Impact of involvement of individual joint groups on subdimensions of functional ability scales in juvenile idiopathic arthritis

S. Meiorin[1], G. Filocamo[1], A. Pistorio[1], S. Magni-Manzoni[2], F. Sztajnbok[1],
A. Cespedes-Cruz[1], A. Magnani[1], N. Ruperto[1], A. Martini[1,3], A. Ravelli[1,3]

[1]Istituto di Ricovero e Cura a Carattere Scientifico G. Gaslini, Genova, Italy;
[2]Fondazione Istituto di Ricovero e Cura a Carattere Scientifico Policlinico S. Matteo, Pavia, Italy;
[3]Università degli Studi di Genova, Genova, Italy.

Abstract

Objective

To investigate the influence of arthritis in individual joint groups on subdimensions of functional ability questionnaires in children with juvenile idiopathic arthritis (JIA).

Methods

206 patients were included who had the Childhood Health Assessment Questionnaire (C-HAQ) and the Juvenile Arthritis Functionality Scale (JAFS) completed simultaneously by a parent and received a detailed joint assessment. In each patient, joint involvement (defined as presence of swelling, pain on motion/tenderness and/or restricted motion) was classified in 3 topographic patterns: Pattern 1 (hip, knee, ankle, subtalar and foot joints); Pattern 2 (wrist and hand joints); Pattern 3 (elbow, shoulder, cervical spine and temporomandibular joints). Frequency of reported disability in each instrument subdimension was evaluated for each joint pattern, present either isolatedly or in mixed form.

Results

Among patients with Pattern 1, the JAFS revealed the greatest ability to capture and discriminate functional limitation, whereas impairment in the C-HAQ was more diluted across several subdimensions. Both C-HAQ and JAFS appeared to be less reliable in detecting functional impairment in the hand and wrist (Pattern 2) than in other body areas. Overall, the JAFS revealed a superior ability to discriminate the relative functional impact of impairment in individual joint groups among patients with mixed joint patterns.

Conclusion

In children with JIA, a functional measure focused to assess the function of individual joint groups (the JAFS) may detect with greater precision the functional impact of arthritis in specific body areas than does a standard questionnaire based on the assessment of activities of daily living (the C-HAQ).

Key words

Juvenile idiopathic arthritis, functional assessment, disability, health outcomes.

Clinical and Experimental Rheumatology 2009; **27**: 527-533.

Silvia Meiorin
Giovanni Filocamo, MD
Angela Pistorio, MD, PhD
Silvia Magni-Manzoni, MD
Flavio Sztajnbok, MD
Adriana Cespedes-Cruz, MD
Alessandra Magnani, MD
Nicolino Ruperto, MD, MPH
Alberto Martini, MD
Angelo Ravelli, MD

Dr Silvia Meiorin is recipient of an European League Against Rheumatism (EULAR) scholarship. Drs Flavio Sztajnbok and Adriana Cespedes-Cruz are recipients of an Alpha Scholarship from the European Union (contract no. AML/B7-311/970666/II-0246-FI).

Please address correspondence to:
Angelo Ravelli, MD,
Pediatria II, Istituto G. Gaslini,
Largo G. Gaslini 5,
16147 Genova, Italy.
E-mail:
angeloravelli@ospedale-gaslini.ge.it

Received on August 27, 2008; accepted in revised form on December 1, 2008.

Competing interests: none declared.

Introduction

The assessment of functional ability is of primary importance in the clinical evaluation of children with juvenile idiopathic arthritis (JIA) (1, 2). Self-reported or parent's proxy-reported physical functioning with questionnaires has become a critical outcome measure in both clinical trials (3) and long-term observational studies (4, 5), and has been recommended for inclusion in standard patient care (6,7). Several functional status tools have been developed and validated for use in JIA (8-13), the most popular of which is the Childhood Health Assessment Questionnaire (C-HAQ) (10).

The level of physical functioning in children with JIA is usually determined as the sum or average of the scores of all subscales included in the instrument used. Furthermore, associations of clinical variables with parent's/patient's reported function are generally evaluated as correlations with the total score. However, this approach may not be appropriate for a heterogeneous disease such as JIA. The distribution of joint disease in children with chronic arthritis is widely variable and may range from monoarthritis to asymmetric oligoarthritis, to symmetric polyarthritis. In children with oligoarticular-onset JIA, which is the most common disease subtype in Western countries (14), joint disease is often restricted to the large joints in the lower limbs. Since JIA patients differ in the topography of affected joints, functional questionnaires may contain many items that are irrelevant and uninformative for the particular patient. Assessment of functional tasks that are unlikely to be affected in an individual child (*e.g.* "lift up a glass to mouth" in a child with arthritis only in the lower extremity joints or "walk on flat ground" in a child with arthritis only in the wrist and hand joints) may "dilute" the global score, leading to a potential underestimation of functional impairment. It would, thus, be desirable to ask only specific questions that are relevant for the patient's distribution of joint disease and to drop other questions.

We recently developed a new functional status questionnaire, the Juvenile Arthritis Functionality Scale (JAFS) (6), which is designed differently from previous tools used in JIA. Instead of exploring the child's ability to perform the common activities of daily living (ADL), the JAFS assesses, for the most part, the basic functions that underlie the ADL. Furthermore, functional activities are grouped in 3 different areas (lower limbs, wrist/hand, and upper segment), that are identified by the topography of the joints or joint groups that are involved in each activity. The JAFS yields a total score and a separate score for each of the 3 functional areas. However, it is unclear whether this approach is more advantageous than the traditional assessment of the ADL in dissecting the influence of impairment in individual joints on specific functions.

In the present study, we have compared the ability of an ADL-based questionnaire (the C-HAQ) with that of the JAFS to capture the functional impact of arthritis in individual joint groups in children with JIA.

Patients and methods

Patient selection

Patients included in this study were part of a previous analysis aimed to validate the JAFS (6). The eligibility criteria for the original study were the following: 1) diagnosis of JIA by ILAR criteria (15); 2) age <18 years at study visit; 3) informed consent by the parent/guardian. To be included in the present study, patients had to have the C-HAQ and the JAFS completed simultaneously by a parent and a detailed joint assessment available for review. The study sample is composed of patients seen consecutively in the authors' clinics between April and September 2005. The study protocol was approved by the Istitutional Review Board of the Istituto G. Gaslini of Genova, Italy.

Functional ability assessment

Prior to the study visit, the mother or, if the mother did not attend the clinic, the father of each patient was asked to complete the Italian version of the C-HAQ (16) and the Italian version of the JAFS (6). The 2 questionnaires were presented to the raters in random order, using a computer-generated allocation schedule. The C-HAQ measures the child's ability in performing functions included in 8 areas (Dressing and Grooming, Arising, Eating, Walking, Hygiene, Reach, Grip, and Activities). Each question is scored from 0 to 3 (0 = no difficulty, 1 = some difficulty, 2 = much difficulty, 3 = unable to do). A “not applicable” column is added for those activities that a child is unable to perform because of developmental immaturity. The question with the highest score determines the score for that functional area. If aids or devices are used or help is needed to complete tasks in a certain area, a minimum score of 2 is recorded for the corresponding functional area. The scores for each of the 8 functional areas are averaged to calculate the C-HAQ disability index (DI), which ranges from 0 to 3 (0 = best; 3 = worst).

The JAFS is a 15-item questionnaire in which functional tasks are grouped into 3 functional areas, each composed by 5 items: lower limbs, hand/wrist and upper segment. The ability of the child to perform each task is scored as follows: 0 = without difficulty, 1 = with difficulty, 2 = unable to do. An “unable to assess” column is included to designate functions that cannot be performed because of developmental immaturity. The total score ranges from 0 to 30. A separate score for each area (range 0-10) can be calculated. In case an item is scored as unable to assess, the item is given the mean score of the applicable items in the functional area rounded to the nearest integer. No questions regarding aids or devices or need of help from another person are included.

Clinical assessment

At the time of the study visit, the following information was obtained for each patient: sex, age at disease presentation, JIA ILAR category, disease duration and age at study visit. The following clinical assessments were made by the attending pediatric rheumatologist: physician’s global assessment of overall disease activity on a 10-cm VAS (0 = no activity; 10 = maximum activity) and count of joints with swelling, pain on motion/tenderness, functional limitation, and active arthritis (defined as the presence of swelling or, if swelling was not present or detectable, as the presence of pain on motion/tenderness and restricted motion) (17).

The parent who completed the functional ability questionnaires was also asked to provide a global rating of the child’s well-being on a 10-cm visual analogue scale (VAS) (0 = very good; 10 = very poor) and to rate the intensity of the child’s pain on a 10-cm VAS (0 = no pain; 10 = very severe pain). The two scales were presented in separate sheets, as suggested (18). The same parent was also asked to evaluate the child’s health-related quality of life (HRQL) through the Italian version of the Child Health Questionnaire (CHQ) (16).

Laboratory assessments included erythrocyte sedimentation rate (ESR) (Westergren method) and C-reactive protein (CRP) (nephelometry).

Definition of joint patterns

In each patient, joint involvement was classified in the following 3 patterns: Pattern 1=involvement of hip, knee, ankle, subtalar, foot joints; Pattern 2=involvement of wrist, hand joints; Pattern 3=involvement of elbow, shoulder, cervical spine, temporomandibular joints. A joint was defined as “involved” if it had either swelling, pain on motion/tenderness, or restricted motion on standard joint assessment (17). Depending on the distribution of joint involvement, patients could have only a single pattern or a combination of patterns (mixed patterns). Patients with no signs of joint involvement were classified as having Pattern 0. Joint patterns that were detected only in 5 or less patients were excluded from the analyses.

Statistics

Descriptive statistics are reported in terms of means, standard deviations, medians and ranges for continuous variables and in terms of absolute frequencies and percentages for categorical variables. Because the score range of the C-HAQ and the JAFS differ, for quantitative comparisons the score of the two instruments was normalized to a 0-100 scale using the following formula: [(observed score – min score value) / (score range)] *100. The statistical package used was the “Statistica” (StatSoft Corp., Tulsa, OK).

Results

Patients’ characteristics

Of the 211 patients included in the original study (6), 206 met the criteria for inclusion in the present study. Fifty-seven (27.7%) patients were boys and 149 (72.3%) were girls. The age at disease onset ranged from 0.6 to 15.6 years (mean ± SD: 4.5±3.3 years; median: 3.5 years), the age at study visit ranged from 2.2 to 18 years (mean ± SD: 8.8 ±4.5 years; median: 8.4 years), and the disease duration ranged from 0.3 to 17.1 years (mean ± SD: 4.3±3.5 years; median: 3.6 years). The ILAR category was systemic arthritis in 15 (7.3%) patients, persistent oligoarthritis in 91 (44.2%) patients, extended oligoarthritis in 50 (24.3%) patients, rheumatoid-factor negative polyarthritis in 35 (17%) patients, rheumatoid-factor positive polyarthritis in 4 (1.9%) patients, psoriatic arthritis in 5 (2.4%) patients, and enthesitis-related arthritis in 6 (2.9%) patients; 156 (74.4%) patients were antinuclear antibody-positive. Overall, the patients’ features reflect the high prevalence in the authors’ country of the JIA subset characterized by early onset, female predilection, oligoarticular presentation, presence of circulating ANA, asymmetric arthritis, and risk of chronic iridocyclitis (18-20). The values of juvenile idiopathic arthritis outcome measures at study entry are presented in Table I. The low median values of physician’s and parent’s global ratings, functional status measures, joint counts, duration of morning stiffness, and acute phase reactants indicate that, on average, patients had a low level of disease activity and functional disability at the time of the study visit.

Assessment of joint patterns

Seventy-eight patients (37.9%) had only a single joint pattern (46 had Pattern 1, 27 had Pattern 2 and 5 had Pattern 3), whereas 68 patients (33%) had a mixed pattern (30 had Pattern 1/2, 13 had Pattern 1/3 and 25 had Pattern 1/2/3). Pattern 2/3 was not observed. Sixty patients (29.1%) had Pattern 0. Because isolated Pattern 3 was detected only in 5 patients, it was excluded from the analyses.

Frequency of reported disability by joint pattern

Table II shows the percentage of patients with C-HAQ and JAFS total score > 0 and the frequency of reported disability in each questionnaire subdimension by joint pattern. Among patients with no affected joints (Pattern 0), the total score of the C-HAQ was more frequently abnormal than that of the JAFS (33.3% *vs.* 25%). The most and least frequently reported disability was in the "eating" (16.7%) and "walking"/"arising" (3.3%) subdimensions of the C-HAQ, respectively, and in the "lower limbs" (13.3%) and "wrist-hands" (8.3%) subdimensions of the JAFS, respectively.

The total score of both questionnaires was abnormal (*i.e.* >0) in around half of the patients who had a single joint pattern, either Pattern 1 or Pattern 2. Among patients who had a mixed pattern, those with Pattern 1/3 had a more frequently abnormal instrument total score (76.9% for the C-HAQ and 69.2% for the JAFS) than those with Pattern 1/2 (48.3% for the C-HAQ and 56.7% for the JAFS). As expected, Pattern 1/2/3 had the greatest functional impact, with as many as 84% and 92% of patients with this pattern having an abnormal total C-HAQ and JAFS total score, respectively.

Among patients with isolated involvement of the lower extremity joints (Pattern 1), disability was reported most and least frequently in the "activities" (42.2%) and "grip" (8.7%) subdimensions of the C-HAQ, respectively, and in the "lower limbs" (50%) and "hand-wrist" (6.5%) subdimensions of the JAFS, respectively. As expected, the "lower limb" area of the JAFS, which is focused to assess the function of the lower extremities, captured much better the functional impact of this joint pattern than did the other questionnaire subdimensions. Although disability in the C-HAQ was also more frequently reported in the subdimensions that contain items that assess the function of the lower extremities, impairment appeared to be diluted across several subdimensions, perhaps reflecting the presence of items that assess the function of the upper extremities as well as the trunk simultaneously. The greater discriminative ability of the JAFS in patients with Pattern 1 was confirmed by the comparison of the mean standardized scores of the two questionnaires (Fig. 1).

Table I. Values of juvenile idiopathic arthritis outcome measures at study entry.

	Range of possible values	Mean±SD	Median	Range
Physician's global assessment - cm	0-10	2.8 ± 3.3	1	0-10
Parent's global assessment - cm	0-10	2.3 ± 2.6	1.2	0-9.5
Parent's pain assessment - cm	0-10	2.3 ± 2.7	1	0-9.7
C-HAQ score	0-3	0.30 ± 0.4	0.13	0-1.9
JAFS score	0-30	1.9 ± 2.8	0	0-11
JAFS-Lower limbs score	0-10	1.1 ± 1.9	0	0-9
JAFS-Hand-wrist score	0-10	0.5 ± 1.1	0	0-5
JAFS-Upper segment score	0-10	0.4 ± 0.9	0	0-6
Swollen joint count	0-60	2.5 ± 4.2	1	0-24
Tender joint count	0-67	2.8 ± 7.1	0	0-62
Restricted joint count	0-65	2.4 ± 5.3	0	0-36
Active joint count	0-67	3.2 ± 6.0	1	0-42
CHQ-Physical summary score	-§	46.5 ± 10.8	49.7	16.4-62.8
CHQ-Psychosocial summary score	-§	48.5 ± 8.3	49.4	18.1-63.3
ESR - mm/h	< 20	22.0 ± 20.6	14	1-103
C-reactive protein - mg/dl$^{\&}$	< 0.3	1.5 ± 3.5	0.5	0.3-29.1

C-HAQ: Childhood Health Assessment Questionnaire; JAFS: Juvenile Arthritis Functionality Scale; CHQ: Child health Questionnaire; ESR: erythrocyte sedimentation rate; §mean ± SD norm based score for both physical and psychosocial summary scores: 50±1; $^{\&}$all negative values were converted to 0.3 mg/dl.

Table II. Frequency of impairment (*i.e.* score > 0) of functional status questionnaire subdimensions by joint pattern. Percentages are indicated in parenthesis.*

	Joint pattern					
	0 (n=60)	1 (n=46)	2 (n=27)	1,2 (n=30)	1,3 (n=13)	1,2,3 (n=25)
C-HAQ disability index	20 (33.3)	23 (50)	14 (51.9)	14 (48.3)	10 (76.9)	21 (84)
Dressing & grooming	8 (13.3)	6 (13.6)	6 (22.2)	9 (32.1)	3 (23.1)	14 (56)
Arising	2 (3.3)	10 (21.7)	2 (7.4)	6 (20.7)	6 (46.2)	8 (32)
Eating	10 (16.7)	6 (13)	3 (11.1)	4 (13.8)	2 (16.7)	7 (28)
Walking	2 (3.3)	12 (26.7)	1 (3.7)	6 (20.7)	8 (61.5)	5 (20)
Hygiene	7 (11.7)	10 (22.2)	4 (14.8)	4 (13.8)	5 (38.5)	12 (48)
Reach	9 (15)	12 (26.1)	5 (18.5)	5 (17.2)	7 (53.8)	16 (64)
Grip	9 (15)	4 (8.7)	3 (11.1)	2 (6.9)	4 (30.8)	11 (44)
Activities	9 (15)	19 (42.2)	5 (18.5)	6 (20.7)	7 (58.3)	12 (48)
JAFS total score	15 (25)	23 (50)	12 (44.4)	17 (56.7)	9 (69.2)	23 (92)
Lower limbs	8 (13.3)	23 (50)	6 (22.2)	14 (46.7)	8 (61.5)	15 (60)
Hand-wrist	5 (8.3)	3 (6.5)	7 (25.9)	8 (26.7)	2 (15.4)	17 (68)
Upper segment	6 (10)	5 (10.9)	4 (14.8)	4 (13.3)	6 (46.2)	19 (76)

*C-HAQ: Childhood Health Assessment Questionnaire; JAFS: Juvenile Arthritis Functionality Scale. See text for definition of joint patterns.

Among patient with involvement of the sole hand and wrist joints (Pattern 2), disability was reported most and least frequently in the "dressing & grooming" (22.2%) and "walking" (3.7%) subdimensions of the C-HAQ, respectively, and in the "hand-wrist" (25.9%) and "upper segment" (14.8%) subdimensions of the JAFS, respectively. Unexpectedly, the "eating" and "grip" subdimensions of the C-HAQ, that are aimed to explore specifically the function of the hand and wrist joints, were affected in only 11.1% of the patients. Also unexpectedly, disability in the "lower-limb" subdimension of the JAFS was reported in as many as 22.2% of the patients. Altogether, these observations suggest that both C-HAQ and

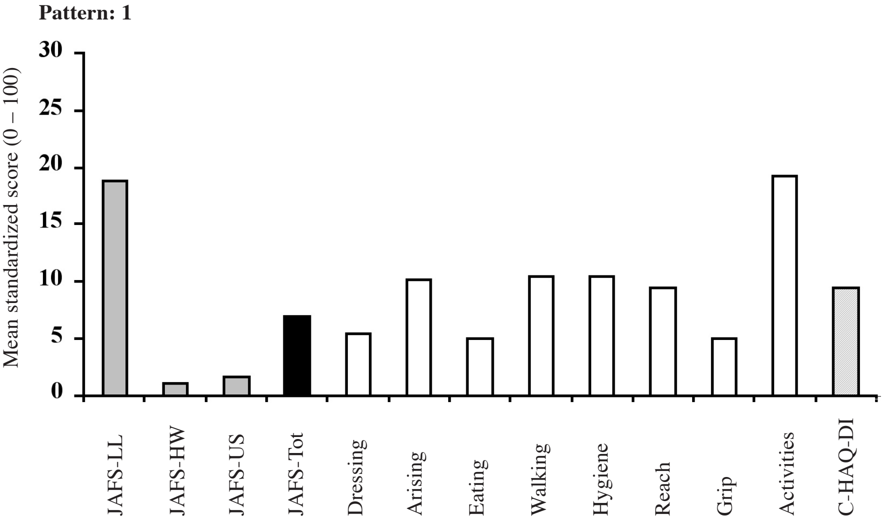

Fig. 1. Maximum possible score of functional status questionnaire total scores and subdimensions in patients with Pattern 1. JAFS: Juvenile Arthritis Functionality Scale; C-HAQ: Childhood Health Assessment Questionnaire; LL: lower limbs; HW: hand-wrist; US: upper segment; DI: disability index.

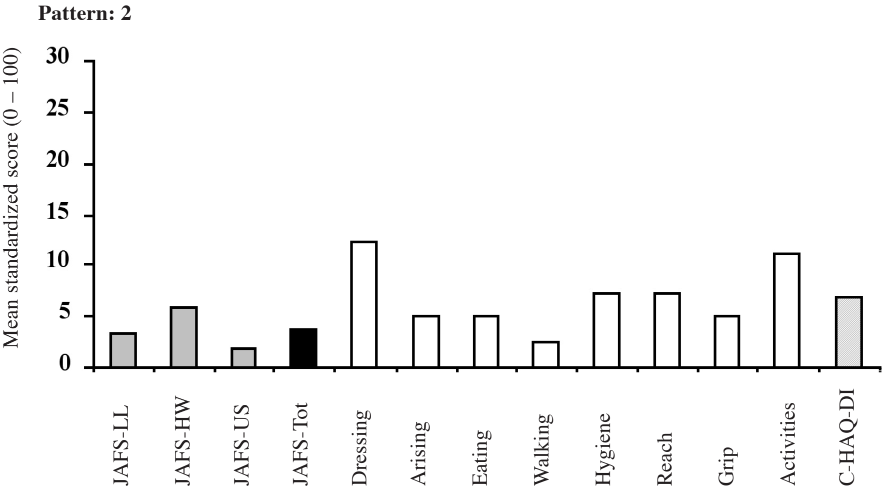

Fig. 2. Maximum possible score of functional status questionnaire total scores and subdimensions in patients with Pattern 2. See Fig. 1 for abbreviations.

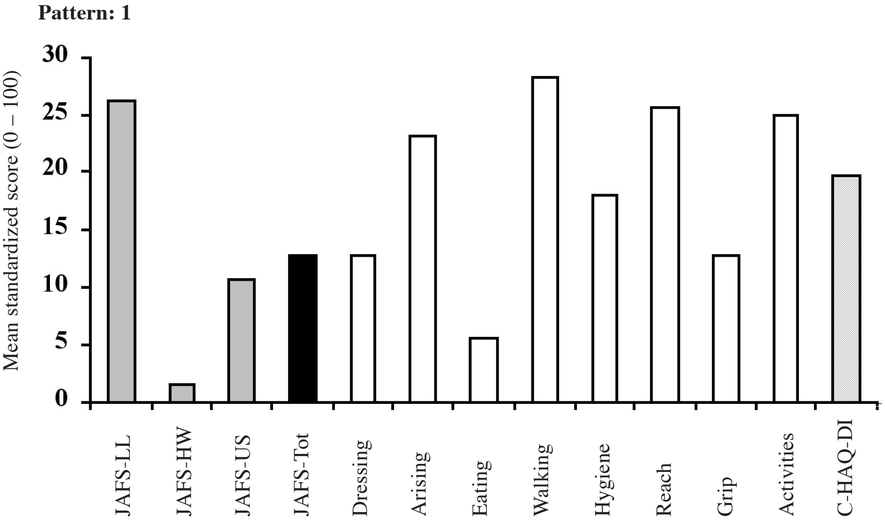

Fig. 3. Maximum possible score of functional status questionnaire total scores and subdimensions in patients with Pattern 1/3. See Fig. 1 for abbreviations.

the JAFS might not be reliable enough to detect and discriminate functional impairment in the hand and wrist joints. This is also demonstrated by the analysis of the mean standardized scores of the two questionnaires (Fig. 2).

Concerning mixed patterns, the concomitant presence of Patterns 1 and 3 had a generalized greater impact on questionnaire subdimensions than the association of Patterns 1 and 2. Among patient who had all 3 joint patterns simultaneously, disability was reported most and least frequently in the "reach" (64%) and "walking" (20%) subdimensions of the C-HAQ, respectively, and in the "upper segment" (76%) and "lower limbs" (60%) subdimensions of the JAFS, respectively. Overall, the JAFS revealed a superior ability to capture and discriminate the influence of impairment in individual joint groups on questionnaire subdimensions among patients with mixed joint patterns. Indeed, patients with Pattern 1/2 had a greater frequency of reported disability in the correspondent "lower limb" and "wrist hand" areas; patients with Pattern 1/3 had a greater frequency of reported disability in the correspondent "lower limb" and "upper segment" areas; patients with Pattern 1/2/3 had a similarly high frequency of reported disability in all 3 areas. In the C-HAQ, impairment was much more diluted across subdimensions. An example of the greater discriminative ability of the JAFS for mixed patterns is provided in Figure 3, which shows the comparison of the mean standardized score of the two instruments in patients with Pattern 1/3.

Discussion

Several studies have shown that total scores on functional ability measures reflect both disease activity and damage and are associated with swollen, tender and restricted joint counts in children with JIA (17, 21). However, little is known about the influence of involvement of individual joints on subdimensions of physical function scales. Knowing the relative impact of disease in particular joints on children's functioning is important to determine the optimal plan of intraarticular corticosteroid treatment and of physical and occupational therapy interventions. This might be particularly relevant for a disease like JIA, which is often characterized by asymmetric involvement of few joints.

To enable a more precise assessment of the functional impact of disease in single joints, we recently developed a new functional status questionnaire, the JAFS (6), in which functional activities are grouped in 3 different body areas (lower limbs, wrist/hand, and upper segment) and are selected to be specifically related to the joints belonging to the area. We felt that this approach was advantageous over that of standard ADL-based questionnaires, such as the C-HAQ (10), which contain many items that explore activities involving the upper and lower limbs as well as the trunk simultaneously.

In the present study, we investigated whether the JAFS attains its goals by exploring the extent to which swelling, pain on motion/tenderness and/or restricted motion in the joints of children with JIA, grouped in 3 topographic patterns as in the JAFS, affected the 3 subdimensions of the JAFS. Furthermore, we compared the JAFS with a standard ADL-based questionnaire (the C-HAQ).

An interesting observation in our study was that a considerable proportion of patients who had a normal joint assessment (Pattern 0) were judged as having at least some impairment in physical function (*i.e.* were given a score >0) by their parents in both questionnaires. This incongruence may be explained by the persistence of weakness of muscles surrounding previously affected joints, by the difference between parent's and physician's assessments, which reflected the child's average performance over the preceding week and the clinical evaluation of the child only at one point in time, respectively, or by the tendency of some parents to underestimate their children's functional ability. That this phenomenon was more pronounced for the C-HAQ than for the JAFS may be related, at least in part, to some questions in the C-HAQ, particularly those concerning the activities in which the child needs help from another person, being not answered correctly or misunderstood by the parents (6). The discrepancy in patients with Pattern 0 between the higher frequency of lower limb function impairment in the JAFS and the low frequency of involvement of the walking area in the C-HAQ may be explained by a greater impact of arthritis in the lower extremities on other C-HAQ areas, such as arising, hygiene and activities.

Both questionnaires captured well-isolated impairment in the lower extremity joints (Pattern 1), with subdimensions exploring locomotor activities being most frequently affected. However, the JAFS subdimensions appeared superior over those of the C-HAQ in discriminating the functional impact of Pattern 1, owing to the presence of the "lower limb" area, which contains items that assess functions involving specifically the lower extremity joints. Impairment was more diluted across the C-HAQ subdimensions, likely reflecting the presence in many of them of items that assess the function of the lower and upper extremities as well as the trunk simultaneously.

The analysis of patients with mixed joint Patterns 1/2 and 1/3 revealed that the functional impact of involvement of the upper segment joints (elbow, shoulder, cervical spine and temporomandibular) tended to be greater than that of the hand and wrist joints. Furthermore, both instruments appeared to be less reliable, among patients with an isolated Pattern 2, in exploring activities that involve the use of the latter joints. Taken together, these findings suggest that current functional ability tools may not be powerful enough to assess fine movements of the upper extremities. It should be taken into account, however, that children with oligoarticular JIA, which constituted the majority of our patients, often have asymmetric involvement only a few small joints in the hands. This means that fine movements may be less impaired in these children as compared to those with polyarthritis who have symmetric (*i.e.* diffuse) involvement of finger joints.

The superior discriminant ability of the JAFS for impairment in specific joint groups was particularly manifest among patients with mixed patterns, among whom each pattern was associated with a greater frequency of reported disability in the correspondent JAFS subdimension. Once more, impairment was much more diluted across C-HAQ categories. The better discriminant ability of the JAFS was strengthened by the comparison of the mean standardized score of the two instruments. This finding suggests that the JAFS is superior in capturing selectively the impairment in individual joint groups in patients who have joint disease in different part of the body.

Our results should be viewed in the light of several potential limitations. We should acknowledge that the combination of joint patterns with reference to the JAFS areas may have facilitated the better performance of this tool. Because joints in the same body area may have different functional importance (22), assessment functional impairment of individual joints, rather than joint groups, might have been more appropriate. We did not assess the influence of alterations in muscle strength, which is an important factor contributing to decreased functional ability. We asked the parents to rate the health status of their children, but did not obtain information on children's self-reporting. However, using only parent's proxy reports instead of both parents' and patients' self reports would fail to capture that parents and children may differ in their perception of health (23-25). The overrepresentation of the oligoarthritis subtype and the low level of disease activity and disability in most of our patients may have limited the generalizability of our findings. However, our patients represent a consecutive sampling of our clinic population and are likely representative of the patients seen in most tertiary pediatric rheumatology centers. We have evaluated the Italian version of the two questionnaires. It is possible that parents elsewhere might respond differently to the questions due to cultural and language diversities. Nevertheless, our study provides important information that is useful to design future functional ability tools for children with JIA. It has been recently suggested that the time has come to improve patient's/parent's reported outcomes taking advantage of the newer statistical and technological methodologies, with the goal of improving their precision, ease to use, and responsiveness to clinical change (26). In line with the approach followed in the development of the JAFS, recent expert consensus has proposed to conceptualize "Physical Function/Disability" as containing the following 4 subdomains: "upper extremity", "trunk", "lower extremity", and "complex activities" (*i.e.* instrumental ADL) (27).

In conclusion, we found evidence that a functional measure focused to assess the function of individual joint groups enables capturing with greater accuracy the functional impact of arthritis in specific body areas than does a standard ADL-based questionnaire in children with JIA. This approach may be of help to take future functional ability tools to a greater level of precision, while reducing the length of items posed to the individual respondent. Additional analyses in different patient populations are needed to further explore our findings.

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