

The Juvenile Arthritis Foot Disability Index: Development and Evaluation of Measurement Properties

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ABSTRACT. Objective. To develop a new juvenile arthritis foot disability index (JAFI) and to test it for validity and reliability.

Methods. Samples of 14 children/adolescents and 30 children/adolescents with juvenile idiopathic arthritis (JIA) and 29 healthy children/adolescents participated. We used a questionnaire derived from the International Classification of Functioning, Disability and Health that included 27 statements divided into the dimensions Impairment, Activity Limitation, and Participation Restriction. Comments on the contents were invited from parents and adolescents. Convergent and divergent construct validity was examined by comparing the 3 JAFI dimensions to joint impairment scores, the Childhood Health Assessment Questionnaire (CHAQ), and self-rated, foot-related participation restriction. Known groups construct validity was assessed by comparing answers from children with JIA to those from healthy children. Test-retest stability was investigated over one week.

Results. One item was added after suggestions from 2 participants. A consistent pattern of increasing JAFI scores was found with increasing joint impairment scores, CHAQ scores, and self-rated foot-related participation restriction. Foot-related disability as assessed by JAFI was more pronounced in children with JIA than in healthy controls. One statement showing a floor effect was excluded. No internal redundancy ($r_s > 0.90$) between items was found, and internal consistency within each subscale was satisfactory ($r_s > 0.50$) for all items but one. No systematic differences were found between test and retest, and weighted kappa coefficients for the 3 JAFI dimensions were 0.90, 0.85, and 0.88.

Conclusion. The JAFI appears to be valid and reliable for assessing foot-related disability among children/adolescents with JIA. Its sensitivity to change remains to be investigated. (J Rheumatol 2004;31:2488–93)

Key Indexing Terms:

JUVENILE RHEUMATOID ARTHRITIS
REPRODUCIBILITY

QUESTIONNAIRES

FOOT JOINTS
RESULTS

Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease in childhood, with synovitis, pain, stiffness, deformity, growth disturbance, and fatigue as main consequences¹. The importance of physical activity for children

with JIA has been stressed, but symptoms may limit the ability to be active²⁻⁴.

Foot involvement is frequently described as a common clinical manifestation of JIA^{5,6}. Foot problems have been categorized as inflammation, limitation of motion, and abnormal alignment. Ninety-four percent of 144 children with JIA examined consecutively had one or more of the categorized foot problems, and inflammation may affect all foot joints. The most common malalignments observed in JIA are the valgus foot, cavovarus foot, and varus heel position⁵.

Ferrari⁷ advocates physiotherapy and splinting as the main conservative treatments for foot deformity in JIA, in conjunction with drug therapy. Although orthoses are frequently prescribed to reduce or prevent deformity and pain, their efficacy has not been scientifically validated.

Optimal treatment of foot related disability may improve the possibilities for physical activity and weight-bearing exercise. To our knowledge there are no reported studies of the outcome of physiotherapy treatment, such as exercise

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and/or orthotics, aimed at improved foot functioning. One reason may be the lack of appropriate outcome measures. Questionnaires for the assessment of foot functioning and disability have been developed for adults with rheumatic disease^{8,9}. However, in pediatric rheumatology there are still no similar questionnaires. General disability questionnaires such as the Childhood Health Assessment Questionnaire (CHAQ)¹⁰ are probably not sensitive enough to capture foot functioning more specifically.

We developed a new questionnaire designed to assess foot related disability among children and adolescents with JIA, and tested it for validity and reliability.

MATERIALS AND METHODS

Participants. Thirty-six children (age < 10 yrs) and adolescents (age ≥ 10 yrs) with JIA diagnosed according to the criteria of the European League of Associations Against Rheumatism (EULAR)¹¹, and with foot arthritis during the previous 6 months, were recruited from a pediatric rheumatology department. Sample I consisted of 7 children and 7 adolescents strategically chosen to represent different ages, sexes, and type, severity and subgroups of JIA. Sample II consisted of 15 children, including 4 from sample I, and 15 adolescents, also including 4 from sample I, recruited consecutively (Table 1). A healthy sample included 29 participants, 15 adolescents and 14 children, matched for age, sex, and social context, recruited among friends and relatives of the participants with JIA (Table 1).

Questionnaire development. Two physical therapists, one experienced in pediatric rheumatology (MA) and the other in adult rheumatology (CHS), developed a new questionnaire, the Juvenile Arthritis Foot Disability Index (JAFI). The content was based on the therapists' clinical experience combined with the content of 2 questionnaires on foot related disability developed for adults with rheumatoid arthritis, the Foot Function Index⁸ and the Sundbom Arthritis Foot Evaluation Index (SAFE)⁹. This process generated 27 statements for a preliminary version of JAFI, and these were divided into 3 dimensions according to the International Classification of Functioning, Disability, and Health (ICF)¹²: Impairment (n = 9), Activity Limitation (n = 14), and Participation Restriction (n = 4). Five-step Likert scales were attached to each statement (0 = never, 1 = occasionally, 2 = sometimes, 3 = frequently, 4 = always). The statements focused on foot related disability the

previous week and the worst foot (Table 2). Total scores for each dimension were calculated as medians for all statements included.

Assessments. All participants were assessed by the same pediatric physical therapist (MA), as follows.

Lower extremity joint impairments in hips, knees, ankles, hind/midfeet, and forefeet were assessed by scoring the presence of (1) capsular swelling or effusion (not for the hips or hind/midfeet), (2) tenderness or pain, and (3) loss of motion. A total score varying from 0 (no impairment) to 26 (maximal impairment) was derived by adding the scores from each joint.

Lower extremity activity limitation was assessed with 4 dimensions, Getting up, Walking, Reaching, and Activities, of the Swedish CHAQ¹⁰. The CHAQ is available in parents' and children's versions. Total score may vary from 0 (no limitation) to 3 (extensive limitation).

Self-rated, foot related restriction of participation was assessed on a verbal rating scale, with 5 answer options from 0 (never) to 4 (always).

Three single questions were used to examine the content of the preliminary JAFI: "Do you think that any of the statements is unnecessary or difficult to understand?", "Should additional statements on other issues you consider important be included?", and "Do you have any other comments on the questionnaire?". The first 2 questions were answered "yes" or "no"; space for comments was available. The third question was open-ended.

Procedure. The children's parents consistently filled out their questionnaires, while the adolescents completed theirs themselves. All questionnaires were filled out at home and mailed to the clinic. The sample I participants answered the 3 questions on the content of the preliminary JAFI. The sample II participants took part in joint impairment assessments, and filled out the CHAQ and the preliminary JAFI on the same day. One week later they filled out the JAFI again and mailed it back to the clinic. The healthy children filled out the JAFI once.

Evaluation of JAFI measurement properties. Nonparametric statistical methods were used for the most part. Descriptive data are presented as medians with ranges. Content validity was secured by using the ICF as a theoretical framework and using input from professionals, parents, and adolescents. Convergent and divergent construct validity were examined by comparing increases in scores for the 3 JAFI dimensions with those for joint impairment (lower extremity), CHAQ (lower extremity), and self-rated, foot related participation restriction (descriptive data). It was hypothesized that changes in joint impairment scores would relate best to those for JAFI impairment, CHAQ (lower extremity) to JAFI activity limitation, and self-rated participation restriction to the JAFI participation restriction.

Table 1. Demographic data on participants in the 3 study samples.

	JIA, Sample I		JIA, Sample II		Control Sample	
	Children, n = 7	Adolescents, n = 7	Children, n = 15	Adolescents, n = 15	Children, n = 14	Adolescents, n = 15
Age, yrs, median (range)	7 (3–9)	12 (11–18)	7 (2–9)	13 (10–19)	8 (3–10)	13 (10–19)
Disease duration, yrs, median (range)	5 (1–8)	4 (1–15)	3 (0–6)	7 (1–15)	NA	NA
Girls, n (%)	5 (72)	5 (72)	13 (87)	14 (93)	10 (71)	14 (93)
Subgroup, Oligo/Poly/JAS, n	3/4/0	3/3/1	6/8/1	4/9/2	NA	NA
Participants with joint impairment in						
Hips/knees, n	NA	NA	3/7	3/3	NA	NA
Ankles, n	NA	NA	11	10	NA	NA
Hindfeet/midfeet, n	NA	NA	12	11	NA	NA
Forefeet, n	NA	NA	6	9	NA	NA
Impairment score: lower extremity 0–26, median (range)	NA	NA	4 (2–15)	7 (0–14)	NA	NA
CHAQ: lower extremity, 0–3, median (range)	NA	NA	0.75 (0–2.25)	0.50 (0–2.00)	NA	NA
Self-rated foot problems, 0–4, median (range)	3 (1–4)	3 (1–4)	3 (0–4)	3 (1–4)	0 (0–1)	0 (0–2)

NA: not assessed, JAS: juvenile ankylosing spondylitis.

Table 2. Instructions for the JAFI and 2 sample items from each of the 3 dimensions Impairment, Activity Limitation, and Participation Restriction.

The below statements concern your foot problems the past week and in your worse foot. There are 5 possible answer alternatives about the frequency of the problems: Never, Occasionally (less than once a week), Sometimes (once a week), Frequently (2–3 times a week), and Always.

I have morning stiffness in my foot/feet.	<input type="checkbox"/> Never	<input type="checkbox"/> Occasionally	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Frequently	<input type="checkbox"/> Always
I have pain in the foot/feet when I put on my shoes.	<input type="checkbox"/> Never	<input type="checkbox"/> Occasionally	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Frequently	<input type="checkbox"/> Always
I interrupt activities and playing because of my foot problems.	<input type="checkbox"/> Never	<input type="checkbox"/> Occasionally	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Frequently	<input type="checkbox"/> Always
I am able to run a short distance (20 meters) without difficulties despite my foot problems.	<input type="checkbox"/> Never	<input type="checkbox"/> Occasionally	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Frequently	<input type="checkbox"/> Always
The foot problems prevent me from participation in physical activities, e.g., physical education at school, dancing, and sports.	<input type="checkbox"/> Never	<input type="checkbox"/> Occasionally	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Frequently	<input type="checkbox"/> Always
The foot problems prevent me from participation in social activities, e.g., excursions, socializing with friends after school, and going to the movies.	<input type="checkbox"/> Never	<input type="checkbox"/> Occasionally	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Frequently	<input type="checkbox"/> Always

Known-groups construct validity was assessed by comparing JAFI answers from participants with JIA and their healthy peers (descriptive data). The calculations of sensitivity, specificity, and positive and negative predictive values¹³ were based on JAFI responses from participants with JIA and their healthy peers. Floor and ceiling effects were considered to be present if 50% of the answers to any item or dimension were assigned 0 or 4, respectively. Test-retest stability was examined by comparing 2 sets of JAFI answers separated by one week. The sign test was used to analyze systematic variations, and the weighted kappa coefficient (K_w) to analyze systematic and random variations. Values 0.41–0.60 were considered moderate, 0.61–0.80 good, and 0.81–1.0 very good¹³.

Internal redundancy and internal consistency were analyzed with Spearman's correlation coefficient (r_s); $r_s > 0.90$ was considered to indicate internal redundancy, and $r_s < 0.50$ to indicate poor internal consistency. The minimum significance level was set to $p < 0.05$.

All the participants gave informed consent and the ethics committee of the Karolinska Hospital, Stockholm, approved the study.

RESULTS

Content validity. All the participants in sample I considered each statement relevant and easy to understand. All participants but one considered the Likert scale easy to understand. An additional scale step was suggested by one adolescent, another had difficulties understanding the concept “physical activity” included in some statements. One parent and one adolescent suggested inclusion of a statement regarding other people's understanding of foot problems. This process resulted in minor linguistic revision and a supplementary statement. Thus, the measurement properties of a 28-statement JAFI were further investigated.

Construct validity. A generally consistent pattern of increasing JAFI scores was found with increasing joint impairment

Table 3. JAFI impairment, activity limitation, and participation restriction scores from 30 participants with JIA categorized according to lower extremity joint impairment score (0–26), lower extremity CHAQ (0–3), and self-rated foot related participation restriction, respectively (0–4).

	Joint Impairment Score: Lower Extremity				
	0 n = 1 md	1–4 n = 13 md	5–8 n = 7 md	> 9 n = 9 md	
Impairment	0	1	2	3	
Activity limitation	1	1	2	3	
Participation restriction	2	1	2	2	
	CHAQ: Lower Extremity				
	0 n = 6 md	0.25–1.0 n = 15 md	1.25–2 n = 7 md	2.25–3 n = 2 md	
Impairment	0	2	2	3.5	
Activity limitation	1	2	2	3.5	
Participation restriction	0	1	2	3.5	
	Self-rated Participation Restriction				
	0 n = 1 md	1 n = 4 md	2 n = 7 md	3 n = 14 md	4 n = 4 md
Impairment	0	0.5	2	3	3.5
Activity limitation	1	0.5	1	3	3.5
Participation restriction	0	0	1	2	3

md: median

scores, CHAQ (lower extremity) scores, and self-rated foot problems. As hypothesized, the JAFI impairment scores increased most pronouncedly with increasing joint impairment scores, the JAFI activity limitation scores increased progressively with increasing CHAQ (lower extremity) scores, and the JAFI participation restriction scores with self-estimated foot related participation restriction (Table 3).

Impairment, activity limitation, and participation restriction were more pronounced in children with JIA than in the healthy controls. This pattern was consistent through all statements for the children as well as for the adolescents. For the subjects with JIA, median values ranged between 1 and 3 for the impairment and the activity limitation statements, and between 0 and 2 for the children and 0 and 3 for the adolescents in participation restriction (Table 4).

Sensitivity and specificity. The sensitivity for single JAFI statements varied between 0.57 and 0.97, while the specificity varied between 0.62 and 1.0. For the 3 JAFI dimen-

sions, sensitivity was 0.83, 0.86, and 0.77, respectively, and specificity 0.93, 0.93, and 1.0, respectively.

Ceiling and floor effects. There were no ceiling effects in any statement. One floor effect was detected in the statement about need for an elevator in school (participation restriction). Further, the statement was indicated as not applicable to 11 of the subjects (no elevator in their school) and more than half of the remaining 19 subjects scored 0.

Reliability. For the participants with JIA no systematic differences in single statements or in total scores were found between 2 sets of JAFI answers separated by one week (sign test, $p > 0.05$). Weighted kappa coefficients for the total scores on the 3 dimensions were 0.90, 0.85, and 0.88. Weighted kappa coefficients for single statements varied between 0.64 and 0.92 in the impairment dimension, between 0.56 and 0.91 in the activity limitation dimension, and between 0.68 and 0.91 in the participation restriction dimension (Table 5).

Table 4. Descriptive JAFI data on 30 participants with JIA and 29 healthy controls. Response range: 0 represents "never" and 4 "always".

Statements	Children		Adolescents	
	JIA, n = 15, median (range)	Control, n = 14, median (range)	JIA, n = 15, median (range)	Control, n = 15, median (range)
Impairment, 0–4				
Morning stiffness	3 (0–4)	0 (0–1)	3 (0–4)	0 (0–0)
Swelling standing/walking	1 (0–4)	0 (0–1)	1 (0–4)	0 (0–2)
Morning pain in bed	2 (0–4)	0 (0–1)	1 (0–4)	0 (0–0)
Pain, front foot	2 (0–4)	0 (0–1)	2 (0–4)	0 (0–2)
Pain, hind foot	3 (0–4)	0 (0–1)	2 (0–4)	0 (0–2)
Pain after activities	3 (0–4)	0 (0–1)	3 (2–4)	0 (0–3)
Pain at putting on shoes	1 (0–4)	0 (0–1)	1 (0–2)	0 (0–0)
Loading the whole foot	2 (0–4)	0 (0–1)	2 (0–4)	0 (0–1)
Foot fatigue when active	2 (0–4)	0 (0–1)	2 (1–4)	0 (0–1)
Impairment, total	2 (0–4)	0 (0–1)	2 (0–4)	0 (0–1)
Activity limitation				
Balance barefoot	1 (0–4)	0 (0–1)	1 (0–4)	0 (0–0)
Balance with shoes	1 (0–4)	0 (0–1)	1 (0–3)	0 (0–0)
Interrupt activity/playing	1 (0–4)	0 (0–0)	2 (0–4)	0 (0–0)
Avoid activity/playing	1 (0–4)	0 (0–0)	2 (0–4)	0 (0–0)
Walk fast	1 (0–4)	0 (0–1)	2 (0–4)	0 (0–1)
Walk barefoot	1 (0–4)	0 (0–1)	2 (0–4)	0 (0–1)
Walk far	3 (0–4)	0 (0–0)	3 (1–4)	0 (0–1)
Walk outdoors	3 (1–4)	0 (0–1)	3 (0–4)	0 (0–1)
Walk stairs	3 (0–4)	0 (0–1)	1 (0–4)	0 (0–1)
Run short distance	2 (0–4)	0 (0–1)	1 (0–4)	0 (0–0)
Run long distance	3 (1–4)	0 (0–1)	3 (0–4)	0 (0–1)
Find comfortable shoes	2 (0–4)	0 (0–3)	2 (0–4)	0 (0–2)
Sadness, foot problems	1 (0–4)	0 (0–1)	2 (0–4)	0 (0–1)
Anxiety, participate activity/playing	2 (0–4)	0 (0–1)	2 (0–4)	0 (0–1)
Activity limitation, total	2 (0–4)	0 (0–1)	2 (0–4)	0 (0–1)
Participation restriction, 0–4				
Restrict physical activity	1 (0–4)	0 (0–0)	2 (0–4)	0 (0–1)
Restrict social activities	0 (0–4)	0 (0–0)	1 (0–3)	0 (0–0)
Need lift/car/bus to preschool/school	2 (0–4)	0 (0–0)	2 (0–4)	0 (0–0)
Need lift in school*	0 (0–3)	0 (0–0)	0 (0–3)	0 (0–0)
Difficulties in understanding from the environment	2 (0–4)	0 (0–0)	3 (0–4)	0 (0–0)
Participation restriction, total	1 (0–4)	0 (0–0)	2 (0–4)	0 (0–0)

* The statement excluded from the suggested JAFI.

Table 5. JAFI scores at one test occasion and at retest one week later for 29 participants with JIA. Response range: 0 represents "never" and 4 "always."

Statements	Test	Retest	Sign test, p	Weighted Kappa Coefficient, K_w
Impairment, 0–4				
Morning stiffness	3 (0–4)	3 (0–4)	NS	0.74
Swelling standing/walking	1 (0–4)	2 (0–4)	NS	0.92
Morning pain in bed	1 (0–4)	1 (0–4)	NS	0.77
Pain, front foot	2 (0–4)	2 (0–4)	NS	0.82
Pain, hind foot	2 (0–4)	3 (0–4)	NS	0.80
Pain after activities	3 (0–4)	3 (0–4)	NS	0.87
Pain at putting on shoes	1 (0–4)	1 (0–4)	NS	0.84
Loading the whole foot	2 (0–4)	2 (0–4)	NS	0.86
Foot fatigue when active	2 (0–4)	2 (0–4)	NS	0.64
Impairment, total	2 (0–4)	2 (0–4)	NS	0.90
Activity limitation, 0–4				
Balance barefoot	1 (0–4)	1 (0–4)	NS	0.77
Balance with shoes	1 (0–4)	1 (0–4)	NS	0.84
Interrupt activity/playing	2 (0–4)	2 (0–4)	NS	0.72
Avoid activity/playing	2 (0–4)	2 (0–4)	NS	0.74
Walk fast	2 (0–4)	2 (0–4)	NS	0.65
Walk barefoot	1 (0–4)	1 (0–4)	NS	0.65
Walk far	3 (0–4)	3 (0–4)	NS	0.56
Walk outdoors	3 (0–4)	2 (0–4)	NS	0.66
Walk stairs	1.5 (0–4)	1 (0–4)	NS	0.86
Run short distance	1.5 (0–4)	1 (0–4)	NS	0.73
Run long distance	3 (0–4)	3 (0–4)	NS	0.80
Find comfortable shoes	2 (0–4)	2 (0–4)	NS	0.90
Sadness, foot problems	2 (0–4)	2 (0–4)	NS	0.91
Anxiety, participate activity/playing	2 (0–4)	2 (0–4)	NS	0.91
Activity limitation, total	2 (0–4)	2 (0–4)	NS	0.85
Participation restriction, 0–4				
Restrict physical activity	2 (0–4)	2 (0–4)	NS	0.83
Restrict social activities	1 (0–4)	0 (0–4)	NS	0.68
Need lift/car/bus to preschool/school	2 (0–4)	1 (0–4)	NS	0.91
Need lift in school*	0 (0–3)	0 (0–4)	NS	0.89
Poor understanding from environment	3 (0–4)	3 (0–4)	NS	0.85
Participation restriction, total	2 (0–4)	1 (0–4)	NS	0.88

* The statement excluded from the suggested JAFI. NS: nonsignificant ($p > 0.05$).

Internal redundancy and internal consistency. Within each JAFI dimension, no statement correlated above $r_s = 0.90$ with any other statement. All statements except 2 for impairment, one for activity limitation, and one for participation restriction correlated above $r_s = 0.50$ with its dimension's total score. The nonconsistent statements were those about balance difficulties, finding comfortable shoes, and poor understanding from the environment (data not shown).

Suggestions for the JAFI. The participation restriction item on need for an elevator in school was deleted. Thus, a 27 item JAFI consisting of 3 dimensions including 9, 14, and 4 statements, respectively, is suggested for further evaluation.

DISCUSSION

Our results indicate that the JAFI questionnaire is a valid and reliable measure for the assessment of foot related disability among children and adolescents with JIA. It might be useful for the assessment of physiotherapy treatment outcomes, but also for other local treatments such as intraartic-

ular corticosteroid injections or surgery. A similar measure, the Foot Function Index, is used as a primary outcome measure in adult rheumatology to determine foot related disability from the patient's perspective¹⁴.

Most participants considered the statements of the preliminary JAFI to be relevant. Similar suggestions from 2 participants resulted in the addition of one statement about understanding from one's environment, which later performed well in the analyses. One statement about elevator use in school was dropped due to poor performance: the statement about walking up and down stairs evaluates the ability to move between floors. Thus, the content validity of the JAFI is probably satisfactory.

As for construct validity, our hypotheses about relations between the 3 JAFI dimensions and other measures of impairment, activity limitation, and participation restriction, respectively, were generally confirmed. Our finding that the children/adolescents with JIA scored higher on each statement than the group of healthy peers indicates that the JAFI

does not assess general “disability” among growing children and adolescents. Sensitivity and specificity values indicate that the JAFI is sensitive enough to record foot related disability among children with JIA, but still specific enough to exclude individuals without this condition. It might be argued that foot disability may be hard to separate from other lower extremity disability. However, our impression is that this was not a major problem for our participants as each JAFI statement is explicitly focused on foot problems. Nevertheless, in future studies it would be of interest to investigate whether the JAFI is also specific enough to discriminate between those with lower extremity problems with and without foot involvement.

Test-retest reliability of the JAFI statements and dimensions was generally good or very good. However, one statement about the possibility to walk as far as one wanted performed less well ($K_w = 0.56$). This was not the case with statements specifying a walking distance or a certain skill. Thus, we believe that variations in emotional state between test and retest might have influenced the stability rather than the wording of the question. Our decision to retain the 3 nonconsistent items was based on them performing well in all other aspects tested.

The administration of questionnaires to children always requires special attention, as the development of writing and reading skills might vary for the same age. While it is still important to be able to evaluate treatment outcome among younger children, parents were involved in the development of the JAFI. It has also been found that parents are able to rate their children’s disease consequences well¹⁵. To ensure that all adolescents in our study had appropriate reading, writing, and cognitive skills, the cutoff age was set at 10 years. While a 7-grade Likert scale might have been optimal from a statistical viewpoint, we considered a 5-grade scale best suited for adolescents.

Pediatric rehabilitation, also in rheumatology, has developed from hands-on treatment to a wide range of interventions aimed at improving patients’ skills to cope with everyday life. This is also true in physical therapy and the need for physical activity in the JIA population has recently been stressed⁴. The development of new treatment also necessitates the development and use of outcome measures other than single tests of impairment. The ICF as a base for the development of the JAFI gives clinicians and researchers a possibility for comprehensive outcome assessment of various interventions.

The JAFI needs to be tested further for sensitivity to change for various interventions. While it has been developed and validated in Sweden, translation and cross-cultural adaptation will be needed before it can be used in other countries¹⁶.

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