ARTIGO ORIGINAL

Cross-cultural validation of the portuguese version of the Educational Needs Assessment Tool (PORTENAT)

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ABSTRACT

Objectives: To undertake a cross-cultural adaptation and validation of the educational needs assessment tool (ENAT) into Portuguese.

Methods: The first phase of this research (cross-cultural adaptation) utilised a well-established translation method comprising five sequential steps: forward--translation, synthesis of translations, back-translation, expert committee and field-testing of the adapted version. The second phase involved collecting data from 123 patients and subjecting them to Rasch analysis for validity testing including cross-cultural invariance.

Results: The translation and field-testing phase went smoothly giving rise to minor adjustments in the phrasing of some items. The preliminary analysis of the 39 items, revealed some deviations from the model with the overall item-person interaction fit statistics 2(df) =56.025 (39), p = 0.038. Significant item-item correlations caused artificial inflation of the internal consistency, therefore violating the model assumption of local independence of items. To correct this, all locally dependent items were then grouped into their respective domains, creating a 7 testlet-scale which demonstrated a good fit to the Rasch model, 2(df) = 2.625(7), p = 0.917 and internal consistency PSI = 0.975. Analysis of the pooled (Portuguese and the English) data revealed cross-cultural DIF, requiring adjustments in two testlets: 'treatments' and 'support' which ensured cross--cultural equivalence.

Conclusions: This study confirms the Portuguese ENAT is a robust unidimensional tool with which to **Keywords**: Patient Education; Self-management; Rheumatoid Arthritis; Cross-cultural adaptation; Tool validation.

INTRODUCTION

People with arthritis want to know more about their arthritis and the best way to manage it in their daily lives^{1,2}. In the face of well-entrenched arthritis myths and insufficient social marketing or public awareness campaigns, patient education (PE) and self-management programs are important, particularly given the substantial and increasing burden of arthritis on health-care resources and society3.

PE plays a particularly important role in the management of the patients with Rheumatoid Arthritis (RA)4 and usually begins when a person is first diagnosed. It can be both an illuminating and frustrating process, not only for the patients but also for their family, friends, coworkers and employers, and Health Professionals.

A Cochrane review in 2003 cast some doubts on the effectiveness of PE on health status in RA5. However, most studies in the review did not take into account the appropriateness of interventions at different stages of the patient's adjustment to their RA, which is unsurprising as a literature search found no tool that could be used for this purpose.

PE is a multi-dimensional process encompassing patients' beliefs, provider factors, and content and delivery methods, all of which complicate the choice of outcome measures and the assessment of effects. Over

assess the educational needs of Portuguese people with RA. Cross-cultural adjustments are required only if the data from Portugal and the UK are pooled or compared. The tool is now available for use in clinical practice and research.

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the past 10 years PE has advanced and newer studies suggest that PE is based on patients' needs and individual learning capabilities^{6,7}. This view has been reflected in recent RCTs which have been more specific in their methods and some long-term effects have been found⁸.

The Educational Needs Assessment Tool (ENAT)⁹ was developed as a quick and simple method of collecting data that ensures that patient education is relevant, appropriate and timely for the individual. The tool is a self-completed questionnaire comprising 39 items in 7 domains:

- 1. *Managing pain* individual medications, using heat/cold, distraction, relaxation, exercise, acupuncture, hydrotherapy.
- 2... *Movement* practical devices, lifting, energy conservation, rest/sleep, joint protection.
- 3. Feelings dealing with stress, moods/depression, fatigue.
- 4. *Arthritis process* cause, type of arthritis, heredity, treatments, disability, future.
- 5. *Treatments* need for medication, how to take it, side effects, reason for blood tests, X-rays, surgery, appliances.
- 6. *Self-help measures* alternative therapy, vitamins, what to avoid doing, home exercises, how much exercise, when to contact a doctor or a nurse.
- 7. *Support systems* helpful organisations, financial help, coping groups, getting the most out of consultations.

Patients score the items by ticking 5-point Likert scales ranging from 'not at all important' to 'extremely important'. There is also a front sheet for collecting demographic data and a space for patients to add any topics/questions that are not included in the questionnaire. It takes the patient only a few minutes to complete and provides data that enables the health professional to provide timely and meaningful education and information that is pertinent to each individual patient.

The ENAT was developed in the United Kingdom and was shown to be reliable (test/retest: ICC=0.823; p<0.01), valid and acceptable to patients who also commented on its ease of completion^{9,10}. Rasch analysis of the English version demonstrated its unidimensionality, reliability and robustness – working in the same way across different patient groups^{10,11}. The ENAT's measurement properties suggest that it can also be used as a research tool to accurately assess educational interventions¹²⁻¹⁴. The aim of this study was to

translate the ENAT into Portuguese (PortENAT) and to assess its cross-cultural validity in RA by using Rasch analysis.

METHODS

PARTICIPANTS

Participants were patients with RA attending the Rheumatology Department Outpatients Clinic at Coimbra University Hospital, in Coimbra, Portugal. The inclusion criteria were age >18 years, diagnosis of RA and ability to complete the questionnaire unaided. Exclusion criteria were (i) having any other rheumatic disease such as systemic lupus erythematosus, systemic sclerosis, psoriatic arthritis, ankylosing spondylitis and osteoarthritis, (ii) inability to read or write and (iii) those unwilling to participate. Participation was voluntary and ethical approval was obtained from Coimbra University Hospital Ethics Committee.

PROCEDURE

The study design was cross-sectional and followed standardised guidelines for cross-cultural adaptation and validation of patient-reported outcome measures^{15,16}. It was undertaken in two phases: (i) cross-cultural adaptation into Portuguese and (ii) validation of the adapted ENAT (PortENAT) using Rasch analysis.

PHASE 1: CROSS-CULTURAL ADAPTATION INTO PORTUGUESE:

The ENAT was translated into Portuguese using an established process for cross-cultural adaptation of patient reported outcome measures¹⁵. It comprises five stages: initial translation, synthesis of these translations, back translation, expert committee assessment and field-testing.

INITIAL TRANSLATION

The first stage in adaptation was a 'forward translation' from English (source language) into Portuguese (the target language), carried out by two independent translators whose mother tongue was Portuguese. The first translator was a professional bilingual translator (FA) and the second was a bilingual lay person (CA). The two translations were then compared, and discrepancies such as ambiguous wording in the original language, or discrepancies in how a word is translated were identified. Poor wording choices were discussed and resolved. The two translators each produced a written report

(T1 and T2)¹⁵ of their translation. Comments were included to highlight challenging phrases or uncertainties along with the rationale for final choices.

SYNTHESIS OF THESE TRANSLATIONS

To produce a synthesis of the two translations, a third, unbiased person was added to the team (MP). The role of this person was to serve as a mediator in the discussion of translation differences, and to produce a written documentation of the process. Working from the original questionnaire, as well as from the first (T1) and the second translator's (T2) version, a synthesis of these translations was produced, resulting in one common translation (T-12). A written report documenting the process, the issues addressed and how they were resolved was completed.

BACK-TRANSLATION

Working from the T-12 version of the ENAT, and totally blind to the original version, the questionnaire was then translated back into English by two bilingual back-translators (FA and CA), with English as their mother tongue, producing translations BT1 and BT2. This is a process of validity checking to make sure the translated version accurately reflects the item content of the original version.

EXPERT COMMITTEE

The composition of the expert committee included a methodologist (HJ), health professionals (MA), all the translators (both forward and backward) and the translation synthesis recorder. The original developer of the questionnaire was also included. The expert committee consolidated all the versions and components of the questionnaire and all translated versions (T1, T2, T12, BT1, BT2), and a final version of the ENAT was produced for field testing.

TEST OF THE ADAPTED VERSION

The field test of the adapted ENAT comprised 30 RA patients who completed the questionnaire unaided. They were then interviewed to probe what they thought was meant by each questionnaire item and their response. Both the meaning of the items and responses were explored. This ensured that the adapted version retained its equivalence. The distribution of responses was examined to look for a high proportion of missing items or single responses. Once completed, the questionnaires were summarised and analysed descriptively using the IBM SPSS software version 19¹⁷.

PHASE 2: VALIDATION OF THE ADAPTED ENAT BY RASCH ANALYSIS

The final translated version of the ENAT, the PortENAT was then completed by a consecutive sample of 123 patients with RA fulfilling the inclusion criteria. They were asked to return it at the end of the clinic consultation. The resultant questionnaires were entered into a database and prepared for analysis.

DATA ANALYSIS

The measurement properties of the PortENAT were tested by Rasch analysis using the Masters Partial Credit Model parameterisation¹⁸ in RUMM2020¹⁹ software. Rasch analysis is a mathematical modelling technique used to assess properties of outcome measures against a measurement model developed by the Danish mathematician Georg Rasch²⁰. The observed data from the adapted PortENAT were measured against the model to assess their goodness of fit, with 'good fit' indicating a criterion-related construct validity, reliability and statistical sufficiency²¹⁻²³. For the model fit, the observed value for the residuals of each item is expected to lie within lie within ±2.5, and to have a mean of zero and standard deviation of one. The overall fit statistics are given in terms of a c2 (item-person) interaction and its associated probability, which is expected to be non-significant (i.e. not deviating from the Rasch model). A more detailed description of the Rasch analysis approach, its use in rheumatology and the interpretation of fit statistics is given elsewhere²⁴.

For this analysis, the data from PortENAT were assessed for threshold ordering, individual item-fit and the assumption of local dependence of items. In addition, we tested the overall (item-person interaction) fit, internal consistency and the strict assessment of unidimensionality. Lastly, invariance to age, gender, disease duration and education background were assessed. Local dependency was defined as item-item correlation of greater than ±0.325. The locally dependent items were subsequently combined into subscales and each subscale treated as a 'testlet', which is defined as a subset of items that is treated as a measurement unit in test construction, administration and/or scoring²⁶. Strict unidimensionality of the PortENAT was assessed by using the independent t-test method suggested by Smith²⁷. The internal reliability was reported using Person Separation Index (PSI), which provides the estimate of the internal consistency of the scale.24 In order to avoid type I errors resulting from to multiple testing28 all p-values for fit statistics were Bonferroni-adjusted to the alpha level (i.e. p = 0.05/number of tests carried out). The expected values for perfect model fit are presented at the bottom of tables of results.

A questionnaire item is required to measure the trait of interest across different groups of people without bias. When people from different groups (age, gender, educational background) with the same level of latent trait have a different probability of giving a certain response on a questionnaire item, the item is said to display a differential item functioning (DIF)29. DIF was assessed using the inbuilt facility within RUMM2020 software, which uses a 2-way ANOVA of the person--item deviation residuals with person factors (e.g. age group, country of origin) and class intervals (group along the trait) as factors. Cross-cultural invariance is a requirement for questionnaires intended for multinational use30,31. The original UK dataset for RA was pooled with the Portuguese data to assess if PortENAT had retained its construct validity following its translation from the original (English) ENAT. The pooled dataset was also assessed for fit, local dependence and DIF by culture (cross-cultural DIF).

RESULTS

PATIENT CHARACTERISTICS

A total of 153 Portuguese patients were recruited in to this study, 30 for the cross-cultural adaptation phase and 123 for the cross-cultural validation phase. Of the 30 patients in the adaptation phase, 9 (30%) were male and 21 (70%) women. Their mean age was 51.3 years (range 23, 72) and disease duration 13.9 years (range 2, 35). The characteristics of patients in the validation phase are summarised in table I. Most of the respondents had a minimum of 11 years of formal education. Those with primary school education 53 (43.1%), secondary education 28 (22.8%) and university education were 33 (26.8%).

ADAPTATION INTO PORTUGUESE

In the translation of the ENAT, there were some minor difficulties associated with two items, one in the 'feelings' domain and the other in the 'arthritis process' domain. These were solved in the expert committee meeting carried out by all the translators and health professionals. In the pilot testing, the adapted version was well accepted by patients and minor changes in the treatment domain were needed — 'appliances' was changed to 'devices or appliances'. No additional questions were necessary.

TABLE I. CHARACTERISTICS OF INCLUDED PATIENTS FOR VALIDATION PHASE

| Characteristics | Values |
|--------------------------------|-------------|
| Age, Median (IQR) | 52 (43, 60) |
| Gender, number of women (%) | 88 (71.5) |
| Disease duration, Median (IQR) | 12 (7, 18) |
| Formal education, years (IQR) | 14 (11, 18) |
| Do you want education? (about | 118 (95.9) |
| rheumatoid arthritis) (% yes) | |
| How much information? | |
| Nothing | 0 (0) |
| Some things | 21 (17.1) |
| Lots of things | 32 (26.0) |
| Everything | 70 (56.9) |

CROSS-CULTURAL VALIDATION PHASE

Assessment of the response structure in the 39 items, revealed ordered thresholds in most items, indicating that the 5-point category response structure (not at all important, a little important, fairly important, very important and extremely important) was working as expected. This structure did not work well in few (6/39) items where patients failed to distinguish between 'a little important' and 'fairly important'.

The overall scale (39 items) had an excellent internal consistency (Cronbach's Alpha = 0.973). The test of fit revealed that 35/39 items residuals were within the expected (2.5) range. All items had a non-significant Bonferroni-adjusted Chi-square probability, indicating fit to the model (Table II).

While item-trait Chi-square statistics in table II suggested most of the 39 items fit the Rasch model; an assessment of the residual correlation matrix revealed significant item-item correlations (>0.3) indicating local dependency, which is a violation of the Rasch model. These locally dependent items were combined into 7 corresponding domains and the ENAT was re-analysed as a 7-testlet scale, resulting in acceptable fit to Rasch model expectations (Table III).

Table IV presents the results of a further test of fit, taking account of person ability (item-person interaction) suggesting initial (39 items) scale deviation from the Rasch model c2(df) = 56.025 (39), p = 0.038; PSI = 0.985 (Table IV, analysis 1) and subsequent fit to the Rasch model following correction for the local dependence (Table IV analysis 2). Analysis 1 is the preliminary analysis of the 39 items and analysis 2 is the analysis of the 7-testlet ENAT (having combined indivi

| Domains | Item | Location | SE | Fit residuals | DF | χ^2 | *P value |
|---------------------|------|----------|-------|---------------|---------|----------|----------|
| | 1 | -0.982 | 0.159 | 0.121 | 107.090 | 0.829 | 0.362 |
| | 2 | -0.472 | 0.138 | 0.437 | 107.090 | 0.179 | 0.673 |
| D : | 3 | -0.411 | 0.132 | -0.440 | 107.090 | 1.455 | 0.228 |
| Pain | 4 | 0.231 | 0.124 | 0.768 | 106.150 | 0.069 | 0.792 |
| | 5 | 0.379 | 0.126 | 1.392 | 105.210 | 1.323 | 0.250 |
| | 6 | 0.961 | 0.110 | 3.042 | 107.090 | 2.382 | 0.123 |
| | 7 | 0.953 | 0.113 | 3.135 | 107.090 | 2.114 | 0.146 |
| | 8 | 0.521 | 0.117 | 2.923 | 107.090 | 1.509 | 0.219 |
| Movement | 9 | 0.164 | 0.131 | 0.453 | 107.090 | 0.060 | 0.806 |
| | 10 | -0.046 | 0.126 | 0.348 | 107.090 | 0.017 | 0.897 |
| | 11 | -0.055 | 0.120 | 2.130 | 106.150 | 3.347 | 0.067 |
| | 12 | 0.189 | 0.135 | 0.600 | 107.090 | 0.055 | 0.815 |
| c 1: | 13 | 0.342 | 0.125 | -0.745 | 107.090 | 2.120 | 0.145 |
| Feelings | 14 | 0.359 | 0.120 | -0.913 | 106.150 | 0.144 | 0.704 |
| | 15 | 0.379 | 0.118 | -0.971 | 107.090 | 0.640 | 0.424 |
| | 16 | -0.120 | 0.119 | 1.355 | 107.090 | 0.086 | 0.770 |
| | 17 | -0.195 | 0.134 | 0.161 | 107.090 | 2.361 | 0.124 |
| | 18 | -0.366 | 0.132 | 2.209 | 107.090 | 0.251 | 0.616 |
| Disease process | 19 | -1.514 | 0.149 | -0.978 | 107.090 | 0.044 | 0.834 |
| • | 20 | -0.785 | 0.141 | -1.799 | 106.150 | 3.731 | 0.053 |
| | 21 | 0.110 | 0.120 | -1.502 | 107.090 | 4.305 | 0.038 |
| | 22 | -0.844 | 0.141 | 1.476 | 107.090 | 0.007 | 0.934 |
| | 23 | 0.160 | 0.130 | 0.585 | 107.090 | 3.999 | 0.046 |
| | 24 | -0.422 | 0.152 | 0.256 | 107.090 | 0.285 | 0.593 |
| | 25 | -0.483 | 0.150 | 0.308 | 107.090 | 0.283 | 0.595 |
| Treatments | 26 | 0.065 | 0.131 | -0.839 | 107.090 | 0.256 | 0.613 |
| | 27 | 0.115 | 0.131 | -1.141 | 107.090 | 0.013 | 0.908 |
| | 28 | 0.203 | 0.124 | 1.046 | 107.090 | 1.408 | 0.235 |
| | 29 | 0.755 | 0.118 | -0.234 | 107.090 | 0.406 | 0.524 |
| | 30 | 1.171 | 0.107 | 3.762 | 107.090 | 10.032 | 0.002 |
| | 31 | 0.079 | 0.126 | 0.312 | 107.090 | 0.932 | 0.334 |
| | 32 | -0.485 | 0.136 | -0.657 | 107.090 | 1.226 | 0.268 |
| Self-help | 33 | -0.450 | 0.148 | -0.938 | 107.090 | 1.783 | 0.182 |
| | 34 | -0.309 | 0.139 | -0.718 | 107.090 | 1.988 | 0.159 |
| | 35 | -0.002 | 0.139 | -0.100 | 106.150 | 0.044 | 0.834 |
| | 36 | 0.601 | 0.130 | 1.765 | 107.090 | 0.072 | 0.789 |
| | 37 | 0.363 | 0.124 | 0.436 | 106.150 | 0.622 | 0.430 |
| Support | 38 | 0.816 | 0.127 | 0.138 | 107.090 | 2.348 | 0.125 |
| | 39 | -0.973 | 0.151 | -0.561 | 106.150 | 3.302 | 0.069 |
| Expected values for | | | | Within ±2.5 | | | >0.05* |

DF, degrees of freedom; SE, standard error; *Bonferroni adjusted p-value > 0.0013 for model fit (i.e. 0.05/39 tests)

dual items into their respective domains. The 'testlet' solution resulted in an improved scale with better fit statistics c2(df) = 2.625 (7), p = 0.917 and internal consistency PSI = 0.975. To allow for cross-cultural in-

variance analysis, the Portugal dataset was pooled together with the original UK dataset and analysed in the same procedure described above (Table IV, analysis 1 and analysis 2).

TABLE III. INDIVIDUAL TESTLET-FIT STATISTICS

TABLE IV DECLUTE OF DACCU ANALYSIS

Expected values

for perfect fit

| Testlet | Location | SE | Fit Residuals | DF | Chi Square | *P-value |
|---------------------|------------------|-------|---------------|--------|------------|----------|
| Pain | 0.020 | 0.036 | 1.092 | 92.040 | 0.175 | 0.676 |
| Movement | -0.056 | 0.039 | 1.291 | 92.860 | 0.554 | 0.457 |
| Feelings | 0.175 | 0.042 | -1.181 | 92.860 | 1.158 | 0.282 |
| Disease process | -0.389 | 0.033 | 0.252 | 92.860 | 0.096 | 0.756 |
| Treatments | 0.170 | 0.033 | -0.238 | 93.680 | 0.080 | 0.777 |
| Self-Help | -0.088 | 0.037 | -0.125 | 92.860 | 0.070 | 0.792 |
| Support | 0.169 | 0.043 | 1.069 | 92.860 | 0.491 | 0.484 |
| Expected values for | perfect model fi | t | Within ±2.5 | | | >0.05* |

DF, degrees of freedom; SE, standard error, *Bonferroni adjusted p-value >0.0071 for model fit (i.e. 0.05/7 tests)

| TABLE IV. RESULTS OF RASCH ANALYSIS | | | | | | | | | | | |
|-------------------------------------|--------------|----------|-------|----------|-------|---------------|----------|-------|-----|----------------------|--|
| | | Item | Fit | Perso | n Fit | Chi-Squa | are | | | Independent | |
| | | Residual | | Residual | | Interaction | | | | T-Tests | |
| Country | Analysis | Mean | SD | Mean | SD | Value (DF) | p-value* | PSI | N | (95% CI) | |
| Portugal | Analysis 1 | 0.426 | 1.355 | -0.515 | 2.624 | 56.025 (39) | 0.038 | 0.985 | 114 | 0.105 (0.065, 0.145) | |
| Tortugar | Analysis 2 | 0.309 | 0.901 | -0.449 | 1.337 | 2.625 (7) | 0.917 | 0.975 | 114 | 0.105 (0.065, 0.145) | |
| UK | Analysis 1 | 0.340 | 1.686 | -0.269 | 1.008 | 71.281 (39) | 0.001 | 0.972 | 119 | 0.068 (0.028, 0.107) | |
| UK | Analysis 2 | 0.541 | 0.699 | -0.308 | 1.168 | 7.116 (7) | 0.417 | 0.947 | 119 | 0.008 (0.028, 0.107) | |
| Pooled | Analysis 1 | 0.607 | 2.188 | -0.486 | 2.472 | 275.635 (117) | < 0.001 | 0.980 | 233 | 0.065 (0.027, 0.002) | |
| rooieu | Analysis 2 | 0.481 | 1.137 | -0.457 | 1.352 | 19.824 (21) | 0.532 | 0.961 | 233 | 0.065 (0.037, 0.093) | |
| DIF Adjus | ted analysis | 0.468 | 1.033 | -0.450 | 1.353 | 15.860 (27) | 0.956 | 0.962 | 233 | | |

SD, standard deviation; DF, degrees of freedom; *p-value >0.5 for model fit; PSI, person separation index; Analysis 1, preliminary analysis with 39 items; Analysis 2, analysis of testlets

The pooled dataset was invariant (no DIF) to age, gender, disease duration and educational background. Cross-cultural non-invariance (DIF by culture) was present on two testlets, 'treatments' and 'support' where the Portugal dataset was consistently under-discriminating and over-discriminating in the latter (Figure 1).

While the PortENAT works with no bias when used in Portugal, adjustment for the cross-cultural bias is required if the data from Portugal are pooled or compared with the UK data. Cross-cultural DIF adjustments were undertaken resulting in the 'adjusted conversion chart' (Table V). The conversion chart helps to transform the raw data, which are at ordinal level into interval-level data allowing more flexible statistical analyses and also provides equivalence of measurements when comparing the data from Portugal and the UK.

DISCUSSION

This study used standardised methods for cross-cultural adaptation of outcome measures to develop a Portuguese version of the ENAT (PortENAT). The adaptation into Portuguese was seamless, needing no significant changes. The translated version (PortENAT) was well received by patients. Rasch analysis demonstrated that the construct validity and its measurement properties were maintained after adaptation process. Indeed the tool worked without bias across different groups (gender, age groups, disease duration and educational backgrounds). However there was DIF on some items, which is not uncommon in patient-reported outcome measures, 11,32,33 and adjustment for this is required (using the provided conversion table) in order to ensure accurate estimates when data is com-

>0.05 | >0.85

Lower bound CI

< 0.05

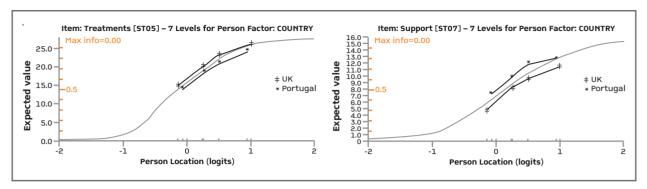


FIGURE 1. Item characteristic curve displaying cross-cultural DIF in 'treatments' and 'support'

| TABLE V. CONVERSION CHART ADJUSTED FOR CROSS-CULTURAL DIF | | | | | | | | | | |
|---|------|----------|----------|------------|------------|----------|-----------|---------|----------|--|
| Rasch transformed scores | | | | | | | | | | |
| Raw | | | | Arthritis | UK | | | Support | Support | |
| scores | Pain | Movement | Feelings | Treatments | Treatments | Portugal | Self-Help | UK | Portugal | |
| 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | |
| 1.0 | 1.1 | 2.0 | 1.3 | 0.8 | 2.4 | 0.9 | 0.6 | 1.4 | 1.7 | |
| 2.0 | 1.9 | 3.4 | 2.2 | 1.5 | 4.1 | 1.5 | 1.2 | 2.4 | 3.0 | |
| 3.0 | 2.5 | 4.4 | 2.9 | 2.0 | 5.3 | 2.0 | 1.7 | 3.3 | 3.9 | |
| 4.0 | 2.8 | 5.3 | 3.5 | 2.4 | 6.3 | 2.3 | 2.3 | 3.9 | 4.5 | |
| 5.0 | 3.5 | 6.0 | 4.1 | 2.8 | 7.0 | 2.6 | 2.6 | 4.6 | 5.2 | |
| 6.0 | 4.1 | 6.8 | 4.6 | 3.2 | 7.7 | 3.1 | 3.0 | 5.3 | 5.8 | |
| 7.0 | 4.5 | 7.4 | 5.2 | 3.6 | 8.4 | 3.4 | 3.6 | 6.1 | 6.4 | |
| 8.0 | 5.0 | 8.2 | 5.8 | 4.0 | 9.1 | 3.6 | 4.0 | 7.1 | 7.0 | |
| 9.0 | 5.5 | 9.0 | 6.5 | 4.4 | 9.8 | 4.1 | 4.5 | 8.1 | 7.6 | |
| 10.0 | 6.1 | 9.8 | 7.3 | 4.8 | 10.4 | 4.4 | 5.1 | 9.1 | 8.3 | |
| 11.0 | 6.9 | 10.6 | 8.2 | 5.4 | 11.1 | 4.9 | 5.9 | 10.0 | 9.0 | |
| 12.0 | 7.9 | 11.4 | 9.2 | 6.0 | 11.8 | 5.3 | 7.4 | 10.9 | 9.8 | |
| 13.0 | 9.2 | 12.2 | 10.2 | 7.0 | 12.5 | 5.7 | 9.4 | 11.8 | 10.8 | |
| 14.0 | 10.6 | 13.0 | 11.6 | 8.6 | 13.3 | 6.5 | 11.2 | 12.8 | 12.0 | |
| 15.0 | 11.9 | 13.8 | 13.4 | 10.4 | 14.0 | 7.5 | 12.9 | 14.2 | 13.7 | |
| 16.0 | 13.2 | 14.5 | 16.0 | 12.3 | 14.7 | 8.7 | 14.3 | 16.0 | 16.0 | |
| 17.0 | 14.3 | 15.4 | | 14.1 | 15.5 | 9.9 | 15.5 | | | |
| 18.0 | 15.3 | 16.5 | | 15.7 | 16.2 | 11.2 | 16.5 | | | |
| 19.0 | 16.3 | 17.9 | | 17.0 | 17.0 | 12.5 | 17.4 | | | |
| 20.0 | 17.3 | 20.0 | | 18.2 | 17.7 | 13.8 | 18.4 | | | |
| 21.0 | 18.4 | | | 19.2 | 18.5 | 15.0 | 19.4 | | | |
| 22.0 | 19.7 | | | 20.1 | 19.2 | 16.3 | 20.6 | | | |
| 23.0 | 21.6 | | | 21.0 | 20.0 | 17.5 | 22.1 | | | |
| 24.0 | 24.0 | | | 22.0 | 20.9 | 18.9 | 24.0 | | | |
| 25.0 | | | | 23.0 | 22.0 | 20.3 | | | | |
| 26.0 | | | | 24.4 | 23.2 | 22.0 | | | | |
| 27.0 | | | | 26.0 | 25.1 | 24.6 | | | | |
| 28.0 | | | | 28.0 | 28.0 | 28.0 | | | | |

The bold columns indicate the adjustment needed if the two countries were to be pooled or compared

pared or pooled30,34.

This research has validated the PortENAT in RA. and it can now be used with confidence in the clinical practice or in patient education research. In the clinical practice, the clinicians can use it as a template to assess patients' perception of their priority educational needs and it does not require any scoring. Patients completing the ENAT have expressed how it enables them to identify needs which they would not have otherwise considered^{10,35}. The clinician using the ENAT can then provide the education taking into account of patient's perceived needs. This enables the provided education to be relevant and likely to be more meaningful to patients. The use of PortENAT for research or audit purposes ensures accurate estimation of the educational needs of patients with RA. The instructions of how the PortENAT is used and scored, is provided in the online supplementary material. The tool can be obtained by writing to the Psychometric Laboratory at the University of Leeds: http://www.leeds.ac.uk/ medicine/rehabmed/psychometric/index1.htm

The main limitations to this research is that the data were collected from one rheumatology centre in Portugal and further cross-cultural validation may be required if PortENAT is to be used in other Portuguese speaking countries. Secondly, inevitably, the ENAT items do not cover everything that is known about RA and future developments will address this limitation by creating item banking for computerised adaptive assessment, which will ensure more and 'dynamic' items delivered according to need.

A gold standard translation process has been used to develop a Portuguese version of the Educational Needs Assessment Tool – PortENAT. Rasch analysis has confirmed that PortENAT is a robust, 7-subscale measure of educational needs for people with RA in Portugal. PortENAT can be used with confidence in Portugal and cross-cultural comparisons can be undertaken using the calibrated scales.

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ANEXO

COMO UTILIZAR E PONTUAR A VERSÃO PORTUGUESA DO QUESTIONÁRIO DE AVALIAÇÃO DAS NECESSIDADES EDUCACIONAIS (PORTENAT)

INFORMAÇÃO INICIAL

O Questionário de Avaliação das Necessidades Educacionais é um questionário auto administrado que contém 39 questões que avaliam as necessidades educacionais dos doentes com artrite reumatóide. As questões estão agrupadas em 7 domínios ou «super itens» que avaliam aspetos específicos das «necessidades educacionais». Os itens são:

- 1. Gestão da dor
- 2. Movimento
- 3. Sentimentos
- 4. Conhecimentos sobre a artrite
- 5. Tratamento por profissionais de saúde
- 6. Medidas de autoajuda
- 7. Apoio de outros

UTILIZAÇÃO DO ENAT

O PortENAT pode ser utilizado por profissionais de saúde nas enfermarias ou consultas para avaliar quais as necessidades educacional/informação prioritárias do ponto de vista do doente. Esta informação, em conjunto com a percepção do profissional de saúde acerca da informação que o doente precisa, irá permitir uma oferta educacional mais oportuna e significativa, à medida das necessidades individuais de cada doente.

O PortENAT pode também ser utilizado por investigadores para avaliar as necessidades educacionais dos doentes ao longo do tempo e após uma intervenção educacional. Por exemplo, alterações nas necessidades educacionais podem ser avaliadas comparando os resultados do PortENAT no início e no final de um determinado estudo.

COMO É QUE O PORTENAT É PREENCHIDO

O PortENAT foi desenhado para ser preenchido pelo doente sozinho. Esta metodologia fornece informações objetivas livres de viés. A primeira página fornece informações sobre as características pessoais e uma informação geral das necessidades educacionais do doente. Esta página não é uma parte integrante do ENAT e cabe ao profissional de saúde decidir se esta informação é necessária. Por exemplo, pode ser útil para fins de investigação, mas não para a prática clínica.

Os itens do PortENAT começam na página 2. Cada item é avaliado usando uma escala de Likert de 5 pontos com os seguintes descritivos: «Nada importante», «Pouco importante», «Bastante importante», «Muito importante» e «Extremamente importante».

A partir deste momento, o paciente deve colocar um visto " $\sqrt{}$ " na caixa que corresponde ao nível de importância que atribui em cada pergunta. Apenas uma caixa deve ser assinalada para cada pergunta.

COMO É QUE O PORTENAT É PONTUADO?

O PortENAT pode ser utilizado na prática clínica como *checklist*, ou como uma ferramenta de investigação (ou em auditorias).

PORTENAT UTILIZADO NA PRÁTICA CLÍNICA COMO CHECKLIST

O profissional de saúde pode querer saber qual é o item mais importante para o doente num determinado momento, permitindo-lhe concentrar-se sobre esse tema durante a sua consulta. Neste caso, as necessidades educacionais prioritárias para o doente podem ser determinadas observando o PortENAT sem a necessidade de pontuar (Exemplo 1).

Exemplo 1: Este item é relacionado com os seus sentimentos:

| Neste momento, qual é a importância | Nada | Pouco | Bastante | Muito | Extremamente |
|--|------------|------------|------------|------------|--------------|
| que dá a saber mais sobre o seguinte: | importante | importante | importante | importante | importante |
| Maneiras de lidar com o stress | √ | | | | |
| Maneiras de lidar com as variações | | | | | |
| de humor ou com a depressão | | √ | | | |
| Porque me sinto cansado(a) | | | | | V |
| Porque me sinto em baixo ou deprimido(a) | | | | V | |

PORTENAT UTILIZADO COMO FERRAMENTA DE INVESTIGAÇÃO OU DE AUDITORIA

Para utilização no processo investigação ou de auditoria, o PortENAT precisa ser codificado e pontuado seguindo os seguintes passos:

(i) As escalas de Likert do PortENAT devem ser codificadas e pontuadas da seguinte forma:

Nada importante = 0
Pouco importante = 1
Bastante importante = 2
Muito importante = 3
Extremamente importante = 4

Ver o exemplo 2 em baixo:

Exemplo 2: Este item é relacionado com os seus sentimentos:

| Neste momento, qual é a importância que dá a saber mais sobre o seguinte: | Nada importante (0) | Pouco importante (1) | Bastante importante (2) | Muito importante (3) | Extremamente importante (4) |
|---|---------------------------|----------------------|-------------------------|----------------------|-----------------------------|
| Maneiras de lidar com o stress | V | | | | |
| Maneiras de lidar com as variações de humor ou com a depressão | | V | | | |

- (i) Após a codificação, as pontuações de cada pergunta são então somadas para fornecer a **pontuação do domínio**. No exemplo acima, a pontuação do domínio é = 8 (pontuação do domínio sentimentos deve variar entre 0 16).
- (ii) A pontuação dos domínios obtidos em (i) precisa ser transformada em escala linear, para permitir a sua utilização em análises paramétricas. Isto é feito utilizando a tabela de conversão fornecida abaixo. No exemplo 2 relativo aos sentimentos, a pontuação do domínio bruto de 8, corresponde a uma **pontuação do domínio transformado** de 7,7 (Veja a tabela de conversão).
- (iii) Somando-se todas as pontuações dos domínios transformados numa escala linear obtém-se a **pontuação to-tal do PortENAT** que é uma estimativa das necessidades educacionais dos doentes (variação = 0 -156)

TABELA I. CONVERSÃO DA PONTUAÇÃO DOS DOMÍNIOS EM VALORES OBTIDOS POR TRANSFORMAÇÃO RASH

Valores obtidos por transformação Rash Pontuação do domínio Sentimentos Dor Movimento Artrite Tratamento Autoajuda Apoio 0.0 0.0 0.0 0.0 0.0 0.0 0.0 0.0 2.2 1.0 1.9 1.8 2.1 1.5 2.7 1.8 2.0 4.5 3.1 3.1 3.6 3.6 2.7 3.0 3.0 5.6 4.1 4.0 4.6 4.6 3.6 4.0 4.0 4.8 4.8 5.4 5.6 4.3 4.8 6.6 5.0 7.3 5.7 6.3 5.0 5.5 5.6 6.2 7.1 5.5 6.0 8.1 6.2 6.3 6.9 6.1 7.0 8.7 6.8 7.0 7.5 7.8 6.1 6.8 8.0 9.3 7.4 7.7 8.2 8.4 6.8 7.5 9.0 9.9 8.1 8.3 8.9 9.1 7.5 8.1 10.0 10.5 8.7 9.0 9.5 9.8 8.2 8.9 11.0 11.1 9.3 9.7 10.3 10.4 9.1 9.6 12.0 11.6 10.0 10.5 11.2 11.3 10.2 10.4 13.0 12.2 10.7 11.4 12.0 12.1 11.3 11.3 14.0 12.8 11.5 12.5 13.0 13.1 12.4 12.3 15.0 13.9 13.5 13.9 13.4 12.3 13.9 14.1 16.0 14.1 13.1 16.0 15.1 14.9 14.4 16.0 17.0 14.6 14.3 15.9 15.9 15.3 18.0 15.3 15.5 16.9 16.7 16.2 19.0 16.1 17.4 17.7 17.4 17.1 20.0 17.0 20.0 18.4 18.2 18.0 21.0 17.9 19.2 19.0 18.9 22.0 19.3 20.0 19.7 20.0 23.0 21.1 20.8 20.5 21.7 24.0 24.0 21.6 21.3 24.0 25.0 22.6 22.3 26.0 23.9 23.7 27.0 25.6 25.3 28.0 28.0 28.0

Preparado por Mwidimi Ndosi & Jackie Hill (2011)