Pediatric rheumatology

Design and validation of a new scale to assess the functional ability in children with juvenile idiopathic arthritis (JIA)

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ABSTRACT

Objective

The assessment of the functional ability is one of the items of the core set to define improvements in patients with JIA, CHAQ being the most used scale already validated in 32 countries.

The aim of this study was to design and validate a new scale named CAPFUN (capacidad funcional = functional ability) to assess functional ability in children with JIA.

Methods

This scale includes 20 items, 8 of upper limbs, 8 of lower limbs, 3 combined, and 1 of cervical spine, developed in two steps according with OMERACT. Each item is scored: 0 when it is impossible to be performed, 1 when it is performed incompletely or with difficulties, and 2 when it is well performed.

Seventy three patients with JIA according to ILAR criteria were assessed: 25 boys (34.2%) and 48 girls (65.8%) whose average age was 12.8 years (95% CI 11.8 – 13.8) and the time from disease onset was 5.02 years (95% CI 3.9 – 6.1). For validation purposes, it was applied to 91 healthy children and adolescents. In every patient, correlation with active joints count and functional class according to Steinbrocker was assessed and with CHAQ in 31 patients in this series.

Results

The CAPFUN index obtained in all healthy children was 2. Patients' media CAPFUN index was 1.54 (95%CI 1.38 – 1.68). The CAPFUN index for Steinbrocker's class I was 1.84 ± 1.8; for class II 1.60 ± 1.5 and for class III 0.91 ± 1 (F 24.1 $p < 0.001$). CAPFUN showed significant correlation with CHAQ (Spearman coefficient –0.79 $p < 0.001$), with active joints count (Spearman coefficient –0.72 $p < 0.001$) and with Steinbrocker functional classes (Spearman coefficient –0.69 $p < 0.001$). This scale showed a good internal reliability (alpha coefficient equal to 0.94), its construct validity is demonstrated by its good correlation with Steinbrocker's scale and with CHAQ.

Conclusion

CAPFUN is a new instrument in order to assess functional ability in children with JIA. This scale showed a good internal reliability. Construct validity is demonstrated by its high correlation with Steinbrocker's scale and with CHAQ. This study demonstrates the usefulness of CAPFUN for the assessment of functional ability in children with JIA.

Key words

Functional ability, juvenile idiopathic arthritis, assessment of functional ability, validation, childhood health questionnaire, daily living activities, physical therapy.

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Introduction

Juvenile Idiopathic Arthritis (JIA) refers to a group of chronic diseases that can lead to functional, physical and psycho-social disability with higher or lower severity.

During the last two decades, concern on developing functional ability and the quality of life measuring instruments in children with JIA has increased. This instruments allows to establish the impact of disease on patient's Daily Living Activities (DLA), to take decisions on rehabilitation programs and assess the changes caused by the disease or by therapeutic interventions. (1-3).

The assessment of functional ability is one of the items of the core set to define assess improvements in patients with JIA, being CHAQ the most used scale already validated in 32 countries. (2, 4).

The specific instruments designed for patients with JIA are questionnaires that measure: Physical disability and pain (CHAIMS) (5), the ability of children older than seven to perform certain physical tasks(JAFAR) (6); disability and discomfort (CHAQ) (2, 7, 8); physical and psychosocial function (JAQQ) (9). The JAFAS (10) is a test that measures the time to perform predefined tasks, requires skilled personnel in an office or hospital-based setting and using special standardized equipment (7).

Either CHAQ or other questionnaires, are self-administered to parents or children. This may result in biased answers as it can be influenced by level of understanding and emotional condition of the child and his family leading to underestimate or overvalue the real functional ability of the patient.

Objective

The aim of this study was to design and validate a new observational scale named CAPFUN to measure functional ability in children with JIA.

Material and methods

Description of the scale

The scale consists of 20 items which assess: 8 activities of upper limbs, 8 of lower limbs, 3 combined, and 1 of cervical spine. The scale was developed in two steps according with OMERACT (11, 12): 1- three physical therapists, three pediatric rheumatologists and three pediatricians, based on the clinical history and physical examination by Southwood *et al.* (13) and according to their experience, defined the most necessary movements to perform the DLA common in children and those most affected by JIA. 2- In a second step, a further analysis reduced the number of items to 20 in order to avoid redundancy.

These items were gathered in two groups: the first one, with predominance of lower limbs, and the second, with predominance of upper limbs to notice the most involved body segment more rapidly and effectively.

Each item was scored: 0 when it was impossible to be performed, 1 when it was performed incompletely or with difficulties, and 2 when it was well performed.

Grip strength was assessed with an aneroid manometer with a 7cm-wide handle. Once it rolled, it was put in the patient's dominant hand, between fingers and palm. It was then inflated 20 mm and the child is asked to apply the maximum strength and maintain it for 3 seconds; repeated three times and registered the average of the three values. The grip strength was measured in 91 healthy children between 6 and 18 years old, the average and the standard deviations (SD) were obtained, considering the score 2 up to minus two SD (higher than 128 mm Hg), the score 1 up to minus three SD (between 127 and 72 mm Hg) and score 0 to the inferior values (lower than 72 mm Hg).

The mean value of the upper and lower limb score were added and mean value of both was defined as CAPFUN (Fig. 1). The final index range between 0 and 2, being this value for healthy individuals or for those without loss of functional ability.

Studied population

Signed informed consent from parents of healthy children and patients was obtained. This scale was applied to 91 healthy children and adolescents without chronic pathologies or growth and

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ASSESSMENT OF FUNCTIONAL ABILITY FOR JUVENILE IDIOPATIC ARTHRITIS PATIENTS

Name and Surname: ..... **MH:** .....

DATE:			
1- WALK			
2- WALK ON HEELS			
3- TIPTOE			
4- GO UP AND DOWN THE STAIRS U/D			
5- STAND ON ONE LEG L/R			
6- SIT ON THE FLOOR AND STAND UP			
7- SIT CROSS-LEGGED			
8- BE IN A FOUR-LEG POSITION			
9- SQUAT			
10-KNEEL DOWN, LEAN A FOOT FORWARD L/R			
SUBTOTAL 1			
1- JOIN HANDS OVER THE HEAD			
2- PUT HANDS ON THE NAPE L/R			
3- PUT HANDS ON THE BACK L/R			
4- PUT HANDS ON SHOULDERS L/R			
5- PUT HANDS ON BUTTOCKS L/R			
6- JOIN HANDS BEFORE THE BODY			
7- CLENCH FISTS L/R			
8- GRIP STRENGTH OF THE DOMINANT HAND (VALUE:)			
9- TOUCH THE FOOT WITH BOTH HANDS L/R			
10-RAISE THE HEAD			
SUBTOTAL 2			
TOTAL			
CAPFUN INDEX:			

REFERENCES : 2- It is well performed.
1- It is incompletely performed or with difficulty.
0- It cannot be performed.

Fig. 1. CAPFUN form.

Table I. Features of the assessed population.

Normal population		
• Total : 91 healthy schoolchildren		
• Age : mean 11.9 years old (95% CI 11.2 – 12.5)		
• Sex : 42 males (46%) - 49 females (54%)		
Patients with JIA (ILAR critera)		
• Total: 73 patients		
• Age: mean 12.8 years old (95% CI 11.8 – 13.8)		
• Sex: 25 males (34.2%) - 48 females (65.8%)		
• Disease time from onset x 5.02 years old (95% CI 3.9 – 6.1)		
Disease type	N° of patients according to onset	N° of patients according to course
Polyarticular	29 pat. (39.7%)	55 pat. (75.3%)
Oligoarticular	23 pat. (31.5%)	18 pat. (24.7%)
Systemic	21 pat. (28.8%)	
Disease activity		
Active	27 pat. (37%)	
Remission on medication	36 pat. (49.3%)	
Remission without medication	10 pat. (13.7%)	
Functional class (Steinbrocker)		
Class I	23 pat. (31.5%)	
Class II	38 pat. (52%)	
Class III	12 pat. (16.4%)	
Active joints count x: 15.3 (CI 95% 11.3-19.3)		

developments disorders that attend a primary and secondary school in Buenos Aires city. Forty-two were boys (46%) and 49 girls (54%). Mean age was 11.9 years old (95% CI 11.2 – 12.5) (Table I).

In accordance with the ILAR criteria, 73 patients with JIA were assessed: 25 boys (34.2%) and 48 girls (65.8%) whose mean age was 12.8 years old (95% CI 11.8-13.8). Time from disease onset was 5.02 years (95% CI 3.9 – 6.1) (Table I). The JIA onset, its course, activity, count of active joints and functional class according to Steinbrocker (14) were assessed. Since we had the Argentine validated version of CHAQ (8) we could apply it to 31 patients of this series. The disease was considered active (persisting symptoms and signs under medication), in remission with medication; and in remission without medication.

Statistical methods

Descriptive analysis was performed, estimating central tendency statistics and 95% CI for each variable. The internal reliability was assessed by Crombach alpha using the principal components method. Association with CHAQ, active joints count and Steinbrocker´s classes were estimated by Spearman correlation coefficient.

Results

The CAPFUN index obtained in all healthy children was 2. The distribution of patient by disease onset was as follows: polyarticular 29 (39.7%), oligoarticular 23 (31.5%) and systemic 21 (28.8%). The course of the disease was polyarticular in 55 patients (75.3%) and oligoarticular in 18 (24.7%) (Table I).

The disease was active in 27 patients (37%), in remission with medication in 36 (49.3%), and in remission without medication in 10 (13.7%) (Table I).

The functional class according to Steinbrocker was class I in 23 patients (31.5%), class II in 38 (52%) and class III in 12 patients (16.4%) (Table I).

Mean of active joints count was 15.3 (95% CI 11.3 - 19.3).(Table I)

Reliability analysis has shown an alpha coefficient equal to 0.94

Patients' mean CAPFUN index was 1.54 (95% CI 1.38 – 1.68). The CAPFUN index for Steinbrocker's class I was 1.84 ± 1.8; for class II 1.60 ± 1.5 and for class III 0.91 ± 1 (F 24.1 $p < 0.001$) (Table II).

CAPFUN shows significant correlation with CHAQ (Spearman coefficient -0.79 $p < 0.001$), active joints count (Spearman coefficient -0.72; $p < 0.001$), and Steinbrocker's Functional Classes (Spearman coefficient -0.69; $p < 0.001$) (Figs. 2 and 3).

Table II. Mean CAPFUN value for each of Steinbrocker's Functional Classes.

Steinbrocker	CAPFUN media	CAPFUN SD	CAPFUN mediana
Class I	1.84	0.13	1.86
Class II	1.6	0.22	1.58
Class III	0.91	0.36	1.08

F 24.1 $p < 0.001$.

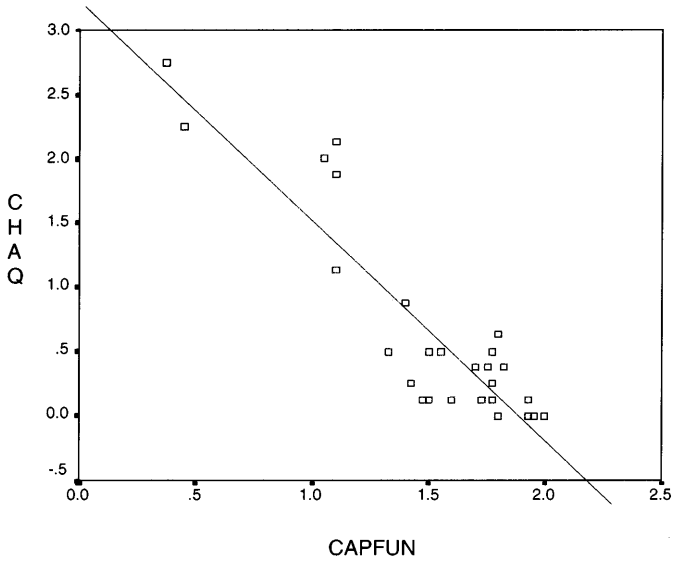

Fig. 2. Correlation between CAPFUN and CHAQ.

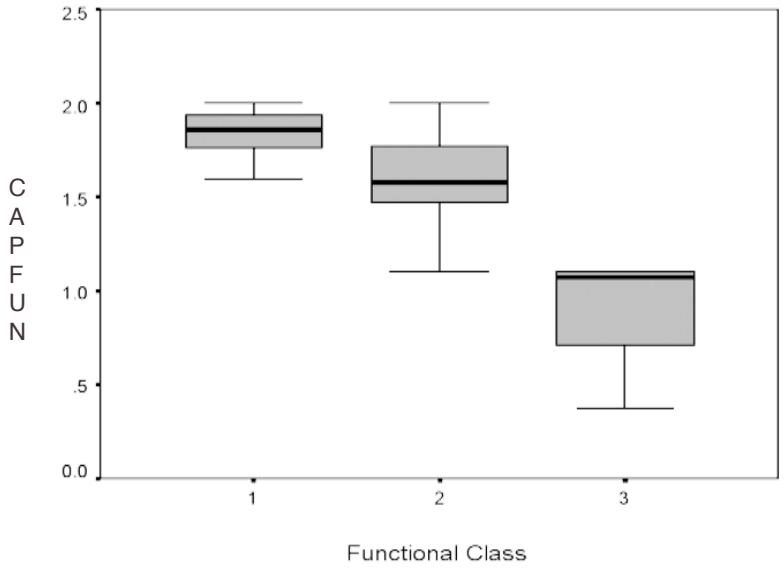

Fig. 3. Distribution of CAPFUN values by Steinbrocker's Functional Classes.

Discussion

During the last 20 years, concern on rheumatic diseases outcome has increased in order to get more information, to provide better treatments, maximize efficiency and minimize the economic burden in a managed health care environment. (1-3).

Relevance of functional ability assessment increased after the development of the core set for definition of improvement in JIA. (4).

Many scales developed to assess the health condition of patients with JIA are focused on assessing the quality of life or disability by means of questionnaires answered by parents or children with proper understanding. (5-10).

When parents and/or children complete a questionnaire, answers depend on the understanding level and subjective evaluation about their health, which is quite related to their emotional condition and may not show the real functional ability.

Our scale is based on the assessment of movements and the muscular strength needed for the DLA, which do not have significant changes in different cultures; objectively shows the functional ability of the patient and provide a useful instrument to guide the medical and rehabilitation treatment.

Our results show that the correlation of CAPFUN with Steinbrocker's scale and CHAQ was satisfactory.

Figure 3 clearly shows that, even though a good correlation exists between CAPFUN and Steinbrocker, CAPFUN index varies within each class with a wide range of variability. We consider that this feature from the scale presented may be useful in order to demonstrate changes after introducing a new therapeutic agent or starting a new rehabilitation plan. Further studies will be necessary in order to demonstrate sensitivy to change.

The objectiveness of our scale allows to show parents the true possibilities of the patients to perform independently the typical DLA according to their age. Frequently, overprotection does not allow a child to make some activities in spite of having the ability to do so.

This scale has also the advantage that it objectively shows the most involved body segment, it individualizes the most involved joint/s and which DLA the child performs with difficulties.

CAPFUN is a new instrument in order to assess functional ability in children with JIA. This scale showed a good internal reliability. Construct validity is demonstrated by its high correlation with Steinbrocker's scale and with CHAQ.

The CAPFUN scale is easily obtained during a physical therapy or a rheumatology routine visit, in a few minutes and without special equipment.

As the CAPFUN index shows a wide range of values within each Steinbrocker class, further studies will be necessary in order to demonstrate more accurate sensitivity to change after introducing a new therapeutic agent or starting a new rehabilitation plan.

We suggest using CHAQ and CAPFUN simultaneously and, in case of disagreement between them, the objectiveness of CAPFUN would allow to guide the patient and his family about the true abilities of the child and the physical therapy treatment.

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15- APENDIX I

GUIDELINES TO OBTAIN THE SCALE:

The activities were scored as 2 if well performed, 1 incompletely performed or with difficulty and 0 if can not be performed.

Walk:
The patient must walk barefoot a five-meter stretch, four times completing a total of 20 mts.

Walk on heels:
The patient must walk barefoot a five-meter stretch, forward and back, completing a total of 10 mts., on heels without leaning forefeet and keeping an erect posture.

Tiptoe:
The patient must walk barefoot a five-meter stretch, forward and back, completing a total of 10 mts., on toes without leaning heels and keeping an erect posture.

Go up and down stairs:
The patient must go up and down a four-step stairs at a normal pace and without taking the rail.

Stand on one leg:
The patient must keep standing on one leg, and maintain the balance for, at least, 5 seconds.

Sit on the floor and stand up:
The patient must sit and stand up from the floor with no difficulties or assistance.

Sit cross-legged:
The patient must sit cross-legged with separated knees on the floor and must remain in that position for, at least, 5 seconds, balanced and with no support.

Be in a four-leg position:
The patient adopt the four-leg position, with support on his knees and the whole palms, with stretched out elbows and arms vertically, remaining in that position for 5 seconds.

Squat:
From being standing, the patient must crouch down to squat, until buttocks reach heels which must be separated from the floor; the patient must remain in that position for 5 seconds.

Kneel down, lean a foot forward:
Kneel down on the floor, the patient is asked to lean a foot forward, forming a right angle with his knee while maintaining the trunk and the thigh of the leant knee vertically. The patient must remain in that position for 5 seconds.

Join hands over the head:
The patient must join hands over the head, with outstretched elbows and arms in a vertical position.

Put hands on the nape:
The patient must overlap his hands on the nape, with open elbows and erect head.

Put hands on the back:
The patient must put his hands on the back and raise them to touch, at least, the inferior angle of the scapula with thumbs.

Put hands on shoulders:
The patient must touch the anterior shoulder area with the middle finger with elbows close to the body.

Put hands on buttocks:
The patient must touch the intergluteal area with each hand, palms and every finger.

Join hands before the body:
The patient must join palms and fingers vertically in front of the body at the level of his face, and must lower them separating elbows without separating palms to reach a level below elbow height with wrists.

Clench fists:
The patient must touch the middle part of the palm with four fingers except for the thumb.

Grip strength of the dominant hand:
For the grip strength assessment, an aneroid manometer with a 7cm-wide handle is used. Once it is rolled, it is put on the patient's dominant hand, between fingers and palm. It is then inflated 20 mm and the child is asked to apply the maximum prehension and maintain it for 3 seconds; this is repeated three times considering the average of the three values.

Touch a foot with both hands:
Sat on a chair, the patient must touch toes with both hands simultaneously.

Raise the head:
The patient must be able to maintain the head erect and move it back in a complete way.
If the items 5 and 10 from the first group and 2, 3, 4, 5, 7 and 9 from the second group show differences between both limbs, the average will be registered as in the case of item four, that differentiates between going up and down the stairs.