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

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

ABSTRACT
We report the cross-cultural adaptation and validation into Brazilian-Portuguese of the parent's version of two health related quality of life instruments. 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 Questionnaire (CHQ) is a generic health instrument designed to capture the physical and psychosocial well-being of children regardless the underlying disease. The Brazilian CHAQ was revalidated, while the CHQ has been derived from the Portuguese version. A total of 471 subjects were enrolled: 157 patients with JIA (27% systemic onset, 38% polyarticular onset, 9% extended oligoarticular subtype, and 26% persistent oligoarticular subtype) and 314 healthy children. The CHAQ discriminated clinically healthy subjects from JIA patients, with the systemic, polyarticular and extended oligoarticular subtypes having a higher degree of disability, pain, and lower overall well-being scores when compared to their healthy peers. Also the CHQ discriminated clinically healthy subjects from JIA patients, with the systemic onset, polyarticular onset and extended oligoarticular subtypes having a lower physical and psychosocial well-being score when compared to their healthy peers. In conclusion the Brazilian versions of the CHAQ-CHQ are reliable and valid tools for the combined physical and psychosocial assessment of children with JIA.

Introduction
The aim of this study was to cross-culturally adapt and validate the Brazilian parentís 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). This project was part of a large international survey conducted by PRINTO and supported by the European Union (contract BMH4 983531 CA) (3-5), to evaluate the health-related quality of life in children with JIA as compared to their healthy peers.

Patients and results
The methodology is reported in the introductory paper of this supplement (6). The complete Brazilian 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 of the parents, children were recruited into a prospective study performed from December 1999 to November 2000. Patients included children with JIA of either systemic onset, polyarticular onset, extended oligoarticular or persistent oligoarticular subtype (Durban criteria) (7). The controls were healthy children (6 to 18 years) attending local schools.

Demographic and clinical characteristics
471 subjects were enrolled: 157 JIA patients (27% systemic onset, 38% polyarticular onset, 9% extended oligoarticular subtype, and 26% persistent oligoarticular subtype) and 314 healthy children (Table I). CHAQ-CHQ were completed in 89% of the cases by the mother (mean age 37.9 ± 5.6 yrs), and in 11% of the cases by the father (mean age 40.3 ± 5.8 yrs).

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 discriminated clinically healthy subjects from JIA patients, with the systemic, polyarticular and extended oligoarticular subtypes having a higher degree of disability, pain, and lower overall well-being scores 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 two summary scores, the physical (PhS) and psychosocial (PsS). The CHQ discriminated clinically healthy subjects from JIA patients, with the systemic onset, polyarticular onset and extended oligoarticular subtypes having lower physical and psychosocial well-being scores when compared to their healthy peers.

Cross cultural adaptation
The Brazilian version of CHAQ-CHQ has been derived from the Portuguese version (8, 9) that was fully cross culturally adapted with 3 forward and 3 backward translations. Despite the high similarity in the language structure, as the target population has another culture, standard Portuguese (mother tongue) was adapted with regard the Brazilian cultural context, addressing the idiomatic equivalence of concepts and experiences beyond the literal translation of individual words and sentences. Adaptation was required in 16/69 lines of the CHAQ and 26/99 lines of the CHQ, with replacement of words of different meaning and grammatical-orthographic changes for a colloquial style (10).

Probe technique
Most of the 69 lines in the translated CHAQ were understood by more than 80% of the 20 parents tested (median = 100%; range: 65-100%), exceptions being lines 18 and 24. Most

Table I. Demographic and clinical characteristics of the Brazilian sample.

	Systemic onset n = 42	Polyarticular onset n = 60	Extended oligoart. n = 14	Persistent oligoart. n = 41	Healthy controls n = 314
Age of the children[1]	11.1 ± 4.5	11.3 ± 4.0	11.4 ± 4.4	11.3 ± 3.7	11.3 ± 3.5
Disease duration[1]	5.4 ± 4.2	5.0 ± 4.1	6.5 ± 4.6	4.3 ± 2.7	
ESR[1,2]	35.7 ± 24.2	33.3 ± 22.3	23.9 ± 17.9	19.6 ± 13.6	
MD VAS (0-10 cm)[1,2]	3.0 ± 2.8	2.8 ± 2.3	2.6 ± 2.4	1.6 ± 1.7	
No. swollen joints[1,2]	5.0 ± 7.4	8.0 ± 9.1	4.1 ± 6.1	1.3 ± 1.6	
No. joints with pain[1,2]	7.1 ± 11.5	10.0 ± 13.6	3.1 ± 4.7	0.7 ± 1.1	
No. joints with limited range of motion[1,2]	15.1 ± 15.2	15.3 ± 12.6	7.3 ± 5.6	1.0 ± 1.2	
No. active joints[1,2]	8.3 ± 10.7	11.8 ± 11.8	5.4 ± 6.6	1.4 ± 1.6	
Female[3]	26 (62%)	46 (77%)	10 (71%)	21 (51%)	144 (46%)
Persistent systemic features[3]	25 (66%)	0	0	0	
Antinuclear antibody[3]	2 (5%)	15 (27%)	6 (43%)	8 (20%)	
Rheumatoid factor[3]	1 (2%)	13 (24%)	2 (15%)	0	
Chronic iritis[3]	0	1 (2%)	2 (14%)	5 (12%)	

[1]Mean ± SD; [2]ANOVA p < 0.05; [3]number and percentage.

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 ± SD.

	Systemic onset n = 42	Polyarticular onset n = 60	Extended oligoart. n = 14	Persistent oligoart. n = 41	Healthy controls n = 314
Dressing	1.2 ± 1.3	1.0 ± 1.1	0.9 ± 1.0	0.5 ± 0.9	0.3 ± 0.7
Arising	1.2 ± 1.2	1.0 ± 1.0	0.5 ± 0.8	0.4 ± 0.7	0.0 ± 0.1
Eating	0.7 ± 1.0	0.7 ± 1.0	0.6 ± 0.9	0.1 ± 0.4	0.2 ± 0.4
Walking	0.9 ± 1.1	0.7 ± 0.9	0.5 ± 0.7	0.2 ± 0.5	0.0 ± 0.0
Hygiene	1.0 ± 1.1	0.7 ± 1.0	0.2 ± 0.4	0.3 ± 0.6	0.1 ± 0.3
Reach	1.4 ± 1.3	1.3 ± 1.1	1.1 ± 1.1	0.4 ± 0.8	0.1 ± 0.3
Grip	1.1 ± 1.2	1.2 ± 1.2	0.6 ± 0.9	0.1 ± 0.5	0.1 ± 0.4
Activities	1.2 ± 1.3	1.0 ± 1.1	1.0 ± 0.9	0.4 ± 0.6	0.2 ± 0.5
Disability index	1.1 ± 1.0	0.9 ± 0.8	0.7 ± 0.6	0.3 ± 0.4	0.1 ± 0.2
Parent's evaluation of pain	2.5 ± 3.0	2.9 ± 2.8	2.6 ± 2.7	1.1 ± 1.6	0.1 ± 0.7
Parent's evaluation of overall well-being	2.5 ± 3.0	2.5 ± 2.9	1.6 ± 1.6	0.9 ± 1.4	0.0 ± 0.3

ANOVA p < 0.001 for all variables.

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

	Systemic onset n = 42	Polyarticular onset n = 60	Extended oligoart. n = 14	Persistent oligoart. n = 41	Healthy controls n = 314
Global health (GGH)	58.2 ± 27.6	58.2 ± 27.8	55.4 ± 25.7	67.2 ± 27.9	92.7 ± 11.6
Physical functioning (PF)	62.2 ± 33.7	71.7 ± 30.3	82.1 ± 20.3	85.4 ± 23.7	98.5 ± 7.9
Role/social limitations - Emotional/Behavioural (REB)	74.9 ± 33.1	76.6 ± 32.3	86.5 ± 20.1	92.4 ± 16.2	97.1 ± 9.5
Role/social limitations - Physical (RP)	66.7 ± 39.6	72.2 ± 35.5	83.3 ± 26.1	90.2 ± 18.6	98.0 ± 11.0
Bodily pain/discomfort (BP)	58.3 ± 36.3	59.1 ± 30.9	59.3 ± 28.9	78.3 ± 24.3	94.2 ± 12.8
Behaviour (BE)	71.6 ± 15.1	74.8 ± 16.4	67.7 ± 22.3	72.0 ± 19.4	79.5 ± 13.9
Global behaviour (GBE)	78.8 ± 18.6	75.8 ± 25.3	75.7 ± 32.9	81.5 ± 21.7	85.5 ± 16.1
Mental health (MH)	71.9 ± 18.0	72.6 ± 18.6	72.5 ± 22.1	74.5 ± 20.6	78.2 ± 14.3
Self esteem (SE)	81.3 ± 17.8	82.9 ± 20.3	85.1 ± 17.4	89.7 ± 17.1	90.3 ± 15.3
General health perceptions (GH)	54.0 ± 18.1	60.6 ± 15.5	67.0 ± 20.2	64.4 ± 16.9	78.3 ± 12.3
Change in health (CH)	77.4 ± 32.1	69.5 ± 38.7	83.9 ± 21.0	82.9 ± 20.5	65.8 ± 23.0
Parental impact - Emotional (PE)	59.8 ± 33.5	59.1 ± 30.3	64.9 ± 29.3	74.6 ± 24.2	82.3 ± 21.5
Parental impact - Time (PT)	71.0 ± 31.2	79.6 ± 26.4	73.8 ± 32.8	85.8 ± 22.4	94.2 ± 12.5
Family activities (FA)	79.4 ± 20.8	84.1 ± 18.3	84.2 ± 19.9	89.1 ± 15.9	90.5 ± 13.4
Family cohesion (FC)	64.3 ± 30.2	71.9 ± 25.5	77.5 ± 26.6	66.7 ± 29.1	78.1 ± 19.1
Physical summary score (PhS)	41.7 ± 12.2	44.3 ± 11.7	48.8 ± 9.4	51.2 ± 6.5	55.1 ± 3.6
Psychosocial summary score (PsS)	49.2 ± 8.4	49.8 ± 7.9	47.6 ± 11.6	49.9 ± 9.5	53.0 ± 7.0

ANOVA p < 0.05.

of the 99 lines in the translated CHQ were understood by more than 80% of the parents (median = 100%; range: 60-100%), exceptions being lines 4, 58, and 59. All the misunderstood items were replaced and discrepancies were resolved by the committee who interviewed the parents.

Psychometric issues

Descriptive statistics (first Likert assumption). For the CHAQ the total number of missing responses was 2.7% (range 0.2-4.8%); the response pattern were skewed towards normal functional ability. All response choices of the CHAQ items have been used except for hygiene and grip. The mean ± SD of the items within a scale were roughly equivalent. The total number of missing responses on the CHQ was 1.3% (range: 0.7-3.4%); the response pattern was most often normally distributed except for REB, RP, SE, and PT. All response choices of the CHQ items have been used. The means ± 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 roughly equivalent for items within a scale for all of the CHAQ domains except for dressing, hygiene, grip, and activities,and for all CHQ health concepts except for BE, MH, SE, and GH.

Items internal consistency (third Likert assumption). Pearson items scale correlations were 0.4 for 97% of CHAQ items (except activity) and for 88% of the items of the CHQ (except BE, MH, and GH).

Items discriminant validity. For the CHAQ, 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 73% of the items (33% by 2 SE); scaling failure was observed for dressing, walking, 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 94% of the items (84% by 2 SE); scaling failure was observed only for BE, and GH.

Floor and ceiling effect. The CHAQ floor effect had a median of 88% (range 72-94%) while for the CHQ the median was 1.3% (range 0-4%). The CHAQ ceiling effect had median of 0.0% (range 0.0-0.3) while the CHQ had a median of 38% (range 4-83%).

Cronbach's alpha internal consistency. Cronbach's alpha was 0.7 for 7/8 (88%) domains of the CHAQ (overall 0.97; range 0.69-0.89) with the exception of dressing (0.69). Cronbach's alpha was 0.7 for 10/11 (91%) measurable health concepts (*i.e.* health concepts with more than 1 item) of CHQ (overall 0.94; range 0.4-0.94)with the exception of GH (0.4).

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

Test-retest reliability. After a median of 8.5 days (range 7-24; no. of JIA patients re-tested = 14) the intra-class correlation coefficients for the 8 CHAQ domains showed a fair to good reproducibility with a median of 0.7 (range 0.15-1.0) with poor reproducibility only for hygiene (0.15). Also the 15 CHQ health concepts showed a fair to good reproducibility with a median of 0.6 (range 0.2-0.9) with a poor reproducibility only for RP, GH, CH, and PE.

External validity. The Spearman correlation of the CHAQ with the JIA core set variables (11) showed a median of 0.6 (range 0.3 to 0.6), with the highest correlation being with the number of joints with limited range of motion (r = 0.6). For CHQ the median correlation was for the PhS -0.5 (range -0.5 to -0.4) and for the PsS was -0.2 (range -0.3 to -0.0). The best correlation was for the PhS with the parent's evaluation of overall well being (-0.6) and for the PsS with the DI of the CHAQ (-0.4).

Discussion

This study focuses on revalidating by self-administration the Brazilian version of the CHAQ, already published by Len *et al.* (8), in addition to the adaptation and validation of the Portuguese version of CHQ published by Melo-Gomes *et al.* (9).

The disease-specific questionnaire (CHAQ) proved its ability to discriminate clinically the JIA subtypes from healthy controls, with the systemic, polyarticular and extended oligoarticular subtypes having a higher degree of disability, pain, and lower overall well-being scores when compared to their healthy peers. Statistical problems were found in 3 domains (dressing, walking, and reach), which showed different means ± SD, unequal item scale correlation, fairly poor discriminant validity and Cronbach's alpha. These problems were minor and did not bring any modification of the items of the final version of the CHAQ.

The CHQ, as a generic questionnaire proved less able to clinically discriminate 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 scores when compared to their healthy peers. Some minor statistical problems were found as well for the equal item scale correlation, the item internal consistency, and discriminant validity for 2 health concepts (BE and GH).

Adapting equivalent emotional or behavioural expressions into another cultural context and lifestyle may be challenging, especially because the population concerned has a large range of socio-demographic diversity. This paper reports our very first step into self-administration of health related quality of life adapted instruments in a large scale data collection under PRINTO guidelines.

In conclusion, the Brazilian versions of the CHAQ and CHQ have shown excellent psychometric properties and therefore are reliable and valid tools for the combined physical and psychosocial assessment of children with JIA. This may be a starting point for studying functional health and well being in other paediatric rheumatic diseases in the near future.

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