Strong relationships between disease activity, foot-related impairments, activity limitations and participation restrictions in children with juvenile idiopathic arthritis

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Abstract

Objective

To assess possible relationships between disease activity, foot-related impairments, activity limitations and participation restrictions in children with juvenile idiopathic arthritis (JIA).

Methods

Thirty-four children were studied. Disease activity was assessed with the Juvenile Arthritis Disease Activity Score in 71 joints (JADAS-71). Foot-related impairments, activity limitations and participation restrictions were measured with the Juvenile Arthritis Foot Disability Index (JAFI), the Childhood Health Assessment Questionnaire (CHAQ), self-reported or parent-reported and doctor-reported VAS scales. Relationships were quantified with Spearman's correlation coefficient.

Results

The mean age was 12.4±3.7 years, the median disease duration 1.5 years (interquartile range (IQR) 1.0–4.0), 88% were girls, and 76% had polyarticular disease course. The median JADAS-71 score (range 0–101) was 6 (IQR 1–13). On the JAFI sub-scores (range 0–4) 88% of the children reported some foot-related impairments (median 1.1, IQR 0.4–2.0); 82% reported some foot-related activity limitations (median 0.9, IQR 0.3–2.0), and 65% reported some foot-related participation restrictions (median 0.6, IQR 0–2.1). The median CHAQ score was 0.9 (IQR 0.1–1.8). The JADAS-71 correlated with all impairment, activity limitation and participation restriction variables ($r=0.48–0.81$, $p<0.01$). Most of the impairment variables correlated with activity limitation ($r=0.39$, $p<0.05$ to $r=0.92$, $p<0.01$) and participation restriction variables ($r=0.44$, $p<0.05$ to $r=0.81$, $p<0.01$). All activity limitation variables correlated with participation restriction variables ($r=0.62–0.84$, $p<0.01$).

Conclusion

We observed strong relationships between disease activity, foot-related impairments, activity limitations and participation restrictions in children with JIA, and therefore suggest that standard screening for foot problems should be included in follow-up care for JIA patients.

Key words

juvenile idiopathic arthritis, foot, disability evaluation

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Introduction

Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease in childhood, and it is an important cause of short and long-term complaints (1). Foot problems associated with JIA are thought to be common, though research on foot problems is scarce. A descriptive study of foot problems in children with JIA, carried out by Spraul and Koenning (2), showed that over 90% of 144 children had at least 1 out of 21 foot problems in the categories of inflammation, limitation of joint range of motion, and malalignment. Prolonged inflammation of the foot and ankle joints can lead to various problems such as pain, stiffness, altered gait patterns, and structural abnormalities (1, 3-6). Radiological observations have shown that many JIA patients develop radiological abnormalities in the feet and ankles during the course of the disease (7).

Although interest in JIA-related foot problems is growing, there is little information about the relationship between disease characteristics and the resulting impairments (*i.e.* problems in body function or structure, such as pain or limitation of motion), activity limitations (*i.e.* difficulties in performing activities) and participation restrictions (*i.e.* problems with involvement in life situations) (8). Spraul and Koenning (2) investigated the relationship between disease characteristics and foot-related impairments, and found that children with polyarticular JIA often had forefoot limitations, and that the disease duration was related to the development of limited range of motion in the ankles and presence of toe deformities (2).

So far, no studies have yet focused on the relationship between disease characteristics (*i.e.* disease activity in particular), foot-related impairments, activity limitations and participation restrictions in daily physical and social activities in children with JIA. These relationships might be under-estimated, and could have great impact on the quality of life of these patients. Therefore, the aim of the present study was to assess the relationships between disease activity, foot-related impairments, activity limitations and participation restrictions in children with JIA.

Patients and methods

Patient selection

In this cross-sectional study, 34 consecutive eligible children were sampled from a cohort of 180 children with JIA who were treated in the Jan van Breemen Institute in Amsterdam, an outpatient clinic for rheumatology and rehabilitation. Children were included if they were between 1 and 18 years of age at the time of the study, had been diagnosed with JIA according to the International League of Associations for Rheumatology (ILAR) criteria (9, 10), and had a regular follow-up appointment with a paediatric rheumatologist (MvR or KD) in the inclusion period between June and August 2008. Foot and ankle involvement was not a specific selection criterion for inclusion. The only exclusion criterion was the inability of the children or the parents to complete the questionnaires. The local Medical Ethics Committee approved the study protocol, and written informed consent was received from all participants.

Procedure

Data on age, gender, JIA sub-type, disease duration and use of medication were obtained from the medical records. The self-reported or parent-reported measurements were reported by children of ≥10 years of age, or the parents of children <10 years of age, and the doctor-reported measurements were reported by the paediatric rheumatologists. The children or parents, and the rheumatologists completed a data-collection form directly after the consultation.

Measurements

- Disease activity

Disease activity (*i.e.* signs and symptoms related to inflammation) was assessed with the Juvenile Arthritis Disease Activity Score in 71 joints (JADAS-71), a recently developed composite disease activity score for JIA, based on: 1) self-reported or parent-reported global assessment of well-being, 2) doctor-reported global assessment of disease activity, 3) doctor-reported active joint count, and 4) erythrocyte sedimentation rate (ESR) (11). The self-reported or parent-reported global

assessment of well-being was rated on a 100-mm visual analogue scale (VAS) (VAS well-being), with anchors of 0 ('very good') and 100 ('very poor'). The doctor-reported global assessment of disease activity was rated by the rheumatologists on a 100-mm VAS (VAS disease activity), with anchors of 0 ('no disease activity') and 100 ('severe disease activity'). Active (*i.e.* swollen and/or painful) joints (0–71) were assessed by the rheumatologists according to the core set of outcome variables for JIA (12). The blood samples that were taken nearest to the date of the consultation were used to calculate the ESR values. The JADAS-71 was calculated according to the recommendations in the literature, resulting in a score ranging from 0 to 101, with 101 indicating high disease activity (11).

- Impairments

Foot-related impairments, such as pain and morning stiffness in the feet, were assessed according to the impairments sub-score of the Juvenile Arthritis Foot Disability Index (JAFI) (13). The JAFI was developed and validated in Sweden, and for our study we made a single forward translation into Dutch. The JAFI consists of three dimensions: the JAFI impairments sub-score (9 statements), the JAFI activity limitations sub-score (14 statements) and the JAFI participation restrictions sub-score (4 statements). Each statement is rated on a 5-point Likert scale (0=never, 1=occasionally/less than once a week, 2=sometimes/once a week, 3=frequently/2 or 3 times a week and 4=always). The statements refer to foot-related problems during the previous week, focusing on the worst foot. To obtain a dimension sub-score, the scores of the individual statements were summed and divided by the number of statements for the dimension (range 0–4).

Foot-related pain in the previous week was assessed by the children or the parents and the rheumatologists on a 100-mm VAS, (VAS pain feet), with anchors of 0 ('no pain') and 100 ('unbearable pain').

Overall, bodily pain in the previous week was assessed by the children or the parents on a 100-mm VAS (VAS overall bodily pain), with anchors of 0 ('no pain') and 100 ('unbearable pain').

The total number of active and limited joints (0–71) including the number of active and limited joints of the ankle and foot (0–22) were all assessed by the rheumatologists, according to the core set of outcome variables for JIA (12).

- Activity limitations

Foot-related activity limitations, such as difficulties with standing and walking, were assessed with the JAFI activity limitations sub-score (13). (For a description of the JAFI see the 'Impairments' section.)

To measure functional ability, the children or the parents were asked to complete the Dutch version of the Childhood Health Assessment Questionnaire (CHAQ) (14;15). The CHAQ assesses 8 sub-dimensions (dressing, arising, eating, walking, hygiene, reaching, grip and activities), with a score ranging from 0-3 (0=without any difficulty, 1=with some difficulty, 2=with much difficulty and 3=not possible), and 2 other dimensions to determine the activities for which patients need aids and devices. For each sub-dimension the highest scores on the items were summed and mean scores were calculated (range 0–3). In addition to the CHAQ total score, the scores for the sub-dimensions "arising", "walking" and "activities" were analysed separately, because it was assumed that these scores would be specifically influenced by foot and ankle involvement.

Problems with standing and walking in the previous week were also assessed by the children or the parents and the rheumatologists on a 100-mm VAS, (VAS standing and VAS walking, respectively), with anchors of 0 ('never') and 100 ('always').

- Participation restrictions

Foot-related participation restrictions, such as problems in participating in social activities and going to school, were assessed with the JAFI participation restrictions sub-score (13). (For a description of the JAFI see the 'Impairments' section.)

- Statistical analysis

All analyses were performed in SPSS (version 15.0). Descriptive statistics were reported in terms of means with standard deviations (SD) for continuous variables with a normal distribution, and medians with interquartile ranges (IQR) for abnormally distributed continuous and non-continuous variables. Correlations were quantified with Spearman's correlation tests, and two-sided *p*-values of less than 0.05 were considered to be statistically significant.

Results

Patients

A total of 37 children were invited to participate in the study. Three children returned the written informed consent form, but did not come for the assessment. Therefore, 34 children (26≥10 years of age and 8<10 years of age) participated in the study. The demographic and clinical characteristics of these children are summarised in Tables I and II. Eighty-five percent of the patients had a JADAS-71 score >0. In total, 59% (n=20) had one or more active (*i.e.* swollen and/or painful) joints, including 53% (n=18) who had one or more active joints of the ankle and foot, and 27% (n=9) who had a limitation of motion in one or more joints

Table I. Demographic characteristics of the 34 children.

Age (years) [a]	12.4 (±3.7)
Gender (male:female)	4:30
JIA sub-type (n)	
Polyarticular rheumatoid-factor positive	3
Polyarticular rheumatoid-factor negative	23
Oligoarticular persistent	2
Oligoarticular extended	3
Psoriatic	1
Enthesitis-related	2
Disease duration (years)	1.5 (1.0-4.0)
Medication (n)	
NSAIDs	25
DMARDs	33
Anti-TNF	5

Values are median and interquartile range (IQR) unless otherwise indicated. [a] Means with standard deviation. JIA: juvenile idiopathic arthritis; NSAIDs: non-steroidal anti-inflammatory drugs; DMARDs: disease-modifying antirheumatic drugs; Anti-TNF: anti-tumor necrosis factor medication.

Table II. Disease activity, impairments, activity limitations and participation restrictions of the 34 children.

	All children (n=34)	Children with >0 active joints of ankle and foot (n=18)	Children with no active joints of ankle and foot (n=16)
Disease activity			
JADAS-71 (0-101)	6 (1–13)	13 (10–18)	1 (0–4)
Self-reported or parent-reported			
VAS well-being (0-100) †	15 (0–35)	27 (10–46)	0 (0–17)
Doctor-reported			
VAS disease activity (0-100) †	19 (2–40)	39 (24–53)	1 (0–11)
Total number of active joints (0-71)	2 (0–5)	5 (3–8)	0 (0–0)
ESR (mm/hour)	9 (4–28)	16 (4-36)	8 (4–21)
Impairments			
Self-reported or parent-reported			
JAFI impairments sub-score (0-4)	1.1 (0.4–2.0)	1.6 (0.6–2.7)	0.5 (0–1.2)
VAS pain feet (0-100) †	8 (0–39)	28 (2–77)	0 (0–18)
VAS overall bodily pain (0-100) †	18 (0–53)	50 (21–68)	3 (0–16)
Doctor-reported			
VAS pain feet (0-100) †	4 (0–52)	38 (14–70)	1 (0–1)
Total number of limited joints (0-71)	1 (0–3)	3 (1–5)	0 (0–1)
Number of active joints of ankle and foot (0-22)	1 (0–2)	2 (1–2)	–
Number of children with 0 active joints of ankle and foot	16	–	16
Number of children with 1 active joint of ankle and foot	6	6	–
Number of children with ≥2 active joints of ankle and foot	12	12	–
Number of limited joints of ankle and foot (0-22)	0 (0–1)	0 (0–1)	0 (0–0)
Number of children with 0 limited joints of ankle and foot	25	10	15
Number of children with 1 limited joint of ankle and foot	6	5	1
Number of children with ≥2 limited joints of ankle and foot	3	3	0
Activity limitations			
Self-reported or parent-reported			
JAFI activity limitations sub-score (0-4)	0.9 (0.3–2.0)	1.8 (0.9–2.4)	0.4 (0–0.9)
CHAQ total score (0-3)	0.9 (0.1–1.8)	1.6 (0.6–2.0)	0.3 (0–0.9)
CHAQ arising sub-dimension (0-3)	0.5 (0–2.0)	1.5 (0–2.0)	0 (0–1.0)
CHAQ walking sub-dimension (0-3)	0.5 (0–2.0)	2.0 (0–2.0)	0 (0–1.0)
CHAQ activities sub-dimension (0-3)	1.0 (0–2.3)	2.0 (1.0–3.0)	0 (0–1.8)
VAS standing (0-100) †	1 (0–44)	12 (0–84)	0 (0–6)
VAS walking (0-100) †	1 (0–51)	45 (0–83)	0 (0–15)
Doctor-reported			
VAS standing (0-100) †	2 (0–37)	30 (2–82)	0 (0–1)
VAS walking (0-100) †	6 (0–51)	44 (8–91)	0 (0–1)
Participation restrictions			
Self-reported or parent-reported			
JAFI participation restrictions sub-score (0-4)	0.6 (0–2.1)	1.6 (0–2.8)	0.3 (0–1.1)

Values are median and interquartile range (IQR) unless otherwise indicated. †Higher scores indicate worse situation. JADAS-71: Juvenile Arthritis Disease Activity Score in 71 joints; VAS: visual analogue scale; ESR: erythrocyte sedimentation rate; JAFI: Juvenile Arthritis Foot Disability Index; CHAQ: Childhood Health Assessment Questionnaire.

of the ankle and foot. Table II shows that children with active joints of ankle and foot seem to have higher scores on all domains of disease activity, impairments, activity limitations and participation restrictions.

In the JAFI assessment, the most frequently mentioned problems were: pain in the feet at the end of an active day (JAFI impairments sub-score), inability to walk as far as one would like and inability to run longer distances (100 meters) (JAFI activity limitations sub-score), and restrictions in participating in sports, dancing and other daily activities (JAFI participation restrictions sub-score).

Relationships between disease activity and impairments, activity limitations and participation restrictions

The relationships between disease activity and impairments, activity limitations and participation restrictions are shown in Table III. Age was not significantly correlated with any of the variables. Disease activity, assessed with the JADAS-71, correlated significantly with all variables of impairments, activity limitations and participation restrictions (r=0.48 to 0.81, p<0.01).

Relationships between impairments, and activity limitations and participation restrictions

The relationships between impairments, activity limitations and participation restrictions are shown in Table IV. All variables of impairments correlated with activity limitations (r=0.39, p<0.05 to r=0.92, p<0.01). Moreover, six out of eight variables of impairments correlated significantly with par-

Table III. Relationships[1] between disease activity and impairments, activity limitations and participation restrictions.

	Disease activity JADAS-71
Impairments	
Self-reported or parent-reported	
JAFI impairments sub-score	0.73**
VAS pain feet	0.70**
VAS overall bodily pain	0.80**
Doctor-reported	
VAS pain feet	0.74**
Total number of limited joints	0.74**
Number of limited joints of ankle and foot	0.48**
Activity limitations	
Self-reported or parent-reported	
JAFI activity limitations sub-score	0.75**
CHAQ total score	0.71**
CHAQ arising sub-dimension	0.56**
CHAQ walking sub-dimension	0.63**
CHAQ activities sub-dimension	0.74**
VAS standing	0.63**
VAS walking	0.67**
Doctor-reported	
VAS standing	0.76**
VAS walking	0.81**
Participation restrictions	
Self-reported or parent-reported	
JAFI participation restrictions sub-score	0.54**

[1]Spearman's correlation coefficient.
**$p<0.01$. JADAS-71: Juvenile Arthritis Disease Activity Score in 71 joints; JAFI: Juvenile Arthritis Foot Disability Index; VAS: visual analogue scale; CHAQ: Childhood Health Assessment Questionnaire.

ticipation restrictions (r=0.44, p<0.05 to r=0.81, p<0.01).

There were significant correlations between self-reported or parent-reported and doctor-reported VAS pain feet (r=0.74; p<0.01), between self-reported or parent-reported and doctor-reported VAS standing (r=0.64; p<0.01), and between self-reported or parent-reported and doctor-reported VAS walking (r=0.76; p<0.01).

Relationships between activity limitations and participation restrictions

The relationships between activity limitations and participation restrictions are shown in Table V. All variables of activity limitations correlated significantly with the JAFI participation restrictions sub-score (r=0.62 to r=0.84, p<0.01).

Discussion

The aim of this study was to assess the relationships between disease activity and foot-related impairments, activity limitations and participation restrictions in children with JIA. In our sample of 34 children, only three reported no foot-related impairments, activity limitations or participation restrictions, measured with the JAFI. Strong relationships were found between the above-mentioned variables.

We found that girls and children with polyarticular JIA were highly represented, the median disease duration was relatively short, and almost all of the children were taking disease-modifying antirheumatic drugs (DMARDs), with or without anti-tumour necrosis factor (anti-TNF) treatment. This observation, combined with the rather low median values of the different variables of foot-related impairments, activity limitations and participation restrictions, indicates that the majority of the children in our sample had a stable disease under pharmacological treatment. Our results are comparable with the results recently published in a report about the severity of foot problems in 30 English children with JIA (16). In that study the JAFI, the CHAQ, and active/limited joint counts had also been used, and it was found that despite frequent antirheumatic medication and professional foot care, foot problems persist in some children with JIA. Sixty-three per cent of the children participating in that study reported some foot-related impairments (JAFI score >0), 53% reported foot-related activity limitations, and 60% reported foot-related participation restrictions, whereas in our study population these percentages were 88%, 82% and 65%, respectively (16). However, these results cannot be directly compared with our findings, since the afore-mentioned study only included children with a documented history of involvement in two major lower limb joints, involvement of foot joints, or polyarthritis.

The JAFI, one of the main outcome variables in our study, has been validated in Swedish children, but further validation is needed for the Dutch translation (13). In our study, we experienced some problems with 9 of the 27 questions. In contrast to the answers to the other questions, the answer 'never' to these questions referred to the worst situation and the answer 'always' referred to the best situation. Therefore, some children with no complaints tended to answer 'never' to these questions, without reading them carefully. We recommend that for future use in research the Dutch version should be validated with forward-backward translations, based on the international guidelines for the cross-cultural adaptation of self-report measures (17).

Although the CHAQ contains two subdimensions that concern problems with walking and activities, this questionnaire probably does not assess foot functioning as specifically as the JAFI (13, 15). Therefore, the JAFI is an essential supplementary instrument for future evaluation of foot functioning in JIA. These observations are confirmed by the conclusions of a recent study carried out by Meiorin *et al*. (18). The authors concluded that the Juvenile Arthritis Functionality Scale, a recently developed instrument to measure the function of individual joint groups, might detect the functional impact of arthritis in specific body areas with more precision than a general questionnaire concerning activities of daily living (like the CHAQ) (18). With this in mind, it is important to note that, when measuring foot-related participation restrictions with the JAFI, not only foot problems, but also other factors such as limb-length discrepancy, or knee or hip problems may have influence on the score (19). The same bias might have occurred with the measurement of VAS walking and VAS standing, because in these measurements the functioning of other joints of the lower extremity also play an important role.

We used self-reported and doctor-reported VAS scores to assess problems with standing and walking. These instruments have not frequently been used for this purpose, and further validation of VAS scores for the assessment of these activity limitations is needed. However, our results showed that the VAS scores for both standing and walking were strongly related to disease

Table IV. Relationships[1] between impairments, and activity limitations and participation restrictions.

	Impairments							
	Self-reported or parent-reported			Doctor-reported				
	JAFI impairments sub-score	VAS pain feet	VAS overall bodily pain	VAS pain feet	Total no. of active joints	Total no. of limited joints	No. of active joints of ankle and foot	No. of limited joints of ankle and foot
Activity limitations								
Self-reported or parent-reported								
JAFI activity limitations sub-score	0.87**	0.82**	0.74**	0.71**	0.62**	0.47**	0.55**	0.44**
CHAQ total score	0.84**	0.78**	0.76**	0.66**	0.56**	0.40*	0.58**	0.29
CHAQ arising sub-dimension	0.71**	0.67**	0.61**	0.59**	0.39*	0.29	0.41*	0.11
CHAQ walking sub-dimension	0.82**	0.79**	0.78**	0.72**	0.48**	0.42*	0.51**	0.32
CHAQ activities sub-dimension	0.76**	0.67**	0.71**	0.68**	0.59**	0.46**	0.54**	0.32
VAS standing	0.76**	0.87**	0.73**	0.63**	0.46**	0.40*	0.41*	0.53**
VAS walking	0.78**	0.92**	0.79**	0.79**	0.56**	0.46**	0.49**	0.50**
Doctor-reported								
VAS standing	0.65**	0.71**	0.69**	0.83**	0.71**	0.68**	0.64**	0.54**
VAS walking	0.66**	0.75**	0.76**	0.82**	0.80**	0.73**	0.72**	0.57**
Participation restrictions								
Self-reported or parent-reported								
JAFI participation restrictions sub-score	0.81**	0.75**	0.63**	0.63**	0.44*	0.32	0.33	0.45**

[1]Spearman's correlation coefficient. *p<0.05. **p<0.01. JAFI: Juvenile Arthritis Foot Disability Index; VAS: visual analogue scale; CHAQ: Childhood Health Assessment Questionnaire.

Table V. Relationships[1] between activity limitations and participation restrictions.

	Activity limitations								
	Self-reported or parent-reported							Doctor-reported	
	JAFI activity limitations sub-score	CHAQ total score	CHAQ arising sub-dimension	CHAQ walking sub-dimension	CHAQ activities sub-dimension	VAS standing	VAS walking	VAS standing	VAS walking
Participation restrictions									
Self-reported or parent-reported									
JAFI participation restrictions sub-score	0.84**	0.72**	0.62**	0.67**	0.75**	0.76**	0.76**	0.67**	0.64**

[1]Spearman's correlation coefficient. **p<0.01. JAFI: Juvenile Arthritis Foot Disability Index. CHAQ: Childhood Health Assessment Questionnaire. VAS: visual analogue scale.

activity, impairments and participation restrictions, and that there were significant correlations between self-reported or parent-reported and doctor-reported VAS scores of foot pain and problems with standing and walking (respectively r=0.74, 0.64 and 0.76; p<0.01).

Our results show that the correlations of the foot-related activity limitations with the number of active joints tended to be higher than with the number of limited joints. It might therefore be concluded that active joints have more impact on activity limitations than limited joints. An explanation for this finding might be that active joints will result in activity limitations because of the avoidance of loading and any movement of active (painful) joints, whereas limited joints will result in activity limitations due to a change in 'biomechanics'.

Strong relationships were found between disease activity and impairments, activity limitations and participation restrictions, and strong relationships were also found between activity limitations and the JAFI participation restrictions sub-score. The correlation coefficients reached statistical significance, even in our small study population, indicating that the measurement instruments we used can be used for the assessment of foot functioning in children with JIA.

This study does, however, have some potential limitations. Due to the strict planning of the regular follow-up appointments, and the short period of time available for the inclusion of patients, we recruited a small sample only, and female gender and polyarticular JIA were over-represented in this study population. In future research a large sample and a broader representation of both genders, JIA sub-types and disease duration is needed to provide more information about the prevalence of the investigated relationships in JIA. Another recommendation for future research is that more specific attention should be paid to foot deformities observed during physical examination in order to obtain a more complete picture of foot-related impairments.

The primary aim of our study was to investigate the relationship between disease activity and foot related impairments, activity limitations and participation restrictions in children with JIA. We assume that the correlations at issue might have been even stronger if only children with JIA and foot/ankle involvement had been selected for our study. The results show that children with active joints of ankle and foot seem to have higher scores on all domains of disease activity, impairments, activity limitations and participation restrictions. We did not test the statistical significance of the difference between these groups, because the separate groups were too small for such an analysis, and also because this was not in line with the primary aim of our study.

In conclusion, this is the first study that has focused on the evaluation of relationships between disease activity, foot-related impairments, activity limitations and participation restrictions in children with JIA. In this study population strong relationships were found between these variables. In our opinion, these findings imply that standard screening for foot problems should be included in follow-up care for patients with JIA. Moreover, by documenting the strong relationships between these variables in a small group, we have shown the need for further research into the possible long-term effects of foot-related impairments, activity limitations and participation restrictions on the quality of life of children with JIA.

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