

## The validity and reliability of the Juvenile Arthritis Functional Assessment Report (JAFAR) in children/adolescents with Juvenile Idiopathic Arthritis: The Turkish version study

Merve Bali<sup>1</sup>, Elif Gür Kabul<sup>2,\*</sup>, Bilge Başakçı Çalık<sup>1</sup>, Gülçin Otar Yener<sup>3</sup>, Zahide Ekici Tekin<sup>3</sup>, Selçuk Yüksel<sup>3</sup>

<sup>1</sup>Pamukkale University, Faculty of Physiotherapy and Rehabilitation, Denizli, Türkiye

<sup>2</sup>Uşak University, Faculty of Health Sciences, Physiotherapy and Rehabilitation, Uşak, Türkiye

<sup>3</sup>Pamukkale University, Department of Pediatric Rheumatology, Faculty of Medicine, Denizli, Türkiye

### ARTICLE HISTORY

Received: May 10, 2023

Revised: July 10, 2023

Accepted: July 27, 2023

### Keywords:

Juvenile Idiopathic Arthritis,  
Children,  
Adolescence.

**Abstract:** The aim of the study was to describe the validity and reliability of the Turkish version of Juvenile Arthritis Functional Assessment Report (JAFAR) in children/adolescents with Juvenile Idiopathic Arthritis (JIA). Sixty-nine children/adolescents with JIA were included in the study. JAFAR(TR)-Child and Parent forms were applied to the patients with JIA and to their parents for test retest at one-week intervals, the patients did not receive additional treatment and his/her pharmacological treatment did not change for that week. Test-retest reliability was evaluated by intraclass correlation coefficient (ICC), and internal consistency reliability of multi-item subscales was evaluated by calculating Cronbach's alpha coefficient. Correlations between JAFAR(TR)-Child and Parent with the Pediatric Quality of Life Inventory 3.0. Module Arthritis (PedsQL), the Childhood Health Assessment Questionnaire (CHAQ), and the Juvenile Arthritis Disease Activity Score (JADAS) were evaluated to determine construct validity. The ICC value for the test/retest reliability of JAFAR(TR)-Child was 0.963 and of JAFAR(TR)-Parent was 0.576. JAFAR(TR)-Child total score had low to moderate correlations with PedsQL Child ( $r=-0.34$ ;  $p=0.004$ ), CHAQ ( $r=0.40$ ;  $p=0.001$ ), and JADAS total score ( $r=0.42$ ;  $p=0.000$ ). JAFAR(TR)-Parent total score had moderate to high correlations with PedsQL Parent ( $r=-0.55$ ;  $p=0.000$ ), CHAQ ( $r=0.72$ ;  $p=0.000$ ) and JADAS total score ( $r=0.53$ ;  $p=0.000$ ). The Turkish version of JAFAR was found to be clinically valid and reliable in JIA.

## 1. INTRODUCTION

Juvenile Idiopathic Arthritis (JIA) is a chronic autoimmune disease, in which arthritis occurs in one or more joints below 16 years old at least 6 weeks (Petty et al., 2004). Joint pain, muscle atrophy, weakness, contracture, joint swelling, and movement-related abnormalities are seen in the symptoms of individuals diagnosed with JIA (Hansmann et al., 2015).

Knowing to what extent rheumatic diseases, which begin to show their effects in childhood, affect the child's functionality in daily activities is very important information in the management of these children's diseases. JIA is the most common cause of functional disability

\*CONTACT: Elif Gür Kabul ✉ [elifgur1988@hotmail.com](mailto:elifgur1988@hotmail.com) 📧 Uşak University, Faculty of Health Sciences, Physiotherapy and Rehabilitation, Uşak, Türkiye

in childhood. Therefore, early evaluation is important. Studies show that children/adolescents with JIA have less functional ability, physical activity participation, and fitness compared to those of the healthy peers. This inadequacy also causes physical disability in JIA children (Henderson et al., 1995; Takken et al., 2002; Klepper, 2008; 2003; Lelieveld et al., 2008; Tarakci et al., 2011).

Questionnaires are widely used to assess functional status in children/adolescents with JIA. The questionnaires such as The Juvenile Arthritis Functional Assessment Scale (JAFAS), Juvenile Arthritis Self-Report Index, The Juvenile Arthritis Multidimensional Assessment Report (JAMAR), and Childhood Health Assessment Questionnaire (CHAQ) are generally used for evaluation. CHAQ demonstrates high internal reliability and test-retest reliability (Cronbach's  $\alpha \geq 0.98$ ;  $r=0.8$ ) (Singh et al., 1994) and consists of 8 subsections (dressing, reach, eating, arising, walking, grip, hygiene, and activities) and 30 questions. However, some problems have been reported such as difficulty in understanding the questions during the evaluation and the same answers are always given by the patients after a while (Kisaarslan & Sözeri, 2016). The Juvenile Arthritis Functional Assessment Scale (JAFAS) is a scale focused on musculoskeletal function. The assessor looks at how long it takes to do the activities. The Juvenile Arthritis Self-Report Index is a two-part questionnaire consisting of 100 questions focused on physical activity. The fact that the clinical application of these two questionnaires takes a long time and that their Turkish validity and reliability has not been done creates a disadvantage. JAMAR, which has Turkish validity, consists of 15 questions. Physical function is evaluated in the first question and in the other questions, and a general evaluation is made by examining pain, intensity, presence of painful or swollen joints, morning stiffness and duration, disease activity level, treatment content, and school problems; however, it has limitations in questioning functionality.

These questionnaires evaluating functionality are few in number, and only CHAQ and JAMAR have been validated and found reliable in Turkish (Tarakci et al., 2013; Demirkaya et al., 2018). However, the CHAQ and JAMAR alone are insufficient to assess actual functionality. Juvenile Arthritis Functional Assessment Report (JAFAR) is a functional questionnaire that covers assessment of physical function, aids/devices, help from others, and pain. JAFAR evaluates the ability to perform 23 physical functions (based on daily functional movements) without any help for the past week. Each item has a three-point Likert answer system (“0” all the time; “1” sometimes; “2” almost never). It also measures the severity of the child pain for child and her/his parent with a 10 cm line (10=Very Bad Pain, 0=No pain). JAFAR is a simple and convenient questionnaire for clinical studies that can be easily filled by the patient and comprehensively evaluates physical function (Howe et al., 1991). We aimed to examine the validity and reliability of the Turkish version of the Juvenile Arthritis Functional Assessment Report.

## **2. METHOD**

### **2.1. Patients**

Sixty-nine children/adolescents with JIA between the ages of 7-18 (29 boys, 40 girls; mean age= $13.36 \pm 2.97$  years) followed by Pamukkale University Pediatric Rheumatology Clinic and Pediatric Rheumatology Physiotherapy and Rehabilitation Unit were included in the study. In the related literature, the sample size should be 3-10 times the number of scale items in scale studies (Cattell, 1978; Comrey & Lee, 1992; Tavşancıl, 2002, s. 5–6; Hair et al., 2009).

Inclusion criteria were diagnosed with JIA according to the criteria of International League of Associations for Rheumatology to be between the ages of 6-18 in order to be included in the study.

Exclusion criteria were (a) having another autoimmune disease, (b) having neurological disease, (c) presence of any orthopedic, cardiopulmonary problem that can affect functionality and daily living activities, (e) having a psychiatric illness that affects cooperation, and (f) having a history of orthopedic surgery in the last one year.

Approval that there was no ethical problem for the study was obtained from Pamukkale University at the meeting number of 18 dated 24.10.2019. All participants were informed verbally before participating in the study and consent forms were signed by the participants.

## **2.2. Procedures**

A cross sectional study design was planned.

## **2.3. Clinical Data**

All participants were evaluated by the investigator in approximately 40-45 minutes and a session. After the demographic information of the patients was recorded, the quality of life was evaluated with Pediatric Quality of Life Inventory 3.0. Module Arthritis (PedsQL), disability levels with Childhood Health Assessment Questionnaire (CHAQ), and disease activities with the Juvenile Arthritis Disease Activity Score (JADAS). JAFAR questionnaire was applied to children/adolescents with JIA and their parents for test retest at one-week intervals, the patients did not receive additional treatment and his/her pharmacological treatment did not change for that week.

### ***2.3.1. Translation and cultural adaptation of Juvenile Arthritis Functional Assessment Report (JAFAR)***

During the JAFAR cross-cultural adaptation process, previously recommended procedures were followed in five stages (Beaton et al., 2000; Wild et al., 2005). The JAFAR (TR) is presented in [Appendix](#).

### ***2.3.2. Juvenile Arthritis Functional Assessment Report (JAFAR)***

Juvenile Arthritis Functional Assessment Report is a functional assessment criterion developed based on the children with JIA and parents of the children. JAFAR is valid for JIA. JAFAR consists of two forms, Juvenile Arthritis Functional Assessment Report for Children (JAFAR-C) and Juvenile Arthritis Functional Assessment Report for Parents (JAFAR-P). JAFAR evaluates the ability to perform physical functions without assistance with 23 items for the past week. Each item has a three-point Likert answer system (“0” all the time; “1” sometimes; “2” almost never). A lower score means better physical functionality. JAFAR also assesses whether aids/devices are used, whether help from others is needed, and child pain with a 10 cm line (10=Very Bad Pain, 0=No pain) (Howe et al., 1991).

### ***2.3.3. Pediatric Quality of Life Inventory 3.0. Module Arthritis (PedsQL)***

PedsQL 3.0 Arthritis Module was developed to evaluate the quality of life in children with rheumatic disease. PedsQL 3.0 Arthritis Module has “Pain and hurt”, “Daily activities”, “Treatment”, “Worry” and “Communication” subsections and consists of 22 items in total. Each item is evaluated from 0 to 4 (Never-0, Always-4). PedsQL 3.0 Arthritis Module has separate forms for children of different age groups and their parents (2-4 years old, 5-7 years old, 8-12 years old and 12-18 years old). In our study, 8-12 age and 12-18 age child and parent forms were used. As the score decreases, the quality of life decreases (Tarakci et al., 2013).

### ***2.3.4. Childhood Health Assessment Questionnaire (CHAQ)***

CHAQ evaluates functional abilities in children. The scale can be applied to all children between the ages of 6 months and 18 years. The CHAQ is composed of disability and discomfort indexes. CHAQ Disability Index consists of 30 questions and 8 subsections, including dressing, eating, reach, arising, walking, grip, hygiene, and activities. Calculation of

CHAQ Disability Index is based on all scores from 8 sections summed and divided by 8. CHAQ Discomfort Index assessed pain and global evaluation measured by two 0-100 mm visual analog scales. Higher score means more severe functional disability (Ozdogan et al., 2001).

### 2.3.5. Juvenile Arthritis Disease Activity Score (JADAS)

Juvenile Arthritis Disease Activity Score (JADAS) was evaluated for the disease activity for children (Consolaro et al., 2009). JADAS consists of four parts:

1. D-GAS (Doctor- Visual Analogue Scale),
2. H-GAS (Patient- Visual Analogue Scale),
3. Number of active joints (71, 27,10 joints): Active joint is defined as the presence of swollen joint and/or tender joint.
4. Evaluation of sedimentation between 0-10: SEDIM: ESR (mm/hour)-20/10.

If the sedimentation rate is 120 or higher, the score is considered 10.

JADAS is calculated by the arithmetic sum of four parts (Nordal et al., 2012). In our study, JADAS 27 was used. JADAS 27 includes cervical, elbows, wrists, 1-3 metacarpophalangeal joints, proximal interphalangeal joints, hip joints, knees, and ankles (Horneff & Becker, 2014).

### 2.4. Statistical Analysis

SPSS 25.0 software (IBM SPSS Statistics 25 software (Armonk, NY: IBM Corp) was used for the analyses. Categorical variables were shown as number and percent while continuous variables as mean  $\pm$  Standard deviation (SD) and median (minimum – maximum values). The conformity of continuous numerical variables to the normal distribution was examined using the ShapiroWilk test. External construct validity was analyzed with Spearmanrho correlation coefficient. The internal consistency reliability was analyzed with the Cronbach’s alpha coefficients. For intraclass correlation coefficient (ICC), two way mixed was used for test-retest reliability (ICC; <0.50=poor reliability, between 0.50 and 0.75: moderate reliability, between 0.75 and 0.90: good reliability, >0.90: excellent reliability). Statistical significance level was accepted as  $p<0.05$ .

## 3. RESULTS

The mean age of the patients in the study was  $13.36 \pm 2.97$  years and 58% were girls and adolescents. The demographic data of the patients are summarized in Table 1. Descriptive information about the outcome measures is given in Table 2.

### 3.1. Construct validity

Descriptive data of JAFAR Parent and JAFAR Child total scores are given in Table 2.

**Table 1.** Demographic data of patients with JIA.

	n	%	Med (IQR)	Min - Max
Age			13 (11 - 16)	8 – 18
Gender				
Girl	40	58.0		
Boy	29	42.0		
Diagnosis Age (year)			11 (7 - 14)	1 – 17
BMI			20.2 (17.61 - 23.55)	12.62 - 32.95

**Table 2.** Descriptive data of the outcome measures.

PedsQL Child	Mean± S.D.	Med (IQR)	Min - Max
Pain and hurt	70.65 ± 26.8	81.25 (50 - 93.73)	0 - 100
Daily activities	93.38 ± 16.46	100 (92.5 - 100)	10 - 100
Treatment	79.75 ± 20.34	85.7 (69.64 - 96.41)	28.5 - 100
Worry	76.58 ± 26.69	83.33 (62.47 - 100)	0 - 116.66
Communication	82.11 ± 21.46	91.6 (66.66 - 100)	33.3 - 100
Total	80.5 ± 15.44	85.87 (71.33 - 92.65)	43.21 - 100
PedsQL Parent	Mean± S.D.	Med (IQR)	Min - Max
Pain and hurt	70.74 ± 29.19	81.25 (53.13 - 100)	0 - 100
Daily activities	92.68 ± 17.4	100 (97.5 - 100)	10 - 100
Treatment	76.91 ± 20.9	78.57 (60.71 - 94.63)	32.14 - 100
Worry	69.91 ± 29.89	75 (50 - 100)	0 - 100
Communication	84.41 ± 23.44	100 (70.83 - 100)	16.66 - 100
Total	78.93 ± 17.02	81.13 (70.49 - 90.83)	37.49 - 100
CHAQ			
Dressing	0.58 ± 0.95	0 (0 - 1)	0 - 3
Eating	0.26 ± 0.63	0 (0 - 0)	0 - 3
Reach	0.54 ± 0.96	0 (0 - 1)	0 - 3
Arising	0.49 ± 0.8	0 (0 - 1)	0 - 3
Walking	0.39 ± 0.75	0 (0 - 1)	0 - 3
Grip	0.39 ± 0.81	0 (0 - 0.5)	0 - 3
Hygiene	0.45 ± 0.78	0 (0 - 1)	0 - 3
Activities	0.67 ± 1.02	0 (0 - 1)	0 - 3
Disability Index Total	0.47 ± 0.59	0.25 (0 - 0.69)	0 - 3
Pain	35.17 ± 26.25	40 (10 - 55)	0 - 90
Global Evaluation	36.54 ± 26.04	40 (10 - 60)	0 - 90
JADAS			
Total	9.23 ± 6.66	9 (3.5 - 13)	0 - 28
JAFAR			
Child 1. Evaluation Total	1.88 ± 2.85	1 (0 - 3)	0 - 12
Child 2. Evaluation Total (retest)	1.68 ± 2.64	0 (0 - 2.5)	0 - 12
Parent 1. Evaluation Total	3.74 ± 5.32	1 (0 - 6.5)	0 - 23
Parent 2. Evaluation Total (retest)	4.29 ± 14.03	1 (0 - 3)	0 - 100

PedsQL: Pediatric Quality of Life Inventory 3.0. Module Arthritis, CHAQ= Childhood Health Assessment Questionnaire  
 JADAS= Juvenile Arthritis Disease Activity Score, JAFAR= Juvenile Arthritis Functional Assessment Report

### 3.2. External Validation

For the validity of the child and parent forms of JAFAR, the relationship between the JAFAR Child and Parent total score and subsections and total score of the PedsQL Child and Parent forms, subsections and total score of CHAQ Disability Index, Pain and Global Evaluation of CHAQ and the JADAS total score was examined and is given in [Table 3](#).

JAFAR-Child total score had a significant negative correlation with pain and hurt subsection ( $r=-0.521$ ;  $p=0.000$ ) and total score ( $r=-0.347$ ;  $p=0.004$ ) of PedsQL Child. PedsQL score

approaching 100 means better quality of life, while JAFAR total score approaching zero means better physical functionality. For this reason, the negative correlation indicates that JAFAR is also suitable in the evaluation.

JAFAR-Child total score had a significant positive correlation with arising ( $r=0.475$ ;  $p=0.000$ ), walking ( $r=0.320$ ;  $p=0.000$ ), hygiene ( $r=0.305$ ;  $p=0.011$ ), activities ( $r=0.255$ ;  $p=0.035$ ) subsections and total score ( $r=0.401$ ;  $p=0.001$ ) of CHAQ Disability Index, Pain of CHAQ ( $r=0.375$ ;  $p=0.001$ ), Global Evaluation of CHAQ ( $r=0.445$ ;  $p=0.001$ ), and JADAS total score ( $r=0.422$ ;  $p=0.000$ ). The higher the score in CHAQ, the higher the disability level, and the higher the score in JADAS, the higher the disease activity. For this reason, the positive correlation indicates that JAFAR is also suitable in the evaluation.

JAFAR-Parent total score had a significant negative correlation with all subsections (except for Worry) ( $r=-0.679/-0.370$ ;  $p<0.05$ ) and total score ( $r=-0.553$ ;  $p=0.000$ ) of PedsQL Parent.

JAFAR-Parent total score had a significant positive correlation with all subsections and total score of CHAQ Disability Index, Pain of CHAQ, Global Evaluation of CHAQ ( $r=0.723/0.320$ ;  $p<0.05$ ) and JADAS total score ( $r=0.539$ ;  $p=0.000$ ) ( $p<0.05$ ).

**Table 3.** Correlation between JAFAR-Child and JAFAR-Parent with PedsQL, CHAQ and JADAS questionnaires.

	JAFAR-Child rho; p	JAFAR-Parent rho; p
<b>PedsQL Child</b>		
Pain and hurt	-0.521; 0.001	-0.673; 0.001
Daily activities	-0.198; 0.103	-0.468; 0.001
Treatment	-0.085; 0.489	-0.330; 0.006
Worry	-0.178; 0.143	-0.313; 0.009
Communication	-0.136; 0.265	-0.472; 0.001
Total	-0.347; 0.004	-0.652; 0.001
<b>PedsQL Parent</b>		
Pain and hurt	-0.480; 0.001	-0.679; 0.001
Daily activities	-0.314; 0.009	-0.396; 0.001
Treatment	-0.267; 0.027	-0.370; 0.002
Worry	-0.228; 0.059	-0.187; 0.125
Communication	-0.125; 0.306	-0.442; 0.001
Total	-0.372; 0.002	-0.553; 0.001
<b>CHAQ</b>		
Dressing	0.082; 0.504	0.462; 0.001
Eating	0.151; 0.216	0.320; 0.007
Reach	0.135; 0.267	0.595; 0.001
Arising	0.475; 0.001	0.671; 0.001
Walking	0.320; 0.001	0.572; 0.001
Grip	0.160; 0.190	0.357; 0.003
Hygiene	0.305; 0.011	0.541; 0.001
Activities	0.255; 0.035	0.400; 0.001
Disability Index Total	0.401; 0.001	0.723; 0.001
Pain	0.375; 0.001	0.455; 0.001
Global Evaluation	0.445; 0.001	0.527; 0.001
<b>JADAS</b>		
Total	0.422; 0.001	0.539; 0.001

PedsQL: Pediatric Quality of Life Inventory 3.0. Module Arthritis, CHAQ= Childhood Health Assessment Questionnaire  
 JADAS= Juvenile Arthritis Disease Activity Score, JAFAR= Juvenile Arthritis Functional Assessment Report

### 3.3. Internal Consistency Reliability

The internal consistency coefficient for the JAFAR-Parent pain was 0.659, the internal consistency coefficient for the JAFAR-Parent total score was 0.576, the internal consistency coefficient for the JAFAR-Child pain was 0.879, the internal consistency coefficient for the JAFAR-Child total score was 0.963, and the scale was found reliable (Table 4).

**Table 4.** Test-retest reliability of JAFAR-Child and JAFAR-Parent.

	ICC	95% CI of ICC	Reliability
		Lower-upper	
JAFAR-Child Pain	0.879	0.804 – 0.925	Good
JAFAR-Child Total	0.963	0.94 – 0.977	Good
JAFAR-Parent Pain	0.659	0.449 – 0.789	Moderate
JAFAR-Parent Total	0.576	0.315 – 0.737	Moderate

JAFAR: Juvenile Arthritis Functional Assessment Report, CI: Confidence Interval; ICC: Intraclass correlation coefficient two-way mixed model-absolute agreement; Intraclass correlation coefficient values less than 0.50 indicate poor reliability, values between 0.50 and 0.75 indicate moderate reliability, values between 0.75 and 0.90 indicate good reliability, and values greater than 0.90 indicate excellent reliability.

## 4. DISCUSSION and CONCLUSION

The Turkish version of the JAFAR was found to be clinically valid and reliable for use in clinical evaluations and rehabilitation interventions in patients with JIA.

Determination of daily functional abilities of children/adolescents with juvenile chronic arthritis is of primary importance (Murray & Passo, 1995). Functional abilities of children/adolescents with JIA decreased as they were less likely to participate in social activities and tended to lead a more sedentary life (Gare et al., 1993).

CHAQ and JAMAR are widely used for functional evaluation in clinics in Türkiye. A meta-analysis study, examining the functional evaluation of children/adolescents with JIA in the Turkish population, emphasized that the options for functional assessment are limited (Kuntze et al., 2018). Kisaarslan et al. (2016), in their review of outcome measures at JIA, reported that the CHAQ has some problems such as difficulty in understanding the questions during the evaluation and the same answers are always given by the patients after a while. We think that other problems such as the inability to apply for the children's parents and younger children may encounter problems in answering because of the difficulty in understanding some of the CHAQ questions also make the CHAQ less adequate.

The JAMAR, another valid and reliable questionnaire in Turkish, consists of 15 questions. Since only the first question has 15 sub-parameters, it limits the practical evaluation of functional problems in the clinic (Demirkaya et al., 2018). However, JAFAR evaluates functional assessment in detail with 23 questions applied to both parents and children/adolescents with JIA (Howe et al., 1991). The quick, practical and meaningful evaluation is very important in JIA, because the evaluation of functionality guides the management as well as clinical diagnosis and treatment.

The internal consistency of JAFAR was quite good and found to be reliable. As a result of external validity analysis, the relationship between JAFAR-Child, JAFAR-Parent and CHAQ, PedsQL, JADAS, and their subsections was found to be moderately significant.

The limitation of this study is the inability to reach all children and adolescents with JIA diagnosed and followed-up in the clinic, since the evaluation part coincided with the COVID-19 pandemic period.

When the literature is examined, we see that JAFAR is not valid and reliable in any language other than English. Since JAFAR is a questionnaire that can evaluate the functional level quickly and easily, we believe that it will be beneficial in terms of evaluating the perspectives of children and adolescents with JIA and their families, determining the functional disabilities of their children and taking measures for this situation. Therefore, we recommend examining the validity and reliability of this questionnaire in languages other than English.

In conclusion, The JAFAR-TR scale is a valid and reliable outcome measure assessing the physical function of children/adolescents with JIA.

### Declaration of Conflicting Interests and Ethics

The authors declare no conflict of interest. This research study complies with research publishing ethics. The scientific and legal responsibility for manuscripts published in IJATE belongs to the authors. **Ethics Committee Number:** Pamukkale University, 24.10.2019, 60116787-020/75835.

### Authorship Contribution Statement

**Merve Bali:** Collected data, wrote the article. **Elif Gür Kabul:** Design, collected data, statistical analyses. **Bilge Başakçı Çalık:** Design, commented on statistics, critical revision of the manuscript. **Gülçin Otar Yener:** Diagnosed patients and checked eligibility for inclusion criteria. **Zahide Ekici Tekin:** Diagnosed patients and checked eligibility for inclusion criteria. **Selçuk Yüksel:** Commented on statistics, critical revision of the manuscript.

### Orcid

Merve Bali  <https://orcid.org/0000-0002-6955-9596>

Elif Gür Kabul  <https://orcid.org/0000-0003-3209-1499>

Bilge Başakçı Çalık  <https://orcid.org/0000-0002-7267-7622>

Gülçin Otar Yener  <https://orcid.org/0000-0003-2575-6309>

Zahide Ekici Tekin  <https://orcid.org/0000-0002-5446-667X>

Selçuk Yüksel  <https://orcid.org/0000-0001-9415-1640>

### REFERENCES

- Beaton, D.E., Bombardier, C., Guillemin, F., & Ferraz, M.B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine (Phila. Pa. 1976)*, 25(24), 3186–3191. <https://doi:10.1097/00007632-200012150-00014>
- Cattell, R.B. (1978). *The scientific use of factor analysis in behavioral and life sciences* (2nd edition). Plenum.
- Comrey, A.L., & Lee, H.B. (1992). *A first course in factor analysis* (2nd edition). Lawrence Erlbaum.
- Consolaro, A., Ruperto, N., Bazso, A., Pistorio, A., Magni-Manzoni, S., Filocamo, G., Malattia, C., Viola, S., Martini, A., Ravelli, A., & Paediatric Rheumatology International Trials Organisation. (2009). Development and validation of a composite disease activity score for juvenile idiopathic arthritis. *Arthritis and Rheumatism*, 61(5), 658-666. <https://doi:10.1002/art.24516>
- Demirkaya, E., Ozen, S., Sozeri, B., Ayaz, N.A., Kasapcopur, O., Unsal, E., Makay, B.B., Barut, K., Fidanci, B.E., Simsek, D., Cakan, M., Consolaro, A., Bovis, F., Ruperto, N., & Paediatric Rheumatology International Trials Organisation (PRINTO). (2018). The Turkish version of the juvenile arthritis multidimensional assessment report (JAMAR). *Rheumatology International*, 38(1), 395–402. <https://doi:10.1007/s00296-018-3982-8>
- Gare, A.B., Fath, A., & Wiklund, I. (1993). Measurement of functional status in juvenile chronic arthritis; evaluation of a Swedish version of the Child Health Assessment Questionnaire. *Clinical and Experimental Rheumatology*, 11(5), 569-576.

- Hair, J.F., Black, W., Babin, B., & Anderson, R. (2009). *Multivariate data analysis* (7th Edition). Upper Saddle River.
- Hansmann, S., Benseler, S.M., & Kuemmerle-Deschner, J.B. (2015). Dynamic knee joint function in children with juvenile idiopathic arthritis (JIA). *Pediatric Rheumatology Online Journal*, 13(1), 1–11. <https://doi:10.1186/s12969-015-0004-1>
- Henderson, C.J., Lovell, D.J., Specker, B.L., & Campaigne, B.N. (1995). Physical activity in children with juvenile rheumatoid arthritis: Quantification and evaluation. *Arthritis Care and Research*, 8(2), 114–119. <https://doi:10.1002/art.1790080210>
- Horneff, G., & Becker, I. (2014). Definition of improvement in juvenile idiopathic arthritis using the juvenile arthritis disease activity score. *Rheumatology (Oxford)*, 53(7), 1229–1234. <https://doi:10.1093/rheumatology/ket470>
- Howe, S., Levinson, J., Shear, E., Hartner, S., McGirr, G., Schulte, M., Lovell D. (1991). Development of a disability measurement tool for juvenile rheumatoid arthritis. The juvenile arthritis functional assessment report for children and their parents. *Arthritis and Rheumatism*, 34(7), 873–880. <https://doi:10.1002/art.1780340713>
- Kisaarslan, A.P., & Sözeri, B. (2016). The outcome measures in Juvenile idiopathic arthritis: Review. *Türkiye Klinikleri Pediatri*, 25(2), 101–109. <https://doi:10.1002/art.11055>
- Klepper, S.E. (2003). Exercise and fitness in children with arthritis: Evidence of benefits for exercise and physical activity. *Arthritis and Rheumatism*, 49(3), 435–443.
- Klepper, S.E. (2008). Exercise in pediatric rheumatic diseases. *Current Opinion in Rheumatology*, 20(5), 619–624. <https://doi:10.1097/BOR.0b013e32830634ee>
- Kuntze, G., Nesbitt, C., Whittaker, J.L., Nettel-Aguirre, A., Toomey, C., Esau, S., Doyle-Baker, P.K., Shank, J., Brooks, J., Benseler, S., Emery, C.A. (2018). Exercise therapy in Juvenile Idiopathic Arthritis: A systematic review and meta-analysis. *Archives of Physical Medicine and Rehabilitation*, 99(1), 178-193. <https://doi:10.1016/j.apmr.2017.05.030>
- Lelieveld, O.T.H.M., Armbrust, W., van Leeuwen, M.A., Duppen, N., Geertzen, J.H.B., Sauer, P.J.J., van Weert, E. (2008). Physical activity in adolescents with juvenile idiopathic arthritis. *Arthritis and Rheumatism*, 59(10), 1379–1384. <https://doi:10.1002/art.24102>
- Murray, K.J., & Passo, M.H. (1995). Functional measures in children with rheumatic diseases. *Pediatric Clinics of North America*, 42(5), 1127–1154. [https://doi:10.1016/s0031-3955\(16\)40056-8](https://doi:10.1016/s0031-3955(16)40056-8)
- Nordal, E.B., Zak, M., Aalto, K., Berntson, L., Fath, A., Herlin, T., Lahdenne, P., Nielsen, S., Peltoniemi, S., Straume, B., & Rygg, M. (2012). Validity and predictive ability of the juvenile arthritis disease activity score based on CRP versus ESR in a Nordic population-based setting. *Annals of the Rheumatic Diseases*, 71(7), 1122-1127. <https://doi:10.1136/annrheumdis-2011-200237>
- Ozdogan, H., Ruperto, N., Kasapçopur, O., Bakkaloglu, A., Arisoy, N., Ozen, S., Ugurlu, U., Unsal, E., Melikoglu, M., & Paediatric Rheumatology International Trials Organisation. (2001). The Turkish version of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ). *Clinical and Experimental Rheumatology*, 19(4), S158-162.
- Petty, R.E., Southwood, T.R., Manners, P., Baum, J., Glass, D.N., Goldenberg, J., He, X., Maldonado-Cocco, J., Orozco-Alcala, J., Prieur, A.M., Suarez-Almazor, M.E., Woo, P., & International League of Associations for Rheumatology. (2004). International League of Associations for Rheumatology classification of juvenile idiopathic arthritis: Second revision, Edmonton, 2001. *The Journal of Rheumatology*, 31(2), 390–392.
- Singh, G., Athreya, B.H., Fries, J. F., & Goldsmith, D.P. (1994). Measurement of health status in children with juvenile rheumatoid arthritis. *Arthritis and Rheumatism*, 37(12), 1761–1769. <https://doi:10.1002/art.1780371209>

- Takken, T., Hemel, A., Van Der Net, J., & Helders, P.J.M. (2002). Aerobic fitness in children with juvenile idiopathic arthritis: A systematic review. *The Journal of Rheumatology*, 29(12), 2643–2647.
- Tarakci, E., Baydogan, S.N., Kasapcopur, O., & Dirican, A. (2013). Cross-cultural adaptation, reliability, and validity of the Turkish version of PedsQL 3.0 Arthritis Module: A quality-of-life measure for patients with juvenile idiopathic arthritis in Turkey. *Quality of Life Research*, 22(3), 531–536. <https://doi:10.1007/s11136-012-0180-0>
- Tarakci, E., Yeldan, I., Mutlu, E.K., Baydogan, S.N., & Kasapcopur, O. (2011). The relationship between physical activity level, anxiety, depression, and functional ability in children and adolescents with juvenile idiopathic arthritis. *Clinical Rheumatology*, 30(11), 1415–1420. <https://doi:10.1007/s10067-011-1832-0>
- Tavşancıl, E. (2002). *Tutumların ölçülmesi ve SPSS ile veri analizi (1st edition)*. Nobel publishing house.
- Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., Erikson, P., & ISPOR Task Force for Translation and Cultural Adaptation. (2005). Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. *Value in Health*, 8(2), 94-104. <https://doi:10.1111/j.1524-4733.2005.04054.x>

## APPENDIX

## JAFAR - Juvenile Arthritis Functional Assessment Report - Turkish version

## JAFAR - Jüvenil Romatoid Artrit Fonksiyonel Değerlendirme Formu

7 Yaş ve Üstü Jüvenil Romatoid Artritli Çocuklar İçin

Hasta Adı-Soyadı:

Hasta Doğum Tarihi:

Değerlendirme Tarihi:

**1.Bölüm: Yetenek Ölçeği**

Bu anket, çocuğunuzun hastalığının onun günlük yaşamdaki fonksiyonlarını nasıl etkilediğini öğrenmek amacıyla oluşturulmuştur.

Lütfen bu sayfanın arkasına herhangi bir yorum eklemekten çekinmeyin.

**Son bir haftayı** düşünerek çocuğunuzun yapabildiği aktivitelere göre uygun cevabı işaretleyin.

Lütfen bütün soruları cevaplayınız.

Geçtiğimiz hafta,	Her zaman	Bazen	Neredeyse hiç
1. Gömleğini askıdan almak	—	—	—
2. Gömleğini ilikleme	—	—	—
3. Kazağını başının üzerinden giymek	—	—	—
4. Musluk açmak	—	—	—
5. Yere oturup sonrasında kalkmak	—	—	—
6. Havlu ile sırtını kurulamak	—	—	—
7. Yüzünü yıkamak	—	—	—
8. Ayakkabı bağcığını bağlamak	—	—	—
9. Çorap giymek	—	—	—
10. Diş fırçalamak	—	—	—
11. Kollardan destek almadan sandalyeden kalmak	—	—	—
12. Yatağa yatmak	—	—	—
13. Çatal ve bıçak kullanarak yiyecekleri kesmek	—	—	—
14. Boş bardağı ağıza götürmek	—	—	—
15. Daha önceden açılmış kavanozu açmak	—	—	—
16. Yardımsız 50 adım yürümek	—	—	—
17. Beş basamak çıkmak	—	—	—
18. Ayak parmaklarının ucunda yükselmek	—	—	—
19. Başın üzerine uzanmak	—	—	—
20. Yataktan kalmak	—	—	—
21. Ayakta dururken yerden bir şey almak	—	—	—
22. Kapı tokmağını çevirerek açmak	—	—	—
23. Başını döndürüp omzunun üzerinden bakmak	—	—	—

## 2. Bölüm: Yardımcı Araç ve Cihazlar

Çocuğunuzun herhangi bir aktivite sırasında kullandığı araç veya cihazlar varsa işaretleyin.

	Kullanıyor	Kullanmıyor
Baston	—	—
Walker/Yürüteç	—	—
Koltuk Değneği	—	—
Tekerlekli Sandalye	—	—
Kalınlaştırılmış kalem	—	—
Düğme kancası	—	—
Fermuar çekeceği	—	—
Ayakkabı çekeceği	—	—
Özel mutfak gereçleri	—	—
Özel sandalye	—	—
Özelleştirilmiş klozet	—	—
Küvet sandalyesi	—	—
Kavanoz açacağı	—	—
Küvet tutunma barları	—	—
Uzanma çubukları	—	—

Çocuğunuz yukarıdakilerden başka bir yardımcı araç, gereç, alet veya cihaz kullanıyor mu?

Eğer evet ise, tanımlayınız. \_\_\_\_\_

## 3. Bölüm: Başkalarından Yardım

Çocuğunuz aşağıdaki aktiviteler sırasında herhangi birine ihtiyaç duyuyorsa işaretleyin.

	Yardıma ihtiyacı yok	Yardıma ihtiyacı var
Sabahları giyinirken	—	—
Sabahları yıkanırken	—	—
Yatağa girip çıkarken	—	—
Yemek yerken	—	—
Evin etrafında dolaşırken	—	—
Sandalyeye oturup kalkarken	—	—
Nesnelere uzanıp alırken	—	—

## 4. Bölüm: Ağrı

Ayrıca çocuğunuzun hastalığından dolayı ağrıdan etkilenip etkilenmediğini öğrenmek istiyoruz.

GEÇTİĞİMİZ HAFTA çocuğunuzun hastalığından dolayı ne kadar ağrısı olduğunu düşünüyorsunuz? Ağrı şiddetini aşağıda verilen çizgi üzerinde işaretleyiniz.

0	100
Ağrı yok	Çok şiddetli ağrı