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

Taciana A. Pedrosa Fernandes¹ · Claudia Saad Magalhães¹ · Sheila Knupp Oliveira² · Flavio Sztajnbok³ · Juliana de Oliveira Sato¹ · Layla Saba Darze³ · Rozana Gasparello de Almeida³ · Alessandro Consolaro⁴,⁵ · Juliana de Oliveira Sato¹ · Layla Saba Darze³ · Rozana Gasparello de Almeida³ · Alessandro Consolaro⁴,⁵ · Francesca Bovis⁴ · Nicolino Ruperto⁴ · For the Paediatric Rheumatology International Trials Organisation (PRINTO)

Received: 22 December 2017 / Accepted: 11 January 2018 © The Author(s) 2018. This article is an open access publication

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 Brazilian Portuguese 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 three 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 231 JIA patients (14.7% systemic, 43.3% oligoarticular, 22.5% RF negative polyarthritis, 19.5% other categories) and 72 healthy children, were enrolled in three centres. The JAMAR components discriminated well healthy subjects from JIA patients. All JAMAR components revealed good psychometric performances. In conclusion, the Brazilian Portuguese 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

Introduction
The aim of the present study was to cross-culturally adapt and validate the Brazilian Portuguese 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 Brazilian Portuguese 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 May 2012 to May 2015. 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 three 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-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 (five 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 applicable’ 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 at least ten JIA parents and ten 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].

Quantitative data were reported as medians with first and third quartiles and categorical data as absolute frequencies and percentages.

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

**Results**

**Cross cultural adaptation**

The Brazilian Portuguese JAMAR was cross-culturally adapted from the British English version with three forward and two backward translations with a concordance for 115/123 (93.5%) translations lines for the parent version and 116/120 (96.7%) lines for the child version.

In the probe technique analysis, 120/123 (97.6%) lines of the parent version of the JAMAR were understood by at least 80% of the 10 parents tested (median 100%; range 70–100%) and 117/120 (97.5%) lines of the patient version of the JAMAR were understood by at least 80% of the children (median 100%; range 70–100%). Lines 52, 53, and 77 of the parent version of the JAMAR and lines 50, 51, and 75 were modified according to parents’ and patients’ suggestions, respectively.

**Demographic and clinical characteristics of the subjects**

A total of 231 JIA patients and 72 healthy children (total of 303 subjects), were enrolled at three paediatric rheumatology centres. In the 231 JIA subjects, the JIA categories were 14.7% systemic arthritis, 43.3% oligoarthritis, 22.5% RF negative polyarthritis, 4.8% RF positive polyarthritis, 1.7% psoriatic arthritis, 10.8% enthesitis related arthritis and 2.2% undifferentiated arthritis (Table 1).

A total of 296/303 (97.7%) subjects had the parent version of the JAMAR completed by a parent (226 from parents of JIA patients and 70 from parents of healthy children). The JAMAR was completed by 256/296 (86.5%) mothers and 40/296 (13.5%) fathers. The child version of the JAMAR was completed by 265/303 (87.5%) children age 6.0 years 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 (first–third 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, unless otherwise specified, refers mainly to the parent’s version findings.

**Descriptive statistics (first Likert assumption)**

There were no missing results for all JAMAR items, since data were collected through a web-based system that did not allow to skip answers and input null values. 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 for item 8, whereas a reduced number of response choices was used for PF item 15.

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 4% (3–6%) for the HRQoL.

**Floor and ceiling effect**

The median floor effect was 87.2% (80.5–88.5%) for the PF items, 72.6% (65.0–74.3%) for the HRQoL PhH items, and 66.8% (64.2–70.8%) for the HRQoL PsH items. The median ceiling effect was 0.9% (0.9–2.7%) for the PF items, 4.0% (2.7–4.0%) for the HRQoL PhH items, and 3.1% (2.2–3.5%) for the HRQoL PsH items. The median floor effect was 57.5% for the pain VAS, 51.3% for the disease activity VAS and 55.7% for the well-being VAS. The median ceiling effect was 1.8% for the pain VAS, 0.4% for the disease activity VAS and 1.3% for the well-being VAS.
Table 1  Descriptive statistics (medians first third quartiles or absolute frequencies and %) for the 231 JIA patients

|                      | Systemic | Oligoarthritis | RF − polyarthitis | RF + polyarthitis | Psoriatic arthritis | Enthesitis related arthritis | Undifferentiated arthritis | All JIA patients | Healthy |
|----------------------|----------|----------------|-------------------|-------------------|---------------------|----------------------------|--------------------------|------------------|---------|
|                      | N=34     | N=100          | N=52              | N=11              | N=4                 | N=25                       | N=5                      | N=231           | N=72    |
| Female               | 18 (52.9%) | 72 (72%)      | 36 (69.2%)        | 8 (72.7%)         | 3 (75%)             | 2 (8%)                     | 2 (40%)                   | 141 (61%)       | 45 (62.5%) |
| Age at visit         | 13.5 (10.3–16.5) | 12 (9.1–15)   | 11.5 (8.7–14.6)   | 14.6 (12.8–17.3)  | 13.2 (11.6–14.7)   | 14.7 (12.6–17.1)           | 8.9 (7–13.9)          | 13.1 (9.8–15.3)* | 12.1 (9.4–14.6) |
| Age at onset         | 7.6 (4.3–11.6) | 5.5 (2.7–9.7) | 5.3 (2.6–9.1)     | 8.9 (6.9–12.6)    | 8.4 (6.9–10.8)      | 8.7 (6–9.9)                | 6.6 (3.7–6.7)          | 6.4 (3–9.8)*    |         |
| Disease duration     | 3.4 (1.4–7.7) | 4.9 (2.3–7.9) | 4.5 (1.7–8.6)     | 4.7 (2.2–7.6)     | 4.7                  | 5.3 (4.1–9.2)              | 3.2 (2.1–3.3)          | 4.7             | (2.1–8.1) |
| ESR                  | 13 (8–33) | 9 (4–23)      | 14 (6–23)         | 22.5 (15–40)      | 11 (6–15)           | 10 (4–20)                  | 10 (7–13)              | 11 (5–23)       |         |
| MD VAS (0–10 cm)     | 0 (0–4)  | 0 (0–1)       | 1 (0–4)           | 4 (1.5–7)         | 0 (0–2)             | 0 (0–2)                    | 0 (0–0)                 | 0 (0–2)*        |         |
| No. swollen joints   | 0 (0–2)  | 0 (0–1)       | 1 (0–4)           | 2 (0–7)           | 1 (0–3)             | 0 (0–2)                    | 0 (0–0)                 | 0 (0–2)*        |         |
| No. joints with pain | 0 (0–2)  | 0 (0–0)       | 1 (0–3)           | 1 (0–5)           | 0 (0–1)             | 0 (0–0)                    | 0 (0–0)                 | 0 (0–1)*        |         |
| No. joints with LOM  | 0 (0–5)  | 0 (0–0)       | 1 (0–7)           | 4 (2–20)          | 0.5 (0–2.5)         | 0 (0–1)                    | 0 (0–0)                 | 0 (0–2)*        |         |
| No. active joints    | 0 (0–2)  | 0 (0–1)       | 2 (0–4.5)         | 4 (1–7)           | 1 (0–3)             | 0 (0–2)                    | 0 (0–0)                 | 0 (0–2)*        |         |
| Active systemic features | 3 (8.8%) | 0 (0%)        | 0 (0%)            | 0 (0%)            | 0 (0%)              | 0 (0%)                     | 0 (0%)                  | 3 (1.3%)*       |         |
| ANA status           | 1 (2.9%) | 20 (20%)      | 7 (13.5%)         | 1 (9.1%)          | 0 (0%)              | 0 (0%)                     | 1 (20%)                 | 30 (13%)        |         |
| Uveitis              | 1 (2.9%) | 15999 (15.2%) | 2 (3.8%)          | 0 (0%)            | 0 (0%)              | 1 (4%)                     | 0 (0%)                  | 19229 (8.3%)    |         |
| PF Total Score       | 2 (0–7)  | 0 (0–3)       | 2 (0–5)           | 6 (0–12)          | 1.5 (0.5–2.5)       | 0 (0–3)                    | 1 (0–1)                 | 1 (0–4)         | 0 (0–0)* |
| Pain VAS             | 0.3 (0–4) | 0 (0–1.3)    | 1 (0–2.5)         | 0.5 (0–3.5)       | 0.5 (0–0.5)         | 0 (0–4)                    | 0 (0–0)                 | 0 (0–2)         | 0 (0–0)* |
| Disease Activity VAS | 0 (0–4.5) | 0 (0–1)      | 1 (0–5)           | 1.5 (0–3.5)       | 0.5 (0–1)           | 0 (0–4)                    | 0 (0–0)                 | 0 (0–3)         |         |
| Well-being VAS       | 0 (0–4)  | 0 (0–1.3)     | 0.5 (0–2)         | 2 (0–7.5)         | 0.3 (0–1)           | 0 (0–4.5)                  | 0 (0–0)                 | 0 (0–2)         |         |
| HRQoL PH             | 1.5 (0–5) | 1 (0–2)      | 1 (0–4)           | 3 (0–6)           | 0 (0–0.5)           | 1 (0–4)                    | 0 (0–0)                 | 1 (0–3)         | 0 (0–0)* |
| HRQoL PsH            | 1 (0–4)  | 1 (0–3)       | 1 (0–4)           | 2 (0–3)           | 5 (2–6.5)           | 1 (0–3)                    | 1 (1–2)                 | 1 (0–3)         | 0 (0–1)** |
| HRQoL Total Score    | 3.5 (0–10)| 2 (0–5)      | 3 (1–7)           | 3 (1–11)          | 5 (2–7)             | 3 (0–6)                    | 1 (1–3)                 | 3 (0–6)         | 0 (0–2)* |
| Pain/swell. in > 1 joint | 16 (47.1%) | 3196 (32.3%) | 3151 (60.8%)      | 8 (72.7%)         | 0 (0%)              | 10 (40%)                   | 0 (0%)                  | 96226 (42.5%)   | 5/70 (7.1%) |
| Morning stiff. > 15 min | 6 (17.6%) | 796 (7.3%)   | 951 (17.6%)       | 2 (18.2%)         | 0 (0%)              | 3 (12%)                    | 0 (0%)                  | 27226 (11.9%)   | 0 (0%)*  |
| Subjective remission | 13 (38.2%) | 2996 (30.2%) | 2951 (56.9%)      | 8 (72.7%)         | 1 (25%)             | 11 (44%)                   | 0 (0%)                  | 91226 (40.3%)   |         |
| In treatment         | 23 (67.6%) | 5696 (58.3%) | 4451 (86.3%)      | 10 (90.9%)        | 3 (75%)             | 19 (76%)                   | 3 (60%)                 | 158226 (69.9%)  |         |
| Reporting side effects | 8/23 (34.8%) | 10/56 (17.9%) | 12/44 (27.3%)   | 0 (0%)           | 1/3 (33.3%)         | 1/19 (5.3%)                | 1/3 (33.3%)             | 33158 (20.9%)   |         |
| Taking medication regularly | 23/23 (100%) | 52/56 (92.9%) | 40/44 (90.9%)    | 9/10 (90%)        | 3/3 (100%)          | 16/19 (84.2%)              | 3/3 (100%)              | 146158 (92.4%)  |         |

* Significant difference with respect to healthy group.
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 PF items 13 and 15, and for 80% of the HRQoL items, with the exception of items 8 and 9.

Items internal consistency (third Likert assumption)

Pearson items-scale correlations were ≥ 0.4 for 100% of items of the PF and 100% of items of the HRQoL.

Cronbach's alpha internal consistency

Cronbach’s alpha was 0.89 for PF-LL, 0.89 for PF-HW, 0.83 for PF-US. Cronbach’s alpha was 0.85 for HRQoL-PhH and 0.79 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.

Test–retest reliability

Reliability was assessed in 15 JIA patients, by re-administering both versions (parent and child) of the JAMAR after a median of 7 days (7–10 days). The intraclass correlation coefficients (ICC) for the PF total score showed an almost perfect reproducibility (ICC 0.94). The ICC for the HRQoL PhH and for the HRQoL PsH showed an almost perfect reproducibility (ICC 0.92 and ICC 0.87, respectively).

Convergent validity

The Spearman correlation of the PF total score with the JIA core set of outcome variables ranged from 0.4 to 0.5 (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 0.4 to 0.6 (median 0.4), whereas for the PsH ranged from 0.2 to 0.4 (median 0.2). The PhH showed the best correlation with the parent’s assessment of pain ($r = 0.7$, $p < 0.001$) and the PsH with the parent global assessment of well-being ($r = 0.4$, $p < 0.001$). The median correlations between the pain VAS, the well-being VAS, and the disease activity VAS and the physician-centered and laboratory measures were 0.4 (0.3–0.4), 0.4 (0.3–0.5), 0.4 (0.4–0.5), respectively.

Discussion

In this study, the Brazilian Portuguese version of the JAMAR was cross-culturally adapted from the original standard English version with 2 forward and 2 backward translations. According to the results of the validation analysis, the Brazilian Portuguese parent and patient versions of the JAMAR have satisfactory psychometric
properties. The disease-specific components of the questionnaire discriminated well between patients with JIA and healthy controls. Psychometric performance was good for all the JAMAR domains and the overall internal consistency was equally good for all the domains.

In the external validity evaluation, the Spearman’s correlations of the PF and HRQoL scores with JIA core set parameters were 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.

The JAMAR is aimed to evaluate the side effects of medications 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 Brazilian Portuguese version of the JAMAR was found to have satisfactory psychometric properties and it is, thus, a reliable and valid tool for the multi-dimensional assessment of children with JIA.

Acknowledgements We thank all families who participated in the project, the team that prepared and reviewed the forward and backward translations, and all members of PRINTO in Brazil. We thank the staff of the PRINTO International Coordinating Centre in Genoa (Italy) and in particular Marco Garrone for the overall coordination of the translation process, Silvia Scala and Elisa Patrone for data collection and quality assurance, Luca Villa, Giuseppe Silvestri and Mariangela Rinaldi for the database development and management and the remaining PRINTO team for data entry. The Principal Investigator of the study was Prof. Angelo Ravelli, MD. The scientific coordinator and study methodologist was Niccolino Ruperto, MD, MPH. The project coordinators were Alessandro Consolaro, MD, PhD, Francesca Bovis, BSc. We thank also Prof. Alberto Martini, PRINTO Chairman. Funding was provided by the Istituto G. Gaslini, Genoa (Italy). Permission for the use of JAMAR and its translations must be obtained in writing from PRINTO, Genoa, Italy. All JAMAR-related inquiries should be directed to at printo@gaslini.org. Permission for the use of CHAQ and CHQ derived-material is granted through the scientific cooperation of the copyright holder ICORE of Woodside CA and HealthActCHQ Inc. of Boston, Massachusetts USA. All CHQ-related inquiries should be directed to licensing@healthactchq.com. All CHAQ-related inquiries should be directed to gsingh@stanford.edu.

Funding This study was funded and coordinated by Istituto Giannina Gaslini, Genoa, Italy.

Compliance with ethical standards

Conflict of interest Dr. Oliveira Sato, Dr. Albuquerque Pedrosa Fernandes, Dr. Sztajnbok, Dr. Saad Magalhaes report funding support from Istituto Giannina Gaslini, Genoa, Italy, for the translation phase and data collection performed at their sites within the EPOCA project. 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, Abylnx, Amgen, AstraZeneca, Baxalta Biosimilars, Biogen Idec, Boehringer, Bristol Myers Squibb, Celgene, Eli-Lilly, EMER Serono, Gilead Sciences, Janssen, Medimmune, Novartis, Pfizer, RPharm, Roche, Sanofi, Servier and Takeda. Dr. Consolaro, Dr. Bovis, Dr. Darze, and Dr. De Gasparello de Almeida have nothing to disclose.

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.

Open Access This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.

References

1. Filocamo G, Consolaro A, Schiappapietra B, Dalpra S, Lattanzi B, Magni-Manzoni S et al (2011) A new approach to clinical care of juvenile idiopathic arthritis: the Juvenile Arthritis Multidimensional Assessment Report. J Rheumatol 38(5):938–953

2. Ruperto N, Martini A (2011) Networking in paediatrics: the example of the Paediatric Rheumatology International Trials Organisation (PRINTO). Arch Dis Child 96(6):596–601

3. Consolaro A, Ruperto N, Filocamo G, Lanni S, Bracciolini G, Garrone M et al (2012) Seeking insights into the EPIdemiology, treatment and Outcome of Childhood Arthritis through a multinational collaborative effort: Introduction of the EPOCA study. Pediatr Rheumatol Online J 10(1):39

4. Bovis F, Consolaro A, Pistorio A, Garrone M, Scala S, Patrone E et al (2018) Cross-cultural adaptation and psychometric evaluation of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) in 54 languages across 52 countries: review of the general methodology. Rheumatol Int. https://doi.org/10.1007/s00292-018-3944-1 (in this issue)

5. Petty RE, Southwood TR, Baum J, Bhettay E, Glass DN, Manners P et al (1998) Revision of the proposed classification criteria for juvenile idiopathic arthritis: Durban, 1997. J Rheumatol 25(10):1991–1994

6. Petty RE, Southwood TR, Manners P, Baum J, Glass DN, Goldenberg J et al (2004) International League of Associations for Rheumatology classification of juvenile idiopathic arthritis: second revision, Edmonton, 2001. J Rheumatol 31(2):390–392

7. Filocamo G, Sztajnbok F, Cespedes-Cruz A, Magni-Manzoni S, Pistorio A, Viola S et al (2007) Development and validation of a new short and simple measure of physical function for juvenile idiopathic arthritis. Arthritis Rheum 57(6):913–920

8. Lovell DJ, Howe S, Shear E, Hartner S, McGirr G, Schulte M et al (1989) Development of a disability measurement tool for juvenile rheumatoid arthritis. The juvenile arthritis functional assessment scale. Arthritis Rheum 32:1390–1395

9. Howe S, Levinson J, Shear E, Hartner S, McGirr G, Schulte M et al (1991) Development of a disability measurement tool for juvenile rheumatoid arthritis. The juvenile arthritis functional assessment report for children and their parents. Arthritis Rheum 34:873–880

10. Singh G, Athreya BH, Fries JF, Goldsmith PD (1994) Measurement of health status in children with juvenile rheumatoid arthritis. Arthritis Rheum 37:1761–1769

11. Filocamo G, Davi S, Pistorio A, Bertamino M, Ruperto N, Lattanzi B et al (2010) Evaluation of 21-numbered circle and 10-centimeter horizontal line visual analog scales for physician and patient subjective ratings in juvenile idiopathic arthritis. J Rheumatol 37(7):1534–1541

12. Duffy CM, Arsenault L, Duffy KN, Paquin JD, Strawczynski H (1997) The Juvenile Arthritis Quality of Life Questionnaire-developement of a new responsive index for juvenile rheumatoid arthritis and juvenile spondyloarthropathies. J Rheumatol 24(4):738–746

13. Varni JW, Seid M, Knight TS, Burwinkle T, Brown J, Szer IS (2002) The PedsQL(TM) in pediatric rheumatology - Reliability, validity, and responsiveness of the Pediatric Quality of Life Inventory(TM) generic core scales and rheumatology module. Arthritis Rheum 46(3):714–725
14. Landgraf JM, Abetz L, Ware JE (1996) The CHQ user’s manual, 1st edn. The Health Institute, New England Medical Center, Boston
15. Filocamo G, Consolaro A, Schiappapietra B, Ruperto N, Pistorio A, Solari N et al (2012) Parent and child acceptable symptom state in juvenile idiopathic arthritis. J Rheumatol 39(4):856–863
16. Nunnally JC (1978) Psychometric theory, 2nd edn. McGraw-Hill, New York
17. Giannini EH, Ruperto N, Ravelli A, Lovell DJ, Felson DT, Martin A (1997) Preliminary definition of improvement in juvenile arthritis. Arthritis Rheum 40(7):1202–1209
18. Ware JE Jr, Harris WJ, Gandek B, Rogers BW, Reese PR (1997) MAP-R for windows: multitrait/multi-item analysis program—revised user’s guide. Version 1.0 ed. Health Assessment Lab, Boston

Affiliations
Taciana A. Pedrosa Fernandes1 · Claudia Saad Magalhães1 · Sheila Knupp Oliveira2 · Flavio Sztajnbok3 · Juliana de Oliveira Sato1 · Layla Saba Darze3 · Rozana Gasparella de Almeida3 · Alessandro Consolaro4,5 · Francesca Bovis4 · Nicolino Ruperto4 · For the Paediatric Rheumatology International Trials Organisation (PRINTO)

Taciana A. Pedrosa Fernandes
taciana_fernandes@hotmail.com
Sheila Knupp Oliveira
sheila_knupp@hotmail.com
Flavio Sztajnbok
flaviosztajnbok@hotmail.com
Juliana de Oliveira Sato
julianasato@fmb.unesp.br
Layla Saba Darze
layladarze@yahoo.com.br
Rozana Gasparella de Almeida
rozanagasp@yahoo.com.br
Alessandro Consolaro
alessandroconsolaro@gaslini.org

Francesca Bovis
francescobovis@gaslini.org

1 Faculdade de Medicina de Botucatu, Universidade Estadual Paulista (UNESP), Botucatu, São Paulo 18618-970, Brazil
2 Instituto de Puericultura e Pediatria Martagão Gesteira (IPPMG), Universidade Federal do Rio de Janeiro, Rio de Janeiro, Brazil
3 Hospital Universitário Pedro Ernesto, Núcleo de Estudos da Saúde do Adolescente, Rio de Janeiro, Brazil
4 Clinica Pediatrica e Reumatologia, Paediatric Rheumatology International Trials Organisation (PRINTO), Istituto Giannina Gaslini, Via Gaslini, 5, 16147 Genoa, Italy
5 Dipartimento di Pediatrica, Università di Genova, Genoa, Italy