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Psychosocial impact of Parkinson's disease-associated dysarthria: Cross-cultural adaptation and validation of the Dysarthria Impact Profile into European Portuguese

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Aim: The present study sought to make a cross-cultural adaptation of the Dysarthria Impact Profile (DIP) for European Portuguese (EP) and validate it for use in Parkinson's disease (PD) patients.

Methods: The cross-cultural adaptation was carried out in accordance with the guidelines. The EP version of the DIP was administered to 80 people with PD, and 30 sex- and age-matched control participants. Psychometric properties, acceptability, feasibility reliability (internal consistency and intrarater agreement) and validity (construct, convergent and known-groups validity) were assessed using other assessment tools (motor disability and impairment, and voice impact).

Results: Overall, the EP-DIP final version has the same conceptual meaning, semantics, idiomatic and score equivalences as the original version. Statistical analyses showed adequate feasibility (missing data <5%), good acceptability (ceiling or floor effects <15%; high requests of assistance to complete the questionnaire), satisfactory internal consistency (Cronbach's $\alpha = 0.9$), weak-to-moderate intrarater reliability, good construct validity, strong convergent validity (with the Voice Handicap Index; Spearman's $P = -0.8$) and good known-groups validity (between those with PD and control participants).

Conclusions: The EP-DIP version displays the salient features of a valid patient-based assessment tool used to measure the psychosocial impact of slight-to-mild dysarthria in people with PD. **Geriatr Gerontol Int 2018; 18: 767–774.**

Keywords: dysarthria, dysarthria impact profile, Parkinson's disease, psychosocial impact, speech.

Introduction

Parkinson's disease (PD) is the second most prevalent neurodegenerative disease, affecting 1.0–1.5% of individuals aged ≥60 years.[1] Of these, 70–90% will develop speech disorders (hypokinetic dysarthria).[2] People with PD (PwP) can display negative perceptions about their abilities as communicators.[3] Over the past few decades, there has been strong growth in the use of patient-reported outcomes for PwP.[4,5] According to the International Parkinson and Movement Disorder Society (MDS) task force, a tool is "recommended" for use in PwP if: (i) it has been used in clinical studies beyond the group that developed it; (ii) it was used in previous studies of PwP[6,7]; and (iii) its psychometric properties are reported.[8] The original Dysarthria Impact Profile (DIP) is a patient-reported outcome and generic dysarthria tool, it was developed and validated in English,[3] and was translated and preliminarily validated to French and PwP.[6] It has been used in previous studies of individuals with voice and speech disorders secondary to PD[7] and stroke.[9] There is no such instrument in European Portuguese (EP) for this population. The present study sought to undertake the cross-cultural adaptation of the DIP into EP, and validate its use in Portuguese PwP with acquired dysarthria.

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Methods

Cross-cultural adaptation

Approval for the use and translation of the DIP was obtained from its authors and the copyright office of the *International Journal of Language and Communication Disorders*. The translation and cross-cultural adaptation process was carried out in accordance with the guidelines.[10,11] The pre-final EP version of the DIP (EP-DIP) was then passed through pre-testing and cognitive interviewing. Two PwP (aged 68 and 70 years) and two control participants (57 and 60 years old) were asked to complete the EP-DIP, and were after debriefed about what they thought the questions were asking and about any word they did not understand, as well as any word or expression that they found unacceptable. After this process, the pre-final version was accepted. The cross-cultural adaptation was carried out between November 2012 and August 2013.

Validation

Ethical approval for the present study was obtained from the ethics committees of both the Faculty of Medicine and Hospital de Santa Maria (Lisbon, Portugal).

Participants

A total of 80 PwP were recruited at the outpatient movement disorders clinics of Hospital de Santa Maria University Hospital (Lisbon, Portugal) and 30 healthy individuals from the first author's circle of friends from September 2013 to February 2014 (Table 1). The inclusion criteria were individuals without cognitive impairment, no history of hearing problems or other neurological communication disorders (e.g. aphasia), or psychiatric problems that could interfere with the purpose of this study. The criteria of cognitive impairment to exclude participants were Mini-Mental State Examination scores according to educational level or an established diagnosis of cognitive decline. The patient's diagnosis was carried out in accordance with the UK PD Society brain bank clinical diagnostic criteria, and the control participants had no history of speech and/or voice problems.

Instruments

Demographic and clinical data were gathered using a semi-structured interview. The Mini-Mental State Examination[12] was used to assess cognitive state and the Movement Disorders Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS)[13] was used to evaluate the motor disability and impairment. The Voice Handicap Index (VHI) was used to collect the patient's perception of the disadvantage associated with their voice disorders[14]; it is endorsed by MDS-UPDRS and it was included to assess convergent validity. Both Speech and language pathologists (SLP) were certified to apply the MDS-UPDRS and Hoehn and Yahr scales and, after obtaining signed informed consent, carried out the participants' assessment. Both the PD and control group completed the EP versions of VHI and DIP alone, or with assistance according to the instructions of the questionnaire. The assessments were carried out in a single visit.

DIP. The underlying theoretical model of the original DIP is the ICF framework (World Health Organization, 2001).[15] The DIP includes 49 statements, selected from patient interviews, addressing five domains. The individual is asked to rate each statement on a five-point scale between "Strongly agree" and "Strongly disagree." In each of the four sections, there are two similar statements, differently formulated in order to test the responder consistency[3] (e.g. A3 "Even if I am not speaking, I feel that I am a different person now" and A12 "My speech difficulty has not changed me fundamentally as a person"). In the last section, individuals are asked to list four main worries or concerns, in addition to the speech problem. They are then asked to rank these concerns in order from one to five, where five indicates a "minor concern" and one indicates a "major concern or worry." The total score ranges between 49 and 225, with higher values representing the least impact of dysarthria.

Statistical analysis

Data were evaluated according to specific psychometric attributes and standard criteria for tool validation, such as feasibility, acceptability, reliability and validity.[11] Statistical analysis was carried out using R version 3.03 (http://www.r-project.org/). Descriptive statistics were calculated for demographic and clinical variables. Feasibility was assessed by analyzing the quantity of missing data, (<5% was considered adequate). Acceptability was tested by analyzing the depth and the need of assistance to complete the DIP questionnaire. The depth implies that no ceiling and/or floor effects are observed and values <15% are defined as acceptable.[16] Reliability was determined by analyzing internal consistency using Cronbach's α for the total and subtotal scores (Cronbach's α values ≥0.7 are satisfactory).[17] The responder intrarater reliability was determined between two similar statements in each section that were created for this purpose in the original version. The items are scored in the same way; however, the statements are semantic equivalents, and morphologically and syntactically different. The correlation is considered strong (>0.7), moderate (between 0.69 and 0.5) or weak (<0.3).[18] Construct validity was assessed through a

Table 1 Demographic and clinical data

	People with PD n = 80		People with PD n = 30 (from the 80)	Healthy participants n = 30
Sex (Male/Female)†	44	36	12 18	12 18
Mean age, years	66.73 ± 10.87	67.61 ± 11.98	62.8 ± 12.7	62.5 ± 12.4
(range)	(42–87)	(43–96)	(42–87)	(42–87)
Level of education† (International Standard Classification of Education, ISCED, UNESCO, 1997)				
Level 0 (pre-primary)	4 (5%)		1 (3.3%)	1 (3.3%)
Level 1 (1–4 years, primary)	42 (52.5%)		19 (63.3%)	24 (80.0%)
Level 2 (5–9 years, lower secondary)	12 (15%)		2 (6.7%)	2 (6.7%)
Level 3 (10–12) years, upper secondary	9 (11.3%)		4 (13.3%)	2 (6.7%)
Level 4 (post-secondary, no tertiary	3 (3.4%)		1 (3.3%)	–
Level 5 (first stage of tertiary)	9 (11.3%)		3 (10.0%)	1 (3.3%)
Level 6 (second stage of tertiary)	1 (1.25%)		–	–
Occupational status, n (%)				
Working	25 (26%)			11 (36.7%)
Unemployed	2 (2.5%)			1 (3.3%)
Retired	53 (76%)			18 (60%)
MMSE (mean ± standard deviation)				
1–11 years of school education	26.8 ± 2.43			28.1 ± 1.8
>11 years of school education	28.8 ± 1.29			28.3 ± 2.1
Mean no. years from diagnosis (range)	9.6 ± 7.4 (0.5–29)			–
Disease stage Mean H&Y	2.18 ± 1.17			–
MDS-UPDRS (motor disability and impairment)	66.8 ± 30.2	83.5 ± 43.9		
VHI	29.6 ± 26.3	35.4 ± 49.9		
	32.1 ± 37.1			

†Statistical differences between groups identified P-value >0.05 between the total sample of patients (n = 80) and the control group (n = 30). H&Y, Hoehn and Yahr scales; MDS-UPDRS, Movement Disorders Society-Unified Parkinson's Disease Rating Scale; MMSE, Mini-Mental State Examination; PD, Parkinson's disease; VHI, Voice Handicap Index.

confirmatory factor analysis. The loading is considered large (≥0.80), moderate (between 0.50 and 0.79) or small (<0.50). The sample size used (80 patients) is supported in the literature, suggesting a ratio of 1.2 and 1.3 patients for each item of the instrument, DIP has 49 items, which defines a minimal sample size of 66 and 72, respectively.[19,20] Convergent validity refers to the extent to which scores of the tool are related to an independent measure taken as the criterion reference standard. The correlation EP-DIP and VHI scores were estimated by carrying out non-parametric correlations (Spearman's correlations >–0.7 was considered good; and between –0.5 and –0.7 moderate, and weak <0.5). A good correlation between instruments is expected, taking into account that both of them measure the self-perception of disability associated with voice and speech problems. The known-groups validity was computed by examining whether the EP-DIP scores can differentiate between PwP and the control group of responders. A total of 30 patients were matched with the control group according to age and sex, creating a homogenous group of patients to compare with the control group to study the known-group validity. The item 3.1 MDS-UPDRS was used to describe the severity of dysarthria based on the clinical perception. A multiple comparison analysis was carried out in order to study the EP-DIP ability to identify groups with different dysarthria psychosocial impacts considering that they are associated to different severity levels of dysarthria.

Results

Cross-cultural adaptation

The cultural adaptations carried out were related to: (i) vocabulary selection and simplification – some statements were modified in order to achieve idiomatic equivalence; and (ii) visual aspect – capital letters used to write complete words used in titles, subtitles and instructions were replaced according to the Portuguese orthographic rules to lower case. A grid was added in

order to limit the mistakes and missing data; descriptive labels for all the sections were added to the scoring to facilitate interpretation. The final EP-DIP uses a language accessible to the general public, but despite this, some participants had interpretation difficulties specifically with double negative sentences. Comparison between EP-DIP and original DIP is in the supplementary material (Tables S1–S8).

Validation

Feasibility

Demographic and clinical data are summarized in Table 1. The feasibility was 1% of data were missing (<5%). Neither floor nor ceiling effects were observed, as there was not a high proportion in the PwP group scoring the lowest or the highest observed value of the EP-DIP total score. The observed range was 83–211. Relative to the administrative burden, the majority of the individuals (61%) took approximately 25 min to complete the questionnaire and more than half (54%) required assistance.

Validity

Construct validity was based on a confirmatory factor analysis, the loadings are presented in Figure 1. The loading for nine items was large (≥0.80), for 19 items it was moderate (0.50–0.79), whereas for 21 items it was small (<0.50; Fig. 1). The comparative fit index was 0.60, the standardized root mean squared residual was 0.099. The results from convergent validity are shown in Table 2. Relative to the known-groups validity, PD patients achieved significantly lower overall EP-DIP scores ($t = -6.817$, d.f. = 36. 036, $P < 0.01$) compared with the matched controls, with a mean value of 170.09 ± 29.71 for PD versus 218.42 ± 9.42 for controls (Table 3). Relative to PwP, differences within groups according to the severity of dysarthria assessed with item 3.1 of MDS-UPDRS were significant, with a multiple comparison revealing at least one group of dysarthria severity with different mean scores of EP-DIP (*P*-value <0.05). All comparisons were statistically significant, except for the comparison between "without dysarthria" and "slight dysarthria," and between "moderate dysarthria" and "severe dysarthria" (*P*-value >0.05).

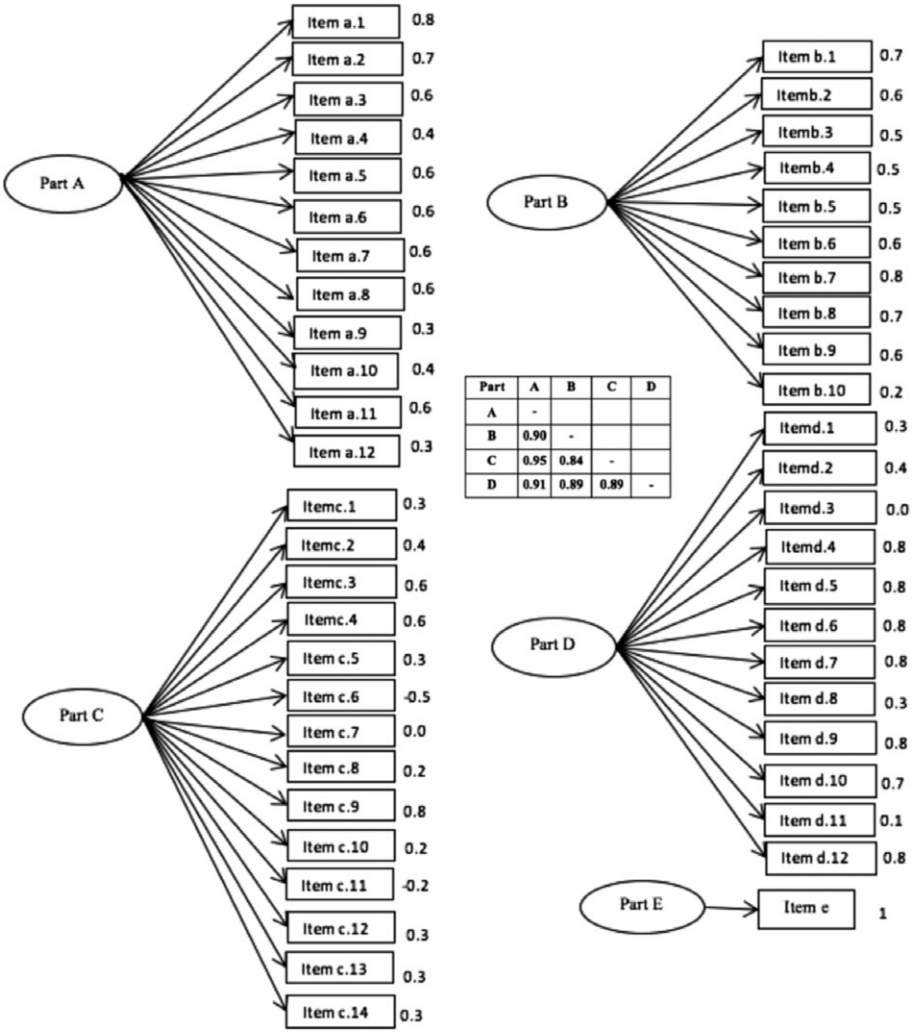

Figure 1 Confirmatory factorial analysis of the European Portuguese version of the Dysarthria Impact Profile.

Table 2 Spearman's correlation between total and subscales of the European Portuguese version of the Dysarthria Impact Profile and Voice Handicap Index

Subscales	VHI – Emotional	VHI – Functional	VHI – Physical	VHI total score
DIP-A The effect of dysarthria on the speaker as a person	−0.8	−0.7	−0.6	−0.7
DIP-B Acceptance of dysarthria	−0.8	−0.8	−0.7	−0.8
DIP-C Perception of others' reaction to speech	−0.7	−0.6	−0.6	−0.7
DIP-D How dysarthria affects communication with others	−0.6	−0.6	−0.5	−0.6
DIP-E Dysarthria relative to other worries and concerns	0.5	−0.5	0.5	−0,5
DIP – Total score	−0.8	−0.8	−0.7	−0.8

P-value <0.05 for all correlations reported. DIP, Dysarthria Impact Profile; VHI, Voice handicap index.

Table 3 Mean scores and standard deviation of the European Portuguese version of the Dysarthria Impact Profile according to dysarthria severity

	People with PD $n = 30$	Healthy participants $n = 30$
DIP overall score	170.09 ± 29.71	218.42 ± 9.42
DIP overall score according to dysarthria severity – item 3.1 MDS-UPDRS		–
Without dysarthria ($n = 17$)	192.94 ± 10.18	–
Slight ($n = 37$)	178.43 ± 19.17	–
Mild ($n = 17$)	155.59 ± 29.28	–
Moderate ($n = 5$)	112.00 ± 31.14	–
Severe ($n = 4$)	129.80 ± 12.97	–

DIP, Dysarthria Impact Profile; MDS-UPDRS, Movement Disorders Society-Unified Parkinson's Disease Rating Scale.

Reliability

The results from the internal consistency are shown in Table 4. The α coefficient was not determined in subscale E because it has only one item. Hypothetical items reduced in order to improve internal consistence are in Table 4. First, the item with negative loading was eliminated, then all the items with loading <0.5 were removed (Table 4). Intrarater reliability item results showed a weak correlation for subsections A (statements 3 and 12; $r = 0.12$, P-value = 0.20) and C ($r = 0.21$, P-value = 0.001; statements 3 and 12), and moderate correlations for subsections B ($r = 0.52$, P-value = 0.00; statements 3 and 12) and D ($r = 0.50$, $P = 0.001$; statements 2 and 10).

Discussion

The difficulties associated with double negative statements might be due to the fact that 52.5% of the PwP group had a low level of education (between 1 and 4 years), which is similar to the data of the general Portuguese population aged ≥65 years.[21]The final EP-DIP was designed to maintain the same concept expounded in the original version, because the researchers' intent was to validate a tool that will allow comparison or aggregation of data across cultures. Despite that, the EP-DIP presents a slightly amended format in comparison with the original English version in order to make it more user-friendly and avoid response failures, a need that was stressed in the validation of the French version.[6]

Table 4 Cronbach's α improvement caused by hypothetical item reduction

DIP	Cronbach's α	Cronbach's α Without items with negative loading[†]	Cronbach's α Without items with loading <0.5[‡] and negative loading[†]
Section A	0.82		0.82
Section B	0.82		0.83
Section C	0.69	0.66	0.60
Section D	0.824		0.89
Total Score	0.92	0.93	0.94

[†]Removed items C6 and C11. [‡]A4, A9, A10, A12, B10, C1, C2, C5, C6, C7, C8, C10, C11, C12, C13, C14, D1, D2, D3, D8, D11. DIP, Dysarthria Impact Profile.

The feasibility of the EP-DIP was adequate, suggesting that the participants were able to complete the questionnaire successfully. Missing data were answers to random items, mainly due to filling errors or issues that participants preferred not to answer, patterns of avoidance of some items were not detected. Data from the present study showed a mean (170.09 ± 29.71) and range (83–211) that are higher than data from the 10 PwP assessed using the original English DIP version (mean 144.9 ± 26.90, range 95–175[3]). Data from the 10 PwP assessed using the French version (mean 148.8±29, range 118–1796) was lower than our results, however, these do not imply that in the EP, those with PD suffer less detrimental impact of dysarthria. The discrepancies between the studies might be related to the fact that Portuguese PwP report that speech was not a major concern (just 19% checked DIP section E as most worried, very worried or worried), whereas in the original English version this was 21%, and in the French study this was 60%. Indeed, the PD patients included in the present study were at a mild-to-moderate stage of the disease, a bias that might be a result of the requirement to be free of dementia, a comorbidity that is more common in the late stages of PD.[22] Also, the level of education (in the EP sample, 50% presented a lower level of education) and disease duration (higher in the EP sample) varied between the studies. The administrative burden would be considerable for clinical practice; however, given the lack of instruments designed to study the psychosocial impact of dysarthria in Portuguese PwP, it remains justifiable; in addition, DIP can be completed with the caregiver's help at home, thus leaving the problematic items to be discussed with the SLP during the session. No information regarding this issue was found in the published related literature.[3,6,7]

Results from confirmatory factor analysis showed that 57.14% (28) of items show moderate-to-large loading, suggesting that these items are able to explain the data variability. Difficulties in understanding the remaining items can explain the values obtained similarly to the French study. The remaining 15 items include sentences in a simple negative form (4 items), which might have led to some difficulties as well. In addition, some of the other items with a simpler syntax are also difficult to understand; for example, the sentence (C7), "People are usually patient when I speak slowly," suggests that by speaking slower the person can be understood more easily, which is not necessarily true in PD because of an apparent lack of self-perception of dysarthria features, such as volume decrease.[23,24] In future, a content validity study of DIP considering an item-by-item exploration, as well as the length and complexity of the questionnaire, will be beneficial to adjust it for use by PwP or other diseases with cognitive decline.

The confirmatory factorial analysis was determinant to show the weakness of several items. The computing of internal validity of the instrument without problematic items (loading <0.5) did not show significant improvement for the sections of the DIP (in fact, section C decreases the internal consistency from 0.69 to 0.60). The root mean square error was <0.06, both results from the comparative fit index and root mean square error should be analyzed carefully. These results suggest a probable benefit from a revision of the EP-DIP, which we recommend.

A good correlation was observed between the EP-DIP and VHI total scores, suggesting that the two scales were able to evaluate a common construct. This is in agreement with the French DIP version.[6] The "Acceptance of Dysarthria" (subscale B) seems to be an important factor that influences disability, showing the strongest correlation with partial and total scores of VHI.

The EP-DIP showed an ability to discriminate between PwP and healthy controls, which is in agreement with the French data.[6] Additionally, EP-DIP showed different scores to different severity levels of dysarthria, suggesting a tendency for the score to decrease as the severity of dysarthria increases.

The internal consistency was satisfactory (0.92). These results are similar to the French (0.93)[6] and the original English (0.80)[3] versions, which is a methodological quality indicator of cross-cultural adaptation and data collection. The maintenance of the general agreement between items, previously described in the other versions of the instrument, is an argument in favor of the maintenance of the original framework of the instrument through the process of translation and cultural adaptation.

The study of internal consistency excluding items with negative and weak loadings did not show a significant improvement. In the French study, the authors argued that the alternation between positive- and negative-worded statements can imply difficulties for both patients and control participants when completing the scale, leading to possible incongruent responses. The intrarater reliability results showed a weak-to-moderate correlation between each pair of items inside their respective subsections designed to study this issue (including negatively-worded statements). This finding was verified during the confirmatory factorial analysis, with negatively-worded questions showing weak or negative loadings. The same phenomenon was observed in the French study, but not in the original version.[3] Therefore, some amendments in the EP version of the scale are required, which is mirrored by the conclusions of the French study.[6]

To the best of our knowledge, this is the first cross-cultural adaptation of the DIP for EP, as well as its first validation in a relatively large sample of PwP. The psychometric properties of the EP-DIP allow the meaningful use of this version to assess the impact in PwP associated with slight-to-mild dysarthria. In addition,

the DIP is now available in three languages: English,[3] French[6] and EP, and therefore, it is suitable for use in multinational collaborative research.

The limitations of the present study are related with the analysis not addressed, which should be developed in future research, such as: (i) sample diversity – people with dysarthria from others etiologies should be included in future studies, as well as people with different educational levels; (ii) burden – The associated burden of this instrument should be adressed in future studies because as a tool for the clinical setting, it is relevant to study if the DIP is easy an brief to administer[16]; and (iii) stability of scores obtained – the test–retest reliability should to be measured.

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Disclosure statement

The authors declare no conflict of interest.

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Supporting information

Additional supporting information may be found in the online version of this article at the publisher's website:

Appendix S1 The dysarthria impact profile/Perfil de impacto da disartria.
Table S1 Page 1 of Dysarthria Impact Profile Comparative presentation (English and European Portuguese) of the instrument instructions and example of filling.

Table S2 Page 2 of Dysarthria Impact Profile Comparative presentation (English and European Portuguese) of section A.
Table S3 Page 3 of Dysarthria Impact Profile Comparative presentation (English and European Portuguese) of section B.
Table S4 Page 4 of Dysarthria Impact Profile Comparative presentation (English and European Portuguese) of section C.
Table S5 Page 5 of Dysarthria Impact Profile Comparative presentation (English and European Portuguese) of section D.
Table S6 Page 6 of Dysarthria Impact Profile Comparative presentation (English and European Portuguese) of section E.
Table S7 Page 7 of Dysarthria Impact Profile Comparative presentation (English and European Portuguese) of the scoring form – page 1.
Table S8 Page 8 of Dysarthria Impact Profile Comparative presentation (English and European Portuguese) of the scoring form – page 2.