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VALIDATION STUDIES

A new biopsychosocial and clinical questionnaire to assess juvenile idiopathic arthritis: JAB-Q

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Abstract

Objective To create a new multidimensional questionnaire for the assessment of juvenile idiopathic arthritis (JIA) patients in standard clinical practice and study the validity and reliability of this questionnaire.

Methods The Juvenile Arthritis Biopsychosocial and Clinical Questionnaire (JAB-Q) was created using the Delphi technique and consensus conference following an initial literature search. The questionnaire has three parts including a clinician form, child form and parent form. This is a patient/parent-centered outcome tool, which helps us to evaluate the biopsychosocial aspects of the patient, including disease activity, posture, functional and psychosocial status, fatigue, and performance in school. From January 2015 to January 2018, 6–18 years old children with JIA were enrolled in the study. The previously validated questionnaires were also applied to each participant to validate the JAB-Q: Juvenile Idiopathic Disease Arthritis Score (JADAS) and Childhood Health Assessment Questionnaire (CHAQ), and the Family Impact Questionnaire (FIS). The same questionnaire was re-administered after one week to assess the test–retest reliability in randomly selected 50 children and their parents.

Results A group of experts were invited to the Delphi survey. After the Delphi tours, the final form of the questionnaire containing three parts as clinician form, child form and parent form was created. This tool was applied to 310 JIA patients and their parents. The children and parents easily handled the JAB-Q and filled the forms in around 10–15 min. The validity of the clinician, child and parents' forms were assessed by the JADAS, CHAQ, and FIS, respectively. The validity of these three scales were determined as moderate. In addition, the test–retest reliability of the clinician, child and parents' forms were considerably high.

Conclusion JAB-Q is a valid and reliable multidimensional biopsychosocial outcome tool that can be used routinely in clinical practice of pediatric rheumatology. The main advantage of this tool is incorporation of patients' and parents' perspectives separately while providing a practical and standard setting for the clinician's evaluation. However, further validation of this tool in an independent cohort is needed to improve its applicability.

Keywords Juvenile idiopathic arthritis · Outcome · Biopsychosocial

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Introduction

Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease in childhood with a prevalence of 16–150 per 100,000 cases [1]. It is defined as chronic, inflammatory arthritis of unknown etiology, lasting at least 6 weeks in children under 16 years of age. According to the International League of Associations for Rheumatology (ILAR), JIA is classified into seven subgroups: systemic, rheumatoid factor (RF) positive polyarticular, RF negative polyarticular, oligoarticular, psoriatic arthritis, enthesitis related arthritis (ERA), and unclassifiable arthritis [2].

Management of a child with JIA requires multidisciplinary approach including a pediatric rheumatologist, ophthalmologist, physical therapist, and psychologist. The main goal of the treatment is not only controlling the disease, but also achieving a good quality of life and reducing long-term functional disability. Over the past 15 years, outcome results in pediatric rheumatologic diseases improved dramatically, with the introduction of more targeted therapies such as the biologic drugs [1]. Thus, outcome measurement has become an essential component of health care, including assessment of disease activity, severity, damage, as well as impact of the disease on quality of life. Many outcome tools have been developed for this purpose. However, the outcome tools in JIA practice are inadequate to evaluate biopsychosocial aspects of the patients. Each outcome tool evaluates parameters such as functional status, activities of daily living, or fatigue individually. For instance, juvenile arthritis disease activity score (JADAS) has been developed to measure the absolute disease activity [3] whereas childhood health assessment questionnaire (CHAQ) mainly focuses on disability and discomfort [4]. Recently, a group of experts in pediatric rheumatology have created and validated a paternal- and child-centered tool, called juvenile arthritis multidimensional assessment report (JAMAR), which assesses overall well-being, pain, physical function, and health-related quality of life [5, 6]. This measurement has introduced the idea of evaluating the patient with a single, simple, easy, and feasible tool including parameters concerning activity, quality of life, functional status and pain in JIA.

In this study, we aimed to create a new multidimensional questionnaire for the assessment of JIA patients as a whole in different aspects including the disease activity, clinical features, physical well-being and functioning, psychosocial characteristics, and quality of life by incorporating the perspectives of the clinician, patient, and parents.

Patients and methods

Delphi consensus process

The new multidimensional questionnaire was created through a literature search followed by two-rounds of Delphi consensus process. The Delphi method has been widely used in healthcare and especially in developing outcome tools [7]. Delphi method consists of repeated rounds of communications and voting amongst a panel of experts. With this methodology an outcome tool may reflect the collective opinion of the experts. First, the main problems of patients with JIA in clinical practice were documented with a comprehensive literature review. The literature review was based on search in the PubMed, Scopus and PEDro databases, using the following keywords: 'juvenile idiopathic arthritis', 'juvenile rheumatoid arthritis', 'juvenile chronic arthritis', 'juvenile arthritis', 'juvenile arthritis assessment', 'outcomes in juvenile arthritis', 'outcomes in pediatric rheumatology', 'pediatric clinical assessment', 'assessment of functional ability in juvenile idiopathic arthritis', 'functional assessment in juvenile idiopathic arthritis', 'functional disability inventory in juvenile idiopathic arthritis', 'daily living activities in juvenile idiopathic arthritis', 'health outcomes in juvenile arthritis', 'health related quality of life in juvenile arthritis', 'psychosocial aspects in juvenile arthritis', 'impact on family in juvenile arthritis', 'consensus methodology', 'pain assessment in juvenile idiopathic arthritis' and 'pediatric pain questionnaire'. The literature search was limited to English articles and the questionnaires used in JIA evaluation were also documented. Then, clinician, child and parent forms were created based on the most commonly used tools, surveys and tests for evaluating problems of patients with JIA in clinical practice. Subsequently, a group of experts (purposive sample), including physiotherapists, pediatric rheumatologists, pediatric psychiatrists, and child development specialists, were invited to the first round of Delphi survey. This was followed by a consensus conference using nominal group technique (NGT). All items were scored according to expert's answers (1 = not necessary, 2 = partly necessary, 3 = must be replaced, 4 = can take place, 5 = must definitely take place). The draft was reorganized according to the recommendations of the experts and their scores. At the second Delphi round, experts reconsidered the draft. At last step, the final version of the questionnaire, which is called Juvenile Arthritis Biopsychosocial and Clinical Questionnaire (JAB-Q) was applied to the patients aged between 6 and 18 years and their parents. The patients filled their forms on their own without help from their parents or physicians. Randomly selected 50 children and their parents were re-administered the same questionnaire

after one week to assess the test–retest reliability. To validate the JAB-Q, previously validated questionnaires as Juvenile Idiopathic Disease Arthritis Score (JADAS) and Childhood Health Assessment Questionnaire (CHAQ), and The Family Impact Questionnaire—(FIS) were also applied to each participant. Figure 1 demonstrates the overall project methodology.

Patient selection

Juvenile idiopathic arthritis patients who were consecutively referred to the Pediatric Rheumatology Outpatient Clinic of Hacettepe University between January 2015 and January 2018 were enrolled in the study. Patients were classified as having JIA according to ILAR classification criteria [2]. All JIA patients who were evaluated by a pediatric rheumatologist were also consulted to a pediatric physiotherapist at the same clinic control. Demographic data, clinical manifestations, laboratory findings [white blood cell (WBC) count, erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), anti-nuclear antibody (ANA), rheumatoid factor (RF), human leukocyte antigen (HLA)-B27], previous treatments were documented from patient charts retrospectively. The final disease status, treatments, and current symptoms were recorded with face-to-face interview by a pediatric rheumatologist. Subsequently, a pediatric rheumatologist and physiotherapist performed the JAB-Q together.

Statistical analyses

SPSS software version 21 was used to evaluate the statistical analysis and the trial version of the MedCalc® program was applied to graphic designs. The new multidimensional questionnaire was created with Delphi technique [8–10]. Descriptive statistics (mean, standard deviation) were calculated in evaluating the results of two-rounded Delphi tours. The validity of the scales formed after the Delphi analysis was calculated by the Pearson correlation coefficient (r). The Bland–Altman graph was used to show the concordance between the scores of the generated scale and scores considered as the gold standard. The Cronbach's alpha coefficient (R_2) was calculated for test–retest reliability of the same scales. In the comparison of the test–retest scores, paired sample T test was used. Statistical significance level was accepted as $p < 0.05$.

Results

Problems with which JIA patients confronted were determined based on the literature review and classified into two groups in Table 1 as physical and psychosocial/life quality problems. We summarized the main outcome tools in JIA practice in Table 2, which assisted us to determine the items in the JAB-Q [11–32]. The Turkish versions of some of these tools are also available [33–36].

A body of experts including nine physiotherapists, nine pediatric rheumatologists, two pediatric psychiatrists, and two child development specialist were invited to the Delphi survey. Two physiotherapists and two pediatric rheumatologists did not agree to participate in the study. Subsequently, one pediatric psychiatrist left the study in the second part. First draft of the scale depending on the literature review consisted of 224 items. Then, to reduce

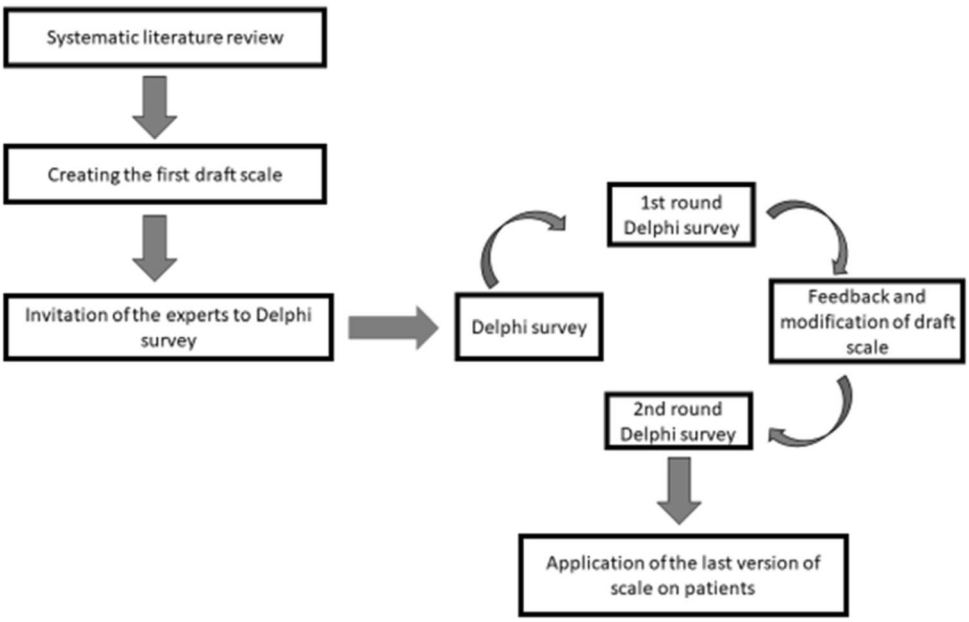

Fig. 1 Project methodology

Table 1 Summary of the problems of juvenile idiopathic arthritis (JIA) patients depending on the literature review

Physical problems	Psychosocial and life quality problems
Pain	Depression and anxiety
Growth retardation	Adolescence and sexual identity
Skin findings	Inadequacies in daily life activities
Joint deformities	Drug adherence
Disease activity	School performance
Hypermobility	Psychosocial problems
Treatment response and adverse reaction	Reduction in health and quality of life
Reduction of cardiovascular capacity	Sleep disorders and fatigue
Inability to muscle strength	
Postural disorders	
Morning stiffness	
Systemic symptoms and their reflection on physical activity	
Walking disorders	

Table 2 The main outcome tools in juvenile idiopathic arthritis (JIA) practice [8, 12–32]

The family impact scale[a]
Beighton score
CAPFUN (capacidad functional = functional ability)
Center for Epidemiological Studies Depression Questionnaire for Children (CES-DC)
Child activity limitations interview (CALI)
Children's Sleep Habits Questionnaire (CSHQ)
Child Health Questionnaire-CHQ[a]
Childhood Health Assessment Questionnaire-CHAQ[a]
Social Anxiety Scale for Children[a]
Pediatric Quality of Life Inventory-PEDsQL[a]
FLACC-Behavioral Pain Assessment Questionnaire
Hamilton Anxiety Rating Scale (HAM-A)
Juvenile Arthritis Functional Assessment Report (JAFAR)
Juvenile Arthritis Disease Activity Score (JADAS)
Juvenile Arthritis Multidimensional Assessment Report (JAMAR)
Juvenile Arthritis Quality of Life Questionnaire (JAQQ)
Non-Communicating Children's Pain Checklist-Revised (NCCPC-R)
Paediatric Gait Arms Legs and Spine (pGALS)[a]
Pain Catastrophizing Scale (PCS)
Penn State Worry Questionnaire for Children
PROMIS Pediatric Item Bank (Pain Interference, Peer Relationships, Depressive Symptoms)
PROMIS Pediatric Profile 25–Profile 37
Revised Child Anxiety and Depression Scale (RCADS)
Screen for Child Anxiety Related Disorders (SCARED)
Somatization Sub Questionnaire of the Child Behavior Checklist (CBCL)
The Juvenile Arthritis Functionality Questionnaire (JAFS)
The Physician's Questionnaire (PQ)

[a]Turkish versions of these tools are also available [33–36]

the number of items, three different drafts consisting of selected questions were sent to different groups of experts (Group 1: Physiotherapist, Group 2: Pediatric Rheumatologist, Group 3: Child Psychiatrist and Child Development Specialist). Parts of the questionnaire, related to the fields of more than one expert group, were sent to all relevant expert groups.

In the first Delphi tour, mean and median appropriateness scores were calculated for each item. Items were selected to move forward based on mean appropriateness score greater than or equal to 4.5. After the second Delphi tour, we created the final form of JAB-Q which had three parts as clinician form, child form and parent form. Both Turkish (original) and English versions of the questionnaire were provided as

supplementary material (Supplementary 1). The English version of JAB-Q was developed using the translation–back translation method [37]. However, this English version has not been validated and it is provided just to inform the readers about the content of the questionnaire. Afterwards, the last version of the questionnaire was applied to 310 patients with JIA and their parents. The demographic characteristics of the patients at the time of the study are summarized in Table 3.

The clinician form of the questionnaire was filled by physicians or physiotherapists, and the child form was filled by children with JIA. The median (min–max) time taken for filling clinician, patient, and parent forms was 15 (10–20); 12 (10–15), and 10 (7–15) minutes, respectively. Although the time taken to fill the form was longer in younger children, there was no significant difference between patients according to their current age. The form which was prepared for the parents was filled by the parents or close relatives (53.5% by mother, 39.6% by father). The validity of the clinician, child and parents' forms were assessed by the JADAS, CHAQ, and FIS, respectively. The correlation coefficients of the clinician, child and parents' forms of the questionnaire were $r=0.523$ ($p<0.001$) ($n=239$), $r=0.667$ ($p<0.001$) ($n=307$), and $r=0.624$ ($p<0.001$) ($n=287$), respectively. The validity of these three scales were determined as moderate.

Analysis of data, by generating a Bland–Altman Plot revealed that the difference between clinician's form and JADAS scores were close to 0; and the scatter plot demonstrated a random distribution that cannot be interpreted as systematical error. Confidence intervals were found to be between − 13.3 and 10.5 with a mean of − 1.4±11.9 (Fig. 2). Since the point intervals of children's form and CHAQ score; and that of parent form and IOF were different, *Z* transformation was applied to ensure standardization of data. Generating the Bland–Altman Plot after *Z* transformation; it was observed that the scatter plot demonstrated a random distribution that cannot be interpreted as systematical error; and that the confidence intervals for forms were respectively found to be: between 1.4 and 1.3 with a mean of 0.0 ± 1.3 and between − 1.60 and 1.73 with a mean of 0.07±1.66. There existed values among data, which exceeded these intervals in both directions. Average of differences were found to be close to 0.

Test–retest results were evaluated for a total of randomly selected 50 children with one week break. Despite a statistically significant difference ($p<0.05$) between the test–retest scores of the clinician form, the Cronbach's alpha coefficient calculated to evaluate test–retest reliability was found to be 0.952 and the form was highly reliable. There was no difference between the test–retest scores of the children and the parents' forms ($p>0.05$) and the Cronbach's alpha

Table 3 Demographic parameters of patients with juvenile idiopathic arthritis (JIA)

	$X \pm$ SD	
Age (year)	12.4 ± 3.67	
Height (cm)	150.21 ± 18.39	
Weight (kg)	44.94 ± 16.28	
Body mass index (kg/m^2)	19.79 ± 4.31	
	N	%
Gender		
Female	174	56.1
Male	136	43.9
JIA subgroup		
Systemic JIA	47	15.2
Oligoarticular JIA	97	31.5
Polyarticular JIA	35	11.2
Enthesitis related arthritis	46	14.8
Psoriatic arthritis	8	2.6
Unclassified	77	24.7
Treatment status		
On treatment	203	65.5
Drug-free	70	22.6
Undefined	37	11.9

$X \pm$ SS; mean ± standard deviation

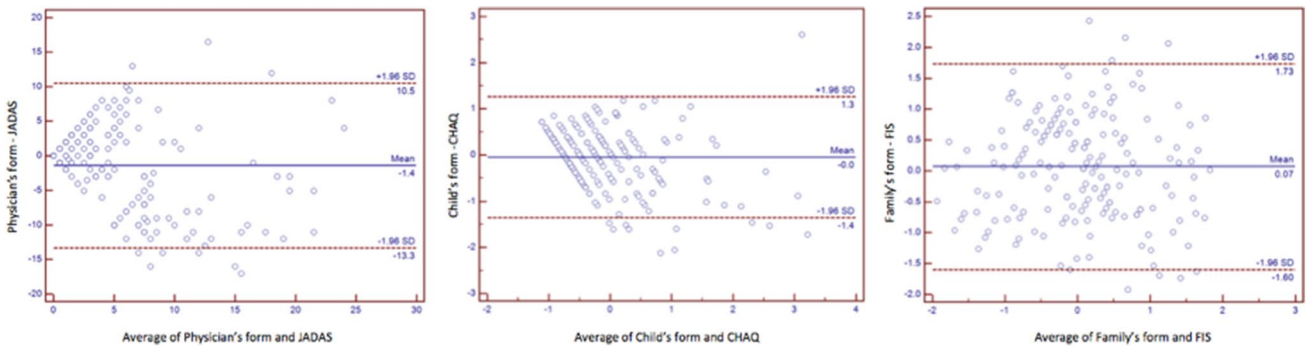

Fig. 2 Bland–Altman plots for forms

coefficients were found to be quite high (0.891 and 0.856, respectively).

Discussion

In this study, a multidimensional questionnaire, JAB-Q, was constructed for assessment of JIA patients, which can be used by clinicians in standard clinical settings. We demonstrated valid and reliable results for JAB-Q using comparisons with previously validated scores and repeated measurements performed within relevant time intervals. JAB-Q consisted of three forms (clinician, child, parent) all of which were found to be reliable and valid.

In clinical practice, patients with JIA not only suffer from physical disabilities, but also they have to cope with the impact of their disease on their psychological states [38–40]. Depression, anxiety, disability in routine daily activities, and reduced quality of life are the most common problems [41]. Hence, outcome assessment tools should incorporate physical, social and emotional aspects of the disease which is deficient in most scales. Another problem is the assumption that parents are able to judge the children's status better than the children themselves [42]. Thus, most of the scales depend on the clinician's or parents' observations. However, children should have the opportunity to express their own perspective about the disease. With this purpose, in the last decade, patient- or parent-reported outcomes have become important [43].

Biopsychosocial model provides a framework for a contemporary understanding of current clinic approach. This model consists of the well-being of an individual with all aspects, including biologic, social, and psychological. Thus, it leads us to provide more holistic approach in clinical practice. This newly developed questionnaire fully meets the biopsychosocial model with assessment of the disease activity, social function, school performance, and the psychologic effect of the illness. JIA has a negative effect on schooling in children [44] and according to adult studies, patients with chronic arthritis who had experienced onset of the disease during childhood, demonstrated lower rates of employment [45]. Thus, it is important to determine and address the impairments in any aspect of the biopsychosocial model early to prevent permanent damage on life.

The clinician's form in JAB-Q comprised assessment of child's overall status, walking, posture, and joints. Validity of this form compared to JADAS, was moderate. JADAS is a tool evaluating the disease activity only. JAB-Q's clinician form is different in principle from JADAS, although it evaluates some disease activity. This difference might have caused the difference in validity. The test/re-test reliability of clinician form was found to be high; suggesting that the clinician could use this questionnaire to consistently assess patient's overall status, walking, and joints.

Patient form (child form) consists of questions related to the child's functionality, psychosocial status, school performance, and fatigue from his/her own perspective. Moderate validity levels were obtained when CHAQ scale was accepted as the gold standard. However, CHAQ scale consisted only of daily routine activities and functionality. Validity of parents' form was assessed with FIS and the validity was found to be again moderate.

In addition, the test–retest reliability of both child and parents' forms was found to be considerably high.

In the literature, there is only one multidimensional score in JIA which is JAMAR [6, 46]. JAMAR evaluates both physical and psychosocial aspects of the disease. However, in this score, the child and his/her parents fill the same questionnaire and respond to the same questions together. This could cause a bias in the answers of children. In JAB-Q, clinician, child and parents fill different forms (with different questions), which eliminates the effect of the parents on the evaluation of the child. In addition, in JAMAR, the authors mentioned that the children had difficulty while answering some questions in the scale and that they could need help from their parents. In JAB-Q, the items questioning different aspects of the disease were easy enough for children to answer on their own. Moreover, inclusion of an open-ended question encourages the child to

use his/her own statements. It was observed that the children and parents were easily adapted to the JAB-Q and filled the forms in about 10–15-minutes. In addition, in the parent form of JAB-Q, the main complaints and school performance of the child are questioned from the perspective of his/her parents. Furthermore, there are items to evaluate the psychosocial status of the parents which is very important in JIA since we know that pain behaviors of children are affected by the parents' attitude [47, 48]. Of note, another difference from JAMAR is that we used Delphi technique to develop JAB-Q.

The main limitations of our study were the limited number of patients and lack of comparison between JAB-Q and JAMAR since the valid Turkish translation of JAMAR is not available when this study has been initiated. In addition, JAB-Q is a long tool including numerous questions. However, it took around 10–15 min in the daily clinical practice. In conclusion, JAB-Q is a valid and reliable multidimensional biopsychosocial outcome tool that can be used routinely in clinical practice of pediatric rheumatology. The main advantage of this tool is incorporation of patients' and parents' perspectives separately while providing a practical and standard setting for clinician's evaluation. Further validation of this tool is required in an independent cohort to improve its applicability and validation in other languages is needed. Multidimensional outcome tools as JAB-Q are important for future multicenter and prospective studies in JIA.

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Author contributions All authors contributed to the study concept, design, acquisition, and interpretation of data. EDB, HES, ZSA, GA, NBK, ES, SD, AO, and FBO drafted the manuscript. Literature review was conducted by NBK, GA, and AO. EU, YB, and SO revised the manuscript critically. DAH and RA performed the statistical analysis. All authors have read and approved the final form of the manuscript for publication.

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Compliance with ethical standards

Conflict of interest The authors declare no conflict of interest.

Ethical approval The study was approved by the ethics committee of Hacettepe University (March 18 2015; GO 15/231-11). Written informed consent was obtained from all participants (both children and their parents).

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