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# Psychosocial Impact of dysarthria: the patient-reported outcome as part of the clinical management

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Short Title: Psychosocial impact of dysarthria

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#### 1. Abstract

Background: Dysarthria in neurological disorders can have psychosocial consequences. The dysarthic speaker's perspective towards the disorder's psychosocial impact is essential in its global assessment and management. For such purposes, assessment tools such as the Dysarthria Impact Profile (DIP) are indispensable.

Objective: We aimed to confirm the relevance of using the DIP to quantify the psychosocial consequences of dysarthria in neurological diseases.

Methods: We studied 120 participants, 15 healthy controls and 105 patients with different kinds of dysarthria induced by several neurological disorders (Parkinson's disease [PD]; Huntington's disease; dystonia; cerebellar ataxia; progressive supranuclear palsy [PSP]; multiple system atrophy; lateral amyotrophic sclerosis). All participants underwent a cognitive evaluation, a speech intelligibility assessment, and completed three self-reported questionnaires: the 36-item short form health survey, the Voice Handicap Index (VHI), and the DIP.

Results: The psychometric properties of the DIP were confirmed, including internal consistency ( $\alpha$ =.93), concurrent validity (correlation with the VHI: r=-.77) and discriminant validity (accuracy=.93). Psychosocial impact of dysarthria was revealed by the DIP for all patients. Intelligibility loss was found strongly correlated with the psychosocial impact of dysarthria: for a similar level of intelligibility impairment, the DIP total score was similar regardless of the pathological group. However, our findings suggest that the psychosocial impact measured by the DIP could be partially independent from the severity of dysarthria (indirectly addressed here via speech intelligibility): the DIP was able to detect patients without any intelligibility impairment, but with a psychosocial impact.

Conclusions: All patients reported a communication complaint, attested by the DIP scores, despite the fact that not all patients, notably PD, ataxic and PSP patients, had an intelligibility deficit. The DIP should be used in clinical practice to contribute to a holistic evaluation and management of functional communication in patients with dysarthria.

#### 2. Introduction

Dysarthria is common in neurological movement disorders and represents 53% of acquired communication impairments[1]. Six kinds of dysarthria were initially described by Darley et al.[2] (Fig.1). Hypokinetic and hyperkinetic dysarthrias result from subcortical dysfunctions respectively associated to reduced and increased movements; ataxic dysarthria is associated with cerebellar dysfunctions. Bilateral upper motoneuron alterations can induce spastic dysarthria, while the dysfunction of the final motor pathway can lead to flaccid dysarthria. A mixed dysarthria results from multiple brain alterations. Duffy[1] introduced two additional dysarthria types resulting from a unilateral upper motor deficit and from undetermined etiology. Dysarthria is generally assessed from a pathophysiological perspective, in that a specific disease is viewed to be the cause of a particular speech impairment. During a routine consultation, neurologists frequently rely on rating speech intelligibility, and if required, further clinical assessments and acoustic analyses can provide additional information, such as objective measures on laryngeal and supra-laryngeal articulations.

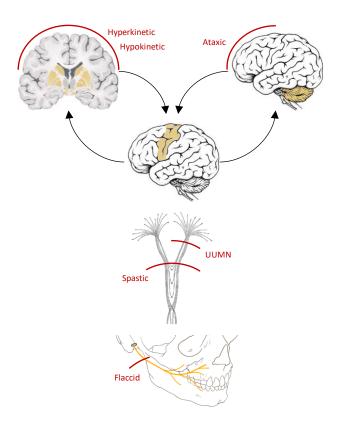


Fig.1. The different types of dysarthria according to the location of pathophysiological dysfunctions (based on previous dysarthrias classification).

Hypokinetic and hyperkinetic dysarthrias are associated to basal ganglia dysfunctions, while ataxic dysarthria results from cerebellar dysfunction. Unilateral Upper Motor Neuron (UUMN), spastic and flaccid dysarthrias are the sequel of pyramidal tract dysfunctions (upper motor neuron and unilateral for UUMN, upper motor neuron and bilateral for spastic dysarthria, and lower motor neuron for flaccid dysarthria). Not mentioned in this representation: mixed dysarthrias (resulting from multiple subcortical/cortical lesions) and dysarthria of undetermined etiology.

Dysarthria leads to communication deficits, which frequently induce social isolation[3], a decrease in quality of life[4], and alterations in daily-living activities[5]. Such deficits also increase the risk of developing psycho-emotional disorders such as depression[6], or even cognitive deterioration[7]. Yet, the majority of assessments dedicated to speech/voice impairments are based on the symptoms themselves[8,9], and not on the symptoms' consequences. A "biomedical model of illness is inadequate in understanding the full impact of communication disorders" and "psychosocial factors should be considered"[10]. This practice leaves unanswered the symptoms' effects on quality of life, despite quality of life being dependent on those consequences that affect physical, psychological and social components[11]. A method of bridging the gap between symptom consequences on quality of life is to monitor patient-reported outcomes (PROs). PROs appear as particularly important contributions to clinical practice, especially because they report functional facts that are not systematically in agreement with the degree of severity of the symptom[12]. As stated by the PRO Harmonization Group (www.eriqa-project.com), PROs allow clinicians: 1) to better acquaint themselves with symptom consequences; 2) to assess the relevance of a treatment; 3) to guide medical choices; 4) and to improve the interpretation of clinical outcomes[13].

Among the assessments of PROs is the Dysarthria Impact Profile (DIP), which was developed and validated in English, with patients presenting with different kinds of dysarthria[14]. Its adaptations in French[15] and European Portuguese[16] have been performed, but only for hypokinetic dysarthria in PD patients. We propose here a revised French version for which all previously acknowledged limitations[15] were overcome. The objectives of the present study were to confirm the psychometric properties of this revised version of the French DIP with patients presenting with different kinds of dysarthria, and to further demonstrate the relevance of using psychosocial indicators as part of the global assessment and management of dysarthria.

## 3. Materials and Methods

## 3.1. Participants

We recruited 105 patients pertaining to seven pathological groups (15 per group) and associated with five kinds of dysarthria, including: hypokinetic (Parkinson's disease [PD]), hyperkinetic (Huntington disease [HD]; dystonia), ataxic (degenerative cerebellar ataxia) and mixed (progressive supranuclear palsy [PSP]; multiple system atrophy [MSA]; amyotrophic lateral sclerosis [ALS]). The only inclusion/exclusion criteria was that patients had had no neurostimulation, and that they were able to understand and complete the questionnaires. The patients, under usual medication, were recruited during routine outpatient visits to Neurological and ENT wards, based on neurological diagnosis and not on the presence of dysarthria. The local Ethics Committee Review Board ensured that all ethics criteria were granted in this research, which was conducted after informed consent of the patients. A group of 15 healthy controls (HC) was also recruited. Demographic and clinical characteristics of participants are summarized in Table.1.

Table 1: Demographic data and clinical outcomes of participants.

Dysarthria	Participant	N (F/M)	N (E/NA) A go (v)	Education	Disease	MoCA	Intelligibility	DIP	VHI	SF-36
type	group	IN (F/IVI)	Age (y)	duration (y)	duration (y)	MOCA	(%)	DIF		
	HC	7/8	61.2 ± 6.1	14.5 ± 3.3	-	28.4 ± 1.1	99 ± 2.1	204.5 ± 18.5	7.8 ± 7.2	78.9 ± 15.3
Hypokinetic	PD	1 / 14	62.7 ± 11.4	13.8 ± 3.6	7.5 ± 4.9	25.8 ± 2.9	96.7 ± 4.5	169.1 ± 22.9	31.3 ± 22	51.7 ± 16.3
Hyperkinetic	HD	11 / 4	57.8 ± 14.6	13.1 ± 3.6	9.3 ± 9.6	20.5 ± 5.9	74 ± 26.7	152.5 ± 26.2	33.9 ± 28.7	46.4 ± 21.5
	Dystonia	9/6	59.7 ± 11.3	12 ± 3	16.6 ± 12.2	26.2 ± 2.4	79.3 ± 19.5	147.9 ± 32.1	63.3 ± 27.9	63.1 ± 18.2
Ataxic	Ataxia	10/5	52.2 ± 14.7	13.6 ± 2.9	8.5 ± 6.4	23.7 ± 6.6	91 ± 18.9	155.2 ± 27.4	38 ± 21.5	49.9 ± 18.3
	PSP	8/7	72.3 ± 8.6	12.7 ± 3.2	3.6 ± 2.9	22.9 ± 4.1	83 ± 20.1	142.5 ± 22.9	49.3 ± 29.3	40.4 ± 15.3
Mixed	MSA	2 / 13	66.9 ± 9.7	11.9 ± 4.2	5.3 ± 4.7	24.6 ± 2.1	73.3 ± 21.8	140.3 ± 24.3	59.7 ± 23.7	37.7 ± 13.3
	ALS	9/6	70.1 ± 10.7	13.3 ± 3.8	1.7 ± 1.5	24.1 ± 3.2	48.3 ± 34.7	137.7 ± 14.7	64.3 ± 23	43.9 ± 20.5

ALS: Amyotrophic Lateral Sclerosis; DIP: Dysarthria Impact Profile; F: Female; HC: Healthy control; HD: Huntington's disease; M: Male; MoCA: Montreal Cognitive Assessment; MSA: Multiple System Atrophy; N: number of participants; PD: Parkinson's disease; PSP: Progressive Supranuclear Palsy; SD: Standard Deviation; SF-36: 36-Item Short Form Health Survey; VHI: Voice Handicap Index. For intelligibility, DIP and SF-36: the higher the score, the lower the degree of perceived handicap. For VHI: the higher the score, the higher the degree of perceived handicap.

#### 3.2. Acoustic measures & clinical assessments

Speech intelligibility was assessed by a speech pathologist on the basis of speech records provided by the intelligibility section of the Frenchay Dysarthria Assessment (FDA-2). The participants read ten words and ten sentences, randomly and blindly chosen from a list of 116 words and 50 sentences. Intelligibility scores were reported as percentages of correctly transcribed items[17].

Among acoustic parameters, means and standard deviations of fundamental frequency (F0) and speech loudness (SPL, sound pressure level) were extracted from the sentences read by the patients. These measures were focused on in our study since monopitch and monoloudness are particular deficits often displayed in dysarthric speech.

The Montreal Cognitive Assessment (MoCA[18]) was performed to detect any cognitive impairment.

The 36-Item Short Form Health Survey (SF-36[19]) is a non-specific quality of life self-questionnaire, which examines four physical and four mental subdomains. Each subdomain is scored from 0 (maximal disturbance) to 100 (normal).

The Voice Handicap Index (VHI[8]) is often considered as the gold standard for voice self-perception[9]. It includes 30 items split into three domains: physical, functional, emotional. Each item is scored from 0 to 4: the higher the score, the higher the degree of perceived handicap.

The DIP[14–16] is composed of four numerical subscales (A: 'the effect of dysarthria on me as a speaker'; B: 'accepting my dysarthria'; C: 'how I feel others react to my speech'; D: 'how dysarthria affects my communication with others'). Each item is scored from 1 (major impact) to 5 (no impact): the lower the score, the higher the degree of psychosocial handicap. The last subscale (part E) was not included in this analysis since it is a qualitative section that does not provide any numerical score.

## 3.3. Statistical analyses

All statistical analyses were performed with R software. We calculated Cronbach's  $\alpha$  to assess the internal consistency of the DIP (an adequate consistency would correspond to a coefficient of at least .70). We performed Pearson's correlations (after Holm's correction) between the scales in order to estimate the concurrent validity of the DIP, and Receiver Operating Characteristic (ROC) analyses between: 1) HC and all patients to determine discriminant validity (sensitivity, specificity, accuracy [area under the curve], power and cut-off) of the DIP, and 2) for each items of the DIP, between HC and patients to determine discriminant items and between each group of patients and the other patients to determine any specificity of each disease. Also, Hedges' g effect sizes were calculated to compare HC to patients. Considering the number of analyses performed, and the rather small number of participants by group, we considered as meaningful only large effect sizes (g≥.8). Finally, we performed one linear regression to determine the influences of both intelligibility and the pathological group on the DIP total score.

#### 4. Results

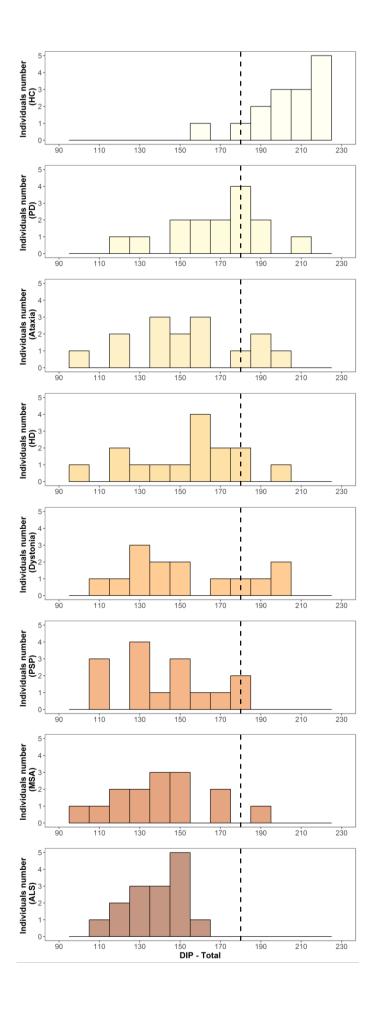
## 4.1. Psychometric properties of the DIP

For the total DIP score, internal consistency was confirmed for all groups ( $\alpha$ >.7; Table.2.A); it was also confirmed for the four subscales when we considered all participants together: A ( $\alpha$ =.81), B ( $\alpha$ =.71), C ( $\alpha$ =0.79) and D ( $\alpha$ =.85). The correlations we generated demonstrated that the DIP had good construct validity (Table.2.B): the total DIP score was highly correlated to the total VHI (r=-.77), SF-36 (r=.53) and speech intelligibility (r=.43). No correlation was found between the DIP and any acoustic measure. The highest correlations were found between the emotional part of the VHI and the subscales A, B and C of the DIP (respectively, r=-.65, r=-.62, r=-.63), and between the functional part of the VHI and the subscale D of the DIP (r=-.78). Discriminant validity was confirmed for the total DIP score (accuracy=.95; cut-off=180/240) and for each of the subscales: A (accuracy=.91; cut-off=44/60), B (accuracy=.87; cut-off=38/50), C (accuracy=.87; cut-off=48/70) and D (accuracy=.96; cut-off=48/60; Table.2.C). The cut-off of the total DIP score allowed us to determine the proportion of patients who had a communication complaint: 66.6% of PD patients, 73.3% of ataxic patients, 80% of dystonic patients, 86.6% of HD patients, 93.3% of MSA patients; 100% of PSP patients and 100% of ALS patients (Fig.2).

Table 2: Psychometric properties of the DIP: A) internal consistency (Cronbach's  $\alpha$ ), B) construct validity (Pearson's correlations) and C) discriminant validity (ROC).

		,		,, ().		
				DIP		1
		Part A	Part B	Part C	Part D	Total score
A) Internal con	sistency (Cronk	oach's α)				
	HC	.72	.70	.83	.70	.90
Hypokinetic	PD	.79	.60	.77	.71	.91
Hyperkinetic	HD	.77	.66	.74	.82	.92
riyperkilletic	Dystonia	.85	.85	.90	.86	.95
Ataxic	Ataxia	.80	.70	.78	.82	.90
	PSP	.70	.59	.72	.79	.89
Mixed	MSA	.79	.52	.66	.79	.89
	ALS	.59	.66	.68	.83	.87
А	II	.81	.71	.79	.85	.93
B) Construct va	alidity (Pearson	's correlation	s)			•
	Part F	61	53	59	78	74
VHI	Part P	58	52	55	62	66
VПI	Part E	65	62	63	73	77
	Total score	65	59	62	75	77
Intellig	Intelligibility		.32	.31	.46	.43
F0 - Mean (	Z-Score )	.04	.01	.14	.06	.08
F0 - SD ( 2	Z-Score )	07	.03	08	22	12
SPL - Mean	( Z-Score )	11	11	18	14	16
SPL - SD (	Z-Score )	15	07	04	02	09
Мо	CA	.21	.19	.18	.25	.25
SF-	36	.49	.42	.43	.49	.53
C) Discriminan	t validity (ROC)					
Sensi	tivity	.86	.80	.93	.93	.93
Speci	ficity	.80	.77	.70	.86	.85
Accu	racy	.91	.87	.87	.96	.95
Pov	ver	.99	.99	.99	1	1
Cut-	off	44 / 60	38 / 50	48 / 70	48 / 60	180 / 240

Grey values indicate that A) Cronbach'  $\alpha$  was insufficient ( $\alpha$  < . 7) and B) correlation was not significant (p > .05) after Holm's correction. ALS: Amyotrophic Lateral Sclerosis; DIP: Dysarthria Impact Profile (A: "the effect of dysarthria on me as a speaker"; B: "accepting my dysarthria"; C: "how I feel others react to my speech"; D: "how dysarthria affects my communication with others"); F: Female; F0: Fundamental frequency; HC: Healthy control; HD: Huntington's disease; M: Male; MoCA: Montreal Cognitive Assessment; MSA: Multiple System Atrophy; PD: Parkinson's disease; PSP: Progressive Supranuclear Palsy; ROC: Receiver Operating Characteristic; SD: Standard Deviation; SF-36: 36-Item Short Form Health Survey; SPL: sound pressure level; VHI: Voice Handicap Index (F: functional; P: physical; E: emotional).

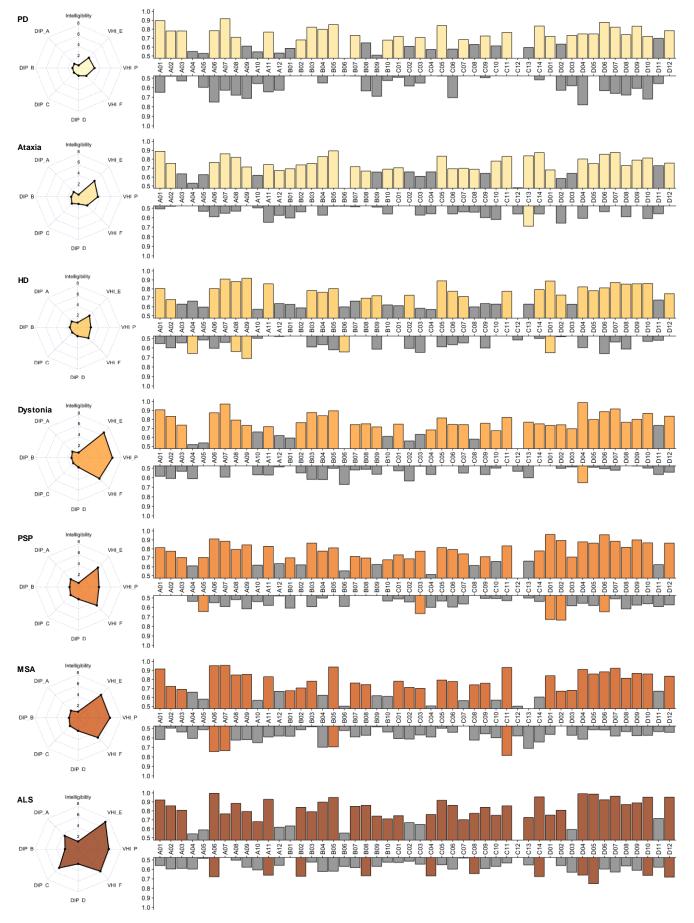


## Fig. 2. DIP score distributions by pathological group according to the calculated cut-off.

The vertical line represents the cut-off (180/240) for the DIP total score obtained with the ROC analysis: below 180, the DIP reveals statistically a psychosocial impact of dysarthria; above 180, the DIP score does not report an impact with functional meaning. ALS: Amyotrophic Lateral Sclerosis; DIP: Dysarthria Impact Profile; HC: Healthy control; HD: Huntington's disease; MSA: Multiple System Atrophy; PD: Parkinson's disease; PSP: Progressive Supranuclear Palsy.

## 4.2. Patient phenotypes according to the communication complaint

Patient phenotypes were ranked according to the total DIP score, from the smallest to the highest complaint: PD ( $\overline{x}$ =169.1), Ataxia ( $\overline{x}$ =155.2), HD ( $\overline{x}$ =152.5), Dystonia ( $\overline{x}$ =147.9), PSP ( $\overline{x}$ =142.5), MSA ( $\overline{x}$ =140.3) and ALS ( $\overline{x}$ =137.7). Hedges' g effect sizes between patients and HC for the DIP and VHI subscales demonstrated that all patients reported a dysarthria complaint (g>.8). However, PD, ataxic and PSP patients did not show any decrease of intelligibility (g<.8). Most of the items were discriminant between each group of patients and the controls (Fig.3, upper part of the right panels). No items reached the threshold of accuracy between PD patients and other patients, while only one item was significant for ataxic patients (C13; p=.008) and dystonic patients (D04; p=.027). For HD, PSP and MSA patients, between 4 and 5 items were significantly discriminant from other patients (Fig.3). Lastly, for ALS patients, eleven items, ranging from A06 to D12 were significant (p<.05). We also observed that both the pathological group (F<sub>(7;104)</sub>=12.97; p<.001) and the intelligibility score (F<sub>(1;104)</sub>=6.87; p=.01) had an effect on the total DIP score, but without any significant interaction (F<sub>(7;104)</sub>=0.97; p=.45).



#### Fig.3. Dysarthria phenotypes according to the pathological groups.

Left panel: the profile diagrams are based on Hedges' g effect sizes between healthy controls and each group of patients. Right panel: accuracy scores for each DIP items (from A01 to D12) between the pathological group and the healthy control group (top panel), and between the pathological group and the other pathological groups (bottom panel). The colored bars correspond to meaningful items. ALS: Amyotrophic Lateral Sclerosis; DIP: Dysarthria Impact Profile (A: "the effect of dysarthria on me as a speaker"; B: "accepting my dysarthria"; C: "how I feel others react to my speech"; D: "how dysarthria affects my communication with others"); HD: Huntington's disease; MSA: Multiple System Atrophy; ns: not significant; PD: Parkinson's disease; PSP: Progressive Supranuclear Palsy; VHI: Voice Handicap Index (F: functional; P: physical; E: emotional).

#### 5. Discussion

All patients reported a communication complaint, regardless of the presence of speech impairment clinically estimated via speech intelligibility. Interestingly, PD, ataxic and PSP patients did not show any deficit of speech intelligibility. Our study suggests that it would be relevant to take into account psychosocial indicators of dysarthria in patients with neurodegenerative disorders.

## 5.1. Psychometric confirmation of the DIP

Our study confirmed the psychometric properties of the revised French version of the DIP, thus validating the use of this self-questionnaire for estimating the impact of dysarthria in patients with several neurodegenerative disorders. The original DIP was administered to 31 people with different types of dysarthria[14], and consecutive adaptations in other languages confirmed its relevance for the management of PD[15,16]. Our results go one step beyond the use of the DIP as part of the clinical assessment of dysarthria, providing such evidence from a protocol that overcame the limitations of the previous version. Notably, we included a larger number of participants with different diseases and different kinds of dysarthria, we rephrased unclear statements and we perfected the formal presentation of the questionnaire (Supplementary material). In addition, the new formal organization of the DIP makes it easy to quickly determine whether the questionnaire has been properly completed: answering the questionnaire requires alternating between the responses "agree" and "disagree". As suggested by the absence of correlation between the DIP and the MoCA, the DIP score is either not or only weakly driven by the cognitive status of the patients. The DIP can thus be administered to patients with mild cognitive impairment, but we recommend that patients with higher cognitive impairments fill out the DIP with the help of a clinician or a caregiver.

## 5.2. Speech intelligibility is not functional communication

Our findings suggest that intelligibility loss is crucially correlated to the psychosocial impact of dysarthria. This means that, for a similar level of intelligibility impairment, the DIP total score is similar regardless of the pathological group. Nevertheless, the intelligibility score remains insufficient to address the psychosocial impact of dysarthria for at least two reasons: 1) the intelligibility score explained only 18.5% of the total DIP score (determination coefficient; r²); 2) two patient groups (PD

and Ataxia) displayed a significant DIP score (in comparison to the controls), but a level of speech impairment not so significant to impair intelligibility. Our findings suggest that the psychosocial impact measured by the DIP could be partially independent from the severity of dysarthria (indirectly addressed here via speech intelligibility): the DIP was able to detect patients without any intelligibility impairment, but with a psychosocial impact. This might be related to the observed independence between the perspective of the patients and those of the caregivers on communication effectiveness[20]. Thus, the assessment of speech intelligibility, which is central in the neurological investigation of dysarthria, remains insufficient to address the patient's complaints and could not represent per se the sole indicator of speech evaluation and management in clinical routine[21]. Indeed, one study showed that the majority of patients with Parkinsonian syndromes reported a communication impairment, even if some of them remained intelligible [22]. It is necessary to consider that communication ability depends on intelligibility, but also on how patients feel about the perception of others[22]. For example, based on a literature review, only 5% of scientific research in 2007 focused on psychosocial aspects of dysarthria[23]. The ROC analysis of DIP items demonstrated (especially for PD, ataxic and PSP patients who had no significant intelligibility deficit) that psychosocial consequences of dysarthria could be due to the reactions of others ("I never feel that others laugh or make fun of my speech" [C13, significant for ataxic patients]). The analysis also showed that psychosocial consequences could lower patients' self-perception ("I am as confident now as I was before I had a speech problem" [A05, significant for PSP patients]) and contribute to the isolation of patients ("Although I have difficulty speaking I do not avoid communicating with people I know" [D01, significant for PSP patients]; "My social life has not changed as a result of my dysarthria" [D02, significant for PSP patients]). Thus, our results are in agreement with a previous qualitative report that focused on acquired dysarthria and for which several themes were frequently mentioned by patients: "communication has changed", "people treat me differently", "dysarthria resulting in negative emotions", "barriers to communicate", "life is different now" [24]. So far, this statement remains topical and underlies the fact that dysarthria is a functional symptom which is still undervalued.

## 5.3. Enhancing clinical assessment and management of dysarthria with the PRO

On the exclusive basis of the neurological assessment, patients with dysarthria are generally referred to a speech therapist/pathologist only when intelligibility is significantly impaired. This might explain the gap between the number of patients with dysarthria complaints and the number of patients who have received speech therapy. For example, it has been reported that 70 to 90% of PD patients complain about speech impairment; 29% of the patients reported that dysarthria had a significant impact in their life; but only 3% accessed speech therapy[25]; though these numbers have recently improved[26]. Speech therapy can improve communication abilities and reduce social isolation[27]. Thus, patients should be seen earlier than they are currently to help reduce the psychosocial impact. Indeed, a recent study on PD reported that a longer disease duration is associated with a lower speech therapy efficacy[28]. The ROC analyses we conducted provided a cut-off of the DIP, below which the complaint of the patients should be further discussed with them and possibly, the patients could be referred to a speech/language therapist for additional counselling: clinicians could use the DIP as a tool to precisely estimate the psychosocial consequences of dysarthria[29]. Furthermore, to better manage dysarthria, it is crucial to include patient-reported difficulties in functional communication[26] as

indicators of both dysarthria's psychosocial impact[29] and speech therapy management[27,30,31]. Thus, using the DIP as a psychosocial indicator can be useful to correctly adjusting a speech rehabilitation program[32,33].

## **5.4.** Limitations of the study

Our study included some limitations. First, our patient groups included an amount of intra-group heterogeneity in terms of symptom expression, etiology, disease severity, disease duration, etc. However, our objective was to highlight the relevance of using the DIP with patients suffering from different neurodegenerative diseases, with no specific criteria of exclusion (except other neurological or psychiatric history). Second, we did not have access to information related to social environment, professional context and even cultural information. These data could be of importance to better identify complaints of communication, and have to be considered in clinical practice on a patient-by-patient individual basis. Finally, we did not evaluate depression, apathy or anhedonia, which could contribute to altering functional communication. Additional and specific studies are still required to overcome these limitations.

#### 6. Conclusion

Dysarthria is a frequent and debilitating symptom of neurological disorders, and is from the patient perspective, a multidimensional symptom, impacting also social and emotional daily-living components[24]. However, the proportion of patients who access speech therapy is significantly lower than the proportion of patients who complain about communication. Integrating an additional tool such as the DIP, which provides the patient's point-of-view, is important to better identify patients with a communication complaint, especially when these patients remain intelligible. Thus, communication ought to be assessed from a holistic perspective, including both professional expertise and the patient's feelings.

## 7. Statements

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## 7.2. Statement of Ethics

Subjects have given their informed consent.

The study protocol was approved by the local research institute's committee on human research.

## 7.3. Disclosure Statement

The authors have no conflicts of interest to declare.

## 7.4. Funding Sources

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## 7.5. Author Contributions

1. Research Project: A. Conception, B. Organization, C. Execution;

2. Statistical Analysis: A. Design, B. Execution, C. Review and Critique;

3. Manuscript Preparation: A. Writing the First Draft, B. Review and Critique.

CAC: 1A;1B;1C;2A;2B;3A

AL: 1A;1B;1C;3B

GB: 1C;2C;3B

MCC: 1C;2C;3B

LVD: 1C;2C;3B

CR: 1C;3B

MB: 1A;1C;3B

DR: 1C;3B

JPA: 1C;3B

LD: 1C;3B

JF: 3B

AE: 1C;3B

CM: 1C;3B

SP: 1A;1B;2C;3A

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## 9. Supplementary materiel

# A) L'EFFET DE LA DYSARTHRIE SUR MOI EN TANT QU'INDIVIDU

A.1	Mon pro	blème de parole a eu	un effet négatif sui	r la façon dont je me	e perçois	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-
A.2	Quan	nd je parle, j'ai l'impre	ession d'entendre q	uelqu'un d'autre qu	e moi	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-
A.3	Maintenant, m	ême quand je ne parl	e pas, j'ai l'impress	ion d'être une perso	onne différente	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-
A.4	Je n'ai	pas l'impression de	ne pas être à la hau	ıteur à cause de ma	parole	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
A.5	Mainter	nant, je suis autant sí	ûr(e) de moi qu'ava	nt mon problème de	e parole	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-
A.6	En raison de m	na parole, je suis maii	ntenant plus dépen auparavant	dant(e) des autres d	que je ne l'étais	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
A.7		Je ne me sens	pas embarrassé(e)	par ma parole		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-
A.8		Je ne me sens pas	incompétent(e) à ca	ause de ma parole		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
A.9		Je ne me sens pas	idiot(e) lorsque je	suis incompris(e)		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-
A.10		Je me sens stupid	le lorsqu'on me der	mande de répéter		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
A.11	Maintenant, j'a	ai l'impression d'avoi	r moins de contrôle	e sur ma vie à cause	e de ma parole	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-
A.12	Mon problèm	ne de parole ne m'a p	as fondamentaleme	ent changé(e) en tar	nt qu'individu	
		•			-	

# B) L'ACCEPTATION DE MA DYSARTHRIE

B.1		Je n'essaye pas c	le cacher mes diffi	cultés de parole			
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
B.2		Je me fâche quan	d les gens ne me c	omprennent pas			
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
B.3		Je ne suis pas sati	sfait(e) de ma parc	ole en l'état actuel			
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
B.4		Je suis susc	eptible concernan	t ma parole			
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
B.5		Je ne me	e soucie pas de ma	ı parole			
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
B.6	Cela	ne me dérange pas	d'admettre que j'ai	un problème de par	ole		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
B.7	B.7 Je préfère perdre le fil des conversations plutôt que d'admettre avoir un problème de parole						
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
B.8		Ma parole a influen	cé ma vie plus que	e tout autre chose			
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
B.9	Je ne m	e mets pas en colère	e lorsque je ne peu	x pas me faire comp	rendre		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
B.10	En de	ehors de ma parole, j	'ai beaucoup d'aut	res qualités importa	ntes		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	

# C) COMMENT JE PERÇOIS LA REACTION DES AUTRES FACE À MA PAROLE

C.1	Je s	suis conscient de la ré	eaction des autres v	is-à-vis de ma pard	ole		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
C.2 Ma famille n'est jamais ennuyée quand elle ne comprend pas ce que je dis							
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
C.3	Je n'ad	ccorde pas d'importar	nce à ce que les gen	s pensent de ma p	arole		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
C.4	Les autres me tra	aitent comme si j'étais	s stupide parce qu'il	s ne peuvent pas	me comprendre		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
C.5	Les gen	s ne sont pas gênés l	orsque je n'arrive pa	as à me faire comp	rendre		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
C.6	Les inconnus n	e me considèrent pas	négativement parc	e que j'ai un probl	ème de parole		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_	
C.7	Les	s gens sont généralen	nent patients lorsqu	e je parle lenteme	nt		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
C.8	Mes	s amis font plus d'effo	orts pour me compre	endre que ma fami	lle		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
C.9	Les personnes	font semblant de me	comprendre alors qu	ue je sais que ce n	'est pas le cas		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
C.10	Les	gens pensent parfois	que j'ai bu alors qu	ie ce n'est pas le c	as		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
C.11	Laı	plupart des gens font	un effort pour comp	orendre ce que je d	lis		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	-	
	desaccord		. ,		4,000.4		
C.12		rde de l'importance à	l'opinion des autres	s à l'égard de ma p			
C.12		rde de l'importance à En désaccord	l'opinion des autres Pas sûr(e)	s à l'égard de ma p En accord		-	
C.12 C.13	J'acco Fortement en désaccord		Pas sûr(e)	En accord	Fortement en accord	-	
	J'acco Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	  -  -	
	J'acco Fortement en désaccord  Je n'ai ja Fortement en désaccord	En désaccord mais le sentiment que	Pas sûr(e) e les autres rient ou Pas sûr(e)	En accord  se moquent de ma  En accord	Fortement en accord a parole Fortement en accord	-  -	

# D) COMMENT LA DYSARTHRIE AFFECTE MA COMMUNICATION AVEC LES AUTRES

D.1	Malgré mes diffic	ultés à parler, je n'évit	e pas de communiqu	er avec les gens qu	ie je connais	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.2 Ma vie sociale n'a pas changé à la suite à ma dysarthrie						
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.3	Quand les gens n	e me comprennent pas	s, j'essaye de faire pa moyens	isser mon message	par d'autres	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.4		J'évite d'utiliser le	téléphone à cause de	e ma parole		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.5		J'évite de demande	r des articles dans de	es magasins		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.6	Je compte	sur les autres pour par	ler à ma place à chac	que fois que c'est p	ossible	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.7	A cause o	le ma parole, j'écoute լ	olus que je ne prends	s part aux conversa	tions	_
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.8		Je n'évite pas	s de parler à des inco	onnus		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.9	Je me sens à l'aise p	our m'exprimer dans l	a plupart des situatio	ns, tant à la maisor	n qu'à l'extérieur	
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.10		Mes difficultés de	parole limitent ma v	ie sociale		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.11		J'évite de parler seu	ılement lorsque je su	is fatigué(e)		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_
D.12		A cause de ma parol	e, je me suis isolé(e)	socialement		
	Fortement en désaccord	En désaccord	Pas sûr(e)	En accord	Fortement en accord	_

# E) LA DYSARTHRIE PARMI L'ENSEMBLE DE MES PREOCUPATIONS

Citer 4 preoccupations qui vous derangent ou vous inquietent, a l'exception de la parole ou de la communication
A B C D Ajouter maintenant à cette liste votre problème spécifique de parole
E. Trouble de la parole
······································
Donner une priorité à ces difficultés de 1 à 5, où 1 correspondra à votre plus grande préoccupation et 5 à celle qui vous inquiète le moins ; c'est-à-dire :
<ul> <li>[1] - La plus préoccupante/ inquiétante</li> <li>[2] - Très préoccupante/ inquiétante</li> <li>[3] - Préoccupante/ inquiétante</li> <li>[4] - Peu préoccupante/ inquiétante</li> <li>[5] - La moins préoccupante/ inquiétante</li> </ul>
□ Ce questionnaire a été rempli par (cocher une seul case) :
<ul> <li>□ Moi seul</li> <li>□ Moi, avec l'aide d'un parent ou un ami</li> </ul>