









Portuguese translation and validation of the Patient Generated Index instrument for patients with Chronic Obstructive Pulmonary Disease: individualized quality of life assessment

Renato Fleury Cardoso^{1,2} , Danny Ruta³ , Thessália Miranda de Oliveira¹ , Maria Carolina Barbosa Costa¹ , Alenice Aliane Fonseca^{1,2} , Pedro Henrique Scheidt Figueiredo^{1,2} , Alessandra de Carvalho Bastone^{1,2} , Marcus Alessandro de Alcântara^{1,2} , Ana Cristina Rodrigues Lacerda^{1,2} , Vanessa Pereira Lima^{1,2} 

1. Departamento de Fisioterapia, Universidade Federal dos Vales do Jequitinhonha e Mucuri, Diamantina (MG) Brasil.
2. Programa de Pós-graduação em Reabilitação e Desempenho Funcional, Universidade Federal dos Vales do Jequitinhonha e Mucuri, Diamantina (MG) Brasil.
3. Guy's Cancer Centre, Guy's Hospital, Great Maze Pond, London, United Kingdom

Submitted: 15 August 2019.

Accepted: 06 December 2019.

Study carried out in the Laboratório de Fisiologia do Exercício, Universidade Federal dos Vales do Jequitinhonha e Mucuri, Diamantina (MG), Brasil.

ABSTRACT

Objective: To translate, adapt and validate the Patient Generated Index (PGI) for Brazilians with chronic obstructive pulmonary disease (COPD). **Methods:** 50 volunteers with COPD, mostly men (74%), with 73.1 ± 8.9 years of age, FEV1 of $52.3 \pm 14.5\%$ of predicted and FEV1 / FVC of $56.2 \pm 8.6\%$ of predicted responded to PGI, to the Saint George Respiratory Questionnaire (SGRQ) and to perform Glitter Activities of Daily Living test (Glitter ADL). After 1-2 weeks, PGI was again applied for the analysis of relative and absolute reliability. **Results:** The translation occurred without changes in the questionnaire. The score obtained in PGI had weak correlation with the SGRQ total score ($r = -0.44$, $p < 0.001$) and with the impact domain ($r = -0.40$, $p < 0.05$), presented a moderate correlation with the symptoms domain of the SGRQ ($r = -0.55$, $p < 0.001$) and weak correlation with the activity domain ($r = -0.31$, $p < 0.05$). A weak correlation was observed between PGI and Glitter ADL ($r = -0.30$; $p < 0.05$). It was observed high reliability among the measures of PGI (ICCr = 0.94). **Conclusion:** This study shows that the Brazilian version of PGI is a reliable and valid instrument to measure health-related quality of life (HRQL) in patients with COPD. It is a new and individualized form of evaluation of COPD patient-centered quality of life.

Keywords: Quality of life; Chronic obstructive pulmonary disease; Reproducibility of results and translations.

INTRODUCTION

The study of health-related quality of life (HRQoL) in individuals with chronic obstructive pulmonary disease (COPD) has traditionally been carried out using structured questionnaires such as the *Saint George's Respiratory Questionnaire* (SGRQ),⁽¹⁾ the *Chronic Respiratory Questionnaire* (CRQ),⁽²⁾ and the *Airways Questionnaire 20* (AQ20).⁽³⁾ Such questionnaires are structured in domains and each one, has questions that specifically address an area that is known to be affected by COPD. Although extremely useful in clinical practice, structured questionnaires do not allow stipulating the relevance or importance of a particular factor or domain in an individualized way. Thus, tools that enable patient-centered assessment can provide additional information on the importance of a particular aspect of HRQoL, as well as infer which components

of the International Classification of Functionality and Disability (ICF) could be most affected.

Given the patient-centered approach, Ruta et al.⁽⁴⁾ developed the questionnaire **Patient Generated Index (PGI)**, which uses an innovative approach to measure HRQoL and can be adapted to different diseases and/or treatment conditions.⁽⁴⁾ Patients are directed to define the most important areas of their lives that are affected by the disease, reporting the degree of importance for each area and classifying them in terms of relevance.⁽⁵⁾

This instrument is valid, reliable and responsive in several health conditions⁽⁴⁻⁷⁾ however, to date, there are no versions translated into Portuguese and its application in COPD patients is not known. Therefore, the main objective of the present study was to carry out the cross-cultural adaptation of the PGI to the Portuguese language spoken

Correspondence to:

Vanessa Pereira Lima. Departamento de Fisioterapia, Universidade Federal dos Vales do Jequitinhonha e Mucuri, Campus JK, Rodovia MGT 367, Km 583, 5000, Alto da Jacuba, CEP 39100-000, Diamantina, MG, Brasil.

Tel.: 55 38 3532-8994. E-mail: vanessa.lima@ufvjm.edu.br

Financial support: Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq), Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) and Fundação de Amparo à Pesquisa do Estado de Minas Gerais (FAPEMIG).

in Brazil and to evaluate the validity in a population of individuals with COPD. As a secondary objective, to analyze the content of the PGI responses regarding the components of the ICF.

METHODS

It is a study of cross-cultural adaptation and analysis of measurement properties, which was carried out in two phases: translation into Portuguese and cross-cultural adaptation of the PGI instrument; and analysis of psychometric properties for patients with COPD. The convergent analysis was performed using the Glittre ADL test and the competitor with the Saint George's Respiratory Questionnaire (SGRQ). The study was approved by the Research Ethics Committee of the Federal University of Vales do Jequitinhonha e Mucuri (UFVJM) (CAAE n. 73581917.4.0000.5108), and all participants signed the Free and Informed Consent Form (TCLE). The study was conducted from May 2017 to March 2019.

The methodology for translation and cross-cultural adaptation was based on

Guillemin et al.⁽⁸⁾ The use of the instrument was authorized by the author who recommended the version of the PGI used for the disease-specific adaptation of the version developed by Camfield and Ruta.⁽⁹⁾

The translation of the questionnaire was carried out by two independent bilingual translators, fluent in English and native speakers in Portuguese. After the reconciliation in which a third translator proposed a final translation, the version was then back-translated into English, by 2 independent translators, bilingual native speakers of English and fluent in Portuguese. Both back-translations were sent to the author of the original instrument for consideration. Since no divergences were found between the original and translated versions, the pre-test stage started in individuals with COPD.

In the Portuguese version, the name and abbreviation of the instrument in English were maintained to facilitate its recognition (Figure 1).

Participants were recruited at a University Physiotherapy School Clinic, doctors' offices and hospitals in the city. The study inclusion criterion was the clinical diagnosis of COPD confirmed by spirometry.⁽¹⁰⁾ The exclusion criteria were: illiterate individuals or those unable to understand the questionnaire or follow the instructions, cognitive impairment, clinical instability in the month before the evaluation, presence of severe or limiting disease and individuals unable to perform any of the evaluations. To characterize the sample, participants underwent spirometry (Pony Graphic, Cosmed, Rome, Italy), following the Guidelines for Lung Function

Name: _____ Date: _____

Part 1. List the areas	Part 2. Score the areas	Part 3. Distribute points																																																
<p>In this part, we would like you to think about the five most important areas of your life that are affected by your health problem / special needs, and write them in the spaces below.</p>	<p>Please rate each area you listed in Part 1. The note must show how much you have been affected by your health problem / special needs in the past week. Give each area a score by circling a number.</p>	<p>We want you to "spend" 10 points to show which areas of your life you consider most important to your overall quality of life. Spend more points in the areas that you consider most important to you and fewer points in areas that you consider less important. You do not need to spend points in all areas. You cannot spend more than 10 points in total.</p>																																																
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Figure 1. Final version of the PGI in Portuguese.

Tests.⁽¹¹⁾ Anthropometric measurements were recorded. The strategy for PGI validation included convergent validity with the SGRQ questionnaire and divergent validity with the Glittre ADL functional test and analysis of test-retest reliability and absolute reliability, by calculating the Standard Error of the Measure (EPM) and the Minimum Detectable Difference (MDD). The pre-test sample consisted of 5 individuals who completed the PGI (translated and back-translated version), with no misinterpretation of the text; this version was used in the study.

Fifty individuals⁽¹²⁾ diagnosed with COPD composed the sample for validation of the instrument. 7-14 days after the first assessment and application of the PGI, the patients responded to the PGI again. PGI and SGRQ were applied in the form of an interview, and the same researcher conducted all the interviews.

Patient-Generated Index (PGI) is completed in three stages: (1) individuals identify, at most, the five most important areas of their life affected by COPD, (2) then assess how much each area has been affected by the disease using a scale of 0 to 6, where 0 is the worst imaginable and 6 exactly as they would like it to be; (3) in the final stage, individuals distributed 10 points seeking to reflect their relative importance, that is, giving more points for the most important areas in their life and fewer points for the less important areas identified in step 1. All 10 points must be distributed.⁽⁹⁾ The calculation of the total PGI score is given according to Figure 2.

SGRQ is a questionnaire structured in 76 items, where each item has a certain score and the assessment of the quality of life is divided into the domains: symptoms,

activity and psychosocial impact of respiratory disease. The final result is the sum of the scores of the items in each domain, generating a score, which ranges from 0 (without reducing the quality of life) to 100 (maximum quality of life reduction); considering the percentage reached by the patient regarding the maximum score and the total score obtained for that domain, in addition to the percentage of this maximum.⁽¹³⁾

Glittre ADL was carried out in a 10-meter corridor, bounded on one side by a chair and on the other by a bookcase. The volunteer started the test sitting on the chair, carrying a backpack containing a weight of 2.5 kg for women or 5 kg for men. The marking of the time spent for the execution, using a stopwatch, was started immediately after the individual was notified of the start of the test. The volunteer was instructed to walk the corridor through a three-step staircase located in the middle of the corridor and towards the bookcase. On the shelf there were three weights of 1 kg each, located on a shelf adjusted to the height of one's shoulder girdle. The individual was instructed to transfer the weights to a lower shelf, adjusted to the height of his pelvic girdle and then to the floor. Then, he/she should return the weights to the same shelves and the highest shelf and return the route until he/she sits back on the chair. The test execution time was recorded using a stopwatch. The volunteer had to do this route five times, in the shortest time possible, without running.⁽¹⁴⁾

The analysis of PGI responses was based on the linking process according to the methodology proposed by Cieza et al.⁽¹⁵⁾ These are ten rules for linking the domains or issues addressed in an instrument and the ICF. To analyze the content of the responses rules 5 (Identify and document the categorization of response

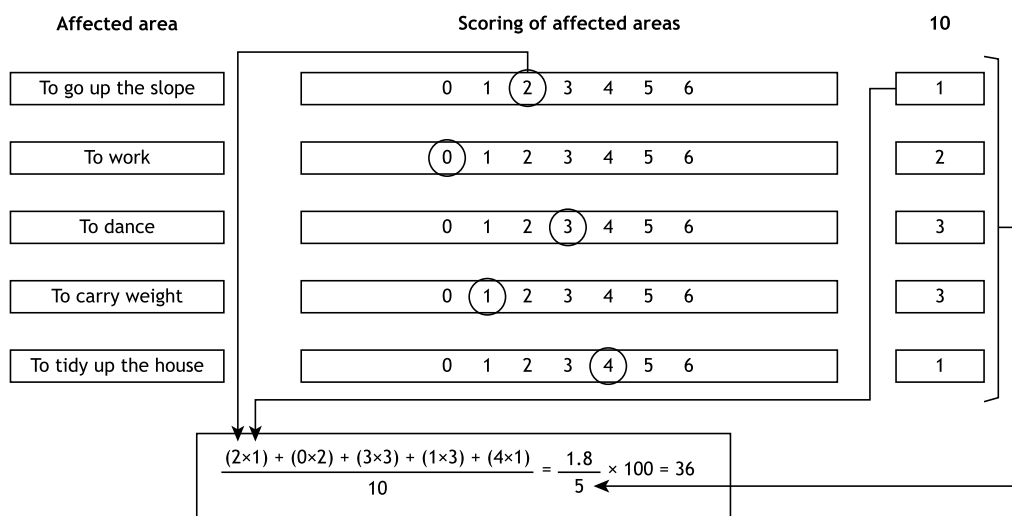


Figure 2. Score of the PGI questionnaire. The PGI score is calculated by multiplying the classification score in phase 2 by the proportion of the 10 points allocated in phase 3 for each area, adding the results and dividing them by 10. To generate a scale score of 100, divide the result obtained by the number of areas identified in phase 1 and multiplies by 100, with Zero being the worst possible HRQoL and 100 being the best HRQoL.

options) and 6 (Link the main, relevant and/or additional concepts to the most accurate category of the ICF) were applied since the PGI is a patient-centered instrument. Two independent researchers proceeded to link the responses to the ICF concepts; a third researcher with experience in using the ICF⁽¹⁵⁾ resolved potential divergences.

For statistical analysis, the program IBM SPSS Statistics, version 20.0 (IBM Corporation, Armonk, NY, USA) was used. The normality of the data was assessed by the Shapiro-Wilk test. The validity analysis was performed using Spearman's correlation coefficients. Coefficients between 0 and 0.25 showed a negligible correlation; 0.25 and 0.50 weak correlation; 0.50 and 0.75 moderate correlation; and > 0.75 strong correlation.⁽¹⁶⁾ Test-retest reliability was analyzed using the intraclass correlation coefficient (ICCr), alpha model, two-way random effects (model alpha, 2-way random-effects model) and agreement using the Bland-Altman diagram. High reliability was considered when ICCr \geq 0.90. Absolute reliability was assessed by EPM and MDD, according to the equations described below.⁽¹⁷⁾ EPM was estimated by the equation: $EPM = DP * \sqrt{(1-r)}$, in which DP represents the standard deviation of the sample and r the ICCr. MDD was estimated using the formula: $MDC_{indiv} = EPM * 1,65 * \sqrt{2}$, where 1.65 represents the z-score of the 90% confidence interval and $\sqrt{2}$ represents the number of errors associated with the repeated measure. The comparison between the two tests was performed using the paired Wilcoxon test. Statistical significance was considered when $p < 0.05$ in all analyzes.

RESULTS

The Portuguese translation of the PGI instrument was carried out, obtaining a version without major adaptations. Of 52 individuals evaluated, two individuals were excluded: one for having a hypertensive peak before starting Glittre ADL and the other for not being able to perform it (balance deficit). Fifty COPD patients made up the final sample. The sample characteristics are shown in Table 1. The mean PGI score was 43.5 ± 15.0 points. The 50 patients listed 229 areas, on the first day of PGI administration, which were grouped into 28 categories; the five most cited categories were walking fast, climbing a slope/ladder, working, lifting weights and dancing. Additional material can be found in the [Supplementary Material](#) (Chart S1 and Table S1).

The score obtained in the PGI had a weak correlation with the total score of the SGRQ ($r = -0.44$; $p < 0.001$) and with the impact domain ($r = -0.40$; $p < 0.05$); moderate correlation with the symptoms domain ($r = -0.55$; $p < 0.001$); and weak correlation with the activities domain ($r = -0.31$; $p < 0.05$). Weak correlation was found with Glittre ADL ($r = -0.30$; $p < 0.05$).

When classifying the categories cited according to the ICF, we found that most of the patients' responses comprised the activities and participation domains, with the activities domain being the predominant one (126 responses) (Table S1). The results presented in Figure 3 point to 229 responses distributed in 28 categories after the content analysis (Chart S1), which were distributed in 20 items for the activities and participation component (d), one item for environmental factors and two items for personal factors. No response included domains of the body functions and structures component.⁽¹⁸⁾

Seven domains of the activity and participation component were mentioned in the participants' responses: mobility, self-care, home life, interpersonal interactions and relationships, main areas of life and community, social and civic life. The mobility domain stood out with eight items affected among individuals with COPD.

There was no statistically significant difference between the 1st and 2nd measurements of the PGI (95% CI -1.6-2.1); $p = 0.788$. Excellent test-retest reliability was observed ICCr = 0.94 (IC 95%: 0.91-0.97). EPM and MDD for PGI were 4.7 and 10.8, respectively. The Bland-Altman diagram showed agreement between measures 1 and 2 of the PGI, with Bias = 0.3 (Figure 4).

Table 1. Sample characteristics (n= 50).*

Age (years)	73.14 \pm 8.96
BMI (Kg/m ²)	24.13 \pm 3.60
FVC (L)	2.85 \pm 0.60
FVC% of predicted	72.50 \pm 14.94
FEV ₁ (L)	1.75 \pm 0.63
FEV ₁ % of predicted	52.99 \pm 14.50
FEV ₁ /FVC %	56.18 \pm 8.63
GOLD, stages II-III-IV, n (%)	
II	38 (76)
III	6 (12)
IV	6 (12)
Schooling in years, n (%)	
0 to 4 years	12 (24)
5 to 9 years	22 (44)
More than 9 years	16 (32)
PGI (Day 1)	43,50 \pm 14,95
PGI (Day 2)	42,25 \pm 14,47
Total SRGQ	45.56 \pm 14.53
Activity	55.83 \pm 17.72
Impact	38.19 \pm 15.61
Symptoms	49.33 \pm 19.18
Glittre ADL (min)	06.25 \pm 1.89

BMI: body mass index; FVC: forced vital capacity; FEV₁: forced expiratory volume in the first second; FEV₁/FVC: the relationship between forced expiratory volume in the first second and forced vital capacity; PGI: *Patient-Generated Index*; SGRQ: *Saint George Respiratory Questionnaire*; Glittre ADL: *Glittre Activities of Daily Living*. *Data presented as mean \pm standard deviation, except where indicated.

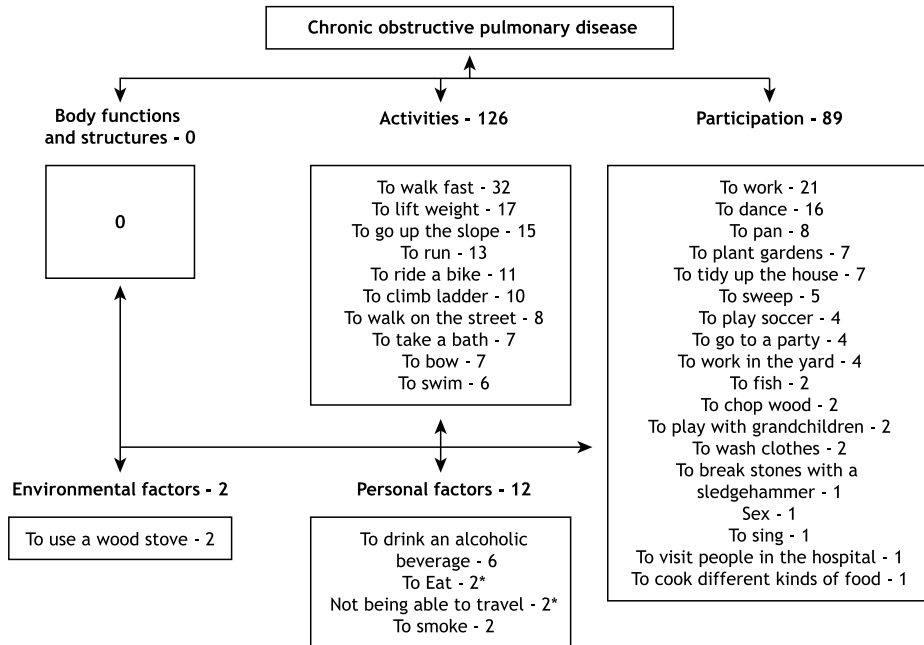


Figure 3. Categories cited by patients in response to PGI classified according to the ICF. *Items that are not classified in the ICF.

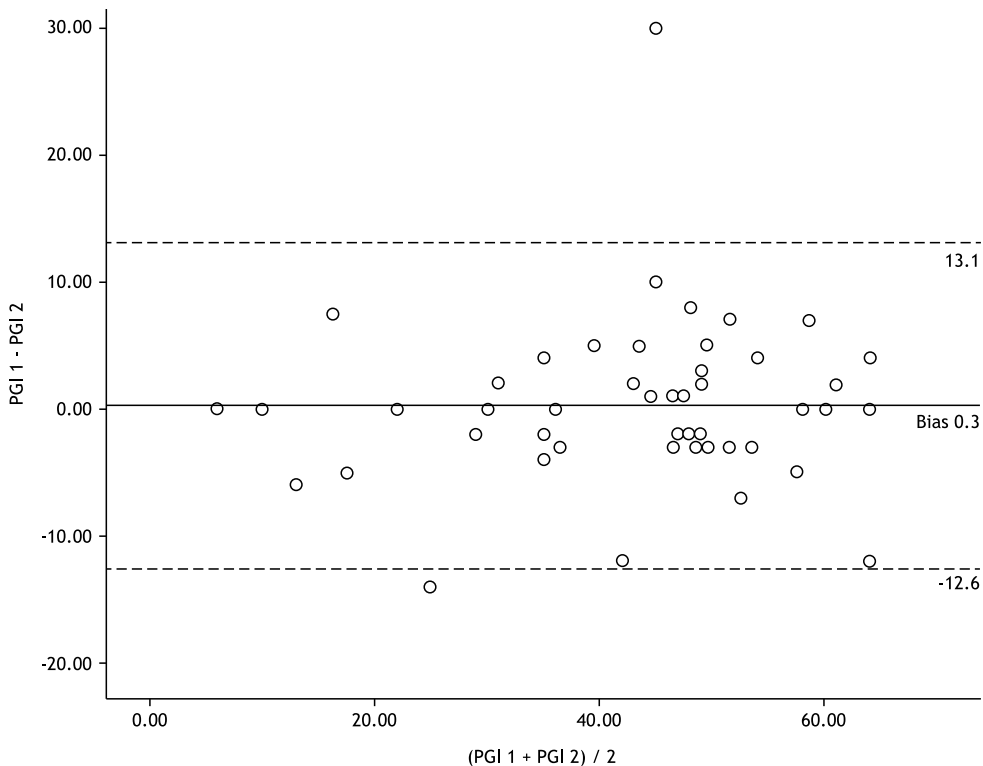


Figure 4. Bland-Altman graph plot of test-retest reliability. (PGI 1: PGI Day 01; PGI 2: PGI Day 2).

DISCUSSION

This study presents the translation into Portuguese and validation of the PGI questionnaire for patients with COPD. Despite cultural differences between

Brazil and England, the Brazilian version of the PGI questionnaire did not require major adaptations. This is probably because PGI is a simple and conceptually universal instrument.

To our knowledge, this is the first study that prepared a Brazilian version of the PGI questionnaire, which has already been adapted and validated in countries such as the United States⁽¹⁹⁻²¹⁾ and Canada^(5,22,23) and the cross-cultural adaptation was made to Norway.⁽²⁴⁾ Besides, a modified version of the PGI has been validated in Ethiopia, Thailand and Bangladesh, covering Bengali, Thai, Amharic and Oromo.⁽⁹⁾

As it is a questionnaire that is framed within a specific disease, the PGI has validation for several diseases such as low back pain,⁽⁴⁾ multiple sclerosis,⁽²⁰⁾ cancer,⁽²⁵⁾ arthritis,⁽²⁶⁾ atopic dermatitis,⁽⁷⁾ HIV⁽²⁷⁾ among others. However, this is the first study reporting the validation of PGI for a population with COPD.

Convergent and concurrent validation for COPD was performed through the correlation analysis of PGI with Glittre ADL and SGRQ, validated tools for assessing HRQoL and functional performance in patients with COPD.⁽¹¹⁾ Although the PGI obtained a weak correlation with the impact and activity domain of the SGRQ, and with the total score, the symptoms domain showed a moderate correlation with the PGI. When we standardized PGI responses according to the ICF, we obtained a higher prevalence of responses in the activities domain. This result can be explained by the differences in the questionnaire characteristics. While in the structured questionnaire (SGRQ), the weight of a given item is predetermined, in patient-centered questionnaires (PGI) the individual is the one who assigns the weight to a specific item on his HRQoL.

The moderate relationship observed with the symptoms domain of the SGRQ with the PGI suggests an influence of changes in the structure and function of the body on the components of ICF activity and participation. Besides, the PGI data allow us to infer that the influence of symptoms on HRQoL is due to its outcomes in the individual's activity and participation and not due to the symptoms themselves. Thus, the PGI appears as a complementary tool to the structured questionnaires useful for assessing HRQoL, especially regarding aspects related to the ICF activity and participation domains. These items are often not easily detected in structured questionnaires, which makes PGI a strong ally in the more detailed and globalized complementary assessment of individuals with COPD. As an example, we name the most cited areas in the PGI that do not constitute daily life activities (DLA) such as, dancing, cycling, swimming, playing football, drinking alcoholic beverages and going to parties. These activities had a direct impact on the quality of life assessed by the PGI of these patients, sometimes being more cited than the symptoms.

Previous studies have also demonstrated low to moderate correlations of PGI with generic^(5,9,23,28) or specific^(5,29) quality of life instruments. This demonstrates the peculiarity of the PGI, where, differently from what occurs with structured questionnaires, the individual is invited to describe and score the items that, in his point of view, have greater meaning and relevance in

his quality of life; while, in structured instruments, the items to be scored are previously described.

Although we have not identified any other study that correlates PGI with a functional test, we chose to use Glittre ADL. The choice was made because it is a test that mimics activities of daily living. Skumlien et al.,⁽¹⁴⁾ observed a moderate correlation between SGRQ and Glittre ADL only in the activity domain. In our study, we identified a weak correlation between PGI and Glittre ADL. Considering that PGI is a generic questionnaire, this weak correlation suggests that there may be a compromise in the performance of ADL by the individual, which could affect the HRQoL of patients with COPD, but other factors may also be determinants.

PGI is based on the assumption that health problems affect individuals and their quality of life differently and, therefore, are better defined by the patient individually. This study sought to identify in which aspects COPD affects HRQoL, and to what extent PGI can provide information not addressed by a specific HRQoL instrument.

Patients determined 229 areas of their lives that, in some way, were affected by COPD. These 229 areas were grouped into 28 categories. By comparing the PGI response categories with the SGRQ items, we were able to identify that many of the areas identified by COPD patients (16 of the 28 categories) were covered by the SGRQ. The nine categories most cited in the PGI assessment (walking fast, climbing uphill / stairs, working, lifting weights, dancing, doing heavy work, running, tidying up and cycling) were included directly among the items of the SGRQ.

Some of the remaining categories could be contemplated indirectly by some items, such as singing, an area identified by a patient, which could perhaps be identified in the item "I feel short of breath when I speak". However, interestingly, singing for this patient weighted 30% in the total PGI score, while the item "I have no air when I speak", had zero weight in the SGRQ score, which can demonstrate the greater sensitivity of the PGI. We also identified areas such as sex, "mood for cooking different foods", drinking an alcoholic beverage, using a wood stove, "to visit people in the hospital" and even to smoke, which were mentioned as having an impact on the HRQoL of these patients, but are not covered by the SGRQ.

Thus, we consider that the PGI may be able to exclude issues that are not of direct interest to the individual and can capture areas of life that are important from an individual point of view, which are not usually represented in the structured HRQoL tools.

Our study demonstrated high test-retest reliability of the PGI, with an ICCr value within the minimum acceptable for the reliability of clinical tests.⁽¹⁷⁾ Similar levels of reliability have been found in other studies with comparable versions and populations.^(23,28,29) For clinical practice, there is a 68% probability that repeated measurement of the PGI is within 1 Standard Error of the Measure (EPM), or 4.7 points, and a

96% probability of being within 2 EPM or 9.4 points. The EPM value was used to calculate the Minimum Detectable Difference (MDD), which is clinically applied to differentiate a real change from a change related to the individual measurement variation. Thus, variations of 10.8 points in the PGI indicate clinically relevant variations in patients with COPD. No other study was found that have assessed the absolute reliability of PGI.

Our results suggest that PGI can be considered an instrument with the potential for being used in clinical practice as a complementary instrument in the assessment of patients with COPD, which would allow individualized strategies for its treatment.

As limitations of our study, we highlight that our sample was mostly composed 76% (38) by individuals classified as GOLD II, which could limit the external validity of the study. Also, the PGI was applied in the region of Diamantina, Minas Gerais, a region with a human development index (HDI) below the national average. We also emphasize the strong culture of mining and the common presence of the wood stove at homes, which justify the answers found in the PGI. Another limitation is that the time

spent by patients to answer the instrument was not recorded, however roughly speaking, we saw that it takes around 10 minutes.

In summary, this study shows that the Brazilian version of PGI is a reliable and valid instrument for measuring HRQoL in patients with COPD; able to highlight areas that are not captured by generic instruments, and can be applied in a complementary way to traditional instruments for assessing HRQoL in COPD.

ACKNOWLEDGMENTS

The authors would like to acknowledge to Prof. Dr. Tania Janaudis-Ferreira (McGill University), for the for guidance and support during all project execution. To Professors Dr. Janaina Martins Andrade and Dr. Camila Ribeiro Coimbra from the Universidade Federal dos Vales do Jequitinhonha e Mucuri – UFVJM, for their availability and assistance in recruiting volunteers. To the Laboratório de Fisiologia do Exercício (LAFIEX) of the Universidade Federal dos Vales do Jequitinhonha e Mucuri – UFVJM. Moreover, to the volunteers, for their availability to participate in the study.

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SUPPLEMENTARY MATERIAL

Supplementary material accompanies this paper.

Chart S1. PGI responses according to ICF.

Table S1. Categories cited by patients in response to PGI and the number of times they were cited.

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