The Relationship Between Physical Activity Levels and Pain in Children with Juvenile Idiopathic Arthritis

Elizaveta Limenis, Haddas A. Grosbein, and Brian M. Feldman

ABSTRACT. ***Objective.*** Pain and reduced physical activity levels are common in children with juvenile idiopathic arthritis (JIA). Currently, there is no consensus about the role of physical activity in managing pain in JIA. The purpose of our study was to assess the relationship between physical activity level and pain in children ages 11 to 18 years with JIA.

Methods. A random sample of 50 patients with JIA were approached by mailed questionnaires. Physical activity was determined using the Physical Activity Questionnaire (PAQ). Pain measures included the Numerical Rating Scale (pain severity), SUPER-KIDZ body diagram (number of painful areas), and the Child Activities Limitations Inventory-21 (pain interference). Generalized linear models were used to assess the relationship between physical activity and pain, as well as the roles of sex and age.

Results. The response rate was 84%. Thirty-four respondents completed the questionnaire package. The median age was 15 years. The mean PAQ score was 2.16/5. Physical activity declines with increasing age in youth with JIA ($r = 0.53$, $p = 0.0014$). Lower physical activity is associated with greater pain interference ($r = 0.39$, $p = 0.0217$) and more severe pain ($r = 0.35$, $p = 0.0422$).

Conclusion. Children with JIA report significantly less activity than healthy children based on PAQ scores, with physical activity declining throughout adolescence. Physical activity is inversely related to pain interference and severity in children with JIA. Our findings suggest that physical activity interventions may play an important role in the management of pain in JIA. (First Release Dec 15 2013; J Rheumatol 2014;41:345–51; doi:10.3899/jrheum.130734)

Key Indexing Terms:
JUVENILE IDIOPATHIC ARTHRITIS PHYSICAL ACTIVITY PAIN

Juvenile idiopathic arthritis (JIA) is a common and serious chronic illness of childhood. A review of 34 epidemiological studies since 1966 reported the prevalence of JIA to be 0.07 to 4.01 per 1000 children[1]. Children with JIA commonly experience pain, joint stiffness, and decreased mobility, leading to both physical restriction and social isolation[2]. The prognosis for children with JIA has significantly improved over the past several decades. However, concern remains over the short-term and longterm morbidity of the disease itself and its pharmacologic treatment on physical and social well-being[3]. Thus, JIA remains a prevalent and serious diagnosis.

Pain is a cardinal symptom of JIA that can reduce quality of life (QOL). Almost all children with JIA report chronic or recurrent pain[4]. One study reported a pain prevalence of 86% among 293 children with JIA[5]. Another study, through the Cincinnati Juvenile Arthritis Databank, reported a pain prevalence of 60% at disease onset, 50% at 1-year followup, and 40% at 5-year followup[6]. A large review found that most children with JIA report pain in the mild to moderate range[7]. However, up to 25% of children report pain in the higher ranges of the pain intensity scale[8], and children with polyarticular arthritis report pain on up to 70% of days[9]. A study assessing the self-management needs of adolescents with JIA found that management of pain was one of adolescents' primary concerns[10]. Clearly, pain is a hallmark of JIA and reduces the QOL for many affected children.

Physical activity is reduced in children with JIA. Pain, together with the other clinical manifestations of JIA, is thought to predispose children to a sedentary lifestyle[11]. Children with JIA have been reported to be significantly less active than their peers[11]; they spend more time sedentary and less time engaged in vigorous physical activity compared to age- and sex-matched controls[12]. In one study, only 23% of children with JIA met the American Public Health physical activity recommendations, compared to 66% of controls[13]. A study in Turkey also reported that children with JIA had significantly lower physical activity levels and energy expenditure than controls[14]. Thus, it appears that the majority of children with JIA are not sufficiently active.

Reduced physical activity in JIA may create a vicious

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cycle between inactivity and disability[3]. An increasingly sedentary lifestyle may trigger a process of physical de-conditioning, leading to reduced aerobic capacity and cardiovascular fitness, and increased muscle fatigue[11]. This results in increasingly lower levels of physical activity, as children become more disabled and discouraged[11]. In a study involving a large cohort of children with JIA, 95% of all subjects had a lower aerobic capacity and 94% had a lower anaerobic capacity compared to age- and sex-matched reference values, suggesting that deconditioning is nearly universal in JIA[15]. This deconditioning cycle, if uninterrupted, continues to lead to greater disability, pain, and morbidity in children with JIA.

Studies in adults have shown that there is potential for physical activity intervention to disrupt the above cycle. Physical activity has been shown to improve pain and physical function in adults with rheumatoid arthritis, as demonstrated by a 16-week training intervention program[16]. A metaanalysis reported that community-deliverable exercise programs significantly improve pain and physical function in adults with rheumatic conditions[17]. In the adult arthritis population, physical activity has been clearly shown to reduce pain and is an established component of therapy.

Studies exploring the relationship between physical activity and pain in JIA have reported variable findings. A large review looking at exercise therapy in JIA reported that there is no clear and consistent evidence that exercise therapy improves functional ability, QOL, aerobic capacity, or pain[18]. However, a randomized controlled trial in which 80 children with JIA participated in a 12-week training program – either a high-intensity aerobics program (experimental group) or qigong (a light exercise control group) – found that both groups showed significant improvements in physical function after the intervention[19]. Further, a review of exercise in pediatric rheumatic diseases suggested that there is some evidence that moderate to vigorous aerobic and strength exercise may improve physical function and pain[20]. Currently, there is no consensus about the relationship between physical activity and pain in JIA, or about the potential for physical activity to play a role in the treatment of pain in JIA.

The relationship between pain and physical activity is likely to be complex, as greater pain is likely to lead to less activity, and less activity may lead to more severe and bothersome pain. The exact nature of this relationship in the context of JIA remains unclear.

We asked the question: In children ages 11 to 18 years with JIA, is greater physical activity associated with less pain?

MATERIALS AND METHODS

Approval for the study was obtained from the Research Ethics Board at The Hospital for Sick Children in Toronto. We obtained a list of all patients with JIA ages 11 to 18 years followed at the rheumatology clinic. Each individual was assigned a random, computer-generated number, from which numbers 1–50 were selected for the study, to generate a random representative sample. We chose to contact 50 patients to aim for an overall sample size of at least 30. At a power of 0.8 and α of 0.05, a sample size of 30 would provide precision around a moderate to large correlation ($r > 0.4$). The study was limited to children over the age of 11 years to ensure greater reliability of self-reported data and to maintain consistency between measurement tools, because the questionnaires that have been validated to measure pain and physical activity in older children are different from those in younger children.

We contacted families using the Tailored Design Method[21], which incorporates a series of letters and phone calls. The following points of contact were made: a prenotice letter explaining the study; 1 week later, the questionnaire package, including a cover letter, consent forms and a prepaid return envelope; 2 weeks later, a reminder letter to those who had not responded; 2 weeks later, a second reminder letter; and 1 week later, a telephone call. Up to 4 telephone calls were made over the course of 3 weeks if families had not yet been reached.

Physical activity level was assessed using 1 of 2 versions of the Physical Activity Questionnaire: (1) Physical Activity Questionnaire for Older Children (PAQ-C) for children ages 11 to 14 years (elementary school students), or (2) Physical Activity Questionnaire for Adolescents (PAQ-A) for children ages 14 to 18 years (high school students). Questions refer to the amount and nature of both school-based and extracurricular physical activities in the preceding 7 days. The PAQ-C and PAQ-A were selected based on a systematic review of self-reported physical activity measurement tools in youth, which found these to be valid and reliable instruments[22].

Three different measures of pain were taken. The first was pain severity using the Numerical Rating Scale, which has been preliminarily validated in children greater than 8 years of age[23]. The questionnaire assesses pain intensity on a scale from 0 to 10 at the time of questionnaire completion and over the preceding 7 days. The next was the number of painful areas using the SUPER-KIDZ body diagram, a revised version of the Pediatric Pain Questionnaire body diagram, which is a well-established and widely used measure of pain location in children[24]. Children are asked to shade in areas on the body diagram where they have experienced pain in the preceding 7 days. Finally, pain interference was measured using the self-reported version of the Child Activity Limitations Interview-21 (CALI-21). The CALI-21 was chosen over other tools because it measures pain interference with physical activities specifically, rather than more general indicators of QOL. The CALI-21 has been shown to be valid and reliable in assessing the extent to which pain interferes with various activities in children[25]. Twenty-one activity-specific statements are scored between 0 and 4, with a higher final score out of 84 indicating greater pain-related activity limitation. The time frame was adapted from the preceding 4 weeks to 7 days to maintain consistency with the other questionnaires.

Response rate was determined by the proportion of children who responded by either declining to participate or completing the questionnaires. The final sample consists only of those subjects who completed the questionnaires.

DataDesk 6.3 (Data Description Inc.) and R (Comprehensive R Archive Network) were used to perform the statistical analyses. Simple linear regression was used to determine whether sex and age predict physical activity level and pain scores. General linear modeling and Spearman correlation coefficients were used to determine whether physical activity level is associated with pain.

RESULTS

The overall response rate was 84% (42/50). The participation rate (the proportion of individuals who completed the questionnaires) was 68%, with a final sample size of 34. Of

the 34 respondents, 23 (68%) were female and 11 (32%) were male. The median age was 15 years, with a range of 11 to 18 years. The distributions of JIA subtypes for this study and our institution are shown in Table 1.

The overall median PAQ score was 2.10 (score/5). The mean PAQ score was 2.16. This is significantly lower than mean PAQ scores of 3.07 ($t = 7.68$, $df = 33$, $p \leq 0.0001$) and 3.7 ($t = 12.98$, $df = 33$, $p \leq 0.0001$) reported in studies on cohorts of healthy youth[26,27]. The mean PAQ score was 2.23 for females and 1.98 for males, which was not a statistically significant difference ($p = 0.46$). The overall distribution of PAQ scores in our study is shown in Figure 1.

The median Numerical Rating Scale (pain severity) score was 1/10 at the time of questionnaire completion, and 2/10 in the preceding 7 days, with a range of 0–9. The median number of painful areas as assessed by the SUPER-KIDZ body diagram was 2, with a range of 0–17. The median CALI-21 (pain interference) score was 4.5/84. The distribution of CALI-21 scores is shown in Figure 2.

There was no significant difference between males and females in any of the pain measures. Pain levels did not vary with age. Physical activity decreased with increasing age (Figure 3).

Pain severity and pain interference showed significant relationships to physical activity level (Figures 4, 5). The remaining pain measures were not significantly correlated with physical activity.

Table 1. Sample and institution distributions of juvenile idiopathic arthritis (JIA) subtypes.

JIA Subtype	Participants, n (%)	Followed at Institution, n (%)
Oligoarthritis	12 (35)	521 (39)
Polyarthritis	10 (29)	368 (27)
Enthesitis-related arthritis	5 (15)	161 (12)
Psoriatic arthritis	4 (12)	75 (6)
Systemic arthritis	1 (3)	114 (8)
Unspecified	2 (6)	110 (8)
Total	34	1349

DISCUSSION

We have found that youth with JIA report significantly less physical activity than healthy children, based on PAQ scores. On average, children with JIA report pain of mild severity and interference. Physical activity decreases with increasing age in youth with JIA. Lower physical activity is associated with more severe and bothersome pain. Greater physical activity promotion and exercise therapy interventions could play an important role in the management of pain in JIA.

Children with JIA score significantly lower on the PAQ than healthy children. This finding supports those of other studies, that children with JIA engage in less vigorous

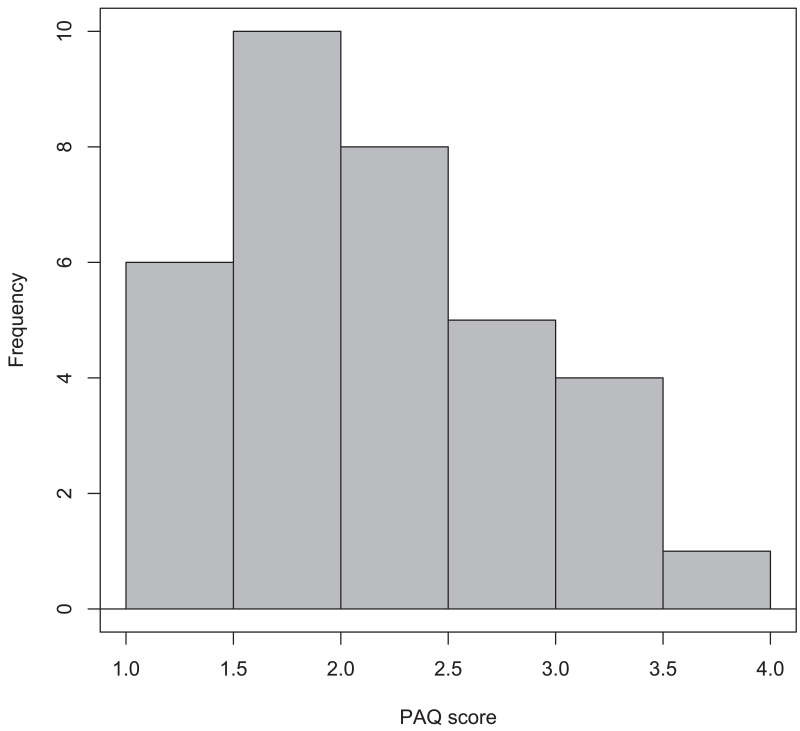

Figure 1. Sample distribution of Physical Activity Questionnaire (PAQ) scores (scored out of 5).

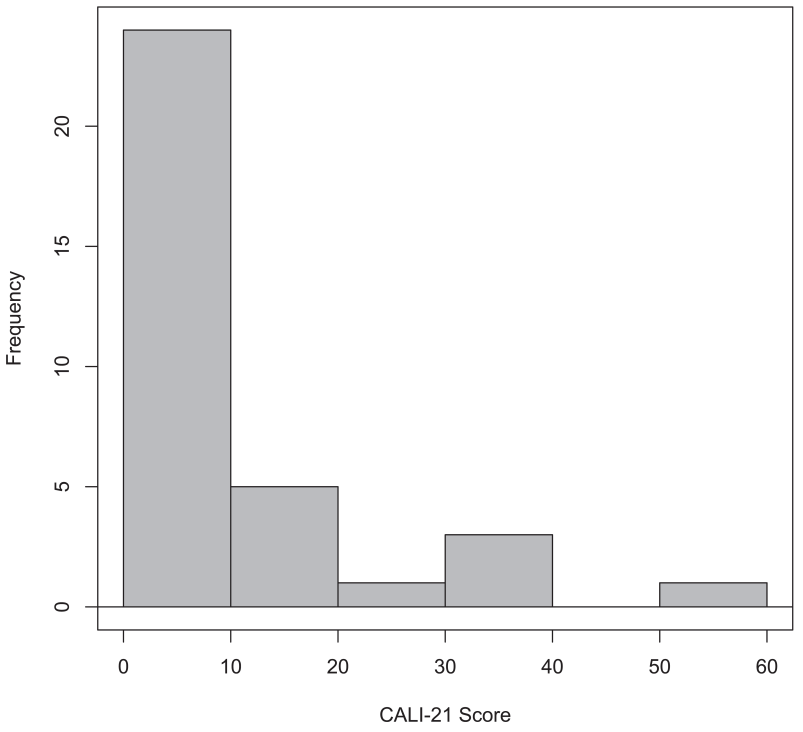

Figure 2. Sample distribution of Child Activity Limitations Interview-21 (CALI-21) pain interference scores (scored out of 84).

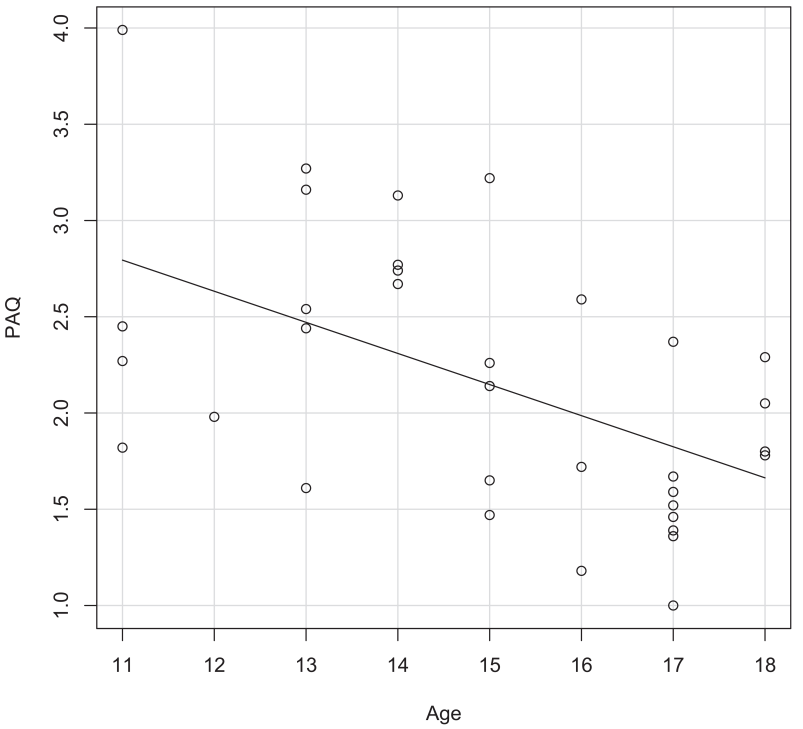

Figure 3. The x-axis shows the subject's age. The y-axis shows the subject's Physical Activity Questionnaire (PAQ) score (physical activity level). Physical activity decreases with increasing age ($F = 12.2$; df = 1 and 32; $r = -0.53$; $p = 0.0014$). The least squares regression line is PAQ = 4.57 – 0.16×(age).

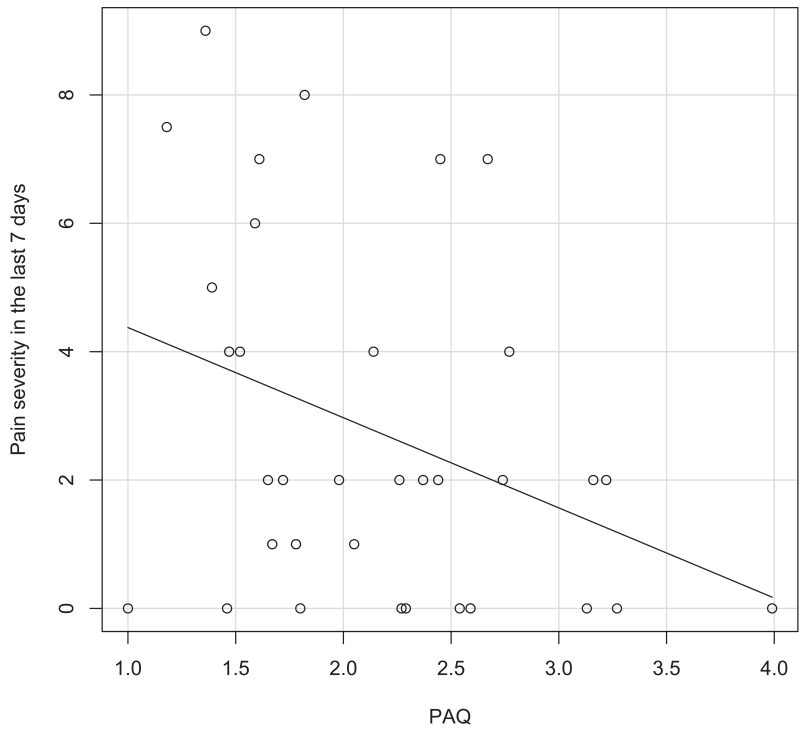

Figure 4. The x-axis shows the subject's Physical Activity Questionnaire (PAQ) score (physical activity level). The y-axis shows the subject's pain severity in the 7 days preceding questionnaire completion. Greater physical activity level is associated with lower pain severity (F = 4.48; df = 32; r = –0.35; p = 0.0422). The least squares regression line is Pain Severity = 5.78 – 1.41×(PAQ).

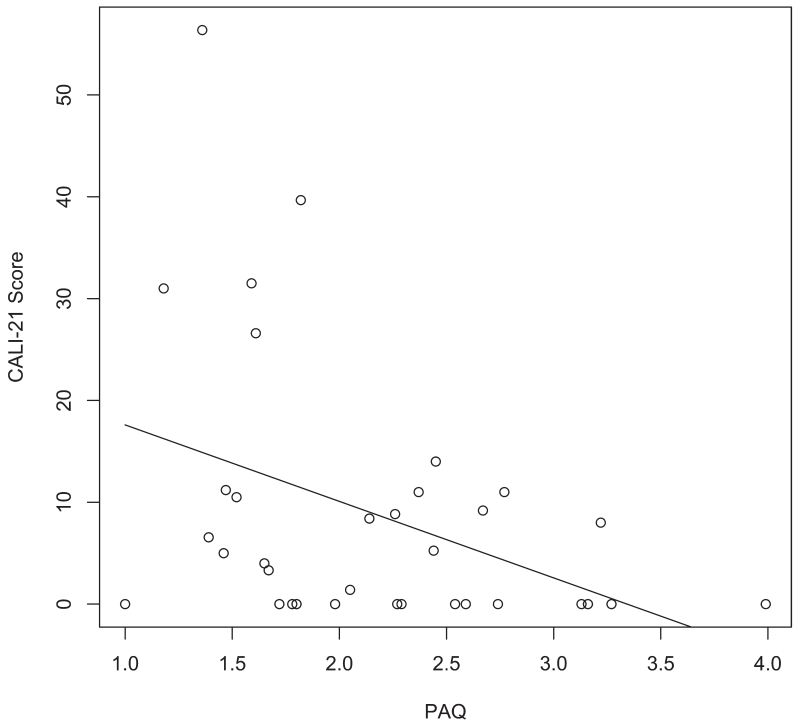

Figure 5. The x-axis shows the subject's Physical Activity Questionnaire (PAQ) score (physical activity level). The y-axis shows the subject's Child Activity Limitations Interview-21 (CALI-21) score (pain interference). Greater physical activity level is associated with less bothersome pain (F = 5.83; df = 1 and 32; r = –0.39; p = 0.0217). The least squares regression line is CALI-21 = 25.11 – 7.51×(PAQ).

activity and are more sedentary than their healthy peers[16,20,28]. The studies with which we compared our PAQ scores only included youth up to 15 years of age. Thus, we do not have comparable PAQ scores for youth ages 16 years and older. However, it is evident that children with JIA under the age of 16 years are less active than their healthy peers. This carries important consequences for their physical and social well-being, and requires the attention of healthcare and education providers.

Our findings suggest that physical activity decreases with age in youth with JIA (Figure 3). This finding has been reported previously in a study exploring the relationship between physical activity level and measures of physical fitness in children with JIA[29]. Based on a large review looking at youth physical activity level internationally, this same trend has been reported consistently in healthy youth[30]. Adolescence is characterized by increased psychosocial difficulties and pressures as compared to early childhood. The nature of physical activity also evolves from being play-focused to being largely dependent on self-motivation. The challenges of maintaining healthy activity levels may be more pronounced in youth with JIA, for whom chronic illness leads to an increased risk for adopting a sedentary lifestyle[11] and developing emotional problems[31]. Stress and mood have been found to be important predictors of daily disease symptoms, function, and activity participation in children with polyarthritis[9]. One study reported that depression prevalence in youth with JIA ages 10 to 18 years is 35%, compared to 12% of controls[31]. Body image issues are also more common in youth with JIA[32]. We speculate that these challenges may lead to social isolation and reduced participation in activities with peers, including physical activities, which are especially sensitive to factors such as motivation, self-esteem, and body image. In our study, we did not measure psychosocial barriers, emotionality, motivation, self-esteem, or body image. These personal and environmental factors should form research priorities in future studies on physical activity in children and youth with JIA.

We have demonstrated that a lower reported physical activity level is associated with more severe and bothersome pain (Figures 4, 5). As the relationship between physical activity and pain is likely to be bidirectional, we propose that targeting one of these variables is likely to affect the other. On one side, medical management of pain remains an important component of JIA treatment and can likely improve physical function and consequently, activity level. In the reverse direction, it is likely that there is an important role for exercise therapy in pain reduction in JIA, a notion that has received support in the literature. A recent review of exercise programs in JIA reported that among the most important benefits was an improvement in pain, joint stiffness, and quality of life[20]. In addition to vigorous exercise, it has also been shown that low-intensity activity[19] and aquatic exercises[33] may lead to similar benefits. It is clear that physical activity and pain in JIA are closely intertwined. Medical- and school-based physical activity interventions may prove effective in improving pain in children with JIA.

Our findings must be interpreted in light of several potential limitations. First, our sample of 34 is somewhat small, but we were nonetheless able to produce meaningful and statistically significant results, suggesting that our sample was sufficiently large to avoid type II errors. Moreover, our randomly selected sample is likely, therefore, to be generalizable. Second, the PAQ-C and PAQ-A have not been validated in JIA populations. However, there are very few studies on the validity of self-reported physical activity measures in patients with JIA. Self-reported physical activity data are not as reliable as objective measurements, such as those obtained through accelerometry, and may lead to poorer precision. However, both the PAQ-C and PAQ-A have been validated as excellent physical activity measurement tools in children attending school[22], and we obtained significant results using these tools. It is probable that the relationship would be even stronger if more precise measurements were used. Third, several factors that may influence the experience of pain, including disease activity and ethnicity, were not included in this study. These should be included in future studies assessing pain. Lastly, given that the relationship between pain and physical activity in JIA is likely bidirectional, it was not possible to specifically isolate how physical activity level affects pain in our study. Randomized controlled trials that follow participants over the course of an exercise intervention program are needed to determine the therapeutic benefits of physical activity in children with JIA. Despite these limitations, we have demonstrated that physical activity and pain in JIA are closely associated.

Our findings support those reported in the literature — that youth with JIA are significantly less physically active than their peers. While the overall severity and interference of pain in our sample was mild, pain in JIA remains an important problem and a barrier to well-being. We found that physical activity decreases with increasing age in youth with JIA. We speculate that this may be related to psychosocial factors that surface in adolescence and are more prevalent in youth with chronic illness. These factors should be measured in future studies of physical activity in children and youth with JIA in order to determine their role. We found that lower physical activity is associated with more severe and bothersome pain, although prospective studies are needed to specifically isolate the effect of physical activity on pain reduction. Our findings nonetheless suggest that physical activity interventions and pain control may play important roles in the management of patients with JIA.

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