Cross cultural adaptation and validation of the Arabic version of the Childhood Health Assessment Questionnaire for measuring functional status in children with juvenile idiopathic arthritis

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ABSTRACT

Objective

To cross culturally adapt the American-English version of the Childhood Health Assessment Questionnaire (CHAQ) and to evaluate the validity and reliability of the modified translated version on children with juvenile idiopathic arthritis (JIA).

Methods

A cohort of 62 children suffering from JIA (32 Egyptian, 30 Saudi Arabian) were recruited and asked to participate in the study. Two questions had been changed to suit the Arabic culture and to tackle some aspects that are more typical of the Arabic culture. After modification, translation and back translation of the questionnaire, it was administered to the selected patients as well as their parents and tested for internal consistency, reliability and construct validity by correlating the yield of the questionnaire with other disease activity parameters. The questionnaire was administered again after a one-week interval for evaluation of the reliability of this test. The modified questions were tested for their loyalty to the principal component and their correlation with that of the other unchanged items was compared.

Results

CHAQ proved to be valid in clinically discriminating between healthy subjects and patients with different patterns of JIA. Test-retest showed strong reliability with a high percentage of agreement and high kappa values. Internal consistency showed a high value for the standardized Cronbach's alpha (0.951), and this value did not show any significant change when any one of the items was eliminated. The modified questionnaire showed a strong and significant validity when its results were correlated with disease activity parameters.

Conclusion

The Arabic CHAQ is a reliable and valid instrument that can be administered to Arabic children suffering from JIA and to their parents, to evaluate the patients' functional disability. Its measurement properties were comparable to versions in other languages.

Key words

Juvenile idiopathic arthritis, CHAQ, Arabic.

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Introduction

In the last decade the concept of health-related quality of life has become increasingly important and many authors have developed instruments to measure it both quantitatively and qualitatively. These instruments are now used for the evaluation of new therapies and to measure the influence that a certain disease has on the everyday activities of a patient (1). Notably, in recent years there has been increasing interest in the assessment of the quality of life in rheumatic diseases in both adults and children. Indeed, while in the past the assessment of patients with rheumatoid disease traditionally focused on the measurement of disease activity, more emphasis is now being placed on incorporating estimates of physical, social and mental functioning into the health assessment (2). To evaluate the quality of life, several instruments have been developed, initially in adults and then in corresponding versions for children.

The term "juvenile idiopathic arthritis of childhood" refers to a group of chronic diseases that can lead to functional, physical and psychosocial disabilities that may range from minor to severe in extent, but is a condition that clearly has a major impact on the everyday quality of life (3, 4). Performing controlled trials in JIA has always been a difficult task for two main reasons: the relative rarity of the disease, and the lack of reliable and internationally recognized outcome measures.

Since all of the instruments created to assess functional disability were originally developed in American English and were designed for use in the North American population, there was an important need to adapt it cross-culturally to the characteristics of different countries in order to facilitate international collaborative studies. The researchers of the Pediatric Rheumatology International Trials Organization (PRINTO) selected the parent-administered version of the Childhood Health Assessment Questionnaire as the principal disease-specific instrument to be used for JIA. The CHAQ was selected because it is already being widely used in the pediatric rheumatology research field, and it is particularly simple to administer and score. In addition the CHAQ was selected because it is a generic instrument that can be used for other pediatric rheumatoid diseases such as juvenile dermatomyositis, juvenile systemic lupus erythematosus, linear scleroderma, and systemic sclerosis (1).

The aim of this study was to cross culturally adapt the American-English version of the CHAQ and to evaluate the validity and reliability of the modified translated version in children with JIA.

Patients and methods

Population sample

Data were obtained from a cohort of 62 children with JIA and their parent(s). They were 32 Egyptian and 30 Saudi Arabian patients. Children with JIA were classified as having systemic onset (5), polyarticular onset (23), extended oligoarticular (17) or persistent oligoarticular (17) JIA, according to the Durban classification (5). All other subtypes of JIA (psoriatic arthritis, enthesitis-related arthritis, and other forms of arthritis that did not fit into the Durban classification) were excluded from the study.

All patients underwent clinical, rheumatological and laboratory assessments to evaluate the current status of the 6 variables included in the core set of outcome measures for JIA (6, 7), which are: (i) the physician's evaluation of current disease activity on a 10-cm visual analogue scale (VAS); (ii) the parental assessment of overall well-being on a 10-cm VAS; (iii) a functional assessment (the exact instrument to be used was not specified in the original core set); (iv) the number of joints with active arthritis; (v) the number of joints with limited range of motion; and (vi) the erythrocyte sedimentation rate (ESR, Westergren method) and C-reactive protein (CRP, by ELISA).

All patients were interviewed twice, once on the first day of assessment and then one week later when they were interviewed to discuss the results of their investigations as well as the prescribed therapy. The nature of the study

Childhood Health Assessment Questionnaire استبيان تقييم صحة الطفل

هـذا الاستبيان يساعد في تقييم مدى تأثير المرض على حياة طفلك اليومية. فضلاً اختار الدرجة والتي تعبر عن تأثر حياة طفلك بصفة عامة خلال الأسبوع الماضي وعلى مدار اليوم كله. ويجب مراعاة أن الدرجـة الـتي تعطيها لطفلك تعبر بصفة أساسية عن تأثير المرض عليه. أما إذا كان طفلك لا يستطيع عمـل أي من هذه الأنشطة لصغر سنه وليس بسبب المرض فضلاً ضع علامة أمام "لا يمكن عمل ذلك لصغر سنه". إذا كان له أية إضافات أو تعليقات أخرى فضلاً كتابتها على ظهر هذه الصفحة.

		بسهولة	مع بعض الصعوبة	بصعوبة شديدة	لا يستطيع	لا يمكن القيام بذلك لصغر سنه
	اللبس والاعتناء بالمظهر					
	هل يستطيع طفلك أن:					
1	يلبس ملابسه، ويربط حذاءه، الربط الأزرار؟	☐	☐	☐	☐	☐
2	يغسل شعره بالشامبو؟	☐	☐	☐	☐	☐
3	يخلع الشراب (الجوارب) من قدمه؟	☐	☐	☐	☐	☐
4	يقلم أظافره؟	☐	☐	☐	☐	☐
	القيـــام					
	هل يستطيع طفلك أن:					
5	الوقوف بعد جلوسه على الأرض أو على كرسي منخفض؟	☐	☐	☐	☐	☐
6	الاستلقاء على السرير والنوم والقيام من على السرير في الصباح / الوقوف داخل سرير الطفل؟	☐	☐	☐	☐	☐
	تناول الطعام					
	هل يستطيع طفلك أن:					
7	يقطع اللحم لنفسه بنفسه؟	☐	☐	☐	☐	☐
8	رفع الفنجان أو كوب إلى فمه ليشرب؟	☐	☐	☐	☐	☐
9	يفتح علب [illegible] الجافة في الثلاجة؟	☐	☐	☐	☐	☐
	السـير					
	هل يستطيع طفلك أن:					
10	السير على أرض مستوية خارج المنزل؟	☐	☐	☐	☐	☐
11	صعود ٥ درجات من السلم؟	☐	☐	☐	☐	☐

فضلاً ضع علامة أمام أي من الأجهزة المساعدة والتي يحتاجها طفلك عادة لأداء أي من الأنشطة السابقة:

☐	أجهزة مساعدة في ارتداء الملابس (إبرة الأزرار [illegible])	☐	عصا
☐	[illegible]	☐	مشاية
☐	[illegible]	☐	عكاز
☐	[illegible]	☐	كرسي متحرك
	[illegible]		

فضلاً ضع علامة أمام أي من هذه الأنشطة والتي عادة ما يحتاج طفلك لمساعدة شخص آخر لعملها بسبب مرضه.

☐	تناول الطعام	☐	اللبس والاعتناء بالمظهر
☐	السير	☐	القيام

		بسهولة	مع بعض الصعوبة	بصعوبة شديدة	لا يستطيع	لا يمكن القيام بذلك لصغر سنه
	النظافة الشخصية					
	هل يستطيع طفلك أن:					
12	غسل وتجفيف جسمه بالكامل؟	☐	☐	☐	☐	☐
13	الجلوس والقيام من على المرحاض (مرحاض أفرنجي) أو [illegible]	☐	☐	☐	☐	☐
14	الاستحمام في البانيو (الدخول والخروج من البانيو)؟	☐	☐	☐	☐	☐
15	غسل أسنانه بالفرشاة؟	☐	☐	☐	☐	☐
16	تسريح شعره؟	☐	☐	☐	☐	☐
	التنـاول					
	هل يستطيع طفلك أن:					
17	الوصول والتقاط شيء ثقيل نسبياً مثل لعبة كبيرة أو كتاب من مستوى أعلى من رأسه قليلاً؟	☐	☐	☐	☐	☐
18	الانحناء لالتقاط ملابس / أو ورقة من على الأرض؟	☐	☐	☐	☐	☐
19	إدخال رأسه في البلوفر [illegible]	☐	☐	☐	☐	☐
20	تحريك رقبته لينظر خلفه؟	☐	☐	☐	☐	☐
	الإمسـاك					
	هل يستطيع طفلك أن:					
21	الإمساك بالقلم جيداً أو رصاص ليكتب أو يخطط في ورقة؟	☐	☐	☐	☐	☐
22	فتح باب السيارة؟	☐	☐	☐	☐	☐
23	فتح برطمان [illegible] سبق فتحه من قبل؟	☐	☐	☐	☐	☐
24	فتح وقفل حنفية (صنبور) المياه؟	☐	☐	☐	☐	☐
25	الإمساك بمقبض الباب (الأكرة) وتحريكه لفتح الباب؟	☐	☐	☐	☐	☐
	أنشطة أخرى					
	هل يستطيع طفلك أن:					
26	القيام بالمشاوير [illegible]	☐	☐	☐	☐	☐
27	الركوب والنزول من السيارة / سيارة لعبة / أتوبيس المدرسة	☐	☐	☐	☐	☐
28	ركوب عجلة	☐	☐	☐	☐	☐
29	القيام ببعض الأعمال المنزلية [illegible]	☐	☐	☐	☐	☐
30	الجري واللعب	☐	☐	☐	☐	☐

فضلاً ضع علامة أمام أي من الأجهزة المساعدة التي يحتاجها طفلك عادة لأداء أي من الأنشطة السابقة:

☐	مقعد على التواليت (مرحاض أفرنجي)	☐	[illegible]
☐	مقعد للاستحمام في البانيو	☐	[illegible]
☐	[illegible]	☐	[illegible]

فضلاً ضع علامة أمام أي من هذه الأنشطة والتي عادة ما يحتاج طفلك لمساعدة شخص آخر لعملها بسبب مرضه.

☐	النظافة الشخصية	☐	الإمساك وفتح الأشياء
☐	التناول	☐	القيام بالأعمال المنزلية أو المهام الصغيرة

من المهم لنا أن نعلم درجة الألم الذي يشعر به طفلك بسبب مرضه. في رأيك ما هي الدرجة التي تعطيها والتي تعبر عن شدة الألم الذي يشعر به طفلك بسبب مرضه في خلال الأسبوع الماضي بصفة عامة.

لا يوجد ألم 0 |—|—|—|—|—|—|—|—|—|—| 100 ألم شديد جداً

حالياً تقيم مدى تأثير المرض [illegible] على حياة ابنك. ما هي الدرجة التي تعطيها. فضلاً ضع علامة للتعبير عن الدرجة المناسبة.

جيد جداً 0 |—|—|—|—|—|—|—|—|—|—| 100 سيء للغاية

was explained to the parents recruited for this study and verbal consent was obtained from each child's parents.

Original questionnaire
The CHAQ (6) was completed each time (twice) by the parent(s) or the legal representative(s) of each child. Parents were instructed to take note only of impairment due to the disease in the preceding week. The items with the highest score in a domain determined the score for that domain, while the use of any aids or devices or help from another person was assigned a minimum score of 2 for that domain. These 8 domains were then averaged into a summary score called the disability index (DI) which may range from 0 to 3 with higher scores meaning higher disability. The CHAQ also provided an assessment of discomfort using a 10-cm VAS for the evaluation of pain and a 10-cm VAS for the evaluation of overall well being.

Translation of HAQ
Before conducting the present study, the investigators discussed the activities most typically engaged in by Arabic children generally, as well as by the patients. The translation of HAQ into Arabic (AHAQ) was done following the proposed guidelines by Guillemin *et al*. (15). Three translators were involved, who included two professional translators with a medical background and one of the authors (Y.M.). Two different professional translators and another author (M.G.) carried out the back translation. The translators were instructed that it was important for them to translate the exact activity listed in the original questionnaire precisely and accurately, but using literal, simple Arabic words that would be understood by all Arabic cultures.
Two questions were modified to reflect Arabic culture. In the section on eating, instead of the fourth question "Open a new cereal box" we used "Open a new pack of chips (fried potato slices)", as this is more likely to be used among the Arab children. The second question was in the "Grip" section, where instead of the question "Push open a door when he/she has to turn a door knob?" we used "Push open a door when he/she has to turn a door handle" which is more likely to be present in the Arab culture. A pilot study was performed before starting the present study to test the applicability and comprehensibility of the questionnaire as well as the alterations performed.

Control group
66 healthy controls of matched age and sex were recruited from the children accompanying their parents/brothers or sisters attending the clinics. A child was defined as healthy based on the parent's declaration and after clinical assessment by a physician.

Statistical analysis
Test-retest reliability of the Arabic version of the CHAQ was assessed using % agreement between the initial results and the post-one week results of the administered questionnaire. Kappa statistics were also calculated. Correlation of the revised items to the principal component was tested. Crohnbach's alpha was calculated for each of the 8 subscales and for the 30 items in the questionnaire to validate the internal consistency of the instrument. The yield of each item in the modified translated Arabic CHAQ to the principal component as well as the changed items was tested by conducting a factor analysis. Spearman's correlation coefficient was used to test the inter-subscale correlations and the correlation of the CHAQ subscales to disease activity parameters. Kruskall-Wallis and Mann-Whitney tests were employed to detect statistical differences in the 8 subscales of the CHAQ among the 4 patterns of juvenile idiopathic arthritis.

Results
A total of 62 children diagnosed as having juvenile idiopathic arthritis were included in this study, and compared to 66 healthy controls matched for age and sex. The patients' age ranged between 5 and 14 years; about 68% of them were above 10 years of age. Table I shows the demographic and clinical characteristics of the patients and control subjects included in this study.

Translation and comprehensibility
All of the questions in the translated CHAQ were rated as quite comprehensible or extremely comprehensible by almost all of the interviewed parents, with a percentage ranging between 96.8% and 100.0% across the 30 items of the translated questionnaire.

Construct validity
A correlation matrix demonstrated that all 8 subscales of the translated HAQ were significantly correlated to each other. Almost 80% of all variability was accounted for by the first principal component. All 30 items had a similar correlation coefficient with this principal component ranging between 0.667 and 0.978. The 2 revised items showed a similar correlation to the first principal component, as well as to the other unchanged items (0.939 for question no. 9 and 0.875 for question no. 25).

Reliability
Test-retesting showed almost perfect agreement, reaching 100.0% for the "eating"and "hygiene"subscales. Kappa statistic was the lowest (0.73) for the re-testing of the "activities" subscale of the CHAQ, although this value (> 0.7) was still considered to be of high significance (Table II).
Cronbach's alpha showed a strong internal consistency, with a standardized alpha of 0.951 for the 8 subscales of the tested instrument. The subscale with the highest correlation to the total instrument was "activities" (0.901) and that with the lowest correlation to the total instrument was "eating" (0.680).

External validity
All subscales of the translated CHAQ showed a significant correlation to all the disease activity parameters, the highest being with VAS (Table III). Comparing the translated CHAQ subscales for the 4 patterns of JIA, the HAQ subscales showed higher values for patients with all patterns of the disease compared to healthy controls (healthy control subjects reported averages of 0.0 for all the HAQ subscales). Both "polyarticular" and "systemic" patterns exhibited higher values for all the 8 HAQ subscales compared to the

"extended" and "oligoaritcular" patterns of the disease (Table IV).

Discussion

Disability measurement in patients with chronic illness has always been a subject of importance for all workers in this field. However, the creation of an internationally recognised scale upon which a clinician can rely for the evaluation of disease progression and treatment effects requires the standardization of this tool, in order that the results may be comparable among different studies carried out in different parts of the world. Translated versions of the CHAQ have been published for several countries (10-17), and for some countries there was an adaptation of already translated versions involving the changing of specific words (18, 19). A translated Arabic version of the CHAQ has already been published (20), but this instrument was a direct translation of the original questionnaire without any adaptation to the Arabic culture. The aim of our study was to create a standardised version of the CHAQ adapted to the Arabic culture, which is considerably different from American, European, Asian and African cultures.

The results of this study confirm the previously reported validity of the CHAQ in clinically discriminating between healthy subjects and patients with systemic or polyarticular onset JIA and a higher degree of disability and pain and lower overall well-being than their healthy peers. The results agree with those reported in several other studies in which the CHAQ was culturally adapted to other cultures (21-23).

In agreement with the observations reported by Ruperto *et al.* (1), our results confirm the finding that, after following the translation guidelines (9), this instrument proved to be both easy to apply and reliable. It is worth noting that in the project carried out by PRINTO to cross culturally adapt and validate the American English version of the CHAQ in 32 different member countries, some concern was raised regarding the comprehensibility of certain parts of the questionnaire that deal with items relating to everyday life in North America (such as "the cereal box" and the "the door knob") that are not commonly found in other countries (1). As in their report, in the context of Arabic culture we modified the two questions from the original HAQ regarding "the cereal box" and "the door knob". The changes were made keeping in mind two points: first, the modified item had to be equivalent to the original question in that it tested the same function, and secondly it is in fact often performed in countries of Arabic culture. We believe that such modifications are important for cross-cultural adaptations. Similar modifications to the original CHAQ were introduced in the Korean version of the CHAQ (25) and showed strong validity and reliability.

Factor analysis revealed the principal component that explained a good percentage (78.9%) of all variability. These findings confirm the validity of the questionnaire as a tool for the assessment of functional abilities. The

Table I. Age and sex distribution of JIA patients, and pattern of joint involvement.

	Patients	Control subjects
*Age		
Mean ± SD	10.2 ± 2.5	10.3 ± 2.6
* Sex		
Male	14 (22.6%)	16 (24.2%)
Female	48 (77.4%)	50 (75.8%)
* Pattern		
Extended	17 (27.4%)	
Polyarticular	23 (37.1%)	
Oligoarticular	17 (27.4%)	
Systemic	5 (8.1%)	

Table II. Agreement and kappa statistic of the test-retest results of the 8 subscales of the Arabic CHAQ.

	% Agreement	Kappa statistic
Dressing	91.9	0.87
Arising	96.8	0.94
Eating	100.0	1.00
Walking	98.4	0.97
Hygiene	100.0	1.00
Reach	98.4	0.97
Grip	96.8	0.94
Activities	82.2	0.73

Table III. Correlation of the different subscales of the Arabic CHAQ to disease activity parameters.

	AAJC	LJC	VAS	CRP	ESR
Dressing	0.563	0.551	0.947	0.578	0.548
Arising	0.482	0.571	0.970	0.631	0.581
Eating	0.439	0.452	0.929	0.488	0.478
Walking	0.649	0.638	0.979	0.705	0.644
Hygiene	0.586	0.637	0.978	0.682	0.598
Reach	0.477	0.538	0.976	0.642	0.534
Grip	0.642	0.642	0.981	0.714	0.622
Activities	0.557	0.641	0.977	0.679	0.577
Total HAQ	0.602	0.631	0.966	0.695	0.636

AAJC: number of joints with active arthritis; LJC: number of joints with limited range of motion; VAS: pain on visual analogue scale; CRP: C-reactive protein; ESR: erythrocyte sedimentation rate.
Values represent the Spearman's correlation coefficient and were all statistically significant at $p < 0.001$.

Table IV. Variations in the Arabic CHAQ for different patterns of JIA.

	Extended	Polyarticular	Oligoarticular	Systemic
Dressing*	1.23 ± 0.4	2.22 ± 0.7	1.35 ± 0.5	2.20 ± 0.8
Arising*	1.65 ± 0.5	2.30 ± 0.5	1.71 ± 0.5	2.40 ± 0.5
Eating*	1.23 ± 0.4	1.91 ± 0.5	1.47 ± 0.5	2.00 ± 0.0
Walking†	1.65 ± 0.5	2.17 ± 0.4	1.35 ± 0.5	1.80 ± 0.4
Hygiene‡	1.76 ± 0.4	2.22 ± 0.4	1.35 ± 0.5	2.20 ± 0.8
Reach*	1.53 ± 0.5	2.22 ± 0.4	1.53 ± 0.6	2.20 ± 0.8
Grip*	1.53 ± 0.5	2.22 ± 0.4	1.35 ± 0.5	2.20 ± 0.8
Activities*	1.65 ± 0.5	2.17 ± 0.7	1.35 ± 0.5	2.40 ± 0.5
Total HAQ*	1.53 ± 0.4	2.18 ± 0.4	1.43 ± 0.4	2.17 ± 0.6
Pain (100 mm VAS)	5.71 ± 1.3	7.43 ± 1.5	4.65 ± 1.5	5.8 ± 1.1
Patient's global assessment	7.06 ± 1.8	6.91 ± 1.9	6.23 ± 1.7	7.5 ± 1.2

*The polyarticular and systemic subgroups showed significantly higher values for this subscale in comparison to both the extended and the oligoarticular subgroups ($p < 0.05$).
† The polyarticular subgroup demonstrated significantly higher values for this subscale in comparison to both the extended and the oligoarticular subgroups ($p < 0.05$).
‡ The extended, polyarticular and systemic groups reported a significantly higher values for this subscale than the oligoarticular group, and the polyarticular group reported a significantly higher values than the extended group of JIA ($p < 0.05$).

two revised items showed a significant correlation with the first principle component, i.e. 0.939 for the first revised question regarding the eating element, while for the second question concerning grip it was 0.875; these results are comparable with other studies that showed values ranging between 0.66 and 0.81 (11, 12).

The test-retest reliability of the Arabic-CHAQ was comparable with previous reports. The test-retest correlation of the HAQ items in the cross-culturally adapted versions for the Argentinean, Austrian, Brazilian, French, Hebrew, German and British populations ranged from 0.7 to 0.99 (19, 26-31). The results of this study reported a similar reproducibility with values ranging between 0.73 and 1.0 that agree with the former results. A Cronbach's alpha of 0.951 demonstrated that the internal consistency of the Arabic-CHAQ was similar to that reported in other studies, where it ranged between 0.7 and 0.97 (26-31). This modified questionnaire yielded the same outcome under different conditions and after repeat performances, confirming the consistency and feasibility of the instrument.

Although the overall CHAQ disability index represents the pooled expression of 8 different activities, the total index showed different levels of significance in its correlation with the 8 subscales of the modified questionnaire. Similarly, the total CHAQ index showed a significant correlation to the disease activity parameters; in particular the pain score on the 100-mm VAS showed the highest correlation coefficient with the total CHAQ (0.966). These results match with those reported in similar studies done on other versions (21-31)

In conclusion, the Arabic-CHAQ is a reliable and valid instrument that can be administered to Arabic children suffering from juvenile idiopathic arthritis to evaluate their functional disability. Its measurement properties were comparable to versions in other languages.

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