The Responsiveness of the Modified Childhood Health Assessment Questionnaire

Shannon Peters, Sylvia Ota, Emily Bolous, Erin Reich, Samantha Chait, and Brian M. Feldman

ABSTRACT. ***Objective.*** To determine the ability of the revised version of the Childhood Health Assessment Questionnaire (CHAQ), the VAS_{CHAQ}, to detect clinical change over time in pediatric patients with juvenile idiopathic arthritis (JIA). We studied the relative responsiveness of the VAS_{CHAQ} as compared to the original CHAQ-30 and revised CHAQ-38, as well as the parent-patient, physician-patient, and physician-parent concordance.

Methods. The CHAQ-38 and VAS_{CHAQ} were administered to 30 parents and patients (if older than 8 years) with any subtype of JIA before and after the start of a new treatment. The standardized response means (SRM) were calculated for the VAS_{CHAQ}, the original CHAQ-30, and the CHAQ-38. Comparisons of SRM were made using the relative SRM. Parent-patient, physician-patient, and physician-parent concordances were assessed by calculating a series of intraclass correlation coefficients.

Results. Twenty-seven parents and 21 patients completed questionnaires at both visits. All questionnaires demonstrated large responsiveness; however, the VAS_{CHAQ} was found to be about 25% more responsive than both the original CHAQ-30 and CHAQ-38.

Conclusion. The VAS_{CHAQ} was moderately more responsive than the CHAQ-30 and CHAQ-38 in both parent and patient groups and should be considered for use in studies evaluating change in function over time. (J Rheumatol First Release August 1 2016; doi:10.3899/jrheum.151139)

Key Indexing Terms:
JUVENILE IDIOPATHIC ARTHRITIS
HEALTH STATUS
SELF-ASSESSMENT
OUTCOME ASSESSMENT

Juvenile idiopathic arthritis (JIA) is a chronic musculoskeletal condition that affects childhood functional ability. Decreased functional ability is caused by impairments such as a loss of joint motion, joint swelling, and pain[1].

The Childhood Health Assessment Questionnaire-Disability Index (CHAQ) is a self-report questionnaire of patient functional ability in 8 domains of function: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities.

The CHAQ has become a widely used tool for measuring functional ability in children with JIA and other childhood rheumatic conditions. The CHAQ demonstrated high validity, reliability, and good responsiveness in clinical trials and rehabilitative interventions[2]. These positive results have led to the widespread use of the CHAQ cross-culturally[3]. The CHAQ is used to assess functional ability in other childhood chronic conditions including systemic lupus erythematosus[4] and juvenile idiopathic myopathies[5], and has become a primary outcome tool in the management of juvenile dermatomyositis[6].

However, the original CHAQ (CHAQ-30) exhibits a ceiling effect. Questionnaire scores are commonly clustered around 0, representing no disability[7,8]. Thus, the CHAQ-30 is insensitive to detecting clinical changes in mild cases of JIA; false-negative outcomes may occur in patients who are close to the ceiling.

The limitations of the CHAQ-30 warranted a revision to the questionnaire. Lam, *et al* proposed a revised CHAQ, the CHAQ-38, with an additional 8 more challenging questions[9]. Additionally, Lam, *et al* proposed 3 revised versions of the CHAQ with different rating scales: choice, categorical, and visual analog scale (VAS). It was determined that the VAS_{CHAQ} demonstrated the best ability to discriminate

From the Child Health Evaluative Sciences, and the Division of Rheumatology, The Hospital for Sick Children; Communicable Disease Surveillance Unit, Communicable Disease Control, Toronto Public Health; Department of Medical Imaging, University of Toronto, Diagnostic Radiology residency program; Department of Pediatrics, Faculty of Medicine, and the Institute of Health Policy Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada; School of Medicine and Medical Sciences, University College Dublin, Dublin, Ireland.

S. Peters, BS, School of Medicine and Medical Sciences, University College Dublin; S. Ota, MHSc, Communicable Disease Surveillance Unit, Communicable Disease Control, Toronto Public Health; E. Bolous, MD, Department of Medical Imaging, University of Toronto, Diagnostic Radiology residency program; E. Reich, MD, CCFP, Child Health Evaluative Sciences, The Hospital for Sick Children; S. Chait, HBMSc, Child Health Evaluative Sciences, The Hospital for Sick Children; B.M. Feldman, MD, MSc, FRCPC, Professor, Department of Pediatrics, Faculty of Medicine and the Institute of Health Policy Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, and Child Health Evaluative Sciences, Division of Rheumatology, The Hospital for Sick Children.

Address correspondence to Dr. B.M. Feldman, Department of Pediatrics, Division of Rheumatology, The Hospital for Sick Children, 555 University Ave., Toronto, Ontario M5G 1X8, Canada.
E-mail: brian.feldman@sickkids.ca

Accepted for publication June 20, 2016.

between patient and control groups, and scores differed the least from a normal distribution. In recent studies the addition of 8 more challenging questions and the removal of domain scoring reduced the ceiling effect in both patient and control groups[10,11]. However, revised categorical response options (questions asked in relation to the child's peers) reduced the ceiling effect, but demonstrated lower discriminatory ability[11].

The revised CHAQ, VAS_{CHAQ}, was modified from the CHAQ-38 by removing consideration for aids and devices or help, using response options where questions are asked in relation to the child's peers, and having a 10-cm visual analog rating scale for each question. Similarly, the removal of aids and devices or help is consistent with research by Saad-Magalhães, *et al*, because the removal of these items in a methotrexate (MTX) trial did not alter the interpretation of disability at a group level[12].

It is important to evaluate the child and parent-proxy agreement for the patient self-reported measures, because parents are the principal medical decision-makers in pediatric populations. In the preliminary study of the CHAQ-30 it was determined that parents can reliably report on their child's functional abilities[2]. In other studies of patients with JIA, parents have been shown to be fair[13], good[8], and excellent[14] proxy reporters for the CHAQ. Good patient-parent agreement is vital for a parent-proxy to effectively report on their child's functional abilities, and thus assist clinicians in medical management.

Physicians are unable to assess day-to-day disease activity, and therefore it is imperative to evaluate the concordance between physician assessments at clinic visits and patient or proxy reports of daily functional abilities. Discordance was frequent between proxy-reported and physician objective assessment of functional ability in a study by Ravelli, *et al*[15]. Further, Armbrust, *et al* determined that parents tend to overestimate their child's active joints[16]. However, agreement between patient-reported and physician-objective assessments on the number of total active joints was reasonable in a study by Dijkstra, *et al*[17]. Good concordance may result in more effective treatment regimens that reflect both the patients' perceptions of their disease activity and the physician's objective assessments.

It is necessary to measure the responsiveness of disease outcome instruments to validate the instrument's use in assessing disease improvement and worsening[18]. The CHAQ-30 demonstrated adequate responsiveness in a study by Brown, *et al*[19]. A more responsive tool improves the power of study; it allows researchers to conduct studies with fewer subjects, making the studies less expensive and easier to perform.

The primary aim of our study was to determine the responsiveness of the self-reported and proxy-reported VAS_{CHAQ}. Therefore we asked whether the VAS_{CHAQ} is more responsive to a physician-implemented new intervention compared to the original CHAQ-30 in a population of pediatric patients with any subtype of JIA. We also examined the VAS_{CHAQ}'s responsiveness compared to the CHAQ-38, using its original response options. Secondary aims of our study were to evaluate the agreement between parent proxies and patient self-reports, between physician assessments and patient self-reports, and between physician assessments and parent reports using reports of total active joints and joints with a limited range of motion (ROM). It was hypothesized that the VAS_{CHAQ} would be more responsive than both the original CHAQ-30 and CHAQ-38.

MATERIALS AND METHODS

Study design. The Research Ethics Board at The Hospital for Sick Children (SickKids; Toronto, Canada) approved the study, and both parents and patients provided signed informed consent (or assent). Two questionnaires, the CHAQ (the original version plus the extra 8 questions to make the CHAQ-38) and VAS_{CHAQ}, were administered to parents and patients (if older than 8 years) using a repeated measures design. Questionnaires were administered at baseline and at a followup visit, 4–6 weeks after the implementation of a new therapeutic intervention. This timeline was chosen because it is the expected length of time to permit a change in a patient's physical function. Researchers worked from an interview script at both baseline and followup visits to ensure clear instructions were given on how to complete the self-report questionnaires. Parents and patients completed the questionnaires separately at both visits. Researchers completed an interview quality recording sheet to assess the degree of difficulty the respondents had in answering the questions.

Subjects. Patients were recruited from rheumatology clinics and medical day care at SickKids during their normally scheduled clinic visits. Patients were included in the study if they had a confirmed diagnosis of any subtype of JIA and were about to start a new treatment. Parents and patients were excluded from the study if they were unable to complete the questionnaires in English. Basic patient demographic information was obtained at baseline, which included date of birth, sex, subtype, and duration of JIA. Basic information about the parent-proxy was also obtained at baseline including date of birth, sex, and educational level.

Sample size consideration. There is no generally accepted method of calculating sample size for a responsiveness study[20]. We used the formula for the CI around a standardized response mean[21], with a 95% CI and effect size estimate of 1.0, to determine that at least 30 patients are needed to achieve adequate precision to distinguish a moderate standardized response mean effect size (> 0.5) from a large effect size.

Treatments. Patients started a new treatment that was expected on average to be associated with a change in function. These new treatments included intraarticular steroid injections (IAS), MTX, etanercept, oral corticosteroids, infliximab, and nonsteroidal antiinflammatory drugs, or a combination of these treatments.

Questionnaires. The same series of questionnaires were administered to parents and patients separately at both baseline and followup visits. The CHAQ-38 and VAS_{CHAQ} were administered in a computer-generated random order. Further, parents and patients completed a global assessment report to record the patient's overall well-being during the past week. This measurement was recorded on a 10-cm VAS anchored by "excellent well-being" and "extremely poor well-being." The physician completed a Global Assessment report of disease activity on a similar scale, anchored by "no disease" and "extremely active disease." At the followup visit only, parents, patients, and physicians also answered a yes/no question: "Has [your, your child's, this child's] arthritis improved since starting the newest treatment?"

The original CHAQ contains 30 questions, each scored on a 4-point scale (0–3). Increasing scores represent decreasing functional ability. The 30 questions are separated into 8 domains of physical function, as above. The

question with the greatest score in each domain is used as the score for that domain. If patients require aids and devices or help from others in any of the domains, a minimum score of 2 is assigned to that domain. Domain scoring (computing the average of all 8 domain scores) is used to calculate the Disability Index (DI) score for the original CHAQ-30. A "not applicable" option is available for each question to avoid developmental bias. Assessment of functional ability was the focus of our study; therefore the VAS scales for pain and disease effect were not assessed.

The CHAQ-38 contains the same items and response options as the original CHAQ-30, with an additional 8 more challenging questions in the Activities domain[9]. The summary score for the CHAQ-38 was calculated by averaging all question scores, with no consideration for the domain structure, as per Lam, *et al*[9].

The VAS_{CHAQ} contains the same items as the CHAQ-38 but functional ability is answered relative to "other kids my age." Each question is answered on a 10-cm VAS, with scores ranging from 0, or the worst functional ability, to 100, or the best functional ability, for each question. The VAS_{CHAQ} does not use the domain structure, and does not inquire about a child's need for aids and devices or help from others. The average of the 38 questions is taken as the overall score for the VAS_{CHAQ}. If a question does not apply to the child, it is marked as "not applicable" and is excluded from the score calculation.

Joint counts. Self-reported and proxy-reported joint counts for tenderness or pain and ROM were completed at both the baseline and followup visits. The number of total active joints was assessed as joints reported to experience tenderness or pain and demonstrate a limited ROM.

Physicians assessed the number of total active joints at both the baseline and followup visits. The EPM-ROM scale[22] was used at the baseline visit to measure the number of joints with a limited ROM. This scale has shown to be valid, reliable, and sensitive to change[22,23].

Responsiveness. The correlation between measures of improvement was determined using the Pearson product-moment correlation. The standardized response mean (SRM) was calculated for the patient- and parent-completed CHAQ-30, CHAQ-38, and VAS_{CHAQ}. The 95% CI were calculated assuming normal distribution. According to Zou[21], the SRM is the only necessary measure to quantify the responsiveness in a 2-timepoint (pre-post) or repeated measures study design. The results were interpreted as large if the SRM was > 0.8, as moderate (0.5–0.8), or as small (0.2–0.5)[20]. Comparisons of SRM were made using the relative SRM.

Agreement. To assess the concordance between patients, parent-proxies, and physician assessments, a series of intraclass correlation coefficients (ICC) were calculated. ICC were calculated for the VAS_{CHAQ} (patient-parent concordance only), the total active joint count, and for the number of joints with limited ROM. The ICC was considered to indicate poor agreement if the value was < 0, slight agreement at 0.00–0.20, fair agreement at 0.21–0.40, moderate agreement at 0.41–0.60, substantial agreement at 0.61–0.80, and almost perfect agreement at 0.81–1.00[24].

RESULTS

Subjects. The study included 30 subjects. Thirty parents and 23 patients completed the questionnaires at the baseline visit only. At both visits, 27 parents and 21 patients completed the questionnaires. The average followup time between visits was 8.5 weeks. Patient demographics are presented in Table 1. The average age of the parent proxies was 41.6 years (SD 6.0), and the majority of the 30 parents were female (73.33%) and had attended either college or university (83.33%).

Treatments. The majority of patients received IAS (Table 1).

Questionnaires. The median questionnaire scores, parent and patient global assessment scores, and physician global assessment of disease activity scores are shown in Table 2.

Table 1. Patient demographics (n = 30): age, sex, JIA subtype, new interventions.

Median patient age, yrs (IQR)	11.00 (8.00)
Median duration of JIA, yrs (IQR)	5.00 (1.50)
No. females (%)	23 (76.67)
JIA subtype, n (%)	
Enthesitis-related arthritis	2 (6.67)
Oligoarthritis extended	6 (20.00)
Oligoarthritis persistent	5 (16.67)
Polyarthritis RF–negative	8 (26.67)
Polyarthritis RF–positive	5 (16.67)
Psoriatic arthritis	2 (6.67)
Systemic arthritis	1 (3.33)
Undifferentiated	1 (3.33)
New interventions, n (%)	
IAS	18 (60.00)
Synthetic DMARD	6 (20.00)
Biologics	4 (13.33)
NSAID	2 (6.67)

JIA: juvenile idiopathic arthritis; IQR: interquartile range (Q3-Q1); RF: rheumatoid factor; IAS: intraarticular steroid injections; DMARD: disease-modifying antirheumatic drugs; NSAID: nonsteroidal antiinflammatory drugs.

Most patients, parents, and physicians indicated improvement in the patient's JIA after treatment; however, 7 patients had either parent, patient, or physician indicate "No" to improvement. Although the median scores indicated that our sample improved in the majority of our outcome variables, we observed worsening scores for several patients in several variables.

Table 2. Scores: CHAQ-30, CHAQ-38, VAS_{CHAQ}, and joint counts at baseline and followup.

	Baseline		Followup		
Parent, n = 30			n = 27		
	Median	IQR	Median	IQR	SRM (95% CI)
Global assessment	26.50	50.50	20.00	40.50	
CHAQ-30	0.56	1.12	0.25	0.60	0.89 (0.44–1.34)
CHAQ-38	0.72	1.13	0.25	0.61	0.89 (0.44–1.34)
VAS_{CHAQ}	46.61	22.97	47.97	19.94	1.14 (0.65–1.62)
Total active joints	1.50	1.00	1.00	2.00	
Joints with limited ROM	2.00	1.75	1.00	2.50	
Patient, n = 23			n = 21		
Global assessment	42.00	47.50	21.00	24.00	
CHAQ-30	0.38	0.81	0.25	0.75	0.85 (0.35–1.36)
CHAQ-38	0.56	0.83	0.33	0.56	0.84 (0.34–1.34)
VAS_{CHAQ}	49.53	14.03	49.84	16.95	1.08 (0.53–1.62)
Total active joints	1.00	2.00	1.00	2.00	
Joints with limited ROM	1.00	2.50	1.00	3.00	
Physician			n = 30		
Global assessment	23.50	42.25	6.00	23.50	
Total active joints	2.50	5.75	1.00	2.50	
Joints with limited ROM	2.00	3.00			

CHAQ: Childhood Health Assessment Questionnaire; VAS_{CHAQ}: visual analog scale CHAQ; ROM: range of motion; IQR: interquartile range (Q3-Q1); SRM: standardized response mean.

Joint counts. The results of the joint count assessments are presented in Table 2.

Responsiveness. Questionnaire scores and our other outcome variables indicated that some patients improved and some patients worsened. Pearson product-moment correlations were calculated (Supplementary Table 1, available online at jrheum.org), and it was determined that the change in questionnaire scores was correlated with the change in the other outcome variables such as proxy-reported total active joint counts and counts of joints with a limited ROM. This correlation justified using the absolute values of the questionnaire score differences from baseline to followup when calculating the SRM (Table 2). All questionnaires demonstrated moderate to large responsiveness in both parent and patient groups.

The relative SRM statistic was calculated using either the CHAQ-30 or CHAQ-38 as the standard of comparison (Table 3). The VAS_{CHAQ} was more responsive than the CHAQ-30 and the CHAQ-38 in both patient and parent groups. The CHAQ-30 and CHAQ-38 demonstrated about the same responsiveness in both patient and parent groups.

To further evaluate the revised questionnaires compared to the original CHAQ-30, a regression of the difference in questionnaire scores from baseline to followup was completed for the CHAQ-38 (Supplementary Figure 1) and VAS_{CHAQ} (Supplementary Figure 2, both available online at jrheum.org).

Parent-child agreement. The concordance was measured for the CHAQ-30 (ICC 0.83, 95% CI 0.60–0.93), CHAQ-38 (ICC 0.84, 95% CI 0.63–0.93), VAS_{CHAQ} (ICC 0.49, 95% CI -0.18 to 0.78), total active joint count (ICC 0.74, 95% CI 0.39–0.89), and counts of joints with limited ROM (ICC 0.75, 95% CI 0.42–0.89).

Physician-child agreement. The concordance was measured for the total active joint count (ICC 0.58, 95% CI 0.033–0.82), and counts of joints with limited ROM (ICC 0.59, 95% CI 0.045–0.82).

Physician-parent agreement. The concordance was measured for the total active joint count (ICC 0.19, 95% CI -0.69 to 0.61), and counts of joints with limited ROM (ICC 0.16, 95% CI -0.75 to 0.6).

DISCUSSION

We found that all 3 questionnaires (CHAQ-30, CHAQ-38, VAS_{CHAQ}), both self-reported and proxy-reported, demonstrated moderate to large responsiveness. The CHAQ-30 and CHAQ-38 were equally responsive in both patient and parent groups. We found that parents are effective proxy-reporters, demonstrating substantial and almost perfect agreement with their child for the CHAQ-30, CHAQ-38, and reported joint counts. Overall, the VAS_{CHAQ} was more responsive than the CHAQ-30 and CHAQ-38 in both parent and patient groups and should be preferred for use in studies evaluating change in function over time.

Parent-child agreement was substantial or almost perfect for all measurements except for the VAS_{CHAQ}. This moderate agreement may be explained by the nature of the VAS_{CHAQ}'s response options. The VAS_{CHAQ} asks respondents to answer questions in relation to the child's peers and record their response on a 10-cm VAS. Parents may have a different understanding of how their child relates to his or her peers. When the VAS_{CHAQ} is used, therefore, careful consideration should be made to choose the most appropriate respondent group.

Physician-child agreement was moderate or substantial for all measurements. Physician assessments are often regarded as the gold standard. Therefore, this finding suggests that self-report measures of health status, such as self-reported joint counts, are accurate assessment tools.

Physician-parent concordance demonstrated slight agreement for total active joint counts and counts of joints with a limited ROM, similar to the findings of Armbrust, *et al*[16]. Parents may overestimate their child's active joint count by including joints with secondary symptoms of JIA, such as pain. Thus, it is important to educate parents on the difference between the symptoms of JIA, pain, and functional disability before they can be reliable proxy-reporters[16].

Our results must be considered in light of several potential limitations. First, 3 of our subjects did not complete a followup visit; therefore we were missing some data and our sample size was somewhat lower than planned. However, 90% of enrolled subjects completed all necessary assessments. Additionally, researchers reported that all interviews were of high quality and easy to conduct, validating the quality of our measured variables. Also, despite fewer

Table 3. Comparing responsiveness of CHAQ-30, CHAQ-38, and VAS_{CHAQ}: relative standardized response means. Means were calculated by dividing SRM of VAS_{CHAQ} or CHAQ-38 by the standard of comparison (either CHAQ-30 or CHAQ-38).

Parent, n = 27	(95% CI)	Patient, n = 21	(95% CI)
VAS_{CHAQ}/CHAQ-30	1.27 (0.84–2.10)	VAS_{CHAQ}/CHAQ-30	1.26 (0.65–2.77)
VAS_{CHAQ}/CHAQ-38	1.27 (0.84–2.08)	VAS_{CHAQ}/CHAQ-38	1.28 (0.68–2.76)
CHAQ-38/CHAQ-30	1.00 (0.92–1.09)	CHAQ-38/CHAQ-30	0.99 (0.85–1.13)

CHAQ: Childhood Health Assessment Questionnaire; VAS_{CHAQ}: visual analog scale CHAQ; SRM: standardized response mean.

subjects than planned, our CI around the relative SRM were still quite tight, indicating an acceptable level of precision. Additionally, our study subjects received a variety of interventions, which may have led to reports of clinical worsening after the administration of a new intervention. This limited our ability to analyze the average responsiveness of the questionnaires. Despite this heterogeneity in our study population, the change in questionnaire scores correlated with the direction and change in our other outcome variables, which justified using the absolute value of the change in our SRM calculations.

We found that all 3 questionnaires demonstrated moderate to large responsiveness. The VAS_{CHAQ} was about 25% more responsive to a new treatment compared to both the CHAQ-30 and CHAQ-38. The VAS_{CHAQ} demonstrated moderate parent-child concordance, possibly because of the nature of the response options. The observed results suggest that the VAS_{CHAQ} is a better assessment of functional ability in populations of patients with JIA because it is moderately more responsive to change over time, and does not have a ceiling effect. The VAS_{CHAQ} should be considered for use in future trials because it may reduce the cost and time needed to determine effective treatments and may help guide better disease management.

ONLINE SUPPLEMENT

Supplementary data for this article are available online at jrheum.org.

REFERENCES

1. Bekkering WP, ten Cate R, van Suijlekom-Smit LW, Mul D, van der Velde EA, van den Ende CH. The relationship between impairments in joint function and disabilities in independent function in children with systemic juvenile idiopathic arthritis. J Rheumatol 2001;28:1099-105.
2. Singh G, Athreya BH, Fries JF, Goldsmith DP. Measurement of health status in children with juvenile rheumatoid arthritis. Arthritis Rheum 1994;37:1761-9.
3. Ruperto N, Ravelli A, Pistorio A, Malattia C, Cavuto S, Gado-West L, 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:S1-9.
4. Meiorin S, Pistorio A, Ravelli A, Iusan SM, Filocamo G, Trail L, et al. Validation of the Childhood Health Assessment Questionnaire in active juvenile systemic lupus erythematosus. Arthritis Rheum 2008;59:1112-9.
5. Huber AM, Hicks JE, Lachenbruch PA, Perez MD, Zemel LS, Rennebohm RM, et al. Validation of the Childhood Health Assessment Questionnaire in the juvenile idiopathic myopathies. Juvenile Dermatomyositis Disease Activity Collaborative Study Group. J Rheumatol 2001;28:1106-11.
6. Huber AM, Lang B, LeBlanc CM, Birdi N, Bolaria RK, Malleson P, et al. Medium- and long-term functional outcomes in a multicenter cohort of children with juvenile dermatomyositis. Arthritis Rheum 2000;43:541-9.
7. Bode RK, Klein-Gitelman MS, Miller ML, Lechman TS, Pachman LM. Disease activity score for children with juvenile dermatomyositis: reliability and validity evidence. Arthritis Rheum 2003;49:7-15.
8. Dempster H, Porepa M, Young N, Feldman BM. The clinical meaning of functional outcome scores in children with juvenile arthritis. Arthritis Rheum 2001;44:1768-74.
9. Lam C, Young N, Marwaha J, McLimont M, Feldman BM. Revised versions of the Childhood Health Assessment Questionnaire (CHAQ) are more sensitive and suffer less from a ceiling effect. Arthritis Rheum 2004;51:881-9.
10. Norgaard M, Thastum M, Herlin T. The relevance of using the Childhood Health Assessment Questionnaire (CHAQ) in revised versions for the assessment of juvenile idiopathic arthritis. Scand J Rheumatol 2013;42:457-64.
11. Groen W, Unal E, Norgaard M, Maillard S, Scott J, Berggren K, et al. Comparing different revisions of the Childhood Health Assessment Questionnaire to reduce the ceiling effect and improve score distribution: Data from a multi-center European cohort study of children with JIA. Pediatr Rheumatol Online J 2010;8:16.
12. Saad-Magalhães C, Pistorio A, Ravelli A, Filocamo G, Viola S, Brik R, et al. Does removal of aids/devices and help make a difference in the Childhood Health Assessment Questionnaire disability index? Ann Rheum Dis 2010;69:82-7.
13. Brunner HI, Klein-Gitelman MS, Miller MJ, Trombley M, Baldwin N, Kress A, et al. Health of children with chronic arthritis: relationship of different measures and the quality of parent proxy reporting. Arthritis Rheum 2004;51:763-73.
14. Doherty E, Yanni G, Conroy RM, Bresnihan B. A comparison of child and parent ratings of disability and pain in juvenile chronic arthritis. J Rheumatol 1993;20:1563-6.
15. Ravelli A, Viola S, Migliavacca D, Pistorio A, Ruperto N, Martini A. Discordance between proxy-reported and observed assessment of functional ability of children with juvenile idiopathic arthritis. Rheumatology 2001;40:914-9.
16. Armbrust W, Kaak JG, Bouma J, Lelieveld OT, Wulffraat NM, Sauer PJ, et al. Assessment of disease activity by patients with juvenile idiopathic arthritis and the parents compared to the assessment by pediatric rheumatologists. Pediatr Rheumatol Online J 2013;11:48.
17. Dijkstra ME, Anink J, van Pelt PA, Hazes JM, van Suijlekom-Smit LW. Patient-reported joint count in juvenile idiopathic arthritis: the reliability of a manikin format. J Rheumatol 2015;42:527-33.
18. Fortin PR, Stucki G, Katz JN. Measuring relevant change: an emerging challenge in rheumatologic clinical trials. Arthritis Rheum 1995;38:1027-30.
19. Brown GT, Wright FV, Lang BA, Birdi N, Oen K, Stephens D, et al. Clinical responsiveness of self-report functional assessment measures for children with juvenile idiopathic arthritis undergoing intraarticular corticosteroid injections. Arthritis Rheum 2005;53:897-904.
20. Beaton DE, Hogg-Johnson S, Bombardier C. Evaluating changes in health status: reliability and responsiveness of five generic health status measures in workers with musculoskeletal disorders. J Clin Epidemiol 1997;50:79-93.
21. Zou GY. Quantifying responsiveness of quality of life measures without an external criterion. Qual Life Res 2005;14:1545-52.
22. Len C, Ferraz MB, Goldenberg J, Oliveira LM, Araujo PP, Quaresma MR, et al. Pediatric Escola Paulista de Medicina Range of Motion Scale: a reduced joint count scale for general use in juvenile rheumatoid arthritis. J Rheumatol 1999;26:909-13.
23. Vliet Vlieland TP, van den Ende CH, Breedveld FC, Hazes JM. Evaluation of joint mobility in rheumatoid arthritis trials: the value of the EPM-range of motion scale. J Rheumatol 1993;20:2010-4.
24. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977;33:159-74.