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Psoriatic Arthritis Quality of Life Questionnaire: translation, cultural adaptation and validation into Brazilian Portuguese language

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Abstract

Introduction: Psoriatic arthritis (PsA) is a multifaceted inflammatory disease that can cause joint destruction and impair quality of life. The Psoriatic Arthritis Quality of Life Questionnaire (PsAQoL) was the first disease-specific tool for determining the impact of the disease on the quality of life of people with PsA.

Objectives: The primary objective was to develop and validate a Brazilian Portuguese version of the PsAQoL.

Methods: The UK PsAQoL was translated into Brazilian Portuguese using two translation panels. This translation then checked for face validity and construct validity with new samples of patients. Finally, a test-retest validation study was conducted with 52 patients with PsA. The survey included the Nottingham Health Profile (NHP) as a comparator instrument.

Results: Internal consistency and reproducibility were both excellent for the new adaptation (0.91 and 0.90 respectively). Scores on the PsAQoL were found to correlate as expected with the comparator measure and the instrument was able to detect differences in score related to perceived severity of PsA, general health status and presence of a flare.

Conclusion: The Brazilian PsAQoL was found easy to understand and complete and has excellent reliability and construct validity. The new measure will be a valuable new tool for use in routine PsA practice and clinical trials.

Keywords: Psoriatic arthritis, Quality of life, Validation, Translation

Introduction

Psoriatic arthritis (PsA) is a chronic inflammatory disease that is part of the group of spondyloarthropathies, affecting up to 1% of the population [1]. It is a complex disease which, in addition to the cutaneous involvement, the patient presents musculoskeletal problems (related to the spine, enthesitis and peripheral joints) and may also present extra-muscular manifestations including the intestine or the eye [1]. PsA is the most prevalent extra-

cutaneous manifestation in patients with psoriasis, affecting between 8 and 42% of psoriatic patients [2].

PsA has been shown to have a negative impact on patients' quality of life (QoL) [3]. It is therefore important to be able to assess the extent to which an individual's life is affected by their condition and to evaluate the value gained by patients from new and existing treatment strategies. The articular condition (arthritis, tenosynovitis, enthesitis and/or dactylitis) may significantly limit functional ability, including activities of daily living and employment. This may well lead to important socio-economic impacts [4].

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One of the measures available for assessing outcome is the Health Assessment Questionnaire (HAQ) [5]. However, The HAQ assesses health status rather than QoL. The latter has become an important outcome for both physicians and patients. It is now necessary for clinical studies to show the impact on patient-reported outcomes, such as QoL, in addition to efficacy and safety [6].

McKenna et al. developed and validated the Psoriatic Arthritis Quality of Life (PsAQoL) questionnaire [3]. Rather than measuring symptoms and functional limitations, the PsAQoL assesses the degree to which patients are able to meet their fundamental human needs [7]. The PsAQoL is the only patient-centric outcome measure that is able to assess the true impact of PsA and its treatment on the overall lives of patients. The aim of the present study was to produce a Brazilian Portuguese version of the PsAQoL for use in clinical practice, international trials and research settings.

Methods

The adaptation of the PsAQoL consisted of three stages: translation; assessment of face and content validity; psychometric evaluation.

Translation of the PsAQoL

The dual-panel methodology [8] was adopted to translate the UK English PsAQoL into Brazilian Portuguese. This involves running two independent panels – a bilingual panel and a lay panel. An initial translation of the PsAQoL was produced by the bilingual panel. This consisted of a group of professional individuals who were native speakers of Brazilian Portuguese and also fluent in English. Their role was to work together to produce conceptually equivalent translations of the questionnaire items, instructions and response options. The translated version was then presented to a lay panel for consideration. This consisted of a group of monolingual Portuguese-speakers with an average educational level. These individuals were invited to comment on the comprehension of the translations and suggest changes, where necessary, to ensure the final wording of items was easy to understand and expressed in natural, everyday language.

Both panels were led by the same moderator who encouraged the panel members to work as a team and ensured the original meaning of each item was maintained in the final translation. A representative from the team that developed the UK English questionnaire also attended both panels to ensure the precise conceptual meaning of the items was conveyed to the moderator. Individuals with PsA were not invited to take part in the panels as the purpose of this stage was to produce an

appropriate translation of the questionnaire, not to test the suitability of the content.

Assessment of face and content validity

Cognitive debriefing interviews (CDIs) were conducted with PsA patients to assess the extent to which the translated questionnaire was relevant, comprehensive and easy to complete. The interviews took the form of a one-to-one semi-structured approach. Respondents were asked to complete the questionnaire while an interviewer observed and noted any obvious difficulties or hesitations. Respondents were then asked to provide feedback on the questionnaire, including whether all important aspects of their experience of PsA had been covered.

Psychometric evaluation

A postal survey was conducted to establish the psychometric properties of the Brazilian Portuguese PsAQoL. Individuals who satisfied the Classification Criteria for Psoriatic Arthritis (CASPAR) were recruited from the outpatient rheumatology department at the Hospital das Clínicas, UFPE. The PsAQoL was administered to participants on two occasions, with 14 days between administrations. The measure consists of 20 items with a dichotomous response format (True/Not True). The number of 'True' responses is summed to produce a total score ranging from 0 to 20, with a higher score indicating poorer quality of life. At the first administration, – the Nottingham Health Profile was included in the postal survey as a comparator questionnaire (NHP) [9]. The NHP is a generic measure of perceived distress consisting of 38 items covering six sections: physical mobility, pain, energy level, emotional reactions, sleep and social isolation. For each section, scores range from 0 to 100, with higher scores indicative of greater perceived distress. Demographic and disease information was also collected from participants. An ID number was allocated to all participants to ensure anonymity and to allow the data collected at each administration to be matched.

The following analyses were conducted on the survey data.

Descriptive statistics for the PsAQoL at both time points and NHP scores at baseline were calculated. PsAQoL scores were also compared by age group (above median versus below median) and gender. Internal consistency is a measure of the extent to which items in a scale are inter-related. This was assessed using Cronbach's alpha coefficients. An alpha value above 0.7 indicates that the items are sufficiently related to form a scale. Test-retest reliability is an estimate of reproducibility over time, assuming no change in condition has occurred. This was assessed by correlating PsAQoL scores obtained on the two administrations, using Spearman's rank correlation coefficients. A value of 0.85 or

above indicates that the instrument produces low levels of random measurement error.

Convergent validity was assessed by measuring the association between scores on one scale and those on a comparator measure that measures the same or related constructs. PsAQoL scores were correlated with scores on the NHP sections using Spearman rank correlation coefficients. Known group validity was demonstrated by testing the ability of the PsAQoL to distinguish between groups of people that differed according to their perceived general health (poor/fair/good/excellent), perceived disease severity (mild/moderate/quite severe/very severe) and whether they were currently experiencing a flare (yes/no). Mann-Whitney U tests were used to investigate whether there were differences in PsAQoL scores between these groups.

The statistical analyses were conducted using SPSS (version 25.0). Non-parametric tests were employed due to the data collected measuring at the ordinal level.

Results

Translation of the PsAQoL

The bilingual panel consisted of four female and two male participants aged between 19 and 25 years. Overall, the panel found the questionnaire items and instructions easy to translate. There was discussion concerning the 'True/Not true' response options, in which the panel suggested 'Yes/No' (Sim/Não) as this was considered more natural in Brazilian Portuguese. The item 'I take it out on people close to me' was considered particularly difficult to translate because it is a colloquial expression in English. After much discussion, the panel was able to find an appropriate translation that captured the intended meaning.

The lay panel consisted of three male and two female patients aged between 48 and 60 years. Only minor changes were made to three items, including the removal of pronouns and replacing 'the disease' with 'my disease' to improve immediacy and clarity. All panel members agreed that the final translations were easy to understand and sounded natural in Brazilian Portuguese.

Assessment of face and content validity

Ten CDIs were conducted with PsA patients, of whom eight were female. The mean time taken to complete the questionnaire was 4 min (range = 3–6 min). Overall, the questionnaire was considered clear and easy to understand and complete. All patients felt that the items reflected their own situation well and they could relate to the ideas expressed. No items were thought to be irrelevant or inappropriate, resulting in no changes being made to the questionnaire following this stage.

Psychometric evaluation

Fifty-two participants took part in the validation study and completed the PsAQoL on two occasions.

Demographic and disease information of the sample is provided in Table 1.

Scores obtained on the PsAQoL and NHP are shown in Table 2. The median score for the Brazilian Portuguese PsAQoL did not change between administrations of the postal survey. No floor or ceiling effects were observed for the PsAQoL. In contrast, half of the NHP sections (energy level; sleep; social isolation) demonstrated

Table 1 Demographic and disease information of postal survey sample ($n = 52$)

Age (years)	
Mean (SD)	54.7 (11.8)
Range	24.5–78.6
Gender (%)	
Male	17 (32.7)
Female	35 (67.3)
Marital Status (%)	
Married/Living as Married	31 (59.6)
Divorced	4 (7.7)
Widowed	4 (7.7)
Single	13 (25.0)
Work Status (%)	
Full-time	10 (19.2)
Part-time	4 (7.7)
Retired	14 (26.9)
Long term sick leave	10 (19.2)
Homemaker	7 (13.5)
Unemployed	7 (13.5)
Perceived disease severity (%)	
Mild	16 (30.8)
Moderate	19 (36.5)
Quite Severe	14 (26.9)
Very Severe	3 (5.8)
Perceived general health (%)	
Excellent	2 (3.8)
Good	14 (26.9)
Fair	30 (57.7)
Poor	6 (11.5)
Flare (%)	
Yes	14 (26.9)
No	38 (73.1)
Disease Duration (years)	
Mean (SD)	8.9 (6.6)
Range	0.5–30

Table 2 Descriptive statistics for the PsAQoL and NHP sections

	n	Median (IQR)	Min - Max	% scoring minimum	% scoring maximum
PsAQoL (Time 1)	52	9.0 (3.0–14.0)	0.0–19.0	7.7	0.0
PsAQoL (Time 2)	52	9.0 (2.0–13.8)	0.0–20.0	11.5	1.9
NHP					
Energy level	52	33.3 (0.0–91.7)	0.0–100.0	36.5	25.0
Pain	52	56.3 (25.0–75.0)	0.0–100.0	13.5	5.8
Emotional reactions	52	44.4 (22.2–77.8)	0.0–100.0	13.5	3.8
Sleep	52	40.0 (0.0–80.0)	0.0–100.0	32.7	13.5
Social isolation	52	20.0 (0.0–40.0)	0.0–100.0	36.5	3.8
Physical mobility	52	50.0 (25.0–62.5)	0.0–87.5	9.6	0.0

PsAQoL Psoriatic Arthritis Quality of Life scale, NHP Nottingham Health Profile, IQR Inter-quartile range

large floor effects. Respondents scored highest on the pain and physical mobility NHP sections.

The PsAQoL demonstrated high internal consistency. Cronbach's alpha coefficients for the PsAQoL were 0.91 and 0.93 at Time 1 and 2, respectively, indicating that the items are sufficiently inter-related. A correlation coefficient of 0.90 was found for test-retest reliability, suggesting the questionnaire will produce low levels of random measurement error.

Correlation coefficients between scores on the PsAQoL and NHP sections are presented in Table 3.

PsAQoL scores correlated most strongly with the emotional reactions section of the NHP. Strong correlations were observed between PsAQoL scores and those obtained on the energy level, physical mobility and social isolation NHP sections.

Table 4 shows PsAQoL scores for patients grouped by gender and age (above versus below median age). No significant difference in PsAQoL scores was found between older and younger patients. However, a significant difference in PsAQoL scores between males and females was observed, with females scoring significantly higher than males. A chi-square test of independence was performed to explore whether females had worse general health or disease severity compared to males. No significant association was found between gender and

perceived disease severity ($\chi^2 (52) = 0.12, p = 0.73$) or between gender and perceived general health, ($\chi^2 (52) = 0.24, p = 0.62$).

Due to the relatively small number in each group, the categories for perceived disease severity were grouped into 'mild/moderate' and 'quite severe/very severe' for the known group analyses. The categories for perceived general health were grouped into 'excellent/good' and 'fair/poor' for the same reason.

Mann Whitney U tests demonstrated significant differences in PsAQoL scores between patients who differed according to their perceived disease severity (Fig. 1), perceived general health (Fig. 2) and whether they were experiencing a flare (Fig. 3).

Discussion

The dual-panel methodology resulted in a Brazilian Portuguese version of the PsAQoL that was comprehensible, natural and reflected the same concepts as the original UK English. Cognitive debriefing interviews confirmed that the content of the measure was appropriate to Brazilian patients. The PsAQoL was considered relevant, comprehensive and easy for local respondents to complete. The new language version demonstrated excellent internal consistency, test-retest reliability and was capable of detecting meaningful differences between PsA

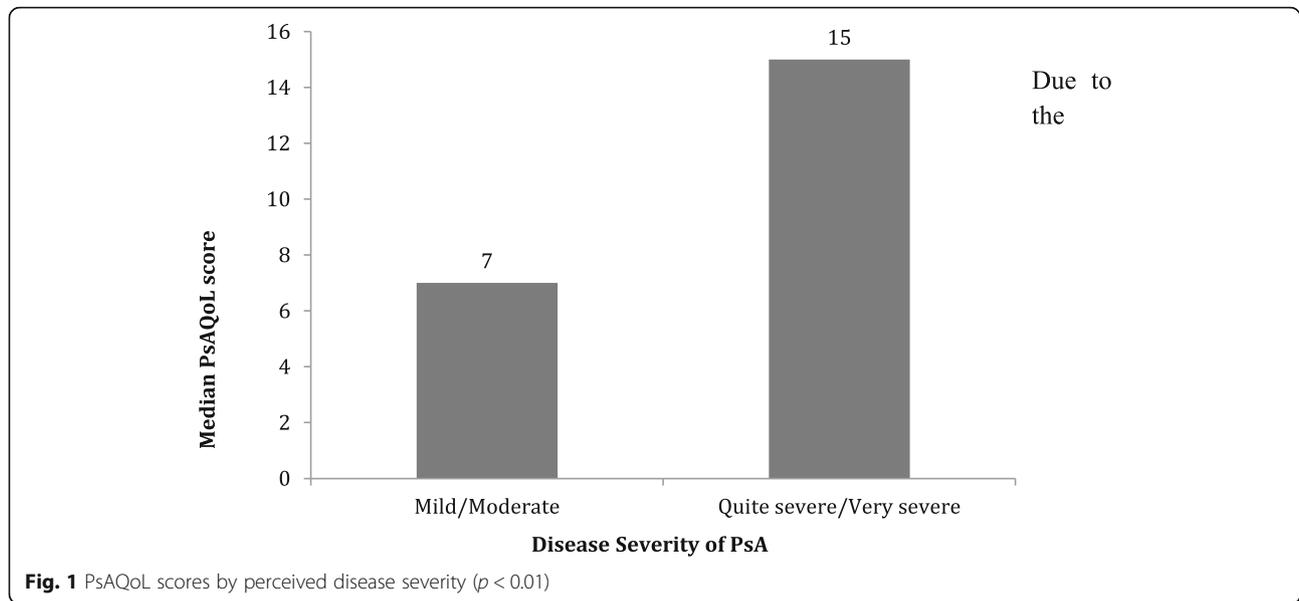
Table 3 Association between PsAQoL and NHP section scores (n = 52)

	PsAQoL
NHP	
Energy level	0.75
Pain	0.69
Emotional reactions	0.89
Sleep	0.65
Social isolation	0.71
Physical mobility	0.75

All correlations significant at the 0.01 level (2-tailed)

Table 4 Median PsAQoL scores by demographic factors

	n	Median (IQR)
Gender		
Male	17	3 (1–10.5)
Female	35	11 (5–15)
p		< 0.05
Age		
Below Median	25	8 (1–15)
Above Median	26	9 (4.8–13.3)
p		0.41

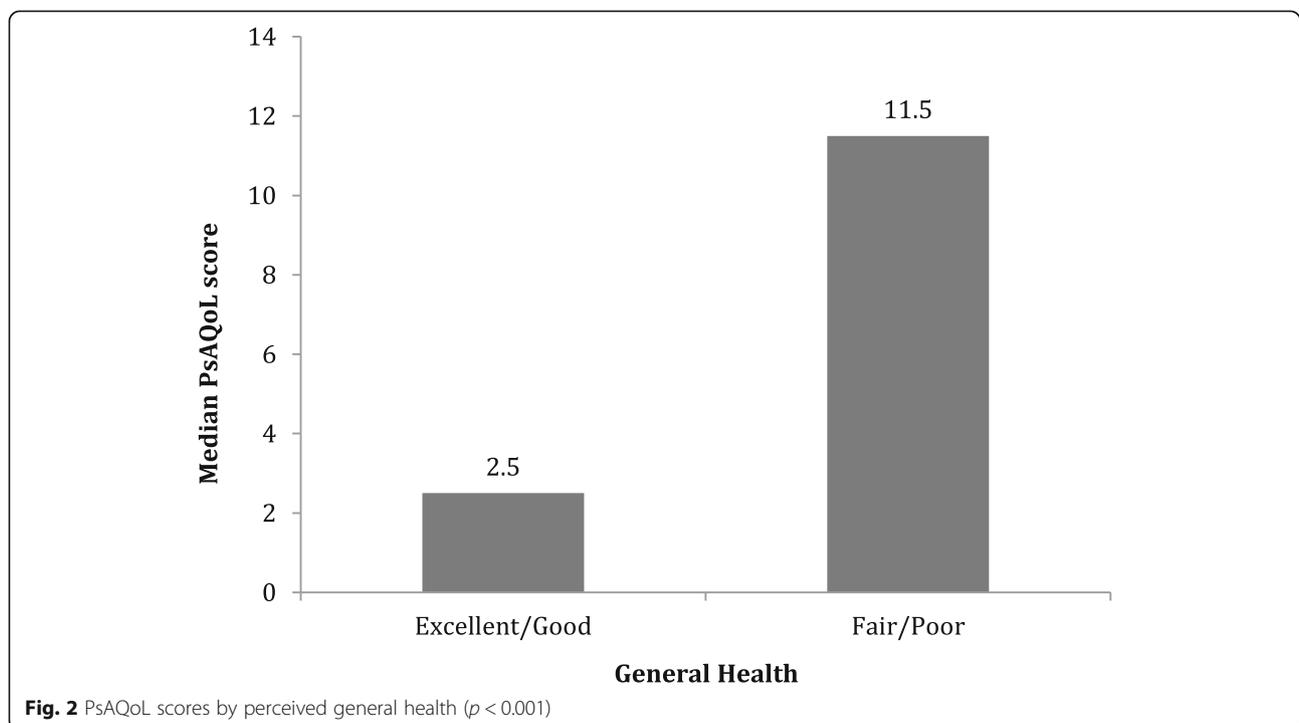


patients in terms of perceived ratings of disease severity, general health and presence of flare.

Cronbach’s Alpha coefficients for at both administrations of the PsAQoL were above 0.9, suggesting the items are adequately related to form a measure. The high value obtained for test-retest reliability indicates that the Brazilian Portuguese PsAQoL will produce low levels of random measurement error. This means that smaller samples are required to detect changes in QoL resulting from treatment. The PsAQoL correlated as

expected with NHP sections, demonstrating that QoL is largely influenced by pain and physical mobility. However, the PsAQoL was also capable of detecting the impact of emotional and social issues associated with PsA, suggesting QoL is dependent on multiple factors in this patient group. Findings to support known group validity were in line with the results of other studies that have validated new language versions of the PsAQoL [10–12].

The PsAQoL is a widely used measure of QoL specific to PsA patients. It is one of several disease-specific



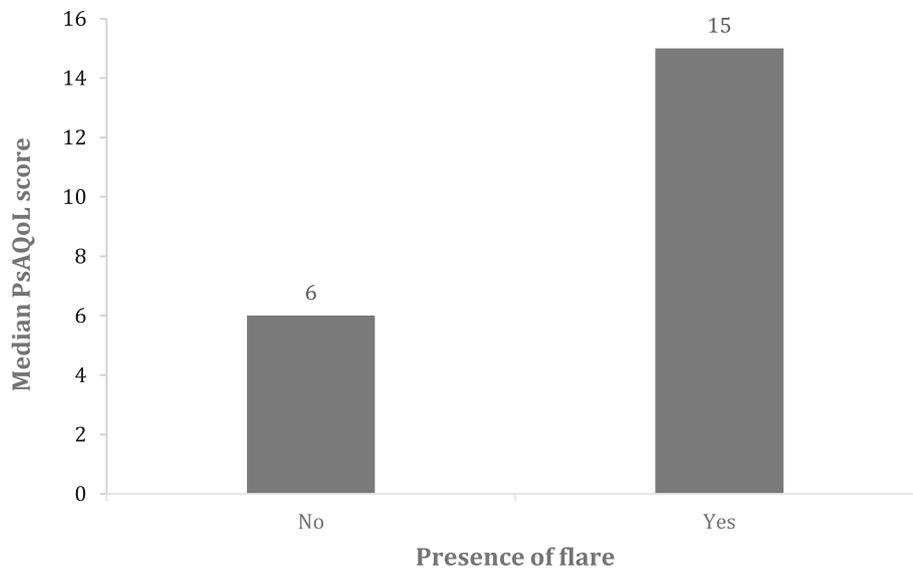


Fig. 3 PsAQoL scores by presence of flare ($p < 0.001$)

instruments based on the needs-based model of QoL that are used in rheumatology [13, 14]. These instruments differ from traditional patient-reported outcome measures, which predominantly assess HRQL. Whereas HRQL collects information that is primarily of interest to clinicians, needs-based questionnaires cover relevant issues that are important to the lives of patients and are truly patient-based. Because the PsAQoL assesses a different type of outcome to other available PROMS, it can be used in combination with measures such as the HAQ and NHP.

Differences in QoL scores between males and females were found, in contrast to other adaptations studies of the PsAQoL and the original UK English version [3, 12, 15]. An additional adaptation of the Cambridge Pulmonary Hypertension Outcome Review (CAMP HOR; a measure of HRQL and needs-based QoL) [16] was recently conducted for use with Pulmonary Hypertension patients in Brazil [17]. Significant differences in scores between males and females were found on all CAMP HOR scales, which appeared to be caused by gender differences in ratings of perceived general health. However, research conducted across 14 countries suggested that despite having similar levels of disease activity, female PsA patients demonstrated worse patient-reported outcomes across quality of life, level of disability and impact of disease [18]. This finding that the impact of PsA seems to be greater in women is one possible explanation for the gender differences in QoL scores that were found in the current sample.

The availability of a Brazilian Portuguese version of the PsAQoL provides a valid and reliable means of evaluating QoL as well as determining the value gained

by patients from both clinical and non-clinical interventions. The new language version can also be incorporated in international clinical trials, which are increasingly including South American countries.

The main limitation of the present study is the relatively small sample size. Further research is required to evaluate the responsiveness of the new language version.

Conclusion

The Brazilian Portuguese version of the PsAQoL demonstrated excellent psychometric properties. The new language version will prove to be a valuable addition to the PsA community, offering a means of evaluating QoL in routine clinical practice, research studies and international clinical trials in Brazil.

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Authors' contributions

Study concept and design: SPM and AH. Data collection: RSGG, JBC, MELV, MCMB, GAP, ALBPD. Statistical analysis and data interpretation: AH and SPM. RSGG prepared the first version of the manuscript and all authors contributed to critical revision of the manuscript. All authors gave final approval of the version to be published.

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Availability of data and materials

All data is available if needed.

Ethics approval and consent to participate

This study was approved by the Research Ethics Committee Involving Human Beings at Hospital das Clínicas, da Universidade Federal de Pernambuco (UFPE), EBSE RH (CEP do HC/UFPE/EBSE RH), CAAE 11631519.7.0000.8807.

Consent for publication

All authors consented.

Competing interests

The authors report no conflicts of interest in this work.

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