

ORIGINAL ARTICLES

Linguistic and cultural adaptation of the EARP Questionnaire to European Portuguese

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ABSTRACT

Objective: This study aims at the linguistic and cultural adaptation of the Early ARthritis for Psoriatic Patients (EARP) questionnaire into European Portuguese, for psoriatic patients attending dermatology medical examination.

Methods: Firstly, we performed a process of translation and back-translation of the English version of the EARP Questionnaire to European Portuguese, with interim and final harmonization. The resulting Portuguese version was approved by the EARP original author. Secondly, individual interviews were conducted to complete the linguistic and cultural adaptation of the initial translated Portuguese version, with the think-aloud and probe methods. At this stage, we conducted eight interviews, four with rheumatology and dermatology doctors (experts), and four with patients with psoriasis and psoriatic arthritis. Finally, the version resulting from the adaptation process was back-translated from Portuguese to English.

Results: Our results showed that EARP Questionnaire's items are easy to understand and do not raise comprehension concerns in experts or patients. Our findings suggested that items demanding health literacy from patients and that do not include a precise cue to signal the inflammatory nature of the joint pain may lead to confusion while answering, potentially leading to the patient's need for assistance.

Conclusion: The Portuguese version of the EARP Questionnaire demonstrated adequate comprehension properties. Our findings support the use of this measure in clinical practice and future research, however, a validation study with Portuguese patients is needed.

Keywords: Psoriatic arthritis; Psoriasis; EARP questionnaire; Linguistic and cultural adaptation.

INTRODUCTION

In Portugal, the prevalence of psoriasis is estimated to be 2.5%, which corresponds to 250.000 patients. Nevertheless, the percentage of Portuguese patients with psoriatic arthritis (PsA) among those with psoriasis is still unknown. It is well known that patients with psoriasis may have musculoskeletal complaints related to PsA, a chronic and potentially disabling inflammatory disease that may affect up to a third of those patients¹.

Psoriasis is a disease that mainly affects the skin (e.g.^{2,3}), PsA is associated with joint swelling, stiffness

and pain or lower back pain and overall fatigue and may ultimately lead to joint destruction². Usually, patients notice skin changes before they notice joint discomfort, which prompts them to seek help in the dermatology clinics^{4,5}. Evidence suggests that up to 15.5% of patients with psoriasis have undiagnosed PsA⁶. Dermatologists are thus recommended to ask patients with psoriasis for specific signs of inflammatory joint disease needed for early detection and treatment of PsA. However, it remains difficult for the non-rheumatologist to distinguish PsA from other forms of arthritis and iden-

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tify those patients warranting further assessment by the rheumatologists⁷. As PsA is a highly heterogeneous disease characterized by a set of different manifestations, many criteria have been developed to help establish its diagnosis.

There is a need for short and easy-to-perform screening tools, to help dermatologists effectively separate patients with common complaints from patients with potential PsA. Recent research developed different screening tools to detect PsA in dermatology and primary healthcare centres. These include the Toronto Psoriatic Arthritis Screening Questionnaire (TOPAS)⁸; Psoriasis Epidemiology Screening Tool (PEST)⁹ comparing people with and without psoriatic arthritis. The instruments were compared using receiver operating curve (ROC; Psoriatic Arthritis Screening and Evaluation (PASE)¹⁰, and the Psoriasis and Arthritis Screening Questionnaire (PASQ)¹¹. However, these tools did not reveal to be a simple and fast self-report experience for the patient and are not focused on detecting PsA at early stages¹². Moreover, most of the questionnaires require high health literacy from patients, making them difficult to propose in a medical context where human resources and time are scarce and hardly meet population needs.

The Early Arthritis for Psoriatic Patients (EARP) questionnaire¹² has shown to have good measurement properties in its original Italian version. The main advantages of the EARP over the previously mentioned questionnaires are that it is simple and requires low or no assistance from clinicians, features that make a tool useful to dermatologists¹³. Furthermore, the initial validation study for the EARP showed that it identified a large percentage of the patients who had not previously reported PsA symptoms. The EARP Questionnaire consists of a self-report measure with a simple and fast completion by patients that allows an accurate assessment of patients' symptoms related to articulations discomfort and pain.

A recent study comparing the four measures for the early diagnosis of PsA (TOPAS II, PASE, PEST and EARP) showed that EARP had the highest sensitivity (91%) and showed strong specificity (88%)¹⁴. Moreover, the EARP questionnaire was translated and validated into several languages and populations, showing robust properties¹⁵⁻¹⁹.

The Portuguese dermatology clinical setting context is still lacking an accurate and simple tool aimed at improving the diagnosis of PsA. The aim of this study was to translate EARP Questionnaire to European Portuguese and culturally adapt to the Portuguese population. The linguistic and cultural adaptation of the EARP Questionnaire aims to understand how each item is perceived by experts, its potential users, and pa-

tients, and at defining what linguistic changes need to be made in each item of the questionnaire to assure the measure's precision.

MATERIAL AND METHODS

The EARP Questionnaire

The original EARP questionnaire is composed of 10 items (Table 1) and was developed through a review of the typical symptoms and signs seen among patients with an established diagnosis of PsA. The questionnaire was composed of dichotomous ("yes"/"no") items; the total score was calculated by summing the score of each question and the scored from 0 (all negative responses to 10 (all affirmative responses). The cut-off point is 3: a score of 3 or more indicates the possible presence of PsA¹².

Procedures for the linguistic and cultural adaptation

The process underlying the development of the Portuguese version of the EARP occurred in three phases, 1) translation of the English version of the survey and culture, 2) linguistic adaptation to European Portuguese, and 3) back-translation of the final Portuguese version. This research was developed in collaboration with Dr. Tinazzi, the tool's original author, in all its phases.

In the first phase, we conducted a blind translation and back-translation of the English version of the EARP Questionnaire to European Portuguese, made by qualified translators, which resulted in the first Portuguese version of the questionnaire.

The linguistic and cultural adaptation of the EARP Questionnaire was based on the Cognitive Interviewing methodology, which consists of an interviewing methodology designed to assess the cognitions associated with each item of a questionnaire, such as the users' understanding of the terminology, their representation of the concepts presented and their contextual associations with the content elicited (e.g., time perception).

For the second phase of the research, individual interviews were conducted. The interviewing methodology used in this research included two variations of the cognitive interviewing format: 1) the "Think-aloud" method, to capture the perceptions elicited by each item; and 2) the "Probes" method, to capture the perceptions of anticipated sources of confusion of the questionnaire.

For the last phase, the questionnaire's version that resulted from the analysis was backtranslated to English, reviewed and approved by Dr. Tinazzi. The focus of the assessment of the questionnaire was to understand the expert's perceptions – rheumatologists and dermatologists – as well as relevant potential users of the questionnaire – patients with psoriasis and patients with psoriatic arthritis.

TABLE I. Original EARP Questionnaire

| Question | Yes | No |
|----------------------------------------------------------------------------------------------|-----|----|
| Do your joints hurt? | 1 | 0 |
| Have you taken anti-inflammatory more than twice a week for joint pain in the last 3 months? | 1 | 0 |
| Do you wake up at night because of low back pain? | 1 | 0 |
| Do you feel stiffness in your hands for more than 30 minutes in the morning? | 1 | 0 |
| Do your wrists and fingers hurt? | 1 | 0 |
| Do your wrists and fingers swell? | 1 | 0 |
| Does one finger hurt and swell for more than 3 days? | 1 | 0 |
| Does your Achilles tendon swell? | 1 | 0 |
| Do your feet or ankles hurt? | 1 | 0 |
| Do your elbow or hips hurt? | 1 | 0 |

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Interviews- Protocol

To conduct the interviews, we developed a protocol including 1) practice of the thinking aloud method; 2) think aloud interviewing; and 3) probing anticipated sources of confusion for each item. The script included anticipated sources of confusion for the Probes interviewing method according to three dimensions: understanding, retrieval and response.

Considering the *understanding* dimension, we found potential sources of confusion in the 10 items. These sources of confusion were related to the interpretation of the symptoms, which would require clarification of the distinction between pain and swelling and between movement pain or inflammatory pain and related with items focused on the joint's identification and location.

For potential sources of confusion regarding Retrieval, we identified 3 items that describe time intervals (e.g., twice a week (...) in the last 3 months), for which we clarified the ease of recalling symptoms within the given periods.

Finally, for the *Response* dimension, we identified 6 items in which the response format *Yes/No* could lead to confusion when answering that specific item. For example, an item could elicit participants to provide more information (e.g., the need to describe all the pills when asked about the anti-inflammatory ones) or could evoke the tendency to answer *No* to the presence of a symptom if the item asked about two types of joints (e.g., *wrists and fingers, feet, or ankles*).

Participants

Participants' selection followed a purposive sampling

approach based on language exposure (European Portuguese as their first language) and disease exposure, which includes participants' expertise (doctors) and participants' experience with joint disease (patients). We invited doctors with expertise in rheumatology and dermatology, with wide experience in different medical contexts (public and private medical contexts) and have an average of 8 years of practice. Accordingly, patients were also followed by rheumatology or dermatology doctors and had different levels of education and different types of professional occupations. To define sample size, participants' selection followed the criteria of thematic saturation. Based on the simplicity and clarity of the EARP's items, and the *Probes* methodology of the script we expected lower divergency and fast thematic saturation, consequently leading to a sample size inferior to 10 participants. However, the think-aloud methodology could lead to high answers' divergency and slow thematic saturation, thus potentially increasing the sample size.

Eight participants - four doctors and four patients - were interviewed.

Participants were invited and consented to voluntarily participate in the study for the linguistic and cultural adaptation of the EARP Questionnaire without additional incentive.

Participants were told they were participating in a study for the linguistic and cultural adaptation of the EARP Questionnaire. Interviews were conducted online, using Zoom Colibri, and were recorded after participants gave their oral informed consent to record the interview and to participate in the study. This consent

was confirmed once the recording started. Interviews started with a short exercise to practice the think-aloud method and to emphasize the reasoning processes underlying the answer to a simple question.

Subsequently, for each item, participants were asked to think aloud about that item and asked to answer the probes for anticipated sources of confusion. In the think-aloud method, while patients were asked to say out loud what they were thinking about when answering each question; experts were asked to explain each item in their own words as if they are presenting the questionnaire to their typical patient. The probes were presented in a similar format to both experts and patients, as described above in the section *Interviews-Protocol*. After providing participants with the opportunity for further questions or comments, the interview ended.

The study was approved by NOVA Medical School Ethics Board, in compliance with the Declaration of Helsinki 1964 and its later amendments.

RESULTS

While collecting data, we achieved thematic saturation in the third participant, for the group of doctors, and achieved saturation in the fourth participant, for the group of patients. The saturation of sources of confusion and the consistency of participants' answers led us to meet our research goal and conclude data collection after conducting eight interviews. This decision was also guided by the data minimization principle and convenience.

The analysis of the interviews was based on the identification of content diversity and frequency for the two sample groups, experts, and patients. For each group, it was identified the different emerging sources of confusion, their total frequency, and the suggested solutions to deal with the identified sources of confusion.

Experts

For the experts' group, think-aloud and probed sources of confusion were analysed separately. In the think-aloud method, our results showed that Items 1, 5, 6, 9, and 10 were spontaneously perceived as clear and easy to understand by all experts (100%). The sources of confusion identified by experts have been categorized into three groups: 1) health literacy demands; 2) questions have a cognitively demanding structure; 3) questions do not capture the inflammatory nature of the disease with precision.

For the health literacy demands, four items raised concerns in experts about the patient's low health literacy and anticipated the patients would not be able to autonomously identify certain health concepts. Specifically, 4/4 of experts considered that patients could

not rigorously identify *anti-inflammatory medication* (item 2) and *Achilles tendon* (item 8) without clarification. Moreover, 3/4 of experts raised concerns about the correct identification of the *lumbar region* (item 3) and the concept of "stiffness" (item 4) without further explanation.

For the demands of the sentence structure, experts identified that some items were long and complex, especially due to the presence of more than one-time adverbs. Specifically, 4/4 of experts identified it as difficult to understand the time adverb in item 7, and 3/4 of experts identified that item 2 was too long and complex.

In turn, the capacity of the items to capture the inflammatory nature of the disease raised concerns in four items. Specifically, 2/4 of experts identified that items 9 and 10 were missing cues (such as the continuity of discomfort/pain and its intensity in the morning/awakening period) that would allow patients to capture the inflammation pain and distinguish it from non-inflammatory traumatic joint pain. Moreover, 2/4 of experts also identified that the toes were a missing cue in item 7; and 1/4 of experts identified that the lack of precision in the period mentioned in item 3 could mislead patients in the identification of joint symptomatology.

For the probed part of the interviewing, we anticipated 3 types of sources of confusion: 1) patients' understanding of joint pain and swallowing (understanding); 2) patient's perception of time (retrieval); 3) patients' confusion with the overlap of symptoms in the items that grouped symptoms in one question (response). Regarding patients' perception of joint pain, 4/4 of experts considered that the concept of joint pain in item 1 would be easily understood by patients, however, they identified possible potential confusion between joints and bones (1/4) and between larger and smaller joints (1/4).

Regarding, the perception of time, when asked about the easiness to recall symptoms in the defined periods, for items 2 and 3, 3/4 of experts considered it would be easy to recall symptoms occurring in the given periods, especially if symptoms were salient (1/4) or if the time used a more colloquial language (state half an hour instead of 30 minutes) (1/4). When asked about the capacity of patients to distinguish pain from swelling, which would be required to answer items 5 and 6, 4/4 of experts identified that patients would easily distinguish one symptom from the other, especially considering the order of the items. For items 7 and 8, the need to identify swelling was clear for patients; however, experts showed concerns about how the sentence could elicit the concept of the general hand swelling, and not fluently elicit the focus on the finger(s), as it is intended by the item.

When asked about the potential confusion coming

TABLE II. Change made in Items of the EARP Questionnaire

| Item | Changes | Comments |
|--------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2 | 1. Addition a description of anti-inflammatory examples (Naproxeno, Ibruprofeno, Diclifenac) 2. Change time adverbs (twice a week to at least twice a week) | 1. Experts considered that patients could not rigorously identify anti-inflammatory medication Patients showed insufficient health literacy or low confidence in their health knowledge to answer autonomously. 2. Experts identified that this item was too long and complex, especially due to the presence of two time adverbs |
| 3 | 1. Replacement lumbar region to low back pain 2. Replacement wakes up at night to wake up spontaneously at night | 1. Experts raised concerns about the correct identification of the lumbar region 2. Experts identified that the lack of precision in the period mentioned could mislead patients in the identification of joint symptomatology |
| 4 | 1. Addition of an explanation of the "stiffness" concept 2. Change morning period to awakening period | 1. Experts raised concerns about the correct identification of the concept of "stiffness" 2. Experts showed concerns with the lack of specific contextual cues associated with the symptoms |
| 5 and 6 | 1. Change "wrists and fingers" to "wrists or fingers" | 1. Experts considered that although the conjunction of symptoms could potentially generate confusion |
| 7 | 1. Change time adverb to 3 or more days | 1. Experts identified it as difficult to understand the time adverb |
| 8 | 1. Addition of an explanation of Achilles tendon | 1. Experts considered that patients could not rigorously identify Achilles tendon Patients showed insufficient health literacy or low confidence in their health knowledge to answer autonomously. |
| 5,6,9 and 10 | 1. Change the verb tense | 1. Patient's answers showed diversity in the representation of joint pain. Adapting the verb tense to elicit a more continuous representation of pain, focusing on inflammatory pain, and avoiding movement-related pain |

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from the conjunction in items 5, 6, 9, and 10 (e.g., *Do your wrists and fingers hurt?*), 4/4 of experts considered that although the conjunction of symptoms could potentially generate confusion, and suggested change the "and" to "or" or to "and/or" (4/4 experts). However, experts also reported that patients have the tendency to report their symptoms (not to hide or neglect) and would reply *Yes*, even if they only had symptoms in one part of the body (3/4).

Patients

For the patients' group, the content elicited in the think-aloud procedure did not elicit a significant quantity and quality of content spontaneously, in comparison with the experts' interviews, which led to the predominant use of the probe's method. For this reason, we analysed the immediacy (vs. hesitation) of patients' answering process as a proxy for the easiness of their understanding of the question and analysed the content from think-aloud and probes procedures together, con-

trary to the experts' data analysis.

Considering the immediacy of patients' answers, we found that 4/4 of patients had an immediate answer in five of the 10 items of the scale (items 1, 3, 4, 7, 9); 3/4 of patients had an immediate answer for item 1. In items 5, 6 and 8, only 2/4 of patients were immediate in providing their answers. Finally, in item 2, only 1/4 of patients answered without hesitation. This result suggests a robust easiness of response in most of the EARP items.

The sources of confusion identified by patients were categorized in the following dimensions: 1) precise understanding of joint pain and swallowing; 2) health literacy; 3) perception of time; and 4) confusion with the overlap of symptoms in the items that were grouped symptoms in one question.

Regarding the patient's representation of joint pain, we found moderate qualitative divergence in all 5 items (out of 10) that asked about joint pain. Specifically, patients referred to persistent and continuous joint pain

more (11 times) than movement pain (7 times). For all the items that asked about swelling (3 out of 10), 4/4 patients reported it was easy to distinguish pain from swelling. To better understand how patients represent the location of the pain, we analysed the pain location in item 1, due to its role in guiding patients' mindset in the extant items of the questionnaire; and in the three items that focused on the hands and fingers. For item 1, our results showed that 3/4 of patients characterize joint pain as persistent and continuous pain and 2/4 also added the sensation of compromised hand movements and pain when moving the fingers. In items 5, 6 and 7, which focused on the hands, we found that 3/4 of patients focused on the hand when asked about pain in the wrists and fingers (item 5); 3/4 of patients considered the fingers when asked about swelling in wrists and fingers, and 3/4 patients considered the hand or fingers as whole when asked about at least one finger hurt and swallowed.

For the health literacy demands, patients showed insufficient health literacy or low confidence in their health knowledge to answer autonomously items 2, 3 and 8, since 3/4 patients identified anti-inflammatory medication, 2/4 identified the lumbar region, and 3/4 identified the Achilles tendon. Regarding the concept of stiffness (item 3), 4/4 of patients described stiffness and the difficulty in moving the fingers and lack of strength in the hands and 2/4 of patients described stiffness and difficulty in walking.

For the potential sources of confusion regarding time perception, 4/4 of patients reported it was easy to recall symptoms in the presented periods. The same pattern of results was observed for the items including two types of symptoms, since 4/4 of patients reported they would answer *Yes* without hesitation, even when only one symptom was present.

DISCUSSION AND CONCLUSION

This research showed that the EARP questionnaire addresses the most important dimensions of the assessment of psoriatic arthritis and consists of a simple and short questionnaire that allows patients to focus on their joint pain and swelling and identify whether they have or not the symptoms described in each item. Our findings resulting from the linguistic and cultural adaptation of the EARP Questionnaire led to small changes, approved by the tool's main author, in some of the questionnaire items (Table II). This allowed us to develop a measure that eases the completion of the tool in a self-report format and favours a less diversified interpretation of the most confusing items, a version that is adapted to Portuguese patients' needs (Table III).

The cultural and linguistic adaptation of the questionnaire led to adapt the items with higher health lit-

TABLE III. Portuguese version of the EARP Questionnaire

1. Tem dores nas articulações?
2. Nos últimos três meses, tomou medicamentos anti-inflamatórios pelo menos duas vezes por semana?*
3. Acorda espontaneamente durante a noite devido a dores no fundo das costas?
4. Ao acordar, sente dificuldade em abrir e fechar as mãos, por prisão dos movimentos, por mais de 30 minutos?
5. Os seus pulsos ou dedos das mãos costumam doer?
6. Os seus pulsos ou dedos das mãos costumam inchar?
7. Pelo menos um dos seus dedos mãos ou dos pés dói e fica inchado durante 3 dias ou mais?
8. A região traseira do seu tornozelo (tendão de Aquiles) costuma inchar?
9. Costuma ter dores nos pés ou tornozelos?
10. Costuma ter dores nos cotovelos ou ancas?

*Nota da questão 2. Se existir confusão em relação ao que são medicamentos anti-inflamatórios, considerar os seguintes exemplos de medicamentos anti-inflamatórios: Naproxeno, Ibuprofeno, Diclofenac. EARP - Early Arthritis for Psoriatic Patients

eracy demand. As reported by experts and patients, the questionnaire required a medium level of health literacy from patients, which could prevent an autonomous completion of the tool or lead to misleading answers. To meet these potential sources of confusion, we substituted or added descriptions of medical concepts (e.g., the lumbar region was substituted by low back pain).

Our findings also led to adapting items in which the representation of joint pain was not unanimously clear. Experts showed concerns with the lack of specific contextual cues associated with the symptoms (e.g., refer to the awakening period instead of the morning period) and the lack of explicit reference to the continuous nature of pain and its presence in rest, but not in movement. This, thus, had the potential to induce misleading answers. Accordingly, patients' answers showed diversity in the representation of joint pain, since movement-related pain was referred to almost as frequently as continuous and persistent pain. These results led to adapting the verb tense of the respective items, to elicit a more continuous representation of pain, focusing on inflammatory pain, and avoiding movement-related pain.

Additionally, our findings showed that the potential source of confusion anticipated by experts regarding patients' capacity to process longer and more complex sentences was not perceived as such by patients, which showed that the sentences and periods were easy to un-

derstand.

It is noteworthy, however, that patients' answers showed diversity in the representation of joint pain, which was particularly evident in the initial item and the items focused on the hands. If in the first item the diversity of pain representations may be expected due to the item's general nature, in the items about specific body parts, this reason does not apply. The misrepresentation in the items that mention specific body parts may be explained by the poor distinction between types of symptoms, and continuous pain from swelling. However, our results showed that patients easily distinguished pain and swelling, leading us to argue that one of the major sources of this confusion may be the conjunction of the body parts in the same item. Although this does not reveal a limitation in patient's experience with the tool since patients tend to answer Yes even if they only have one symptom, the impact of this potential confusion should be investigated in future research.

In conclusion, we developed a Portuguese version of the EARP Questionnaire that can be used with confidence as a triage tool for PsA in dermatology consultations, thus contributing to reducing the underdiagnosis of PsA in Portugal. However, linguistic and cultural adaptation is not the final step. A validation study to assess the translation's measurement properties (validity, sensitivity) must be done for the Portuguese population to ensure the proposed tool behaves similarly to the original questionnaire. This validation study is already being developed.

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