

Participation in Leisure Activities by Children and Adolescents with Juvenile Idiopathic Arthritis

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ABSTRACT. Objective. To describe leisure activities of children and adolescents with juvenile idiopathic arthritis (JIA) in terms of diversity, intensity, and enjoyment, and to identify potential determinants.

Methods. One hundred 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, which measures involvement in leisure (recreation, active physical, social, skill-based, self-improvement). Disease characteristics and sociodemographic 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 ($p = 0.016$) and less intense ($p = 0.011$) participation in active physical activities, and less frequent involvement in informal activities ($p = 0.043$) compared with 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. (J Rheumatol First Release June 15 2015; doi:10.3899/jrheum.140844)

Key Indexing Terms:

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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 cure¹. 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}. Cardio-respiratory fitness, muscle strength, and participation in leisure physical activity may be limited in children with JIA in comparison with their healthy peers^{4,5,6,7,8,9,10}. 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 contacts¹¹.

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 childhood¹³. Engaging in leisure activities offers the child and teenager ample opportunity to take part in challenging and focus-oriented activities, as well as to acquire cognitive and social skills important for development^{14,15} that can contribute to better

academic achievement and competencies, as well as overall well-being¹⁶.

The WHO's International Classification of Functioning, Disability and Health framework highlights how factors related to the child and their health condition, the family, and the environment may interact to influence the level of participation¹². This biopsychosocial model of functioning and disability recognizes the role and potential effect of body structure and functions, activities, personal factors, and environmental factors on participation, as well as the relevance of the health condition¹². 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, 2-parent households, higher annual household revenue, and parents' preferences for recreational-oriented activities increases the frequency of child/adolescent participation in leisure activities¹⁷.

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 our study were (1) to assess patterns of involvement in (5 different types of) leisure among children with JIA, (2) to compare leisure participation in the JIA cohort according to sociodemographic 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.

MATERIALS AND 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 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 minimum 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 involvement¹⁹.

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 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 of the 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 1 of the following clinical symptoms assessed by the treating pediatric rheumatologist and reported in the medical file: (1) active joint, (2) enthesitis, and (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 socioeconomic status²⁰.

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 1) with help provided by a research assistant over the phone or in person during a home visit as per the family's preference²¹. The 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 intensity²¹. The CAPE is a standardized 55-item questionnaire designed to examine how children and adolescents (6 to 21 yrs) with or without physical disabilities participate in physical and other more sedentary leisure activities²¹. It takes 30 to 45 min to complete and refers to participation over the last 4 months. Scores for the CAPE are provided for 2 domains (formal and informal activities; Table 1), and for 5 types of activities (recreational, active physical, social, skill-based, self-improvement; Table 1). Data were collected 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 was "every day" and 1 was "once in the last 4 mos"). 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 0.81²¹. The CAPE demonstrates good construct validity ($r = 0.71$) when compared with other measures of leisure participation²¹.

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 leisure across seasons.

Analysis. Descriptive statistics were carried out to characterize the sample in terms of frequencies, percentages, means, and SD. 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 factors (age and sex) were examined with bivariate analysis (Student *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 Student *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. For all inferential statistical analyses, the significance level was fixed at $\alpha = 0.05$.

RESULTS

Sample characteristics. Among the 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

Table 1. 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 face. The remaining items are informal activities. CAPE: Child Assessment of Participation and Enjoyment.

questionnaire, citing that 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 CAPE (response rate 91.5%). There were no statistically significant differences between participants with JIA and nonparticipants 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 girls. More than 50% had oligoarthritis, just over 20% had polyarthritis, and 16% had enthesitis-related arthritis. Sociodemographic, disease-related, and treatment characteristics of the JIA sample are described in Table 2.

Leisure participation. A profile of the children's participation in leisure activities is described in Tables 3 and 4. The 5 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 sixth), and biking (ranked seventh; Table 3). In general, children and teens with JIA proportionally engaged in a larger number of informal (41.8% out of 55 possible items) than formal (20.0% out of 15 possible 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% out of 10 possible items) and recreational (61.9% out of 12 possible 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 activities [mean 1.11, SD 0.85; $t(106) = 45.5, p < 0.0001$]. 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 4). The level of enjoyment was highest for social activities (mean 4.18, SD 0.47) and lowest for self-improvement activities (mean 3.16, SD 0.57).

Leisure participation in JIA and sociodemographic characteristics. Younger children with JIA (8 to 11 yrs) were more actively involved in recreational pursuits and enjoyed these more than the older group (12 to 17 yrs), while older children participated more in social activities than did the younger children (Table 5). 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 6). 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 with 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 reported less diverse (mean 3.80, SD 1.76, $p = 0.028$) and less intense (mean 1.24,

Table 2. Sociodemographic, disease-related, and treatment characteristics of children and teenagers with JIA (n = 107).

Characteristics	Mean (SD)	Range	n (%)
Sociodemographic characteristics			
Age, yrs	12.8 (2.7)	8.0–17.8	
Age at diagnosis, yrs	7.4 (4.5)	1.1–16.8	
Female			75 (70.1)
Median family income, Can\$*	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, yrs	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 1 arthritis medication			80 (74.8)
NSAID			52 (48.6)
MTX			43 (40.2)
Corticosteroids			5 (4.7)
TNF- α inhibitors			11 (10.3)
Other DMARD			10 (9.3)
Subcutaneous drugs			34 (31.8)
No. prescribed arthritis medications	1.26 (1.04)	0–5	

* Median income was based on the first 3 characters of the family's home postal code (Statistics Canada, 2006) and expressed in Canadian dollars. JIA: juvenile idiopathic arthritis; CHAQ: Childhood Health Assessment Questionnaire; NSAID: nonsteroidal antiinflammatory drugs; MTX: methotrexate; TNF- α : tumor necrosis factor- α ; DMARD: disease-modifying antirheumatic drugs.

SD 0.71, $p = 0.007$) participation in active physical activities in comparison with those without (mean 4.86, SD 2.70 and mean 1.69, SD 0.95, respectively). Further, participation in informal activities was less frequent among those with active disease as compared with 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 years (3.4). Of these, 7 dyads were of the same sex. There were no statistically significant differences for age (mean age difference 1.9 yrs, $p = 0.465$); 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 than their siblings. They also took part more often in recreational ($p = 0.040$) and informal ($p = 0.040$) activities. However, nearest age- and sex-matched siblings engaged more frequently in active physical activities than did their sibling with JIA, 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 patients with JIA and their siblings. 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 by patients with JIA using a validated and standardized tool. Our findings demonstrate that children and adolescents with JIA participate in a vast array of leisure activities, the majority of which are informal. Further, children and adolescents with JIA participate less in physical activities compared with siblings without JIA, even when adjusting for family environment. Similar results were described in other studies investigating leisure as measured

Table 3. Top activities performed daily and weekly by children and teenagers with JIA (n = 107).

Activities	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.

by the CAPE in children and teenagers living with physical disabilities^{17,23,24,25,26,27}.

There are no official norms published for the CAPE; however, studies including large samples of healthy Canadian children and adolescents provide some normative data^{22,26}. When compared with 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 sample²⁶. Those with JIA must contend with fluctuating disease activity characterized by periods of joint flares, pain, and physical limitations¹. As a result of 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 planned (formal) activities focused on skill-building and physical activity. Some children with arthritis may also demonstrate poor self-concept and/or limited competency for either athletics or other skill-based activities, leading them to engage more in free play (recreational)⁶.

Results for diversity and intensity in social activities among our participants with JIA parallel normative findings²². Those with JIA enjoy and participate in as many different energetic physical activities, albeit less frequently than healthy peers. The interest in being active is equally strong between both groups, but engagement may be hindered by illness. On the other hand, those with JIA display similar levels of

Table 4. Mean (SD) scores for activity types by leisure dimensions of those with JIA and other Canadian children and adolescents without a physical disability.

Activity Types	107 Canadian Children and Adolescents with JIA, 8–17 Yrs Mean (SD), range	22 Siblings without JIA of Children and Adolescents with JIA Matched for Age, 8–17 Yrs Mean (SD)	354 Canadian Children and Adolescents without Disabilities, 6–14 Yrs ²² 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	3.76 (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)

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. JIA: juvenile idiopathic arthritis.

Table 5. Mean (SD) leisure (diversity, intensity, and enjoyment) scores as measured by the CAPE for children with JIA grouped by age (n = 107).

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

Differences between age group pairs significant at: * p < 0.05, ** p < 0.01, and *** p < 0.001. Analysis was performed on data from 41 children aged 8–11 years and 66 children aged 12–17 years. CAPE: Child Assessment of Participation and Enjoyment; JIA: juvenile idiopathic arthritis.

Table 6. Mean (SD) leisure (diversity, intensity, and enjoyment) scores as measured by the CAPE for children with JIA grouped by sex (n = 107).

Leisure Scores	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)

Differences between pairs of boys and girls by activity type significant at: * p < 0.05, ** p < 0.01, and *** p < 0.001. Analysis was performed on data from 75 girls and 32 boys. CAPE: Child Assessment of Participation and Enjoyment; JIA: juvenile idiopathic arthritis.

enjoyment and involvement in skill-based activities as healthy children.

On a daily basis, most children and teens with JIA (> 50%) participate in passive and home-based activities (listening to music, doing homework, and watching television). These findings parallel results from other studies of childhood disability^{17,23,24,25,26,27} 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 behavior compared with their healthy counterparts⁵.

The association of age and sex with leisure participation is frequently studied^{22,23,30}. Often boys are reported to participate more frequently in energetic physical activities than girls^{17,23,30,31}. However, our findings displayed no differences between boys and girls with JIA when examining the diversity, intensity, and enjoyment of participation in such physical activities^{17,30}. According to the review by Larson and Verma³² of healthy children, girls generally spent more time in self-improvement activities such as homework,

chores, and reading. As they got older, they spent more time talking to peers and engaging in social activities than did boys, who spent more time watching television³². Among our participants with JIA, the younger the child, the more they participated in recreational activities, whereas the older children engaged most often in social activities. These results reflect age-appropriate leisure participation^{14,32}. As children got older, they become less involved in play and more engaged in socially oriented activities^{23,33}.

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., bicycles, ice skates, rollerblades, video games and consoles, computer). Other studies support that lower-income families demonstrated less diversity in leisure activities¹⁷.

Those with JIA who had active disease were less likely to participate as often and in as many physical activities as those who showed no signs of active arthritis. Similarly, Takken, *et al* demonstrated that disease activity (number of swollen joints) hinders participation in physical activities in JIA³⁴.

Others, however, found no association between the presence of disease activity and the level of physical activity⁴.

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 that greater participation in both skill-based (e.g., music lessons, playing an instrument) and self-improvement (e.g., doing homework, reading) activities contributes to cognitive development and may promote academic success^{14,15,16}. In a population-based longitudinal study, those living with JIA were reported to achieve higher academic success than their siblings³⁵. Packham and Hall discussed how those with JIA may be less distracted from their studies by other activities³⁵, a finding that may at least partly explain differences in leisure across our study groups. Further, 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 ones (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 energetic 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 boys²².

There are several limitations to our study. The cross-sectional nature of the study precluded us from accounting for any fluctuations in disease status that are typical in those living with JIA. However, our sample included people with active and inactive 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. Further, these comparison results should be interpreted with caution because of 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 affect responses. However, we expect that more-active children and adolescents are likely to remain active across seasons.

Our 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 because of 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 the 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 favor a healthier lifestyle. A 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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REFERENCES

1. Cassidy JT, Petty RE. Chronic arthritis in childhood. In: Cassidy JT, Petty RE, Laxer RM, Lindsley CB, eds. *Textbook of pediatric rheumatology*, 5th edition. Philadelphia: Elsevier Saunders; 2005:206-60.
2. Bloom BJ, Owens JA, McGuinn M, Nobile C, Schaeffer L, Alario AJ. Sleep and its relationship to pain, dysfunction, and disease activity in juvenile rheumatoid arthritis. *J Rheumatol* 2002; 29:169-73.
3. Sturge C, Garralda ME, Boissin M, Doré CJ, Woo P. School attendance and juvenile chronic arthritis. *Br J Rheumatol* 1997;36:1218-23.
4. Maggio AB, Hofer MF, Martin XE, Marchand LM, Beghetti M, Farpour-Lambert NJ. Reduced physical activity level and cardiorespiratory fitness in children with chronic diseases. *Eur J Pediatr* 2010;169:1187-93.
5. Lelieveld OT, Armbrust W, Van Leeuwen MA, Duppen N, Geertzen JH, Sauer PJ, et al. Physical activity in adolescents with juvenile idiopathic arthritis. *Arthritis Rheum* 2008;59:1379-84.
6. Huygen AC, Kuis W, Sinnema G. Psychological, behavioural, and social adjustment in children and adolescents with juvenile chronic arthritis. *Ann Rheum Dis* 2000;59:276-82.
7. Giannini MJ, Protas EJ. Aerobic capacity in juvenile rheumatoid arthritis patients and healthy children. *Arthritis Care Res* 1991;4:131-5.
8. Malleson PN1, Bennett SM, MacKinnon M, Jespersen DK, Coutts KD, Turner SP, et al. Physical fitness and its relationship to other indices of health status in children with chronic arthritis. *J Rheumatol* 1996;23:1059-65.
9. Fan JS, Wessel J, Ellsworth J. The relationship between strength and function in females with juvenile rheumatoid arthritis. *J Rheumatol* 1998;25:1399-405.
10. Broström E, Nordlund MM, Cresswell AG. Plantar- and dorsiflexor strength in prepubertal girls with juvenile idiopathic arthritis. *Arch Phys Med Rehabil* 2004;85:1224-30.
11. Reiter-Purtill J, Gerhardt CA, Vannatta K, Passo MH, Noll RB. A controlled longitudinal study of the social functioning of children with juvenile rheumatoid arthritis. *J Pediatr Psychol* 2003;28:17-28.
12. World Health Organization. *International classification of functioning, disability and health*. Geneva: World Health Organization; 2001.
13. Hackett J. Perceptions of play and leisure in junior school aged

- children with juvenile idiopathic arthritis: what are the implications for occupational therapy? *Br J Occup Ther* 2003;66:303-10.
14. Larson RW. Toward a psychology of positive youth development. *Am Psychol* 2000;55:170-83.
 15. Masten AS, Coatsworth JD. The development of competence in favorable and unfavorable environments. Lessons from research on successful children. *Am Psychol* 1998;53:205-20.
 16. Simpkins SD, Ripke M, Huston AC, Eccles JS. Predicting participation and outcomes in out-of-school activities: similarities and differences across social ecologies. *New Dir Youth Dev* 2005;105:51-69.
 17. Law M, King G, King S, Kertoy M, Hurley P, Rosenbaum P, et al. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Dev Med Child Neurol* 2006;48:337-42.
 18. Takken T, Van Der Net J, Kuis W, Helders PJ. Aquatic fitness training for children with juvenile idiopathic arthritis. *Rheumatology* 2003;42:1408-14.
 19. Harter S. The perceived competence scale for children. *Child Dev* 1982;53:87-97.
 20. Statistics Canada. Profile for Canada, provinces, territories and forward sortation areas, 2006 census. Ottawa: Government of Canada; 2006.
 21. King G, Law M, King S, Hurley P, Rosenbaum P, Hanna S, et al. Children's assessment of participation and enjoyment (CAPE) and preferences for activities of children (PAC). San Antonio: Harcourt Assessment Inc.; 2004.
 22. King G, Law M, Hurley P, Petrenchik T, Schwellnus H. A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. *Int J Disabil Dev Educ* 2010;57:77-107.
 23. King GA, Law M, King S, Hurley P, Hanna S, Kertoy M, et al. Measuring children's participation in recreation and leisure activities: construct validation of the CAPE and PAC. *Child Care Health Dev* 2006;33:28-39.
 24. Shikako-Thomas K, Shevell M, Lach L, Law M, Schmitz N, Poulin C, et al; QUALA group. Picture me playing-a portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy. *Res Dev Disabil* 2013;34:1001-10.
 25. Majnemer A, Shevell M, Law M, Birnbaum R, Chilingaryan G, Rosenbaum P, et al. Participation and enjoyment of leisure activities in school-aged children with cerebral palsy. *Dev Med Child Neuro* 2008;50:751-8.
 26. King G, Petrenchik T, Law M, Hurley P. The enjoyment of formal and informal recreation and leisure activities: a comparison of school-aged children with and without physical disabilities. *Int J Disabil Dev Educ* 2009;56:109-30.
 27. Longo E, Badia M, Orgaz BM. Patterns and predictors of participation in leisure activities outside of school in children and adolescents with cerebral palsy. *Res Dev Disabil* 2013;34:266-75.
 28. Colley RC, Garriguet D, Janssen I, Craig CL, Clarke J, Tremblay MS. Physical activity of Canadian children and youth: Accelerometer results from the 2007 to 2009 Canadian Health Measures Survey. *Health Rep* 2011;22:15-23.
 29. Koezuka N, Koo M, Allison KR, Adlaf EM, Dwyer JJ, Faulkner G, et al. The relationship between sedentary activities and physical inactivity among adolescents: results from the Canadian community health survey. *J Adolesc Health* 2006;39:515-22.
 30. Sallis JF, Prochaska JJ, Taylor WC. A review of correlates of physical activity of children and adolescents. *Med Sci Sports Exerc* 2000;32:963-75.
 31. Garton AF, Pratt C. Leisure activities of adolescent school students: predictors of participation and interest. *J Adolesc* 1991;14:305-21.
 32. Larson RW, Verma S. How children and adolescents spend time across the world: work, play, and developmental opportunities. *Psychol Bull* 1999;125:703-36.
 33. Orlin MN, Palisano RJ, Chiarello LA, Kang LJ, Polansky M, Almasri N, et al. Participation in home, extracurricular, and community activities among children and young people with cerebral palsy. *Dev Med Child Neurol* 2010;52:160-6.
 34. Takken T, van der Net J, Kuis W, Helders PJ. Physical activity and health related physical fitness in children with juvenile idiopathic arthritis. *Ann Rheum Dis* 2003;62:885-9.
 35. Packham JC, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: education and employment. *Rheumatology* 2002;41:1436-9.
 36. Tarakci E, Yeldan I, Kaya Mutlu E, Baydogan SN, Kasapcopur O. The relationship between physical activity level, anxiety, depression, and functional ability in children and adolescents with juvenile idiopathic arthritis. *Clin Rheumatol* 2011;30:1415-20.