The Dutch translation of the revised Childhood Health Assessment Questionnaire: a prelimary study of score distribution

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Abstract

Background

The Childhood Health Assessment Questionnaire (CHAQ30) is the most commonly used physical functioning questionnaire for children with Juvenile Idiopathic Arthritis (JIA). By revising the CHAQ30 Lam et al. succeeded in decreasing the ceiling effect of this questionnaire in a North American population of children with diverse musculoskeletal diseases.

Objective

To examine the score distribution of the revised CHAQ in a population of children with JIA.

Methods

In this Dutch multicentre study 72 children with JIA participated (55 girls), with a mean age of 11.0 (± 3.1) and a mean disease duration of 4.6 year (± 3.7). The score distribution of the original CHAQ30 and four versions of the revised CHAQ was analysed with the median, range and interquartile range (IQR) and visualised with box-and-whisker plots. The normality of the score distribution was tested by the Kolmogorov-Smirnov one-sample test of normality.

Results

Although the addition of 8 more challenging items improved the spread of the scores of the revised CHAQ versions, the original CHAQ30 showed a better distribution of the scores.

Conclusions

The revised CHAQ38 with the distribution characteristics, found in this study, might be especially relevant in interventions for patients with JIA at the mild end of the disability spectrum.

Key words

Childhood Health Assessment Questionnaire (CHAQ), JIA, ceiling effect.

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Introduction

The Childhood Health Assessment Questionnaire (CHAQ) is the most widely used self-administered questionnaire for children with juvenile idiopathic arthritis (JIA) (1, 2). Developed from the adult Stanford Health Assessment Questionnaire (3), the CHAQ assesses functional ability in 8 domains of physical function (30 items) for children between the ages of 6 month up to 18 years. The 8 domains are dressing, arising, eating, hygiene, walking, reach, grip and outside activity. The CHAQ scores perceived performance in activities of daily life and the utilisation of aid(s) and/or assistance in daily activities, which is summarised in the CHAQ-disability index (1).

Although the psychometric properties have long been satisfactory (1, 2), the CHAQ is currently suffering from a ceiling effect (4). An apparent decrease of the impairment of the JIA population, most likely influenced by new medication strategies (5, 6), and early multidisciplinary intervention, have their impact on functional outcome (6). Assessment of disability and improvement of functional ability in children with JIA at the mild end of the disability spectrum is therefore becoming increasingly insufficient. Lam *et al*. (2004) constructed a revised version of the CHAQ. By adding 8 more challenging items (Table I), the use of new categorical response options and deleting the scales for aid(s) and/or assistance, Lam *et al*. attempted to decrease the ceiling effect of the CHAQ. With the new, more challenging items, especially less impaired children with JIA might be able to gain function at the higher end of the activity spectrum. To be able to measure perceived physical ability as well as inability, the children with JIA compared themselves with the performance of 'most' of their peers during 'the last week'. These new response options, 'visual analogue scale', 'categorical' and 'choice' emphasise the assessment of patients' physical abilities instead of their disability as is in the original CHAQ30, which reflects a more recent development in health outcome research and disease management. The concept also allows for continuity of scores through the whole range, from unable to very able, and therefore might be better suited for future use in health research (7).

The original CHAQ score system for calculating the CHAQ-Disability Index is rather complex (1). The influence on the total CHAQ score of the utilisation of special aids and assistance in daily activities decreases the sensitivity to change (8). Therefore Lam *et al*. only calculated the mean of all answered items and left out the application for aids and assistance. This revised CHAQ with 38 items showed greater discriminant validity and a more normal distribution when studied in children with mixed musculoskeletal conditions. Of all response options that Lam *et al*. proposed, the CHAQ 'categorical' showed after the CHAQ 'visual analogue scale' the second best discriminant validity. Moreover, all three new response options decreased the ceiling effect (4). A partly retrospective study using the Dutch translation of the revised CHAQ with 38 items, obtained in two different cohorts of patients, also showed a normalisation of the distribution of the scores (9).

The aim of this prospective cross-sectional multicentre study in the Netherlands was to compare the score distribution of the Dutch language version of the original CHAQ30 with the revised CHAQ with 38 items in patients with JIA. We hypothesised that the addition of the 8 more challenging items has a positive influence on the score distribution of the revised CHAQ with 38 items compared to the original CHAQ30. To analyse the distribution of the scores, the original CHAQ30 was compared with four forms of the revised CHAQ, namely CHAQ*1and CHAQ*2 (revised CHAQ with the original response options, the average of all answered items and with 30 and 38 items respectively); CHAQ*3 and CHAQ*4 (revised CHAQ with the new categorical response option and with 30 and 38 items, respectively).

Methods

Participants

The convenience sample of children with JIA was recruited from January 2008 to April 2008 by five paediatric physiotherapists from five Dutch tertiary centres with a Paediatric Rheumatology programme. Presuming that the eight

Table I. The eight more challenging items of the revised CHAQ.

1. I think I could have **done climbing activities** by myself (examples: climbing trees, rocks, or climbing over a fence).
2. I think I could have **played team sports with others in my class** (examples: basketball, baseball, soccer, hockey).
3. I think I could have **played some sports by myself** or **with a few friends** (examples: dribbling and shooting basketball).
4. I think I could have **played team sports in competitive leagues** (examples: local basketball, baseball, soccer, or hockey teams).
5. I think I could have **kept my balance while playing rough games** (examples: tag, wrestling, karate, judo).
6. I think I could have **done activities** I usually enjoy **for a long time without getting tired out** (examples: swimming, jogging, tennis, badminton, rowing, skiing).
7. I think I could have **run in a race** (example: 100-meter dash).
8. I think I could have **worked carefully with my hands** (examples: building Lego, making models, sewing, making bead necklaces).

Table II. Score range, amount of items, response options and the score method for the original CHAQ30 and four forms of the revised CHAQ.

Original CHAQ	Original CHAQ30	
	• Score range 0 – 3 • **30** items • Original response options • The average of the highest score of each domain • Minimum domain score of 2 when aids or assistance are scored	
4 forms of the revised CHAQ	CHAQ*1	CHAQ*2
	• Score range 0 – 3 • **30** items • Original response options • The average of all answered items	• Score range 0 – 3 • **38** items • Original response options • The average of all answered items
	CHAQ*3	CHAQ*4
	• Score range -2 to +2 • **30** items • Categorical response options • The average of all answered items	• Score range -2 to +2 • **38** items • Categorical response options • The average of all answered items

CHAQ: Childhood Health Assessment Questionnaire
Original response options: children's self-perceived physical ability is assessed. Each item is scored from 0 to 3 (0 = with no difficulty, 1= with some difficulty, 2 = with much difficulty, 3 = unable to do so) (1).
Categorical response options: children compare their physical abilities to most other (*i.e.* healthy) children of their own age. This option is scored on a five point Likert scale (-2 = much worse than my peers, -1 = a little worse than my peers, 0 = the same as my peers, 1 = a little better than my peers, 2 = much better than my peers) (6).

new, more challenging items (Table I) are less applicable for children younger than 7 years of age, only children from 7–16 years diagnosed according to the ILAR criteria (10) with polyarthritis, systemic arthritis, and oligoarthritis (extended and persisted) were included.

Demographics

Information was collected regarding gender, age, diagnosis, duration and state of the disease and the use of medication. The location and number of the affected joints were described. Furthermore, the VAS-scores of the pain and severity of the disease and the scores of the original and four revised forms of the CHAQ were gathered.

Questionnaires

The Dutch language versions of the original CHAQ30 and the revised CHAQ were edited in a worksheet that combined the original and new questions and response options, and the original and the categorical score system in a comprehensive form.

In the original CHAQ30 response option the children's self-perceived physical ability is assessed. Each item is scored from 0 to 3 (0 = with no difficulty, 1 = with some difficulty, 2 = with much difficulty, 3 = unable to do so) (1). With the categorical response option, the children compare their physical abilities to most other (*i.e.* healthy) children of their own age. This option is scored on a five point Likert scale (-2 = much worse than my peers, -1= a little worse than my peers, 0 = the same as my peers, 1 = a little better than my peers, 2 = much better than my peers) (Lam *et al*., 2004). Table II summarises the score ranges, amount of items, response options and score methods of the original CHAQ30 and the four forms of the revised CHAQ that are subject to analysis.

The 5 participating physiotherapists structurally make use of the original CHAQ30 in their daily practice and are there for considered skilful assessors. As a proxy measure the original CHAQ30 as well as the CHAQ*4 have a good and substantial concordance respectively (11, 12, 6). In the daily clinical routine the participating physiotherapists fill out the CHAQ during an anamnestic interview of the child/parent. In the study the use of the CHAQ was standardised by instructing the physiotherapists to interview the children with JIA per item. Per item the original response option was filled out first followed by the categorical response option.

Procedure

The Medical Ethics Committee of the University Medical Centre Utrecht approved the study design and this was adopted by all local boards. Informed consent of all subjects and/or their parents was requested.

Statistical analysis

The demographic data were described with descriptive statistics. The score distribution of the original CHAQ30 and the four forms of the revised CHAQ

were analysed with the mean, median and interquartile range (IQR). Box-and-whisker plots were used to visualise the score distribution. The normality of the distribution of the scores was tested with the Kolmogorov-Smirnov (K-S) one-sample test.

Results

Demographics

Seventy-two children with JIA were recruited from five tertiary centre for paediatric rheumatology in Nijmegen (n=9), Rotterdam (n=15), Utrecht (n=18), Leiden (n=14) and Groningen (n=16). The diagnostic classification according to the ILAR criteria (10), gender and the mean of the age, the duration and state of the disease and the VAS-scores of pain and severity of the disease are described in Table IIIa. The mean score of the original CHAQ30 and the four forms of the revised CHAQ are described in Table IIIb. The location, median and IQR of the scores of the affected joints per patient at the time of the study are shown in Table IIIc.

Questionnaires

Compared to all other score options, the score '0', meaning 'no problem' (original CHAQ30, the CHAQ*1 and CHAQ*2) or 'the same as my peers' (CHAQ*3 and CHAQ*4), has been filled out most frequently. In the original CHAQ30 and the CHAQ*1 the score '0' was filled out 14 times (19.4%). In the CHAQ*4 the score '0' was filled out 9 times (12.5%). In the questionnaires with the new response options, the CHAQ*3 and CHAQ*4 the score '0' was filled out 5 times (7%). The median, range and IQR of all questionnaires are shown in Table IV.

Distribution of the scores

The scores of the original CHAQ30 showed a wider distribution (IQR 1.09) compared with the CHAQ*4 (IQR 0.51). The CHAQ*4 showed the best distribution of all revised versions of the CHAQ. The distribution of the scores of all questionnaires is presented with box-whisker-plots (Fig. 1).

In all questionnaires the distribution of the scores were skewed. The scores of the CHAQ*4 was compared to all questionnaires more normal distributed. This is also reflected in the K-S statistics of 1.34 with a *p*-value of 0.10 for the original CHAQ30 and 1.25 with a *p*-value of 0.23 (statistically significantly normal) for the CHAQ*4.

The CHAQ*2 and CHAQ*4 showed compared to the CHAQ*1 and CHAQ*3 a wider distribution of the score (Fig. 1 and Table IIIb). Compared to the original CHAQ30, the addition of the 8 more challenging items has no direct positive influence on the score distribution of the CHAQ*4 and therefore the hypothesis was denied.

Table IIIa. Gender, age, diagnosis, disease duration, state of the disease, use of medication pain and severity of the disease of JIA patients (n=72).

Male/female*	17 (23.6%) / 55 (76.4)
Age^	11.9 (± 3.1)
Diagnosis according to the ILAR criteria*	**
- polyarthritis	37 (51.4%)
- systemic arthritis	13 (18.0%)
- persisted oligoarthritis	12 (16.6%)
- extended oligoarthritis	7 (9.7%)
Disease duration^	4.6 (± 3.7)
Remission*	39 (54.2%)
On medication*	70 (%)
VAS Pain^	2.5 (± 2.7)
VAS Disease severity^	2.4 (± 2.8)

JIA: Juvenile idiopathic arthritis; *number and percentage; ^ mean (standard deviation); **3 missing diagnosis (4.3%); ILAR: International League of Associations for Rheumatology; VAS: Visual Analogue Scale.

Table IIIb. Mean (SD) scores of the original CHAQ30 and 4 forms of the revised CHAQ of JIA patients (n=72).

Original CHAQ30	0.76 (± 0.7)
CHAQ*1	0.33 (± 0.4)
CHAQ*2	0.40 (± 0.4)
CHAQ*3	- 0.30 (± 0.4)
CHAQ*4	- 0.37 (± 0.4)

JIA: Juvenile idiopathic arthritis; CHAQ: Childhood Health Assessment Questionnaire.
CHAQ*1and CHAQ*2: revised CHAQ with the original response options, the average of all answered items and with 30 and 38 items respectively.
CHAQ*3 and CHAQ*4: revised CHAQ with the new categorical response options, the average of all answered items with 30 and 38 items respectively.

Table IIIc. Median, range and IQR of the number of affected joins per joint of JIA patients (n=72).

Joints	N	Median	Range		IQR
			Minimum	Maximum	
shoulder	72	0.00	0	4	0.75
elbow	72	0.00	0	2	1.00
wrist	72	0.00	0	2	2.00
hand/fingers	72	0.00	0	16	4.00
hip	72	0.00	0	2	0.00
knee	72	0.00	0	2	2.00
ankle	72	0.00	0	2	2.00
foot/toe	72	0.00	0	10	0.00
temporo-mandibular	72	0.00	0	2	0.00
vertebrae	72	0.00	0	3	0.00

IOR: Interquartile range, JIA: Juvenile idiopathic arthritis.

Table IV. Median score, range and interquartile range of the original CHAQ30 and four forms of the revised CHAQ in JIA patients (n=72).

CHAQ version	Median score (range)	IQR (P25-P75)
Original CHAQ30	0.50 (0.00 – 2.50)	1.09
CHAQ*1	0.19 (0.00 – 1.55)	0.39
CHAQ*2	0.26 (0.00 – 1.70)	0.52
CHAQ*3	- 0.17 (-1.45 – 0.40)	0.43
CHAQ*4	- 0.24 (-1.52 – 0.42)	0.51

JIA: Juvenile idiopathic arthritis; CHAQ: Childhood Health Assessment Questionnaire; IQR: Interquartile range.
CHAQ*1and CHAQ*2: revised CHAQ with the original response options, the average of all answered items and with 30 and 38 items respectively.
CHAQ*3 and CHAQ*4:revised CHAQ with the new categorical response options, the average of all answered items with 30 and 38 items respectively.

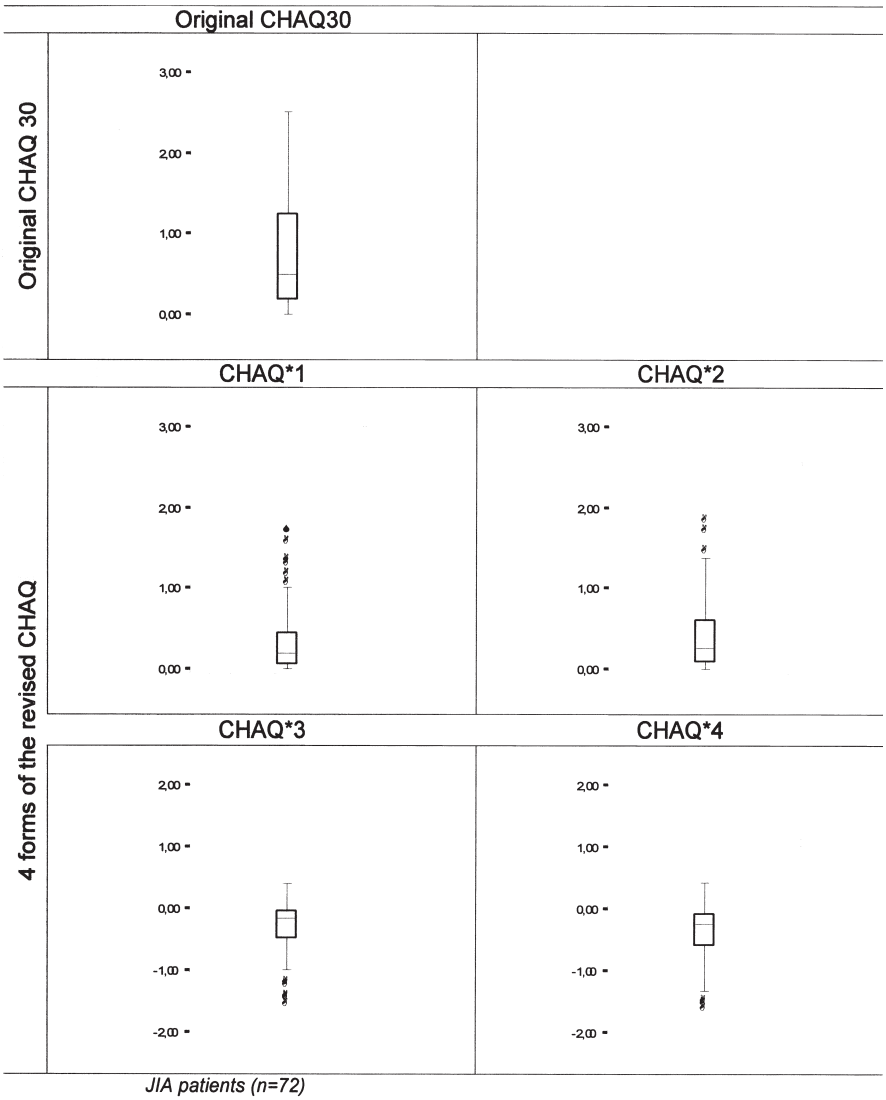

Fig. 1. Box-and-whisker plots of the original CHAQ and four forms of the revised CHAQ in JIA patients (n=72).
JIA: Juvenile idiopathic arthritis; CHAQ: Childhood Health Assessment Questionnaire.
CHAQ*1and CHAQ*2: revised CHAQ with the original response options, the average of all answered items and with 30 and 38 items, respectively).
CHAQ*3 and CHAQ*4:revised CHAQ with the new categorical response options, the average of all answered items with 30 and 38 items, respectively.

Discussion

In a multi-centre study in children with JIA, the Dutch language version of the revised CHAQ*4 demonstrated a smaller standard deviation compared to the original CHAQ30 and both show a statistically significant normal distribution of the scores. The addition of 8 more challenging items did not directly have a positive influence on the distribution of the scores of the revised CHAQ*4.

In contrast with the results of Lam *et al*. (2004) we found a narrower distribution of the CHAQ*3 and CHAQ*4 scores. Ouwerkerk *et al*. (2008) found comparable narrow distribution of scores. This might have been caused by the homogeneity of the populations studied in both Dutch samples. In both Dutch samples only children with JIA were included, while in the Canadian study of Lam *et al*. (2004) children with diverse musculoskeletal diseases were included, *i.e*. children with injuries, fractures, spina bifida, and children with haemophilia who had a history of haemarthroses as well as children with JIA or other rheumatic disorders. The lack of presence of musculoskeletal symptoms in this convenience sample, 52.7% of the children with JIA were in a remission, in itself may have contributed to the score findings in this study. The implication of this could be that future studies that involve either heterogeneous musculoskeletal or homogeneous populations demand different sizes to acquire enough statistical power.

There might be cultural differences between both samples as well. The Dutch and Canadian children may in the CHAQ*4 respectively under- or overestimate their self-perceived physical ability compared to healthy peers. This might be introduced by the differences in competitiveness between both the Northern American and Western European societies. Therefore further cross-cultural validation of the CHAQ*4 is highly relevant in an era that is in great demand of international multicentre trials.

The score distribution found in this study is most certainly influenced by a selection bias as in the five participating Dutch tertiary centres for paediatric

Rheumatology where children with the more severe/chronic forms of JIA are treated. The sample of children with JIA in this prospective cross-sectional multicentre study is therefore primarily representative for the tertiary setting. The outcome of patients with self-remitting oligo articular JIA, which are under represented in this sample, most likely will show lower scores which would have contributed to even less distribution and more ceiling effect in this study.

Nineteen percent of this population achieved the lowest possible score of the original CHAQ30, meaning no physical problem which makes that the original CHAQ30 is suffering from a ceiling effect according to the criteria of Terwee *et al*. (2007) (13). Through the bi-directional score method of the new response options the CHAQ*3 and CHAQ*4 did not reach the highest and lowest possible scores and are thus free of a ceiling or floor effect. In this study the lowest possible score 'the same as my peers' was scored by 7% of the children with JIA.

In this study all questionnaires were filled out by the physiotherapists by interviewing the child/parent. The scores therefore represent the daily practice of the participating physiotherapists. The reliability of the method of interview face to face with adolescents is found to be moderate (13). How our results would have been influenced when the questionnaires were self-administrated was not a part of this study.

The response options of the CHAQ*4 are easy to complete and calculate, and showed in an earlier study a substantial concordance as a proxy measure (4). Good proxy concordance has been reported in earlier studies on the original version of the CHAQ as well (11, 12). Using the CHAQ*4 as a proxy report in the Dutch language therefore may be a valid choice for studying the effects of interventions.

Through the bi-directional score method, *i.e*. 'better physical ability' or 'worse physical ability' than peers, the CHAQ*4 might be capable to identify if physical activities become more difficult or easier. This score system is the major reason for which no ceiling effect occurs, as there always seems to be room for improvement of physical skills. This might be of importance in the management of children with JIA, who increasingly have no or very few difficulties with their physical activities during their disease course. It allows for studies that explore physical interventions with more ambitious endpoints.

The addition of the 8 more challenging items accomplished a wider distribution of the score of all applied versions of the revised CHAQ. Therefore the addition of the 8 items is relevant for clinical follow-up, especially for children with JIA at the mild end of the disability spectrum.

As this prelimary study was limited to a cross-sectional design, this study did not generate knowledge on the sensitivity to change and changes over time or the smallest meaningful difference of the CHAQ*4, this needs further studying.

Conclusion

The CHAQ*4 (*i.e*. CHAQ with 'categorical' response option and 38 items) has great potential for future intervention studies as it has shown improved psychometric characteristics over the original CHAQ30. The revised version is especially relevant in interventions for children with JIA at the mild and of the disability spectrum. In addition to this it embodies more modern qualities such as an emphasis on ability instead of inability and continuity of scores through the whole range, from unable to very able, and therefore it might be better suited for future use in health research.

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