

**MEASURING QUALITY OF LIFE IN THE PERSON WITH DYSARTHRIA:
RELIABILITY AND VALIDITY OF THE EUROPEAN PORTUGUESE VERSION OF THE QoL-DYS**

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ABSTRACT

Background: The impact of acquired dysarthria on the person's life is recognized and has implications for intervention and for outcome measurement.

Objectives : The purpose of this study was to evaluate the validity and the reliability of the European Portuguese version of the Quality of Life in the Person with dysarthria (QoL-DyS)

Methods: This research was conducted in three phases: i) cultural and linguistic adaptation; II) feasibility and reliability ; and iii) validity . The sample was composed of 105 subjects with dysarthria and 103 healthy subjects., the QAD (Quick Assessment for Dysarthria), the PEAT10 (Portuguese Eating Assessment Tool), the EQ-5D (EuroQol five-dimension scale), age and sex were used for validity and reliability

Results and Conclusion The QoL-DyS correlated positively with the QAD and PEAT-10 and also with the EQ5D. The Cronbach's α was 0.973 and it remained excellent when any item was deleted. The QoL-Dys score mean difference between the non-dysarthric cohort and the dysarthric cohort was significant. Confirmatory factor analysis did not validate the original 40 items scale but a 33 item scale with the same 4 domains. A significantly higher perception of QoL was found among the non-dysarthric group. This results indicate that the European Portuguese version of the QoL-DyS is a reliable and valid tool to assess Quality of Life (QoL) in patients with dysarthria and may be used for screening in clinical practice and in research.

Key Words: Dysarthria, Quality of life, Self-assessment, Reliability, Validity

INTRODUCTION

The Quality of Life (QoL) concept is based on how people feel about their health and is a major concept in healthcare. Methods for investigating QoL are regarded as useful supplements to the clinical decision-making process as they provide important insights into the impact of disease from the persons's perspective [1] .

A large body of research has recently been devoted to the development of health-related quality of life (HRQoL) measures. These techniques are used i) to determine the impact of medical intervention on QoL, ii) to assess the outcome of health care services and iii) to assess the impact of a specific disease. Almost all the measures developed so far have been in the English language and are intended for use in English. There is nonetheless a need for measures specifically designed to be used in non English-speaking countries since cultural groups vary in disease expression and in their use of various health care systems. There are two ways of meeting this need for scales in a specific language: (1) a new measure can be developed, or (2) a measure previously developed in another language can be used. The first option, the generation of a new HRQoL measure is a time consuming process in which the bulk of the effort is devoted to the conceptualization of the measure and the selection and reduction of its items. In the second option, if the measure is transposed from its original cultural context by simple translation, it is unlikely to be successful because of language and cultural differences. Furthermore, the perception of QoL and the ways in which health problems are expressed vary from culture to culture. A systematic approach must be taken to the translation and cross-cultural adaptation process of HRQoL measures for this option to be successful.

Dysarthria is defined as a neurological motor speech disorder characterized by imprecise and/or uncoordinated movements of the speech musculature and it can be classified as progressive or non-progressive [2]. It is often categorized in perceptually based types [3] and/or according to the degree of severity [2]. It is difficult to obtain a comprehensive picture of the subjective consequences of living with a speech disorder caused by a neurological condition.

Several self-assessment tools have been developed for specific clinical conditions in the fields of voice and swallowing disorders [4]. There has been considerable research into the development of assessment methods to capture the different aspects of activity limitation and participation restriction caused by dysarthria. Restrictions in communicative participation need to be evaluated primarily by the person with dysarthria in order to reflect the nature of the problem [5]; they can be explored using both qualitative and quantitative methods.

In recent years, a considerable number of instruments were designed to elicit information about how a communication problem affects a person's life [6]. In fact, in the field of dysarthria, several attempts have been made to describe subjective communication problems using self-report questionnaires [7]. In the Situation Intelligibility Survey [7], different situations can be scored according to how often the person has difficulty in understanding a specific situation. Lubinsky et al [6] developed a number of designed questions to elicit information about how the person with dysarthria defines the communication problem and its impact on his/her life.

Another assessment tool was created and tested in persons with amyotrophic lateral sclerosis (ALS) with the aim of analyzing communicative effectiveness in a social context [8]. The self-reported questionnaire Living with Neurologically Based Speech Difficulties was developed to find out how individuals with dysarthria perceive themselves and their speech difficulties [9]. It is intended for use in a clinical setting, and can be administered in a relatively short time. In addition, Donovan et al. [10] developed the Communicative Effectiveness Survey to be used in persons with Parkinson's disease. Also the Dysarthria Impact Profile (DIP) was created to measure the psychological impact of acquired dysarthria on self-perception, self-concept and self-esteem from the speaker perspective. The scale is regarding further validation [11]. The study by Lettanneux et al [12] aimed to adapt the Dysarthria Impact Profile (DIP) to French and to confirm its relevance for the assessment of the psychosocial impact of dysarthria in Parkinson's disease (PD). Another cross-cultural adaptation of DIP was to European Portuguese (EP) and it was validated for use in PD. Both DIP versions display the features of a valid person-based assessment tool used to measure the psychosocial impact of dysarthria in people with PD [13]. The Longer Communication Profile for Speakers with Motor Speech Disorders [14] applied the constructs to dysarthria as a chronic condition. This self-reported questionnaire consists of specific statements concerning perceived characteristics of the disorder, situational difficulty, compensatory strategies and the perceived reactions of others. A corresponding set of questions was posed to family members about demands, resources and the definition of the problem.

While all these tools appear to be useful in describing subjective communication problems, their applicability in daily practice can be complicated due to the time taken and the cognitive demands to complete them [9,15,16]. In fact, some tools were designed to assess QoL in specific diseases and would not be applicable to all persons with dysarthria. Others only analyze some aspects of QoL related to dysarthria [8,10], such as the situations in which the person experiences difficulties in a social context, and do not assess how the person perceives his/her own speech. The DIP focuses more on the psychological impact of dysarthria; the validation process for the various types of dysarthria is still being refined [11].

The QoL-DyS was designed for the Italian language and analyzes how persons perceive their speech and their difficulties in different situations [15]. It is a 40-item instrument based on a previous 100-item instrument [16]. The new version is easier to use in daily practice due to its length and it is applicable to people with dysarthria of any origin and however severe. It is a standardized self-administered index of speech-related problems encompassing four domains: SC (speech characteristics of the word), SD (situational difficulty), CS (compensatory strategies), and PR (perceived reaction of others). Each domain contains 10 items and is measured by a verbal rating scale from 0=Never to 4=Always. The total score ranges between 0 and 160, with a maximum of 40 in each domain. A score of 0 would suggest an optimal QoL, while a score of 160 would indicate it is severely compromised. This is also a comprehensive tool that has been used for the validation of other instruments [9].

The aim of the current research is to produce a European Portuguese version of the Quality of Life Questionnaire for the Dysarthric Speaker (QoL-DyS). The scale should be fast and easy to use in daily practice and should be applicable to Portuguese persons with dysarthria of any origin or degree of severity.

METHODS

This study was carried out in three phases: i) cultural and linguistic adaptation to European Portuguese; ii) feasibility and reliability tests of the version obtained in Phase I and iii) validity tests to adopt a final version.

Phase I: Cultural and Linguistic Adaptation

We followed the translation/back-translation process [17] to create the Portuguese version of the QoL-DyS. After formal permission had been granted by the authors of the original version [15], two Portuguese translators were asked to independently translate the QoL-DyS into European Portuguese. Both versions were merged to obtain a consensus version. The consensual version was then given to a native English translator to translate it back to English and this was subsequently compared with the original version. A speech and language therapist (SLT) with extensive experience with person with dysarthrias performed a clinical review of the European Portuguese version of the QoL-DyS. All items were analyzed to assess the quality of the translation. The European Portuguese version was then discussed in a larger group of experts to confirm the quality of the translation. The expert panel was constituted by 5 SLT who had extensive experience with persons with dysarthria.

After assessing for comprehensiveness, length, adequacy, redundancy and text clarity, some changes were made to the semantics and syntax of the written Portuguese. No

additional items were added or dropped and no changes were made to the content of the questions after this discussion. For a cognitive debriefing (i.e. the process in which the person questionnaire is tested with representatives of the target population and target language group to determine whether they understand the questionnaire to mean the same as the original), 10 persons with different types of dysarthria were interviewed during which they completed the translated version of the QoL-DyS. This group of persons was selected by convenience in a rehabilitation day center. All persons were previously evaluated according to their cognitive skills and reading comprehension.

Each question was thoroughly analyzed in this focus group. Lastly, the final version was reviewed linguistically to obtain a grammatically corrected version. The 0-4 point scale from the Italian version was used in the final European Portuguese Version. The final version of the QoL-DyS instrument with the 40 items translated in English, Italian and Portuguese is shown in the Appendix A.

Phase II: Feasibility and Reliability

Following the pilot project, the Portuguese version of the QoL-DyS was tested for feasibility based on the criteria of how long it took respondents to complete the questionnaire and the difficulties they experienced in doing so.

We also determined the floor and ceiling effects, i.e., the percentage of answered scores of the lowest and highest anchors of the scale. A distribution of scores is characterized as having a floor or ceiling effect if more than 15% of the answers are located in the first or last category, respectively [18]. [Vogt, W. Paul (2005). Dictionary of Statistics & Methodology: A Nontechnical Guide for the Social Sciences (Third ed.). SAGE.]

Temporal stability was evaluated to confirm whether the scores obtained by the measure were independent from the measurement moment. Temporal stability was tested by performing a one-week test-retest in a sub-sample of 17 subjects, randomly selected, diagnosed with different types of dysarthria: 4 with dysarthria unilateral upper motor neuron (UMN), 4 Flaccid; 4 Hypokinetic, 3 Ataxic and 2 spastic dysarthria.

Intraclass correlation coefficient (ICC) was computed and a score greater than 0.7 means a good level of agreement; the minimum acceptable value is 0.5 [19].

The concept of reliability incorporates internal consistency to determine how free the measure is from random error. Internal consistency was measured through the Cronbach's α coefficient and the item-total correlations. A value of α greater than 0.8 is considered 'good' and a value greater than 0.9 'excellent'; values greater than 0.7 are considered

acceptable [19]. An item-total correlation of at least 0.50 within each subscale was used as the standard for supporting the item convergent validity of the QoL-DyS. The composite or construct reliability (CR) and the average variance explained (AVE) were also used to evaluate reliability.

Phase III: Validity

A measurement instrument is classified as valid when it measures what it is intended to measure [20]. It includes the analysis of the content validity, the construct validity and the criteria validity.

Content validity assesses whether the instrument measures the appropriate concept as well as all its dimensions. The content validity was examined to assess the clarity, understanding, cultural relevance, and the setting of the words. This type of validity is guaranteed by means of cultural and linguistic adaptation, which has already been described in the previous section.

Construct validity evaluates whether the theoretical framework of the instrument is confirmed by the European Portuguese version. This includes the factorial validity of the four domains, convergent validity, discriminant validity and testing the instrument for socio demographic variables.

Confirmatory Factor Analysis (CFA) was performed to test the factorial measurement model of 4 latent variables. CFA hypothesizes an explicit a priori model of the construct structure, estimates its parameters and examines whether this model is an adequate fit with the measured data. The match between the hypothesized CFA model and the observed data is evaluated with different fit statistics (Chi-square goodness of fit statistic (χ^2), Normed Chi-square ($\chi^2/\text{degrees of freedom}$), Root Mean-Square Error of Approximation (RMSEA), Comparative Fit Index (CFI) and Expected Cross-Validation Index (ECVI)). An overall very good model fit is verified by a normed Chi-square lower than 2 and a RMSEA not higher than 0.05 and values of CFI higher than 0.90. However, values of normed Chi-square lower than 5 and a RMSEA not higher than 0.08 show reasonable and acceptable model fit. When comparing different models, the one with highest CFI and lowest ECVI [21] is the best.

Confirming construct validity also entails evaluating convergent and discriminant validity. The presence of convergent validity can be assessed in different ways: magnitude and significance of factor loadings, squared multiple correlation coefficients for each of the observed variables, average variance extracted (AVE), Cronbach's α coefficient and composite reliability (CR) for each latent variable. Factor loadings should be significant and at least 0.60, preferably higher than 0.70; an AVE value higher than 0.50 indicates the

construct is able to explain more than half of the variance of its observed variables; both Cronbach's α and CR measure the internal consistency of a construct and must not be lower than 0.60. Discriminant validity is confirmed for each latent variable with positive differences between AVE and the squared correlation of that construct with the other constructs, providing evidence of the uniqueness of each construct [18].

Hypothesis testing of socio demographic and clinical variables was applied to evaluate the instrument validity for different socio demographic groups and to determine whether they were sensitive enough to the dysarthric condition. The parametric t-test for equality of two population means was used to assess the differences between the two gender groups and between the case and the control groups; one-way ANOVA was applied to test for equality of more than two population means. Therefore, the following hypotheses were proposed for the total score as well as for the domains:

H₁: QoL-DyS scores are not sensitive to age, gender and educational level

H_a: QoL-DyS scores are sensitive to the dysarthric condition.

Criterion validity represents the degree of agreement between the measurement instrument and other reference measures for the same construct. For criteria validity, correlations were calculated with instruments that measure similar concepts. The measurement instruments used in this study were:

- The QAD (Quick Assessment for Dysarthria) is a commercial four-page assessment instrument that includes diagnostic questions and checklists to assess respiration, phonation, articulation, resonance, and prosody [22] with an ordinal scale ranging from 0 (obviously abnormal or non-functional) to 5 (obviously normal or functional).
- The PEAT-10 (Portuguese Eating Assessment Tool) is a self-reported assessment to evaluate the individuals' risk of dysphagia and symptoms [23,24]. It is formed by 10 sentences scored from 0 (no, never) to 4 (yes, always)
- The EQ-5D-3L (EuroQoL five-dimension scale, 3 level version), is a generic quality of life instrument composed of a descriptive system and a visual analogue scale (VAS) [25]. The descriptive system includes five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) with three levels of intensity for each dimension, defining a total of $3^5=243$ health status. VAS was designed to look like a vertical thermometer with a scale from 0, the worst imaginable health status score, to 100, the best imaginable health status [26]. An econometric model permits the calculation of preference-based values (utilities) for all health status. For the

Portuguese population, the EQ-5D utility index varies between -0.536 and 1000. The negative scores correspond to health status valued as worse than death.

The QoL-DyS and the European Portuguese versions of the QAD were correlated in order to identify the relationship between dysarthria severity and perceived QoL. Moreover, some studies showed that a high correlation between swallowing function and all levels of speech intelligibility identifying a speech disorder were a predictor of dysphagia, notably of oral stage problems [27]. Therefore, the European Portuguese version of EAT 10 (PEAT10) was used for validation. The following hypotheses were proposed as above:

H₃: QoL-DyS scores are correlated with QAD scores;

H₄: QoL-DyS scores are correlated with PEAT10 scores.

To evaluate criteria validity, the QoL-DyS scores and the Portuguese EQ-5D index were also correlated. There were two main reasons for choosing a generic QoL measure like EQ-5D to test criteria validity. The only scale that is already published in European Portuguese is only for people with PD [13]. Secondly, dysarthria symptoms undoubtedly have a marked impact on persons' QoL. The following hypothesis was proposed.

H₅: QoL-DyS scores are correlated with EQ-5D index

All data analyses were carried out with the statistical software SPSS and AMOS version 24.

Ethics

This study was implemented in accordance with the Declaration of Helsinki and approved by the Institutional Review Board. Moreover, each person or his/her representative included in the study gave their written informed consent.

RESULTS

Cultural and Linguistic Adaptation

The cognitive debriefing involved three males and seven females with an average age of 81.1 ± 11.4 years, ranging from 51 to 91 years, with medium to low education (0 to 4 years = low education and 5 to 9 years = medium education) A number of issues were raised during this meeting. As an outcome of this cognitive debriefing, one question was re-written to clarify its meaning. No other major changes were necessary.

The Sample

A sample of two groups of native Portuguese individuals was selected. The first group included persons diagnosed with dysarthria of different types from all regions of mainland Portugal (n=105). The second group included individuals with no morbid condition leading to dysarthria (n=103). The minimum age is the same for both groups (18 years); the maximum age is 87 and 102 years for the control and dysarthric groups, respectively; only 7 persons are over the age of 87 years in the dysarthric group. Results remain the same when these individuals are excluded from the analysis.

The inclusion criterion for both groups was individuals with cognitive ability within normal limits measured by the Portuguese version of the Mini Mental State Examination. This means that individuals aged 65 or more were included if their MMSE scores were higher than 22 for 0-2 years of education, 24 for 3-6 years of education and 27 for more than 6 years of education [28]. An effort was made to include persons from different origins and with different levels of the severity of dysarthria and functional communication skills. Moreover, all participants with dysarthria had speech therapy before and/or during data collection. The effects of speech therapy on persons' quality of life was not evaluated as it does not fall within the scope of the present study. Future studies that investigate the impact of Speech Therapy on QoL of people with dysarthria are warranted.

The two groups were described using descriptive statistics including frequency tables, measures of location (means) and dispersion (standard deviations). The data base has no information on participants' occupation or working status. In the dysarthric group, around 50% of the individuals are aged 65 or more, so these are expected to be retired. The other socio demographic and clinical characteristics and QoL-DyS scores are presented in table 1.

Insert table 1 here

The dysarthric group included 52 women (49.5%) with a mean age of 64.0 ± 16.5 years. The majority were married (62.0%) and had, on average, about eight years of education. They included persons diagnosed with both progressive and non-progressive neurological disorders. The distributions of QoL-DyS scores are presented in table 2. The average score of the QoL-DyS total Score was 78.5 ± 35.1 . For the total score and for each dimension, there are mean differences between the major dysarthric groups: spastic and ataxic groups generally show the highest means, while UMN shows the lowest average scores; however, these differences are not significant.

A control group of 103 healthy individuals without speech disturbances was also involved. It was constituted by 72 women with a mean age of 50.6 ± 17.3 years.

Feasibility and Reliability

The mean QoL-DyS completion time was 10 ± 3 minutes ranging from 7 to 12 minutes. All items were filled in by the subjects. We assessed the floor and ceiling effects of the QoL-DyS by analyzing the distribution of each item. No floor or ceiling effects were found.

We asked a subsample of 17 persons, randomly selected, to fill in the QoL-DyS with a one-week interval between the two administrations. This interval was selected because no substantial change was expected to take place in the person's speech within that period. This group included seven (41.2%) females with an average age of 61.1 ± 20.4 years, an average level of education of 8.2 ± 4.4 years, and diagnosed with various types of dysarthria.

Using the intraclass correlation coefficient (two-way ICC mixed model), the reproducibility indicator for the total score was 0.776 for the total QoL-DyS score with a correspondent 95% confidence interval between 0.484 and 0.913. ICC was also conducted for each item and each dimension. We also assessed internal consistency on the QoL-DyS scores of person with dysarthrias. For the total score, we obtained a Cronbach's α of 0.973. This indicator ranges from 0.866 for the CS domain to 0.968 for the SD domain. All results point to high levels of internal consistency (Table 2) and temporal stability with the exception of the SD domain that presents values of ICC lower than 0.4 for 5 items (SD2, SD4, SD5, SD6 and SD7). These results do not have a statistical interpretation. The authors believe the results are related to the type of questions reporting situational factors. Those questions may have different interpretations depending on whether the person has already experienced the situation.

Insert table 2 here

Construct Validity

To assess the construct validity of the given instrument, we looked at the socio demographic effects on the total QoL-DyS score as well as on the four domain scores. Regarding the demographic variables, we posed the hypothesis H1. As presented in table 3, we failed to prove any socio demographic effect on the total QoL-DyS score for the dysarthric group. Similar results occurred with all dimensions of QoL-DyS. Non-significant results are still obtained when age enters the different models as a covariate.

Insert table 3 here

Next, we compared the QoL-DyS scores obtained in the sample of dysarthric persons (case) and a control group with t-test for independent samples. The estimates of effect size provided by the partial eta squared statistic describe the proportion of total variability attributable to the dysarthric group when compared to the control group. A small size effect is one greater than 0.10 but not more than 0.25; values between 0.25 and 0.40 show a medium effect size; and a large effect size is a value greater than 0.40. [Sheskin, DJ (2004) Handbook of Parametric and Nonparametric Statistical Procedures. Chapman & Hall/CRC] The results are presented in table 4.

Insert table 4 here

As observed, the QoL-DyS total score and its dimensions are discriminant for the dysarthric persons since mean differences between the case and the control groups are highly significant. A large effect size is shown for the SC (speech characteristics of the word) dimension and medium effect sizes for the SD (situational difficulty), and PR (perceived reaction of others) dimensions. However, a small effect size is shown for the CS (compensatory strategies) dimension, pointing to its relatively smaller capacity to discriminate between the two groups.

Factorial Validity

CFA was applied and four different models were estimated to evaluate factorial validity. Model 1 includes (table 5) the initial 40 items divided equally into 4 constructs: SC (speech characteristics of the word), SD (situational difficulty), CS (compensatory strategies), and PR (perceived reaction of others).

Insert table 5 here

Although loadings are all significant ($p < 0.001$), the following items have low loadings ($\lambda < 0.60$) and therefore should be removed from the model: SC7 and SC9 from the construct speech characteristics of the word; CS1, CS3, CS6, CS7 and CS8 from the construct compensatory strategies.

The results therefore show that factorial validity is not assured for the previous seven items of these two constructs. Model 1a was then estimated with the remaining 33 items, and fit indices were all improved. It is worth noting that the compensatory strategy dimension is now reduced to 5 items (CS2, CS4, CS5, CS9 and CS10).

Since item-total correlations are quite low for the excluded items of CS, an alternative to the previous models was estimated with 5 constructs resulting from the partition of the CS dimension (model 2) into two sub-dimensions: CS_D1 with items CS2, CS4, CS5, CS9 and CS10; CS_D2: with items CS1, CS3, CS6, CS7 and CS8.

Model 2 (total of 40 items split into 5 dimensions) fit indices are slightly better than those of model 1 but worse than model 1a. Loadings are all significant but lower than 0.60 for items SC7 and SC9, CS1 and CS3. In the next step, model 2a is estimated by excluding these 4 items. Results show a better fit when compared to Model 2 but not as good as the fit of model 1a.

Convergent Validity

From the previous results, the two best models (model 1a with 4 constructs and 33 items excludes 2 items from the SC domain and 5 items from the CS domain; model 2a with 5 constructs and 36 items excludes the same 2 items from the SC domain and only 2 items from the CS domain) were chosen to be evaluated in terms of convergent and discriminant validity. As regards convergent validity (table 6), AVE values are all higher than 0.5 with the exception of the CS construct when its content is reduced to 5 items (CS2, CS4, CS5, CS9 and CS10), showing that this dimension is able to explain slightly less than half of the variance of its observed variables; however, both Cronbach's α and CR show high levels of convergent validity for all dimensions, thus proving that the items in each construct share a high level of common variance, and that the level of variance captured by the constructs is higher than the level due to measurement error.

Insert table 6 here

Discriminant Validity

To assess discriminant validity, AVE for each construct is compared to the squared correlations between this construct and all others. Results show that discriminant validity is not assured (table 7). AVE of speech characteristics (SC) is lower than the squared correlations of this construct with situational difficulties (SD) and perceived reactions to others (PR), meaning that there is some overlap of the first dimension with the two last dimensions. A similar conclusion can be drawn for the first sub dimension of compensatory strategies (CS_D1). However, results for the two sub dimensions of compensatory strategies provide evidence of the uniqueness of each one since AVE values are clearly higher than the correlation between them.

Insert table 7 here

Criteria Validity

The correlation between QoL-DyS scores and QAD, PEAT-10, EQ-5D scores were assessed using Pearson's correlation. To test the criteria validity, we first correlated the total QoL-DyS score with the EQ-5D index. Though significant, the correlation with the EQ-5D index appears to be moderate ($r=-0.432$). The correlations of QoL-DyS scores with QAD and PEAT-10 are presented in table 8.

Insert table 8 here

We can conclude from this table that all QoL-DyS scores and dimensions always have a significant correlation with QAD and with PEAT-10 (with the exception of the CS dimension, all correlations are significant and moderate). Correlation increases when calculated for the dimensions SC (8 items) and CS (5 items) as defined in model 1a.

DISCUSSION AND CONCLUSION

This paper reports the development and psychometric validation of the QoL-DyS. The research included a study group composed of person with dysarthrias and a control group with no morbid conditions related to dysarthria. Within the study group, all the persons recruited presented a dysarthria impairment ranging from slight to severe.

The QoL-DyS was easily completed by the persons and showed good internal consistency and test-retest reliability. Furthermore, it presented significantly higher scores in dysarthric persons when compared with the control group. There are mean differences between the major dysarthric groups for the total score and for each dimension: spastic and ataxia groups generally show the highest means, while UNM shows the lowest average scores but these differences are not significant. The internal consistency of the QoL-DyS was good. In the four subscales, the internal consistency ranged from good to satisfactory, which is considered acceptable values. Similar findings were reported in the validation of other QoL instruments [29-35]. Test-retest reliability was excellent for the QoL-Dys, suggesting high stability and reproducibility of scores over time. This is of particular importance since it supports the application of the QoL-DyS in future studies on QoL related with progressive and non-progressive dysarthria. For the CS dimension, although there were significant differences between the control group and the dysarthric group, estimates of effect size show they were not so large as for the other dimensions. This is probably due to the fact that compensatory strategies are also commonly used in people without dysarthria

whenever the message to communicate is complex or oral communication is limited by environmental barriers. The same result was reported by the original authors [15].

The correlations between the PEAT10 and the QoL-DyS were significant albeit moderate. Although speech and swallowing functions are strongly related, the perceived meaning for the individuals' QoL may be different. Furthermore, the prevalence of concomitant dysphagia in dysarthric persons is quite high regardless of the primary etiology and time elapsed since onset. However, the relationship between the two functions is more complex than it appears as the prevalence and severity of dysphagia vary markedly according to the type of dysarthria [36]. There is a broad range of severity levels among persons in the flaccid, spastic, and mixed categories with many individuals being severely impaired, while persons in the ataxic, hypokinetic, and unilateral upper motor neuron categories seldom have severe concomitant swallowing problems. Furthermore, the correlation between conversational intelligibility and swallowing function varies considerably depending on the type of dysarthria and also can be used as a validity criteria [37].

The correlations found between QoL-Dys and EQ-5D suggest the relative independence of dysarthria-specific QoL and generic quality of life. These findings do not cast doubt on the validity of either person-based or speech measures. Quite the contrary, clinical skepticism about QoL measures sometimes occurs when they covariate too strongly with clinical outcomes, thus yielding information perceived as redundant [38]. Conversely, when QoL and clinical measures correlate weakly, this suggests that both measures provide independent, but complementary, information about person function [39,40]. The fact that socio demographic variables such as age, gender and education had no significant impact on perceived communicative difficulties highlights the fact that these problems are indeed subjective and cannot be predicted on the basis of simple background factors. Although the severity of dysarthria measured by the QAD had a statistically significant effect, it did not show a very strong correlation; this means that perceived communicative difficulties may have a different impact on the individual, despite the severity of the disease. Some authors have stressed the importance of exploring the relationship between the severity of dysarthria and perceived communicative difficulties [15,41]. The authors emphasize that the relationship between the different levels of dysarthric impairment and perceived communicative abilities is not likely to be linear and that it is important to assess each level separately; in other words, the severity of dysarthria does not necessarily predict the extent of communicative participation. A study conducted by Yorkston et al [16] only found a significant difference between severity groups in perceived reactions of others. According to the study by Piacentini et al [15], there seems to be no unequivocal relationship between the severity of dysarthria and perceived communicative difficulties, and the issue should be explored further.

The fact that communicative difficulties are perceived very differently indicates the need for individualized treatment planning. Subjective difficulties do not necessarily reflect the severity of speech symptoms, and systematic protocols are required to help identify problems that need addressing in intervention. Systematic subjective reports should always be included in the assessment of individuals with acquired dysarthria. The current study suffers from a number of limitations that call for caution in the interpretation of results. The classification of severity of dysarthria was crude and obtained after just one test, the only one available in European Portuguese. Although the selection of questionnaire items was based on published scales and data appeared to have good validity, a few statements proved problematic in that they could be related to several different factors such as those included in the compensatory strategies domain.

Overall, the specific hypotheses established for construct validity and reliability were corroborated: QoL-DyS scores are not sensitive to gender, age group, or education level (H₁), but highly sensitive to the dysarthric condition (H₂). Criteria validity is assured since QoL-DyS scores correlate significantly with other scales such as the QAD and the PEAT10 (H₃ and H₄). Therefore, psychometric properties confirmed the adequate adaptation of the QoL-DyS to the European Portuguese culture and indicate the need to adjust the original questionnaire to each specific population.

In conclusion, the QoL-DyS is reliable and appears easily applicable in daily practice for the self-assessment of the QoL in person with dysarthrias. However, statistical analyses validate a 4 dimension tool and show that 7 items should be removed from the European Portuguese version of the QoL-Dys instrument: SC7, SC9 from the Speech Characteristics dimension, and items CS1, CS3, CS6, CS7 and CS8 from the Compensatory Strategies dimension. The application of this reduced version of the QoL-DyS (with 33 of the original 40-item Italian scale) is recommended in clinical practice as well as in descriptive, efficacy and outcome research in European Portuguese person with dysarthrias.

The study conducted by Cardoso et al [13] also showed salient features of a valid person-based assessment tool used to measure the psychosocial impact of slight-to-mild dysarthria but only in people with PD. Both instruments in European Portuguese should be complementary in future research.

Mention must also be made of the following limitations to the study the age differences between the study group and the control group, given that people may interpret QoL differently during life span; and the heterogeneous distribution of the sample by type of dysarthria, as this does not allow the type and severity of dysarthria and QoL to be compared. Moreover missing data for occupation and residential area is a concern as both variables can affect access to the health system and/or to activities and participation which

may have a strong impact on QoL. The validation of the QoL-Dys for European Portuguese allows the instrument to be used in future research for specific diseases and for outcome measures in the treatment of dysarthria

Conflict of interest

The authors have no conflict of interest to declare.

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