The Portuguese version of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ)

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Supported by a grant from the European Union (BMH4-983531 CA), by IRCCS Policlinico S. Matteo (Pavia, Italy), and by Telecom Italy.

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Clin Exp Rheumatol 2001; 19 (Suppl. 23): S126-S130.

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Key words: Portuguese Childhood Health Assessment Questionnaire (CHAQ), Portuguese Child Health Questionnaire (CHQ), cross cultural adaptation and psychometric evaluation, health related quality of life, juvenile idiopathic arthritis (JIA), healthy children.

ABSTRACT

We report herein the results of the cross-cul tural adaptation and validation into the Portuguese language of the parent's version of two health related quality of life instru ments. The Childhood Health Assessment Questionnaire (CHAQ) is a disease specific health instrument that measures functional ability in daily living activities in children with juvenile idiopathic arthritis (JIA). The Child Health Ouestionnaire (CHO) is a generic health instrument designed to cap. ture the physical and psychosocial well being of children independently from the underlying disease. The Portuguese CHAQ CHQ were fully validated with 3 forward and 3 backward translations. A total of 130 subjects were enrolled: 69 patients with JIA (32% systemic onset, 19% polyarticular onset,26% extended oligoarticular subtype, and 23% persistent oligoarticular subtype) and 61 healthy children. The CHAQ clini cally discriminated between healthy sub jects and JIA patients, with the systemic, polyarticular and extended oligoarticular subtypes having a higher degree of disabili ty, pain, and a lower overall well being when compared to their healthy peers. Also the CHQ clinically discriminated between healthy subjects and JIA patients, with the systemic onset, polyarticular onset and extended oligoarticular subtypes having a lower physical and psychosocial well being when compared to their healthy peers. In conclusion the Portuguese version of the CHAQ-CHQ is a reliable, and valid tool for the functional, physical and psychosocial assessment of children with JIA.

Introduction

The aim of this study was to cross-culturally adapt and validate the Portuguese parent's version of the Childhood Health Assessment Questionnaire (CHAQ) (1) and the Child Health Questionnaire (CHQ) (2) in a cohort of healthy children and in patients with juvenile idiopathic arthritis (JIA) being followed by the Portuguese members of both the Paediatric Rheumatology Study Group of the Portuguese Rheumatology Society (Sociedade Portuguesa de Reumatologia) and the Paediatric Rheumatology International Trials Organisation (PRINTO). This project formed a part of a larger international survey conducted by PRINTO and supported by the European Union (contract BMH4 983531 CA) (3-5), whose scope is to evaluate the health-related quality of life in children with JIA as compared to their healthy peers.

Patients and results

The methodology used is described in detail in the introductory paper of this supplement (6). The complete Portuguese version of the CHAQ-CHQ, with the corresponding lines of the original American-English questionnaires marked in the left column, is reproduced at the end of this paper.

In brief, after obtaining ethics committees approval of the respective participating institutions and the consent of at least one parent per child, children were recruited into a prospective study performed from April 1998 to March 2000, by the Portuguese members of PRINTO. Patients included children with JIA of either systemic onset, polyarticular onset, extended oligoarticular or persistent oligoarticular subtype (Durban criteria) (7). The controls consisted of healthy children (6 to 18 years of age) attending local schools and/or healthy sibling(s) of the JIA participants. *Demographic and clinical characteristics of*

the subjects (Table I)

A total of 130 subjects were enrolled: 69 patients with JIA (32% systemic onset, 19% polyarticular onset, 26% extended oligoarticular subtype, and 23% persistent oligoarticular subtype) and 61 healthy children. The CHAQ-CHQ were completed in 84% of the cases by the mother (mean age 39.6 \pm 6.8), and in 16% of the cases by the father (mean age 42.0 \pm 9.3).

Clinical discriminant validity

Table II reports the results (mean \pm SD) for the 8 CHAQ domains, the disability index (DI) and the 2 VAS scores for parental assessment of pain and overall well being. The CHAQ clinically discriminated between healthy subjects and JIA patients, with the systemic, polyarticular and extended oligoarticular subtypes having a higher degree of disability, pain, and a lower overall well being when compared to their healthy peers.

Table III reports the CHQ results (mean \pm SD) for the 15 health concepts (see table for abbreviation) and summary scores. The CHQ clinically discriminated between healthy subjects and JIA patients, with the systemic onset, polyarticular onset and extended oligoarticular subtypes having a lower physical and psychosocial well being when compared to their healthy peers.

Cross cultural adaptation

The Portuguese CHAQ was fully cross-culturally adapted with 3 forward and 3 backward Table I. Demographic and clinical characteristics of the Portuguese sample.

	Systemic onset $n = 22$	Polyarticular onset $n = 13$	Extended oligoart. n = 18	Persistent oligoart. n = 16	Healthy controls n =61
Age of the children ¹	10.0 ± 5.0	12.2 ± 5.0	12.8 ± 5.0	10.9 ± 4.9	12.9 ± 4.8
Disease duration ¹	6.0 ± 4.4	5.4 ± 4.6	6.3 ± 3.9	5.4 ± 3.8	
ESR ^{1, 2}	47.5 ± 29.1	45.8 ± 28.9	22.6 ± 18.1	13.4 ± 8.4	
MD VAS (0-10 cm) ^{1, 2}	3.4 ± 3.2	4.0 ± 1.9	2.1 ± 1.3	1.3 ± 1.9	
No. swollen joints ¹	3.9 ± 6.7	4.7 ± 4.7	1.9 ± 2.0	0.9 ± 1.1	
No. joints with pain ^{1, 2}	5.3 ± 9.8	16.5 ± 14.2	3.2 ± 3.6	1.4 ± 1.5	
No. joints with limited range of motion ^{1, 2}	7.3 ± 8.2	14.8 ± 13.4	3.7 ± 3.9	1.4 ± 1.5	
No. active joints ^{1, 2}	4.9 ± 8.1	11.2 ± 10.5	2.7 ± 2.6	1.3 ± 1.4	
Female ³	14 (64%)	10 (77%)	13 (76%)	7 (44%)	30 (49%)
Persistent systemic features ³	17 (85%)	0	0	0	
Antinuclear antibody ³	1 (5%)	4 (31%)	4 (24%)	9 (56%)	
Rheumatoid factor ³	0	5 (42%)	0	0	
Chronic iritis ³	0	0	3 (17%)	4 (25%)	

Table II. The 8 CHAQ domains (range 0-3), the disability index (DI) (range 0-3), and the 2 VAS scores (range 0-10 cm) for pain and parent assessment of the child's overall well being. Lower scores indicate better functional ability. Values are expressed as means \pm SD.

	Systemic onset $n = 22$	Polyarticular onset $n = 13$	Extended oligoart. n = 18	Persistent oligoart. n = 16	Healthy controls n =61
Dressing	1.7 ± 1.2	1.9 ± 1.3	0.8 ± 1.0	0.5 ± 0.8	0.3 ± 0.6
Arising	1.1 ± 1.1	1.8 ± 1.2	0.3 ± 0.6	0.4 ± 0.6	0.0 ± 0.1
Eating	0.6 ± 0.8	1.1 ± 1.1	0.4 ± 0.6	0.4 ± 0.7	0.1 ± 0.4
Walking	0.7 ± 0.9	1.5 ± 0.8	0.4 ± 0.7	0.4 ± 0.7	0.0 ± 0.3
Hygiene	1.2 ± 1.0	1.6 ± 1.3	0.3 ± 0.8	0.4 ± 0.6	0.0 ± 0.1
Reach	1.2 ± 1.1	1.6 ± 1.2	0.6 ± 0.9	0.5 ± 0.6	0.0 ± 0.2
Grip	0.8 ± 1.1	1.4 ± 1.3	0.5 ± 0.8	0.2 ± 0.4	0.0 ± 0.1
Activities	1.2 ± 1.1	1.7 ± 1.2	0.7 ± 0.9	0.4 ± 0.5	0.2 ± 0.4
Disability index	1.1 ± 0.8	1.6 ± 1.0	0.5 ± 0.5	0.4 ± 0.4	0.1 ± 0.2
Parent's evaluation of pain	3.6 ± 3.0	2.9 ± 2.6	2.7 ± 2.6	1.8 ± 2.8	0.1 ± 0.5
Parent's evaluation of overall well being	3.6 ± 3.0	4.0 ± 2.6	2.7 ± 2.2	1.8 ± 1.7	0.1 ± 0.2

ANOVA p < 0.001 for all variables.

Table III. The 15 CHQ health concepts (and their abbreviations) and the 2 summary scores. Higher score indicates better physical or psychosocial well being (range 0-100). Values are expressed as means \pm SD.

	Systemic onset $n = 22$	Polyarticular onset $n = 13$	Extended oligoart. n = 18	Persistent oligoart. n = 16	Healthy controls n =61
Global health (GGH)	40.0 ± 23.3	30.0 ± 27.4	40.0 ± 29.3	50.6 ± 24.0	88.5 ± 15.9
Physical functioning (PF)	59.9 ± 35.4	51.7 ± 33.9	71.3 ± 23.8	82.6 ± 14.0	98.8 ± 8.0
Role/social limitations -	64.6 ± 38.4	66.7 ± 26.1	74.7 ± 29.2	90.3 ± 15.6	98.2 ± 6.1
Emotional/Behavioural (REB)					
Role/social limitations - Physical (RP)	61.1 ± 38.8	60.6 ± 38.2	72.2 ± 30.8	94.8 ± 11.7	99.7 ± 2.1
Bodily pain/discomfort (BP)	58.6 ± 25.5	58.3 ± 24.8	63.3 ± 26.6	72.5 ± 24.1	93.4 ± 12.9
Behaviour (BE)	77.8 ± 15.9	90.0 ± 7.5	78.8 ± 11.9	84.7 ± 11.7	85.2 ± 10.9
Global behaviour (GBE)	65.5 ± 23.6	73.8 ± 27.2	61.4 ± 23.0	70.6 ± 21.5	81.3 ± 18.0
Mental health (MH)	66.7 ± 15.9	76.3 ± 22.7	76.1 ± 15.9	79.1 ± 8.4	79.8 ± 16.0
Self esteem (SE)	72.0 ± 19.7	74.5 ± 18.8	76.0 ± 20.2	74.2 ± 17.5	90.2 ± 14.3
General health perceptions (GH)	49.8 ± 13.0	48.1 ± 15.3	58.1 ± 15.9	62.3 ± 11.2	80.1 ± 13.1
Change in health (CH)	59.1 ± 31.4	57.7 ± 35.9	61.1 ± 30.0	66.7 ± 27.8	58.9 ± 18.4
Parental impact - Emotional (PE)	38.6 ± 21.6	32.1 ± 18.9	39.4 ± 27.7	64.6 ± 23.5	80.5 ± 24.8
Parental impact - Time (PT)	56.8 ± 33.4	61.5 ± 25.1	78.4 ± 23.5	82.6 ± 15.7	95.1 ± 10.6
Family activities (FA)	68.5 ± 27.2	82.3 ± 22.2	89.5 ± 12.9	96.4 ± 6.4	92.6 ± 16.6
Family cohesion (FC)	66.4 ± 30.7	76.3 ± 23.8	68.3 ± 25.3	71.3 ± 22.1	75.6 ± 22.5
Physical summary score (PhS)	38.5 ± 13.5	37.6 ± 12.3	43.3 ± 10.3	50.1 ± 4.7	55.0 ± 2.4
Psychosocial summary score (PsS)	46.3 ± 6.0	50.2 ± 7.1	48.9 ± 7.7	50.1 ± 5.5	54.2 ± 6.9

ANOVA p < 0.05 except for CH (p = 0.87), and FC (p = 0.55).

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translations; there was a concordance with the original American English version of the CHQ in at least 2 out of 3 back translations for 54/69 (79%) lines of the translations. The Portuguese CHQ was fully cross-culturally adapted with 3 forward and 3 backward translations; there was a concordance with the original American English version of the CHQ in at least 2 out of 3 back translations for 93/99 (94%) lines of the translations.

Probe technique

For the 69 lines of the translated CHAQ, all the lines of translation were understood by more than 80% of the 20 parents tested (median = 100%; range:90-100%). For the 99 lines of the translated CHQ, all the lines of translation were understood by more than 80% of the parents (median = 100%; range: 95-100%). No change inthetextof the Portuguese CHAQ-CHQ was necessary after the probe technique. *Psychometric issues*

Descriptive statistics (first Likert assumption). For the CHAQ the total number of missing responses was 3.9% (range 0.4-9.2%) with dressing and activity having more missing values; the response pattern were skewed towards normal functional ability. All response choices of the CHAQ items have been used except for items in eating, hygiene, grip, and activity. The mean \pm SD of the items within a scale were not equivalent for most of the CHAQ domains (except for walking). The total number of missing responses on the CHQ was 2.3 (range: 0.5-4.6%); the response pattern was most often normally distributed except for REB, RP, and FA. All response choices of the CHQ items have been used except for BE, and SE. The means \pm SD of the items within a scale were roughly equivalent except for GH. Equal items-scale correlation (second Likert assumption). Pearson items-scale correlations corrected for overlap were not equivalent for most of the CHAQ domains except for walking while were equivalent for most of the CHQ health concepts except for BE, MH, SE, GH, PE, PT, and FA.

Items internal consistency (third Likert as sumption). Pearson items scale correlations 0.4 for 90% of the CHAO items were (except for arising, and activity), and for 73% of the CHQ items (except BE, MH, and GH). Items discriminant validity. For the CHAO, Pearson items correlations with its scale corrected for overlap were greater than at least 1 standard error (SE) of the correlation with other scales for 62% of the items (10% by 2 SE); scaling failure was observed for dressing, arising, eating, and reach, where the items were better correlated with other domains. For the CHQ, Pearson items correlations with its scale were greater by at least 1 SE for 92% of the items (73% by 2 SE); scaling failure was observed only for BE, and GH.

Floor and ceiling effect. The CHAQ floor effect had a median of 82% (range 64-84%) while for the CHQ the median was 1% (range

0-7.3%). The CHAQ ceiling effect had median of 0.0% (range 0.0-0.0) while the CHQ had a median of 26% (range 6-76%).

Cronbach's alpha internal consistency. Cronbach's alpha was 0.7 for 7/8 (88%) domains of the CHAQ (overall 0.96; range 0.3-0.9) with the exception being arising (0.31). Cronbach's alpha was 0.7 for 9/11 (82%) measurable health concepts (*i.e.* health concepts with more than 1 item) of the CHQ (overall 0.94; range 0.5-0.97) with the exception being BE (0.64), and GH (0.51).

Inter scale correlation. The Pearson correlation of each domain with all other domains of the CHAQ-CHQ was lower than their Cronbach's alpha only for walking, grip, and active for the CHAQ domains. For the CHQ all 11 measurable health concepts have correlation lower than their Cronbach's alpha except for GH, and PT.

Test-retest reliability. After a median of 6.5 days (range 2-7; number of JIA patients retested = 10) the intra-class correlation coefficients for the 8 CHAQ domains showed a fair to good reproducibility with a median of 0.8 (range 0.2-0.9) with a poor reproducibility only for arising (0.2). Also the 15 CHQ health concepts showed a fair to good reproducibility with a median of 0.8 (range 0.1-0.9) with a poor reproducibility with a median of 0.8 (range 0.1-0.9) with a poor reproducibility only for PE (0.1).

External validity. The Spearman correlation of the CHAQ with the JIA core set variables (8) showed a median of 0.6 (range 0.5 to 0.7), with the highest correlation being with the number of joints with limited range of motion (r = 0.7). For the CHQ the median correlation was for the PhS -0.6 (range -0.8 to -0.5) and for the PsS was -0.0 (range -0.4 to -0.2). The best correlation was with the parent's evaluation of overall well being for both the PsS (-0.8) and the PsS (-0.4).

Discussion

The results of the present study show that the Portuguese versions of the CHAQ-CHQ have excellent psychometric properties. In this study the Portuguese CHAQ was fully cross-culturally adapted from the original American English version with 3 forward and 3 backward translations. This disease-specific questionnaire proved its ability to clinically discriminate between the JIA subtypes and healthy controls, with the systemic, polyarticular and extended oligoarticular subtypes having a higher degree of disability, pain, and a lower overall well being when compared to their healthy peers. The most problematic domains were arising, eating, and reach, which showed different means \pm SD, and problems for internal consistency, discriminant validity, Cronbach s alpha, and test-retest reliability.

In this study the Portuguese CHQ was fully cross-culturally adapted from the original American English version with 3 forward and 3 backward translations. The generic CHQ questionnaire proved less able to clinically discriminate between the different JIA types than the CHAQ with the JIA patients with systemic, polyarticular onset or extended oligoarticular subtypes having a lower physical and psychosocial well being when compared to their healthy peers. Some minor statistical problems were found for the equal item scale correlation, the item internal consistency, discriminant validity, Cronbach's alpha for BE, and GH. In conclusion,the Portuguese version of the CHAQ-CHQ is a reliable and valid tool for the functional, physical and psychosocial assessment of children with JIA.

Acknowledgements

We are indebted to Dr. J. Landgraf *et al.*, developers of the CHQ, to Dr. Luciana Gado-West reviewer of the CHAQ, to Dr. Anna Tortorelli for data entry, and to the committee which prepared and reviewed the forward and backward translations (Dr. Helena Santos, Mrs Maria Conceição Pereira, Captain Pereira, Mrs Nadia Seskin and Mrs Suzanne Boyer).

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