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Evaluation of Quality of Life in Juvenile Idiopathic Arthritis Using Juvenile Arthritis Multidimensional Assessment Report (JAMAR)

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Abstract

Objective: *To evaluate the quality of life in children diagnosed with JIA using juvenile arthritis multidimensional assessment report (JAMAR)*

Methods: *The Juvenile Arthritis Multidimensional Assessment Report (JAMAR) includes 15 parent or patient-centered measures or items that assess well-being, pain, functional status, health-related quality of life, morning stiffness, disease activity, disease status and course, joint disease, extra - articular symptoms, side effects of medications, therapeutic compliance, and satisfaction with illness outcome. The questionnaire was applied to 44 children who attended the pediatric rheumatology clinic in Alexandria University Children's hospital, Egypt. The questionnaire was repeated to all patients after 6 months*

Results: *Results of this study revealed that the JAMAR questionnaire was valid, reliable and sensitive to change of the disease activity The JAMAR provided thorough information for the study patients about recent medical history and current health status.*

Conclusion: *Integrating patient reported outcome measures into standard clinical practice is feasible and applicable. Development of the JAMAR introduces a new approach in pediatric rheumatology practice. This new questionnaire may help enhance the quality of care of children with JIA.*

Introduction

Juvenie idiopathic arthritis is defined as arthritis of unknown etiology starting before the child's 16th birthday and persisting for at least 6 weeks, where known causes have been excluded as regard symptoms and signs.[(1)]

Juvenile idiopathic arthritis is the most common chronic rheumatic disease in children and an important cause of short-term and long-term disability that impair the normal child life. Studies in developed countries have reported a prevalence that varies between 16 and 150 per 100 000. One view is that the prevalence of this disease is underestimated. A community- based survey in Australia reported a prevalence of400 per 100 000 on the basis of clinical examination of school children by a paediatric rheumatologist.[(2)] Egyptian retrospective study showed charts of 196 Egyptian children fulfilled the International League of Associations for Rheumatology (ILAR) classific-ation and were followed up between 1990 to 2006in Cairo University Children Hospital, the male to female ratio was 1:1.09.[(3)]

In recent years, there has been an increasing interest in parent/ patient-reported outcomes (PRO) in juvenile idiopathic arthritis (JIA)[(4-8)]. Incorporation of these measures in patient assessment is deemed

important as they reflect the parents' and children's perception of the disease course and effectiveness of therapeutic interventions. Because the physician's evaluation of the disease status drives therapeutic decisions, and these decisions are of foremost importance to parents and patients, integration of their perspective in clinical evaluation may facilitate concordance with physician's choices and compliance with therapeutic prescriptions and help to take appropriate plan easily.[9-11]

A number of measures for the assessment of PRO in children with JIA have been developed over the years, including visual analog scales (VAS) for rating of child's overall well-being and intensity of pain, and questionnaires for the evaluation of functional ability and health-related quality of life (HRQOL),[4-23].

However, other PRO not addressed by conventional instruments, such as evaluation of morning stiffness and overall level of disease activity, rating of disease status and course, proxy- or self-assessment of joint involvement and extra-articular symptoms, description of side effects of medications, and assessment of therapeutic compliance and satisfaction with the outcome of the illness, may provide valuable insights into the influence of the disease, its treatment and prognosis.

The JAMAR was devised by a group of 7paediatric rheumatologists (GF, AC, SMM, NR, SV, AM, AR), based on their experience (3 to > 20 years) in clinical assessment of children with JIA, and on a literature review on PRO in adult and paediatric patients with chronic arthritis,[24-27]. To make the JAMAR feasible and practical, it was decided that all measures included in the instrument should be short and easy to complete and score. A total of 32measures were considered for inclusion in the instrument. After extensive discussion of the relative importance and suitability of each measure, a measure was retained only when there was agreement of at least 6/7 members of the panel that it should be kept in the questionnaire. Thus, content validity was obtained by the members of the panel. The following 15 measures/items were included:

(1) Assessment of functional ability, through the Juvenile Arthritis Functionality Scale (JAFS)
(2) Rating of the intensity of child's pain on a 21-numbered circle VAS
(3) Assessment of HRQOL, through the Paediatric Rheumatology Quality of Life Scale (PRQL)
(4) Rating of child's overall well-being ona 21-numbered circle VAS
(5) Assessment of the presence of pain or swelling in joints
(6) Assessment of morning stiffness.
(7) Assessment of extra-articular symptoms (fever and rash).
(8) Rating of the level of disease activity on a 21-numbered circle VAS
(9) Rating of disease status
(10) Rating of disease course
(11) Listing of medications the child is taking.
(12) Description of side effects of medications.
(13) Report of difficulties with medication administration.
(14) Report of school problems caused by the disease.
(15) A question about satisfaction with the outcome of the illness.

Patients and Methods

This prospective study was conducted on 44 children diagnosed as JIA who were attending the paediatric rheumatology clinic, Alexandria University Children's Hospital, Egypt.

Theparents/children pairs were invited to a private room and subjected to:

1. Thorough history taking.
2. Complete physical examination (including chest, heart, abdomen and musculoskeletal system).
3. Laboratory investigations, acute phase reactant (CBC, ESR, and CRP) at time of questionnaire were done.
4. Disease Activity Scoring (DAS score) was done to all patients.
5. The translated and validated Arabic version of Juvenile Arthritis Multidimensional Assessment Report (JAMAR) was explained to parents/ children pairs and they were asked to fulfil.

The questionnaire was repeated for the same patients and the results were statistically analysed after 6 months.

Results

Demographic data

27 patients (61.4 %) were females and 17 patients (38.6%) were males. The age of studied patients in the clinic ranged from 3 to 16 years (9.03 ± 3.52years). The age at onset ranged from one year to thirteen years (6.13 ± 3.10years). The duration of the disease ranged from 0.5 to 10 years (2.89 ± 2.47years)

Table (1): Demographic Data

	No.	%
Sex		
Male	17	38.6
Female	27	61.4
Age (years)		
≤10	27	61.4
>10	17	38.6
Min. – Max.	3.0 – 16.0	
Mean ± SD.	9.03 ± 3.52	
Median	9.0	
Age at onset (years)		
Min. – Max.	1.0 – 13.0	
Mean ± SD.	6.13 ± 3.10	
Median	6.0	
Disease duration (years)		
Min. – Max.	0.50 – 10.0	
Mean ± SD.	2.89 ± 2.47	
Median	2.0	

ILAR category

9 patients (20.5%) were diagnosed as seronegative Systemic onset JIA, 13 patients (29.5%) were diagnosed as seronegative Oligo-aricular JIA, 2 patients (4.5%) were diagnosed as seropositive Oligo-aricular JIA, 16 patients (36.4%) were diagnosed as seronegative Polyarticular JIA and 4 patients (9.1%) were diagnosed as seropositive Polyarticular JIA.

Table (2): Distribution of the studied cases according to ILAR category

Diagnosis	No.	%
Systemic onset JIA		
-ve	9	20.5
Oligoaricular		
-ve	13	29.5
+ve	2	4.5
Polyarticular JIA		
-ve	16	36.4
+ve	4	9.1

Joint affection

24 patients (54.5%) had joint affection in the 1st assessment with mean of (2.92 ± 1.93) joints affected(3 patients had one joint affection, 13 patients had two joints affection,2 patients had three joints affection, 2 patients had four joints affection, two patients had six joints affection, one patient had seven joints affection and one patient had eight joints affection) , while only 12 patients (**27.3**%) had joint affection in the 2nd assessment with mean of (2.0 ± 1.07) joints affected (3 patients had one joint affection, 4 patients had two joints affection,2 patients had three joints affection, 1 patient had four joints affection, two patients had seven joints affection).

Table (3): Distribution of the studied cases according to joint affection

	1st assessment (n=44)		2nd assessment (n=44)	
	No.	**%**	**No.**	**%**
Number of affected joints				
No	20	45.5	32	72.7
Yes	**24**	**54.5**	**12**	**27.3**
1	3	12.5	3	25.0
2	13	54.2	4	33.3
3	2	8.3	2	16.7
4	2	8.3	1	8.3
5	0	0.0	0	0.0
6	2	8.3	0	0.0
7	1	4.2	2	16.7
8	1	4.2	0	0.0
Min. – Max.	1.0 – 8.0		1.0 – 7.0	
Mean ± SD.	2.92 ± 1.93		2.92 ± 2.11	
Median	2.0		2.0	

Disease activity score (DAS)

DAS score code from 0to 10 being 0 is the best, 10 the worst. The mean DAS score was 3.13 ± 1.17 in the 1st assessment while the mean DAS score was2.37 ± 0.78 in the 2nd assessment. There was highly statistically significant difference between the 1st and 2nd assessment (being better in the 2nd assessment) ($p<0.001$)

Table (4) Distribution of cases according to DAS score

Dis activity score	1st assessment (n=44)	2nd assessment (n=44)	T	P
Min. – Max.	1.14 – 6.06	1.13 – 4.47		
Mean ± SD.	3.13 ± 1.17	2.37 ± 0.78	4.769*	<0.001*
Median	3.03	2.31		

T,P: t and p values for **Paired t-test** for comparing between 1st and 2nd assessment
*: Statistically significant at $p \leq 0.05$

Juvenile arthritis functionality score (JAFS)

The JAFS score code from 0 to 30 being 0 the best,30 the worst. The mean JAFS was 4.66 ± 7.2514in the 1st assessment while the mean JAFS was 3.43 ± 7.17 the 2nd assessment. There was statistically significant difference between the 1st and 2nd assessment according to JAFS score (being better in the 2nd assessment) (p<0.05).

Table (5) Comparison between 1st and 2nd assessment according to JAFS

	1st assessment (n=44)	2nd assessment (n=44)	Z	P
PRQL				
Min. – Max.	0.0 – 30.0	0.0 – 30.0		
Mean ± SD.	8.70 ± 6.54	5.30 ± 6.56	3.851*	<0.001*
Median	8.0	4.50		

Z, p: Z and p values for **Wilcoxon signed ranks test** for comparing between 1st and 2nd assessment
*: Statistically significant at $p \leq 0.05$

Pediatric Rheumatology Quality of Life scale (PRQL)

PRQL score codes from 0 to 30 being 0 the best, 30 the worst. The mean PRQL was 8.70 ± 6.54 in the 1st assessment while the mean PRQL was 5.30 ± 6.56 in the 2nd assessment. There was highly statistically significant difference between the 1st and 2nd assessment according to PRQL score (being better in the 2nd assessment) (p<0.001).

Table (6) Comparison between 1st and 2nd according to and PRQL

	1st assessment (n=44)	2nd assessment (n=44)	Z	P
JAFS score				
Min. – Max.	0.0 – 30.0	0.0 – 30.0		
Mean ± SD.	4.66 ± 7.25	3.43 ± 7.17	2.468*	0.014*
Median	2.0	0.0		

Z, P: Z and p values for **Wilcoxon signed ranks test** for comparing between 1st and 2nd assessment
*: Statistically significant at $p \leq 0.05$

Visual analogue scale

The VAS score code from 0 to 10 being 0 is the best, 10 is the worst

The mean VAS scale for well-being was 1.99 ± 2.13 and 1.51 ± 1.82 in the 1st and 2nd assessment respectively. The mean VAS scale for pain was 2.09 ± 2.55 and 1.51 ± 2.06 in the 1st and 2nd assessment respectively. The mean VAS scale for disease activity was 2.74 ± 5.47 and 1.50 ± 2.01 in the 1st and 2nd assessment respectively. A statistically significant difference between the 1st and 2nd assessment was detected regarding VAS disease activity (p<0.05).but difference between 1st and 2nd assessment regarding VAS well-being and pain are not asatistically significant (p>0.05)

Table (7) Comparison between 1st and 2nd assessment according to VAS

VAS	1st assessment (n=44)	2nd assessment (n=44)	Z	P
Well being				
Min. – Max.	0.0 – 7.0	0.0 – 7.0		
Mean ± SD.	1.99 ± 2.13	1.51 ± 1.82	1.742	0.081
Median	1.50	1.0		
Pain				
Min. – Max.	0.0 – 7.50	0.0 – 7.0		
Mean ± SD.	2.09 ± 2.55	1.51 ± 2.06	1.857	0.063
Median	1.0	1.0		
Disease activity				
Min. – Max.	0.0 – 35.0	0.0 – 8.0		
Mean ± SD.	2.74 ± 5.47	1.50 ± 2.01	2.417*	0.016*
Median	1.0	1.0		

Z, p: Z and p values for **Wilcoxon signed ranks test** for comparing between 1st and 2nd assessment
*: STATISTICALLY SIGNIFICANT AT $P \leq 0.05$

Disease status

22 patients (50%) had continued activity in the 1st assessment while only 11 patients (25%) had continued activity in the 2nd assessment. 20 patients (45%) had remission in the 1st assessment and 33 (75%) patients had remission in the 2nd assessment. 2 patients (4.5%) had relapse in the 1st assessment while no patients had relapses in the 2nd assessment. There was a statistically significant difference between the 1st and 2nd assessment regarding the disease status (MHP < 0.05).

Table (8): Comparison between 1st and 2nd according to disease status

Disease status	1st assessment (n=44)		2nd assessment (n=44)		MHp
	No.	%	No.	%	
Continued activity	22	50.0	11	25.0	0.020*
Remission	20	45.0	33	75.0	
Relapse	2	4.5	0	0.0	

MH: **Marginal Homogeneity Test** for comparing between **1st**and **2nd assessment**
*: STATISTICALLY SIGNIFICANT AT P ≤ 0.05

Disease course (table 9)

31 patients (70.5%) were much improved in the 1st assessment while 34 patients (77.3%) were much improved in the 2nd assessment. 10 patients (22.7%) were slightly improved in the 1st assessment while 6 patients (13.6%) were slightly improved in the 2nd assessment. one patient (2.3%) had stationary course in the 1st assessment while 4 patients (9.1%) had stationary course in the 2nd assessment. one patient (2.3%) had slightly worse course and one patient (2.3%) had much worse course in the 1st assessment while no patients had neither slightly worse nor much worse course in the 2nd assessment. There was no statistically significant difference between the 1st and 2nd assessment according to (MHP < 0.05).

Table (9) Distribution of the studied cases according to disease course

Disease course	1st assessment (n=44)		2nd assessment (n=44)		MHp
	No.	%	No.	%	
Much improved	31	70.5	34	77.3	0.411
Slightly improved	10	22.7	6	13.6	
Stationary	1	2.3	4	9.1	
Slightly worse	1	2.3	0	0.0	
Much worse	1	2.3	0	0.0	

MH: **Marginal Homogeneity Test** for comparing between1st and 2nd assessment

Laboratory investigations

Acute phase reactants (ESR and CRP)

The mean ESR for the 1st hour was 28.34 ± 23.36 min. in the 1st assessment and 26.39 ± 21.11 min. in the 2nd assessment. The mean ESR for the 2nd hour was 52.50 ± 30.36 min. in the 1st assessment and 46.02 ± 25.80 min. in the 2nd assessment. There was statistically significant difference between the 1st and 2nd assessment (p< 0.05), being better in the 2nd assessment.

The mean CRP was 16.69 ± 36.14in the 1st assessment while the mean CRP was 13.57 ± 17.32in the 2nd assessment. There was statistically significant difference between the 1st and 2nd assessment (P< 0.05), beind better in the 2nd assessment.

Table (10): Comparison between 1st assessment and 1st assessment according to acute phase reactants

	1st assessment (n=44)	2nd assessment (n=44)	Z	P
ESR				
1st hour				
Min. – Max.	15.0 – 133.0	5.0 – 109.0	3.605*	<0.001*
Mean ± SD.	38.1 ± 22.35	26.39 ± 21.11		
Median	29.50	21.0		
2nd hour				
Min. – Max.	18.0 – 160.0	11.0 – 110.0	2.481*	0.013*
Mean ± SD.	57.5 ± 30.36	46.02 ± 25.80		
Median	49.0	45.50		
CRP				
Min. – Max.	5.1 – 165.0	1.0 – 99.0	2.078*	0.038*
Mean ± SD.	21.6 ± 36.14	12.5 ± 17.2		
Median	9.0	7.0		

Z, p: Z and p values for **Wilcoxon signed ranks test** for comparing between**1st and 2nd assessment**
*: Statistically significant at p ≤ 0.05

Medications for treatment

Thirty two patients (72.7%) were on steroids in the 1st assessment while 20 patients (45.4%) were on steroids in the 2nd assessment. 37 patients (84.1%) were on methotrexate in the 1st assessment while 34 patients (77.3%) were on methotrexate in the 2nd assessment. 40 patients (90.9%) were on NSAIDs in the 1st assessment while 38 patients (86.3%) were

on NSAIDs in the 2nd assessment. 2 patients (4.5%) were on azathioprine in the 1st assessment while 6 patients (13.6%) were on azathioprine in the 2nd assessment. 3 patients (6.8%) were on biological treatment in the 1st assessment and the same number in the 2nd assessment. 35 patients (79.5%) were on folic acid in the 1st assessment while 32 patients (72.7%) were on folic acid in the 2nd assessment. No patients were on leflunomidein the 1st assessment while 4 patients (9.1%) were on leflunomidein the 2nd assessment.

Table (11): Distribution of the studied cases according to medication

Medication	1st assessment (n=44)		2nd assessment (n=44)	
	No.	%	No.	%
CST	32	72.7	20	45.4
MTX	37	84.1	34	77.3
NSAIDs	40	90.9	38	86.3
Azathioprin	2	4.5	6	13.6
Bilogical treatment	3	6.8	3	6.8
Folic acid	35	79.5	32	72.7
Leflunomide	0	0.0	4	9.1

Follow up of steroids

10 patients (22.7%) did not have any change in the dose of CST. 9 patients (20.5 %) had decreased the dose of CST. 12 patients (27.3%) had stopped CST. One patient had added CST.

Table (12): Distribution of the studied cases according to follow up of CST

Follow up of CST	No.	%
No change	10	22.7
Decreased	9	20.5
Stopped	12	27.3
Added cst	1	2.3

Side effects of the disease

Ten patients (22.7%) had fever in the 1st assessment while no patients had fever in the 2nd assessment. 2 patients (4.5%) had uveitis in the 1st assessment while 1 patient (2.3%) had uveitis in the 2nd assessment.2 patients (4.5%) lost weight in the 1st assessment while no patients had lost weight in the 2nd assessment. 2 patients (4.5%) had headache in the 1st assessment while no patients had headache in the 2nd assessment. 1 patient (2.3%) had sleep disturbance in the 1st assessment and also 1 patient (2.3%) had sleep disturbance in the 2nd assessment.

Table (13) Distribution of the studied cases according to side effects of the disease

Side effect	1st assessment (n=44)		2nd assessment (n=44)	
	No.	%	No.	%
Fever	10	22.7	0	0.0
Uveitis	2	4.5	1	2.3
Loss of weight	2	4.5	0	0.0
Headache	2	4.5	0	0.0
Sleep disturbance	1	2.3	1	2.3

Side effects of the drugs

Fourty three patients (97.7%) had change of mood in the 1st assessment while 41 patients (93.2%) had change of mood in the 2nd assessment. 20 patients (45.5%) had abnormal growth of hair (increase hair growth of face, arms and legs) in the 1st assessment while 12 patient (27.3%) had abnormal growth of hair in the 2nd assessment.8 patients (18.2%) had vomiting in the 1st assessment while no patients had vomiting in the 2nd assessment. 25 patients (56.8%) gained weight in the 1st assessment while 26 patients (59.1%) gained weight in the 2nd assessment. 32 patient (72.7%) had pain in injection site in the 1st assessment while 30 patients (68.2%) had pain in injection site in the 2nd assessment. 8 patients (18.2%) had gastritis in the 1st assessment and also 8 patients (18.2%) had gastritis in the 2nd assessment.

Table (14): Distribution of the studied cases according to side effect of the drugs

Side effect	1st assessment (n=44)		2nd assessment (n=44)	
	No.	%	No.	%
Change of mood	43	97.7	41	93.2
Abnormal growth of hairwith steroid	20	45.5	12	27.3
Vomiting	8	18.2	0	0.0
Weight gain	25	56.8	26	59.1
Pain in injection site with MTX	32	72.7	30	68.2
Gastritis	8	18.2	8	18.2

School attendance

6 patients (13.6%) did not go to school because of arthritis in the 1st assessment while only 4 patients (9.1%) did not go to school because of arthritis in the 2nd assessment.

Table (15): Distribution of the studied cases according to school attendance

	1st assessment (n=44)		2nd assessment (n=44)	
	No.	**%**	**No.**	**%**
Going to school				
No	11	25.0	10	22.7
Yes	33	75.0	34	77.3
Absent from school because of arthritis				
No	5	86.4	6	90.9
Yes	**6**	**13.6**	**4**	**9.1**

Adherence to treatment

41 patients (93.2%) were adherent to treatment in the 1st assessment and 43 patients (97.7%) were adherent to treatment in the 2nd assessment.

Table (16): Distribution of the studied cases according to adherence to treatment

Adherence	1st assessment (n=44)		2nd assessment (n=44)	
	No.	**%**	**No.**	**%**
No	3	6.8	1	2.3
Yes	41	93.2	43	97.7

Satisfaction with the outcome

41 patients (93.2%) were satisfied with outcome in the 1st assessment while 43 patients (97.7%) were satisfied with the outcome in the 2nd assessment.

Table (17): Distribution of the studied cases according to satisfaction with the outcome

Satisfaction with the outcome	1st assessment (n=44)		2nd assessment (n=44)	
	No.	**%**	**No.**	**%**
No	1	2.3	3	6.8
Yes	43	97.7	41	93.2

Discussion

JAMAR is a multidimensional questionnaire that combines the traditional patient-reported outcomes used in the clinical evaluation of children with JIA, such as assessment of overall well-being, pain, functional status, and HRQOL, with other PRO not addressed by conventional instruments, including measurement of morning stiffness and overall level of disease activity, of disease status and course, joint involvement and extra-articular symptoms, description of side effects of medications, and assessment of therapeutic compliance and satisfaction with outcome. The JAMAR enables the registration of all these data in a single instrument in a standardized manner.[28]

The questionnaire is not intended to serve as a "measure" for research or clinical trials. Rather, it has been specifically designed for regular administration in daily clinical practice. However, some components that yield quantitative scores (i.e., the physical function and the VAS scales) or that are categorical (i.e., assessment of disease state and course, and morning stiffness) can be used in clinical research.[28]

Although a number of instruments are available for assessment of PRO in children with JIA [12-16], most of these measures are not routinely administered in most paediatric rheumatology centers. This is partly explained by the concern that questionnaires may interfere with office routine and time management, with consequent increased costs and time. However, it has been suggested that data from a brief questionnaire designed for standard care can provide an important saving of time (after a brief "learning curve," as required with any new activity). With administration of such a questionnaire, information concerning functional status, HRQOL, global status, pain, morning stiffness, burden of arthritis, disease course from previous visit, and medication side effects are already known by the physician at the start of the visit, rather than when acquiring basic data from the parent. This facilitates focus on matters that require attention, leading to more efficient and effective clinical care.[24]

The JAMAR has been designed specifically for busy clinical settings, with particular attention to feasibility and acceptability in daily care. To avoid making it too lengthy and complex, 2 simple and short measures were selected for assessment of the central domains of physical function and HRQOL. The VAS for pain, well-being, and disease activity are presented as 21-numbered circles, rather than in the traditional 10-cm horizontal line format, to

facilitate scoring without a ruler. Use of the simpler 21-circle horizontal line VAS has been found to increase the precision of parent/patient ratings, particularly regarding definition of remission.[29]

Results of this study revealed that the JAMAR questionnaire was valid, reliable and sensitive to change of the disease activity. Health related quality of life measures were assessed using the combined inflammatory arthritis questionnaire for functional disability and quality of life. The combined questionnaire items covered the main components identified by the International Classification Of Functioning (ICF) Core Set for RA [30]. earlier findings[31,32], which revealed that the combined inflammatory arthritis questionnaire was a valid and reliable tool for assessment of health related quality of life as well as functional disability measures in patients with inflammatory arthritis. In the study carried out by Uhlig et al.[33], the ICF Core Set for RA demonstrated moderate responsiveness in the real-life setting of patients where minor changes occurred during treatment. However, it has to be highlighted that the ICF was not designed as a measure of health status, and the main objective of the ICF was to describe important aspects of health and not to measure them. Results of this study showed that the JAMAR questionnaire did manage to cover this gap, being comprehensible, valid, reliable and showed good response to therapy.

Regular use of the JAMAR enables keeping a flow sheet of patient's course over time. A flow sheet may facilitate the recognition of possible changes in functional capacity, pain, fatigue, and psychological status from previous visits. This method of handling clinical data appears very useful in the management of a chronic disease such as JIA as it allows the clinician to record serial parent/patient data, together with joint examination findings, laboratory tests, medication regimen, and other information.

In our study the 1st assessment revealed weak points in the lines of management which have been taken in consideration. The 2nd assessment revealed improvement in quality of life, school attendance, and decreased steroids dosage which proves that JAMAR is reliable and sensitive to change.

Our work should be viewed in the light of some potential limitations. The JAMAR may not provide sufficient details regarding PRO of sleep disturbance, fatigue, coping, and family life. Further development of the JAMAR requires continuing research, with introduction of possible modifications based on clinical experience. We recognize that the way parents and children are asked about compliance may not be sufficiently accurate and that appropriate assessment of therapeutic compliance or adherence requires the use of a more specific and detailed instrument.

Conclusion

Integrating patient reported outcome measures into standard clinical practice is feasible and applicable. Development of the JAMAR introduces a new approach in paediatric rheumatology practice. This new questionnaire may help enhance the quality of care of children with JIA.

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