensity of (….'s) pain or discomfort? We defined levels of functional limitations and perceived pain as: 0= none; 1=mild; 2=moderate to severe. We dichotomised medication use as 0 = less than once a week and 1 = at least once a week. A large number of children who do not respond to non-steroidal drug treatment are often prescribed weekly doses of the disease-modifying antirheumatic drug methotrexate (MTX). The use of rehabilitation services was scored as 0 when received less than once a month, whereas a score of 1 reflected use at least once a month. Finally, we recoded the answers to the question 'What prevents [your child] from doing more social or physical leisure activities?' as yes = 1 and no = 0, for each of the following: availability of local recreational facilities, cost of leisure activities and the child's need for assistance.

Analysis

All statistical analyses were performed using the SAS 9.3 statistical software as well as the SAS-callable SUDAAN for Windows (release 9.0.0), to account for the PALS's sample survey design and to allow the estimates of the coefficients of variation (CV) for the corresponding parameters of statistical analyses. Weights were applied to the data to obtain representative estimates. Weighted results were rounded to the nearest 10 and percentages to the nearest one in order to respect Statistics Canada data disclosure regulations. For all inferential statistical

analyses the significance level was fixed at alpha = 0.05. For the calculation of our independent t-tests given that we've conducted 11 independent t-tests for each of our 6 outcomes it was necessary to control for type -1 error (family wise error) by applying a modified Bonferroni correction. This enabled us to adjust for a predefined alpha level of 0.05 (adjusted alpha: 0.05/11=0.005).

Descriptive statistics were carried out to characterise the sample in terms of frequencies, percentages, means and confidence intervals. Bivariate analysis (t –tests) was used to explore relationships between each independent variable and outcomes. Outcomes included the following: overall leisure, active physical, sedentary, non-sport skill-based, formal and informal by diversity (total number of different activities) and frequency of participation in different activities.

We entered all potential predictors at once in multiple linear regression models to assess the potential associations between predictors and the frequency of leisure participation for each activity subcategory. Receipt of rehabilitation services and restriction in mobility and in hand use were placed in separate models to control for their multicollinearity (variance inflation factor (VIF) > 7). All multiple linear regression models were adjusted for age and sex.

Results

Sample. In Canada in 2006, an estimated 174 810 children aged 5 to 14 years had a disability. Among them 3% had arthritis. The mean age of children with arthritis was 10.7 years (CI

95%=9.9, 11.4), 65% were girls and 59% reported disease duration at 5 years or longer (Table I). The mean household income for families living with a child with arthritis was 79 811$ (CI 95%=65 073, 94 549) which is 4.3% lower than that reported for the average Canadian in the 2006 census (83,407$) (25). Nearly 40% of the PALS participating families earned less than 60 000$ per year. Furthermore, 25% of parents reported that their child was unable to participate in activities they would have enjoyed, because these were not adapted to their child's needs. Fourteen percent of parents reported that most of their child's activities were restricted by pain or discomfort. Ambulatory restrictions (i.e. difficulty walking) and hand function restrictions (i.e. difficulty grasping or holding objects) were reported in 37% and 34% of cases, respectively. Seventy- percent of children with arthritis participated in physical activity at least once weekly, whereas only 33 % participated daily (Fig. 1). Forty percent of participants took part in non-sport skill-based activities weekly, however none participated in these activities daily. On the other hand, nearly all claimed to engage in daily sedentary behaviour (Fig. 2). Most children participated in weekly informal activities and 70% in formal leisure. Fifty-six percent of parents reported arthritis restricted their child's participation in leisure. When asked directly about what reasons could have explained their child's limited participation, these parents identified the lack of locally available recreational facilities (19%), the high cost of activities (30%) and their child's need for assistance (61%) as potential factors.

Girls took part in a greater number of non-sport skill-based activities and more frequently than did boys (Table II, Table III). Children and youth who took medication at least once weekly participated in a larger number of different activities in overall (p=0.029) and in formal

(p=0.016) leisure activities (Table II). Similarly they reported more frequent participation in overall (p=0.023), in active physical (p=0.024), in non-sport skill-based (p=0.037) and in formal (p=0.014) leisure activities (Table III). Persons who had access to recreational facilities had higher mean diversity and frequency scores for overall and formal activities (Table II, Table III). Additionally, having fewer locally available recreational facilities was associated with less frequent participation in physical activities (Table III). Children and adolescents who required assistance with leisure activities displayed lower mean frequency scores in overall leisure and non-sport skill-based activities (Table II, Table III). Frequency of participation in non-sport skill-based activities was lower when costs of activities were higher (p=0.004). When adjusted for family type 1 error the differences in mean of physical activity (diversity and frequency) by the availability of recreational facilities and the differences in mean of non-sport skill-based frequency by activity cost and child's need for assistance remained significant for $\alpha < 0.005$.

Families reporting a yearly family income greater than 60 000$ CAD tended to participate in almost twice the number of activities (p=0.061) and more frequently (p=0.051) than families earning less (Table II, Table III).

The multiple regression models revealed no significant associations with diversity of leisure activity participation. However, frequency of overall participation and informal leisure activity were both associated with higher family income (Table IV). Also, a report of mild to severe pain intensity was associated with participation in sedentary (screen time and reading) and informal leisure activity (Table IV). Although statistically insignificant (p=0.073), the

effect size (β=0.75, 95% CI= -0.07, 1.58) for income on active physical leisure was the largest of all other regression variables (Table IV).

Discussion

A greater proportion of children with arthritis participated in weekly informal activities - owing in large part to sedentary pursuits - when compared to formal activities. Although similar trends are found among children without chronic conditions (26,27), those with JIA show higher tendencies for sedentary behaviour compared to their healthy counterparts (28). Interestingly, the percentage of children with arthritis from our study participating regularly in organised sports closely resembles that of Canadian children in 2005 (29). Possibly, those with arthritis who are highly motivated and interested in organised sports may undertake these despite potential challenges posed by their illness (30).

Despite the lack of a healthy comparator group, our findings have contributed to illustrating the patterns of leisure participation among Canadian children living with arthritis.

The association of age and sex with participation is frequently studied (31). The younger the child the more active they tend to be (32,33), however similar to other research findings (31,34) ours showed no statistically significant association between age and any level of leisure participation. Moreover, we found no association between sex and physical activity, even though others have reported that boys are more physically active than girls (9,31,34,35).

We found girls to be more involved in non-sport skill-based activities, which mirrors other studies (9,31,34,35).

Families earning less than 60 000$ yearly had children who tended to participate less frequently in active physical leisure activities. Organised activities often incur registration fees, purchase of equipment and may need parent to drop-off the child multiple times per week for lessons. Understandably, parents with lower income may find it more challenging to afford these added expenses. Their children might be more inclined to participate in sedentary types of activities. Similarly, higher perceived cost of activities was correlated with lower participation of non-sport skill-based activities. Our findings, however, also support that families with lower income participate less in informal activities. Therefore, expenses related to unorganised activities (e.g. biking, skating, playing video games, internet use) may still be out of reach for some families.

Although we expected restricted ambulation and hand use to limit leisure in these children, this was not reflected in our results. We did, however, find that those reporting pain engaged more frequently in sedentary and informal activities than those who did not. Increased daily symptoms of pain are linked to reduced participation in social and school activities (36). Those experiencing painful symptoms frequently may opt for less active and unstructured activities to avoid exacerbating symptoms with activity or potentially missing scheduled practices. Furthermore, they may want to refrain from sharing their painful and often invisible symptoms with friends, peers, coaches and instructors to avoid scrutiny and disbelief, therefore opting for unstructured activities (37). Some children with arthritis may also

demonstrate poor self-concept, limited competency for either athletics or other skill-based activities leading them to prefer free play (11). Children with JIA may have gross motor delays (38), which may limit confidence in athletic abilities and readiness for sports and other active pursuits (39).

Interestingly, the frequency of involvement in overall, active physical, non-sport skill-based and formal activities was higher for those taking weekly medication compared to those who did not. This finding may reflect that regular medication use results in positive effects, whereas those not adhering to a prescribed medication regimen continue to suffer effects of the disease resulting in less participation (40). This would need to be substantiated in future studies.

Availability of local recreational facilities was associated with more frequent active physical and formal activities and higher diversity in formal activities, supporting that if the infrastructure that houses community activities is not easily accessible, children may be less inclined to participate. By default, they may engage in sedentary leisure activities and informal activities, which may be more accessible and may or may not require special equipment or lessons from a hired coach or instructor. Then again parents may favour organised physical activity to free play. Another potential barrier to participation in physical activity may be the lack of physical literacy. In light of their arthritis certain children may be less inclined to be physically active, which may hinder the development of gross motor skills required to engage in sports and other physical activities (39). Our findings underline how more accessible recreational facilities may encourage participation in active physical and

formal leisure activities. Sallis et al. (1993) showed that a greater number of available play spaces (e.g. ice rink) within walking distance from the home was significantly associated with greater participation in physical activities among healthy children (41). However, there is a lack of information on the influence of environmental factors on the level of participation in leisure among children with arthritis.

Study limitations. Our study has limitations that should be noted. Our study relied on parental report, which may differ from that of their child. Research on parents and their children with arthritis indicated that agreement was generally good for pain and function, however lower for adherence to medication use (42,43). Although our analysis may have benefitted from a comparator, no data on healthy controls was collected for the PALS post-census survey as it was tailored specifically for participants having reported a disability in the 2006 census precluding comparison of our results to those of children without arthritis. Moreover, the self-report nature of the survey may have led to an overestimation of physical activity levels. The use of accelerometers in future studies may help limit the bias in reporting on physical activity. Lastly, the cross-sectional nature of the study precludes us from accounting for any fluctuations in disease status.

Barriers to involvement in leisure among children with arthritis may extend beyond socio-demographic and disease-related factors to include contextual predictors such as proximity to recreational services. Policy changes resulting in an increased number of publicly funded recreational facilities in a given neighborhood may help improve access to leisure activities among Canadian children with arthritis. Furthermore, to respect the right of each child to

engage in leisure activities of their choosing, policies must ensure they are accessible (44) for all children regardless of disability (45). Ultimately, the identification of the determinants of leisure among children with arthritis may allow healthcare professionals to assess the child's health needs and develop health promotion initiatives favouring active life styles. Prospective national studies would be valuable in illustrating predictors of leisure while considering the fluctuations in disease status among children with arthritis.

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Table I. Demographic and clinical characteristics (Weighted n = 4350)

	Weighted n (%)
Child's age (Mean=10.7, CI95%=0.4, 9.9 years)	
≥ 5 and ≤ 11	2550 (58)
≥ 12	1810 (42)
Sex	
Female	2810 (65)
Male	1540 (35)
Region of residence[Ŧ]	
Atlantic	290 (7)
Quebec	840 (19)
Ontario	1790 (41)
Western	1410 (32)
North	20 (1)
Family income (Mean=79811, CI95%=65 070, 94 549) CAD	
≤30 000$	630 (14)
>30 000$ and < 60 000$	1130 (25)
≥ 60 000$	2710 (61)
Disease duration (Mean=4.7, CI95%=1.5, 7.6 years)	
<5 years	1770 (41)
≥5 years	2580 (59)
Difficulty walking	
None	2750 (63)
Mild	1180 (27)
Moderate to Severe	420 (10)
Difficulty using hands	
None	2840 (65)[¥]
Mild	800 (18)
Moderate to severe	710 (16)
Pain intensity	
None	2390 (57)
Mild	760 (18)
Moderate to Severe	1020 (24)
Medication[§] use	
None	1080 (25)
At least once weekly	3270 (75)
Rehabilitation services	
None	2630 (62)
At least once yearly	1200 (28)
At least once monthly	440 (10)

[Ŧ] Regions of residence: Atlantic = Prince-Edward Island, Nova Scotia, New Brunswick, Newfoundland/Labrador; Quebec; Ontario; Western Canada = British Columbia, Alberta, Manitoba and Saskatchewan and; North = Nunavut, Yukon, Northern territories.

[¥]The sum of the values for each category may differ from the total due to rounding to the 10th unit.

[§] Medication use includes both prescription and non prescription medication taken by the participant.

Figure 1. Percentage of weekly active physical involvement per activity group

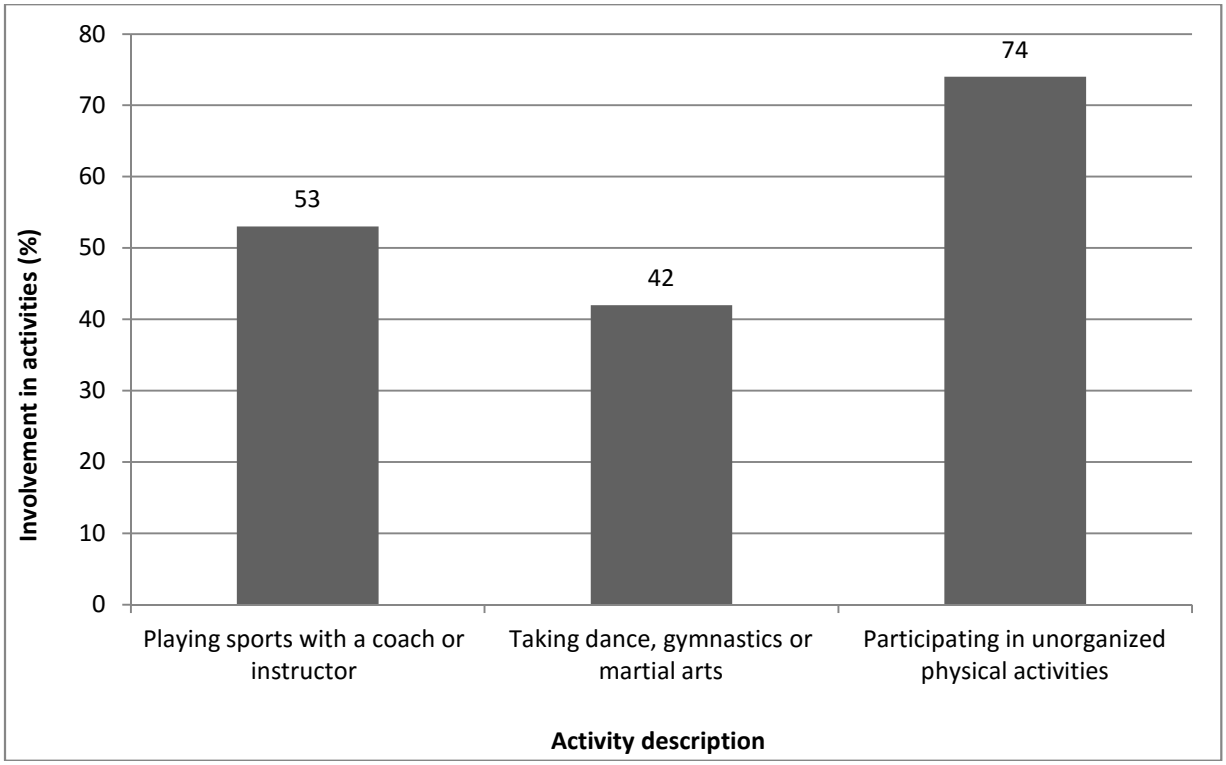
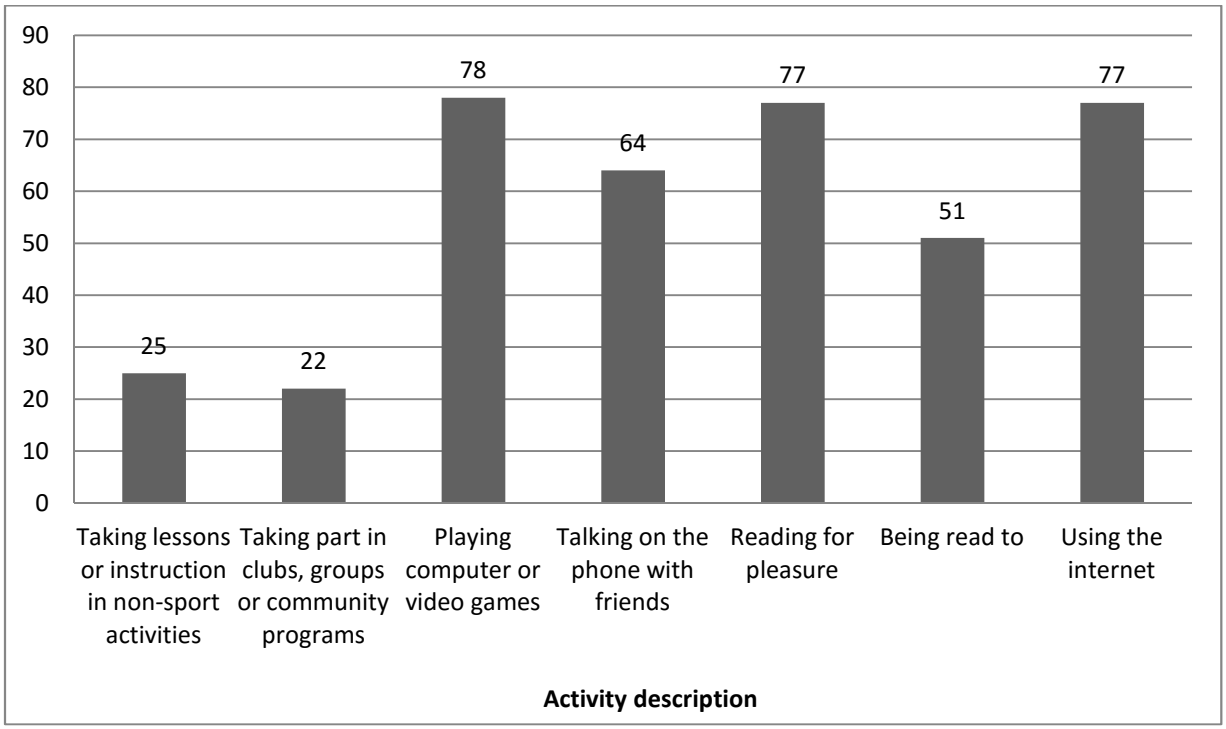


Figure 2. Percentage of weekly non active physical involvement per activity group



Note: The near totality of participants watched television daily.

Table II: Difference in mean scores for diversity of participation in overall, active physical, sedentary, non-sport skill-based, formal and informal leisure activities according to socio-demographic and disease-related factors

	Overall leisure	Active physical	Sedentary	Non-sport skill-based	Formal	Informal
	Mean (CI95%)	Mean (CI95%)	Mean (CI95%)	Mean (CI95%)	Mean (CI95%)	Mean (CI95%)
Age (years)						
5≤Age ≤ 11	6.5 (5.5, 7.5)	1.6 (1.1, 2.1)[§]	4.3 (3.8, 4.8)[§]	0.6 (0.2, 1.0)[E]	1.5 (0.8, 2.2)[§]	5.0 (4.6, 5.4)
Age ≥ 12	5.8 (4.0, 7.0)	1.3 (0.8, 1.9)[§]	4.1 (3.3, 4.9)[E]	0.3 (0.1, 0.5)[E]	1.1 (0.7, 1.5)[§]	4.7 (3.7, 5.6)
Sex						
Female	6.3 (5.3, 7.4)	1.3 (0.8, 1.9)[§]	4.1 (3.5, 4.7)[E]	0.6[d] (0.3, 1.0)[E]	1.0 (0.4, 1.6)	5.0 (4.3, 5.6)[§]
Male	6.0 (4.8, 7.1)	1.6 (1.1, 2.1)	4.4 (3.7, 5.1)[§]	0.2[d] (0, 0.4)[E]	1.5 (0.9, 2.1)	4.8 (4.1, 5.5)
Total family income (CAD/yr)						
< 60 000	5.6 (4.7, 6.5)	1.1 (0.6, 1.6)[§]	4.2 (3.6, 4.8)[§]	0.3 (0.1, 0.6)[E]	1.0 (0.4, 1.6)[E]	4.6 (4.2, 5.1)
≥ 60 000	6.6 (5.5, 7.7)	1.8 (1.2, 2.3)	4.3 (3.7, 4.9)[§]	0.6 (0.2, 1.0)[E]	1.6 (1.0, 2.2)[§]	5.0 (4.3, 5.8)
Difficulty walking						
None	6.1 (5.1, 7.1)	1.4 (0.9, 1.8)[§]	4.3 (3.7, 4.9)[§]	0.5 (0.1, 0.8)[E]	1.1 (0.7, 1.6)[§]	5.0 (4.3, 5.6)
Mild to Severe	6.3 (5.0, 7.6)	1.7 (1.0, 2.4)[§]	4.1 (3.4, 4.7)[E]	0.5 (0.2, 0.8)[E]	1.6 (0.8, 2.4)[§]	4.7 (4.0, 5.3)
Disease duration (years)						
<5	6.3 (5.3, 7.3)	1.6 (0.9, 2.4)	4.1 (3.5, 4.7)[§]	0.6 (0.3, 0.8)[E]	1.5 (0.8, 2.3)	4.8 (4.2, 5.3)
≥5	6.1 (5.0, 7.3)	1.4 (1.0, 1.8)	4.3 (3.7, 4.9)[E]	0.4 (0, 0.8)[E]	1.2 (0.7, 1.8)	4.9 (4.2, 5.7)
Difficulty using hands						
None	6.3 (5.2, 7.3)	1.4 (0.9, 1.8)	4.4 (3.8, 5.0)[§]	0.5 (0.2, 0.9)[E]	1.3 (0.7, 1.8)[§]	5.0 (4.4, 5.7)
Mild to Severe	6.0 (4.8, 7.3)	1.8 (1.0, 2.5)[§]	3.9 (3.3, 4.6)[E]	0.4 (0, 0.7)[E]	1.5 (0.7, 2.3)[§]	4.6 (3.9, 5.3)
Pain intensity						
No pain	6.4 (5.2, 7.5)	1.6 (1.0, 2.2)[§]	4.2 (3.6, 4.8)[§]	0.6 (0.2, 1.0)[E]	1.5 (0.9, 2.2)[§]	4.9 (4.2, 5.5)
Mild to Severe	6.0 (5.0, 7.0)	1.3 (0.9, 1.8)	4.3 (3.6, 5.0)[E]	0.4 (0.1, 0.1)[E]	1.1 (0.6, 1.6)[§]	4.9 (4.2, 5.7)
Medication use						
Never	5.0 (3.8, 6.2)[a]	1.0 (0.4, 1.6)[§]	3.8 (3.0, 4.6)[§]	0.2 (0, 0.4)[E]	0.7[g] (0.1, 1.2)[E]	4.3 (3.4, 5.2)
At least once weekly	6.6 (5.8, 7.4)[a]	1.7 (1.3, 2.1)	4.4 (3.9, 4.9)[E]	0.6 (0.2, 0.9)[E]	1.6[g] (1.1, 2.1)	5.1 (4.5, 5.6)

Table II. Continued.

Rehabilitation services received						
< once monthly	6.4 (5.5, 7.2)	1.5 (1.1, 2.0)	4.4 (3.9, 4.8)[§]	0.5 (0.2, 0.8) [E]	1.4 (0.9, 1.9)[§]	5.0 (4.5, 5.5)
≥ once monthly	5.3 (3.4, 7.1)[§]	1.3 (0.7, 1.8)[§]	3.7 (2.7, 4.7)[E]	0.3 (0, 0.7) [E]	0.9 (0.2, 1.6)[E]	4.4 (3.2, 5.7)
Locally available recreational facilities						
No	4.0 [b] (2.6, 5.4)[§]	0.3 [c] (-0.1, 0.7) [E]	3.5 (2.0, 5.1)[§]	0.2 (-0.1, 0.5) [E]	0.3[h] (-0.1, 0.7)[E]	3.7[§] (2.4, 5.1)
Yes	6.0 [b] (4.7, 7.3)	1.3[c] (0.8, 1.9)[§]	4.3 (3.9, 4.8) [E]	0.5 (0.2, 0.8) [E]	1.2[h] (0.6, 1.8)[§]	4.8 (4.1, 5.6)
High cost of leisure activities						
Yes	4.6 (3.5, 5.7)	0.7 (0.0, 1.4)[E]	3.7 (2.5, 5.0)[E]	0.1[e] (-0.1, 0.3) [E]	0.4 (-0.1, 1.0)[E]	4.1 (3.1, 5.1)
No	6.2 (4.7, 7.7)	1.3 (0.8, 1.9)[§]	4.4 (3.9, 4.8)[§]	0.6[e] (0.3, 0.9) [E]	1.3 (0.6, 2.0)[§]	4.9 (3.9, 5.8)
Child's need for assistance						
Yes	5.0 (3.6, 6.4)	0.9 (0.2, 1.6)[§]	3.9 (3.0, 4.9)[E]	0.2[f] (-0.1, 0.1) [E]	0.7 (0.2, 1.2) [E]	4.3 (3.3, 5.3)
No	6.8 (5.2, 8.3)	1.5 (1.0, 2.1)[§]	4.4 (4.0, 4.9)[§]	0.6[f] (0.3, 1.0) [E]	1.6 (0.7, 2.6)[§]	5.2 (4.4, 5.9)

[§]= 16.6%<Coefficient of variation ≤33.3% → use with caution. [E] = Coefficient of variation >33.3% → unreliable. Pairs statistically significant for alpha levels (α = 0.05) are assigned the same lower case letter; pairs that remain significant based on adjusted Bonferroni correction (i.e. α/11=0.0045) are in bold

Possible range for diversity leisure scores (Minimum, maximum): Overall leisure (0-11); Active physical (0-3); Sedentary (0-6); Non-sport skill-based (0-2); Formal (0-4); Informal (0-7)

Table III. Difference in mean scores for frequency of participation in overall, active physical, sedentary, non-sport skill-based, formal and informal leisure activities according to socio-demographic and disease-related factors

	Overall leisure	**Active physical**	**Sedentary**	**Non-sport skill-based**	**Formal**	**Informal**
	Mean CI95%)$^{\overline{T}}$	**Mean (CI95%)$^{\overline{T}}$**	**Mean (CI95%)$^{\overline{T}}$**	**Mean (CI95%)$^{\overline{T}}$**	**Mean (CI95%)$^{\overline{T}}$**	**Mean (CI95%)$^{\overline{T}}$**
Age (years)						
5≤Age ≤ 11	2.2 (1.8, 2.5)	1.9 (1.4, 2.5)	2.6 (2.4, 2.9)§	1.3 (0.6, 1.9)^{E}	1.4 (0.8, 2.0)	2.6 (2.4, 2.9)
Age ≥ 12	2.0 (1.6, 2.4)	1.6 (1.0, 2.2)	2.7 (2.2, 3.1)§	0.7 (0.2, 1.1)^{E}	1.0 (0.7, 1.4)	2.6 (2.1, 3.1)
Sex						
Female	2.2 (1.9, 2.6)	1.9 (1.3, 2.5)	2.7 (2.3, 3.0)§	1.3^{f} (0.8, 1.9)^{E}	1.5 (1.0, 2.0)	2.6 (2.3, 3.0)
Male	1.9 (1.6, 2.3)	1.6 (1.0, 2.2)	2.6 (2.3, 2.4)§	0.5^{f} (0, 1.0)^{E}	0.9 (0.3, 1.4)	2.6 (2.2, 2.9)
Total family income (CAD/yr)						
< 60 000	1.9 (1.6, 2.2)	1.3 (0.8, 1.9)	2.6 (2.3, 2.9)§	0.7 (0.2, 1.2)^{E}	0.9 (0.4, 1.4)	2.5 (2.2, 2.7)
≥ 60 000	2.3 (1.9, 2.7)	2.1 (1.6, 2.6)	2.7 (2.4, 3.1)§	1.3 (0.7, 1.9)^{E}	1.5 (1.0, 2.0)	2.7 (2.3, 3.1)
Disease duration						
<5	2.2 (1.7, 2.6)	1.9 (1.1, 2.7)	2.6 (2.3, 2.9)§	1.2 (0.6, 1.9)^{E}	1.4 (0.7, 2.1)	2.6 (2.2, 2.9)
≥5	2.1 (1.7, 2.4)	1.7 (1.2, 2.3)	2.7 (2.3, 3.0)§	0.9 (0.3, 1.5)^{E}	1.1 (0.7, 1.6)	2.6 (2.3, 3.0)
Difficulty walking						
None	2.1 (2.4, 2.1)	1.7 (1.2, 2.2)	2.7 (2.4, 2.9)§	0.9 (0.4, 1.4)^{E}	1.1 (0.7, 1.5)	2.6 (2.3, 2.9)
Mild to Severe	2.2 (1.7, 2.7)	3 (1.3, 2.7)	2.6 (2.2, 3.1)^{E}	1.3 (0.5, 2.0)^{E}	1.5 (0.8, 2.2)	2.6 (2.2, 3.1)
Difficulty using hands						
None	2.1 (2.4, 2.1)	1.7 (1.2, 2.2)	2.7 (2.4, 3.0)§	1.0 (0.4, 1.6)^{E}	1.2 (0.7, 1.7)	2.6 (2.3, 2.9)
Mild to Severe	2.2 (1.7, 2.7)	2.0 (1.3, 2.8)	2.6 (2.3, 3.0)^{E}	1.1 (0.4, 1.8)^{E}	1.4 (0.6, 2.1)	2.6 (2.3, 3.0)
Pain intensity						
No pain	2.1 (1.7, 2.5)	1.9 (1.2, 2.6)	2.6 (2.3, 2.8)§	1.1 (0.4, 1.8)^{E}	1.4 (0.8, 2)	2.5 (2.2, 2.9)
Mild to Severe	2.1 (1.8, 2.5)	1.7 (1.2, 2.2)	2.8 (2.4, 3.2)§	1.0 (0.5, 1.5)^{E}	1.1 (0.7, 1.6)	2.7 (2.3, 3.1)
Medication use						
Never	1.7^{a} (1.3, 2.1)	1.1^{d} (0.5, 1.8)	1.9 (1.5, 2.3)	0.5^{g} (-0.3, 1.0)^{E}	0.6^{l} (0.1, 1.1)	2.3 (1.9, 2.7)
At least once weekly	2.3^{a} (2.0, 2.5)	2.0^{d} (1.6, 2.5)	2.4 (2.1, 2.6)	1.2^{g} (0.7, 1.7)^{E}	1.5^{l} (1.0, 1.9)	2.7 (2.5, 3.0)
Rehabilitation services received						
< once monthly	2.2 (1.9, 2.5)	1.8 (1.4, 2.3)	2.3 (2.1, 2.6)§	1.1^{h} (0.6, 1.6)^{E}	1.3 (0.9, 1.7)	2.7 (2.4, 2.9)
≥ once monthly	1.8 (0.2, 2.5)	1.5 (0.9, 2.1)	1.9 (1.2, 2.6)§	0.8^{h} (-0.1, 1.7)^{E}		2.3 (1.7, 3.0)
Locally available recreational facilities						
No	1.4^{b} (1.0, 1.7)	**0.4^{e} (-0.2, 0.9)^{E}**	1.7 (1.2, 2.2)^{E}	0.3^{i} (-0.2, 0.8)^{E}	0.3^{m} (-0.1, 0.6)^{E}	2.0 (1.5, 2.5)
Yes	2.0^{b} (1.6, 2.3)	**1.6^{e} (1.0, 2.3)**	2.1 (1.8, 2.4)§	1.1^{i} (0.6, 1.6)^{E}	1.1^{m} (0.6, 1.7)§	2.5 (2.8, 2.1)
High cost of leisure activities						
Yes	2.0 (1.6, 2.4)	0.8 (0.0, 1.6)^{E}	1.8 (1.5, 2.2)^{E}	**0.3^{j} (-0.1, 0.7)^{E}**	0.4 (-0.1, 1.0)^{E}	2.2 (1.8, 2.6)
No	6.1 (1.2, 1.9)	1.7 (1.0, 2.4)§	2.1 (1.8, 2.5)§	**1.2^{j} (0.7, 1.7)^{E}**	1.2 (0.6, 1.9)§	2.4 (2.1, 2.8)
Child's need for assistance						
Yes	1.6^{c} (1.2, 2.0)	1.1 (0.3, 1.9)^{E}	1.8 (1.5, 2.2)§	**0.4^{k} (0, 0.8)^{E}**	0.6 (0.2, 1.1)§	2.2 (1.8, 2.7)
No	2.2^{c} (1.9, 2.6)	1.9 (1.2, 2.6)	2.4 (2.0, 2.7)§	**1.4^{k} (0.8, 1.9)^{E}**	1.6 (0.7, 2.4)§	2.6 (2.4, 2.8)

$^{\overline{T}}$= Mean (95% Confidence Interval) excluding missing values. §= 16.6%<Coefficient of variation ≤33.3% → use with caution
^{E} = Coefficient of variation >33.3% → unreliable. Pairs statistically significant for alpha levels (α = 0.05) are assigned the same lower case letter; pairs that remain significant based on adjusted . Bonferroni correction (i.e. α/11=0.005) are in bold

Table IV. Multiple linear regression: Factors explaining participation in overall, active physical, sedentary, non-sport skill-based and informal leisure activities. Models are adjusted for age and sex of the child.

	Overall leisure	**Active physical**	**Sedentary**	**Non-sport skill-based**	**Formal**	**Informal**
	β (95% CI)	**β (95% CI)**	**β (95% CI)**	**β (95% CI)**	**β (95% CI)**	**β (95% CI)**
Total family income (CAD/yr)						
≥ 60 000	0.45 (0.05, 0.86)*	0.75 (-0.07, 1.58)	0.34 (-0.02, 0.70)	0.29 (-0.36, 0.95)	0.41 (-0.21 , 1.03)	0.47 (0.09, 0.85)*
< 60 000 (reference)	-	-	-	-	-	-
Disease duration (years)						
< 5	-0.23 (-0.71, 0.25)	-0.13 (-1.02, 0.75)	-0.32 (-0.72, 0.07)	-0.09 (-0.97, 0.80)	-0.11 (-0.92, 0.70)	-0.30 (-0.70, 0.11)
≥ 5	-	-	-	-	-	-
Rehabilitation Services						
At least once monthly	-0.19 (-1.26, 0.88)	0.07 (-1.28, 1.42)	-0.62 (-1.73, 0.50)	0.71 (-0.53, 1.95)	0.50 (-0.63, 1.62)	-0.58 (-1.73; 0.57)
None (reference)	-	-	-	-		-
Pain intensity						
Mild to severe	0.39 (-0.14, 0.93)	0.11 (-0.71, 0.94)	0.61 (0.11, 1.10)*	0.14 (-0.71, 0.99)	0.04 (-0.73, 0.82)	0.59 (0.07, 1.10)*
None (reference)	-	-	-	-	-	-
Medication use						
At least once weekly	0.52 (-0.11, 1.15)	0.84 (-0.18, 1.86)	0.34 (-0.26, 0.95)	0.57 (-0.15, 1.30)	0.71 (-0.10, 1.51)	0.41 (-0.22, 1.04)
None (reference)	-	-	-	-	-	-

β (95% CI), β coefficient and 95% confidence interval
*=$p < 0.05$

Article 3

Participation in leisure activities by children and adolescents with juvenile idiopathic arthritis

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Author contributions: The PhD candidate contributed to developing the study design, was responsible for all data collection and management, conducted all analyses and drafted the entire manuscript. Dre. Feldman contributed through discussions about study design, analyses and provided feedback on several drafts of the manuscripts. Dre. Majnemer provided feedback on study design, analysis and on the final draft of the manuscript. Dr. Duffy facilitated data collection and provided feedback on the final draft of the manuscript.

Abstract:

Objectives: To describe leisure activities in children and adolescents with juvenile idiopathic arthritis (JIA) in terms of diversity, intensity (i.e. frequency) and enjoyment, and to identify potential determinants.

Methods: One hundred and seven children and adolescents aged 8-17 years diagnosed with JIA and their families participated in this cross-sectional study. Participants answered the Children's Assessment of Participation and Enjoyment (CAPE), which measures involvement in leisure (recreation, active physical, social, skill-based, self-improvement). Disease characteristics and socio-demographic factors were abstracted from the child's medical file.

Results: In terms of intensity, individuals with JIA were more often engaged in informal rather than formal leisure activities ($t(106) = 45.5$, $p<0.0001$). When intensity scores were compared across activity type, results showed that participants with JIA were most often involved in social and recreational activities ($p < 0.001$). The level of enjoyment was highest for social activities and lowest for self-improvement activities ($p < 0.001$). Those with active arthritis displayed less diverse ($p=0.016$), less intense ($p=0.011$) participation in active physical activities, and less frequent involvement in informal activities ($p=0.043$) compared to those who were asymptomatic.

Conclusion: Children and adolescents with JIA tend to participate more in sedentary types of activities. Greater disease activity may dissuade children and adolescents from participating in more active pursuits, which places them at greater risk for adopting sedentary lifestyles. The identification of determinants of leisure activities in children and adolescents with arthritis may allow healthcare professionals to assess children's health needs with more precision and promote a healthier lifestyle.

Introduction

Juvenile idiopathic arthritis (JIA), the most common chronic childhood autoimmune disease, is a heterogeneous inflammatory condition, with periods of unpredictable flare and remission and no known cure (1). During periods of joint inflammation (i.e. active disease) children experience increased pain, fatigue, tender joints and morning stiffness which may interfere with age-appropriate activities (physical, self-care and leisure) both at home and at school (2,3). Cardiorespiratory fitness, muscle strength and participation in leisure physical activity may be limited in children with JIA in comparison to their healthy peers (4-10). Involvement in leisure activities is of critical importance in childhood and adolescence to maintain a fit lifestyle, to form friendships and to refine life skills needed throughout adulthood, as well as to develop social contacts (11).

Participation is defined by the World Health Organization (WHO) as the 'involvement in life situations' (12). During childhood and early adolescence, time spent outside of school is devoted to play and leisure, making participation in leisure activities a primary role of childhood (13). Engaging in leisure activities offers the child and teenager ample opportunity to take part in challenging and focus-oriented activities, as well as acquire cognitive and social skills important for development (14,15) that can contribute to better academic achievement and competencies, as well as overall well-being (16).

The WHO's International Classification of Functioning, Disability and Health (ICF) framework and its child and youth version (ICF-CY) highlight how factors related to the child

and their health condition, the family and the environment may interact together to influence the level of participation (12). This bio-psychosocial model of functioning and disability recognizes the role and potential impact of its dimensions *body structure and functions*, *activities*, *personal factors* and *environmental factors* on participation, as well as the relevance of the health condition (12). To date the focus in JIA has been to identify clinical features that can influence participation in activities; very little research has addressed the role of personal and environmental factors as potential predictors. The level and diversity of participation in leisure varies across social contexts (family income, ethnic or cultural background, area of residence, community infrastructure and available resources) (16). For example, two-parent households, higher annual household revenue, and parents' preferences for recreational-oriented activities increases the frequency of child/adolescents participation in leisure activities (17).

For the most part, studies that address participation in children with JIA focus on physical activity without examining other types of leisure activity such as recreational, active physical, social, skill-based and self-improvement (4,18). The objectives of this study were 1) to assess patterns of involvement in (five different types of) leisure among children with JIA; 2) to compare leisure participation in the JIA cohort according to socio-demographic and disease-related characteristics; and 3) to compare leisure participation in children with JIA and their nearest age-matched sibling without JIA. The rationale for this last objective was to control for family environment.

Methods

Design The study was of cross-sectional design.

Participants

Children and their parents were approached during their scheduled visit to the pediatric rheumatology clinic at the Montreal Children's Hospital, McGill University Health Center. The research assistant described the study and its implications to families, and, if they agreed to participate, the patients and their parents signed assent and consent forms. Children and adolescents were eligible to participate if they 1) were 8 to 17 years; 2) had a clear diagnosis of JIA made by a rheumatologist based on the International League of Associations for Rheumatology (ILAR) classification; 3) were actively followed in the rheumatology clinic at the hospital and seen every 3 to 4 months; and 4) were able to speak and write either English or French. We chose to restrict the minimal age of enrollment to 8 years to ensure that the participants would be capable of understanding the format and the content of the study questions, allowing them to report their own perceptions and opinions with minimal parental involvement (19).

When possible, we recruited a sibling without JIA ranging in age from 8 to 17 years with a maximum age difference of 3 years from the JIA patient's age. If the sibling agreed, he or she signed assent forms brought home by the parent.

Ethical approval was obtained from the Montreal Children's Hospital's Research Ethics Board, as well as the *Comité d'Éthique de la Recherche en Santé*, *Université de Montréal*.

Data collection

Information on age, area of residence, disease activity (active joint count and other arthritis related symptoms such as rash or fever), medication use, disease duration and JIA subtype were abstracted from the participant's hospital file. Active disease was defined by the presence of at least one of the following clinical symptoms assessed by the treating pediatric rheumatologist and reported in the medical file: 1). active joint; 2). enthesitis; 3). systemic manifestation (e.g. arthritis related fever, rash). We used median household income for the area of residence (based on Census Canada Data) as a proxy for socio-economic status (20).

Measures

Leisure participation - The self-administered version of the Children's Assessment of Participation and Enjoyment (CAPE) was used to measure participation in leisure activities (Table I) with assistance provided by a research assistant over the phone or in person during a home visit as per the family's preference (21). The intraclass correlations coefficients of the self-administered version and the interview-assisted version which uses activity and category cards, as well as visual response pages were highly correlated (ICC > 0.80) for participation intensity (21). The CAPE is a standardized 55-item questionnaire designed to examine how children and adolescents (6 to 21 years old), with or without physical disabilities participate in physical and other more sedentary leisure activities (21). It takes 30 to 45 minutes to complete and refers to participation over the last four months. Scores for the CAPE are provided for two domains

(formal and informal activities) (Table I); and for five types of activities (recreational, active physical, social, skill-based, self-improvement) (Table I). Data on diversity (number of activities by activity type and by domain) and intensity (frequency of participation measured on a 7-point ordinal scale, where 7 is 'every day' 1 is 'once in the last 4 months') are collected. In addition, the CAPE measures the level of enjoyment of performing the activities on a scale from 1 'Not at all' to 5 'Love it' (21). The CAPE has demonstrated good internal consistency for intensity and diversity ranging from 0.67 to 0.84 and good test-retest reliability scores of participation intensity ranging from 0.72 to 0.81 (21). The CAPE demonstrates good construct validity (r=0.71), when compared to other measures of leisure participation (21).

Data on leisure participation was collected during the school year (Fall, Winter and Spring) between October 2010 and June 2012 to control for common activities done at school (e.g. sitting in class throughout the day) and excluding vacation. Moreover, the CAPE accounts for seasonal differences by investigating on leisure across seasons.

Analysis

Descriptive statistics were carried out to characterise the sample in terms of frequencies, percentages, means and standard deviations. The leisure outcome (CAPE) was described in terms of activity subtype (recreational, active physical, social, skill-based and self-improvement), activity domain (informal and formal) and by dimension of activity (diversity, intensity and enjoyment). The differences in patterns of leisure across demographic (age and sex) factors were examined with bivariate analysis (t-tests). The association between leisure with: age as a continuous variable, active joint count, the number of prescribed medications,

disease duration and the median household income were explored through Pearson correlation. Paired t-tests were conducted to compare leisure patterns (CAPE mean scores) between the patient with JIA and their nearest-age matched sibling without JIA. Factors associated with patient-sibling differences were further explored using multiple linear regression models with the difference between the patient's and the sibling's scores on the CAPE as the dependent variable. The independent variables tested were child's age and sex.

All statistical analyses were performed using SPSS 22 statistical software (Armonk, NY: IBM Corp.). For all inferential statistical analyses the significance level was fixed at alpha = 0.05.

Results

Sample characteristics

Among 172 eligible patients with JIA, 55 refused to participate in the study (enrollment rate 62.2%). The main reasons for refusal were: not interested (n=47), too busy (n=5) and involved in too many other studies (n=3). Another 10 patients did not complete the questionnaire citing they were no longer interested (n=8) or no longer had the time (n=2). Of the 117 participants with JIA who agreed to participate, 107 completed the Children's Assessment of Participation and Enjoyment (CAPE) (response rate 91.5%). There were no statistically significant differences between participants with JIA and non participants with JIA in terms of age, sex, disease duration, disease activity and JIA subtype distribution (data not shown). Mean age was 12.8 years and 75% were female. More than 50% had oligoarthritis, just over 20% had polyarthritis and 16% enthesitis-related arthritis. Socio-

demographic, disease-related and treatment characteristics of the JIA sample are described in Table II.

Leisure participation

A profile of children's participation in leisure activities are all described in Tables III and IV. The five top daily activities were: listening to music, doing homework, watching television, playing with pets, and playing computer/video games. Reported weekly physical activities included participating in sports (ranked third), walking (ranked 6th), and biking (ranked 7th) (Table III). In general children and teens with JIA proportionally engaged in a larger number of informal (41.8%, 23 out of possible 55 items) than formal (20.0%, 3 out of a possible 15 items) activities ($t(106) = 47.8$, $p<0.0001$). Significant differences in diversity were noted across activity types ($p<0.0001$). Patients with JIA were involved in a relatively large number of social (76.8%, 7 out of a possible 10 items) and recreational (61.9%, 7 out of a possible 12 items) activities, fewer active physical activities and an even smaller number of skill-based activities ($p<0.001$).

On average those living with JIA were more often engaged in informal (Mean = 2.73, SD = 0.62) and less in more structured formal (Mean = 1.11, SD = 0.85) activities ($t(106) = 45.5$, $p<0.0001$). Patients with JIA were most often involved in social (Mean = 3.15, SD = 1.00) and recreational (Mean = 3.04, SD = 0.98) activities, and to a lesser extent in self-improvement, active physical and skill-based activities ($p<0.001$) (Table IV). The level of enjoyment was highest for social activities (Mean = 4.18, SD = 0.47) and lowest for self-improvement (Mean = 3.16, SD = 0.57) activities.

Leisure participation in JIA and socio-demographic characteristics

Younger children with JIA (8 to 11 years) were more actively involved in recreational pursuits and enjoyed these more than the older group (12 to 17 years) while older children participated more in social activities (Table V). Younger age was correlated with participation in more diverse activities in both recreational ($r= -0.41$, $p<0.001$) and active physical activities ($r= -0.23$, $p=0.02$) and with participation in a greater number of informal activities ($r=-0.20$, $p=0.04$). Girls were engaged in a greater number of different social and skill-based activities and did so more frequently than boys. Moreover girls demonstrated more enjoyment for social, skill-based and self-improvement activities than did boys (Table VI). Participation in informal (spontaneous) types of activities for girls was characterized by greater diversity ($p=0.004$), intensity ($p=0.006$) and enjoyment ($p=0.001$) in comparison to boys. Higher median household income was associated with participation in a larger number of informal types of activities ($r= 0.202$, $p=0.036$).

Relationship between leisure participation and disease-related factors

Patients with active disease displayed less diverse (Mean = 3.80 (SD = 1.76), $p=0.028$) and less intense (Mean = 1.24 (SD = 0.71); $p=0.007$) participation in active physical activities in comparison to those without (Mean = 4.86 (SD = 2.70); Mean = 1.69 (SD = 0.95), respectively). Furthermore, participation in informal activities was less frequent amongst those with active disease as compared to those who were asymptomatic ($p=0.04$).

Comparison of leisure participation between those with JIA and their siblings without JIA

The sibling group included 12 boys and 8 girls (n=20) with a mean (SD) age of 12.9 (3.4) years. Of these 7 dyads were of the same sex. There were no statistically significant differences for age (mean age difference 1.9 years, p=0.465), however sex differed significantly (p=0.049) between dyads. Children with JIA were shown to participate in a greater number of skill-based (p=0.038) and self-improvement (p=0.042) activities, as well as more often in recreational (p=0.040) and informal (p=0.040) activities than did their siblings. However nearest-age and sex matched siblings engaged more frequently in active physical activities than did their JIA sibling with no other significant differences in leisure participation (p=0.020).

Results of the linear regression analysis indicated that only age was significantly associated with the mean differences in leisure participation scores between JIA patients and their sibling. As children got older there were smaller differences in diversity (p=0.022) and intensity (p=0.008) of skilled-based activities.

Discussion

Our study provides the first in depth description of leisure participation in JIA using a validated and standardised tool. Our findings demonstrate that children and teens with JIA participate in a vast array of leisure activities, the majority of which are informal activities. Further, children and adolescents with JIA participate less in physical activities compared to

siblings without JIA, even when adjusting for family environment. Similar results were described in other studies investigating leisure as measured by the CAPE in children and teenagers living with physical disabilities (17,22-26).

There are no official norms published for the CAPE, however studies including large samples of healthy Canadian children and adolescents provide some normative data (25,27). When compared to a reference sample of healthy Canadian children and teenagers, both diversity (JIA, 23.97 ± 5.19; healthy reference, 27.18 ± 3.53) and intensity (JIA, 2.73 ± 0.62; healthy reference, 3.79 ± 0.58)) in informal activities were lower for our JIA study sample (25). Those with JIA must contend with fluctuating disease activity characterised by periods of joint flare-ups, pain and physical limitations (1). Due to the unpredictable nature of their disease it may be difficult to keep up with scheduled classes or practices. Leading them to opt most often for spontaneous (informal) rather than scheduled and preplanned (formal) activities focused on skill building and physical activity. Some children with arthritis may also demonstrate poor self-concept, limited competency for either athletics or other skill-based activities inciting them to engage more in free play (recreational) (6).

Results for diversity and intensity in social activities among our participants with JIA parallel normative findings (27). Those with JIA enjoy and participate in as many different active physical activities albeit less frequently than healthy peers. Displaying how the interest for being active is as strong between both groups, but that engagement may be hindered by illness. On the other hand those with JIA display similar levels of enjoyment and involvement in skill-based activities as normative findings.

On a daily basis, most children and teens (>50%) with JIA participate in passive and home based activities (listening to music, doing homework and watching television). These findings parallel results from other studies in childhood disability (17,22-26) and in general, where discretionary time was spent mostly in media use and other more sedentary activities. Although similar trends are found among children without chronic conditions (28,29), those with JIA have shown to engage more often in sedentary behaviour compared to their healthy counterparts (5).

The association of age and sex with leisure participation is frequently studied (22,27,30). Often boys are reported to participate more frequently in active physical activities than girls (17,22,30,31). However our findings displayed no differences between boys and girls with JIA when examining the diversity, intensity and enjoyment of participation in active physical activities (17,30). According to the review by Larson & Verma (1999) completed on healthy children, girls generally spend more time in self-improvement activities such as homework, doing chores and reading, and as they get older they spend more time talking to peers and engage in more social activities than do boys who spend more time watching television and involved in organised sports (31,32). Among our participants with JIA the younger the child the more they participated in recreational activities, whereas the older child engaged most often in social activities. These results reflect age-appropriate leisure participation (14,32); as children get older they become less involved in play and more engaged in socially oriented activities (22,33).

Higher family income was associated with greater diversity in informal leisure activities. Some families may not have the financial resources to purchase equipment or other paraphernalia needed for participation in informal activities (e.g. bike, ice skates, rollerblades, video games and console, computer). Other studies support that lower-income families demonstrated less diversity in leisure activities (17).

Those with JIA who had active disease were less likely to participate as often and in as many physical activities as those that showed no signs of active arthritis. Similarly Takken et al. (2003) demonstrated that disease activity (number of swollen joints) hinders participation in physical activities in JIA (34). Others however found no association between the presence of disease activity and the level of physical activity (4).

Children and teens with JIA were more likely to participate in a greater number of skill-based and self-improvement activities than their nearest-age matched sibling. There is evidence in the literature to support that greater participation in both skill-based (e.g. taking music lessons, playing an instrument) and self-improvement (e.g. doing homework, reading) activities contribute to cognitive development and may favor academic success (14-16). In a population-based longitudinal study, those living with JIA were reported to achieve higher academic success than their siblings (35). Packham et al. (2002) discuss how those afflicted with JIA may be less distracted from their studies by other activities (35), which may at least partly explain differences in leisure across our study groups. Furthermore, in our study, participants with JIA were more frequently involved than their nearest-age matched siblings in more quiet recreation activities, as well as in informal (free play, spontaneous activities). This

may once again reflect how those living with chronic and often unstable disease may gravitate toward unstructured and often less physically straining activities.

In controlling for both age and sex, we discovered that those with JIA were less inclined to participate in active physical activities than their siblings without JIA. Our findings mirrored those of other comparative studies reporting higher levels of leisure-time physical activity among healthy peers versus those with JIA (4,5,36). There were smaller differences in diversity and intensity of skill-based activities among girls from either group. This is not surprising considering that girls participate more frequently and in larger numbers in these types of activities than boys (27).

There are several limitations to our study. The cross-sectional nature of the study precludes us from accounting for any fluctuations in disease status, which is typical in those living with JIA. However, our sample included persons with active and non-active disease, and the distribution of disease type was similar to that found in the JIA population. Siblings were chosen as a comparator group to control for family environmental factors. Nevertheless, the unique situation of living with a sibling with JIA may in itself diminish leisure participation of the sibling without JIA. Furthermore, these comparison results should be interpreted with caution due to the small sample size for sibling controls. The CAPE inquires about leisure retrospectively over the last 4 months, which may result in recall bias. Seasonal effects specifically for the colder months may also impact responses. However we expect that more active children and adolescents are likely to remain active across seasons.

Conclusion

This study has provided much needed insight into the patterns of leisure participation among children and teenagers living with JIA. Our findings have provided some evidence that involvement in leisure varies with disease activity, however longitudinal studies are needed to substantiate this further. Those with JIA may experience restrictions in participation due to their illness; this in turn may have detrimental consequences on the child's social integration and development. Future studies should identify the barriers to leisure involvement, so that clinicians may acquire the necessary tools needed to guide promotion of leisure involvement in these children. Ultimately, the identification of the determinants of leisure among children with arthritis may allow healthcare professionals to assess the child's health needs and develop health promotion initiatives that favour a healthier life style. Prospective study would be of great value in illustrating predictors of leisure while considering the fluctuations in disease status among children with arthritis.

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Table I. Child Assessment of Participation and Enjoyment (CAPE) activities grouped by type

Activity type	**Activities**
Recreational (12 items)	Doing puzzles; Playing board games or card games; Doing crafts, drawing or coloring; Collecting things; Playing computer or video games; Playing with pets; Doing pretend or imaginary play; Playing with things or toys; Going for a walk or hike; Playing on equipment (e.g. jungle gym); Watching TV or a rented movie; Taking care of a pet
Active physical (13 items)	**Doing martial arts**; **Racing or track and field**; **Doing team sports**; **Participating in school clubs**; Bicycling, in-line skating or skateboarding; Doing water sports; Doing snow sports; Playing games; Gardening; Fishing; Doing individual physical activities; Playing non-team sports; Doing a paid job
Social (10 items)	Talking on the phone; Going to a party; Hanging out; Visiting; Entertaining others; Going to the movies; Going to a live event; Going on a full-day outing; Listening to music; Making food
Skill-based (10 items)	**Swimming**; **Doing gymnastics**; **Horseback riding**; **Learning to sing (choir or individual lessons)**; **Taking art lessons**; **Learning to dance**; **Playing a musical instrument**; **Taking music lessons**; **Participating in community organizations**; Dancing
Self-improvement (10 items)	Writing letters; Writing a story; **Getting extra help for schoolwork from a tutor**; **Doing a religious activity**; Going to the public library; Reading; Doing volunteer work; Doing a chore; Doing homework; Shopping
Formal activities are in bold. The remaining items are informal activities.	

Table II. Socio-demographic, disease-related and treatment characteristics of children and teenagers with JIA (n=107)

	Mean (SD)	Range	n (%)
Socio-demographic characteristics			
Age (years)	12.8 (2.7)	8.0-17.8	
Age at diagnosis (years)	7.4 (4.5)	1.1-16.8	
Female			75 (70.1)
Median family income, CAD*	66 963 (15 696)	32 841-107 626	
Disease-related characteristics			
Active joint count (n=107)			
0			72 (61.5)
1			20 (17.1)
≥ 2			25 (21.4)
Disease duration (years)	5.47 (4.12)	0.04-15.24	
Functional status (CHAQ)	0.3 (0.5)	0.0-2.0	
Disability (mild-moderate or higher)			20 (18.7)
No disability			75 (70.1)
Missing data			12 (11.2)
Distribution of disease subtype			
Oligoarthritis			55 (51.4)
Polyarthritis			22 (20.5)
Systemic arthritis			5 (4.7)
Enthesitis-related arthritis			17 (15.9)
Psoriatic arthritis			6 (5.6)
Undifferentiated			2 (1.9)
Prescribed treatment			
Use of at least one arthritis medication			80 (74.8)
Use of NSAIDs			52 (48.6)
Use of MTX			43 (40.2)
Use of corticosteroids			5 (4.7)
Use of TNF-α inhibitors			11 (10.3)
Use of other DMARDs			10 (9.3)
Use of subcutaneous drugs			34 (31.8)
Number of prescribed arthritis medications	1.26 (1.04)	0-5	

*Median income was based on the three first characters of the family's home address (Statistics Canada, 2006) and expressed in Canadian dollars (CAD)
SD, Standard deviation; NSAIDs, Non-steroidal anti-inflammatory drugs; MTX, Methotrexate; TNF-α inhibitors, Tumor necrosis factor-α inhibitors; DMARDs, Disease-modifying antirheumatic drugs

Table III. Top activities performed daily and weekly by children and teenagers with JIA (n=107)

	n (%)	ranking
Daily activities		
Listening to music	65 (60.7)	1
Doing homework	65 (60.7)	2
Watching television	64 (59.8)	3
Playing with pets	42 (39.3)	4
Playing computer and video games	39 (36.4)	5
Reading	33 (30.8)	6
Doing chores	33 (30.8)	7
Caring for pets	33 (30.8)	8
Hanging out	30 (28.0)	9
Doing crafts and coloring	22 (20.6)	10
Talking on the phone	21 (19.6)	11
Weekly activities		
Hanging out	45 (42.1)	1
Visiting with others	39 (36.5)	2
Participating in team sports	37 (34.6)	3
Playing games	35 (32.7)	4
Preparing food	33 (30.9)	5
Taking a walk	30 (28)	6
Biking	30 (28)	7
Playing board games	35 (32.7)	8
Entertaining visitors at home	27 (25.3)	9
Dancing for fun	27 (25.3)	10

JIA, Juvenile idiopathic arthritis

Table IV. Mean (SD) scores for activity types by leisure dimensions of those living with JIA and other Canadian children and adolescents without a physical disability

	107 Canadian children and adolescents with JIA (8 to 17 years)	22 siblings without JIA of children and adolescents with JIA matched for age (8 to 17 years)	354 Canadian children and adolescents without disabilities (6 to 14 years) (27)
	Mean (SD), range	Mean (SD)	Mean (SD)
Recreation			
Diversity	7.43 (2.16), 3-12	6.59 (2.3)	10.00 (1.72)
Intensity	3.04 (0.98), 0.83-5.25	2.57 (0.91)	4.37 (0.99)
Enjoyment	3.87 (0.52), 2.67-5.00	3.7619 (0.51)	4.06 (0.51)
Active physical			
Diversity	4.46 (2.43), 0-12	5.09 (2.43)	4.73 (1.51)
Intensity	1.52 (0.89), 0.00- 4.46	1.62 (0.87)	2.68 (0.96)
Enjoyment	4.00 (0.61), 2.00-5.00	3.65 (0.82)	4.29 (0.61)
Social			
Diversity	7.68 (2.00), 0-10	7.36 (1.71)	7.64 (1.36)
Intensity	3.15 (1.00), 0.00- 5.40	2.85 (1.05)	3.57 (0.88)
Enjoyment	4.18 (0.47), 2.80-5.00	3.89 (0.64)	4.28 (0.45)
Skill-based			
Diversity	2.49 (1.85), 0-9	1.77 (1.34)	3.21 (1.74)
Intensity	1.21 (1.00), 0.0- 5.20	0.77 (0.65)	1.66 (0.94)
Enjoyment	4.01 (0.77), 1.33-5.17	3.85 (0.69)	4.13 (0.95)
Self-improvement			
Diversity	5.37 (1.47), 2-9	4.86 (1.28)	6.34 (1.42)
Intensity	2.58 (0.72), 1.00- 4.10	2.28 (0.66)	3.15 (0.71)
Enjoyment	3.16 (0.57), 1.83-4.38	3.01 (0.73)	3.21 (0.73)

SD, Standard deviation
Higher diversity scores indicate greater number of activities performed; recreational maximum possible score = 12; active physical maximum possible score = 13; social maximum possible score = 10; skill-based maximum possible score = 10; self-improvement maximum possible score = 10
Higher intensity scores indicate greater frequency of participation in activities with scores ranging from 1 to 7
Higher enjoyment scores indicate greater enjoyment with scores ranging from 1 to 5

Table V. Mean (SD) leisure (diversity, intensity, and enjoyment) scores as measured by the CAPE for children with JIA grouped by age (n=107)

Age groups	Recreational activities	Active physical activities	Social activities	Skill-based activities	Self-improvement activities
Diversity scores					
8-11 years	8.41*** (2.09)	5.00 (2.67)	7.34 (2.29)	2.73 (2.18)	5.22 (1.67)
12-17 years	6.82*** (1.98)	4.12 (2.04)	7.89 (1.78)	2.33 (1.61)	5.47 (1.34)
Intensity scores					
8-11 years	3.49*** (0.94)	1.68 (0.94)	2.77** (0.92)	1.35 (1.16)	2.50 (0.76)
12-17 years	2.76*** (0.90)	1.42 (0.81)	3.39** (0.97)	1.12 (0.88)	2.64 (0.69)
Enjoyment scores					
8-11 years	4.00* (0.49)	4.07 (0.61)	4.22 (0.49)	4.06 (0.89)	3.26 (0.63)
12-17 years	3.78* (0.53)	3.95 (0.61)	4.16 (0.47)	3.98 (0.69)	3.11 (0.53)

SD, Standard deviation
Differences between age group pairs significant at: *p<0.05, ** p<0.01, *** p<0.001.
Analysis was performed on data from 41 children aged 8-11 years and 66 adolescents aged 12-17 years

Table VI. Mean (SD) leisure (diversity, intensity, and enjoyment) scores as measured by the CAPE for children with JIA grouped by sex (n=107)

	Recreational activities	Active physical activities	Social activities	Skill-based activities	Self-improvement activities
Diversity scores					
Girls	7.69 (1.97)	4.32 (2.31)	8.07 (1.74)*	2.99*** (1.83)	5.52 (1.41)
Boys	6.81 (2.47)	4.78 (2.70)	6.78 (2.30)*	1.31*** (1.28)	5.03 (1.58)
Intensity scores					
Girls	3.13 (0.90)	1.42 (0.86)	3.35 (0.92)**	1.48*** (1.00)	2.66 (0.68)
Boys	2.82 (1.13)	1.74 (0.93)	2.70 (1.04)**	0.56*** (0.61)	2.40 (0.77)
Enjoyment scores					
Girls	3.93 (0.49)	4.00 (0.61)	4.26 (0.43)**	4.12*** (0.77)	3.28** 0.52)
Boys	3.72 (0.57)	3.98 (0.61)	3.97 (0.51)**	3.65*** (0.68)	2.90** (0.62)

SD, Standard deviation
Differences between pairs of boys and girls by activity type significant at: *p<0.05, **p<0.01, ***p<0.001.
Analysis was performed on data from 75 girls and 32 boys

Article 4

Personal and environmental factors associated with leisure participation among children and adolescents with juvenile idiopathic arthritis

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Abstract:

Objective: To identify potential factors associated with leisure in children and adolescents with juvenile idiopathic arthritis (JIA) according to the International Classification of Functioning, Disability and Health for Children and Youth framework.

Methods: One hundred and seven children and adolescents (8-17 years) diagnosed with JIA completed the Children's Assessment of Participation and Enjoyment, which measures involvement in leisure (recreation, active physical, social, skill-based, self-improvement). Explanatory variables included socio-demographics, disease characteristics, child's functional status, and child's personal, family and environmental characteristics. Associations were analyzed through hierarchical regression analysis.

Results: Personal (age, sex, preferences for activities, motivation for gross motor tasks) and environmental (cultural background, maternal education, median household neighborhood income) factors were important in explaining leisure participation for different types of activities. Overall, included variables explained between 10.8% (self-improvement) and 29.7% (active physical) of the adjusted total variance.

Conclusions: Leisure participation in JIA is a complex phenomenon that may be explained by a multitude of factors related to the child, the family and the environment. Identification of these variables may help rehabilitation professionals ascertain those with JIA who are at greater risk for decreased participation in leisure, as well as tailor safe and effective treatment strategies to meet the child's and family's needs.

Introduction

Leisure participation is an important part of occupational performance in childhood and adolescence. The World Health Organization has shown increasing interest in the concept of participation defined as the 'involvement in life situations, including leisure and recreation' (1). Participation in leisure activities is a multi-component concept and may be influenced by multiple factors related to the child and the surrounding environment (family, community and school) (2). Greater participation in leisure activities is associated with many benefits such as improved scholastic performance, more opportunities to foster interactions with peers and mentors, less delinquent behaviour such as substance abuse, healthier and more physically fit lifestyles (3). Many theories support that participation in leisure activities is influenced by a number of interactive variables related to the child and the surrounding environment (1,4,5).

Juvenile idiopathic arthritis (JIA), the most common chronic childhood autoimmune disease, is a heterogeneous inflammatory condition characterised by periods of unpredictable flare and remission and no known cure (6). Children and adolescents with JIA may experience fluctuating periods of pain, fatigue, joint swelling and contractures secondary to their disease, which may also lead to physical disability that can be felt well into adulthood (7-9). Furthermore, those with JIA may experience scrutiny and disbelief from teachers, classmates and friends regarding their disease and its often invisible symptoms (10,11). These limitations may interfere with their participation in age-appropriate leisure activities on a long-term basis (12-14). Research supports that children and adolescents with physical limitations participate

in fewer and less varied leisure activities in comparison to their healthy peers, where activities are often more home-based and less social (15-17).

Although rehabilitation professionals are more concerned with a client-centered approach to treatment, little is done in JIA in assessing and identifying the personal and environmental factors that may influence leisure participation. By gaining knowledge of both intrinsic and extrinsic factors that influence the level of participation rehabilitation professionals will be better equipped in identifying at risk groups, devising tailored therapeutic strategies and providing varying sources of support to families in order to promote a more active lifestyle for their child and participation in age-appropriate leisure activities. Programs to promote better health status through improvement of existing policies and treatment plans may therefore be developed.

The aim of our study was to identify factors associated with participation in various types of leisure activities (recreation, active physical, social, skill-based, self-improvement). Our choice of factors was informed by the International Classification of Function, Disability and Health (ICF) and its Children and Youth version (ICF-CY) framework, as well as other theoretical models conceptualising leisure as a function of child, family and environmetal variables (4,18,19). Our study's model is socio-ecological in nature: it considers an intricate network of intrapersonal, interpersonal (family) and structural (environment) factors (5). The ICF-CY framework provides us with the information necessary to properly describe characteristics of children and adolescents with JIA related to their health, body functions and structures, activity limitations, personal and environmental characteristics that may facilitate

or hinder their leisure participation. Therefore our models emphasize the presence of disease and its potential effect, while also considering contextual characteristics as potential predictors of participation in leisure. Factors that have the most influence on participation and are potentially modifiable should be the focus of clinical rehabilitation intervention (4). Moreover, as a secondary objective we explored potentially moderating effects of disease activity, pain and median neighborhood income on the potential effects of age, sex, motivation, athletic competence, physical appearance on involvement in leisure activities.

Methods

Design

We used a cross-sectional design and recruited children and adolescents with JIA and their parents during their scheduled visit to the pediatric rheumatology clinic at the Montreal Children's Hospital, McGill University Health Center.

Participants

Children and adolescents were eligible to participate if they 1) were 8 to 18 years; 2) had a clear diagnosis of JIA made by a rheumatologist; 3) were actively followed in the rheumatology clinic at the hospital and seen every 3 to 4 months; and 4) were able to speak and write either English or French. We restricted the minimal age of enrollment to 8 years to ensure that the participants would be capable of understanding the format and the content of the study questions with little assistance, allowing most to report their own perceptions and opinions with minimal parental involvement (50). The research assistant described the study

and its implications to families, and, if they agreed to participate, the participants with JIA and their parents respectively signed assent and consent forms. Both parent and child/adolescent received questionnaires packages to be completed at home. They were then instructed to return the completed questionnaires in a prepaid stamped envelope.

A telephone meeting or home visit was scheduled approximately 1 to 2 weeks later so that the research assistance could assist in completing a self-reported questionnaire on leisure participation (main outcome) to ensure consistency in reporting across participants. Moreover, at that time the research assistant would answer any questions the family might have.

Ethical approval was obtained from the Montreal Children's Hospital's Research Ethics Board, as well as the *Comité d'Éthique de la Recherche en Santé*, *Université de Montréal*.

Data collection

Factors potentially associated with participation in leisure activity were collected via chart review and questionnaires that were completed by patients and parents. Socio-demographic (age, sex, area of residence) and disease-related (disease activity (active joint count and other arthritis related symptoms such as rash or fever), disease duration and JIA subtype) and treatment-related (medication prescription and rehabilitation services) characteristics were abstracted from the medical chart. Active disease was defined by the presence of at least one of the following clinical symptoms assessed by the treating pediatric rheumatologist and

reported in the medical file: 1). active joint; 2). enthesitis; 3). systemic manifestation (e.g. arthritis related fever, rash).

Measurement tools

Leisure participation - The self-administered version of the Children's Assessment of Participation and Enjoyment (CAPE) was used to measure participation in leisure activities (Table I) with assistance provided by an experienced research assistant over the phone or in person during a home visit as per the family's preference (20). The intraclass correlations coefficients (ICC) of the self-administered version and the interview-assisted version which uses activity and category cards, as well as visual response pages were highly correlated (ICC > 0.80) for participation intensity (20). The CAPE is a valid, reliable, standardized 55-item questionnaire designed to examine how children and youth (6 to 21 years old), with or without physical disabilities participate in physical and other more sedentary leisure activities over the past four months (20). Leisure participation measured across two domains (formal and informal activities) and five types of activities (recreational, active physical, social, skill-based, self-improvement). Intensity scores (frequency of participation) was measured using a 7-point ordinal scale, where 7 is 'every day' 1 is 'once in the last 4 months').

Function/disability in children with arthritis was measured using the ***Childhood Health Assessment Questionnaire (CHAQ)*** a valid and reliable self-report questionnaire completed by children and adolescents (21), and by a parent for those younger than 10 years. There is strong agreement between children and parent mean scores, supporting reliable parental report on their child's function (22). The CHAQ has excellent reliability and demonstrated construct

validity (23). A final disability score is derived by averaging results of all 8 functional domains (like “dressing and grooming”, “eating”, “walking” and “activities”), with 0-1 indicating mild to moderate disability, 1-2 moderate to severe disability, and 2-3 severe to very severe disability (24). Furthermore, the pain subscale of the CHAQ assesses participants pain due to their illness in the last week on a 100 mm ***visual analog scale (VAS)*** (24,25).

Personal characteristics that were measured include mastery motivation, self concept and preference for physical activities. Children and adolescents with JIA reported on their mastery motivation behaviour by completing the ***Dimensions of Mastery Questionnaire (DMQ)***; parent questionnaires were only used when the child’s version had not been completed and research assistant was unable to reach family to complete. The DMQ has good to very good internal consistency (26). Discriminant and concurrent validity are not reported. The ***Self-Perception Profile (SPP)*** was completed by children and adolescents with JIA to assess personal perception of competence among children (8-12 years) and adolescents (13-18 years). This instrument is reliable and valid (27,28).

The child’s preference for recreational and active physical activities was measured using the ***Preferences for Activities of Children (PAC)*** (20). The PAC is reliable with Cronbach’s alpha ranging from 0.67 to 0. 77 and content validity has been established (20).

Environmental characteristics including information on family structure, maternal age, maternal education level and cultural background were obtained through parental report. Information on the area of residence was abstracted from the medical file. We used median

household income for the area of residence (based on Census Canada Data 2006) as a proxy for socio-economic status (29). We assessed perceived social support using the ***Social Support Scale (SSS)***, which collects data on social support provided by four sources: parents, teachers, friends and classmates (30). Internal consistency reliabilities based on Cronbach alpha scores were acceptable to good ranging from 0.78 to 0.88 for the parent and the teacher subscales and 0.72 to 0.83 for the friends and classmates subscales (30). Construct and convergent validity were demonstrated (30). Environmental barriers were evaluated by having parents complete the ***Child and Adolescent Scale of Environment (CASE)*** (31). The CASE is reliable and has demonstrated construct and discriminant validity (32). For children and adolescents with JIA data on family functioning was obtained through parental self-report using the ***Family Environment Scale (FES)***, which collects data across 10 sub-domains (cohesion, expressiveness, conflict, independence, achievement, orientation, intellectual-cultural orientation, active-recreational, moral-religious, organization, control). The FES is reliable. (33,34). Construct and discriminant validity were demonstrated (33,34).

All questionnaires were translated into French using forward and back translation.

Analysis

Descriptive statistics were used to characterise the sample in terms of frequencies, percentages, means and standard deviations. To date there is very little evidence supporting what predictors may be involved in participation in leisure in JIA and therefore we did not test specific hypotheses. Bivariate associations between leisure participation (separately for recreational, active physical, social, skill-based and self-improvement activities) and

continuous variables were explored through Pearson correlations, and simple linear regressions were used for dichotomous variables.

We conducted hierarchical regression analysis to evaluate the best predictive model for specific types of leisure activities: recreational, active physical, social, skill-based and self-improvement. Based on the ICF-CY framework factors were explored in blocks as: 1). body functions and structures (pain, disease activity); 2). activity limitations (level of disability/function), 3). personal (child's self-concept, child's mastery motivation, activity preferences, disease duration) and 4). environmental (child's perceived social support, mother's age, maternal education, family structure, family functioning, parental perceived environmental barriers, median neighborhood income, cultural background, rehabilitation services received, number of arthritis medications prescribed) (Figure 1). We tested 4 models for each of the CAPE intensity scores to obtain the best predictive model: 1). Base model included the body functions/structures and function/disability factors, 2). Base model and the personal factors, 3). Base model and the environmental factors and 4). Base model, personal and environmental factors. As mentioned above, the literature on leisure participation is sparse in JIA, therefore the choice of variables for entry into the models was informed by the literature on leisure in pediatric disability and general pediatrics, as well as our bivariate analysis. Based on our previous work (35) and the literature, age and sex are strong predictors of leisure participation and were introduced into the model last as covariates so as not to mask the contribution of body functions and structures, disability/function and contextual factors on leisure participation (36). Before conducting the regression analyses, possible multicollinearity of the independent variables was examined using the variance inflation

factor(37). Residual plots were assessed to check normality and homogeneity. Adjusted R^2 identified the most parsimonious explanatory model both within and over blocks of variables. Bootstrapping (2000 replications) was used to validate the final models (38).

Independent variables that did not follow a normal distribution were dichotomized. The disability score was dichotomised into mild (CHAQ score of 0 to 1) and moderate to severe (CHAQ score of >1), as well as by using the cut-off 0.6 (mild to moderate disease or above; CHAQ score ≥ 0.6) (39). The pain VAS score was dichotomized at the median (pain ≥ 10 mm). We also wanted to distinguish those with somewhat more substantial pain and also dichotomized the VAS pain score at the midpoint (pain ≥ 50 mm) (40).

We explored interactions to assess possible moderating effects of disease activity, pain and income on the potential effects of age, sex, activity preferences, motivation, athletic competence, physical appearance on participation in leisure across activity types.

All statistical analyses were performed using SPSS 22 statistical software (Armonk, NY: IBM Corp.). For all inferential statistical analyses the significance level was fixed at alpha = 0.05.

Results

Participants

Among 172 eligible patients with JIA, 55 refused to participate in the study (enrollment rate 62.21%). The main reasons for refusal were: not interested (n=47), too busy (n=5) and

involved in too many other studies (n=3). Another 10 patients were no longer interested (n=8) or no longer had the time (n=2). Of the 117 participants who agreed to participate, 107 patients with JIA completed the Children's Assessment of Participation and Enjoyment (CAPE) (response rate 91.45%). There were no statistically significant differences between participants and non participants in terms of age, sex, disease duration, disease activity and JIA subtype distribution (data not shown). Mean age was 12.8 years and 75% were female. More than half had oligoarthritis, one-fifth had polyarthritis and 16% enthesitis-related arthritis. Socio-demographic, disease-related and treatment characteristics of the JIA sample are described in Table I. Further details regarding differences between age groups, sex and disease activity is highlighted in an earlier manuscript (35). Children and adolescents with JIA were most often involved in social (Mean = 3.15, SD = 1.00) and recreational (Mean = 3.04, SD = 0.98) activities, and to a lesser extent in self-improvement, active physical and skill-based activities ($p<0.001$). Younger children with JIA (8 to 11 years) were more actively involved in recreational pursuits than the older group (12 to 17 years) while older children participated more in social activities (35). Girls engaged more frequently in social and skill-based activities than boys (35). Participants with active disease activity (i.e. presence of at least one active joint or one enthesitis or any systemic clinical presentation) participated less frequently on average in active physical activities (Mean (SD) = 1.24 (0.71)) in comparison to those without active disease (Mean (SD) = 1.69 (0.95)), $p=0.007$ (35).

Factors associated with leisure in JIA

Bivariate analysis

Factors associated with increased participation in recreational activities included intrinsic (younger age ($r=-0.397$, $p<0.0001$) and preference for recreation activities ($r=0.481$, $p<0.0001$)) and extrinsic (being of Canadian cultural background ($\beta=0.234$, $p=0.023$)) factors.

For participation in active physical activities, intrinsic factors were age ($r=-0.184$, $p=0.029$), active arthritis ($\beta = -0.244$, $p = 0.011$); pain due to illness ($r=-0.309$, $p=0.002$), preference for active physical activities ($r=0.241$, $p=0.006$), athletic competence ($r=0.333$, $p=0.001$), social persistence with peers ($r=0.226$, $p=0.014$) and gross motor persistence ($r=0.445$, $p<0.0001$) and extrinsic factors were maternal education ($\beta=0.383$, $p<0.0001$); median neighborhood income ($r=0.168$, $p=0.042$) and number of perceived environmental barriers ($r=-0.249$, $p=0.016$).

For participation in social activities, only intrinsic factors showed any correlation. These were age ($r=0.260$, $p=0.003$); sex (girls; reference boys) ($\beta=0.300$, $p= 0.002$), preference for social activities (0.342, $p<0.0001$) and perceived physical appearance ($r=0.217$, $p=0.018$).

For participation in skill-based activities, intrinsic factors were sex (reference boys) $\beta=0.428$, $p<0.0001$, preferences for skill-based activities (0.499, $p<0.0001$) and only one extrinsic factor maternal education (reference high school or less) ($\beta=0.221$, $p=0.034$).

Finally, participation in self-improvement activities was associated with only two factors: preference for self-improvement activities ($r=0.236$, $p=0.003$) and cultural background (reference other than Canadian) ($\beta= - 0.277$, $p=0.007$).

Multivariate analysis

Personal and environmental factors contributed to all types of leisure activities, however body functions and structures were only included in the regression model for active physical activities. Overall, included variables explained between 10.8% (self-improvement) and 29.7% (active physical) of the adjusted total variance (Tables II to VI). Increased participation in recreational activities was positively associated with preference for recreational activities and identifying your cultural background as Canadian (Table II). Greater participation in active physical activities was associated with a greater level of motivation for performing challenging gross motor tasks and maternal education beyond high school (Table III). Increased participation in social activities was positively associated with preference for social activities, higher median neighborhood income and older child age (Table IV). Greater participation in skill-based activities was associated with preference for skill-based activities, higher maternal education and being a girl (Table V). Increased participation in self-improvement activities was positively associated with being of a cultural background other than Canadian (Table VI).

Interactions

The tested interactions were not significant.

Discussion

Our study is the first to demonstrate how both personal and environmental factors other than those related to the disease are potential predictors of participation in leisure activities in children and adolescents with JIA. These results underline how participation in leisure is a complex construct and influenced by a network of intrapersonal, interpersonal and environmental variables (5). The use of the ICF's child and youth (ICF-CY) framework to guide our analysis has helped to shape our understanding of facilitators and barriers to participation in JIA by considering a broad range of possible determinants linked to health and disease. The socio-ecological framework lends itself well to hierarchical analysis and has highlighted how facilitators and barriers to participation vary according to the nature of the activity.

Although disease-related factors such as disease activity and pain due to illness were correlated with participation in certain activities neither remained associated in the multivariate analysis of leisure participation. These factors may not necessarily have a direct effect on the level of participation, but may in fact play a part in moderating the effect of personal and environmental factors on participation in leisure. In a study by Leung et al. (1997), adolescents with either cystic fibrosis or insulin-dependent diabetes mellitus consistently reported lower scores for their illness perception compared to their treating

physician (41). Perception of illness severity among chronically ill children may not necessarily reflect clinical indices of disease (41), and therefore not be associated with their level of participation in leisure. Disease activity was the only disease-related factor that was retained in the predictive model of active physical participation, but it was not significantly associated with participation. Function/disability status did not contribute to participation and was therefore excluded from the regression models, which may in part be explained by the fact that on average participants with JIA presented with mild to moderate disability. Similarly, among adolescents with cerebral palsy functional limitations contributed minimally to explaining the variance of participation as compared to personal and environmental factors (42).

We found that age and sex were important predictors of involvement in leisure in agreement with other studies in pediatric disability (42-46), however their effect was dependent on the type of activity. Older children participated mostly in social types of activities and girls took part in skill-based activities more than boys.

Preference for certain activities was often a predictor of the level of participation in leisure activities. This is consistent with the literature on leisure and recreation, which considers a person's preference as a determinant of their engagement in activities (47,48). This also mirrors the theory of planned behaviour supporting that 'intention is a determinant of one's behaviour where intention is predicted by the individual's attitude' (49). Identifying safe and appropriate activities for individuals with JIA can help shape an efficient treatment plan led by rehabilitation professionals. For the most part, activity preference was at best moderately

correlated with the actual level of participation across leisure activities. This may potentially indicate that those living with JIA are not necessarily taking part in the activities that they prefer. Moreover, when testing multivariate models preference for active physical and self-improvement activities were not associated with participation in their respective leisure activities. This may account for the fact that many of the activities classified as active physical in the CAPE are formal and may require purchase of specialised equipment and registration fees, therefore the parent may govern the child's participation in these activities. Similarly, self-improvement activities such as homework, doing chores and going to church are things that are expected by parents or by teachers and as such most children and adolescents may view them as obligations rather than preferred activities.

Mastery motivation for gross motor performance was an important personal predictor of active physical pursuits, which is consistent with a study among adolescents with cerebral palsy (42). Motivation is often recognised as a key aspect of performing challenging tasks and if it is intrinsically driven it can lead to action (50). This underlines the importance for rehabilitation professionals to use meaningful activities to favour mastery motivation and encourage children and adolescents with JIA to attempt participation in more challenging gross motor activities as long as they are safe and recommended by the rehabilitation and medical team (51). Aquatic activities are low impact alternatives that can also be beneficial in improving the physical limitations and disease presentations in children and adolescents with JIA (52).

Many factors relating to the child's family environment were significant predictors of participation in various types of activities. In general, family environment characteristics

(family income, parental preference for activities, maternal education) are considered to be important in promoting the child's participation (42,53). Family socio-economic status partly explained the frequency of participation in recreational and active physical activities; however it was only a strong predictor of involvement in social activities. Some of the social activities assessed in our study included going to the movies, going to a live event and going on a full-day outing, which may be facilitated if the family has enough disposable income. Lower socio-economic status has been associated with lower participation over time in children with physical disabilities (54) and as such must be taken into account when providing families with options for leisure activities. Higher maternal education was associated with more involvement in active physical and skill-based activities potentially owing to the fact that more educated mothers are better informed and understand the importance of involvement in these types of activities on their child's health and development. Similar findings were reported in healthy youth (55) and in pediatric disability (42). Maternal education can also serve as a proxy for socio-economic status. Finally, the family's cultural background was associated with participation in recreational and self-improvement activities, where those identifying themselves as Canadian were more involved in recreational (playing with toys, playing board games, watching television, playing video games, going for a walk) activities and less in self-improvement (homework, doing chores, reading) activities. Similar results were described in Larson et al.'s international review of leisure in healthy children and adolescents (56). A family's cultural values, beliefs, preferences and behaviours may directly inform their child's participation in various leisure activities and must be considered by rehabilitation professionals when devising an intervention plan (4).

Limitations

Our study has several limitations. Our study design is cross-sectional and as such precludes us from identifying factors associated with leisure participation over time in JIA - a disease characterised by fluctuating clinical symptoms. Although our intention was to undergo structural equation modeling to identify direct and indirect relations between independent variables our final sample size was too small (<200 participants) to allow for a valid analysis. Furthermore, the high proportion of unexplained variance in various types of leisure activities may indicate that some predictors may have been left out of the analyses.

Conclusion

Participation in leisure is a multi-component phenomenon influenced by multiple levels of factors related to the child, the family and the environment. Although the predictors identified were not necessarily amenable to change (e.g. cultural background, socio-economic status, maternal education) they can help rehabilitation professionals ascertain which children and adolescents are at highest risk for low involvement in leisure activities and provide information on how best to tailor interventions to the family's needs. Incorporating assessment of personal and environmental factors can guide treatment choices and promotion of healthier and more active lifestyles in children and youth with JIA.

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Figure 1. Framework depicting the interactions between potential factors associated with leisure based on components of the International Classification of Functioning, Disability and Health Children and Youth version (ICF-CY) (19).

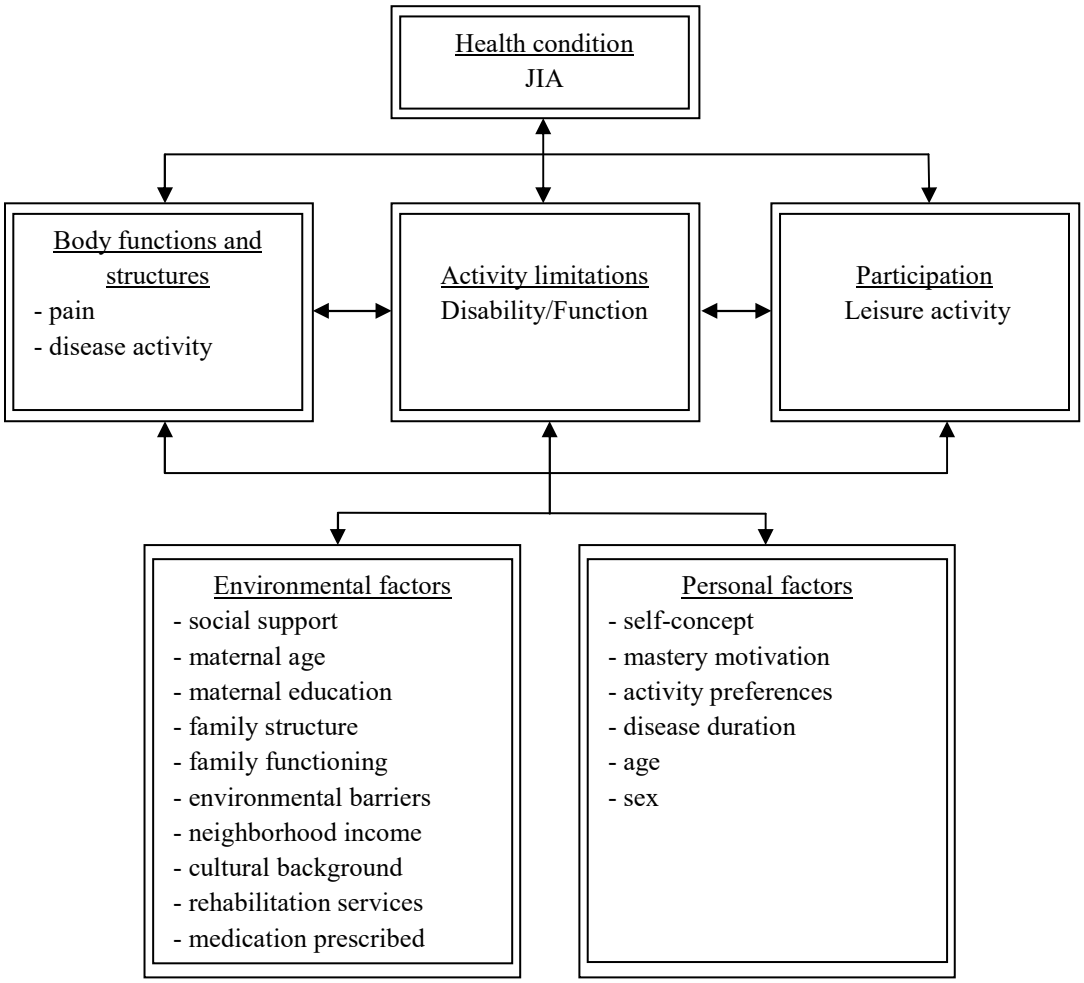

Table I. Socio-demographic, disease-related and treatment characteristics of children and teenagers with Juvenile Idiopathic Arthritis sample (n=107)

	Mean (SD)	**Range**	**n (%)**
Socio-demographic characteristics			
Age, years (n=107)	12.8 (2.7)	8.0-17.8	
Female (n=107)			75 (70.1)
Mother's age (n=91)	42.1 (5.0)	31.0 – 56.0	
Family structure			
Single parent			21 (19.6)
Two parent household			74 (69.2)
Missing data			12 (11.2)
Maternal level of education			
High school completed or not			23 (21.5)
Post-secondary education			69 (94.5)
Missing data			15 (14.0)
Cultural background			
French Canadian			55 (51.4)
English Canadian			18 (16.8)
Other			21 (19.6)
Missing data			13 (12.1)
Median neighborhood income, CAD*(n=107)	66 963 (15 696)	32 841-107 626	
Lower than 60 000 $ CAN			40 (37.4)
60 000 – 70 000 $ CAN			27 (25.2)
More than 70 000 $ CAN			40 (37.4)
Disease-related characteristics			
Age at diagnosis, years (n=107)	7.4 (4.5)	1.1-16.8	
Active joint count			
0			68 (63.6)
1			20 (18.7)
≥ 2			12 (17.7)
Disease duration (years) (n=107)	5.5 (4.1)	0.0-15.2	
Level of perceived pain (n=95)	2.5 (3.0)	0.0-9.2	
Functional status (CHAQ)	0.3 (0.5)	0.0-2.0	
Disability (mild-moderate or higher)			20 (18.7)
No disability			75 (70.1)
Missing data			12 (11.2)

Table I. Continued.

Distribution of disease subtype			
Oligoarthritis			55 (51.4)
Polyarthritis			22 (20.5)
Systemic arthritis			5 (4.7)
Enthesitis-related arthritis			17 (15.9)
Psoriatic arthritis			6 (5.6)
Undifferentiated			2 (1.9)
Prescribed treatment			
Use of at least one arthritis medication			80 (74.8)
Number of prescribed arthritis medications	1.2 (0.9)	0-4	
Rehabilitation services (OT or PT) in the last 6 months			62 (57.9)
Rehabilitation services (OT or PT) in the last 12 months			74 (69.2)

*Median income was based on the three first characters of the family's home address (Statistics Canada, 2006)
SD, Standard deviation; OT, Occupational Therapy; PT, Physiotherapy

Table II. Hierarchical regression model: Predictors of participation intensity in recreational activities (n= 94).

	Parameter estimate		Bootstrap
	Beta	B (95% CI)	B (BCa; 95% CI)
Personal factors			
Preference for recreational activities (PAC)	**0.324****	0.776	0.776
		(0.263, 1.288)	(0.234, 1.320)
Environmental factors			
Cultural background	**0.218***	0.495	0.495
(Canadian; ref. other cultural background)		(0.088, 0.902)	(0.062, 0.925)
Median neighborhood income (ref.≤65000	0.152	0.288	0.288
CAD)		(-0.060, 0.636)	(-0.036, 0.627)
Covariates			
Age of the child (years)	-0.188	-0.066	-0.066
		(-0.141, 0.010)	(-0.146, 0.014)
Sex of the child (Girls; ref. boys)	-0.030	-0.064	-0.064
		(-0.445, 0.317)	(-0.490, 0.308)
Adjusted R^2 for overall model = 0.297, p-value = <0.0001			

Beta, standardized regression coefficient; B, unstandardized regression coefficient; BCa, Bias Corrected Accelerated; CI, Confidence interval; PAC, Preferences for Activities of Children; CAD, Canadian dollar
*p<0.05, **p<0.01, ***p<0.001

Table III. Hierarchical regression model: Predictors of participation intensity in active physical activities (n= 89).

	Parameter estimate		Bootstrap
	Beta	B (95% CI)	B (BCa; 95% CI)
Body Functions and Structures			
Disease activity (ref. no disease activity)	-0.100	-0.169	-0.169
		(-0.490, 0.153)	(-0.442, 0.127)
Personal factors			
Preference for active physical activities (PAC)	0.140	0.309	0.309
		(-0.173, 0.791)	(-0.133, 0.831)
Perceived athletic competence (SPP)	-0.052	-0.059	-0.059
		(-0.340, 0.222)	(-0.327, 0.247)
Social persistence with peers	-0.064	-0.072	-0.072
(children or adolescents) (DMQ)		(-0.326, 0.181)	(-0.315, 0.157)
Gross motor persistence (DMQ)	**0.282***	0.298	0.298
		(0.023, 0.573)	(0.070, 0.541)
Perceived general competence (DMQ)	0.060	0.096	0.086
		(-0.201, 0.373)	(-0.152, 0.325)
Environmental factors			
Maternal education (>HS versus ref. ≤HS)	**0.262***	0.496	0.496
		(0.111, 0.880)	(-0.099, 0.876)
Median neighborhood income (ref.≤65000 CAD)	0.108	0.180	0.180
		(-0.135, 0.493)	(-0.120, 0.484)
Perceived environmental barriers (CASE)	-0.133	-0.010	-0.010
		(-0.026, 0.005)	(-0.026, 0.005)
Covariates			
Age of the child (years)	-0.057	-0.024	-0.024
		(-0.087, 0.039)	(-0.082, 0.035)
Sex of the child (Girls; ref. boys)	-0.127	-0.264	-0.264
		(-0.613, 0.085)	(-0.666, 0.091)
Adjusted R^2 for overall model = 0.252, p-value = <0.0001			

Beta, standardized regression coefficient; B, unstandardized regression coefficient, BCa; Bias Corrected Accelerated; CI, Confidence interval; PAC, Preferences for Activities of Children; SPP, Self-Perception Profile; DMQ, Dimensions of Mastery Questionnaire; HS, High school; CAD, Canadian dollar; CASE, Child and Adolescent Scale of Environment
*p<0.05, **p<0.01, ***p<0.001

Table IV. Hierarchical regression model: Predictors of participation intensity in social activities (n = 92).

	Parameter estimate		Bootstrap
	Beta	B (95% CI)	B (BCa; 95% CI)
Personal factors			
Preference for social activities (PAC)	**0.258****	0.746 (0.205, 1.288)	0.746 (0.224, 1.371)
Perceived physical appearance (SPP)	-0.088	-0.124 (-0.407, 0.159)	-0.124 (-0.400, 0.162)
Environmental factors			
Median neighborhood income (ref.≤65000 CAD)	**0.326****	0.664 (0.298, 1.031)	0.664 (0.341, 1.026)
Covariates			
Age of the child (years)	**0.314****	0.118 (0.043, 0.192)	0.118 (0.036, 0.202)
Sex of the child (Girls; ref. boys)	0.185	0.424 (-0.018, 0.866)	0.424 (-0.056, 0.969)
Adjusted R^2 for overall model = 0.281, p-value = <0.0001			

Beta, standardized regression coefficient; B, unstandardized regression coefficient; CI, Confidence interval; BCa, Bias Corrected Accelerated; PAC, Preferences for Activities of Children; SPP, Self-Perception Profile; CAD, Canadian dollar
*p<0.05, **p<0.01, ***p<0.001

Table V. Hierarchical regression model: Predictors of participation intensity in skill-based activities (n = 92).

	Parameter estimate		Bootstrap
	Beta	B (95% CI)	B (BCa; 95% CI)
Personal factors			
Preference for skill-based activities (PAC)	**0.305****	0.536	0.536
		(0.148, 0.925)	(0.143, 0.945)
Environmental factors			
Maternal education (>HS versus ref. ≤HS)	**0.188***	0.398	0.398
		(0.007, 0.790)	(0.010, 0.783)
Covariates			
Age of the child (years)	-0.068	-0.023	-0.023
		(-0.084, 0.038)	(-0.091, 0.041)
Sex of the child (Girls; ref. boys)	**0.251***	0.517	0.517
		(0.072, 0.962)	(0.114, 0.914)
Adjusted R^2 for overall model = 0.265, p-value = <0.0001			

Beta, standardized regression coefficient; B, unstandardized regression coefficient; CI, Confidence interval; BCa, Bias Corrected Accelerated; PAC, Preferences for Activities of Children; HS, High school
*p<0.05, **p<0.01, ***p<0.001

Table VI. Hierarchical regression model: Predictors of participation in self-improvement activities (n= 90).

	Parameter estimate		Bootstrap
	Beta	B (95% CI)	B (BCa; 95% CI)
Personal factors			
Preference for self-improvement activities (PAC)	0.172	0.310 (-0.084, 0.704)	0.310 (-0.099, 0.708)
Mastery pleasure (DMQ-Child-Teen)	0.149	0.149 (-0.051, 0.350)	0.149 (-0.041, 0.326)
Environmental factors			
Cultural background (Canadian; ref. other cultural backgrounds)	**-0.280****	-0.472 (-0.811, -0.133)	-0.472 (-0.808, -0.159)
Covariates			
Age of the child (years)	0.094	0.024 (-0.028, 0.077)	0.024 (-0.025, 0.074)
Sex of the child (Girls; ref. boys)	0.088	0.139 (-0.198, 0.476)	0.139 (-0.176, 0.488)
Adjusted R^2 for overall model = 0.108, p-value = 0.011			

Beta, standardized regression coefficient; B, unstandardized regression coefficient; CI, Confidence interval; BCa, Bias Corrected Accelerated; PAC, Preferences for Activities of Children; DMQ, Dimensions of Mastery Questionnaire
*p<0.05, **p<0.01, ***p<0.001

Article 5

Physical activity in children and adolescents with juvenile idiopathic arthritis and associated factors

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Author contributions: The PhD candidate contributed to the study design, was responsible for all data collection and management, conducted analyses and drafted the entire manuscript. Dre. Mathieu and Dre. Feldman contributed through discussions about study design, data analysis and provided feedback on several drafts of the manuscripts. Dre. Majnemer, Dre. Maltais, Dr. Duffy and Dr. Henderson provided feedback on the final draft of the manuscript.

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Abstract:

Objectives: We aimed 1) to determine whether children and adolescents with JIA met Canadian health guidelines for physical activity (PA), 2) to compare PA of children and adolescents with JIA to those without JIA, 3) to identify potential factors associated with involvement in PA.

Methods: We analysed data on PA obtained objectively through accelerometer for 76 children and adolescents with JIA between the ages of 8 to 17 years. Data obtained from a study of healthy children and adolescents devoid of JIA or other joint problems (ages 8 to 14 years) was used as a comparator group. Hierarchical regression analysis was used to explore factors associated with PA in children with JIA.

Results: Only 2.9 % of those with JIA met international recommendations of 60 minutes of daily moderate to vigorous physical activity (MVPA). Having JIA was associated with significantly less time (minutes/day) spent in MVPA (β=-12.25, 95% CI= -17.70, -6.81), $p<0.0001$) compared with children and adolescents without JIA. Only younger age, being a boy and identifying as Canadian (versus other cultural backgrounds) were identified as predictors of increased PA.

Conclusion: The identification of personal and environmental factors associated with PA may help guide the development of strategies to promote PA in JIA.

Introduction

Current health recommendations support physical activity (PA) as a means of promoting health and decreasing the risk of disease in children and youth (1,2). The Canadian Society for Exercise Physiology established guidelines on PA for Canadian children (5-11 years) and adolescents (12-17 years) recommending participation in an average of 60 minutes of moderate to vigorous physical activity (MVPA) per day including vigorous physical activity (VPA) at least 3 days per week (3). Aerobic activities and those strengthening both muscle and bone are included in the guidelines (1,4). According to the systematic review on PA in general pediatrics completed by Janssen et al. (2010) engaging in moderate to vigorous PA may help to reduce adiposity (decreasing the risk for obesity), decrease the risk for cardiovascular problems, favor cardiorespiratory fitness, and improve bone mineral density and well-being (1). Research supports that PA should also be encouraged for children living with a chronic condition such as juvenile idiopathic arthritis (JIA) (5,6).

JIA is one of the most common chronic conditions of childhood resulting in functional disability, pain, joint stiffness and swelling (7). Children with JIA have greater limitations in aerobic fitness and muscle strength when compared with healthy children, potentially caused by reduced participation in PA due to disease symptoms (6). Lower levels of PA may lead to decreased muscle mass and physical function, as well as eventual bone abnormalities (eg. osteopenia) (8). Evidence-based practice guidelines endorse PA as an effective means of improving health outcomes and quality of life in children and youth with JIA (9). Involvement in PA and exercise programs may help reduce pain, the number of swollen joints,

as well as improve overall aerobic endurance and bone health (10,11). Despite the reported benefits of PA, youth living with JIA continue to favor sedentary lifestyles and appear to participate less in strenuous PA and sports than their healthy peers (12-19). However this field is limited by studies that generally do not objectively assess PA through accelerometry or when PA is measured by accelerometry, questionable data management procedures have been used (13-15). Moreover, studies have been limited by relatively small sample sizes, particularly when comparing to a control group (13-15).

Rehabilitation professionals work with children and youth with JIA, aiming to improve musculoskeletal function and overall wellbeing. Incorporation of interventions that increase PA into a comprehensive rehabilitation treatment plan would be beneficial in improving muscle strength and bone health (20-24). Understanding potential predictors of involvement in habitual PA could inform these interventions. Predictors may include age, sex, body mass index [BMI], perceived body image, preference for fitness and PA, as well as parental attitudes and involvement in PA, parental and peer support, socio-economic status and season (25,26). Previous studies in pediatric rheumatology have assessed the level of perceived pain, the number of joints affected by arthritis, fatigue and functional status as potential determinants of PA (15,16,27,28), however none to date have investigated the potential influence of personal and environmental factors unrelated to the disease on PA.

In order to ascertain what factors beyond those closely related to the disease may be associated with PA, we have chosen to widen the scope of existing analyses and include the elements of the International Classification of Functioning, Disability and Health for Children and Youth

(ICF-CY) framework. The ICF-CY is a multidimensional conceptual framework characterising health, functioning and participation in life roles across infancy, childhood and adolescence, where participation may be influenced by an interactive process involving multiple components (29): 1) body functions and structures (i.e. pain, disease activity, BMI); 2) activity limitations (i.e. function in gross and fine motor activities, as well as activities of daily living/disability status); 3) personal (i.e. self-concept, mastery motivation, activity preferences, disease duration, age, sex); 4) environmental (i.e. social support, maternal age, maternal education, family structure, family functioning, environmental barriers, neighborhood income, cultural background, treatment services received, season) (29). The socio-ecological nature of this framework guides the analysis of factors beyond those related to the disease and encompasses contextual (personal and environmental) features (30).

In order for rehabilitation professionals to promote daily PA in children and adolescents with JIA it is necessary to quantify the level of PA in this population and identify facilitators and barriers to engagement in PA. Therefore, our study aimed 1) to determine whether the objectively measured PA of children and adolescents with JIA met the current Canadian health guidelines established by the Canadian Society for Exercise Physiology, 2) to compare PA of children and adolescents with JIA to those without JIA, 3) to identify potential factors associated with involvement in PA using the ICF-CY. Furthermore, as a secondary objective we explored whether the potential effects of age, sex, motivation, athletic competence, physical appearance on time spent in MVPA was different according to disease activity, pain and median neighborhood income.

Methods

We used a cross sectional study design and comparator group from another study. Children and adolescents with JIA and their parents were recruited during their scheduled visit to the pediatric rheumatology clinic at the Montreal Children's Hospital, McGill University Health Center, as part of a larger study assessing participation in various leisure activities. Children and adolescents were eligible to participate if they 1) were 8 to 17 years; 2) had a clear diagnosis of JIA made by a pediatric rheumatologist; 3) were actively followed in the rheumatology clinic at the hospital, i.e. seen every 3 to 4 months; and 4) were able to speak and write either English or French. The research assistant described the study and its implications to families, and, if they agreed to participate, the participants with JIA and their parents respectively signed assent and consent forms. We compared PA of participants with JIA with data from a comparator group obtained from the QUebec Adipose and Lifestyle InvesTigation in Youth (QUALITY)[1] cohort study of children and adolescents aged 8 to 14 years (45.2 % girls) without JIA recruited from primary schools in Montreal and the surrounding areas with a family history of obesity (31).

Ethics approval was obtained from the Montreal Children's Hospital's Research Ethics Board, as well as the *Comité d'Éthique de la Recherche en Santé, Université de Montréal*.

[1] QUALITY = QUebec Adipose and Lifestyle InvesTigation in Youth is a familial study designed to study the natural history of obesity and its cardiometabolic consequences in children and adolescents. Any child in the reference groups reporting bone or joint disease was excluded from analysis.

The protocols used in the QUALITY cohort study have received approval from the *Centre Hospitalier Universitaire Sainte-Justine* and *Institut Universitaire de Cardiologie et de Pneumologie de Québec* Ethics Review Boards.

Physical activity - JIA Group

In order to objectively monitor PA, we used the ***ActiGraph GT3X accelerometer*** (ActiGraph LLC, Florida) to measure activity level (light, moderate, vigorous), duration and time of day of PA over a 7 day week (5 week days and 2 consecutive weekend days). Contrary to self-report measures, data collected electronically through accelerometer are not affected by recall bias and may provide a more accurate assessment of PA among children and adolescents (32). Participants with JIA were asked to wear the device around their waist (held with an elastic belt) over their right hip, as well as complete a log informing on wear and non-wear times specifying reasons for removal. The sampling frequency i.e. the epoch was specified at 5 seconds during device initialization. Data collected in short epochs provides information on exposure at the highest possible resolution. Once data were collected we summed data into 60 minutes epochs to facilitate data processing.

The raw accelerometer data registered in the vertical axis were collected over a 7 day period and were expressed as movement counts per minute and uploaded using the ActiLife analysis software program (version 5.8.3 Copyright© ActiGraph 2011). Cut-points based on movement counts per minute were applied to the data to describe the following activity levels: sedentary ($\leq$ 100 counts*min^{-1}), light physical activity - LPA (>100 counts*min^{-1}), moderate physical activity - MPA ($\geq$ 2296 counts*min^{-1}) and vigorous physical activity - VPA ($\geq$ 4012

counts*min^{-1}) (33,34). The proposed cut-points have been recommended for use in children and adolescents (5 to 15 years) and more accurately classify activity level compared with other cut-points (34). Depending on age between 3 to 5 days of PA monitoring will provide reliable ($r>0.70$) information (35). Furthermore, converging findings support that 4 to 7 days of objective PA monitoring are required to estimate reliably daily PA in children and adolescents. In accordance with earlier North American health reports on PA, we retained data from respondents with 4 or more valid days for analysis as required to obtain reliable objective PA monitoring (36,37). Furthermore, we considered a valid day as 10 hours or more of accelerometry wear as has been required for other studies involving children and adolescents to ascertain representative activity levels during waking hours (36,38,39). Nonwear time was defined as at least 60 consecutive minutes of zero counts, with allowance for 1 to 2 minutes of counts between 0 and 100 (36,37). The calibration of the accelerometer was verified before its use with participants. The inter-instrument reliability of the ActiGraph GT3X accelerometer is excellent (ICC = 0.96 – 0.99, CI 95%: 0.81 – 0.99) and concurrent validity of the accelerometer count data and VO_2 was fair to good (rho = 0.67, $p < 0.001$) when assessing walking in children with cerebral palsy (40).

We restricted data collection to the school year (Fall, Spring and Winter) to control for common activities done throughout the day (e.g. sitting in class throughout the day) and avoided wear during vacation time, as physical activity has been shown to differ during this time (41). Furthermore, the literature supports that PA measured by accelerometer varies across seasons, where overall PA is usually lowest in the winter and highest in the spring and

summer months (42,43). We therefore took note of when the accelerometer was worn and controlled for season.

Independent variables

Factors potentially associated with participation in PA were collected from the medical chart, as well as through questionnaires completed by patients and parents. All questionnaires were translated to French using forward and back-translation. Information on disease activity (active joint count and other arthritis related symptoms such as rash or fever), disease duration, JIA subtype, perceived pain, age, sex, area of residence by postal code) and disease activity (active joint count and other arthritis related symptoms such as rash or fever), medication prescription and rehabilitation services were abstracted from the medical chart. Active disease was defined by the presence of at least one of the following clinical symptoms assessed by the treating pediatric rheumatologist and reported in the medical file: 1). active joint; 2). enthesitis; 3). systemic manifestation (e.g. arthritis related fever, rash).

Anthropometric characteristics (weight and height) were abstracted from the child's medical file on the day of recruitment. Weight was measured in kilograms using an electronic scale (Detecto – www.detectoscale.com) and height in centimeters using a stadiometer (Accustat Genentech Stadiometer). BMI percentiles specific for age and sex were calculated using the Center for Disease Control (CDC) growths charts (44). The proposed CDC cut-points are: underweight ($<5^{th}$ percentile), healthy weight ($5^{th} \leq$ percentile $<85^{th}$), overweight ($85^{th} \leq$ percentile $<95^{th}$), Obese ($95^{th} \leq$ percentile).

Children and parents completed questionnaires regarding activity limitations, personal attributes, and environmental features.

Activity limitations were measured by the ***Childhood Health Assessment Questionnaire (CHAQ)***, a valid and reliable self-report questionnaire completed by children and adolescents (45), and by a parent for those younger than 10 years. There is strong agreement between children and parent mean scores, supporting reliable parental report on their child's function (46). A final score is obtained by averaging results of 8 functional domains (like "dressing and grooming", "eating", "walking" and "activities") with 0-1 indicating mild to moderate disability, 1-2 moderate to severe disability, and 2-3 severe to very severe disability (47). The pain subscale of the CHAQ assesses pain in the last week due to arthritis on a 100 mm ***visual analog scale (VAS)*** (47,48).

Personal characteristics that were measured include mastery motivation, self concept and preference for physical activities. Children and adolescents with JIA reported on their mastery motivation behaviour by completing the ***Dimensions of Mastery Questionnaire (DMQ);*** the parent version was only used in the event that the child version was returned incomplete and research assistants were unable to contact family to obtain missing information This 45-item, self-report questionnaire evaluates persistence at object-oriented tasks, gross motor tasks, social persistence with adults and with other children, and also measures mastery pleasure, negative reaction to failure and general competence (49). The DMQ has good to very good internal consistency (49). Discriminant and concurrent validity have not been reported. The ***Self-Perception Profile (SPP)*** was completed by children and adolescents with JIA to assess

personal perception of competence among children (8-12 years) and adolescents (13-18 years). The domains assessed are those related to personal perceptions of academic and athletic competence, social acceptance, physical appearance and behaviour, as well as overall self-worth, where a higher score reflects a more positive view of one's self (50,51). This instrument is reliable and valid (50,51).

The child's preference for recreational and active physical activities was measured using the ***Preferences for Activities of Children (PAC)*** (52). PAC is reliable with Cronbach's alpha ranging from 0.67 to 0. 77 and content validity has been established (52).

Environmental characteristics include information on family structure, maternal age, maternal education level and cultural background, and were obtained through parental report. Information on the area of residence was abstracted from the medical file. We used median household income for the area of residence (based on Census Canada Data 2006) as a proxy for socio-economic status (53). We assessed perceived social support using the ***Social Support Scale (SSS)***, which collects data on social support provided by four sources: parents, teachers, friends and classmates (54). Internal consistency is good to very good (55). Construct and convergent validity were demonstrated (30). Environmental barriers were evaluated by having parents complete the ***Child and Adolescent Scale of Environment (CASE)*** that assesses the impact of physical, social and attitudinal factors in the child's home, school and community, as well as the quality and availability of services. Higher total scores indicate greater environmental problems (56). The CASE is reliable and has demonstrated construct and discriminant validity (57). For children and adolescents with JIA data on family

functioning was obtained through parental self-report using the ***Family Environment Scale (FES)***, which collects data across 10 sub-domains (cohesion, expressiveness, conflict, independence, achievement, orientation, intellectual-cultural orientation, active-recreational, moral-religious, organization, control). The FES is reliable (58,59). Construct and discriminant validity were demonstrated (58,59).

Comparator group – participants without JIA

Data on children and teenagers without JIA were retrieved from the QUALITY cohort study (31), which provided information on PA measured with the ActiGraph GT1M accelerometer among children with a family history of obesity, collected at ages 8 to 12 (time 1) and two years later (time 2). The same cut-points used for the JIA sample had been applied to raw data obtained from the comparison group. There is strong agreement between data collected in the vertical axis with the GT1M and the GT3X (used for the JIA group) (60). Information on age, sex and BMI based on age and sex norms set forth by the CDC was available to include in our analysis. The season of accelerometer wear was derived by the date indicated in the database.

Analysis

Descriptive statistics were carried out to characterise the sample. PA level, frequency and duration were assessed across age groups, sex, disease activity, pain, disease duration, function and BMI, as well as compared to Canadian health guidelines. The differences between groups were assessed using t-tests for continuous variables and chi-square analysis for categorical variables.

We compared PA in the JIA group versus the non JIA group. We needed to contend with the repeated measures of the comparison group (data collected for the same subject over two study periods) and so we used a mixed model to provide a flexible modeling environment for handling of repeated measures (61). We modeled the average time spent (minutes/day) in various activity levels (LPA, MPA, VPA, MVPA) as a function of having JIA or not, adjusted for age, sex, BMI and season.

We conducted bivariate analyses to assess potential associations between independent variables and PA (minutes/day of LPA, MPA, VPA, MVPA). Pearson correlations were used for continuous variables and simple linear regression for dichotomous variables. Independent variables that did not present with a normal distribution were dichotomized. The disability score was dichotomised into mild (CHAQ score of 0 to 1) and moderate to severe (CHAQ score of >1), as well as by using the cut-off 0.6 (mild to moderate disease or above; CHAQ score $\geq$ 0.6) (62). The pain VAS score was dichotomized at the median (pain $\geq$ 6 mm). We also wanted to distinguish between those with somewhat more substantial pain and so dichotomized the VAS pain score at the midpoint (pain $\geq$ 50 mm) (63).

Finally, we constructed a hierarchical regression analysis modeling daily average MVPA as a function of selected factors. Based on the ICF-CY framework the following factors of interest were explored as blocks: of 1) body functions and structures (pain, disease activity, BMI); 2) activity limitations (level of disability/function); 3) personal (self-concept, mastery motivation, activity preferences, disease duration), and 4) environmental (child's perceived social support, mother's age, maternal education, family structure, family functioning, parental

perceived environmental barriers, median neighborhood income, cultural background, number of arthritis medications prescribed, rehabilitation services received) (Figure 1). We tested 4 models for daily average MVPA to obtain the best predictive model: 1) Base model included the body functions/structures and function/disability factors, 2) Base model and the personal factors, 3) Base model and the environmental factors and 4) Base model, personal and environmental factors. Choice of variables for entry into the model was informed by our bivariate analysis, as well as the literature on PA in general pediatrics, pediatric disability and JIA. We used stepwise regression analysis to obtain the best predictive model of variables within each ICF-CY domain. Our analysis was statistical within blocks (ICF-CY domain) and sequential over blocks (64). Based on the literature, age, sex and season are strong predictors of daily physical activity and were included in the model last as covariates so as not to mask the contribution of body functions and structures, disability/function and contextual factors on physical activity(42).

Multicollinearity of independent variables was examined using the variance inflation factor (65). Listwise deletion was applied to manage missing data. Adjusted R^2 identified the most parsimonious explanatory model both within and over blocks of variables. Bootstrapping (2000 replications) was completed to validate the final models (66). All statistical analyses were performed using SPSS 22 (Armonk, NY: IBM Corp.) and SAS 9.3 (SAS Institute, Cary NC) statistical software. For all inferential statistical analyses the significance level was fixed at alpha = 0.05.

Results

Sample characteristics

Of the 117 participants with JIA who agreed to participate in a larger study on leisure participation, 98 agreed to wear the accelerometer. The main reason for refusal was not wanting to wear the accelerometer in public or around peers to avoid drawing attention to their arthritis. Another 10 patients returned the device without having worn it citing they were no longer interested (n=8) or no longer had the time (n=2) to take part in the study. Valid wear time data (i.e. minimum of 10 hours a day for at least 4 days) were only available for 76 of the 88 participants with JIA who wore the accelerometer. There were no statistically significant differences between JIA participants and those who chose not to wear the accelerometer in terms of age, sex, disease duration, disease activity and JIA subtype distribution (data not shown). Mean age of the JIA participants was 12.6 (SD=2.8) years and 77.6% were female. More than 50% had oligoarthritis, just over 20% had polyarthritis and 13.2% had enthesitis-related arthritis. Socio-demographic, disease-related and treatment characteristics of the JIA sample are described in Table I.

Physical activity in JIA

On average children and adolescents with JIA spent 89.6% of the time involved in LPA (Mean = 320.64 minutes/day, SD = 75.81) and much less in MPA (Mean = 22.98 minutes/day, SD = 12.26), VPA (Mean = 5.91 minutes/day, SD = 7.21) and MVPA (Mean = 23.95 minutes/day, SD = 14.63) ($p<0.001$) (Table II). Boys with JIA engaged more in average daily MPA and MVPA than did girls with JIA ($p<0.05$) (Table II). The younger age group (8-11 years) of JIA

participants spent more time in LPA, MPA, MVPA than the older group (12-17 years) (Table II). Average time spent per day in MVPA was greater for boys with JIA (Mean=31.41 ± 16.87 minutes per day) compared to girls with JIA (Mean = 21.80 ± 13.32 minutes per day), p=0.016 (Table II).

In general children and adolescents with JIA spent 24.0 minutes (SD = 14.6) in MVPA per day; 6.6 % of children and youth (5.8% boys; 6.8% girls) with JIA accumulated at least 30 minutes of MVPA at least 6 days a week (Figure 2). Only 2.9 % of those with JIA met international recommendations of 60 minutes of daily MVPA.

Seventy-two percent of children and adolescents with JIA participated in VPA at least once a week for at least 5 minutes. For those with JIA participating in VPA at least 3 days, they did so at a proportion of 22.4% for at least 5 minutes, 11.8% for at least 10 minutes and 3.9% for at least 20 minutes.

When controlled for age, sex, BMI and season a diagnosis of JIA was associated with significantly less time (minutes/day) spent in LPA (β=-25.78, 95% CI= -40.21, -11.36), p=0.0006), VPA (β=-4.32, 95% CI= -6.99, -1.66), p=0.0032) and MVPA (β-12.25, 95% CI= -17.70, -6.81), p<0.0001) compared with children and adolescents without JIA (Table III).

Factors associated with physical activity in JIA

We first used bivariate analysis to study crude associations between factors of PA. Our main outcomes for these analyses was time spent in daily PA (minutes/day)

Intrinsic variables and physical activity

Intrinsic factors associated with PA included age, sex, perceived athletic competence, perceived physical appearance, motivation, and activity preferences. Younger age was strongly correlated with more time spent in LPA ($r=-0.657$, $p<0.0001$), MPA ($r=-0.363$, $p=0.001$) and MVPA ($r=-0.357$, $p=0.002$). Males spent more time in MPA ($\beta=-0.288$, $p=0.012$) and MVPA ($\beta=-0.275$, $p=0.016$). A higher level of perceived athletic competence was mildly to moderately correlated with more time spent in all physical activity intensities (LPA, MPA, MVPA, VPA) with correlation coefficients (r) ranging from 0.242 to 0.338, $p<0.05$. Better perceived physical appearance for the child was mildly correlated with time spent in LPA ($r=0.232$, $p=0.046$) and MPA ($r=0.245$, $p=0.035$). Stronger motivation to perform gross motor tasks as reported by the child was mildly correlated with LPA ($r=0.254$, $p=0.031$), MPA ($r=0.283$, $p=0.016$) and MVPA ($r=0.262$, $p=0.026$). A stronger negative reaction to failure was correlated with less time spent in MPA ($r = -0.282$, $p=0.016$) and MVPA ($r = -0.264$, $p=0.025$). Activity preferences were correlated with certain levels of PA, notably preferences for active physical activity was positively correlated with vigorous physical activity ($r=0.242$, $p=0.035$).

Extrinsic variables and physical activity

Older maternal age was correlated with lower levels of LPA ($r = -0.297$). Being of Canadian cultural background was correlated with more time spent in MPA ($\beta = 0.233$, $p=0.043$), VPA ($\beta = 0.229$, $p=0.046$) and MVPA ($\beta = 0.256$, $p=0.026$). Greater family control (the extent to which set rules and procedures are used to run family life) was positively correlated with

greater participation in VPA (r=0.283). The spring months were correlated with more time spent in VPA (r = 0.337) and MVPA (r = 0.254).

Multivariate analysis

Table IV presents the regression model for MVPA. The adjusted R^2 reflects the percentage of contribution of each sequence of variable groups (ICF-CY domains) adjusted for the expected inflation of the sample's R explaining time spent in PA. The change in R^2 represents the percentage of additional contribution (unadjusted) of that specific group of variables relative to the one entered before explaining time spent in PA. The body functions/structures and activity limitations variables did not contribute to the explained variance of MVPA and were not entered into the final model.

The personal component (athletic competence) accounted for 10.9% of the explained variance (p=0.024) and the environmental component (cultural background) explained an additional 6.1% (p=0.024). The overall model including covariates (age, sex, season) explained a total of 33.4% of the variation in participating in average daily MVPA (p=0.002), where the adjusted R^2 was 28.4%. The most important variables associated with MVPA were cultural background (French or English Canadian; ref: other cultural backgrounds) (β=0.268, p=0.011), child's age (β=-0.320, p=0.004) and sex (girls; ref: boys) (β=-0.289, p=0.008).

Discussion

Our study provides a description of daily PA patterns in JIA youth measured objectively through accelerometry demonstrating that children and adolescents with JIA engage mostly in LPA and participate comparatively less in more intense PA. Fewer than 3% of JIA participants met the established health recommendations of 60 minutes of MVPA per day. This percentage is still lower than the already alarming 7% of Canadian children and youth that meet PA guidelines (36). Furthermore, children and adolescents with JIA participate less in PA compared to children and adolescents without JIA. Of the ICF-CY components, the personal and the environmental domains best explained the variance of MVPA.

In our study, most children and adolescents with JIA were not as physically active as they need to be to reap the health benefits of PA (1,2,36). These results mirror those reported in other studies on PA in pediatric rheumatology patients (15,16). Similar to other studies, ours supports that children and adolescents with JIA spend generally less time participating in more intense activities and at a rate lower than their peers without JIA (13,15,16). Rehabilitation professionals (specifically occupational therapists and physiotherapists) are well suited to provide information on safe and effective evidence-based PA programs tailored to meet the needs of children and adolescents with JIA. Current research supports that aquatic and land-based, weight-bearing and supervised sessions of resistive PA are beneficial in JIA in helping to reduce pain, the number of swollen joints, as well as improving overall aerobic endurance and bone health (10,11). PA may help reduce the risk of comorbidity and disease exacerbation in JIA, as well as favor immune responses, help reduce chronic inflammation and

optimise bone mineral density (8,67-70). Moreover, children and adolescents that are more active may be at lower risk for obesity (71) and if controlled this may help manage joint health.

In our sample age and sex were strong predictors for MVPA. Boys generally spend more time being active and participating in sports, whereas girls will usually be engaged in less active pursuits such as reading, talking with peers and involved in more socially oriented activities (72-77). Among our participants with JIA, the younger the child, the more active they were and the more they participated in MVPA as compared with older children. PA commonly increases throughout middle childhood (78,79) and declines across adolescence, as teenagers pursue less active interests such as watching television, surfing the internet, and more social-oriented (e.g. talking with friends) activities (75,80). The greater the engagement in physical activity during adolescence the better self-reported well-being and the greater the likelihood of involvement in physical activity in adulthood (81,82). As a child reaches adolescence they may become more involved in the decision-making surrounding health related behaviour and disease self-management due to their growing autonomy (83). Therefore, in addition to targeting parents, a comprehensive intervention plan incorporating physical activity and specifically targeting adolescences with JIA may also be needed to favour long-term healthy lifestyles.

In pediatric rheumatology, disease-related factors are often assessed as correlates of involvement in PA. Interestingly, none of the disease-related factors (disease activity, disease duration, pain, and function/disability) were associated with differences in participation in PA.

Similar findings were reported in studies on PA in JIA (15,17,27). These results underline the importance of considering the role contextual (personal and environmental) variables play in influencing the level of PA.

We found that the following contextual factors influenced PA: perceived athletic competence, perceived physical appearance, motivation to perform gross motor tasks, negative reaction to failure, preferences for more active activities, maternal age, cultural background, family functioning and season. Similarly, studies assessing the correlates of PA in general pediatrics have consistently reported the following contextual factors as associated with involvement in PA: perceived physical competence, intention, preferences for PA, barriers, parent support, direct help from parents, support from significant others, program/facility access, opportunities to be active, family participation in physical activity, and time outdoors (73).

Stronger perception of athletic competence was correlated with more time spent in MPA and MVPA. Children with JIA often have physical limitations, which may affect their confidence in their athletic abilities and their readiness for active pursuits and sports (19). Better perceived physical appearance was correlated with PA, as found by others (84,85).

Motivation is an important intrinsic factor correlated with participation in recreational and competitive sport (86), which was reflected in our results. Many PA promotion interventions focus on ways to improve motivation to encourage and favour sustained participation in active pursuits. These include targeting individual preferences for PA, which were associated with participation in PA in our study. Also behavioral interventions to counteract negative

reactions to failure may be helpful as this behaviour may be a deterrent to participating in more intense and potentially more challenging PA (87).

Parental characteristics and family environment may potentially influence PA in youth (88,89). In our sample, a family that strongly values set rules and procedures was positively correlated with VPA suggesting that a stronger commitment from both the child and the parent may be needed to consistently engage in PA. Cultural background was the only other predictor (besides age and sex) of MVPA in our sample. Families that identify themselves as Canadian took part in more active PA. This result is supported by international reviews highlighting the cultural differences in sport participation, where children and adolescents from North America reported more participation in sports than other countries across the world (75,90-92). We found that participation in PA was favoured by higher socio-economic status, similar to other studies (93-95). Younger maternal age was associated with more time spent in LPA implying that younger mothers may be more inclined to be active, which may encourage their child to follow suit. Studies support that increasing participation in PA can be favoured through programs that involve the family and are community based (in schools) to control for socio-economic inequalities (96,97).

Our study has limitations that should be discussed. Although the accelerometer is an objective measure and registers PA throughout the day it is not waterproof and therefore cannot be worn when swimming and is not recommended to be worn during contact sports, as well does not accurately record movement during activities with restricted trunk movement such as cycling (98,99). Therefore physical activity may have been underestimated for these participants. In

light of our small sample size we were at greater risk for type 2 error and so the association of certain factors with the outcome measure may not have been highlighted. Furthermore, the small sample size has precluded us from including all variables of interest in the regression models. Although we collected data on family income through parental report nearly 20% (20/107) of responses were missing and in light of our already small sample size excluding these cases further jeopardised our external validity. Finally, the group of children and adolescents without JIA (i.e. Quality study) were not matched for the municipal region of residence, school attended and socio-economic status. Therefore, due to the lack of representativeness of this sample we must interpret any comparison findings with caution.

Conclusion

Our study supports that PA levels of children and adolescents with JIA remain low and deserve consideration. To our knowledge this is the first study investigating the potential associations of both intrinsic and extrinsic variables as informed by the ICF-CY on participation in PA in JIA. Our findings provided a wider view of the potential predictors to inform promotion PA interventions in children and adolescents with JIA. The identification of determinants of PA in children and adolescents with JIA will allow healthcare professionals to assess children's health needs with more precision, identify groups at risk for decreased PA and guide more effective PA promotion strategies.

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Figure 1. Framework depicting the interactions between potential factors associated with physical activity based on components of the International Classification of Functioning, Disability and Health for children and youth (ICF-CY).

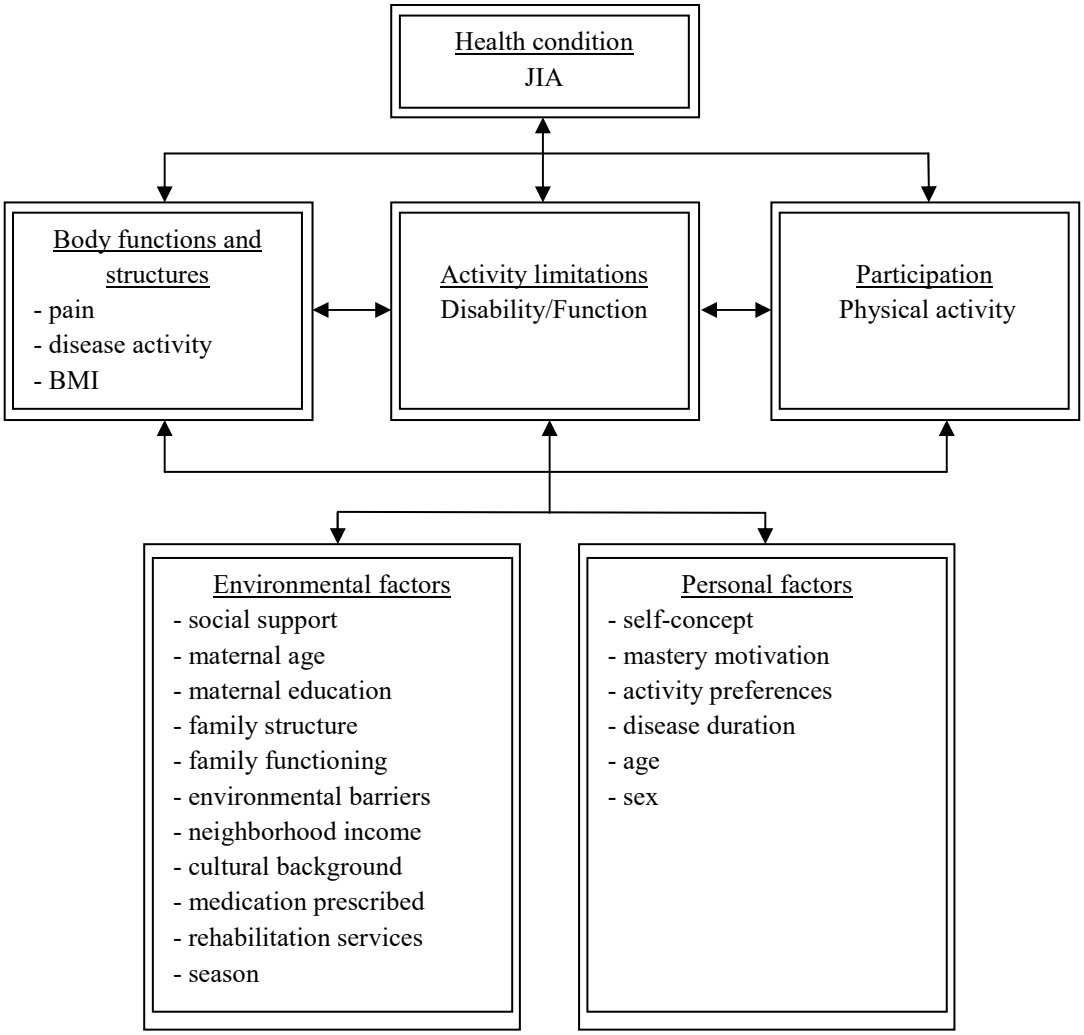


Table I. Socio-demographic, anthropometric, disease-related and treatment characteristics of children and adolescents with juvenile idiopathic arthritis (n=76)

	Mean (SD)	**Range**	**n (%)**
Socio-demographic characteristics			
Age, years	12.6 (2.8)	8.2-17.8	
Sex of the child			
Female			59 (77.6)
Male			41 (22.4)
Family structure			
Single parent			15 (19.7)
Two parent household			61 (80.3)
Maternal level of education			
High school completed or not			17 (22.4)
Post-secondary education			56 (73.7)
Missing data			3 (3.9)
Cultural background			
French Canadian			48 (63.2)
English Canadian			11 (14.5)
Other			17 (22.4)
Median household income, CAD*	67 202 (15 010)		
Anthropometric characteristics			
BMI category			
Underweight (<5th percentile)			0 (0)
Healthy weight (5th ≤ percentile <85th)			58 (76.3)
Overweight (85th ≤ percentile <95th)			11 (14.5)
Obese (95th ≤ percentile)			6 (7.9)
Missing data			1 (1.3)
Disease-related characteristics			
Age at diagnosis, years	7.0 (0.4)	1.2-16.8	
Active joint count			
0			45 (59.2)
1			16 (21.1)
≥ 2			15 (19.7)
Disease duration (years)	5.7 (4.0)	0.0-15.2	
Pain due to illness in the past week (CHAQ-Child/Teen) (n=50)	22 (27)	0-80	
Pain due to illness in the past week (CHAQ-Parent) (n=74)	20 (25)	0-90	
Functional status (CHAQ-Child/Teen)			
Disability (mild-moderate or higher)			14 (18.4)
No disability			43 (56.6)
Missing data			19 (25.0)
Functional status (CHAQ-Parent)			
Disability (mild-moderate or higher)			14 (18.4)
No disability			59 (77.6)
Missing data			3 (3.9)
Distribution of disease subtype			
Oligoarthritis			41 (54.0)
Polyarthritis			16 (21.1)
Systemic arthritis			4 (5.3)
Enthesitis-related arthritis			10 (13.2)
Psoriatic arthritis			3 (4.0)
Undifferentiated			2 (2.6)

Table I. Continued.

Prescribed treatment			
Use of at least one arthritis medication			60 (79.0)
Use of NSAIDs			42 (55.2)
Use of MTX			34 (44.7)
Use of corticosteroids			4 (5.2)
Use of TNF-α inhibitors			8 (10.5)
Use of other DMARDs			8 (10.5)
Use of subcutaneous drugs			27 (35.6)
Number of prescribed arthritis medications	1.3 (1.0)	0-4	
Rehabilitation services (OT or PT) in the last 6 months			46 (60.5)

*Median income was based on the three first characters of the family's home address (Statistics Canada, 2005)
SD, Standard deviation; NSAIDs, Non-steroidal anti-inflammatory drugs; MTX, Methotrexate; TNF-α inhibitors, Tumor necrosis factor-α inhibitors; DMARDs, Disease-modifying antirheumatic drugs

Table II. Activity level of average daily physical activity by sex, age and disease activity for participants living with JIA (n=76)

Physical activity level	Total sample (n=76)	Girls (n=59)	Boys (n=17)	8-11 years (n=34)	12-17 years (n=42)	No active disease (n=44)	Active disease (n=32)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
LPA (minutes/day)	320.64 (75.81)	322.25 (78.27)	315.03 (68.48)	373.13** (60.30)	278.14** (58.74)	329.74 (68.66)	308.12 (84.18)
MPA (minutes/day)	22.98 (12.26)	21.10* (11.47)	29.51 (13.03)	27.19* (14.38)	19.57* (9.05)	23.82 (13.18)	21.82 (10.97)
VPA (minutes/day)	5.91 (7.21)	5.30 (6.45)	8.03 (9.31)	7.55 (4.59)	8.19 (6.09)	5.52 (5.73)	6.46 (8.93)
MVPA (minutes/day)	23.95 (14.63)	21.80* (13.32)	31.41* (16.87)	28.90* (17.40)	19.95* (10.55)	24.69 (14.88)	22.94 (14.47)

Differences between sex, age and disease physical activity pairs significant at: *p<0.05, **p<0.01, ***p<0.001.

Figure 2. Percentage of participants with JIA engaging in MVPA for 30 and 60 minutes per number of days a week (n=76)

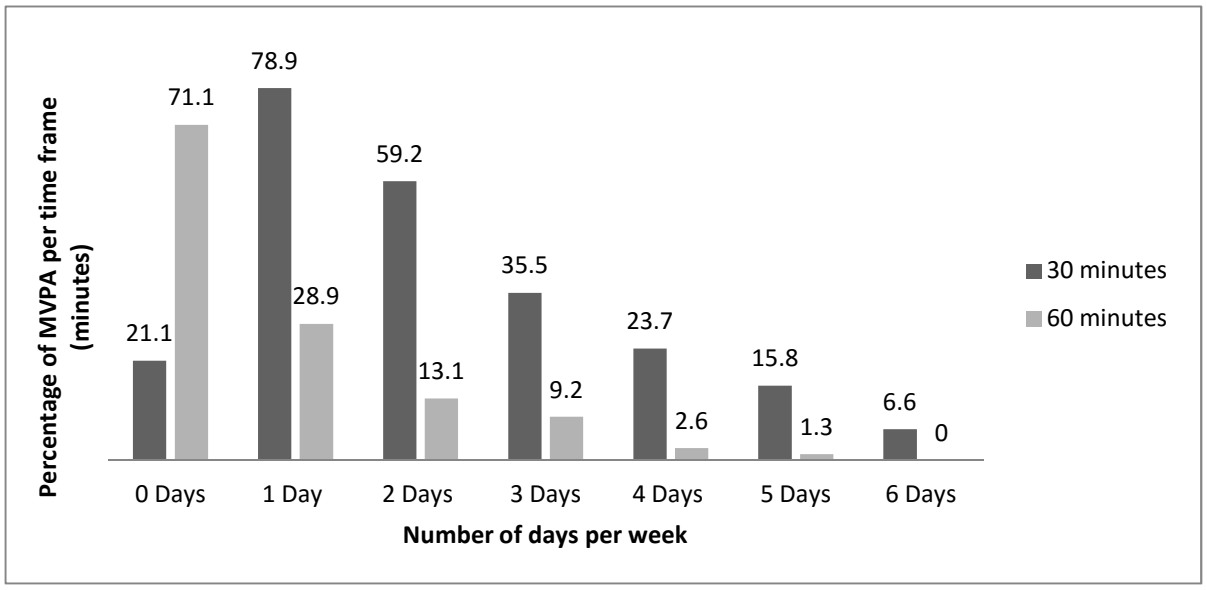


Table III. Multiple linear regression: Average daily physical activity (minutes) as a function of disease status (JIA versus those without JIA) (n=529)

	LPA	MPA	VPA	MVPA
	Parameter estimate (95% CI)	**Parameter estimate (95% CI)**	**Parameter estimate (95% CI)**	**Parameter estimate (95% CI)**
JIA	**-25.78*** **	-2.7509	**-4.3243** **	**-12.2517*** **
	(-40.21, -11.36)	(-6.1881 0.6864)	(-6.9929 -1.6558)	(-17.6953, -6.8080)
ref. without JIA	-	-	-	-
Age	**-19.11*** **	**-2.6568*** **	**-0.81*** **	**-3.3985*** **
	(-21.5399 -16.6893)	(-3.2348 -2.0788)	(-1.26, -0.36)	(-4.3138 -2.4831)
Girls	-0.27	**-11.9182*** **	**- 6.47*** **	**-18.29*** **
	(-7.79 7.24)	(-13.7089, -10.1276)	(-7.86, -5.08)	(-15.45, -21.12)
ref. boys	-	-	-	-
BMI	-0.09	**-0.04708** **	**-0.05 *** **	**-0.099*** **
	(-0.2213 0.03472)	(1.41, 5.84)	(-0.07, -0.03)	(-0.15, -0.05)
Spring	-1.2504	**6.1469*** **	**7.62*** **	**13.6357*** **
	(-10.7263 8.2255)	(3.8887, 8.4051)	(5.86, 9.37)	(10.06, 17.21)
ref. Fall, Winter	-	-	-	-

CI, Confidence Interval, LPA, light physical activity; MPA, moderate physical activity, VPA; vigorous physical activity; MVPA, Moderate to vigorous physical activity; BMI, Body mass index for specific age and sex percentiles
Associations significant for: *p<0.05, **p<0.01, ***p<0.001.

Table IV. Multiple linear regression model: Factors explaining daily average minutes spent in moderate to vigorous physical activity by ICF domain (n=74)

	Parameter estimate		Bootstrap
	β	B (95% CI)	B (BCa; 95% CI)
Personal factors			
Athletic competence (SPP)	0.169	3.367 (-0.942, 7.676)	3.367 (-1.131, 7.860)
Environmental factors			
Cultural background (Canadian; ref. other cultural background)	**0.268***	8.823 (2.100, 15.546)	8.823 (2.965, 14.558)
Covariates			
Age of the child (years)	**-0.320****	-1.608 (-2.691, -0.550)	-1.608 (-2.713, -0.403)
Sex of the child (Girls; ref. boys)	**-0.289****	-9.948 (-17.161, -2.734)	-9.948 (-17.453, -2.276)
Season (Spring; ref. Fall, Winter)	0.123	3.515 (-2.340, 9.371)	-1.608 (-2.713, -0.403)
Adjusted R^2 for overall model = 0.281, p-value = 0.002			

Beta, standardized regression coefficient; B, unstandardized regression coefficient; CI, Confidence interval; BCa, Bias Corrected Accelerated, MVPA, Moderate to vigorous physical activity; SPP, Self-perception profile
*p<0.05, **p<0.01, ***p<0.001

5. Discussion

5.1 Overall summary of study findings

The following discussion summarizes my research findings and highlights commonalities and differences in population characteristics, methods and conclusions across national and specific clinical studies. These findings include the patterns of behaviour in leisure and physical activity in children and adolescents with JIA and, the factors acting as potential facilitators or barriers to participation in leisure and physical activity. Finally, I highlight the weaknesses and strengths of our methods and propose avenues for future research.

The first manuscript systematically assessed and described the state of knowledge in leisure participation among persons living with JIA. Results highlighted how sparse existing research on this topic is and that there is a lack of high quality and adequate sample sized studies completed on this subject in JIA.

Our second, third and fourth manuscripts sought to bridge this knowledge gap by providing an in-depth exploration of participation in leisure among those with JIA using both a nationally representative (second manuscript) and a clinically-based sample of children and adolescents living with JIA (third and fourth manuscripts). Both our studies (population and clinical) aimed to describe leisure participation in terms of diversity of activities and

frequency, as well as explore associated factors, with our clinical study offering insight into the level of enjoyment and preferences for specific activities. Despite the similar research focus there are important methodological differences between studies such as: methods of data collection (proxy versus self-report), measures of leisure participation (post-census survey versus self-report questionnaire), age range of participants (5 to 14 years versus 8 to 17 years) and finally diagnostic criteria (proxy-reported arthritis versus JIA diagnosis delivered by a pediatric rheumatologist and supported by clinical and medical testing). Both studies explored factors that are intrinsic and extrinsic to the child, however the clinical study examined a more expansive list of contextual factors potentially associated with participation. Analysis for the latter study was informed by the (ICF-CY) framework, which proposes an interactive approach to explaining participation highlighting biological, individual and social perspectives (WHO, 2001, p.28) (1,2). Both studies collected information on formal and informal types of activities, however specific activities were different. Children and adolescents with JIA participated in a variety of leisure activities including physical activity, and a number of associated personal and environmental factors were identified.

Physical activity, a subset of leisure, has been the focus of leisure studies in JIA (3-11). Although physical activity is often linked with exercise it can also include vigorous leisure and recreational activities. The benefits of physical activity on health are undeniable among healthy children and adolescents (12,13), as well as among those with JIA (14-18). Therefore in our fifth manuscript we chose to assess time spent in daily physical activity objectively measured by accelerometers. Children and adolescents with JIA were not as physically active compared to those without JIA and most with JIA did not meet national recommendations for

physical activity. Similar to our analysis on leisure, contextual factors informed by the ICF-CY were found to be the most important in explaining physical activity.

The combined findings of our studies are:

1- Children and adolescents with JIA participated in skill-based and active physical leisure less than other types of leisure activities.

2- Boys were less likely to engage in social, skill-based and self-improvement activities compared to girls, and more likely to engage in physical activity.

3- The time spent in physical activity among those with JIA is lower than the national recommendations and lower than children and adolescents without JIA. Those at greater risk for spending less time in daily moderate to vigorous physical activity were female, older and of cultural background other than Canadian.

4- Youth with JIA participate as often in social activities as do similar aged peers without physical disabilities. Preference for social activities, higher socio-economic status and older age were associated with increased participation in social activities.

5- Among those with JIA, neither poor functional status nor the presence of active arthritis were associated with participation in leisure activities.

6- Greater mastery motivation for gross motor skills and higher socio-economic status were associated with increased participation in active physical activities.

7- Preference for skill-based activities, higher maternal education and being a girl were associated with increased participation in skill-based activities.

5.1.1 Patterns of involvement in leisure and physical activities

Our findings support that children and adolescents with JIA participated in an array of leisure activities, and displayed greater participation in unstructured activities such as listening to music, watching television, playing computer/video games, talking on the phone compared to formal activities such as organized sports, or other activities led by a coach or an instructor. In general, we found that those with JIA followed similar activity patterns compared to healthy Canadian children and adolescents where they favored unstructured activities over organized sports (19). As per the CAPE results obtained from our clinical sample, those with JIA were involved in a larger variety and most often in social and recreational activities, and least in active physical and skill-based activities.

Despite the similarities in patterns of leisure participation across our studies, a larger proportion of proxy-respondents from the population-based study reported their child's regular (at least once weekly) participation in active physical activities (74% in unorganised physical activities, 53% playing sports with a coach or instructor and 42% taking dance, gymnastics or martial arts) compared to self-reports of participants with JIA recruited clinically (28% in informal physical activity such as biking and 34.6% in team sports). Various methodological differences may explain this. First, the younger age range of respondents in the population-

based study (5 to 14 years: 58.0% 5-11 years, 42.0% 12-14 years) versus our clinical study (8 to 17 years: 38.3% 8-11 years, 61.7% 12-17 years) may in part account for the higher proportion of participants with JIA engaging in physical activities, as younger children are generally more active than older children or adolescents (20-23). Second, only our clinical study provided information on leisure from the child's unique perspective; these self-reported findings may therefore have provided a more valid portrait of the child's leisure activities in comparison to proxy reports (24). Also, a longer recall period (12 months) as seen in our national findings may contribute to the overestimation of the child's engagement in leisure activities compared to the shorter 4 month recall period used for the CAPE.

Results on physical activity (accelerometer) showed how as few as 28.9% of participants with JIA participated in moderate to vigorous physical activity (MVPA) at least once weekly, whereas a higher proportion (78.9%) engaged in an average of at least 30 minutes of MVPA at least once weekly. Only 2.9 % of those with JIA met international recommendations of 60 minutes of daily MVPA, whereas 6 % of children and youth (5.8% boys; 6.8% girls) with JIA accumulated at least 30 minutes of MVPA at least 6 days a week. Despite the undeniable health benefits of physical activity (12,13), those with JIA do not meet the national health guidelines for a daily average of 60 minutes of MVPA. Our self-report results also corroborate this as formal and informal active physical activities were not performed daily by those with JIA. Regular physical activity among children and adolescents should be encouraged. In fact, recent recommendations underline how those living with JIA can participate in physical activity if the disease is well controlled, and that involvement in impact and competitive sports can be performed within pain limits despite

active arthritis or impairment (25). Furthermore, following a disease flare those with arthritis are encouraged to gradually return to full activity (25) in an effort to limit deconditioning secondary to reduced physical activity.

In order to capitalize on physical and mental health benefits derived from leisure activities those with JIA must take part in a variety of leisure activities. Although those with JIA participated as frequently in skill-based, social and self-improvement activities compared to siblings without illness matched for age and sex, the discrepancy in their engagement in physical activity was noted in our results and has been underlined time and time again in the literature when compared to healthy children and adolescents (3-5,8-10,26). Nevertheless, our findings support that those with arthritis may adapt to their illness and engage socially as much as healthy peers (26-28). Therefore even with severe arthritis those with JIA may find ways to cope with clinical presentations and aspire to pursue normal age-appropriate social activities. Unfortunately, due to the cross-sectional nature of our study we cannot attest or deny the risk of maladjustment in the JIA group over time.

Enjoyment derived from leisure may itself provide health benefits (23,29,30), as well as encourage engagement in various activities. It is also believed that optimal enjoyment is found when an individual voluntarily undertakes meaningful, challenging and skill-based activities (31). Those living with JIA enjoyed social activities most followed by skill-based, active physical activities, recreational and finally self-improvement least, which is similar to patterns of enjoyment among Canadian children and adolescents with or without physical disabilities (32). Interestingly although enjoyment for skill-based and active physical

activities was quite high, actual participation in these activities were the lowest of all activities represented in the CAPE. This may underline how those with JIA may enjoy these activities, however cannot participate as often or as diversely as desired. Rehabilitation professionals may help those with JIA to facilitate participation by counseling them on their choice of activity and proposing adaptive strategies to overcome limitations so that they too may enjoy activities and experience a sense of achievement (31).

5.1.2 Factors associated with leisure participation and physical activity

Our results support the complex nature of leisure participation and how it is a multi-component construct. Although correlates were identified at all levels of the ICF-CY framework (body functions and structures, activity limitations, personal and environmental) only contextual factors contributed significantly to explaining the variation in participation when assessed in the clinical study. Therefore, contextual factors may be more important predictors of leisure compared with disease related symptoms in JIA.

Our study shows that participation in leisure changes across age and varies between girls and boys. Older children (≥ 12 years old) engaged more in social types of leisure compared to younger children, and younger children participated more frequently in recreational activities. No difference between age groups was noted for participation in active physical activity although the younger age group was consistently associated with higher levels of *moderate to vigorous* physical activity. Adolescents with JIA may be at greater risk for inactivity and subsequent long-term consequences on their health and well-being.

In general, girls with JIA engaged in skill-based and social activities more than boys with JIA. These results are echoed in the literature in both general pediatrics and pediatric disability (23,33,34). Although boys with JIA did not spend more time in active physical activities (as measured by the CAPE) than girls with JIA, boys with JIA generally spent more time being physically active (as measured by the accelerometer) than girls with JIA. One other study in JIA corroborated similar results on sex-related differences in physical activity (11). Our results highlight differences between age groups and the sexes in activity participation and may warrant programs tailored specifically to developmental stages and girls or boys.

Beyond age and sex, when assessed in a multivariate model the list of activity predictors differed by activity type, which may indicate that each activity has its own set of demands.

In terms of disease-related factors assessed pain was the only factor associated with increased frequency of sedentary leisure.

Our population-based study showed that proxy reports of even the mildest level of pain among children appeared to favour sedentary behaviour such as watching television; playing computer or video games; talking on the phone with friends; reading for pleasure; using the internet for personal interest. There is much concern that engaging in excessive sedentary behaviour may lead to muscle wasting, joint contractures and osteoporosis among those with

JIA (35-37). Sherry et al. showed that 86% of children with arthritis reported pain during routine clinical checkups when visiting their pediatric rheumatologist (38). Self-management techniques may help those with JIA overcome chronic pain and engage in age-appropriate leisure activities (39).

Interestingly, the presence of active arthritis was only mildly and negatively correlated with participation in active physical activity and did not explain any of the variance in leisure involvement. Although crude, the negative association of parent-reported physical activity level with the number of swollen joints has been documented in children with JIA (7). However no study to date has supported the effect of disease when included in a multivariate model of factors. Our results highlight how restrictions in participation may not uniquely result from impairment but may rather be a product of barriers inherent to the person, the family and social environment. According to Priestley (1998) disability may not be as important in influencing participation in leisure as other factors such as gender or perceived social barriers (40). Poor participation may not simply lay with disease related symptoms but in our study we have shown that contextual factors such as mastery motivation, preference for activities, socio-economic status and cultural background may better discern groups of children and adolescents with JIA that are at risk for poor participation. These factors may be addressed in care plans and potentially modified to promote leisure and physical activity.

Notably, of the personal factors mastery motivation and preferences for activities may be of particular interest to incorporate into a treatment plan. Children's motivation is greater for completing activities that provide them with meaningful experiences offering opportunities

to meet important psychological needs such as the need for control, self-esteem and social relatedness and integration (41,42). Intrinsic motivation drives to action, fuels the person's desire to complete an activity and engage in a specific behaviour (43). Youth who are interested in an activity show stronger self-esteem and stronger sense of control over their actions (strong locus of control) (44), as well as favour greater overall positive emotion. By devising a treatment plan that is tailored to the child's interests the chances for successful promotion of leisure participation and adherence to the proposed activities is favoured (42). In fact, a child's preference for activities plays a major role in the choice and actual participation in leisure activities (34,45).

In terms of environmental factors, children and adolescents with a higher socio-economic status participated more in social (clinical study) and informal (population-based) leisure activities compared to those of lower socio-economic status (characterized by higher neighborhood and household income), as well as in active physical and skill based activities (illustrated by higher maternal education). These results are in-line with the literature regarding children and adolescents with disabilities (46) and those without disabilities (47,48). Moreover parents who are in higher socio-economic groups tend to be more active themselves and involved in various activities (48).

This may reflect that families with greater monetary resources can pay for formal leisure activities, and those with higher education may also be more aware of the potential benefits of participation in skill-based and active physical leisure. Furthermore, parent's

interest, attitudes and support for organised sports or other physical activities may in part impact a child's involvement in more active lifestyles (49).

Parental attitudes and beliefs about leisure may also stem from their cultural background which may influence the child's level of participation. We found that children and adolescents with JIA whose family identified as Canadian (French and English) showed greater involvement in recreational and self-improvement activities, and spent more time in moderate to vigorous physical activity. Interventions targeting participation should be culturally appropriate in order to be effective, that is, the intervention should reflect the family's interest and beliefs in order to favour the child's engagement. Although it is quite possible that the child's interests for activity with age and with a new found identity and independence may change and diverge from those of their family, younger children activities' are for the most part still governed by their parents.

5.2 Clinical implications

A goal of rehabilitation for children with JIA is to enhance participation, including participation in leisure activities. In keeping with a child-centered approach patients with JIA must be included in decision-making surrounding treatment options (50-52). As such leisure-based rehabilitation interventions should be tailored to the child and adolescent with JIA's personal characteristics, such as age, gender and activity preference. For instance, recreational and active physical activities such as playing Sportball (non-competitive sports instruction), swimming lessons, and informal physical activities such as going to the park to play on the

jungle gym or hopscotch may be age-appropriate for younger children (8 to 11 years) with JIA, whereas adolescents with JIA may be more interested in going to the gym, attending yoga classes or playing organised sports to keep active (23). Several intervention studies have focused on incorporating programs tailor-made for girls to encourage moderate to vigorous physical activity through individual physical activity or dance (53,54), whereas boys may prefer strength training programs for improving overall physical activity (55).

Such targeted programs may be pertinent for some children and adolescents with JIA. However organised sports, weight-bearing and other skill-building physical activities typically preferred by healthy boys may not be well suited for many with JIA. With this in mind special consideration may be given to boys with JIA to elicit other interests beyond typically 'male' physical pursuits to avoid feelings of isolation, distress and loneliness and help overcome potentially gender based stigma (56,57). Limited confidence in their athletic abilities may lead boys as well as girls with JIA to feel physically inadequate to pursue competitive sports (58). Decreased confidence may also be coupled with feelings of intimidation and exclusion from group sports and activities, which may lead to decreased involvement and enjoyment of physical activity (59).

Among children and adolescents with JIA, preferences for specific activities may shape interest for leisure and subsequent participation; however as seen in our results they may not be involved in the active physical activities they prefer. Individualised physical activity counseling may help those with JIA discover what activities best match their interests, their health status, as well as available family and community resources. Rehabilitation programs

promoting sports participation and daily physical activity based on the patient's past physical activity, specific interests, facilitators and barriers have resulted in improvements in long term physical activity among adults with various neurological or orthopedic disorders (60,61). However such interventions have yet to be applied to children and adolescents with JIA and will have to be assessed for value.

Therefore, incorporating preferred activities into a comprehensive treatment plan may be a key strategy in favouring motivation and subsequent adherence to physical activity in the long-term in JIA. Having fun while exercising was a motivating factor identified by those living with JIA (62). On the other hand, compliance may be less likely when exercises are deemed boring (28). In addition to reducing disease-related symptoms and improving function, leisure-based treatment for JIA should also consider the level of enjoyment the child experiences rather than simply focusing on the frequency of involvement. More participation may not necessarily be better (63,64), instead the pursuit of meaningful activities may be more beneficial to the child's well-being than less fulfilling activities done more often. Hence, the positive experiences stemming from participation in leisure activities may augment intrinsic motivation needed to sustain engagement in challenging activities throughout the life course (65).

Motivation for gross motor activities may guide engagement in active physical activities among children and adolescents with JIA. Similar to regimented exercise programs, formal leisure activities such as organised sports (i.e. team sports) or skill-based (i.e. piano

lessons) often driven by external motivation (encouraged by parents or peers) rather than internal motivation or self-determination may lead to eventual negative feelings and result in the abandonment of such activities (66). In line with Bandura's social cognitive theory the child or adolescent will be more driven to continue an activity they enjoy and find success in, whereas they are less likely to continue with the activity if they feel forced to participate or feel they lack the necessary competence to succeed (67). As is often the case among children and adolescents with JIA daily, regimented exercises are recommended to help maintain muscle and bone health and have shown to be effective in managing disease symptoms (16,68-70). However these 'forced', repetitive and structured exercise may be of less interest to children and adolescents with JIA. Hence the perception of being forced to perform these exercises may negatively influence their attitude about physical activity preference and hinder actual participation in the long-term (71). This further highlights the importance of tailoring physical activities to children and youths' interests and making them more enjoyable and appealing hence favoring adherence and leading to a reduction in reported arthritis-linked symptoms and better psychosocial functioning (72).

Physical literacy is described as 'the motivation, confidence, physical competence, knowledge and understanding to maintain physical activity throughout the life course.' (73) (p.11). Rehabilitation professionals may incorporate meaningful activities into a comprehensive treatment plan with the aim of improving physical function needed to take part in active pursuits hence improving physical literacy and potentially athletic competence, as well as long-term motivation and involvement in physical activity (43). Moreover,

rehabilitation professionals may modify the tasks and the environment to provide better chances of success thus stimulating motivation and persistence to pursue challenging tasks (74,75). This may be of particular importance amongst adolescents as the need for engagement with and understanding by peers and adults other than their parents increases at this stage in life (76). In addition, rehabilitation professionals play a crucial role in informing children and families on various treatment options, as well as the benefits of these. By helping children, adolescents and families to understand the importance of engaging in active, socially-based and cognitively stimulating activities, rehabilitation professionals may help to motivate them enough to actually take part (77,78). Although those with JIA grasp the short-term need for adhering to home-based exercise programs to help reduce the physical effects of their arthritis, the long-term benefits of physical activity are not as well understood (79). Proper provision of information may favour adherence to treatment and may also improve communication between the health care professional and children and adolescents with JIA and families (80).

Knowledge on how to best manage their disease can help adolescents with JIA gain some control over their disease (81). Proper health literacy may further ensure that those living with JIA will adhere to proposed interventions and adopt healthier lifestyles. Health literacy has been defined as: 'the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course' (82) (p.11). Health literacy has been geared mostly to adolescents, as the effects amongst children is limited (83). In general, benefits of long-term physical activity are not well understood by adolescents, which may preclude adoption of active lifestyle later on in

life placing them at greater risk for type 2 diabetes mellitus, obesity, cardiovascular problems and osteoporosis (84-87). It may at times be counterintuitive to those living with the pain of JIA to engage in physical activities that may potentially exacerbate symptoms and cause further discomfort (39). It is essential that children and adolescents understand why participation in leisure and physical activities is important to their health in order for them to perpetuate healthy behaviours throughout life and well into adulthood (88,89).

An essential role of the rehabilitation professional is to enhance participation among youth with JIA by providing education and support, as well as grant opportunities for decision-making and independence (90).

Encouragement and support provided by rehabilitation professionals to engage in leisure activities may directly help to develop competency, autonomy, self-reliance, involvement in decision-making, identity, initiative, civic duty and social integration (66). In addition to pharmacological and regimented strengthening and stretching exercises, treatment recommendations are beginning to consider recreational and physical activities within the child's pain threshold as a means of disease self-management (25). Early involvement of children and adolescents as key players in their health management may lead to better understanding of their disease and the subsequent steps needed for maintaining health well into adulthood (90).

During childhood the burden of responsibility in managing symptoms of the arthritis rests with the parent; as the child gets older and enters adolescence and adulthood they are

expected to assume a bigger role in disease management. Adolescence is a time when the child develops greater autonomy and the independence in making lifestyle choices. This freedom of choice is a defining element of leisure participation (66). Adolescence is a time for developing passions and interests such as participation in music, art, recreational hobbies and sports that may be pursued throughout adulthood (66). Internet-based interventions using on-line educational documents (films, animations, spoken texts, assignments) to promote physical activity in children with JIA have shown to improve actual engagement in physical activity and aerobic endurance (91). Such on-line interventions may also be helpful for adolescents by facilitating access to information on the benefits of physical activity and safe alternatives to staying active. Similarly, the use of social media sites for promoting physical activity are effective in improving the level of physical activity among young adults (92). Social media may answer the adolescent's strong sense for belonging and social connectedness with peers despite disease symptoms that would otherwise preclude such contact (90,93).

In addition to focusing on the personal needs and interests of the child with JIA a client-centered approach also recognises that the family environment can be targeted for intervention (50). Our results indicated that cultural background may play a role in mediating the behaviour in leisure participation and physical activity among children and adolescents with JIA. In general, children from families' where intellectual, cultural and active recreation activities were valued and encouraged appear to promote positive attitudes of leisure and increased participation as adults (94). When creating promotional programs for youth targeting healthy leisure behaviours it is essential to develop interventions that involve the

family and gain a better understanding of family values and experiences in order to encourage sustained support for the proposed intervention (95). In the clinical context, a therapist must take into account the family's values in order to enhance uptake of the advice/treatment program given. Parental belief that a treatment is beneficial may lead to increased adherence to the prescribed exercise intervention in children and adolescents with JIA (96).

5.3. Implications for Policy

Although much of the intervention in JIA is done on an individual basis specifically at the tertiary health care level there may be room to address disease and socio-economic disparities at the population level. This is important because the Public Health Agency of Canada aims to promote healthy living for all Canadians, including those with chronic conditions and disabilities (97).

Although leisure provides many positive outcomes for children and adolescents, as well as their families (98-100), limited knowledge of benefits of leisure participation and a lack of affordable and accessible specialised activities may limit the family's and the child's opportunity to take part. Moreover, the lack of awareness of existing resources by patients and families, as well as the difficulty in accessing this information may be a source of stress and frustration (101,102).

Understanding how the child's, the family's and the environmental characteristics can interact and influence participation in leisure and physical activity is important for the development of appropriate and effective policies and programs.

One initiative open to children and youth with JIA has been the establishment of a summer camp program. Attending specialised summer camps improved participants' overall knowledge about their disease and its management, as well as better self-concept (103). Community-based programs catering specifically to children and adolescents with JIA require a detailed understanding of barriers and facilitators to their participation in leisure and general physical activity not only in terms of disease-specific factors, but must also consider environmental and community factors (104). Although rehabilitation professionals may recommend specific exercises, as well as guide choices for safe and effective physical activity; opportunities to engage in active pursuits are mostly available within the community and dependent on the child and the family's preferences, lifestyle, accessibility and availability. In response to this need, rehabilitation professionals can also consult and partner with community leaders to develop community-based leisure programs geared specifically to those with JIA (105).

The collaboration between rehabilitation professionals and community workers is illustrated in a study by Hutzal et al. (2009) featuring physical activity programs characterised by aerobic and stretching or qiqong (i.e. fluid and slow movements together with isometric poses) led by instructors trained by rheumatology rehabilitation professionals (physiotherapists) and informed about the clinical presentations of JIA (105). Rheumatology

therapists can offer crucial information and support to help implement rehabilitation programs within the community in non-medically based facilities such as schools or community centers (105).

In addition to provincial policies subsidizing community based adapted sports programs, providing funding for equipment, training sports coaches, as well as promoting active living within schools including those with disabilities may be helpful. There needs to be a concerted effort between health care professionals in rheumatology and school officials to ensure that those living with arthritis be included in physical education classes and that they as much as their peers be included and benefit from curriculum based physical activity. Physical education classes and intramural sports are a good way to provide access to sports and physical activity to families of lower socio-economic status that may not have had access to them otherwise, as well as present these activities to children and adolescents from various cultural backgrounds. If excluded from these classes, children and adolescents with JIA may not be able to explore a variety of activities and may find it difficult to hone in on those that they prefer and that may motivate them the most. It is important to expose children to regular physical activity early on in life in order to encourage an active life style throughout life and well into adulthood (71,89,106).

School based physical and leisure activity programs may be the most accessible to children and adolescents and present a primary prevention mechanism to encourage physical and leisure activity. This is based on the assumption that children from most developed

countries attend school and so the majority of them will be reached and will be able to participate in these regular physical education classes.

Treating and caring for those with JIA implies substantial financial burden on the family, often in the form of out of pocket expenses for medication, regular visits to private health care specialists (private physiotherapy or alternative therapies) and lost wages due to frequent visits to the hospital for follow-ups with rheumatology team (107). Additional costs for leisure activities may be out of reach for some of these parents. Our findings have confirmed that children and adolescents with JIA of lower socioeconomic family backgrounds participated less in leisure activities. Therefore, community-based programs taking into account factors related to the disease (i.e. including children living with orthopedic pain, chronic pain and other chronic issues) geared to those living with JIA need to be affordable. Governmental incentive programs for physical activity in Canada such as the Children's Fitness Tax Credit which came into effect in 2007 may alleviate some of the financial strain felt by parents (108). In addition specialised sport programs may benefit from federal funding for the purchase of equipment and modifying the built environment housing the activity (109). However to our knowledge there is no conclusive evidence supporting its effectiveness in actually increasing the level of physical activity among Canadian children and adolescents (108).

Moreover funding allocations offered by the federal government toward adapted sports programs with executive power reserved to provinces may be helpful. Despite the fact that there are many policies both at the provincial and federal levels supporting equal opportunity

for participation in leisure and physical activity of all children regardless of disability few have clearly defined mechanisms and action plans to accomplish these (110). Although collaboration between health care professionals, patients with JIA and their families, as well as policy makers would favour successful implementation of policies promoting leisure among youth with JIA, little information is made available to health care professionals and families about these specific policies (110).

5.4 Strengths and weaknesses of our study

5.4.1 Strengths

Our study is the first to explore leisure participation comprehensively across various activity types, domains (formal and informal) and dimensions (diversity, frequency, enjoyment) among children and adolescents with JIA. Our clinical study is the first to date to assess leisure participation exclusively among children and adolescents with JIA using the CAPE a reliable and valid pediatric outcome measure used in healthy children and those living with physical disabilities (32). Moreover, the child's self-report on leisure (CAPE) provided us with new insight on the type, the frequency and diversity of leisure in JIA, as well as the activities most enjoyed.

Unlike previous studies in JIA, our study adopted a bio-psychosocial approach to analyse participation in leisure and physical activity allowing us to examine the role of the disease as part of an intricate web of variables including personal and environmental

characteristics. All variables from the clinical study were measured using tools with sound psychometric properties and previously used in pediatric disability research. Ours is the first study in pediatric rheumatology to operationalize participation in leisure and physical activity using a well identified theoretical framework, specifically the ICF-CY. Results were particularly compelling as contextual factors were more important in explaining participation than disease-specific variables. This implies that poor participation in JIA is not merely a result of arthritis but rather hinges on the interaction of the person and the environment within the context of chronic disease. Our findings may help identify those with JIA at greater risk for poor participation, as well as inform rehabilitative treatment plans.

Our study is also the first to provide information on leisure participation across a Canadian representative sample. The use of population-based survey data offers many advantages such as a better representation of the population under study compared to a single clinic setting, the minimisation of geographic biases emerging from a more localised sample, as well as a better and more precise estimate of prevalence compared to smaller samples (111). The combination of both clinical and population-based data has provided us with a more complete picture of leisure participation among children and adolescents with JIA.

Although the sample sizes collected for each outcomes are relatively small, n=107 for the CAPE and n=76 for the accelerometer, these remain much larger than most other studies investigating participation in social activities or physical activity in children and adolescents living with JIA. In fact, studies reporting social activities in JIA through self-report measures had sample sizes ranging between 41 to 56 participants (26,112,113). Similarly most studies

assessing physical activity through self-report mostly ranged in sample size from 23 to 52 (3-10) (only one had an n=108 (9)). Lastly, studies using accelerometers for evaluating physical activity in JIA ranged in size from 23 to 48 (4-7,11).

5.4.2 Weaknesses

There are several weaknesses and limitations to our study. These pertain to aspects of design, bias, psychometrics and sample size, and are discussed in the following sections.

5.4.2.1 Study design

One of the shortcomings of our study is the cross-sectional study design, which precluded us from identifying patterns of participation over time in JIA, as well as identifying potential factors that may be associated with changes in leisure and physical activity. This may be of particular concern in JIA because of the fluctuating nature of disease severity, which may lead to changes in general function and participation in age-appropriate activities. Data collected longitudinally on leisure and potential predictors and analysed using linear mixed modeling could provide us with more complete information. Despite this limitation we have identified factors related to the child and the environment that can help inform promotional interventions in leisure participation and physical activity.

5.4.2.2 Comparator group

Although we have attempted to contrast the patterns of involvement in leisure and physical activity among children and adolescents with JIA to healthy siblings, to reference groups found in the literature, as well as a healthy group of children and adolescents from another study none were optimally representative of study participants with JIA. Specifically the participants without JIA from the Quality group may not have been reasonably representative of the case reference population, as they did not match in age distribution (JIA 8 to 17 years versus healthy Quality group 8 to 14 years), had varying sex ratios (JIA 66% girls versus for Quality group), lived in different municipal regions, frequented different school districts and potentially had different socio-economic status (this however could not be verified as no information on socio-economic status was available for the Quality group). In order for a comparison group to be reasonable representative of the case reference population it is recommended that controls be of similar age, live in a similar geographic area, have a similar sex distribution, frequent a similar school district and be part of a similar socio-economic status (114).

5.4.2.3 Information bias

Another weakness of our study is the self-reported retrospective data collected on leisure participation. Participants were questioned on leisure participation having taken place over the last year via a post-census survey (population-based sample) or over the last 4 months using the CAPE (clinically based sample). This may have led to a recall bias and

potentially less reliable information on participation. A shorter recall period could have limited bias.

A research assistant guided completion of the CAPE by the child or adolescent, and as a result information collection may have suffered from a social desirability bias. Participants with JIA who were less physically active or less involved in skill-building activities may have over-reported their participation in these activities and possibly under-reported their involvement in less healthy behaviours such as watching television or playing video games. This may have underestimated the disparity between JIA and non JIA groups (i.e. siblings without JIA and normative reference samples) for involvement in more active leisure.

In the population-based study, the diagnosis of arthritis was reported by the proxy and was not confirmed through review of the patient's medical forms.

5.4.2.4 Non-response bias

Although no significant differences were found between participants and non participants with regard to the child's age, sex, disease activity, active joint count, disease duration, we could not assess differences in functional status or participation in leisure or physical activity. As a result, non-response bias (115,116) may have occurred if those presenting with lower function or lower levels of participation in leisure or physical activity decided not to participate. However, the results of our population-based sample that is

representative of Canadian children and adolescents with arthritis were similar to our clinical sample results pertaining to function and leisure activity.

5.4.2.5 Selection bias

Participants were recruited from the Rheumatology clinic at the Montreal Children's Hospital, McGill University Health during their regular visit. Certain patients known to have JIA may have been lost to follow-up in clinic and as such could not be approached for recruitment. Selection bias may have occurred if those with JIA and their families who were chronically absent for their clinic visits may have less severe disease and differed in terms of active joint count, disease duration and functional status to patients and families who attended scheduled appointments regularly.

5.4.2.6 External validity

Participants with JIA from our clinical study were recruited systematically from a single hospital-based out-patient rheumatology clinic, which may have weakened external validity. We could not account for differences in health care service provision across multiple regional or national sites such as the frequency of medical follow-up visits, the referral to rehabilitation professionals, as well as the prescription of pharmacological treatment, which may in turn have limited the generalizability of our findings to all children and adolescents living with JIA. Nevertheless, characteristics from our JIA sample closely mirror those from

other studies in pediatric rheumatology in terms of mean age, sex ratio, mean disease duration and JIA subtype distribution (%) (10,117,118).

5.4.2.7 Sample size and power considerations

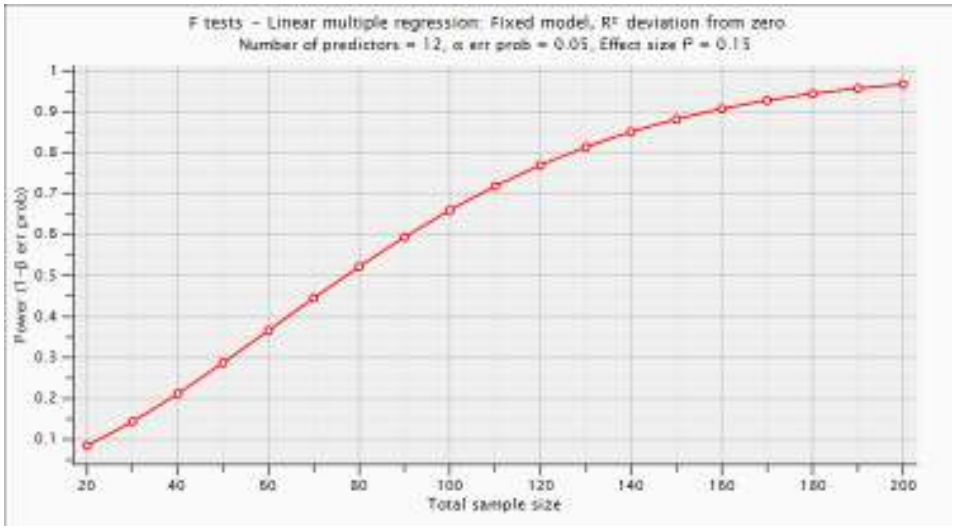
We completed a priori power analysis for all of our statistical tests used in our clinical sample via the G*Power 3 statistical analysis software program version 3.1.2 (Germany, 2010). For univariate analysis of correlations a sample size of 46 was needed to obtain a correlation of 0.4 with 80% power (1-β) for an effect size of 0.15 (medium according to Cohen's guidelines) (119), which was met for both main outcomes the CAPE and the accelerometer, respectively sample sizes were n=107 and n=76.

Our initial power assessment indicated that a sample size of 64 per group for t-tests would be necessary to detect a medium effect size of 0.50 when comparing participation in leisure activities (CAPE) between subgroups in our clinical sample with a power of 0.80 at a significance level of $p \leq 0.05$. However sample sizes for comparison groups, specifically for age and sex, were unequal. We therefore completed post hoc analysis of Cohen's d calculated as follows for non-directional two-tailed cases: $d = | (mA - mB)/\sigma |$ (120). Values for Cohen's effect size d varied from 0.81 to 0.03, where power ranged from 0.98 to 0.05. For the same sample sizes and alpha (0.05) a greater effect size d resulted in larger statistical power (121).

For our multivariate linear regression a sample size of 123 would have given us 80% power for inclusion of 12 predictor variables of participation in leisure and physical activity

(Figure 1). Although the collected sample sizes were smaller than anticipated we respected the principle of 5 to 10 subjects per independent variables for our multivariate analysis, rendering our samples sizes adequate to test the selected variables (122). Therefore for the analysis of our clinical data the CAPE (sample sizes for regression models ranged from 89 to 94) we included between 5 to 11 variables and a maximum of 5 for the accelerometer data (sample size for the regression model was 74). We cannot of course deny that our limited sample size may have been insufficient in reliably rejecting an incorrect null hypothesis (H_0) and discriminating between the null hypothesis and the alternative hypothesis (H_1) of interest (i.e. type 2 errors).

Figure 1. Statistical power analysis graph for JIA sample using the G*Power 3 statistical analysis software program version 3.1.2 (Germany, 2010)



We had initially planned to explore direct and indirect influences of potential determinants on leisure participation using structural equation modeling, however our sample size did not meet the required sample size of 200 participants (123).

5.4.2.8 Missing data

Although we collected data on family income through parental report nearly 20% (20/107) of responses were missing and in light of our already small sample size excluding these cases would further jeopardise our external validity. Therefore in order to include the maximum number of cases in our analysis and compensate for the potential information bias we opted to use median neighborhood income based on the 3 first characters of the participants' postal code (107/107 of participants with JIA). Data for maternal education was also missing; however the number with available data allowed for adequate analysis (92/107 of participants with JIA) and was therefore also included as a secondary proxy for socio-economic status. These have both been used in the past to ascertain a family's wealth and standing (124).

Although we have opted to exclude missing data this may have incurred some bias and of course loss of information. By including only cases with complete data we lost a number of cases, which may have lead to a misestimation of population parameters, underestimation of effect size, loss of power and precision, possibly making our findings less replicable and generalisable (125,126). Bias is an even greater possibility if the data is not missing at random and there is a systematic exclusion of participants (125). We could have managed missing

data differently, such as by using the mean to impute missing data (126). Two types of mean substitution are commonly used.

One procedure proposes substituting the overall sample mean of one specific variable for each individual with missing data. However one concern when using this procedure is by substituting a large portion of the data with the overall mean you run the risk of artificially decreasing the variance of the variable, producing a biased mean, underestimating the standard estimation and correlations and altering the shape of data distribution (126,127). This is even more problematic if at least 20% of the sample is missing, even at random (127). Mean substitution may actually lead to population estimates that are less accurate than those found with simple case deletion when data are not missing completely at random (126).

The other type of mean substitution is used in questionnaires that include multiple, highly correlated questions assessing a single construct (126). The missing data of one scale are averaged and used to substitute for the missing data. This is considered as best practice when the internal consistency of the scale items is strong and the scale is unidimensional (126).

Finally, another complex statistical strategy considered as the gold standard and used for dealing with missing data is multiple imputation (125). This method available in many statistical packages uses techniques, such as expectation-maximization algorithm (EM)/maximum likelihood estimation, propensity score estimation, or Markov Chain Monte Carlo (MCMC) simulation to estimate missing values by creating multiple versions of the

same data set and provides confidence intervals for the resulting estimates (126). This method is especially useful when dealing with large number of missing data (126). Using multiple imputation to compensate for missing data may help favour internal validity by maintaining the study's statistical power, as well as favour external validity.

5.4.3 Confounding

The child's and parent's perceptions and attitudes towards leisure and physical activity, as well as baseline knowledge of the benefits of leisure and physical activity may also influence the level of participation.

Although we analysed associations of disease symptoms and disability with the level of participation, we did not assess the potential influence of illness perception. How the child and parent perceive the impact of the arthritis on their life may moderate the child's desire to engage in activities and similarly may limit the level of parental support for more physically strenuous and structured leisure activities.

A number of additional environmental barriers such as the type of school (i.e. public versus private), the built environment and the number of green spaces surrounding the participant's residence may also influence the level of participation in leisure by providing more or less opportunities for participation. Schools in more affluent neighborhoods may offer more options for after school leisure and physical activity, which may also moderate the level of participation among children and adolescents with JIA. Studies have demonstrated

the potential for the built environment and the proximity to green spaces to influence the level of physical activity among older adolescents and adults (128). Other objectively measured environmental factors such as lower density of high traffic streets in urban settings (129) and close proximity to relatives or friends (i.e. living within a 10 minute walk away) (130) were also associated with increased involvement in physical activity.

We also considered inclusion of variables characterising the built environment and green spaces for our study. In fact, we used the Montreal Epidemiological and Geographical Analysis of Population Health Outcomes and Neighbourhood Effects (MEGAPHONE), a comprehensive geographic information system, to collect information on the number of parks and recreational facilities (density) within various buffer zones (100, 200 and 500 meter radius), as well as the distance of the nearest green space from the child's home (proximity) as potential predictors of leisure participation and engagement in physical activity. Fifty of our participants with JIA resided in the regions targeted by MEGAPHONE (Montréal, Lanaudière, Laurentides, Laval and Montérégie). Bivariate analysis showed no significant correlations between the density and proximity variables with the level of self-reported leisure or objectively measured physical activity. It should be noted, that the lack of a significant association may be the result of type 2 errors, whereas a larger sample size may have yielded significant results.

5.4.4 Interactions

In line with the ICF-CY socio-ecological framework, participation is a result of the interplay between the person and the environment within the context of JIA. As such, we chose to test the interactions between each disease activity, pain and income on the potential effects of age, sex, activity preferences, motivation, athletic competence, physical appearance on participation in leisure and physical activity. However none were significant suggesting that other factors may need to be considered. Although not assessed in our study, other environmental factors such as greater opportunity for leisure and physical activity, positive parental attitudes of and actual participation in leisure and physical activity may play a role in moderating the potential influence of personal factors (i.e. age, sex, activity preference, mastery motivation for gross motor tasks) in increasing the frequency of leisure and physical activity. Although not included in our study the examination of the effects of socio-economic status by disease interactions may also be warranted. A stratification analysis by socio-economic status could help determine whether or not the risk of decreased participation in physical and leisure activity differs between those exposed to JIA and those without. We might expect that the risk of poor participation in certain physical and leisure activities among those with JIA compared to those without may be further amplified by poor socio-economic status. Moreover, further analysis of this interaction may lead us to identify other underlying factors responsible for poor participation in JIA across socio-economic status.

5.5 Future avenues for research

We have identified factors based on the ICF-CY related to the child, the family and the environment to help discern those with JIA who are most at risk for poor participation in leisure and physical activity. These findings may inform future research projects assessing leisure and physical activity in this population, as well as the development of intervention studies involving motivational strategies and the incorporation of preferred activities to favour adherence to treatment.

Additional descriptive studies, such as a longitudinal study design may account more accurately for fluctuations in disease presentations in JIA, the effects of various leisure predictors, the child's growing autonomy and changes in interest for activities, as well as identify other determinants of leisure. Moreover, a qualitative study design can tap into the unique perspective of a child or adolescent with JIA and bring to light factors that may have been overlooked in the existing literature on leisure participation in pediatrics and our current study. Various focus groups composed of children and adolescents with JIA, their parents, clinicians and policy-makers may facilitate a collective discourse on issues surrounding leisure participation such as identifying barriers most encountered by our population, and narrowing down promising treatment options and rehabilitative strategies by informing on its usability, feasibility and appropriateness.

Future intervention studies may range from developing the best possible treatment in terms of providing accessible programs and facilities suitable for those living with JIA,

improving adherence to treatment, favouring gross motor skill building and identifying most optimal activity and frequency of performance. Such treatment options may include development of community-based leisure programs stemming from a collaborative effort between rehabilitation professionals and community workers, leisure-based interventions informed by the client's activity preferences and motivational therapies incorporating meaningful and challenging activities targeting improvement of motor skills. Moreover, e-health (internet, social media) and m-health (mobile phones) technologies may be used to provide information on appropriate and nearby community leisure and physical activity programs, as well as deliver educational and self-management interventions focused on leisure and physical activity to those with JIA.

5.6. Conclusion

Our results confirm that participation in leisure and physical activity may be influenced by a multitude of factors beyond those related to the disease. Successful promotion of leisure participation is contingent on rehabilitation professionals' deeper understanding of barriers and facilitators. Our thesis findings support that promotional efforts to increase participation in leisure and physical activity should target individual preferences and favour mastery motivation, be affordable and culturally appropriate. Moreover, choice of proposed activities will also have to meet gender and age interests to favour adherence and improve frequency of participation. Low participation specifically in active physical leisure has been highlighted in our research as a point of concern and possible focus for future treatment initiatives in JIA.

Future research into leisure and physical activity among children and adolescents with JIA may benefit from a mixed methods approach (qualitative and quantitative) to identify additional factors that may enhance participation in JIA such as those related to green spaces and the built environment. Multi-center prospective studies may better inform on the strengths and weaknesses of specific institutions, which will further inform policy change and benefit implementation of leisure activities catering to those with chronic conditions such as JIA.

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Appendix 1: Search strategy used to identify studies on leisure activities in JIA for our systematic literature review.

The search strategy found below was developed in consultation with a librarian and was applied to the following electronic databases: Medline (1946 to week May week 3 2013)[2], the Cochrane library[3], EMBASE (1974 to 2013 Week 21), Cumulative Index of Nursing and Allied Health Literature (CINAHL) (1982 to December week 1 2013), Base de Données en Santé Publique (June 2013), Education Resources Information Center (ERIC) (1965 to April 2013), Health and Psychosocial Instruments (1985 to April 2013), OT Seeker and PsycINFO (1806 to May Week 3 2013).

The following search strategy was specifically used for OVID MEDLINE and was modified for each of the above databases:

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

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[2] Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Week 3 May 2013

[3] EBM Reviews - Cochrane Database of Systematic Reviews (2005 to March 2013), EBM Reviews - ACP Journal Club (1991 to April 2013), EBM Reviews - Database of Abstracts of Reviews of Effects (2nd Quarter 2013), EBM Reviews - Cochrane Central Register of Controlled Trials (March 2013), EBM Reviews - Cochrane Methodology Register (3rd Quarter 2012), EBM Reviews - Health Technology Assessment (2nd Quarter 2013), EBM Reviews - NHS Economic Evaluation Database (2nd Quarter 2013)

1 juvenile idiopathic arthritis.mp. or exp Arthritis, Juvenile Rheumatoid/ (8644)

2 juvenile arthritis.mp. (618)

3 juvenile chronic arthritis.mp. (1028)

4 juvenile ankylosing spondylitis.mp. (82)

5 juvenile oligoarthritis.mp. (12)

6 juvenile polyarthritis.mp. (47)

7 juvenile psoriatic arthritis.mp. (56)

8 juvenile enthesitis related arthritis.mp. (1)

9 juvenile systemic arthritis.mp. (0)

10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (9027)

11 physical activity.mp. or exp Motor Activity/ (199316)

12 physical activities.mp. (3356)

13 motor activities.mp. (841)

14 leisure.mp. or exp Leisure Activities/ (144832)

15 leisure activity.mp. or exp Leisure Activities/ (139612)

16 leisure participation.mp. (52)

17 leisure involvement.mp. (8)

18 social integration.mp. (1547)

19 participation.mp. or exp Social Participation/ (112737)

20 social activity.mp. (1040)

21 social activities.mp. (2111)

22 exp "Play and Playthings"/ or play*.mp. (725984)

23 sport*.mp. or Racquet Sports/ or Sports/ or Snow Sports/ (59674)

24 exercis*.mp. (238137)

25 exp Recreation/ or recreation*.mp. (129542)

26 accelerometer*.mp. or exp Actigraphy/ (5328)

27 accelerometry.mp. or exp Accelerometry/ (2390)

28 exp Walking/ or Walk*.mp. (71277)

29 exp Monitoring, Ambulatory/ or activity monitor*.mp. (22144)

30 pedometer*.mp. (1266)

31 actigraph*.mp. (2906)

32 sports participation.mp. (877)

33 play participation.mp. (2)

34 exp Swimming/ or aquatic sports.mp. (17662)

35 winter sports.mp. (173)

36 exp Bicycling/ or bicycle*.mp. (15539)

37 biking.mp. (272)

38 cycling.mp. (33268)

39 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 (1336273)

40 10 and 39 (518)

Appendix 2: Ethical approval

SSHRC CRSH

350 Albert Street, P.O. Box 1610
Ottawa ON K1P 6G4
[redacted]

350, rue Albert, C.P. 1610
Ottawa ON K1P 6G4
[redacted]

July 8, 2009

Ms. Sabrina Cavallo
2690 rue Knox
MONTREAL QC H3K 1R4

FILE: CISS-RDC-CAVALLO/ 381814

Dear Ms. Cavallo:

Thank you for submitting an application to the *CISS-Access to the RDC Program*, a joint initiative between Statistics Canada, the Social Sciences and Humanities Research Council and the Canadian Institutes of Health Research. The RDC-Access Granting Committee has now completed the review of your proposal and has approved it. We will now notify Statistics Canada so that it can do the required security check.

We also ask that you contact the RDC analyst and make an appointment to begin the administrative processes to gain access to the centre. [redacted]

You have 1 year from the date of approval of your proposal in order to initiate access to the RDC. If you are unable to commence your research projects within the first 12 months after your project has been approved for RDC access, please contact the RDC analyst to make special arrangements.

If you have not contacted your RDC analyst within the first 12 months after your proposal has been approved, you will need to re-apply to SSHRC in order to re-gain access to the RDC. The reviews of the applications were based on SSHRC peer review procedures. Each proposal was evaluated on the basis of four main criteria: scientific merit and viability of the proposed research; the viability of the methods to be applied given the data on which the analysis will be performed; a demonstrated need for access to detailed micro data; and, the expertise and ability of the researchers to carry out the work.

You will find enclosed an evaluation submitted to SSHRC. Should you have further questions, please feel free to contact the officer responsible for the administration of the *CISS-Access to the RDC Program*, Mika Oehling [redacted].

Sincerely,

[redacted]

Murielle Gagnon
Director
Strategic Programs and Joint Initiatives

cc: Beverley Hunt, Research Data Centres Headquarters Operations

Encl.

L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital

Centre universitaire de santé McGill
McGill University Health Centre

August 25, 2010

Dr. D. Feldman
Rheumatology
MUHC - Montreal Children's Hospital
Room # C-504

Re: **09-261-PED Determinants of Involvement in Active Physical and Other Leisure Activities in Children and Youth with Juvenile Idiopathic Arthritis**
Funded by: **Cdn. Initiatives for Outcomes in Rheumatology Care (COORC)**

Dear Dr. Feldman,

The above-named research proposal received Full Board review at the convened meeting of the Montreal Children's Hospital Research Ethics Board on May 17, 2010 and was found to be within ethical guidelines for conduct at the McGill University Health Centre, and was entered accordingly into the minutes of the Research Ethics Board (REB) meeting. At the MUHC, sponsored research activities that require US federal assurance are conducted under Federal Wide Assurance (FWA) 00000840.

We are pleased to inform you that final approval was provided on August 25, 2010 for the following:

- MUHC Initial Review form
- MCH science approval letter (dated 23-April-2010)
- Protocol, version (undated)
- Juvenile Arthritis Quality of Life Questionnaire (JAQQ)
- The Physical Activity Questionnaire for Older Children (PAQ-C) and Adolescents (PAQ-A) Manual
- Child Health Assessment Questionnaire
- Family environment Scale (Form R) Item Booklet (English & French version)
- Causes of My Illness form
- Project: JIA Étude 1 Formulaire: GENINFO
- Questionnaire sur la motivation des enfants (à l'intention des parents)
- Questionnaire sur la motivation des adolescents (à l'intention des parents)
- Parent Consent (English & French version July 21, 2010)
- Assent for participant, (English & French version July 21, 2010)
- Assent for participant (Sibling), (English & French version July 21, 2010)

All research involving human subjects requires review at a recurring interval and the current study approval is in effect until May 16, 2011 (anniversary of initial review). It is the responsibility of the principal investigator to submit an Application for Continuing Review to the REB prior to the expiration of approval to comply with the regulation for continuing review of "at least once per year".

The Research Ethics Boards (REBs) of the McGill University Health Centre are registered REBs working under the published guidelines of the Tri-Council Policy Statement, in compliance with the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, 1998) and the Food and Drugs Act (7 June, 2001), acting in conformity with standards set forth in the (US) Code of Federal Regulations governing human subjects research, and functioning in a manner consistent with internationally accepted principles of good clinical practice.

We wish to advise you that this document completely satisfies the requirement for Research Ethics Board Attestation as stipulated by Health Canada.

The project was assigned MUHC Study Number **09-261-PED** that is required as MUHC reference when communicating about the research. Should any revision to the study, or other unanticipated development

[redacted]

occur prior to the next required review, you must advise the REB without delay. Regulation does not permit initiation of a proposed study modification prior to REB approval for the amendment.

[redacted]

JM/ec

Cc;

Sasha Lee – Clinical Contracts Office
Evelyn Ortega– Clinical Research Core Service
Alison Burch – Research Institute
Sophia Bamboulas – Clinical Research Group

[redacted]

L'Institut de recherche
du Centre universitaire de santé McGill
The Research Institute
of the McGill University Health Centre

August 26, 2010

Dr. Debbie Feldman
MUHC - MCH
Room C-504
Montreal, Quebec H3H 1P3

Re: MUHC Authorization to Conduct Human Subjects Research 09-261-PED

Dear Dr. Feldman:

We are writing to confirm that the study titled *"Determinants of Involvement in Active Physical and Other Leisure Activities in Children and Youth with Juvenile Idiopathic Arthritis"* was submitted for all institutional reviews required by McGill University Health Centre policy.

The Pediatric (PED) Research Ethics Board (REB) has notified us that ethical approval to conduct your study has been provided.

In addition, all Site Specific Assessments (SSA) received favorable reviews and therefore, you are authorized to conduct the study at the MUHC. Enclosed please find a copy of the decision letter of the applicable reviews for your files.

Please refer to the MUHC Study Code **09-261-PED** in all future correspondence relating to this study.

Important Note: You are required to advise the MUHC once the study has been initiated. Please complete the Study Status Report to indicate the date the study became active and forward as an email attachment to the (1) PED REB, and (2) RI MUHC Central Output Coordinator at [redacted].

On behalf of the MUHC, we wish you every success with the conduct of the research.

Sincerely,

[redacted]

Enclosure

cc: REB Study File
RI MUHC Study File

L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital

Centre universitaire de santé McGill
McGill University Health Centre

March 8, 2010

Dr. Debbie Feldman
MUHC Principal Investigator

Dear Dr. Feldman:

Subject: **Study 09-261-PED**
Determinants of Involvement in Active Physical and Other Leisure Activities in Children and Youth With Juvenile Idiopathic Arthritis

Upon review of the documentation, this is to confirm my approval that the above-named research project takes place at the Montreal Children's Hospital of the McGill University Health Centre.

Sincerely,

[redacted]

Micheline Ste-Marie, M.D.
Associate Director of Professional Services

Université de Montréal

Comité d'éthique de la recherche de la Faculté de médecine

15 June 2011

Objet: Certificat d'éthique – « Determinants of involvment in active physical and other leisure activities among children and youth with juvenile idiopathic arthiritis »

Mme Debbie Feldman, Mme Sabrina Cavallo,

Le Comité d'éthique de la recherche de la Faculté de médecine (CÉRFM) a étudié le projet de recherche susmentionné et a délivré le certificat d'éthique demandé suite à la satisfaction des exigences précédemment émises. Vous trouverez ci-joint une copie numérisée de votre certificat; copie également envoyée au Bureau Recherche-Développement-Valorisation.

Notez qu'il y apparaît une mention relative à un suivi annuel et que le certificat comporte une date de fin de validité. En effet, afin de répondre aux exigences éthiques en vigueur au Canada et à l'Université de Montréal, nous devons exercer un suivi annuel auprès des chercheurs et étudiants-chercheurs.

De manière à rendre ce processus le plus simple possible et afin d'en tirer pour tous le plus grand profit, nous avons élaboré un court questionnaire qui vous permettra à la fois de satisfaire aux exigences du suivi et de nous faire part de vos commentaires et de vos besoins en matière d'éthique en cours de recherche. Ce questionnaire de suivi devra être rempli annuellement jusqu'à la fin du projet et pourra nous être retourné par courriel. La validité de l'approbation éthique est conditionnelle à ce suivi. Sur réception du dernier rapport de suivi en fin de projet, votre dossier sera clos.

Il est entendu que cela ne modifie en rien l'obligation pour le chercheur, tel qu'indiqué sur le certificat d'éthique, de signaler au CÉRFM tout incident grave dès qu'il survient ou de lui faire part de tout changement anticipé au protocole de recherche.

Nous vous prions d'agréer, Mesdames, l'expression de nos sentiments les meilleurs,

Isabelle Ganache, présidente
Comité d'éthique de la recherche de la Faculté de médecine

Université de Montréal

/gp

c.c. Gestion des certificats, BRDV

p.j. Certificat #11-043-CERFM-P

adresse postale
C.P. 6128, succ. Centre-ville
Montréal QC H3C 3J7

Département de kinésiologie
Cepsum
2100 Boul. Édouard-Montpetit
7e étage, bur. 7213
Montréal QC H3T 1J4

[redacted]

Université de Montréal

N° de certificat
11-043-CERFM-P

Comité d'éthique de la recherche de la Faculté de médecine

CERTIFICAT D'ÉTHIQUE

Le Comité d'éthique de la recherche de la Faculté de médecine (CÉRFM), selon les procédures en vigueur, en vertu des documents qui lui ont été fournis, a examiné le projet de recherche suivant et conclu qu'il respecte les règles d'éthique énoncées dans la Politique sur la recherche avec des êtres humains *de l'Université de Montréal.*

Projet	
Titre du projet	**Determinants of involvment in active physical and other leisure activities among children and youth with juvenile idiopathic arthiritis**
Chercheures requérants	**Debbie Feldman** (77637), Professeure titulaire, École de réadaptation. **Sabrina Cavallo** (N.D.), Candidate au doctorat en santé publique, Faculté de médecine -Département de médecine sociale et préventive.

Financement	
Organisme	Canadian Initiative for Outcomes in Rheumatology Care (CIORA)
Programme	Awareness / Advocacy / Education
Titre de l'octroi si différent	
Numéro d'octroi	
Chercheur principal	
No de compte	R0018085

MODALITÉS D'APPLICATION

Tout changement anticipé au protocole de recherche doit être communiqué au CÉRFM qui en évaluera l'impact au chapitre de l'éthique.

Toute interruption prématurée du projet ou tout incident grave doit être immédiatement signalé au CÉRFM .

Selon les règles universitaires en vigueur, un suivi annuel est minimalement exigé pour maintenir la validité de la présente approbation éthique, et ce, jusqu'à la fin du projet. Le questionnaire de suivi est disponible sur la page web du CÉRFM .

[redacted]

Comité d'éthique de la recherche de la Faculté de médecine (CÉRFM)
Université de Montréal

15 juin 2011
Date de délivrance

1er juillet 2012
Date de fin de validité

adresse postale
C.P. 6128, succ. Centre-ville
Montréal QC H3C 3J7

Département de kinésiologie
Cepsum
2100 Boul. Édouard-Montpetit
7e étage, bur. 7213
Montréal QC H3T 1J4

[redacted]

Le 04 novembre 2004

Dre Marie Lambert
Génétique
Étage 6 Bloc 7

HÔPITAL
SAINTE-JUSTINE
Le centre hospitalier universitaire mère-enfant

Pour l'amour des enfants

OBJET: Titre du projet: Étude familiale sur la prévention des maladies cardiovasculaires et du diabète de type 2 chez l'enfant et l'adolescent / Family Study on the prevention of cardiovascular disease and type 2 diabetes in children and adolescents

Responsables du projet: Marie Lambert M.D., investigateur principal. Co-investigateurs: Jennifer O'Loughlin, Ph.D., Angelo Tremblay, Ph.D., Katherine Gray-Donald, Ph.D., James A. Hanley, Ph.D., Émile Levy, Ph.D., Gilles Paradis, M.D. et Paul Poirier, M.D, Collaborateurs: Martin Brochu, Ph.D., Edgard Delvin, Ph.D., Brigitte Lachance, Dt.P, François Lespérance, M.D., Grant Mitchell, M.D., Judith Simoneau-Roy, M.D., Daniel Sinnett, Ph.D. et Lyne Mongeau, Dt.P.

Chère Docteure,

Votre projet cité en rubrique a été approuvé par le Comité d'éthique de la recherche en date d'aujourd'hui. Vous trouverez ci-joint la lettre d'approbation du Comité ainsi que votre formulaire d'information et de consentement estampillé dont nous vous prions de vous servir d'une copie pour distribution. Tous les projets de recherche impliquant des sujets humains doivent être réexaminés annuellement et la durée de l'approbation de votre projet sera effective jusqu'au 4 novembre 2005. **Notez qu'il est de votre responsabilité de soumettre une demande au Comité pour que votre projet soit renouvelé avant la date d'expiration mentionnée.** Il est également de votre responsabilité d'aviser le Comité de toute modification au protocole ou au formulaire de consentement ainsi que de tout effet secondaire survenu dans le cadre de la présente étude.

Votre projet a été envoyé au directeur du Centre pour approbation finale.

Nous vous souhaitons bonne chance dans la réalisation de votre projet et vous prions de recevoir nos meilleures salutations.

[redacted]
Président du Comité d'éthique de la recherche,

Université de Montréal

3175, Côte-Sainte-Catherine
Montréal (Québec)
H3T 1C5

LE COMITÉ D'ÉTHIQUE DE LA RECHERCHE

Un comité de l'Hôpital Sainte-Justine formé des membres suivants:

Jean-Marie Therrien, éthicien et président
Anne-Claude Bernard-Bonnin, pédiatre
Anny Daigneault , infirmière de recherche
Mounib Elchebly, scientifique
Françoise Grambin, représentante du public
Albert Moghragi, hémato-oncologue
Lyne Pedneault, pharmacienne
Delphine Roigt, juriste
Jean-François Saucier, pédo-psychiatre
Chantal Van de Voorde, représentante du public

CENTRE
DE RECHERCHE
DE L'HÔPITAL
SAINTE-JUSTINE
Le centre hospitalier universitaire mère-enfant

Pour l'amour des enfants

Approbation valide jusqu'au 4 novembre 2005

Les membres du comité d'éthique de la recherche ont étudié le projet de recherche clinique intitulé:

> *Étude familiale sur la prévention des maladies cardiovasculaires et du diabète de type 2 chez l'enfant et l'adolescent / Family Study on the prevention of cardiovascular disease and type 2 diabetes in children and adolescents*

soumis par: *Marie Lambert M.D., investigateur principal. Co-investigateurs: Jennifer O'Loughlin, Ph.D., Angelo Tremblay, Ph.D., Katherine Gray-Donald, Ph.D., James A. Hanley, Ph.D., Émile Levy, Ph.D., Gilles Paradis, M.D. et Paul Poirier, M.D, Collaborateurs: Martin Brochu, Ph.D., Edgard Delvin, Ph.D., Brigitte Lachance, Dt.P, François Lespérance, M.D., Grant Mitchell, M.D., Judith Simoneau-Roy, M.D., Daniel Sinnett, Ph.D. et Lyne Mongeau, Dt.P.*

et l'ont trouvé conforme aux normes établies par le comité d'éthique de la recherche de l'Hôpital Sainte-Justine. Le projet est donc accepté par le Comité.

[redacted]
Président du Comité d'éthique de la recherche

Date d'approbation: 04 novembre 2004

3175, Côte-Sainte-Catherine
Montréal (Québec)
H3T 1C5

Appendix 3: Assent form for child and adolescent with JIA

Assent Form (JIA)

Determinants of Involvement in Active Physical and Other Leisure Activities in Children and Youth with Juvenile Idiopathic Arthritis

Investigators: **Dr. Debbie Feldman**
Dr. Annette Majnemer
Dr. Ciarán Duffy
Sabrina Cavallo, M.Sc.

Collaborators: **Dr. Sarah Campillo**
Dr. Gaelle Chedeville
Dr. Karen Duffy
Dr. Claire Leblanc
Dr. Rosie Scuccimarri

Purpose and General Information: The goal of this study is to learn more about the activities, hobbies and sports that children and teens with arthritis like to take part in for fun. We will also be asking children and teens who don't have arthritis if they'd like to take part in this study so that we can compare the 2 groups.

Procedures: If you and your parents agree to take part in this study, you will be asked to answer some questionnaires. This will take about 2-3 hours. You will be asked to answer some of them on your own. For other ones, a research assistant will ask you questions. We will ask you how your arthritis affects your relationships with your friends and family and how it affects you at home and at school. We would also like to know how your arthritis may keep you from taking part in certain activities, hobbies and sports.

We will ask you to wear a small machine, called an accelerometer, around your waist. It can be worn under your clothes. It will measure how active you are during the day by measuring your movements in different directions. You will need to wear it every day for 7 consecutive days and only take it off when you are sleeping, taking a bath or a shower or swimming.

Confidentiality: All of the information gathered during this study will be kept completely confidential. This also includes your parents. Therefore if you do have any questions and prefer to not discuss this with your parents, you can always ask the research assistant to help you rather than asking your parents. Your name will not appear on any of the questionnaires.

Possible Benefits: We hope that the information from this study helps us learn more about how much children and teens with arthritis participate in physical activities and what makes it easier or harder for them to take part. This will help the doctors and therapists, who want to help you take part in physical activities.

Possible Risks: Nothing bad will happen to you or your family by taking part in this study. You may feel sad when answering the questionnaires. If you do feel sad you can talk about it with the clinic nurse.

Voluntary participation: Your mother or father is also reading information about this study. They will talk to you about it. Ask them questions if you do not understand what you have heard or read. They will help you to understand. The doctors and research staff will answer any questions that you have. If you and your parents do not want to be part of this study, that's all right. If you and your parents say yes now but change your mind, you can say no later. If you have any questions, you can call Dr. Debbie Feldman [redacted], Sabrina Cavallo [redacted] or Martine Moïse [redacted].

Assent Form (JIA)

Determinants of Involvement in Active Physical and Other Leisure Activities in Children and Youth with Juvenile Idiopathic Arthritis

Agreement:

I have read this assent form and I understand what I have read. I understand what was explained to me and that I have been given the chance to ask questions. I understand that I don't have to take part in this study. I agree to participate in this study.

Please sign your name below if you are interested in participating in our study.

Thank you.

Name of Participant: _____

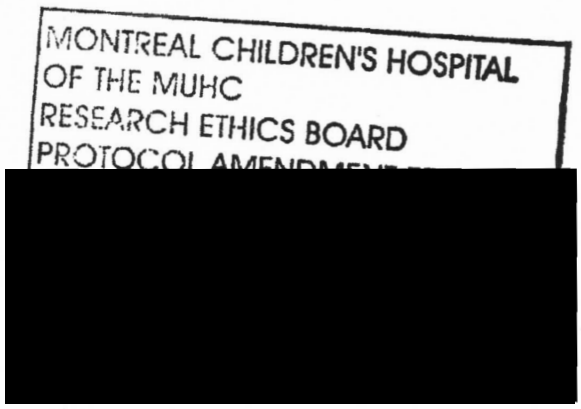
Participant's Signature: _____

Date: _____

Name of Person Who Explained Study: _____

Signature of Person Who Explained Study: _____

Date: _____



Appendix 4: Informed consent (Parent form)

INFORMED CONSENT

Determinants of Involvement in Active Physical and Other Leisure Activities in Children and Youth with Juvenile Idiopathic Arthritis

Investigators: Dr. Debbie Feldman
Dr. Annette Majnemer
Dr. Ciarán Duffy
Sabrina Cavallo, M.Sc.

Collaborators: Dr. Sarah Campillo
Dr. Gaelle Chedeville
Dr. Karen Duffy
Dr. Claire Leblanc
Dr. Rosie Scuccimarri

Funding Source: Canadian Initiative for Outcomes in Rheumatology Care (CIORA)

Purpose and General Information

The goal of this study is to look at the outcome of approximately 200 children and teens between the ages of 8-18 years, who have been diagnosed with Juvenile Idiopathic Arthritis (JIA). When possible, a sibling (within 2 years of age) who does not have JIA will also be invited to take part in this study. This will be done so that we can compare the results of the children who do have JIA with those who do not.

We are specifically interested in your child's participation in various physical and leisure activities, such as sports and other hobbies and how this relates to how they perceive the quality of their life. We would also like to learn about what makes them more or less likely to take part in these activities.

Study Procedures

You and your child will be approached during clinic visit by our research assistant to aske if you are interested in participating in this study. If you agree to participate, you and your children will be asked to complete a series of questionnaires. If your children are unable to answer the questions, you will be asked to do so, on their behalf. These questionnaires ask about physical activity, leisure activities, how your child perceives the quality of his or her life, the support of friends and family, the use of health services and other community-based resources. Questionnaires about your child's motivation,

self-image and activity limitations will also be included. Completion of these questionnaires should take approximately 2 to 3 hours. Most questionnaires can be completed at home and mailed back to our research coordinator, whereas for others, a research assistant will ask you questions in person or over the phone.

We will also ask your child with JIA (and when possible his or her sibling) to wear an accelerometer, which is a small device that measures activity and can be worn under clothing on the waist. The accelerometer will be given to you during your clinic visit. Your child will be asked to wear it all day, every day, for 7 consecutive days. The accelerometer should only be removed when sleeping, taking a shower or a bath or when swimming. The accelerometer can either be mailed back or pick-up during a home visit arranged by our research coordinator, at your convenience.

Possible Risks and Discomforts

Participation in this study does not involve any risks for you or your family. When completing the questionnaires, your child may experience feelings of sadness. If you or your child experiences any such feelings we invite you to bring these up with the clinic's nurse.

Possible Benefits

This study may provide information on the level of participation your child has in various physical and leisure activities and also shed some light on the factors that encourage or discourage participation. The information provided by your family may help our team provide needed services and resources that can increase participation in physical and leisure activities and may also improve the way that children with arthritis perceive the quality of their life.

Compensation

You will not be paid for your participation in the study, however your transportation expenses (e.g. parking) will be compensated.

Alternatives & Voluntary Participation

Your family's participation in this study is entirely voluntary. You may refuse to answer any question, or refuse to participate or withdraw your consent at any time. This will not affect the level of care your child receives at The Montreal Children's Hospital.

Confidentiality

All of the information gathered during this study will be kept completely confidential. No names will appear on the questionnaires. No one will be identified in any reports,

presentations or publications, which may result from this study. The study results can be made available to you upon your request. Data will be stored in a secured cabinet within the Division of Rheumatology at the Montreal Children's Hospital during the study and then in a secure off-site storage, for a maximum of 7 years. Results will be entered into a database to be used for research purposes only. Data will be non-identifiable in order to transfer data onto a laptop for analysis purposes.

The MUHC Research Ethics Office (REO) Quality Assurance may review the data gathered during this study. This is done to make sure that the guidelines put forth by the REO are respected.

Contact Person

If you have any questions, you may contact the study's principal investigator, Dr. Debbie Feldman at [redacted], or the research coordinators Michele Gibbon [redacted], Sabrina Cavallo [redacted] or Martine Moïse [redacted]. If you need further information about your rights as a research subject, you may contact the Patient Representative at [redacted]. This person will also forward your complaints to the coordinator of the Research Ethics Committee of the Faculty of Medicine of the University of Montreal, M. Guillaume Paré at [redacted].

INFORMED CONSENT

Determinants of Involvement in Active Physical and other Leisure Activities in children and youth with Juvenile Idiopathic Arthritis

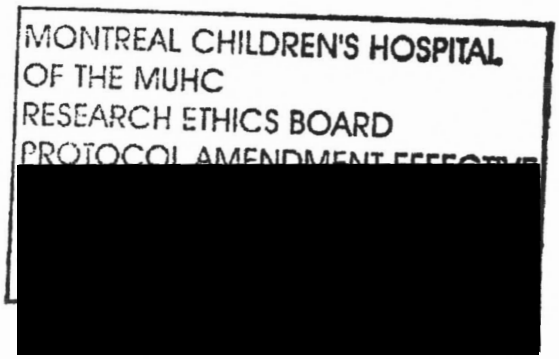
Consent:

I acknowledge that the procedures for this research study were explained to me and that any questions I have asked have been answered to my satisfaction. I understand that participation is voluntary. I am aware of my right to withdraw from the study at any time without compromising the level of care received by my child, at The Montreal Children's Hospital.

A copy of the consent will be given to me.

By my signature below, I grant permission for my participation as well as my child's and his or her sibling's participation in this study.

Name of participant	Name of participant (sibling)
Parent or legal guardian's name	Parent or legal guardian's signature
Relationship to the child	Date (day/month/year)
Name of person who obtained consent	Signature of person who obtained consent
Date (day/month/year)	



Appendix 5: Assent form for sibling without JIA

Assent Form (Sibling)

Determinants of Involvement in Active Physical and Other Leisure Activities in Children and Youth with Juvenile Idiopathic Arthritis

Investigators: **Dr. Debbie Feldman**
Dr. Annette Majnemer
Dr. Ciarán Duffy
Sabrina Cavallo, M.Sc.

Collaborators: **Dr. Sarah Campillo**
Dr. Gaelle Chedeville
Dr. Karen Duffy
Dr. Claire Leblanc
Dr. Rosie Scuccimarri

Purpose and General Information: The goal of this study is to learn more about the activities, hobbies and sports that children and teens with arthritis like to take part in for fun. We will also be asking children and teens like you, who don't have arthritis if they'd like to take part in this study so that we can compare the 2 groups.

Procedures: If you and your parents agree to take part in this study, you will be asked to answer some questionnaires. This will take about an hour and a half. You will be asked to answer some of them on your own. For other ones, a research assistant will ask you questions.

We will ask you to wear a small machine, called an accelerometer, around your waist. It can be worn under your clothes. It will measure how active you are during the day by measuring your movements in different directions. You will need to wear it every day for 7 consecutive days and only take it off when you are sleeping, taking a bath or a shower or swimming.

Confidentiality: All of the information gathered during this study will be kept completely confidential. This also includes your parents. Therefore if you do have any questions and prefer to not discuss this with your parents, you can always ask the research assistant to help you rather than asking your parents. Your name will not appear on any of the questionnaires.

Possible Benefits: We hope that the information from this study helps us learn more about how much children and teens with arthritis participate in physical activities and what makes it easier or harder for them to take part. This will help the doctors and therapists, who want to help your brother or sister take part in physical activities.

Possible Risks: Nothing bad will happen to you or your family by taking part in this study. You may feel sad when answering the questionnaires. If you do feel sad you can talk about it with the clinic nurse.

Voluntary participation: Your mother or father is also reading information about this study. They will talk to you about it. Ask them questions if you do not understand what you have heard or read. They will help you to understand. The doctors and research staff will answer any questions that you have. If you and your parents do not want to be part of this study, that's all right. If you and your parents say yes now but change your mind, you can say no later. If you have any questions, you can call Dr. Debbie Feldman [redacted], Sabrina Cavallo [redacted] or Martine Moïse [redacted]

Assent Form (Sibling)

Determinants of Involvement in Active Physical and Other Leisure Activities in Children and Youth with Juvenile Idiopathic Arthritis

Agreement:

I have read this assent form and I understand what I have read. I understand what was explained to me and that I have been given the chance to ask questions. I understand that I don't have to take part in this study. I agree to participate in this study.

Please sign your name below if you are interested in participating in our study.

Thank you.

Name of Participant: _____

Participant's Signature: _____

Date: _____

Name of Person Who Explained Study: _____

Signature of Person Who Explained Study: _____

Date: _____

Appendix 6: Children's Assessment of Participation and Enjoyment (CAPE)

Children's Assessment of Participation and Enjoyment

Record Form

Child's name _____

Age _____ ☐ Male ☐ Female Date _____

Did the child require assistance to complete the CAPE? ☐ Yes ☐ No

Name of person who assisted the child in completing the CAPE: _____

Relationship to child: _____

Directions

1. Review each of the activities shown in the CAPE by looking at the picture and reading the description of the activity provided.
2. For each activity, ask the child if he or she has done the activity in the past four months. It may be helpful for the child to think of an activity or event that happened approximately four months ago (e.g., a birthday, holiday, spring break, start or end of the school year, or a cultural or religious event celebrated by the child's family) or to look at a calendar.
3. If the child has not done the activity in the last four months, check No and go on to the next item.
4. If the child has done the activity in the last four months, check Yes and complete the rest of the questions for that item. Circle the scores associated with the child's responses.

Always let the child answer first, before offering any assistance. Remind the child that there are no right or wrong answers to the questions.

PEARSON

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9 10 11 12 13 14 15 16 17 18 19 20 A B C D E

PsychCorp

ISBN 076160645-9

9 780761 606451

Example

Here is an example of a completed item to show the child.

1. Ask the child if he or she has brushed his or her teeth in the past four months.

2. Ask the child how often he or she brushes his or her teeth.

3. Next, ask the child with whom he or she does this activity.

   Note. If the child does an activity with two types of people, circle the type with the highest score. For example, if he or she goes to a party with siblings and friends, circle 4, With Friends. If he or she does an activity with three or more types of people, for example, does an activity with family, other relatives, and friends, circle the score of 5, With Others.

4. Next, ask the child where he or she does this activity.

   Note. If the child does the activity at school, it must be outside of regular classes, such as before or after school, at recess, or as part of a school club.

   Neighborhood and Community may need to be defined for the child based on the type of community (urban or rural) in which he or she lives.

5. Ask the child how much he or she likes doing the activity.

Brushing your teeth

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☑ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

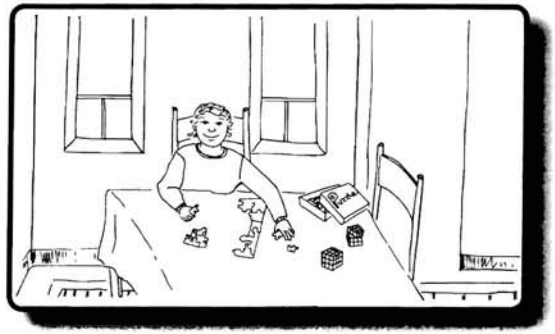
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

Items 1–5

These drawings show kids doing hobbies, crafts, or games. Think about any hobbies, crafts, or games that you have done in the past four months outside of school.

1 Doing puzzles



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2–3 times a month	1 time a week	2–3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
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5. With Others (Instructors, Other individuals, or Mutiple types of people)

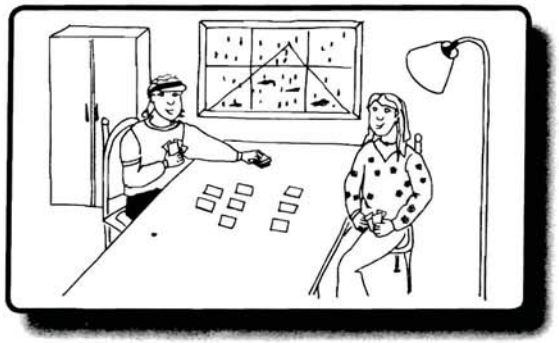
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

2 Playing board or card games



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

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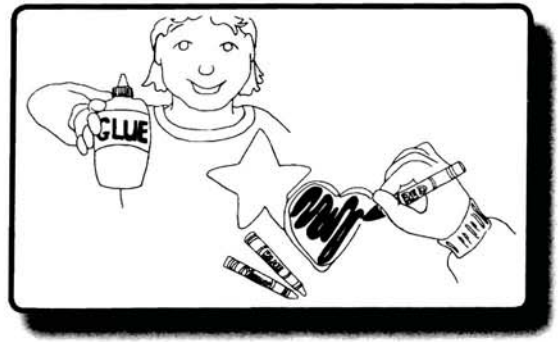
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

3 Doing crafts, drawing or coloring



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
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2. At a Relative's Home
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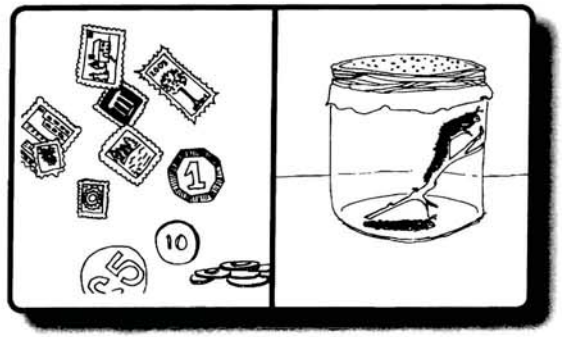
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Hobbies, Crafts, and Games (continued)

4 Collecting things



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
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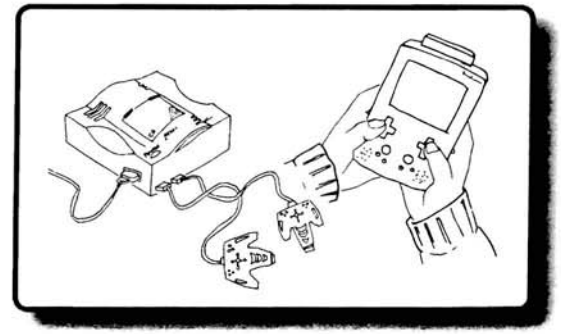
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

5 Playing computer or video games



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
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5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

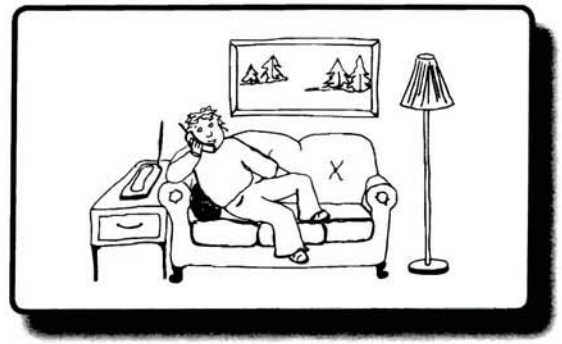
1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Social Activities

Items 6–11

The next drawings show kids doing things with other people. Think about the activities that you have done with other people in the past four months outside of school.

6 Talking on the phone



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2–3 times a month	1 time a week	2–3 times a week	1 time a day or more

With whom do you do this most often?

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Where do you do this most often?

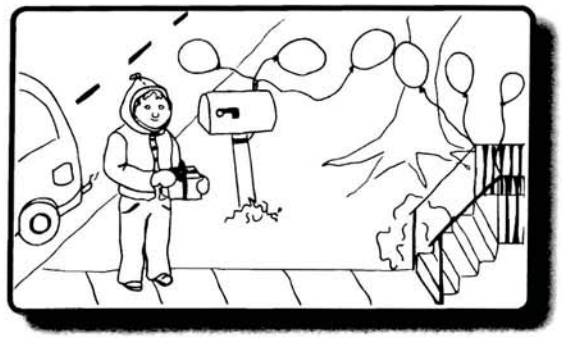
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Social Activities (continued)

7 Going to a party



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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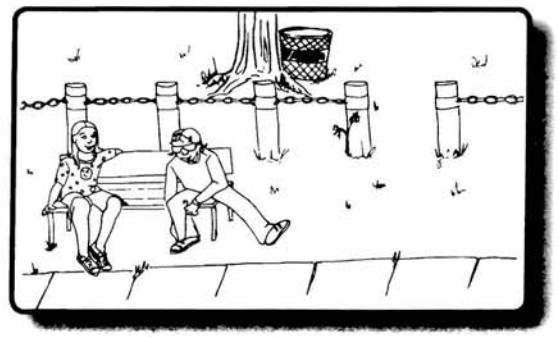
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

8 Hanging out



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
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4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

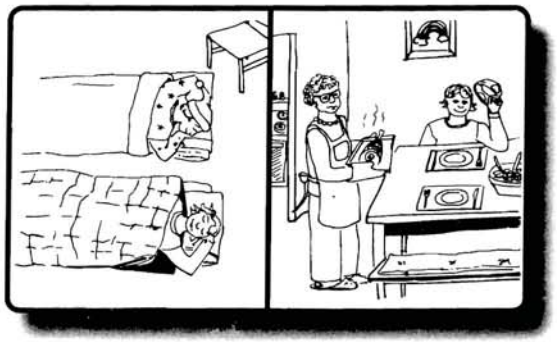
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Social Activities (continued)

9 Visiting



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

10 Writing letters

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

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2. With Family (Parents, Brothers, Sisters)
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5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

11 Entertaining others

Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

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4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

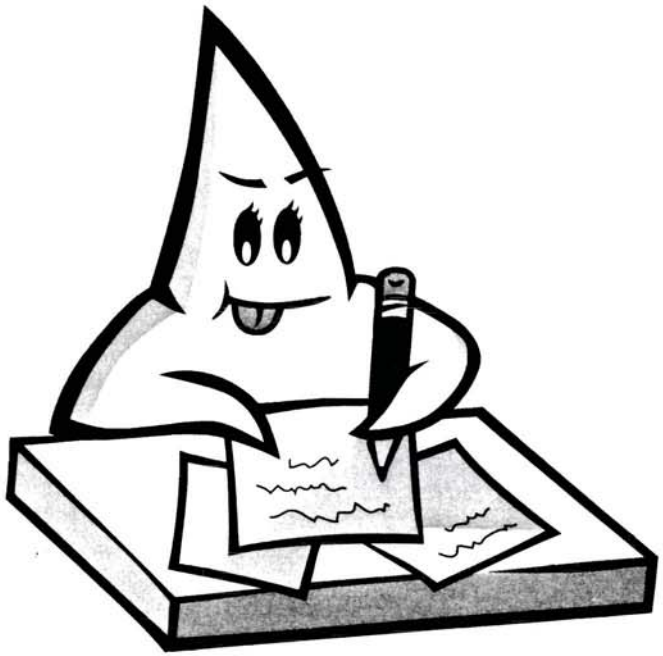
How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Quiet Recreation

Items 12–15

These drawings show kids doing quiet activities. Think about quiet activities that you have done in the past four months outside of school.



12 Playing with pets

Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2–3 times a month	1 time a week	2–3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

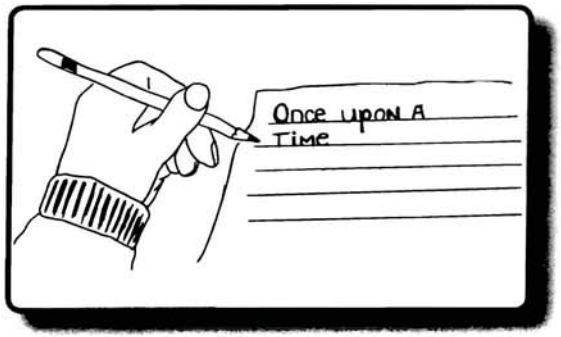
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

13 Writing a story



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1 I time in the past 4 months
2 2 times in the past 4 months
3 I time a month
4 2-3 times a month
5 I time a week
6 2-3 times a week
7 I time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
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Where do you do this most often?

1. At Home
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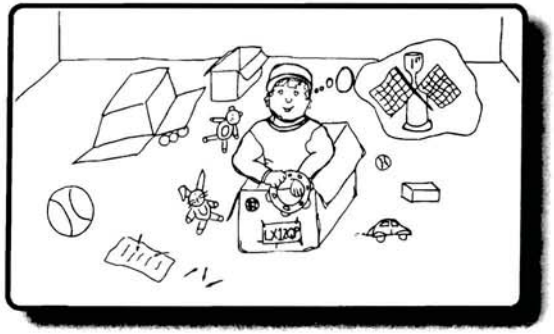
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1 Not at all
2 Somewhat; Sort of
3 Pretty much
4 Very much
5 Love it

14 Doing pretend or imaginary play



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1 I time in the past 4 months
2 2 times in the past 4 months
3 I time a month
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Where do you do this most often?

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3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1 Not at all
2 Somewhat; Sort of
3 Pretty much
4 Very much
5 Love it

15 Playing with things or toys

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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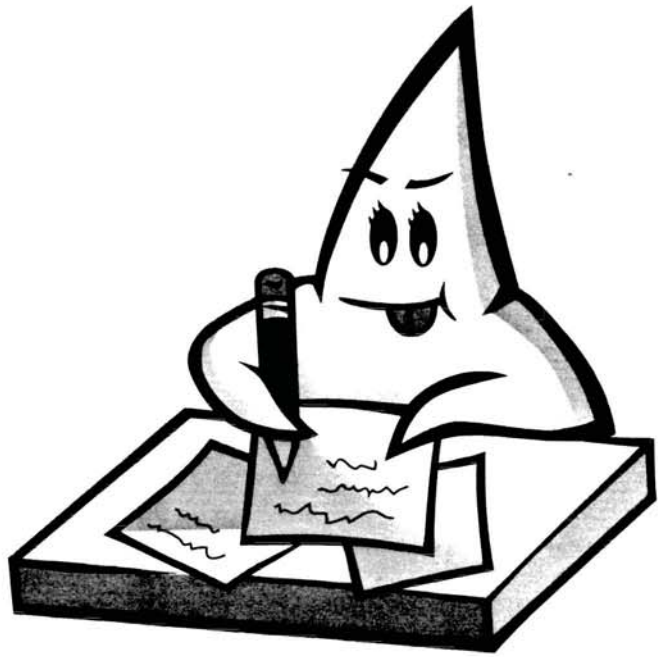
How much do you like or enjoy doing this activity?

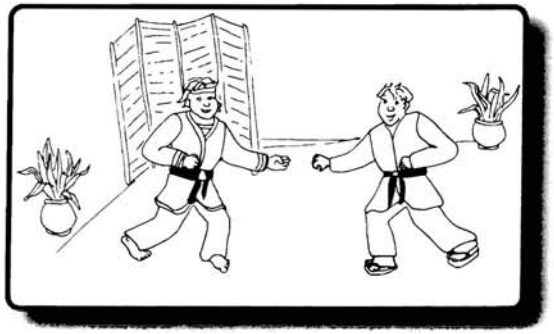
1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it



Items 16-21

In the next group of drawings, you will see kids playing different kinds of sports. The kids playing these sports are usually on sports teams and may play games against other teams. Sometimes these kids will have lessons or practices to get better at their sport. Think about any sports lessons, practices, or games that you have done in the past four months outside of school.

16 Doing martial arts



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
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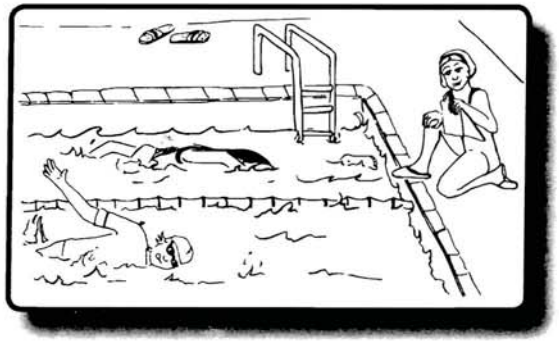
How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

17 Swimming



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
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Where do you do this most often?

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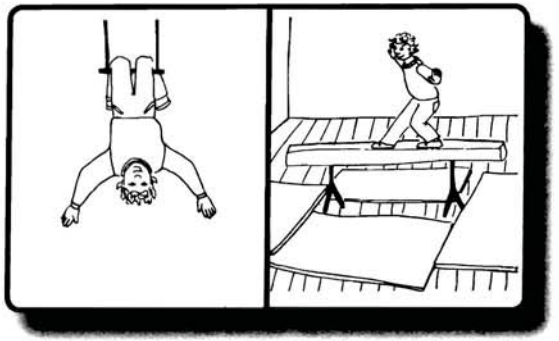
How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

18 Doing gymnastics



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

19 Horseback riding

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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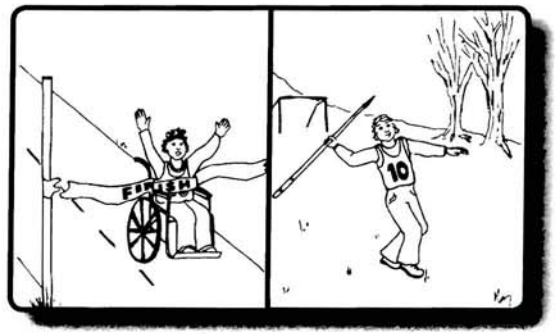
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

20 Racing or track and field



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

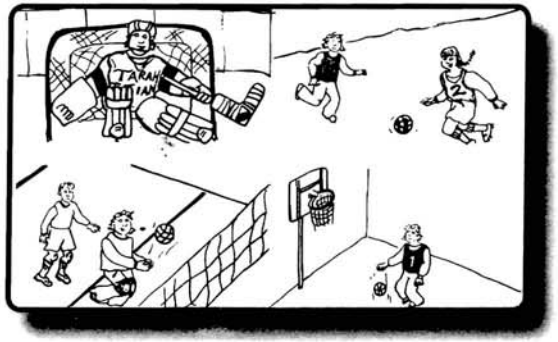
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

21 Doing team sports



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

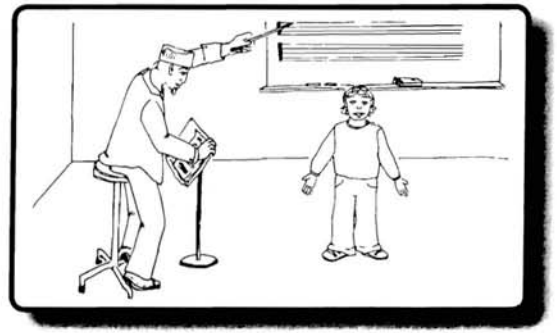
How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Items 22–27

The next group of drawings shows kids taking lessons with an instructor or a tutor. The kids in these drawings are trying to get better at a skill or learn a new skill. These activities also include practices or rehearsals as well as performances such as recitals. Think about any lessons, practices, or performances that you have done in the past four months outside of school.

22 Learning to sing (choir or individual lessons)



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2–3 times a month	1 time a week	2–3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

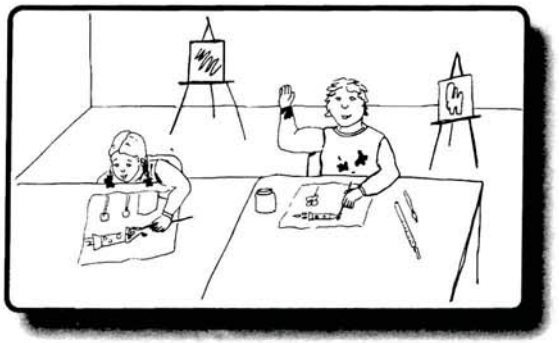
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Other Skill-Based Activities (continued)

23 Taking art lessons



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

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2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

24 Learning to dance

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Other Skill-Based Activities (continued)

25 Getting extra help for schoolwork from a tutor

Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

26 Playing a musical instrument

Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

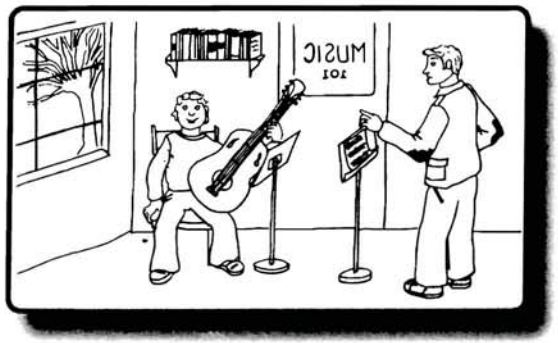
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

27 Taking music lessons



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
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4. With Friends
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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

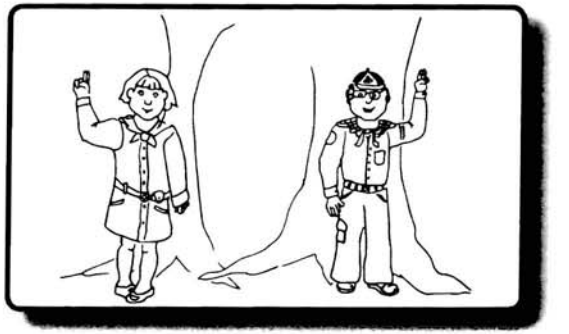
1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Clubs, Groups, and Organizations

Items 28–30

These kinds of activities include any other club or group you might be involved in other than a sports club. A club has to have a leader of some sort, and specific times that it meets. Think about any clubs or groups that you have been a part of in the past four months outside of school.

28 Participating in community organizations



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2–3 times a month	1 time a week	2–3 times a week	1 time a day or more

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4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

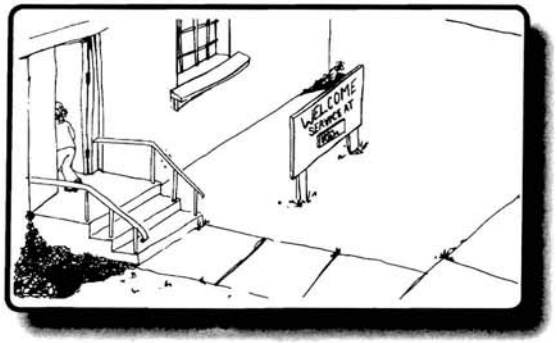
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

29 Doing a religious activity



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
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4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

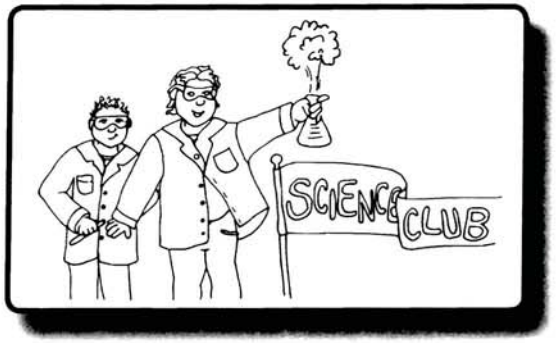
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

30 Participating in school clubs



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

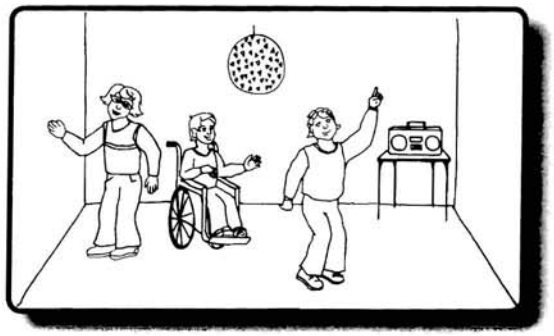
How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Items 31–41

These drawings show kids doing physical recreation activities. Some of the activities are sports that you would play, but these are not organized or team sports. Think about the physical recreation activities that you have done in the past four months outside of school.

31 Dancing



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2–3 times a month	1 time a week	2–3 times a week	1 time a day or more

With whom do you do this most often?

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4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

32 Going for a walk or a hike

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

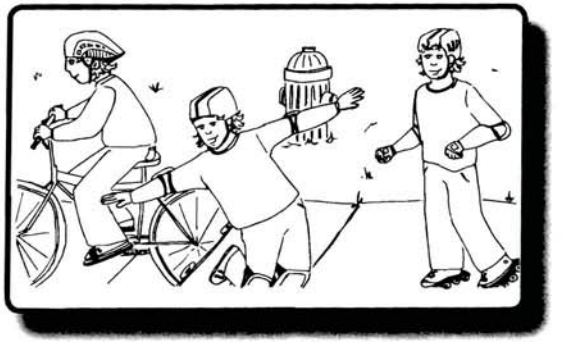
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

33 Bicycling, in-line skating, or skateboarding



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

34 Doing water sports

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

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2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

35 Doing snow sports

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

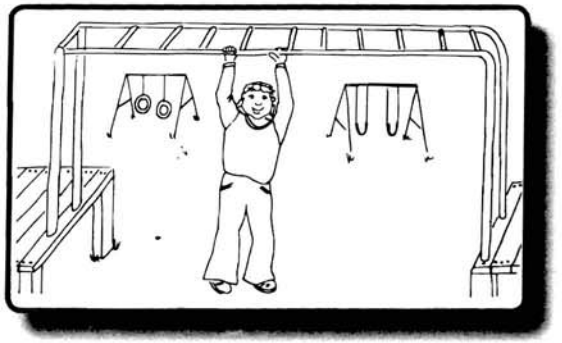
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

36 Playing on equipment



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
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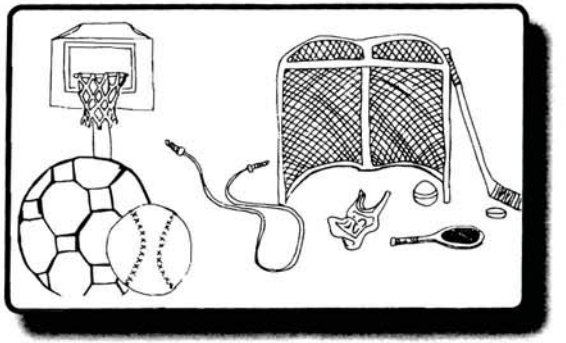
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

37 Playing games



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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1. At Home
2. At a Relative's Home
3. In Your Neighborhood
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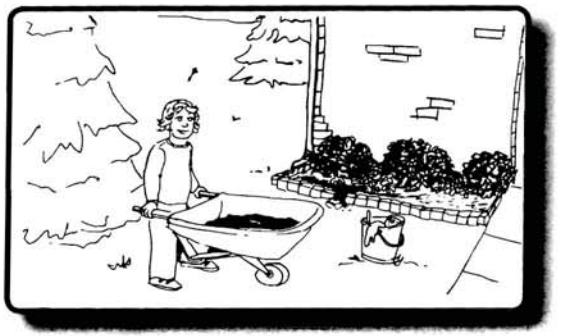
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

38 Gardening



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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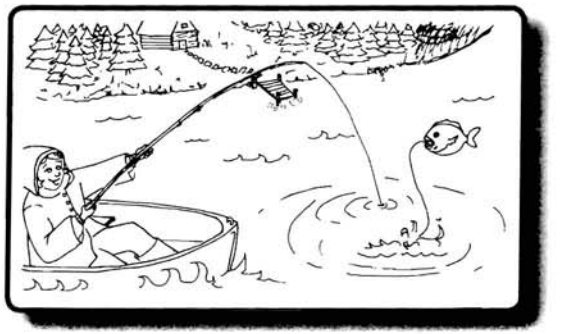
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

39 Fishing



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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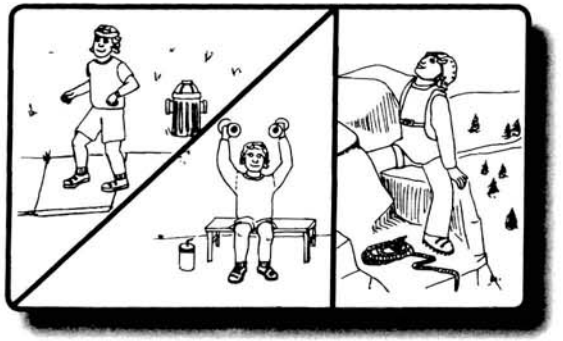
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

40 Doing individual physical activities



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

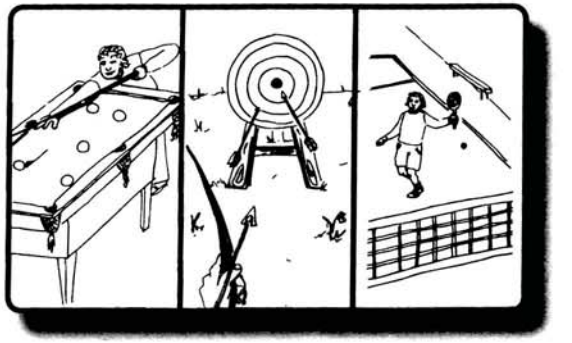
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

41 Playing non-team sports



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

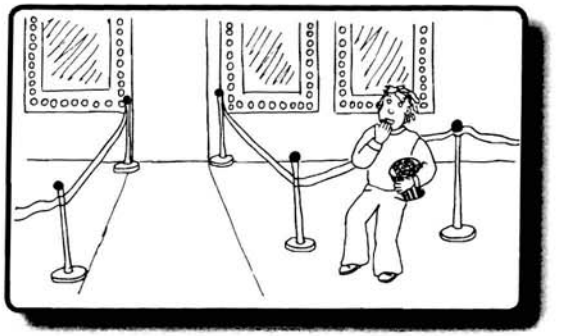
How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Items 42–48

The next group of drawings shows kids who are being entertained or learning new things. These activities do not include field trips that are taken with school. Think about activities you have done in the past four months where you were entertained or you learned something new outside of school.

42 Going to the movies



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2–3 times a month	1 time a week	2–3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

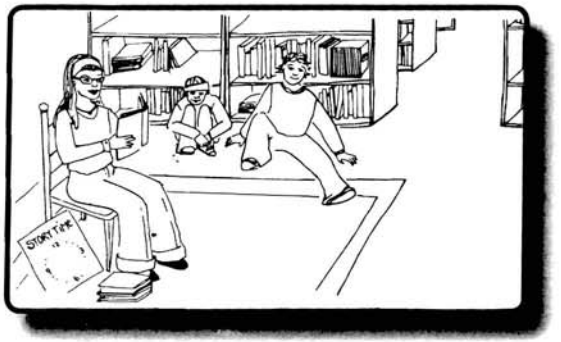
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

43 Going to the public library



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

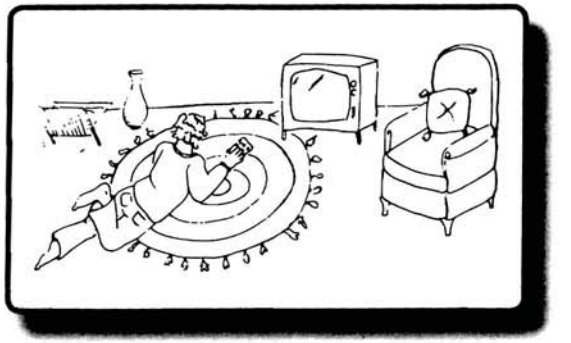
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

44 Watching TV or a rented movie



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

45 Going to a live event

Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

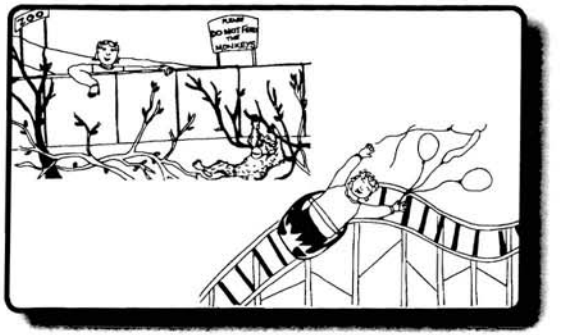
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

46 Going on a full-day outing



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

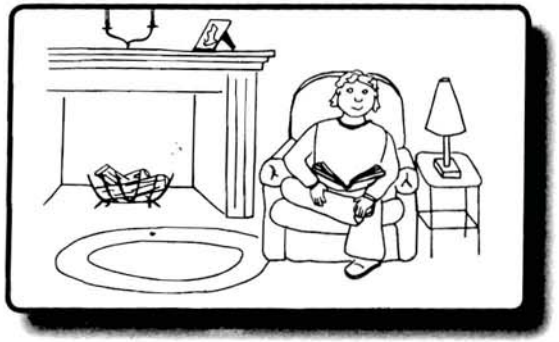
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

47 Reading



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

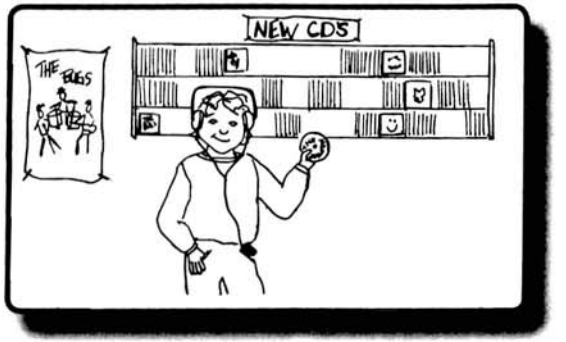
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

48 Listening to music



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Items 49–55

These activities are things kids do, like helping out at home. Think about any jobs or chores that you have done in the past four months outside of school.

49 Doing volunteer work

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2–3 times a month	1 time a week	2–3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

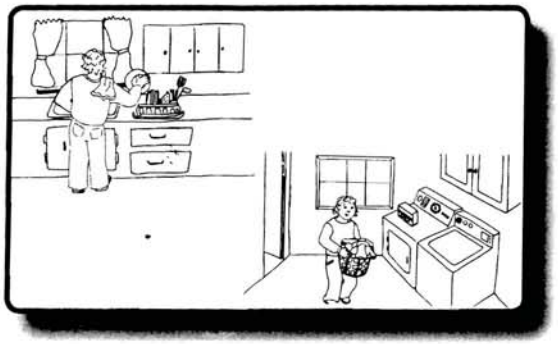
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

50 Doing a chore



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

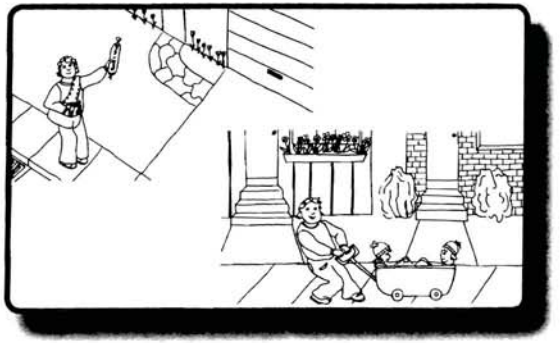
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

51 Doing a paid job



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
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5. With Others (Instructors, Other individuals, or Mutiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

52 Making food

Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

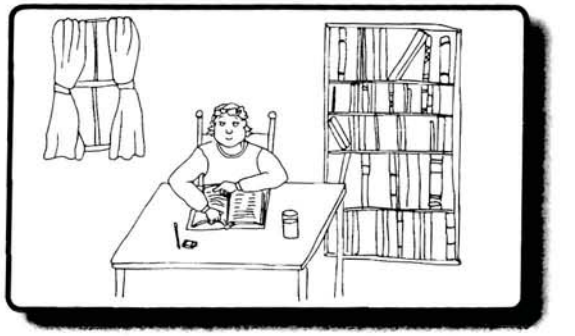
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

53 Doing homework



Have you done this activity in the past four months?

- ☐ No (go to the next item)
- ☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but **not** during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

54 Shopping

Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Mutiple types of people)

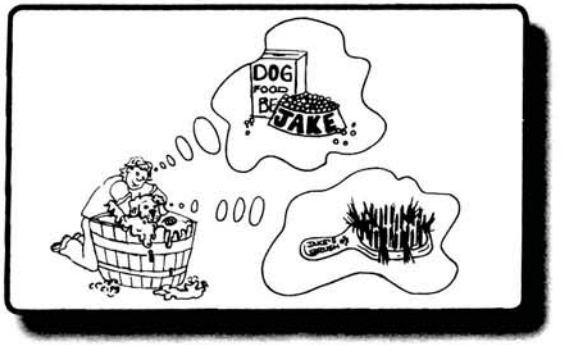
Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

55 Taking care of a pet



Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1	2	3	4	5	6	7
1 time in the past 4 months	2 times in the past 4 months	1 time a month	2-3 times a month	1 time a week	2-3 times a week	1 time a day or more

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Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much you like or enjoy doing this activity?

1	2	3	4	5
Not at all	Somewhat; Sort of	Pretty much	Very much	Love it

Other Activities

Are there any other activities outside of school that we have not talked about? This is an opportunity to add in any other activities you have done in the last four months that we have not asked you about. _____

_____

_____

Appendix 7: Dimensions of Mastery Questionnaire (DMQ)

Children's Motivation Questionnaire
(for children)

Child's Age _____ Circle one: Boy Girl Today's Date_____.
Years Months

Rater's Relationship to the Child: Mother_____ Father _____ Other (please specify) _____ .

CIRCLE the number that best indicates how typical each statement is for you Think of a rating of 3 as an average child.
Please try to answer all questions even if you are not sure.

	NOT AT ALL TYPICAL				VERY TYPICAL
1. I repeat a new problem until I can do it well.	1	2	3	4	5
2. I smile broadly after finishing something.	1	2	3	4	5
3. I give up if I cannot do physical skills well.	1	2	3	4	5
4. I solve problems quickly.	1	2	3	4	5
5. I give up easily if I cannot do something.	1	2	3	4	5
6. I am a little slow understanding things.	1	2	3	4	5
7. I like to try hard problems instead of easy ones.	1	2	3	4	5
8. I enjoy talking with adults and try to keep them interested.	1	2	3	4	5
9. If a toy or task is hard to do, I stop trying after a short time.	1	2	3	4	5
10. I am very good at doing things.	1	2	3	4	5
11. I do not smile after I make something happen.	1	2	3	4	5
12. I try to do well in physical activities even when they are hard for me.	1	2	3	4	5
13. I have some difficulty doing things as well as other children my age.	1	2	3	4	5
14. I complete my school work, even if it takes a long time to finish.	1	2	3	4	5
15. I try hard to interest adults in doing activities with me.	1	2	3	4	5
16. I like sports and try to do them very well.	1	2	3	4	5
17. I explore all ways to solve a problem with a lot of parts before doing something else.	1	2	3	4	5
18. I get excited when I figure something out.	1	2	3	4	5
19. I like to play actively with adults.	1	2	3	4	5
20. I do things that are hard for children my age.	1	2	3	4	5
21. I am pleased or get excited when I solve a hard problem.	1	2	3	4	5
22. I try hard to get adults to understand things.	1	2	3	4	5
23. I work for a long time trying to do something hard.	1	2	3	4	5

OVER PLEASE

	NOT AT ALL TYPICAL				VERY TYPICAL
24. I try to do well on cause and effect activities like video games or magic tricks.	1	2	3	4	5
25. I get very involved in pretend play with friends.	1	2	3	4	5
26. I repeat sports skills until I can do them well.	1	2	3	4	5
27. I try hard to throw balls so I can do it well.	1	2	3	4	5
28. I try hard to make friends with other kids.	1	2	3	4	5
29. I will work for a long time trying to solve a problem for school.	1	2	3	4	5
30. I like to talk with other kids and do it often.	1	2	3	4	5
31. I try to complete games like puzzles even when they are hard.	1	2	3	4	5
32. I try to get included when other children are playing.	1	2	3	4	5
33. I give up quickly when I play with adults.	1	2	3	4	5
34. I look down or away when I try but cannot do something.	1	2	3	4	5
35. I try to keep play going for a long time when playing with other kids.	1	2	3	4	5
36. I repeat skills, such as climbing or gymnastics so I can do them well.	1	2	3	4	5
37. I enjoy discussing things with adults.	1	2	3	4	5
38. I get upset when I don't do well on something.	1	2	3	4	5
39. I avoid getting involved with other children.	1	2	3	4	5
40. I try to do well at athletic games.	1	2	3	4	5
41. I smile when I make something happen	1	2	3	4	5
42. I avoid looking at others after failing at something I tried hard to do.	1	2	3	4	5
43. I get excited when I am successful.	1	2	3	4	5
44. I get upset if I cannot do something I tried hard to do.	1	2	3	4	5
45. I try hard to get better at catching things.	1	2	3	4	5

Appendix 8: Self-Perception Profile (SPP)

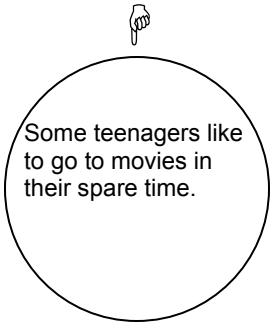
How to Answer the "What I Am Like" Harter Scale Questionnaire

We are interested in knowing what kind of person you are. This is a survey, not a test! There is no right or wrong answer. Since we are different from one another, each of us will have different answers.

Here is an example to show you how to answer the questions in this survey. Consider the following example:

Really true for me	Sort of true for me				Sort of true for me	Really true for me
☐	☐	Some teenagers like to go to movies in their spare time.	BUT	Other teenagers would rather go to sports events.	☐	☐

Step 1: Choose which of the 2 sentences you identify with most, but do NOT check off anything yet.



Really true for me	Sort of true for me				Sort of true for me	Really true for me
☐	☐	Some teenagers like to go to movies in their spare time.	BUT	Other teenagers would rather go to sports events.	☐	☐

OR

Step 2: Once you have chosen the sentence you identify with most, decide if the sentence sounds <u>a bit like you</u> OR <u>a lot like you</u>, and **check the appropriate box on the same side of that sentence.**

Really true for me	Sort of true for me				Sort of true for me	Really true for me
☑	☐	Some teenagers like to go to movies in their spare time.	BUT	Other teenagers would rather go to sports events.	☐	☐

NOTE: You can only check one box for each sentence. There should not be check marks on both sides of the question.

What I Am Like

Name _____ Age _____ Birthday _____ Group _____
Month Day

Boy or Girl (circle which)

SAMPLE SENTENCE

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
(a)	☐	☐	Some kids would rather play outdoors in their spare time	**BUT**	Other kids would rather watch T.V.	☐	☐
1.	☐	☐	Some kids feel that they are very *good* at their school work	**BUT**	Other kids *worry* about whether they can do the school work assigned to them.	☐	☐
2.	☐	☐	Some kids find it *hard* to make friends	**BUT**	Other kids find it's pretty *easy* to make friends.	☐	☐
3.	☐	☐	Some kids do very *well* at all kinds of sports	**BUT**	Other kids *don't* feel that they are very good when it comes to sports.	☐	☐
4.	☐	☐	Some kids are *happy* with the way they look	**BUT**	Other kids are *not* happy with the way they look.	☐	☐
5.	☐	☐	Some kids often do *not* like the way they *behave*	**BUT**	Other kids usually *like* the way they behave.	☐	☐
6.	☐	☐	Some kids are often *unhappy* with themselves	**BUT**	Other kids are pretty *pleased* with themselves.	☐	☐
7.	☐	☐	Some kids feel like they are *just as smart* as as other kids their age	**BUT**	Other kids aren't so sure and *wonder* if they are as smart.	☐	☐
8.	☐	☐	Some kids have *alot* of friends .	**BUT**	Other kids *don't* have very many friends.	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
9.	☐	☐	Some kids wish they could be alot better at sports	**BUT**	Other kids feel they are good enough at sports.	☐	☐
10.	☐	☐	Some kids are *happy* with their height and weight	**BUT**	Other kids wish their height or weight were *different.*	☐	☐
11.	☐	☐	Some kids usually do the *right* thing	**BUT**	Other kids often *don't* do the right thing.	☐	☐
12.	☐	☐	Some kids *don't* like the way they are leading their life	**BUT**	Other kids *do* like the way they are leading their life.	☐	☐
13.	☐	☐	Some kids are pretty *slow* in finishing their school work	**BUT**	Other kids can do their school work *quickly.*	☐	☐
14.	☐	☐	Some kids would like to have alot more friends	**BUT**	Other kids have as many friends as they want.	☐	☐
15.	☐	☐	Some kids think they could do well at just about any new sports activity they haven't tried before	**BUT**	Other kids are afraid they might *not* do well at sports they haven't ever tried.	☐	☐
16.	☐	☐	Some kids wish their body was *different*	**BUT**	Other kids *like* their body the way it is.	☐	☐
17.	☐	☐	Some kids usually *act* the way they know they are *supposed* to	**BUT**	Other kids often *don't* act the way they are supposed to.	☐	☐
18.	☐	☐	Some kids are *happy* with themselves as a person	**BUT**	Other kids are often *not* happy with themselves.	☐	☐
19.	☐	☐	Some kids often *forget* what they learn	**BUT**	Other kids can remember things *easily.*	☐	☐
20.	☐	☐	Some kids are always doing things with *alot* of kids	**BUT**	Other kids usually do things *by themselves.*	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
21.	☐	☐	Some kids feel that they are *better* than others their age at sports	**BUT**	Other kids *don't* feel they can play as well.	☐	☐
22.	☐	☐	Some kids wish their physical appearance (how they look) was *different*	**BUT**	Other kids *like* their physical appearance the way it is.	☐	☐
23.	☐	☐	Some kids usually get in *trouble* because of things they do	**BUT**	Other kids usually *don't* do things that get them in trouble.	☐	☐
24.	☐	☐	Some kids *like* the kind of *person* they are	**BUT**	Other kids often wish they were someone else.	☐	☐
25.	☐	☐	Some kids do *very well* at their classwork	**BUT**	Other kids *don't* do very well at their classwork.	☐	☐
26.	☐	☐	Some kids wish that more people their age liked them	**BUT**	Other kids feel that most people their age *do* like them.	☐	☐
27.	☐	☐	In games and sports some kids usually *watch* instead of play	**BUT**	Other kids usually *play* rather than just watch.	☐	☐
28.	☐	☐	Some kids wish something about their face or hair looked *different*	**BUT**	Other kids *like* their face and hair the way they are.	☐	☐
29.	☐	☐	Some kids do things they know they *shouldn't* do	**BUT**	Other kids *hardly ever* do things they know they shouldn't do.	☐	☐
30.	☐	☐	Some kids are very *happy* being the way they are	**BUT**	Other kids wish they were *different.*	☐	☐
31.	☐	☐	Some kids have *trouble* figuring out the answers in school	**BUT**	Other kids almost *always* can figure out the answers.	☐	☐
32.	☐	☐	Some kids are *popular* with others their age	**BUT**	Other kids are *not* very popular.	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
33.	☐	☐	Some kids *don't* do well at new outdoor games	BUT	Other kids are *good* at new games right away.	☐	☐
34.	☐	☐	Some kids think that they are good looking	BUT	Other kids think that they are not very good looking.	☐	☐
35.	☐	☐	Some kids behave themselves very well	BUT	Other kids often find it hard to behave themselves.	☐	☐
36.	☐	☐	Some kids *are* not very happy with the way they do alot of things	BUT	Other kids think the way they do things is *fine*.	☐	☐

Appendix 9: Preferences for Activities of Children (PAC)

Preferences for Activities of Children

Record Form

Child's name _____

Age _____ ☐ Male ☐ Female Date _____

Did the child require assistance to complete the PAC? ☐ Yes ☐ No

Name of person who assisted the child in completing the PAC: _____

Relationship to child: _____

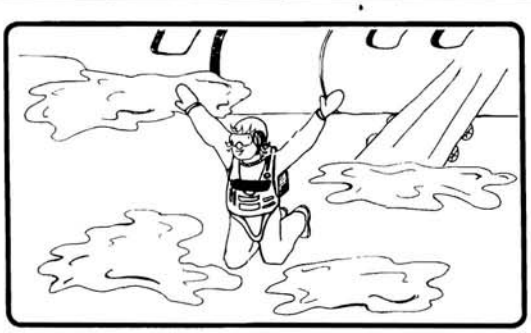
Directions

1. Review each of the activities shown in the PAC by looking at the picture and reading the description of the activity provided.
2. Ask the child if he or she could do anything in the whole world, would he or she like to do the activity in the picture. It is important that the child pretend that he or she can do anything in the world... the sky is the limit.
3. Always let the child answer first, before offering any assistance. Remind the child that there are no right or wrong answers to the questions.
4. Circle the score associated with the child's response.

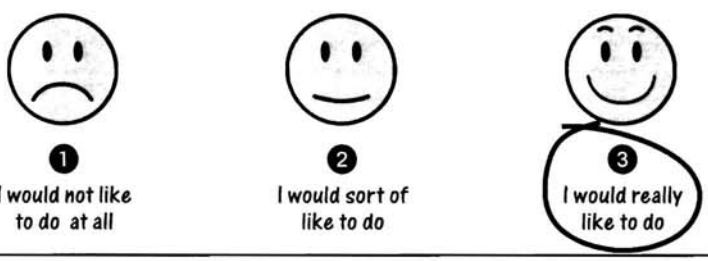
Emphasize that this is not about the activities the child currently does, but about the activities he or she would like to do.

Here is an example of a completed item to show the child.

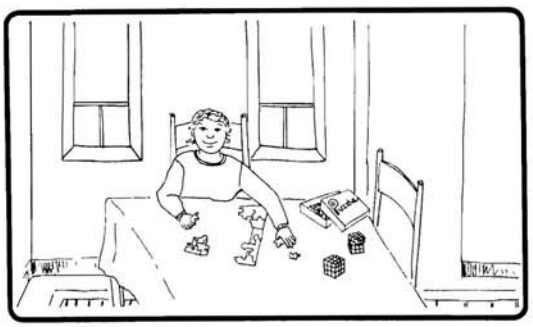
If you could do anything in the whole world, would you like to be...



...skydiving?



If you could do anything in the whole world, would you like to be...



1 ...doing puzzles?

1 I would not like to do at all

2 I would sort of like to do

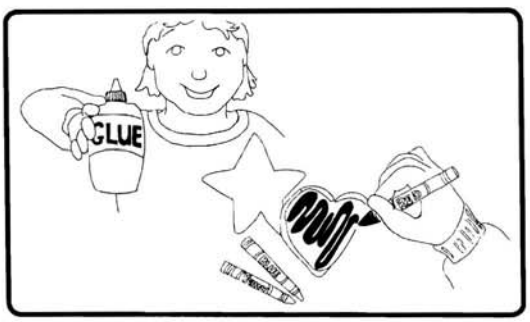
3 I would really like to do

2 ...playing board or card games?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

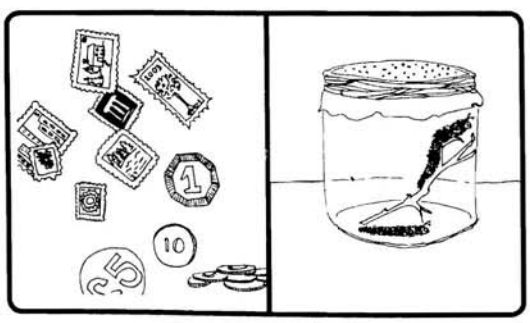


3 ...doing crafts, drawing or coloring?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

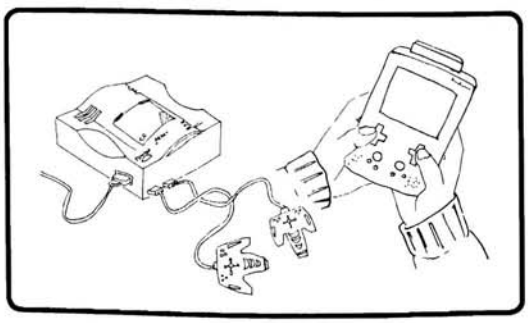


4 ...collecting things?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



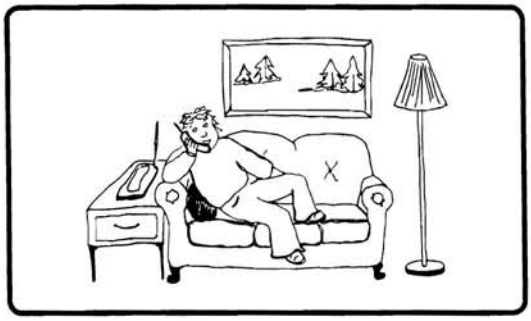
5 ...playing computer or video games?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

If you could do anything in the whole world, would you like to be...

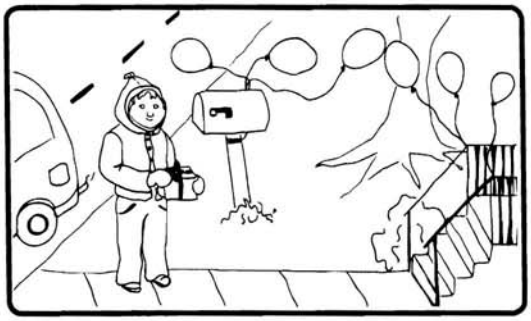


6 ...talking on the phone?

❶ I would not like to do at all

❷ I would sort of like to do

❸ I would really like to do



7 ...going to a party?

❶ I would not like to do at all

❷ I would sort of like to do

❸ I would really like to do

8 ...hanging out?

❶ I would not like to do at all

❷ I would sort of like to do

❸ I would really like to do

9 ...visiting?

❶ I would not like to do at all

❷ I would sort of like to do

❸ I would really like to do

10 ...writing letters?

❶ I would not like to do at all

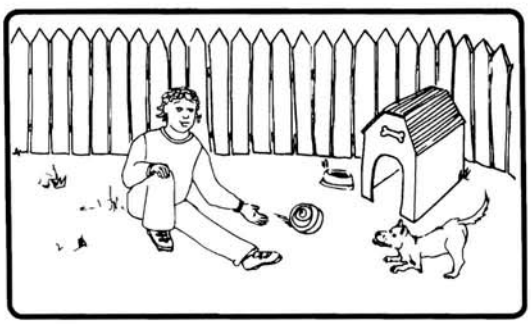
❷ I would sort of like to do

❸ I would really like to do

If you could do anything in the whole world, would you like to be...

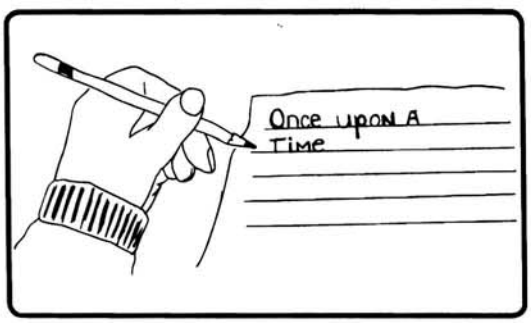
11 ...entertaining others?

☹	😐	☺
1 I would not like to do at all	2 I would sort of like to do	3 I would really like to do



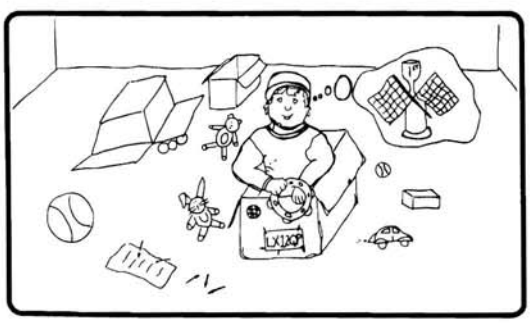
12 ...playing with pets?

☹	😐	☺
1 I would not like to do at all	2 I would sort of like to do	3 I would really like to do



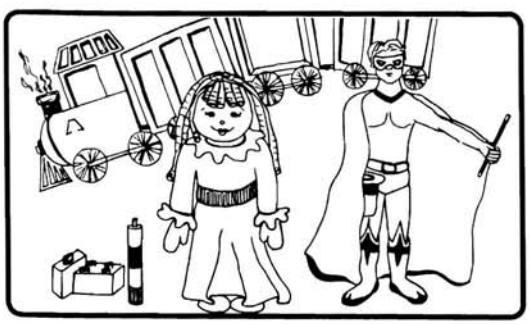
13 ...writing a story?

☹	😐	☺
1 I would not like to do at all	2 I would sort of like to do	3 I would really like to do



14 ...doing pretend or imaginary play?

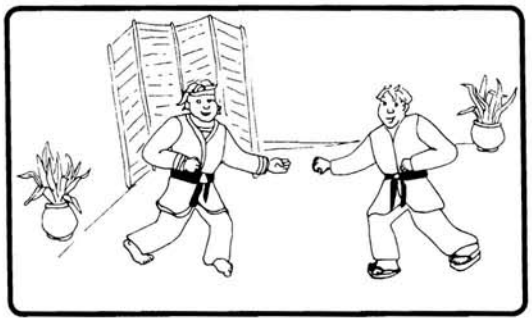
☹	😐	☺
1 I would not like to do at all	2 I would sort of like to do	3 I would really like to do



15 ...playing with things or toys?

☹	😐	☺
1 I would not like to do at all	2 I would sort of like to do	3 I would really like to do

If you could do anything in the whole world, would you like to be...

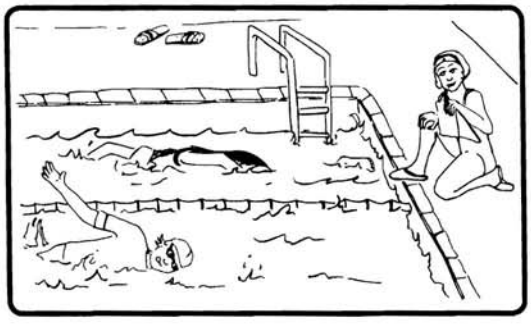


16 ...doing martial arts?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

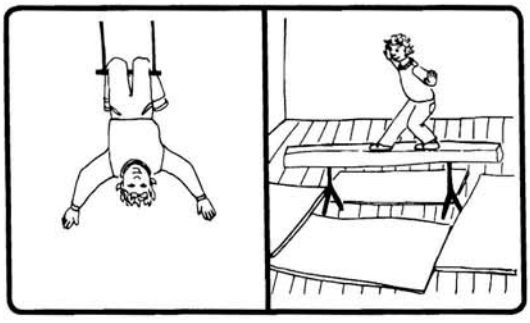


17 ...swimming?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

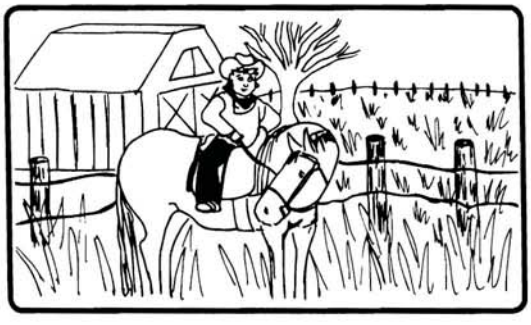


18 ...doing gymnastics?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



19 ...horseback riding?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

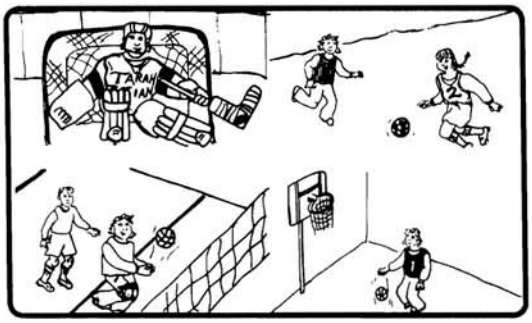
20 ...racing or track and field?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

If you could do anything in the whole world, would you like to be...

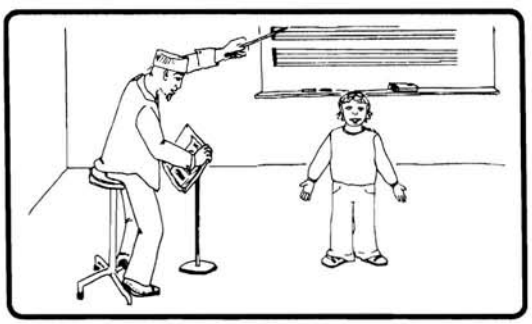


21 ...doing team sports?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

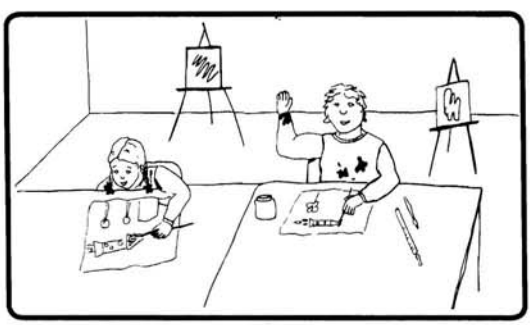


22 ...learning to sing (choir or individual lessons)?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



23 ...taking art lessons?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

24 ...learning to dance?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

25 ...getting extra help for schoolwork from a tutor?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

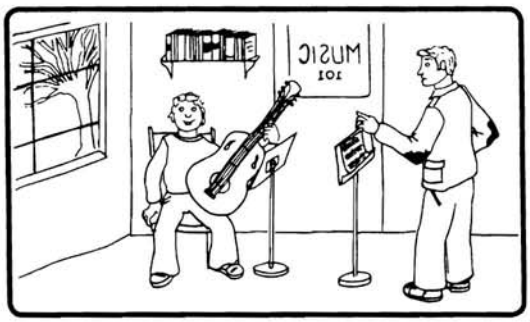
If you could do anything in the whole world, would you like to be...

26 ...playing a musical instrument?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

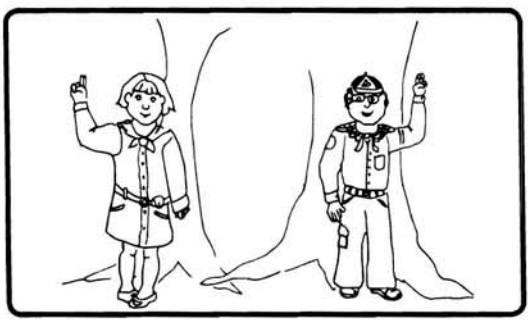


27 ...taking music lessons?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

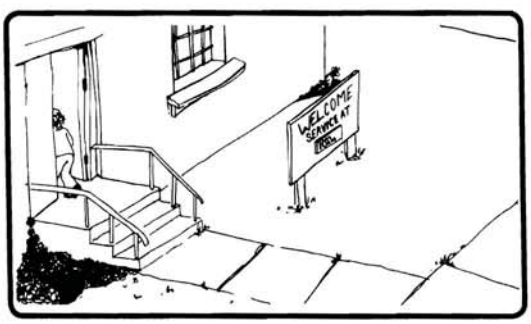


28 ...participating in community organizations?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



29 ...doing a religious activity?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

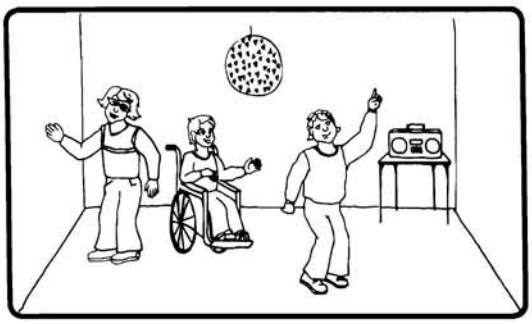
30 ...participating in school clubs?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

If you could do anything in the whole world, would you like to be...

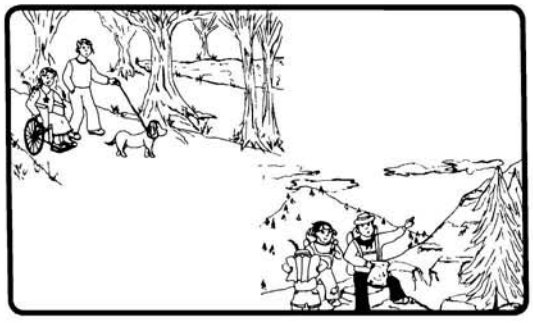


31 ...dancing?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

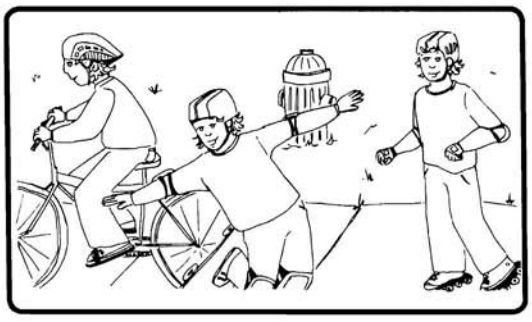


32 ...going for a walk or a hike?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

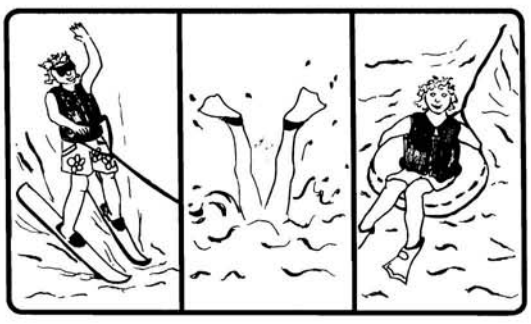


33 ...bicycling, in-line skating, or skateboarding?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

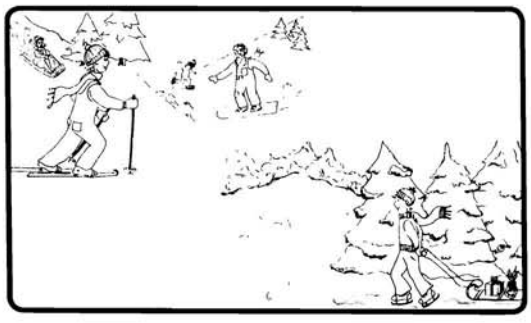


34 ...doing water sports?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



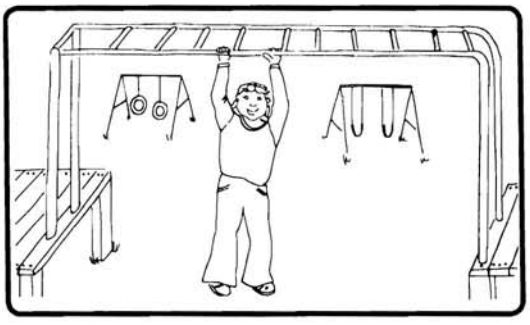
35 ...doing snow sports?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

If you could do anything in the whole world, would you like to be...

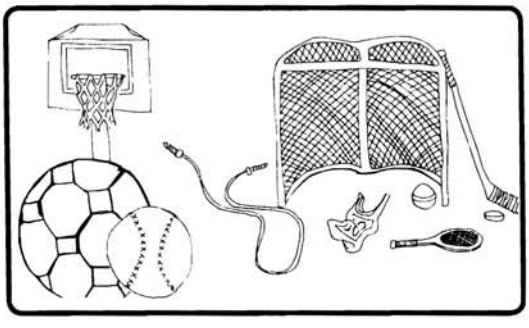


36 ...playing on equipment?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

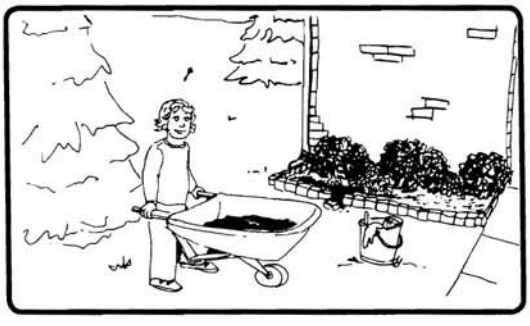


37 ...playing games?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

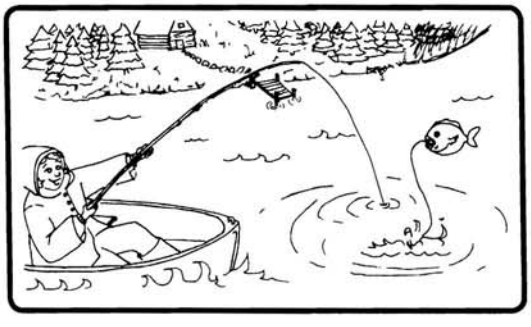


38 ...gardening?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

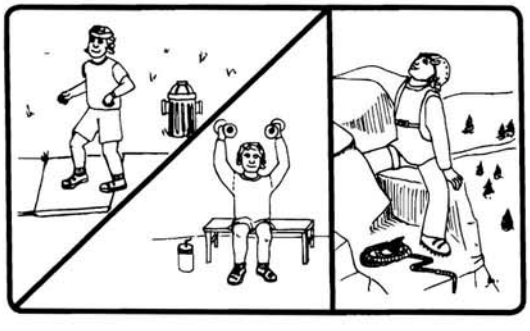


39 ...fishing?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



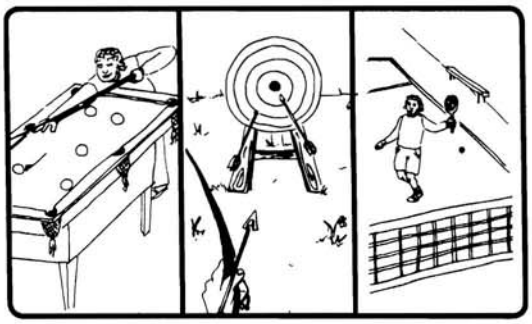
40 ...doing individual physical activities?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

If you could do anything in the whole world, would you like to be...

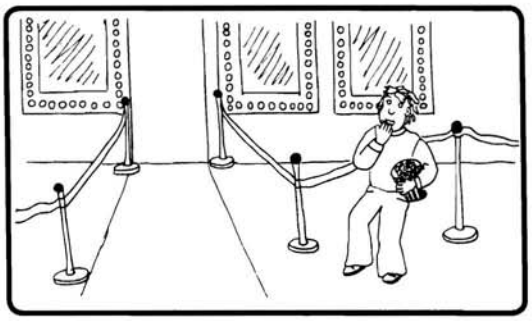


41 ...playing non-team sports?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

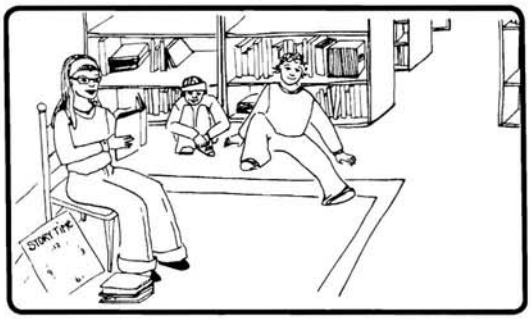


42 ...going to the movies?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

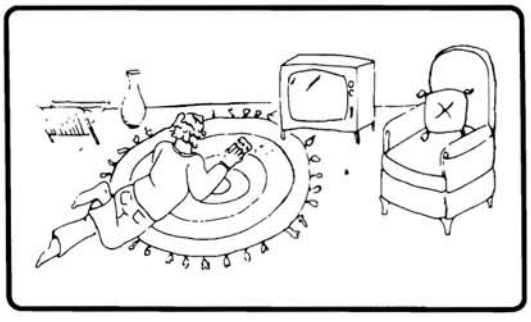


43 ...going to the public library?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



44 ...watching TV or a rented movie?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

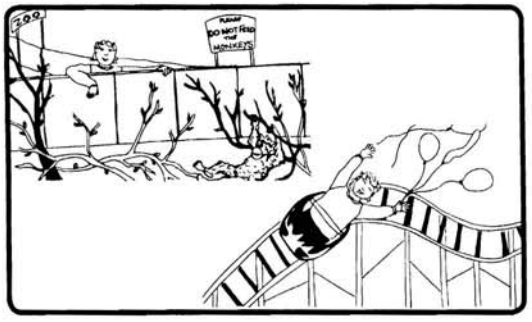
45 ...going to a live event?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

If you could do anything in the whole world, would you like to be...

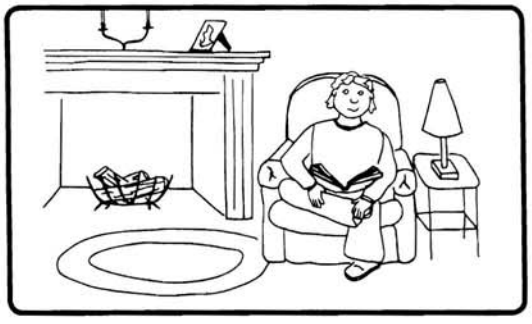


46 ...going on a full-day outing?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

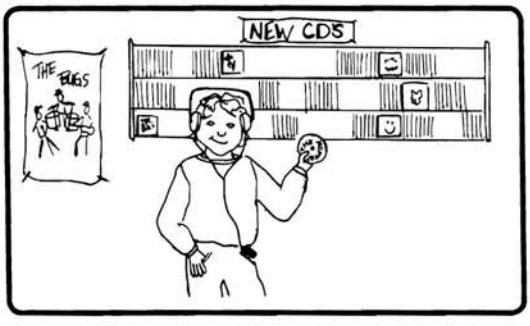


47 ...reading?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



48 ...listening to music?

1 I would not like to do at all

2 I would sort of like to do

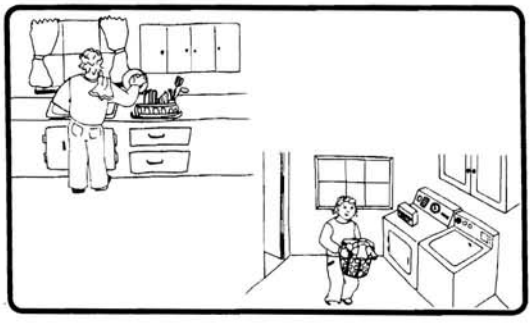
3 I would really like to do

49 ...doing volunteer work?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



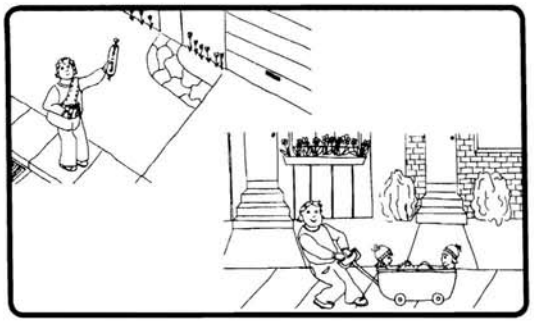
50 ...doing a chore?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

If you could do anything in the whole world, would you like to be...



51 ...doing a paid job?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

52 ...making food?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

53...doing homework?

1 I would not like to do at all

2 I would sort of like to do

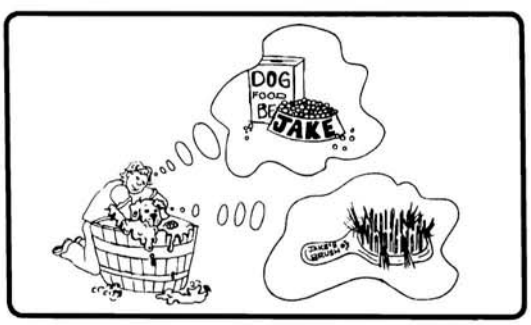
3 I would really like to do

54 ...shopping?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do



55 ...taking care of a pet?

1 I would not like to do at all

2 I would sort of like to do

3 I would really like to do

Appendix 10: Child Health Assessment Questionnaire (CHAQ)

'y Identification Number: Site Identification Number: Date:

☐☐☐☐☐ ☐☐-☐☐☐ YYYY-MM-DD

Child Health Assessment Questionnaire

In this section, we are interested in learning how your child's illness affects his/her ability to function in daily life. Please feel free to add any comments on the extra page provided at the end of this questionnaire package. In the following questions, please mark an X in the box corresponding to the one response which best describes your child's usual activities (averaged over an entire day) **OVER THE PAST WEEK. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS WHICH ARE DUE TO ILLNESS.** If most children at your child's age are not expected to do a certain activity, please mark as "Not Applicable". For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young but NOT because he/she is RESTRICTED BY ILLNESS, please mark as "Not Applicable".

	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To DO	Not Applicable
DRESSING and GROOMING					
Is your child able to: - Dress, including tying shoelaces and doing buttons?	☐	☐	☐	☐	☐
- Shampoo his/her hair?	☐	☐	☐	☐	☐
- Remove socks?	☐	☐	☐	☐	☐
- Cut fingernails?	☐	☐	☐	☐	☐
ARISING					
Is your child able to: - Stand up from a low chair or floor?	☐	☐	☐	☐	☐
- Get in and out of bed or stand up in a crib?	☐	☐	☐	☐	☐
EATING					
Is your child able to: - Cut his/her own meat?	☐	☐	☐	☐	☐
- Lift a cup or glass to mouth?	☐	☐	☐	☐	☐
- Open a new cereal box?	☐	☐	☐	☐	☐
WALKING					
Is your child able to: - Walk outdoors on flat ground?	☐	☐	☐	☐	☐
- Climb up five steps?	☐	☐	☐	☐	☐

Please mark any AIDS or DEVICES that your child usually uses for any of the above activities:

☐ Cane ☐ Walker ☐ Crutches ☐ Wheelchair ☐ Devices used for dressing (button hooks, zipper pull, long handled shoehorn, etc.)

☐ Built up or special utensils ☐ Special or built up chair ☐ Other (specify below) _____

Please mark any categories for which your child usually needs help from another person **BECAUSE OF ILLNESS**:

☐ Dressing and Grooming ☐ Arising ☐ Eating ☐ Walking

Child Health Assessment Questionnaire - continued

	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To DO	Not Applicable
HYGIENE					
Is your child able to: - Wash and dry entire body?	☐	☐	☐	☐	☐
- Take a tub bath (get in and out of tub)?	☐	☐	☐	☐	☐
- Get on and off toilet or potty chair?	☐	☐	☐	☐	☐
- Brush teeth?	☐	☐	☐	☐	☐
- Comb/brush hair?	☐	☐	☐	☐	☐
REACH					
Is your child able to: - Reach and get down a heavy object such as a large game or book from just above his/her head?	☐	☐	☐	☐	☐
- Bend down to pick up clothing or a piece of paper from the floor	☐	☐	☐	☐	☐
- Pull on a sweater over his/her head?	☐	☐	☐	☐	☐
- Turn neck to look back over shoulder?	☐	☐	☐	☐	☐
GRIP					
Is your child able to: - Write or scribble with pen or pencil?	☐	☐	☐	☐	☐
- Open car doors?	☐	☐	☐	☐	☐
- Open jars which have been previously opened?	☐	☐	☐	☐	☐
- Turn faucets on and off?	☐	☐	☐	☐	☐
- Push open a door when he/she has to turn a door knob?	☐	☐	☐	☐	☐
ACTIVITIES					
Is your child able to: - Run errands and shop?	☐	☐	☐	☐	☐
- Get in and out of car or toy car or school bus?	☐	☐	☐	☐	☐
- Ride bicycle or tricycle?	☐	☐	☐	☐	☐
- Do household chores (for example, wash dishes, take out trash, vacuuming, yardwork, make bed, clean room)?	☐	☐	☐	☐	☐
- Run and play?	☐	☐	☐	☐	☐

Child Health Assessment Questionnaire - continued

Please mark any AIDS or DEVICES that your child usually uses for any of the above activities (page 3):

- ☐ Raised toilet seat
- ☐ Bathtub seat
- ☐ Jar opener (for jars previously opened)
- ☐ Bathtub bar
- ☐ Longhandled appliance for reach
- ☐ Longhandled appliance for bathroom

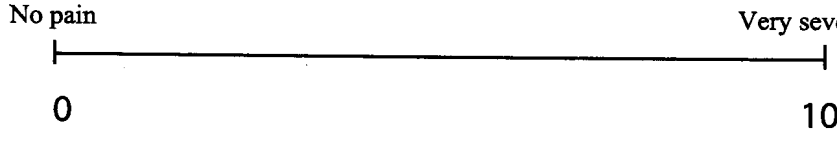
Please mark any categories for which your child usually needs help from another person **BECAUSE OF ILLNESS**:

- ☐ Hygiene
- ☐ Reach
- ☐ Gripping and opening things
- ☐ Errands and chores

We are also interested in learning whether or not your child has been affected by pain because of his or her illness.

How much pain do you think your child has had because of his or her illness IN THE PAST WEEK?

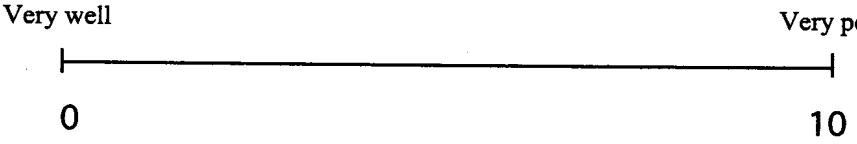
Place a mark on the line below to indicate the severity of the pain.



☐☐☐ **cm**

HEALTH STATUS

1. Considering all the ways that arthritis affects your child, rate how your child is doing on the following scale by placing a mark on the line.



☐☐☐ **cm**

2. Is your child stiff in the morning? ☐ Yes ☐ No

   If YES, about how long does the stiffness usually last (in the past week)? ☐☐ ☐ Hours ☐ Minutes

Date: Y Y Y Y M M D D

Completed by: ☐ Parent/Guardian ☐ Patient

Appendix 11: Social Support Scale for Children and Adolescents (SSS)

SSS

How to Answer the "People in My Life" Harter Scale Questionnaire

We are interested in several kinds of people in your life. This is a survey, not a test! There is no right or wrong answer. Since we are different from one another, each of us will have different answers.

Here is an example to show you how to answer the questions in this survey. Consider the following example:

Really true for me	Sort of true for me				Sort of true for me	Really true for me
☐	☐	Some kids like to do fun things with a lot of other people.	BUT	Other kids like to do fun things with just a few people.	☐	☐

Step 1: Choose which of the 2 sentences you identify with most, but do NOT check off anything yet.

OR

Really true for me	Sort of true for me				Sort of true for me	Really true for me
☐	☐	Some kids like to do fun things with a lot of other people.	BUT	Other kids like to do fun things with just a few people.	☐	☐

Step 2: Once you have chosen the sentence you identify with most, decide if the sentence sounds <u>a bit like you</u> OR <u>a lot like you</u>, and **check the appropriate box on the same side of that sentence.**

Really true for me	Sort of true for me				Sort of true for me	Really true for me
☑	☐	Some kids like to do fun things with a lot of other people.	BUT	Other kids like to do fun things with just a few people.	☐	☐

NOTE: You can only check one box for each sentence. There should not be check marks on both sides of the question.

PEOPLE IN MY LIFE

Name _____ _____
(First) (Last)

	Really True for Me	Sort of True for Me	Sample Item			Sort of True for Me	Really True for Me
	☐	☐	Some kids like to do fun things with a lot of other people	BUT	Other kids like to do fun things with just a few people.	☐	☐
1.	☐	☐	Some kids have parents who *don't* really *understand* them	BUT	Other kids have parents who really *do* understand them.	☐	☐
2.	☐	☐	Some kids have classmates who like them the way they are	BUT	Other kids have classmates who wish they were *different*.	☐	☐
3.	☐	☐	Some kids have a teacher who *helps* them if they are *upset* and have a problem	BUT	Other kids *don't* have a teacher who helps them if they are upset and have a problem.	☐	☐
4.	☐	☐	Some kids have a close friend who they can tell *problems* to	BUT	Other kids *don't* have a close friend who they can tell problems to.	☐	☐
5.	☐	☐	Some kids have parents who *don't* seem to want to hear about their children's problems	BUT	Other kids have parents who *do* want to *listen* to their children's problems.	☐	☐
6.	☐	☐	Some kids have classmates that they can become friends with	BUT	Other kids *don't* have classmates that they can become friends with.	☐	☐
7.	☐	☐	Some kids *don't* have a teacher who *helps* them *to do* their very best	BUT	Other kids *do* have a teacher who *helps* them to do their very best.	☐	☐
8.	☐	☐	Some kids have a close friend who really understands them	BUT	Other kids *don't* have a close friend who understands them.	☐	☐
9.	☐	☐	Some kids have parents who *care* about their feelings	BUT	Other kids have parents who *don't* seem to care very much about their children's feelings.	☐	☐
10.	☐	☐	Some kids have classmates who sometimes make fun of them	BUT	Other kids *don't* have classmates who make fun of them.	☐	☐
11.	☐	☐	Some kids *do* have a teacher who *cares* about them	BUT	Other kids *don't* have a teacher who cares about them.	☐	☐

(OVER)

	Really True for Me	Sort of True for Me			Other kids	Sort of True for Me	Really True for Me
12.	☐	☐	Some kids have a close friend who they can talk to about things that bother them	BUT	Other kids *don't* have a close friend who they can talk to about things that bother them.	☐	☐
13.	☐	☐	Some kids have parents who treat their children like a *person* who really matters	BUT	Other kids have parents who *don't* usually treat their children like a person who matters.	☐	☐
14.	☐	☐	Some kids have class-mates who pay attention to what they say	BUT	Other kids have class-mates who usually don't pay attention to what they say.	☐	☐
15.	☐	☐	Some kids *don't* have a teacher who is *fair* to them	BUT	Other kids *do* have a teacher who is fair to them.	☐	☐
16.	☐	☐	Some kids *don't* have a close friend who they like to spend time with	BUT	Other kids *do* have a close friend who they like to spend time with.	☐	☐
17.	☐	☐	Some kids have parents who like them the *way they are*	BUT	Other kids have parents who wish their children were *different*.	☐	☐
18.	☐	☐	Some kids *don't* get asked to play in games with classmates very often	BUT	Other kids *often* get asked to play in games by their classmates.	☐	☐
19.	☐	☐	Some kids *don't* have a teacher who cares if they feel bad	BUT	Other kids *do* have a teacher who cares if they feel bad.	☐	☐
20.	☐	☐	Some kids *don't* have a close friend who really *listens* to what they say	BUT	Other kids *do* have a close friend who really listens to what they say.	☐	☐
21.	☐	☐	Some kids have parents who *don't* act like what their children do is *important*	BUT	Other kids have parents who *do* act like what their children do is important.	☐	☐
22.	☐	☐	Some kids often spend recess being *alone*	BUT	Other kids spend recess playing with their class-mates.	☐	☐
23.	☐	☐	Some kids have a teacher who treats them like a *person*	BUT	Other kids *don't* have a teacher who treats them like a person.	☐	☐
24.	☐	☐	Some kids *don't* have a close friend who cares about their feelings	BUT	Other kids *do* have a close friend who cares about their feelings.	☐	☐

Appendix 12: Family Environment Scale (FES)

Family Environment Scale

Rudolph H. Moos, Ph.D.

Los Altos Hills, California, U.S.A.

[redacted]

There are 90 statements in this booklet. They are statements about families. You are to decide which of these statements are true of your family and which are false. Make all your marks on the separate answer sheet.

If you think the statement is *true* or mostly *true* of your family, make an X in the box labeled *True*.

If you think the statement is *false* or mostly *false* of your family, make an X in the box labeled *False*.

Please be sure to answer every statement.

1. Family members really help and support one another.	☐ True	☐ False
2. Family members often keep their feelings to themselves.	☐ True	☐ False
3. We fight a lot in our family.	☐ True	☐ False
4. We don't do things on our own very often in our family.	☐ True	☐ False
5. We feel it is important to be the best at whatever you do.	☐ True	☐ False
6. We often talk about political and social problems.	☐ True	☐ False
7. We spend most weekends and evenings at home.	☐ True	☐ False
8. Family members attend church, synagogue, or Sunday School fairly often.	☐ True	☐ False
9. Activities in our family are pretty carefully planned.	☐ True	☐ False
10. Family members are rarely ordered around.	☐ True	☐ False
11. We often seem to be killing time at home.	☐ True	☐ False
12. We say anything we want to around home.	☐ True	☐ False
13. Family members rarely become openly angry.	☐ True	☐ False
14. In our family, we are strongly encouraged to be independent.	☐ True	☐ False
15. Getting ahead in life is very important in our family.	☐ True	☐ False
16. We rarely go to lectures, plays or concerts.	☐ True	☐ False
17. Friends often come over for dinner or to visit.	☐ True	☐ False
18. We don't say prayers in our family.	☐ True	☐ False
19. We are generally very neat and orderly.	☐ True	☐ False
20. There are very few rules to follow in our family.	☐ True	☐ False
21. We put a lot of energy into what we do at home.	☐ True	☐ False
22. It's hard to "blow off steam" at home without upsetting somebody.	☐ True	☐ False
23. Family members sometimes get so angry they throw things.	☐ True	☐ False
24. We think things out for ourselves in our family.	☐ True	☐ False
25. How much money a person makes is not very important to us.	☐ True	☐ False
26. Learning about new and different things is very important in our family.	☐ True	☐ False
27. Nobody in our family is active in sports, Little League, bowling, etc.	☐ True	☐ False
28. We often talk about the religious meaning of Christmas, Passover, or other holidays.	☐ True	☐ False
29. It's often hard to find things when you need them in our household.	☐ True	☐ False
30. There is one family member who makes most of the decisions.	☐ True	☐ False
31. There is a feeling of togetherness in our family.	☐ True	☐ False
32. We tell each other about our personal problems.	☐ True	☐ False
33. Family member hardly ever lose their tempers.	☐ True	☐ False

34. We come and go as we want to in our family.	☐ True ☐ False
35. We believe in competition and "may the best man win."	☐ True ☐ False
36. We are not that interested in cultural activities.	☐ True ☐ False
37. We often go to the movies, sports events, camping, etc.	☐ True ☐ False
38. We don't believe in heaven or hell.	☐ True ☐ False
39. Being on time is very important in our family.	☐ True ☐ False
40. There are set ways of doing things at home.	☐ True ☐ False
41. We rarely volunteer when something has to be done at home.	☐ True ☐ False
42. If we feel like doing something on the spur of the moment we often just pick up and go.	☐ True ☐ False
43. Family members often criticize each other.	☐ True ☐ False
44. There is very little privacy in our family.	☐ True ☐ False
45. We always strive to do things just a little better the next time.	☐ True ☐ False
46. We rarely have intellectual discussions.	☐ True ☐ False
47. Everyone in our family has a hobby or two.	☐ True ☐ False
48. Family members have strict ideas about what is right and wrong.	☐ True ☐ False
49. People change their minds often in our family.	☐ True ☐ False
50. There is a strong emphasis on following rules in our family.	☐ True ☐ False
51. Family members really back each other up.	☐ True ☐ False
52. Someone usually gets upset if you complain in our family.	☐ True ☐ False
53. Family members sometimes hit each other.	☐ True ☐ False
54. Family members almost always rely on themselves when a problem comes up.	☐ True ☐ False
55. Family members rarely worry about job promotions, school grades, etc.	☐ True ☐ False
56. Someone in our family plays a musical instrument.	☐ True ☐ False
57. Family members are not very involved in recreational activities outside work or school.	☐ True ☐ False
58. We believe there are some things you just have to take on faith.	☐ True ☐ False
59. Family members make sure their rooms are neat.	☐ True ☐ False
60. Everyone has an equal say in family decisions.	☐ True ☐ False
61. There is very little group spirit in our family.	☐ True ☐ False
62. Money and paying bills is openly talked about in our family.	☐ True ☐ False
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.	☐ True ☐ False
64. Family members strongly encourage each other to stand up for their rights.	☐ True ☐ False
65. In our family, we don't try that hard to succeed.	☐ True ☐ False
66. Family members often go to the library.	☐ True ☐ False
67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school).	☐ True ☐ False
68. In our family each person has different ideas about what is right and wrong.	☐ True ☐ False
69. Each person's duties are clearly defined in our family.	☐ True ☐ False
70. We can do whatever we want to in our family.	☐ True ☐ False
71. We really get along well with each other.	☐ True ☐ False
72. We are usually careful about what we say to each other.	☐ True ☐ False
73. Family members often try to one-up or outdo each other.	☐ True ☐ False

74. It's hard to be by yourself without hurting someone's feelings in our household.	☐ True ☐ False
75. "Work before play" is the rule in our family	☐ True ☐ False
76. Watching TV is more important than reading in our family.	☐ True ☐ False
77. Family members go out a lot.	☐ True ☐ False
78. The Bible is a very important book in our home.	☐ True ☐ False
79. Money is not handled very carefully in our family.	☐ True ☐ False
80. Rules are pretty inflexible in our household.	☐ True ☐ False
81. There is plenty of time and attention for everyone in our family.	☐ True ☐ False
82. There are a lot of spontaneous discussions in our family.	☐ True ☐ False
83. In our family, we believe you don't ever get anywhere by raising your voice.	☐ True ☐ False
84. We are not really encouraged to speak up for ourselves in our family.	☐ True ☐ False
85. Family members are often compared with others as to how well they are doing at work or school.	☐ True ☐ False
86. Family members really like music, art and literature..	☐ True ☐ False
87. Our main form of entertainment is watching TV or listening to the radio.	☐ True ☐ False
88. Family members believe that if you sin you will be punished.	☐ True ☐ False
89. Dishes are usually done immediately after eating.	☐ True ☐ False
90. You can't get away with much in our family.	☐ True ☐ False

Appendix 13: Child and Adolescent Scale of Environment (CASE)

Child's name _____

Child & Adolescent Scale of Environment (CASE)

- Instructions -

1. This scale asks questions about physical or social aspects of the home and community environment with which your child may experience problems OR that are supportive or helpful to your child.

2. There are no right or wrong answers. You will have to choose, and in some cases write, the answer that best describes the impact that each aspect of the environment has on your child. If you are not sure about how to answer a question, give your best guess.

Thank you

Your name _____

Your relationship to child _____

Date you completed survey_____

(Month / Day / Year)

A. The following is a list of possible problems your child may be experiencing with the physical or social aspects of the home and other places in the community OR with the quality or availability of services or assistance that he or she needs. Please put an X in the box under the appropriate column next to each problem listed below.

Possible Problem:	No Problem	Little Problem	Big Problem	Not Applicable
1. Problem with design and layout of **home** (*Hard to get to places and things, or hard to see or hear important information*)	☐	☐	☐	☐
2. Problem with design and layout of buildings and places your child uses in the **community or neighborhood**	☐	☐	☐	☐
3. Problem with design and layout of **school or work setting** (*Circle school or work*)	☐	☐	☐	☐
4. Lack of support and encouragement for your child in the **community or neighborhood**	☐	☐	☐	☐
5. Lack of support and encouragement for your child at **school or work** (*Circle school or work*)	☐	☐	☐	☐
6. Problems with people's attitudes toward your child at **school or work** (*Circle school or work*)	☐	☐	☐	☐
7. Problems with people's attitudes toward your child in the **community or neighborhood**	☐	☐	☐	☐
8. Inadequate or lack of assistive devices or equipment	☐	☐	☐	☐
9. Inadequate or lack of assistance from people at **home** or in the **community or neighborhood**	☐	☐	☐	☐
10. Inadequate or lack of assistance from people at **school or work** (*Circle school or work*)	☐	☐	☐	☐
11. Inadequate or lack of transportation	☐	☐	☐	☐
12. Inadequate or lack of programs and services at **school**	☐	☐	☐	☐
13. Inadequate or lack of programs and services in the **community or neighborhood**	☐	☐	☐	☐
14. Inadequate or lack of family finances	☐	☐	☐	☐
15. Family stress	☐	☐	☐	☐
16. Crime or violence in the **community or neighborhood**	☐	☐	☐	☐

Possible Problem (Continued):	No Problem	Little Problem	Big Problem	Not Applicable
17. Problems with government agencies and policies	☐	☐	☐	☐
18. Inadequate or lack of information about your child's diagnosis or condition or intervention approaches (e.g., educational, rehabilitation or medical)	☐	☐	☐	☐

- **Other problems or comments (*please specify* →):**

B. Please identify the physical or social aspects of the environment or qualities about the services that your child receives that are supportive or helpful to your child: