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

B. Andersson Gäre¹, N. Ruperto², S. Berg³, S. Hagelberg⁴, N.O. Jonsson¹, B. Magnusson⁴, J. Martinell³, A. Erling³, J.M. Landgraf⁵, for the Paediatric Rheumatology International Trials Organisation (PRINTO)

¹Ryhov's County Hospital, Jönköping, Sweden; ²Laboratorio di Informatica Medica, IRCCS S. Matteo, Pavia, Italy; ³University of Göteborg, Department of Pediatrics, Göteborg; ⁴Astrid Lindgren Children's Hospital, Stockholm, Sweden; ⁵HealthAct, Boston, MA, USA.

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

Please address correspondence and requests for reprints to either: Boel Andersson Gäre, MD, Ryhov's County Hospital, Department of Pediatrics, Ryhov's County Hospital, 551 85 Jönköping, Sweden.

E-mail: boel.andersson-gare@ryhov.ltjkpg.se or PRINTO, IRCCS Policlinico S. Matteo, Pediatria Generale e Reumatologia, Piazzale Golgi, 2, 27100 Pavia, Italy. E-mail: nruperto@smatteo.pv.it WWW: http://www.medit.it/printo/
Clin Exp Rheumatol 2001; 19 (Suppl. 23): S146-S150.

© Copyright Clinical and Experimental Rheumatology 2001.

Key words: Swedish Childhood Health Assessment Questionnaire (CHAQ), Swedish 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 Swedish 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 Questionnaire (CHQ) is a generic health instrument designed to capture the physical and psychosocial well-being of children independently from the underlying disease. The Swedish CHAQ CHQ were already published and therefore were reval idated in this study. A total of 129 subjects were enrolled: 69 patients with JIA (13% systemic onset, 39% polyarticular onset, 25% extended oligoarticular subtype, and 23% persistent oligoarticular subtype) and 60 healthy children. The CHAQ clinically discriminated between healthy subjects and JIA patients, with the systemic, polyarti cular and extended oligoarticular subtypes having a higher degree of disability, 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 oli goarticular subtypes having a lower physi cal and psychosocial well-being when com pared to their healthy peers.

In conclusion the Swedish version of the CHAQ-CHQ are reliable, and valid tools 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 Swedish 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 Swedish members of 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

Patients and results

The methodology used is described in detail in the introductory paper of this supplement (6). The complete Swedish 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 Swedish 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 129 subjects were enrolled: 69 patients with JIA (13% systemic onset, 39% polyarticular onset, 25% extended oligoarticular subtype, and 23% persistent oligoarticular subtype) and 60 healthy children. The CHAQCHQ were completed in 80% of the cases by the mother (mean age 40.7 ± 5.6), and in 20% of thecases by the father (mean age 41.2 ± 8.7). 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 JIApatients, 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 Swedish CHAQ (8)" and the CHQ (2) were already published and therefore they were revalidated in this study.

Probe technique

For the 69 lines of the translated CHAQ, all

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

	Systemic onset $n = 9$	Polyarticular onset $n = 27$	Extended oligoart. $n = 14$	Persistent oligoart. $n = 16$	Healthy controls n =60
Age of the children ¹	10.7 ± 4.1	11.5 ± 4.3	11.0 ± 3.6	8.8 ± 4.4	12.9 ± 1.5
Disease duration ¹	5.8 ± 2.9	4.1 ± 3.6	5.9 ± 4.0	2.9 ± 2.7	
ESR ¹	11.0 ± 10.2	23.1 ± 23.5	10.7 ± 5.4	19.2 ± 12.8	
MD VAS (0-10 cm) ^{1, 2}	1.4 ± 2.0	3.6 ± 3.1	2.2 ± 1.5	1.7 ± 1.3	
No. swollen joints ¹	0.4 ± 1.0	5.3 ± 9.0	2.9 ± 3.6	0.8 ± 0.9	
No. joints with pain ^{1, 2}	0.3 ± 0.7	5.9 ± 8.9	3.4 ± 4.1	1.3 ± 1.3	
No. joints with limited range of motion ^{1, 2}	5.8 ± 14.4	6.2 ± 9.8	1.6 ± 3.2	1.1 ± 1.1	
No. active joints ^{1, 2}	0.7 ± 1.1	6.8 ± 10.6	3.3 ± 3.7	1.1 ± 1.0	
Female ³	5 (57%)	24 (89%)	7 (41%)	12 (75%)	33 (55%)
Persistent systemic features ³	6 (75%)	0	0	0	
Antinuclear antibody ³	2 (22%)	10 (40%)	7 (44%)	5 (36%)	
Rheumatoid factor ³	0	6 (24%)	1 (7%)	0	
Chronic iritis ³	0	3 (12%)	0	1 (8%)	

 1 Mean $\pm\,$ 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 \pm SD.

	Systemic onset $n = 9$	Polyarticular onset $n = 27$	Extended oligoart. $n = 14$	Persistent oligoart. $n = 16$	Healthy controls n =60
Dressing	0.9 ± 1.2	0.8 ± 1.0	0.5 ± 0.7	0.3 ± 0.6	0.1 ± 0.3
Arising	0.3 ± 0.7	1.0 ± 0.9	0.6 ± 0.7	0.4 ± 0.7	0.0 ± 0.0
Eating	0.2 ± 0.7	0.9 ± 0.9	1.0 ± 1.1	0.1 ± 0.3	0.0 ± 0.2
Walking	0.3 ± 0.7	0.8 ± 0.9	0.4 ± 0.6	0.6 ± 0.9	0.0 ± 0.0
Hygiene	0.4 ± 0.7	0.9 ± 0.9	0.9 ± 1.1	0.6 ± 0.9	0.0 ± 0.0
Reach	0.4 ± 0.7	1.0 ± 1.0	0.9 ± 0.9	0.4 ± 0.6	0.0 ± 0.0
Grip	0.6 ± 0.9	1.0 ± 0.9	0.6 ± 0.7	0.3 ± 0.6	0.0 ± 0.1
Activities	0.9 ± 1.2	1.1 ± 1.0	0.6 ± 0.9	0.8 ± 0.9	0.0 ± 0.0
Disability index	0.5 ± 0.7	0.9 ± 0.8	0.7 ± 0.7	0.4 ± 0.5	0.0 ± 0.1
Parent's evaluation of pain	0.7 ± 0.9	3.6 ± 3.5	3.2 ± 3.0	2.5 ± 2.5	0.0 ± 0.1
Parent's evaluation of overall well-being	1.4 ± 1.4	3.6 ± 2.9	2.6 ± 2.5	2.6 ± 2.6	0.0 ± 0.1

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 $n = 9$	Polyarticular onset $n = 27$	Extended oligoart. $n = 14$	Persistent oligoart. n = 16	Healthy controls n =60
Global health (GGH)	64.4 ± 22.7	58.7 ± 30.7	52.9 ± 25.1	86.9 ± 15.0	94.7 ± 13.0
Physical functioning (PF)	71.0 ± 35.4	61.1 ± 32.8	63.4 ± 23.3	69.6 ± 28.0	99.7 ± 1.6
Role/social limitations - 90.1 ± 22.5 Emotional/Behavioural (REB)	76.1 ± 27.2	76.4 ± 25.0	92.6 ± 18.6	94.7 ± 15.1	
Role/social limitations - Physical (RP)	79.6 ± 35.1	64.2 ± 31.9	73.5 ± 19.6	77.8 ± 32.5	98.0 ± 9.8
Bodily pain/discomfort (BP)	60.0 ± 29.6	49.6 ± 32.7	47.5 ± 30.4	59.4 ± 23.8	96.6 ± 8.4
Behaviour (BE)	73.6 ± 8.1	72.5 ± 12.7	63.6 ± 16.5	73.3 ± 15.8	82.7 ± 14.6
Global behaviour (GBE)	69.4 ± 21.1	69.0 ± 24.9	71.3 ± 28.6	77.0 ± 20.9	87.4 ± 21.3
Mental health (MH)	73.5 ± 14.2	65.8 ± 11.8	68.3 ± 14.5	74.1 ± 13.6	77.3 ± 14.3
Self esteem (SE)	66.4 ± 19.9	67.3 ± 14.3	66.4 ± 16.3	81.3 ± 11.6	83.1 ± 15.2
General health perceptions (GH)	51.0 ± 17.3	49.6 ± 17.8	51.5 ± 17.4	71.8 ± 13.8	89.0 ± 15.5
Change in health (CH)	58.3 ± 33.1	51.9 ± 37.9	55.9 ± 28.7	42.2 ± 25.4	53.6 ± 11.1
Parental impact - Emotional (PE)	66.7 ± 24.3	61.2 ± 27.0	71.1 ± 24.7	74.5 ± 27.6	92.5 ± 13.5
Parental impact - Time (PT)	81.5 ± 17.6	75.2 ± 26.0	75.2 ± 30.3	83.7 ± 29.7	94.8 ± 14.3
Family activities (FA)	75.0 ± 21.7	74.7 ± 18.3	72.8 ± 28.2	87.6 ± 16.7	93.0 ± 12.4
Family cohesion (FC)	73.9 ± 23.0	69.1 ± 26.7	67.0 ± 30.6	77.2 ± 18.3	78.9 ± 19.4
Physical summary score (PhS)	46.4 ± 12.2	41.1 ± 11.0	44.2 ± 8.0	45.9 ± 11.0	55.6 ± 2.2
Psychosocial summary score (PsS)	47.9 ± 5.8	47.4 ± 6.0	44.9 ± 10.0	51.2 ± 8.5	53.3 ± 8.0

ANOVA p < 0.01 except for CH (p = 0.47) and FC (p=0.24).

The Swedish version of the CHAQ and CHQ/B. Anderson Gäre et al.

the lines of translation were understood by 100% of the 20 parents tested. For the 99 lines of the translated CHQ, all the lines of translation were understood by 100% of the parents. No change in the text of the Swedish 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 5.5% (range 1.9-10.1%) with dressing having more than 10% missing values; the response pattern were skewed towards normal functional ability. All CHAQ domains have some response choices not used. The mean ± SD of the items within a scale were roughly equivalent except foreating, and reach. The total number of missing responses on the CHQ was 3.3% (range: 0.8-8.8%); the response pattern was most normally distributed except for REB, RP, and PT. All response choices of the CHQ items have been used except for BE, MH,SE, and FA. The means \pm SD of the items within a scale were roughly equivalent.

Equal items-scale correlation (second Likert assumption). Pearson items-scale correlations corrected for overlap were roughly equivalent for items within a scale for most of the CHAQ domains except for dressing, eating, hygiene, and reach, and for most of the CHQ health concepts except for MH, SE, GH, PE, and FA.

Items internal consistency (third Likert as sumption). Pearson items scale correlations were 0.4 for 97% of the CHAQ items (except for dressing) and for 94% of the CHQ items (except BE, MH, and SE).

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 65% of the items (8% by 2 SE); scaling failure was observed for dressing, eating, and walking, 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 95% of the items (60% by 2 SE); no scaling failures were observed.

Floor and ceiling effect. The CHAQ floor effect had a median of 87% (range 82-92%) while for the CHQ the median was 1.1% (range 0-5.6%). The CHAQ ceiling effect had median of 0.0% (range 0.0-0.0) while the CHQ had a median of 39% (range 3.3-70%). Cronbach's alpha internal consistency. Cronbach's alpha was 0.7 for 7/8 (88%) domains of the CHAQ (overall 0.98; range 0.68-0.92) with the exception being walking (0.68). Cronbach's alpha was 0.7 for 11/11 (100%)

measurable health concepts (*i.e.* health concepts with more than 1 item) of the CHQ (overall 0.96; range 0.75-0.94).

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 most of the CHAQ domains except for reach, grip, and activities. For the CHQ most of the 11 measurable health concepts have correlation lower than their Cronbach's alpha except for PE.

Test-retest reliability. After a median of 7 days (range 6-9 days; number of JIA patients retested = 10) the intra-class correlation coefficients for the 8 CHAQ domains showed a good to excellent reproducibility with a median of 1.0 (range 0.9-1.0). Also the 15 CHQ health concepts showed a good to excellent reproducibility with a median of 0.9 (range 0.5-1.0). External validity. The Spearman correlation of the CHAQ with the JIA core set variables (9) showed a median of 0.6 (range 0.2 to 0.8), with the highest correlation being with the parent's evaluation of overall well being (r = 0.6). For the CHQ the median correlation was for the PhS -0.4 (range -0.8 to -0.3) and for the PsS was -0.1 (range -0.4 to -0.0). The best correlation was for the PhS with the parent's evaluation of overall well being (-0.8) and for the PsS with the DI of the CHAQ (-0.4).

Discussion

The results of the present study show that the Swedish versions of the CHAQ-CHQ have excellent psychometric properties.

In this study the Swedish CHAQ was already published and therefore was revalidated. 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. Minor statistical problems were found for dressing, eating, and walking, which showed different means \pm SD, an unequal item scale correlation, and problems for discriminant validity, and Cronbach s alpha.

In this study the Swedish CHQ already published and therefore it was revalidated. Also the generic CHQ questionnaire proved its ability to clinically discriminate between the different JIAtypes, with the JIApatients with systemic, polyarticular onset or extended oligoarticular subtypes having a lower physical and psychosocial well-being when compared to their healthy peers.

In conclusion, the Swedish version of the CHAQ-CHQ are reliable and valid tools for the functional, physical and psychosocial assessment of children with JIA.

Acknowledgements

We are indebted to the parents and the schools in Jönköping, Sweden (Hisingstorpsskolan and Alfred Dahlinskolan) which allowed us to study their children, to Dr. J. Landgraf *et al.*, developers of the CHQ", to Britt Andersson, RN, who administrated the study of the healthy children in Sweden, to Lucy Gado-West reviewer of the CHAQ, to Anna Tortelli for the data entry.

References

- SINGH G, ATHREYA B, FRIES JF, GOLDSMITH DP: Measurement of health status in children with juvenile rheumatoid arthritis. *Arthritis Rheum* 1994; 37: 1761-9.
- LANDGRAF JM, ABETZ L, WARE JE: The CHQ User's Manual. 1st ed., Boston, The Health Institute, New England Medical Center, 1996.
- RUPERTO N, MARTINI A, for PRINTO: A European network for randomised actively controlled clinical trials in paediatric rheumatic diseases: parenteral methotrexate in medium versus higher doses in juvenile chronic arthritis. "XIVEULAR and VI European Paediatric Rheumatology Congress". Ann Rheum Dis 1999; Conference Proceedings, Abstr. 105,pg 25.
- RUPERTO N, MARTINI A, for PRINTO: Use of unlabelled and off licence drugs in children. A European paediatric rule is needed to protect children. BMJ 2000; 320: 1210-1.
- BRUNNER HI, GIANNINI EH: Evidence-based medicine in pediatric rheumatology. Clin Exp Rheumatol 2000; 18: 407-14.
- 6. RUPERTO N, RAVELLI A, PISTORIO A et al.: Cross-cultural adaptation and psychometric evaluation of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ) in 32 countries. Review of the general methodology. Clin Exp Rheumatol 2001; 19 (Suppl. 23): S1-S9.
- 7. PETTY RE, SOUTHWOOD TR, BAUM J *et al*: Revision of the proposed classification criteria for juvenile idiopathic arthritides:Durban, 1997. *J Rheumatol* 1998; 25: 1991-4.
- ANDERSSON GÄRE B, FASTH A, WIKLUND I: Measurement of functional status in juvenile chronic arthritis: evaluation of a Swedish version of the Childhood Health Assessment Questionnaire. Clin Exp Rheumatol 1993; 11: 569-76.
- GIANNINI EH, RUPERTO N, RAVELLI A, LOVELL DJ, FELSON DT, MARTINI A: Preliminary definition of improvement in juvenile arthritis. Arthritis Rheum 1997; 40: 1202-9.