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The Flemish version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR)

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Abstract

The Juvenile Arthritis Multidimensional Assessment Report (JAMAR) is a new parent/patient reported outcome measure that enables a thorough assessment of the disease status in children with juvenile idiopathic arthritis (JIA). We report the results of the cross-cultural adaptation and validation of the parent and patient versions of the JAMAR in the Flemish language. The reading comprehension of the questionnaire was tested in 10 JIA parents and patients. Each participating centre was asked to collect demographic, clinical data and the JAMAR in 100 consecutive JIA patients or all consecutive patients seen in a 6-month period and to administer the JAMAR to 100 healthy children and their parents. The statistical validation phase explored descriptive statistics and the psychometric issues of the JAMAR: the 3 Likert assumptions, floor/ceiling effects, internal consistency, Cronbach's alpha, interscale correlations, test–retest reliability, and construct validity (convergent and discriminant validity). A total of 100 JIA patients (8% systemic, 33% oligoarticular, 24% RF negative polyarthritis, 35% other categories) and 99 healthy children, were enrolled in two centres. The JAMAR components discriminated well healthy subjects from JIA patients. All JAMAR components revealed good psychometric performances. In conclusion, the Flemish version of the JAMAR is a valid tool for the assessment of children with JIA and is suitable for use both in routine clinical practice and clinical research.

Keywords Juvenile idiopathic arthritis · Disease status · Functional ability · Health related quality of life · JAMAR

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Introduction

The aim of the present study was to cross-culturally adapt and validate the Flemish parent, child/adult version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) [1] in patients with juvenile idiopathic arthritis (JIA). The JAMAR assesses the most relevant parent/patient reported outcomes in JIA, including overall well-being, functional status, health related quality of life (HRQoL), pain, morning stiffness, disease activity/status/course, articular and extra-articular involvement, drug-related side effects/compliance and satisfaction with illness outcome.

This project was part of a larger multinational study conducted by the Paediatric Rheumatology International Trials Organisation (PRINTO) [2] aimed to evaluate the epidemiology, outcome and treatment of childhood arthritis (EPOCA) in different geographic areas [3].

We report herein the results of the cross-cultural adaptation and validation of the parent and patient versions of the JAMAR in the Flemish language.

Materials and methods

The methodology employed has been described in detail in the introductory paper of the supplement [4]. In brief, it was a cross-sectional study of JIA children, classified according to the ILAR criteria [5, 6] and enrolled from December 2015 to March 2016. Children were recruited after Ethics Committee approval and consent from at least one parent.

The JAMAR

The JAMAR [1] includes the following 15 sections:

1. Assessment of physical function (PF) using 15-items in which the ability of the child to perform each task is scored as follows: 0 = without difficulty, 1 = with some difficulty, 2 = with much difficulty, 3 = unable to do and not applicable if it was not possible to answer the question or the patient was unable to perform the task due to their young age or to reasons other than JIA. The total PF score ranges from 0 to 45 and has 3 components: PF-lower limbs (PF-LL); PF-hand and wrist (PF-HW) and PF-upper segment (PF-US) each scoring from 0 to 15 [7]. Higher scores indicating higher degree of disability [8–10];
2. Rating of the intensity of the patient's pain on a 21-numbered circle visual analogue scale (VAS) [11];
3. Assessment of the presence of joint pain or swelling (present/absent for each joint);
4. Assessment of morning stiffness (present/absent);
5. Assessment of extra-articular symptoms (fever and rash) (present/absent);
6. Rating of the level of disease activity on a 21-numbered circle VAS;
7. Rating of disease status at the time of the visit (categorical scale);
8. Rating of disease course from previous visit (categorical scale);
9. Checklist of the medications the patient is taking (list of choices);
10. Checklist of side effects of medications;
11. Report of difficulties with medication administration (list of items);
12. Report of school/university/work problems caused by the disease (list of items);
13. Assessment of HRQoL, through the Physical Health (PhH), and Psychosocial Health (PsH) subscales (5 items each) and a total score. The four-point Likert response, referring to the prior month, are 'never' (score = 0), 'sometimes' (score = 1), 'most of the time' (score = 2) and 'all the time' (score = 3). A 'not assessable' column was included in the parent version of the questionnaire to designate questions that cannot be answered because of developmental immaturity. The total HRQoL score ranges from 0 to 30, with higher scores indicating worse HRQoL. A separate score for PhH and PsH (range 0–15) can be calculated [12–14];
14. Rating of the patient's overall well-being on a 21-numbered circle VAS;
15. A question about satisfaction with the outcome of the illness (Yes/No) [15].

The JAMAR is available in three versions, one for parent proxy-report (child's age 2–18), one for child self-report, with the suggested age range of 7–18 years, and one for adults.

Cross cultural adaptation and validation

The process of cross-cultural adaptation was conducted according to international guidelines with 2–3 forward and backward translations. In those countries for which the translation of JAMAR had been already cross-cultural adapted in a similar language (i.e. Spanish in South American countries), only the probe technique was performed. Reading comprehension and understanding of the translated questionnaires were tested in a probe sample of 10 JIA parents and 10 patients.

Each participating centre was asked to collect demographic, clinical data and the JAMAR in 100 consecutive JIA patients or all consecutive patients seen in a 6-month period and to administer the JAMAR to 100 healthy children and their parents.

The statistical validation phase explored the descriptive statistics and the psychometric issues [16]. In particular, we evaluated the following validity components: the first Likert assumption [mean and standard deviation (SD) equivalence]; the second Likert assumption or equal items-scale correlations (Pearson r: all items within a scale should contribute equally to the total score); third Likert assumption (item internal consistency or linearity for which each item of a scale should be linearly related to the total score that is 90% of the items should have Pearson $r \geq 0.4$); floor/ceiling effects (frequency of items at lower and higher extremes of the scales, respectively); internal consistency, measured by the Cronbach's alpha, interscale correlation (the correlation between two scales should be lower than their reliability coefficients, as measured by Cronbach's alpha); test–retest reliability or intra-class correlation coefficient (reproducibility of the JAMAR repeated after 1 or 2 weeks); and construct validity in its two components: the convergent or external validity which examines the correlation of the JAMAR subscales with the 6 JIA core set variables, with the addition of the parent assessment of disease activity and pain by the Spearman's correlation coefficients (*r*) [17] and the discriminant validity, which assesses whether the JAMAR discriminates between the different JIA categories and healthy children [18]. Test–retest reliability of the Flemish version of the JAMAR was not assessed.

Quantitative data were reported as medians with 1st and 3rd quartiles and categorical data as absolute frequencies and percentages.

The complete Flemish parent and patient versions of the JAMAR are available upon request to PRINTO.

Results

Cross cultural adaptation

The Flemish JAMAR was cross-culturally adapted from the Dutch version.

All 123 lines of the parent version of the JAMAR were understood by at least 80% of the 10 parents tested (median = 100%; range 90–100%). All the 120 lines of the patient version of the JAMAR were understood by at least 80% of the children (median = 100%; range 80–100%). The parent and child versions of the Flemish JAMAR were unmodified after the probe technique.

Demographic and clinical characteristics of the subjects

A total of 100 JIA patients and 99 healthy children (total of 199 subjects), were enrolled at two paediatric rheumatology centres.

In the 100 JIA subjects, the JIA categories were 8% with systemic arthritis, 33% with oligoarthritis, 24% with RF negative polyarthritis, 2% with RF positive polyarthritis, 6% with psoriatic arthritis, 13% with enthesitis related arthritis and 14% with undifferentiated arthritis (Table 1).

A total of 189/199 (95%) subjects had the parent version of the JAMAR completed by a parent (90 from parents of JIA patients and 99 from parents of healthy children). The JAMAR was completed by 163/189 (86.2%) mothers and 26/189 (13.8%) fathers. The child version of the JAMAR was completed by 98/199 (49.2%) children age 6.5 or older. Also patients younger than 7 years old, capable to assess their personal condition and able to read and write, were asked to fill in the patient version of the questionnaire.

Discriminant validity

The JAMAR results are presented in Table 1, including the scores [median (1st–3rd quartile)] obtained for the PF, the PhH, the PsH subscales and total score of the HRQoL scales. The JAMAR components discriminated well between healthy subjects and JIA patients. In summary, the JAMAR revealed that JIA patients had a greater level of disability and pain, as well as a lower HRQoL than their healthy peers.

Psychometric issues

The main psychometric properties of both parent and child versions of the JAMAR are reported in Table 2. The following "Results" section refers mainly to the parent's version findings, unless otherwise specified.

Descriptive statistics (first Likert assumption)

For all JAMAR items, the median number of missing responses were 1.1% (0.6–3.3%).

The response pattern for both PF and HRQoL was positively skewed toward normal functional ability and normal HRQoL. All response choices were used for the different HRQoL items except items 6, 7, 8 and 10, whereas a reduced number of response choices was used for all the PF items except items 1, 3, 8 and 10.

The mean and SD of the items within a scale were roughly equivalent for the PF and for the HRQoL items (data not shown). The median number of items marked as not applicable was 1% (0–1%) for the PF and 2.5% (1–4%) for the HRQoL.

Table 1 Descriptive statistics (medians, 1st 3rd quartiles or absolute frequencies and %) for the 100 JIA patients

	Systemic	Oligoar-thritis	RF− Poly-arthritis	RF+ Poly-arthritis	Psoriatic arthritis	Enthesitis related arthritis	Undif-ferentiated arthritis	All JIA patients	Healthy
	N = 8	N = 33	N = 24	N = 2	N = 6	N = 13	N = 14	N = 100	N = 99
Female	6 (75%)	30 (90.9%)	18 (75%)	2 (100%)	5 (83.3%)	3 (23.1%)	8 (57.1%)	72 (72%)**	48 (48.5%)**
Age at visit	13.9 (10.4–14.9)	10.6 (6–14.7)	10.6 (6.6–15.1)	13.1 (8.6–17.6)	14.1 (12.8–15.2)	15.4 (13.9–16.2)	11.3 (10.5–14.2)	12.6 (8.5–15)*	10.9 (7.5–14.4)
Age at onset	9.1 (3–14)	3.6 (1.8–8.7)	5 (1.6–9)	6.1 (5.7–6.5)	11.6 (10.6–13.8)	12.7 (10.3–14.1)	3.8 (1.7–9.6)	6.1 (1.9–10.7)#	
Disease duration	3.4 (0.7–6.5)	3.3 (1.4–6.5)	4.7 (1.6–7)	7 (2.1–12)	2 (1.2–4.2)	2.8 (1.1–4.8)	7.1 (1–8.7)	3.9 (1.4–6.7)	
ESR	1.9 (1–7)	4 (3–15)	5 (3–8)	2 (2–2)	10 (4–14.5)	2 (1–7)	7 (2–18)	4 (2–9)	
MD VAS (0–10 cm)	0 (0–1)	0 (0–1)	0.3 (0–2.3)	2 (1–3)	1.8 (0–3.5)	1 (0–2)	2 (0–2.5)	0 (0–2)	
No. swollen joints	0 (0–0)	0 (0–0)	0 (0–1.5)	0 (0–0)	0 (0–0)	0 (0–0)	0 (0–2)	0 (0–0)	
No. joints with pain	0 (0–0)	0 (0–1)	0 (0–2)	13 (5–21)	1 (0–2)	1 (0–2)	1 (0–3)	0 (0–2)*	
No. joints with LOM	0 (0–1.5)	0 (0–1)	0 (0–1.5)	6 (1–11)	0 (0–0)	0 (0–1)	0 (0–2)	0 (0–1)	
No. active joints	0 (0–0)	0 (0–1)	0 (0–2)	5.5 (0–11)	0 (0–0)	0 (0–1)	0 (0–2)	0 (0–1)	
Active systemic features	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (7.1%)	1 (1%)	
ANA status	0 (0%)	9 (27.3%)	9 (37.5%)	0 (0%)	1 (16.7%)	0 (0%)	6 (42.9%)	25 (25%)	
Uveitis	0 (0%)	8 (24.2%)	5 (20.8%)	0 (0%)	0 (0%)	0 (0%)	2 (14.3%)	15 (15%)	
PF Total Score	1 (0–1)	0 (0–3)	0.5 (0–3)	3.5 (3–4)	2 (1–5)	0 (0–6)	1.5 (0–10)	1 (0–4)	0 (0–0)#
Pain VAS	0.3 (0–1.5)	0 (0–2.5)	2.3 (0.5–3.5)	6.8 (6–7.5)	3.5 (3–7)	2.5 (0.5–6)	1.5 (0–6.5)	1.3 (0–5)	0 (0–0)#
Disease activity VAS	0.3 (0–0.5)	0 (0–3.5)	1 (0–4)	5.8 (4–7.5)	3.5 (3–4)	1.5 (0.5–5)	1 (0–5.5)	1 (0–5)	
Well-being VAS	0.5 (0–1)	0 (0–1)	1.5 (0.5–4)	6.5 (6–7)	5 (3–6.5)	3.5 (0.5–6.5)	1 (0–5)	1 (0–5)*	
HRQoL PhH	0.5 (0–3)	1 (0–3)	1 (0–5)	5 (5–5)	7 (2–9)	4 (0–7)	5.5 (0–9)	2 (0–5)	0 (0–0)#
HRQoL PsH	1 (0–2)	0.5 (0–2)	1 (0–4)	2 (0–4)	1 (1–3)	1 (0–3)	0.5 (0–3)	1 (0–2)	0 (0–0)#
HRQoL total score	2 (1–3)	2 (0–5)	3.5 (1–9)	7.5 (6–9)	8 (3–12)	4 (0–12)	5.5 (1–11)	3 (1–8)	0 (0–1)#
Pain/swell. in > 1 joint	3/6 (50%)	11/30 (36.7%)	8/22 (36.4%)	2 (100%)	4/5 (80%)	7/11 (63.6%)	8 (57.1%)	43/90 (47.8%)	6 (6.1%)#
Morning stiffness > 15 min	0 (0%)	5/29 (17.2%)	4/22 (18.2%)	2 (100%)	2/5 (40%)	2/11 (18.2%)	6 (42.9%)	21/89 (23.6%)**	2 (2%)#
Subjective remission	1/6 (16.7%)	12/30 (40%)	10/22 (45.5%)	2 (100%)	2/4 (50%)	5/10 (50%)	6/12 (50%)	38/86 (44.2%)	
In treatment	5/5 (100%)	20/30 (66.7%)	19/22 (86.4%)	2 (100%)	4/4 (100%)	10/11 (90.9%)	10/12 (83.3%)	70/86 (81.4%)	
Reporting side effects	2/5 (40%)	2/20 (10%)	6/19 (31.6%)	1 (50%)	0 (0%)	5/10 (50%)	4/9 (44.4%)	20/69 (29%)	
Taking medication regularly	4/5 (80%)	20/20 (100%)	17/19 (89.5%)	1 (50%)	4/4 (100%)	9/10 (90%)	9/10 (90%)	64/70 (91.4%)	

Table 1 (continued)

	Systemic	Oligoar-thritis	RF− Poly-arthritis	RF+ Poly-arthritis	Psoriatic arthritis	Enthesitis related arthritis	Undif-ferentiated arthritis	All JIA patients	Healthy
	$N=8$	$N=33$	$N=24$	$N=2$	$N=6$	$N=13$	$N=14$	$N=100$	$N=99$
With problems attending school	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2/3 (66.7%)	3/10 (30%)	0 (0%)	5/61 (8.2%)**	1 (1.1%)*
Satisfied with disease outcome	6 (100%)	21 (77.8%)	16 (76.2%)	1 (50%)	3 (60%)	7 (63.6%)	7 (53.8%)	61 (71.8%)	

Data related to the JAMAR refers to the 90 JIA patients and to the 99 healthy subjects for whom the questionnaire has been completed by the parents

JAMAR Juvenile Arthritis Multidimensional Assessment Report, *ESR* erythrocyte sedimentation rate, *MD* medical doctor, *VAS* visual analogue scale (score 0–10; 0 = no activity, 10 = maximum activity), *LOM* limitation of motion, *ANA* anti-nuclear antibodies, *PF* physical function (total score ranges from 0 to 45), *HRQoL* health related quality of life (total score ranges from 0 to 30), *PhH* physical health (total score ranges from 0 to 15), *PsH* psychosocial health (total score ranges from 0 to 15)

p values refers to the comparison of the different JIA categories or to JIA versus healthy. $*p < 0.05$ $**p < 0.001$ $^{\#}p < 0.0001$

Floor and ceiling effect

The median floor effect was 86.7% (80–92.2%) for the PF items, 55.6% (47.8–66.7%) for the HRQoL PhH items, and 65.6% (64.4–70%) for the HRQoL PsH items. The median ceiling effect was 0% (0–1.1%) for the PF items, 4.4% (4.4–10%) for the HRQoL PhH items, and 0.0% (0–0%) for the HRQoL PsH items. The median floor effect was 38.9% for the pain VAS, 34.4% for the disease activity VAS and 32.2% for the well-being VAS. The median ceiling effect was 0% for the pain VAS, 0% for the disease activity VAS and 0% for the well-being VAS.

Equal items-scale correlations (second Likert assumption)

Pearson items-scale correlations corrected for overlap were roughly equivalent for items within a scale for 87% of the PF items, with the exception of items 11 and 15, and for 90% of the HRQoL items, with the exception of item 1.

Items internal consistency (third Likert assumption)

Pearson items-scale correlations were ≥ 0.4 for 93% of items of the PF (except for PF item 15) and 100% of items of the HRQoL.

Cronbach's alpha internal consistency

Cronbach's alpha was 0.86 for PF-LL, 0.89 for PF-HW, 0.74 for PF-US. Cronbach's alpha was 0.86 for HRQoL-PhH and 0.76 for HRQoL-PsH.

Interscale correlation

The Pearson correlation of each item of the PF and the HRQoL with all items included in the remaining scales of the questionnaires was lower than the Cronbach's alpha, with the exception of Pf items 12, 13 and 14 and HRQoL item 3.

Convergent validity

The Spearman correlation of the PF total score with the JIA core set of outcome variables ranged from 0.3 to 0.6 (median = 0.4). The PF total score best correlation was observed with the parent assessment of pain ($r = 0.6$, $p < 0.001$). For the HRQoL, the median correlation of the PhH with the JIA core set of outcome variables ranged from 0.3 to 0.8 (median = 0.4), whereas for the PsH ranged from 0.1 to 0.4 (median = 0.2). The PhH showed the best correlation with the parent's assessment of pain ($r = 0.8$, $p < 0.001$) and the PsH with the parent global assessment of well-being ($r = 0.5$, $p < 0.001$). The median correlations between the pain VAS, the well-being VAS, and the disease activity VAS and the physician-centred and laboratory measures were 0.3 (0.1–0.4), 0.2 (0.1–0.3), 0.4 (0.2–0.5), respectively.

Discussion

In this study, the Flemish version of the JAMAR is the result of the local adaptation of the translation in Dutch performed by the PRINTO centre in the Netherlands. According to the results of the validation analysis, the Flemish parent and patient versions of the JAMAR possess satisfactory

Table 2 Main psychometric characteristics between the parent and child version of the JAMAR

	Parent $N = 90/189$	Child $N = 53/98$
Missing values (1st–3rd quartiles)	1.1% (0.6–3.3%)	3.8% (1.9–5.7%)
Response pattern	PF and HRQoL positively skewed	PF and HRQoL positively skewed
Floor effect, median		
PF	86.7%	90.6%
HRQoL PhH	55.6%	60.4%
HRQoL PsH	65.6%	73.6%
Pain VAS	38.9%	34.0%
Disease activity VAS	34.4%	28.3%
Well-being VAS	32.2%	34.0%
Ceiling effect, median		
PF	0.0%	0.0%
HRQoL PhH	4.4%	1.9%
HRQoL PsH	0.0%	0.0%
Pain VAS	0.0%	0.0%
Disease activity VAS	0.0%	0.0%
Well-being VAS	0.0%	0.0%
Items with equivalent item-scale correlation	87% for PF, 90% for HRQoL	87% for PF, 80% for HRQoL
Items with items-scale correlation ≥ 0.4	93% for PF, 100% for HRQoL	80% for PF, 80% for HRQoL
Cronbach's alpha		
PF-LL	0.86	0.81
PF-HW	0.89	0.65
PF-US	0.74	0.87
HRQoL-PhH	0.86	0.81
HRQoL-PsH	0.76	0.74
Items with item-scale correlation lower than the Cronbach alpha	80% for PF, 90% for HRQoL	100% for PF, 100% for HRQoL
Spearman correlation with JIA core-set variables, median		
PF	0.4	0.4
HRQoL PhH	0.4	0.5
HRQoL PsH	0.2	0.3
Pain VAS	0.3	0.3
Disease activity VAS	0.2	0.3
Well-being VAS	0.4	0.4

JAMAR Juvenile Arthritis Multidimensional Assessment Report, *JIA* juvenile idiopathic arthritis, *VAS* visual analogue scale, *PF* physical function, *HRQoL* health related quality of life, *PhH* physical health, *PsH* psychosocial health, *PF-LL* PF-lower limbs, *PF-HW* PF-hand and wrist, *PF-US* PF-upper segment

psychometric properties. The disease-specific components of the questionnaire discriminated well between patients with JIA and healthy controls.

Psychometric performances were good for all domains of the JAMAR with few exceptions: 1 PF item ("Bite into a sandwich or an apple") showed a lower items internal consistency. However, the overall internal consistency was good for all the domains, with the exception of PF-US and HRQoL-PsH that were acceptable.

In the external validity evaluation, the Spearman's correlations of the PF and HRQoL scores with JIA core set parameters ranged from week to moderate.

The results obtained for the parent version of the JAMAR are very similar to those obtained for the child version, which suggests that children are equally reliable proxy reporters of their disease and health status as their parents.

Test–retest reliability was not assessed in this patient sample.

The JAMAR is aimed to evaluate the side effects of medication and school attendance, which are other dimensions of daily life that were not previously considered by other HRQoL tools. This may provide useful information for intervention and follow-up in health care. In conclusion, the Flemish version of the JAMAR was found to have satisfactory psychometric properties and it is, thus, a reliable and

valid tool for the multidimensional assessment of children with JIA.

Compliance with ethical standards

Conflict of interest Dr. Ruperto has received grants from BMS, Hoffman-La Roche, Janssen, Novartis, Pfizer, Sobi, during the conduct of the study and personal fees and speaker honorarium from Abbvie, Ablynx, Amgen, AstraZeneca, Baxalta Biosimilars, Biogen Idec, Boehringer, Bristol Myers Squibb, Celgene, Eli-Lilly, EMD Serono, Gilead Sciences, Janssen, Medimmune, Novartis, Pfizer, Rpharm, Roche, Sanofi, Servier and Takeda. Dr Lahdenne, Dr Vahasalo and Dr Kroger report funding support from Istituto Giannina Gaslini, Genoa, Italy, for the translation and data collection performed at their sites within the EPOCA project., Dr. Consolaro, Dr. Bovis, Dr Dehoorne, Dr Joos, Dr Wouters and Dr Swart have nothing to disclose in relation to this manuscript.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study as per the requirement of the local ethical committee.

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