

Research Note

Progression of Self-Perceived Speech and Swallowing Impairment in Early Stage Parkinson's Disease: Longitudinal Analysis of the Unified Parkinson's Disease Rating Scale

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ABSTRACT

Purpose: The purpose of this study was to investigate the presence and progression of self-perceived speech and swallowing impairments in newly diagnosed people with Parkinson's disease (PD) longitudinally across 6 years.

Method: Longitudinal data from the Parkinson's Progression Markers Initiative were analyzed across six consecutive years in a cohort of 269 newly diagnosed people with PD, and a subset of those ($n = 211$) who were assessed at every time point across the 6 years. Dependent variables included self-perceived ratings of speech and swallowing impairment severity from the Unified Parkinson's Disease Rating Scale. Patient-centered factors of age at diagnosis and motor phenotype were also assessed to determine if they were related to the change in self-perceived speech and swallowing impairments.

Results: Overall, self-perceived speech and swallowing impairments were present in newly diagnosed people with PD, although over time, the degree of severity for both remained in the mild range. However, the rate of change over time was significant for perceived speech impairment, $F(5.5, 1158.8) = 21.1, p < .001$, and perceived swallowing impairment, $F(5.2, 1082.6) = 8.6, p < .001$. Changes for speech and swallowing impairment were both in the direction of progressive severity. There were no effects of age at diagnosis or motor phenotype on the degree of change for either speech or swallowing.

Conclusions: Self-perceptions of speech and swallowing impairment changed significantly over time in newly diagnosed people with PD (PWP). Consistent with existing literature, self-perceptions of speech impairment were rated as more severe than those of swallowing impairment. These findings reveal that even in the early years postdiagnoses, PWP are experiencing changes to speech and swallowing function, albeit within the mildly severe range. The presence of self-perceived mild speech and swallowing impairments in the initial years postdiagnosis may support the need for intervention to improve and or sustain function over time.

The physiological manifestations of Parkinson's disease (PD) include hypokinetic dysarthria caused by changes in central and peripheral neuromuscular pathways that control speech movements. The speech impairment of hypokinetic

dysarthria alters speech breathing, voice quality, resonance, articulation, and speech intelligibility. The perceptual features of dysarthria in PD have been described as imprecise articulatory precision, monopitch, monoloudness, reduced vocal intensity, and a breathy or harsh voice quality (Darley et al., 1969). The voice and prosodic abnormalities have been associated with underlying glottal insufficiency and/or impaired dynamic control of fundamental frequency and amplitude scaling (Holmes et al., 2000; Midi et al., 2008; Sapir, 2014;

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Tsuboi et al., 2015), whereas articulatory abnormalities have been associated with lip, jaw, and lingual hypokinesia (Darling & Huber, 2011; Forrest & Weismer, 1995; Forrest et al., 1989; Y. Kim et al., 2009; 2011; Yunusova et al., 2008, 2011). Clinician-confirmed dysarthria can present early in the disease process, with some reports indicating recorded dysarthria within 7 years of the disease onset (Müller et al., 2001.)

Central and peripheral impacts of PD also impair swallowing safety leading to dysphagia. The physiological characteristics of dysphagia in PD can impact all swallowing stages, especially the pharyngeal stage where swallow timing is also characterized by hypokinesia, leading to laryngeal penetration and/or aspiration in a substantial number of people across the degenerative course of the disease (Baijens et al., 2011; Leopold & Kagel, 1997; Michou et al., 2013; Nagaya et al., 1998; Pflug et al., 2018). The underlying neurological pathology leading to hypokinesia is believed to be part of the larger degenerative process tied to abnormal deposits of alpha-synuclein proteins within motor and nonmotor central and peripheral neurons, characterized at autopsy by Lewy neurites and Lewy bodies (Braak & Del Tredici, 2008). The process of Lewy pathology formation is thought to begin a decade or more prior to the onset of salient motor impairments, in what is known as the “preclinical” or “premotor” stage of PD (Del Tredici & Braak, 2012).

Both speech and swallowing impairments can be present in the early nonadvanced stages of PD, although agreement across published studies is not consistent. As an example, Müller et al. (2001) noted a mean postdiagnosis time to dysarthria onset of 84 months in a sample of 17 autopsy-confirmed cases of PD. Holmes et al. (2000) found acoustic differences in the voices of speakers with late stage PD (based on the Webster Rating Scale) compared with normal controls, but no differences between early stage PD and controls. The rate of progression of impairment in neural pathways controlling speech and swallowing might be influenced by the age of PD onset, as later onset (e.g., > 70 years) has been associated with a more severe motor and nonmotor clinical signs compared with early onset (Argolo & Nóbrega, 2019; Pagano et al., 2016). However, this supposition has also been contradicted by recent evidence for both the speech and swallowing impairment severity (Dias et al., 2016; Nienstedt et al., 2019).

Recent studies have reported an effect of PD motor phenotype on subjective (self-perceived) and objective (instrumental) measures of speech and swallowing, which supported previous reports that motor phenotype is a predictor of the rate of disease severity progression (Burk & Watts, 2019; Dumican & Watts, 2020; Foltynie et al., 2002; Selikhova et al., 2009). Motor phenotype has been used to categorize people with PD (PWPD) into those with different clusters of motor impairments, including individuals with tremor-dominant characteristics and those with nontremor dominant characteristics such as gait impairment

and postural instability. Motor phenotype has been determined based on the mean of the Movement Disorders Society–sponsored revision of the Unified Parkinson’s Disease Rating Scale (MDS-UPDRS) items in Sections II and III associated with motor performance (Stebbins et al., 2013). While PD motor phenotype has been shown to influence the severity of overall disease progression in some studies, the nature of speech and swallowing impairment throughout the stages of PD remains unclear, especially in early nonadvanced stages of the disease.

The onset and presence of dysphagia may be underappreciated in PWPD (Kwon & Lee, 2019). The emergence of both the speech and swallowing difficulties typically occur within the first 10 years of disease onset, although the onset of recorded dysphagia has been found to occur later than dysarthria (Müller et al., 2001). Many people with PD and those they interact with may recognize the overt changes in speech and voice more readily than covert changes in swallowing even though both occur in early stages of the disease, perhaps due to the overt nature of oral communication. A recent report indicated that 92% of a survey sample perceived some degree of communication impairment resulting from PD (Schalling et al., 2017).

Some reports have indicated that PWPD do not accurately perceive either the presence or the severity of speech and/or swallowing impairments. As an example, studies have reported that PWPD tend to perceive existing swallowing difficulties as “benign” (Ertekin et al., 2002), and in some cases, swallowing has been perceived as within normal limits even though objective instrumental assessment confirmed the presence of oropharyngeal dysphagia including penetration and aspiration events (Kalf et al., 2008). Previous reports of dissociations between self-perceived and instrumental measures of dysarthria and dysphagia may have resulted from issues with the sensitivity of response items in the surveys used to assess self-perceptual measures. A recent study found that a detailed questionnaire specific to speech and swallowing changes was able to identify self-perceived dysarthria and dysphagia symptoms in a group of PWPD at nonadvanced stages of the disease (Dumican & Watts, 2020). Accurate assessment of self-perceived impairment and resulting quality of life are important for the process of dysarthria and dysphagia treatment as patient-reported perceptions and outcomes remain a central pillar of evidence-based practice and the evaluation of treatment effectiveness (Francis et al., 2017).

The perceptual saliency of speech and swallowing impairments in PD can be broadly assessed using the “speech” and “swallowing” items in the activities of daily living (ADL) and motor subscales of the MDS-UPDRS. While MDS-UPDRS subscale scores do not assess specificity of impairments, moderate and statistically significant associations have been reported for the “speech” subscale score or the total MDS-UPDRS motor section score with clinical

measures of voice and swallowing function (Kwon & Lee, 2019; Majdinasab et al., 2016; Midi et al., 2008; Skodda et al., 2013). Few studies have reported progressive patterns of self-perceived speech and swallowing scores from the MDS-UPDRS, although evidence from reports of total scores of Section II (where the “speech” and “swallowing” subscale items are rated) support the notion that as PWPD progress through the stages of PD (i.e., based on Hoehn and Yahr scale) the severity levels based on MDS-UPDRS scale scores increase (Hosking et al., 2021; Markopoulou et al., 2020). Due to the ubiquitous use of MDS-UPDRS in clinical and research settings along with its assessment of patient self-perceptions of swallowing and speech impairment, it could be a useful tool to track how self-perceived changes in speech and swallowing occur over time in large samples of PWPD. Additionally, if PWPD do perceived speech and swallowing impairments in the initial years postdiagnosis, it may support the need for early intervention to improve and or sustain function over time.

The purpose of this study was to investigate the presence and progression of self-perceived speech and swallowing impairments in newly diagnosed people with PD. We utilized an extant database of 422 de novo cases of PWPD who were followed over a 6-year period. Using “speech” and “swallowing” subscale scores from the MDS-UPDRS (2003) administered at regular clinical examinations, we sought to better understand how self-perceived impairments manifest across the early stages of PD with regards to MDS-UPDRS severity scale scores, and what factors are strongly associated with speech and swallowing impairments identified via patient self-perception responses on the MDS-UPDRS. While “speech” and “swallowing” subscale scores of the MDS-UPDRS lack specificity relative to the signs, symptoms, and physiology of speech and swallowing impairment, the ubiquitous application of the MDS-UPDRS in clinical studies allows for translational comparisons across past and future investigations. The specific research questions addressed were: (a) in a large sample of newly diagnosed PWP, do self-perceptions of speech impairment change across a 6-year period?; (b) in this same sample, do self-perceptions of swallowing impairment change across a 6-year period?; and (c) does the change in self-perceptions of speech and swallowing impairment across a 6-year period differ among age group at time of diagnosis or PD motor phenotypes?

Method

Data Source

Data were obtained from the Parkinson’s Progression Markers Initiative (PPMI) study database (<https://www.ppmi-info.org/access-data-specimens/download-data/>). The

PPMI database includes longitudinal data collected across an 8-year (baseline to 96 months) period. We obtained data from all enrolled patients who had MDS-UPDRS data for speech and swallowing at baseline, and also obtained data from patients in that enrolled cohort who also had MDS-UPDRS speech and swallowing data at Year 6. We chose a 6-year cutoff to maintain a larger sample size, as substantially fewer participants with valid data were observed in the following 2 years due to attrition (<https://www.ppmi-info.org/study-design/study-cohorts/>). Therefore, this study focused on data consisting of seven different measurement periods across the first 6 years: Baseline, 12 months, 24 months, 36 months, 48 months, 60 months, and 72 months. PPMI data sets were merged and restructured for the analysis of this study.

Participants

Each participant underwent comprehensive clinical assessments at regular intervals (every 3 months in Year 1, every 6 months in Years 2–5, and at 12 months in Year 6) from which multivariate data was obtained, including completion of the MDS-UPDRS and Hoehn and Yahr staging. Inclusion criteria for participants consisted of diagnosis at age 30 years or older, confirmed nonadvanced stage of PD (Hoehn and Yahr of Stage 0 to II at baseline assessment), two or more of the cardinal signs of PD (resting tremor, bradykinesia, rigidity), a diagnosis of PD within the past 2 years and currently not taking any PD medication (e.g., no levodopa, dopamine agonists, MAO-B inhibitors, or amantadine) at baseline assessment.

Measures

The primary dependent variables under investigation were MDS-UPDRS “speech” and “swallowing” subscale scores (Items II.1 “Speech” and II.3 “Swallowing,” respectively). High interrater and intrarater reliability for MDS-UPDRS measurements has been documented in previous studies (Bennett et al., 1997; Siderowf et al., 2002), although data has been primarily from trained raters. Each score represents the self-perceived severity of impairment reported by the patient, on a 5-point scale (e.g., 0 = *normal*, 4 = *greatest level of severity*) of ascending severity. Specifically, Item II.1 asks patients to rate speech as 0 = *normal*; 1 = *mildly affected, no difficulty being understood*; 2 = *moderately affected, sometimes asked to repeat statements*; 3 = *severely affected, frequently asked to repeat statements*; 4 = *unintelligible most of the time*. Item II.3 asks patients to rate swallowing as 0 = *normal*; 1 = *rare choking*; 2 = *occasional choking*; 3 = *requires soft food*; 4 = *requires nasogastric tube or gastrostomy feeding tube*.

The 6-year change (Δ) in MDS-UPDRS “speech” and “swallowing” subscale scores was calculated by subtracting the baseline from the Year 6 scores. Positive

change scores indicated milder impairment at the baseline and a progression of deterioration. Negative change scores indicated more severe impairment at baseline and a progression of improvement. Zero change score indicated no change. Potential factors that may influence the MDS-UPDRS “speech” and “swallowing” change included in the analysis were (a) age of PD diagnosis organized into four levels: young, < 50 years; intermediate-young, 50–59 years; intermediate-old, 60–69 years; and elderly, ≥ 70 years (Pagano et al., 2016), and (b) PD motor phenotypes assessed during the “on” period that is the time of day that medications are most effective for the individual: tremor dominant (TD), postural instability/gait dominant (PIGD), and indeterminate (IND). Motor phenotype was determined based on previously published guidelines (Stebbins et al., 2013). The motor impairment severity was also recorded by Hoehn and Yahr staging: 0 = no PD, I = earliest stage, II = early stage, III = mild stage, IV = severe stage, and V = the most advanced stage (Hoehn & Yahr, 1967). The Hoehn and Yahr stage was recorded and reviewed for descriptive purposes.

Analyses

SPSS (version 26; IBM Corp.) was used for all analyses. Frequencies, mean, and standard deviation were obtained to describe the progression of the MDS-UPDRS “speech” and “swallowing” subscale scores at seven time points, pooled across all participants (e.g., regardless of age category or motor phenotype). Bivariate tests, including chi-square, independent-t/Mann–Whitney U, and one-way analysis of variance

(ANOVA)/Kruskal–Wallis tests examined the relationships between the 6-year Δ of MDS-UPDRS “speech” and “swallowing” subscale scores along with age of diagnosis and motor phenotype. One-way repeated-measures ANOVAs using the longitudinal assessments (Baseline [BL], Year 1 [Y1], Year 2 [Y2], etc.) as the within-subject factor were conducted to determine whether there were statistically significant differences in self-perceptions of speech swallowing impairments across the seven assessment periods. Mixed-model ANOVAs using age at diagnosis and motor phenotype at baseline as between-group factor and the longitudinal assessments (BL, Y1, Y2, etc.) as the within-subject factor were conducted to assess the effect of these factors on the change in speech and swallowing impairment scores across the 6-year period. Significance level was set as .05.

Results

A total of 422 de novo (diagnosis ≤ 2 years) PD participants who were initially enrolled in the PPMI study had valid measurements of self-perceived speech and swallowing impairments from the MDS-UPDRS. As the PPMI study progressed over multiple years, there was attrition such that a portion of the enrolled participants either dropped out of the study or were not able to be measured at every assessment period. Table 1 shows demographic data for the initial enrolled participants (“enrolled cohort”) at the baseline assessments. There were 269 patients in the enrolled cohort who also had data available at the Year 6 assessment period

Table 1. Demographic characteristics of the enrolled and final cohorts.

Sample characteristics	Baseline		Year 6 ^{a,b}
	Enrolled cohort (n = 422)	Final cohort (n = 269)	Final cohort (n = 269)
Age at diagnosis	61.1 ± 9.7	60.2 ± 9.6	
< 50 years	59 (13.9%)	41 (15.2%)	
50–59 years	113 (27.0%)	78 (29.0%)	
60–69 years	172 (40.7%)	110 (40.9%)	
≥ 70 years	78 (18.4%)	40 (14.9%)	
Gender			
Male	277 (65.6%)	139 (65.9%)	
Female	145 (34.4%)	72 (34.1%)	
Hoehn & Yahr			n = 268 ^a
Stage 0	—	—	3 (1.1%)
Stage I	185 (43.8%)	134 (49.8%)	17 (6.3%)
Stage II	235 (55.7%)	133 (49.4%)	217 (81.0%)
Stage III	2 (.5%)	2 (.7%)	29 (10.8%)
Stage IV	—	—	2 (.7%)
Motor Phenotype			n = 239 ^b
TD	299 (70.9%)	197 (73.2%)	112 (46.9%)
PIGD	76 (18.8%)	44 (16.4%)	93 (38.9%)
Indeterminate	47 (11.1%)	28 (10.4%)	34 (14.2%)

Note. Em dashes indicate no data in the category. TD = tremor dominant; PIGD = postural instability/gait dominant. ^aThere is one participant who did not report their assessment of speech and swallowing impairment at Year 6. ^bYear 5 is the last year of assessment of motor phenotype available in the PPMI data set; therefore, the data presented in the table is Year 5, not Year 6.

(labeled as “*final cohort*”), with demographic data also shown in Table 1. Of those patients in the final cohort, a subset of 211 had data available at every measurement period across the longitudinal time frame (labeled “*matched cohort*”), while 58 of the final cohort were missing at least one data point at one of the assessments between baseline and Year 6. To illustrate a valid representation of change across time at each assessment period, descriptive graphs charted the matched cohort over time, as illustrated below.

Self-Perceptions of Speech Impairment Across the 6-Year Period

Figure 1 displays self-perceived speech severity scores from the MDS-UPDRS at each assessment interval across the 6-year period for the “*matched*” cohort ($n = 211$). As can be seen by the y -axis scale, self-perceived speech impairments were rated as normal to mild with the mean subscale scores < 1 even at the Year 6 assessment. However, the trend in pooled speech severity scores increased over time, indicating that they were perceived to worsen as time progressed, with exception to Year 5. The mean Δ for speech impairment ratings across the final cohort ($n = 269$) between baseline and Year 6 was 0.51 scale points ($SD = 0.92$). This corresponded to an effect size (d) of 0.55, which was interpreted as a moderate effect.

A one-way repeated-measures ANOVA using the longitudinal assessments (BL, Y1, Y2, etc.) of the matched cohort as the within-subject factor were conducted to determine whether there were statistically significant differences in speech impairment ratings across the seven assessment periods. Mauchly’s test showed that assumption of sphericity

was not met for the speech data, $\chi^2(20) = 65.0, p = .000$, so a Huynh–Feldt correction was used. The mean scores of speech impairment were significantly different between assessment periods, $F(5.5, 1158.8) = 21.1, p < .001$, effect size measure (partial η^2) = .1. Trend analysis on the within-subject factor further revealed that there were linear effects of time for speech, $F(1, 210) = 71.5, p < .001$, partial $\eta^2 = .3$. The partial η^2 indicated that 30% of the variance for speech impairment was explained by the linear effect of time.

Self-Perceptions of Swallowing Impairment Across the 6-Year Period

As can be seen in Figure 2, trends in self-perceptions of swallowing impairment were similar to those of speech (severity was normal-to-mild overall, but worsened over time), although the degree of severity was lower for swallowing (note the scale on y -axis for Figures 1 and 2). The mean Δ for swallowing impairment ratings across the final cohort ($n = 269$) between baseline and Year 6 was 0.25 scale points ($SD = 0.69$). This corresponded to an effect size (d) of 0.36, which was interpreted as a small effect.

A one-way repeated-measures ANOVA using the longitudinal assessments (BL, Y1, Y2, etc.) of the matched cohort as the within-subject factor were conducted to determine whether there were statistically significant differences in swallowing impairment ratings across the seven assessment periods. As with the speech impairment data, a Huynh–Feldt correction was employed. The mean scores of swallowing impairments were significantly different between assessment periods, $F(5.2, 1082.6) = 8.6, p < .001$, partial $\eta^2 = .04$. Trend analysis on the within-subject factor

Figure 1. Self-perceived speech impairment from the Movement Disorders Society revision of the Unified Parkinson’s Disease Rating Scale Item II.5 across a 6-year period. CI = confidence interval.

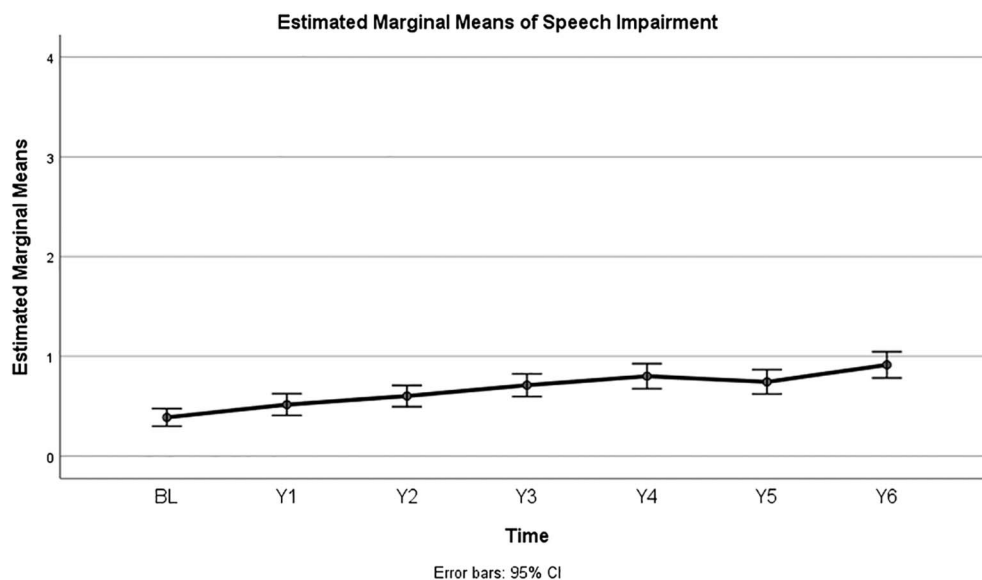
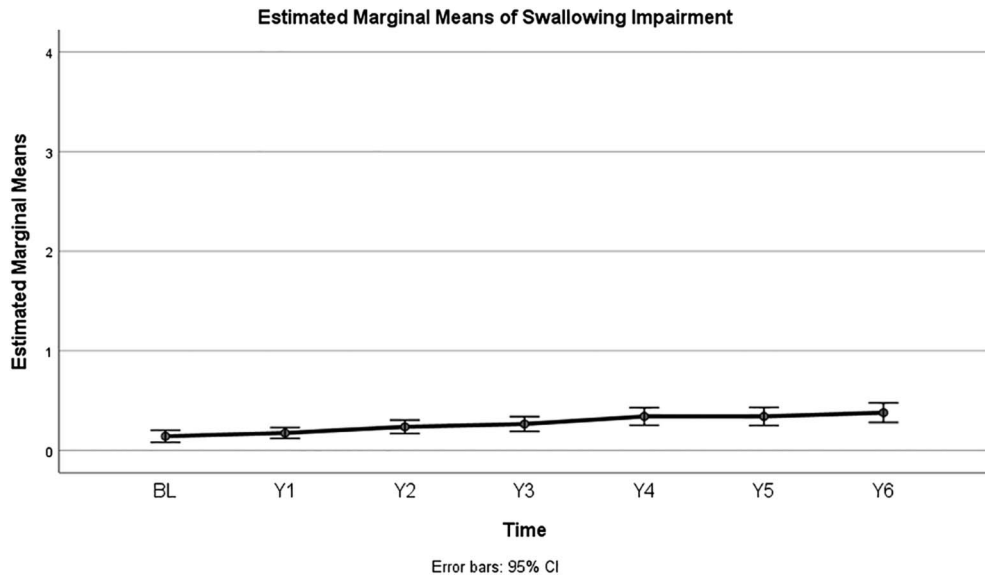


Figure 2. Self-perceived swallowing impairment from the Movement Disorders Society revision of the Unified Parkinson's Disease Rating Scale Item II.7 across a 6-year period. CI = confidence interval.

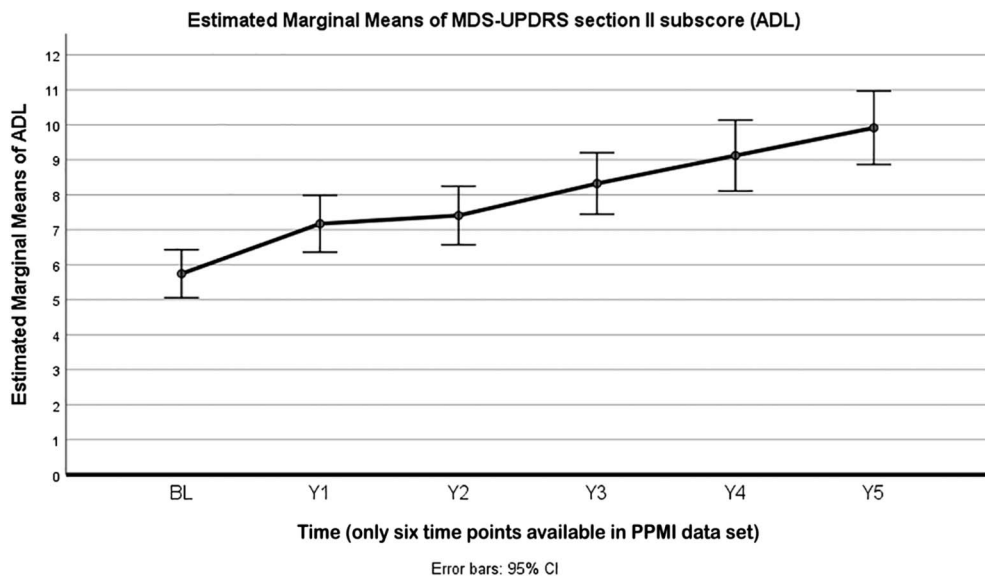


further revealed that there were linear effects of time for swallowing, $F(1, 210) = 30.4, p < .001$, partial $\eta^2 = .1$. The partial η^2 indicated that that only 10% of the variance for swallowing impairment was explained by the linear effect of time.

Similar to the changes of speech and swallowing impairments over time, the mean total scores of the MDS-UPDRS Section II were significantly different between the 5-year assessment periods, $F(3.9, 544.5) = 21.1, p < .001$,

partial $\eta^2 = .21$ (note: Section subscore data were available from baseline to Year 5 in PPMI only). Trend analysis on the within-subject factor also suggested linear effects of time for Section II subscore, $F(1, 139) = 88.3, p < .001$, partial $\eta^2 = .4$. The partial η^2 indicated that that 40% of the variance for Section II total scores, which assessed ADL, was explained by the linear effect of time. Figure 3 presents the change of ADL over a 5-year time period. The slope of the Section II total

Figure 3. Total scores from the the Movement Disorders Society revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS) Section II, which addressed self-perceived Activities of Daily Living (ADL; and included Items II.5 and II.7 assessing speech and swallowing). PPMI = Parkinson's Progression Markers Initiative; CI = confidence interval.



score is steeper than that of speech or swallowing impairments, indicating the changes over time for speech or swallowing were milder compared with those of overall ADLs.

Influence of Age at Diagnosis and Motor Phenotype

The mean age of PD diagnosis of the final cohort ($n = 269$) was 60.2 years ($SD = 9.6$), with the majority (~68%) of the patients in the intermediate age group (60- to 69-year group, ~41%, and 50- to 59-year group, 27%; see Table 1 for exact distributions). According to Hoehn and Yahr staging, motor impairment severity progressed over time for about half of the patient sample (50.8%, 136/268). At baseline, patients were divided almost evenly between Stage I (49.8%) and Stage II (49.4%), with only two patients at Stage III and none at Stage IV. At the Year 6 measurement period, 6.3% of the patients were at Stage I and 81.0% of the patients were at Stage II, while 31 patients progressed to Stages III or IV, representing 11.5% of the final cohort. Motor phenotype also shifted across 6 years. At the baseline assessment, 73.2% of the final cohort were classified as TD subtype, with 16.4% classified as PIGD subtype. By Year 6, these distributions had evolved to 46.9% and 38.9%, respectively.

Table 2 displays the number of patients at each age of diagnosis group and motor phenotype group who demonstrated a certain direction of change in their self-perceptions of speech and swallowing severity from the baseline to the 6-year assessments. Across all age groups, 41.6% of patients reported a deterioration in their perceptions of speech impairment on the MDS-UPDRS. For changes in swallowing impairment, the number of patients experiencing deterioration across 6 years was much lower at 23.4%, irrespective of age group. Perceptions of speech and swallowing impairment as a function of motor phenotype followed a similar pattern, with more patients in each phenotype group indicating declines in speech compared with swallowing. Regardless of the observed

patterns, Pearson's chi-square tests did not reveal any significant relationships.

Adding to the established one-way repeated-measures ANOVA model using the longitudinal assessments (BL, Y1, Y2, etc.) as the within-subject factor, Huynh-Feldt corrected mixed-model ANOVAs using age at diagnosis and motor phenotype at baseline as between-group factor showed that there were no significant main effects of age at diagnosis, speech: $F(3, 199) = .62, p = .60$, partial $\eta^2 = .01$; swallowing: $F(3, 199) = .33, p = .81$, partial $\eta^2 = .005$, and motor phenotype, speech: $F(2, 199) = 1.13, p = .33$, partial $\eta^2 = .01$; swallowing: $F(2, 199) = .16, p = .85$, partial $\eta^2 = .002$, nor significant interaction of time with age at diagnosis, speech: $F(17.33, 1149.63) = .87, p = .607$, partial $\eta^2 = .01$; swallowing: $F(16.10, 1068.06) = 1.00, p = .46$, partial $\eta^2 = .02$, or motor phenotypes, speech: $F(11.55, 1149.63) = 1.16, p = .31$, partial $\eta^2 = .01$; swallowing: $F(32.20, 1068.06) = 1.20, p = .21$, partial $\eta^2 = .04$, for perceptions of both the speech and swallowing impairment. The within-subject factor (i.e., the seven longitudinal assessment time points) remained significant, speech: $F(5.78, 1149.63) = 7.81, p < .001$, partial $\eta^2 = .04$; swallowing: $F(5.37, 1068.06) = 3.65, p = .002$, partial $\eta^2 = .02$. Figures 4–7 illustrate the longitudinal trends for changes in perceptions of speech and swallowing impairment by the groups of age at diagnosis and motor phenotypes across the 6-year time frame. Although the trend lines appear nonparallel for each levels of the group variable suggesting potential group differences, the 95% confidence interval bars are overlapping at each time point, resulting in the lack of statistical significance.

Discussion

This study utilized longitudinal data of speech and swallowing impairment ratings from a multicenter research

Table 2. Change in self-perceptions of speech and swallowing severity as a function of subgroup.

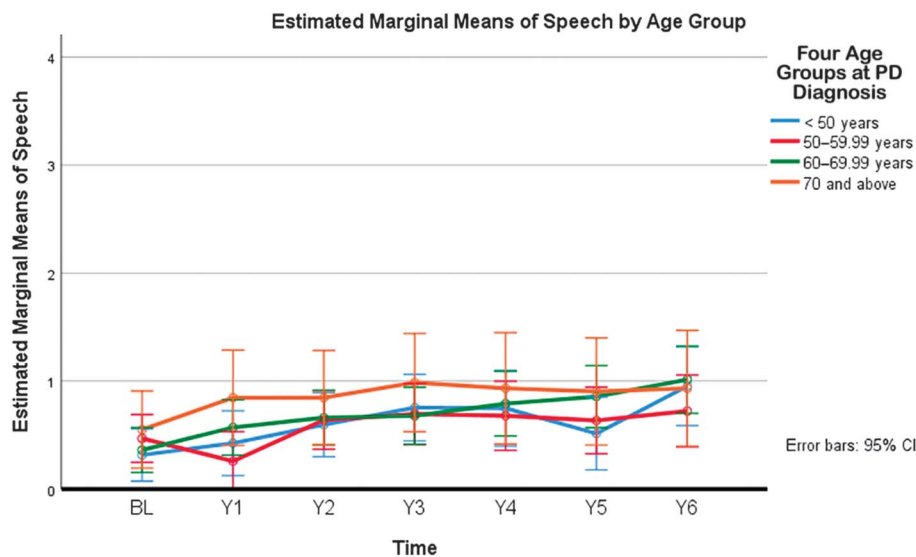
6-year change	Self-perceived speech ($n = 269$)		Self-perceived swallowing ($n = 269$)	
	Improvement or no change*	Deterioration	Improvement or no change	Deterioration
Total	157 (58.4%)	112 (41.6%)	206 (76.6%)	63 (23.4%)
Age at diagnosis				
< 50 years	22 (53.7%)	19 (43.3%) ^a	29 (70.7%)	12 (29.3%) ^b
50–59 years	57 (65.4%)	30 (34.6%)	63 (80.8%)	15 (19.2%)
60–69 years	49 (52.7%)	43 (47.3%)	85 (77.3%)	25 (22.7%)
≥ 70 year	26 (65.0%)	14 (35.0%)	29 (72.5%)	11 (27.5%)
Motor phenotype				
TD	113 (57.4%)	84 (42.6%) ^c	150 (76.1%)	47 (23.9%) ^d
PIGD	25 (56.8%)	19 (43.2%)	36 (81.8%)	8 (18.2%)
Indeterminate	19 (67.9%)	9 (32.1%)	20 (71.4%)	8 (28.6%)

Note. TD = tremor dominant; PIGD = postural instability/gait dominant.

^a $\chi^2 = 4.12, p = .249$. ^b $\chi^2 = 1.95, p = .584$. ^c $\chi^2 = .86, p = .649$. ^d $\chi^2 = 1.11, p = .575$.

*Improvement or no change includes those scoring decreased (improvement) or remained the same (no change) over time. Deterioration includes those scoring increased over time.

Figure 4. Patterns of progression in self-perceived speech impairment as a function of age at diagnosis. PD = Parkinson's disease; CI = confidence interval.



project (PPMI) to investigate three questions. The first research question sought to determine if self-perceptions of speech impairment changed across a 6-year period in people who were newly diagnosed with PD. Results indicated a significant difference across time in self-perceived severity ratings of both speech and swallowing impairment. The trend in these changes was also linear. While mean ratings of speech and swallowing impairments were in the mild range across the longitudinal time frame, the overall ratings of speech were more severe than those of swallowing at each assessment period,

and the Δ in severity ratings from baseline to Year 6 was also greater for ratings of speech impairment.

These findings elucidate at least two important concepts related to speech and swallowing impairments in newly diagnosed PWPDP at early stages of progression. First, although falling within a very mild range of severity, both the speech and swallowing impairments are perceptible near the time of initial PD diagnosis in a large percentage of PWPDP. While voice and speech changes occur in up to 90% of PWPDP across the degenerative course of

Figure 5. Patterns of progression in self-perceived speech impairment as a function of motor phenotype. TD = tremor dominant; PIGD = postural instability/gait dominant; CI = confidence interval.

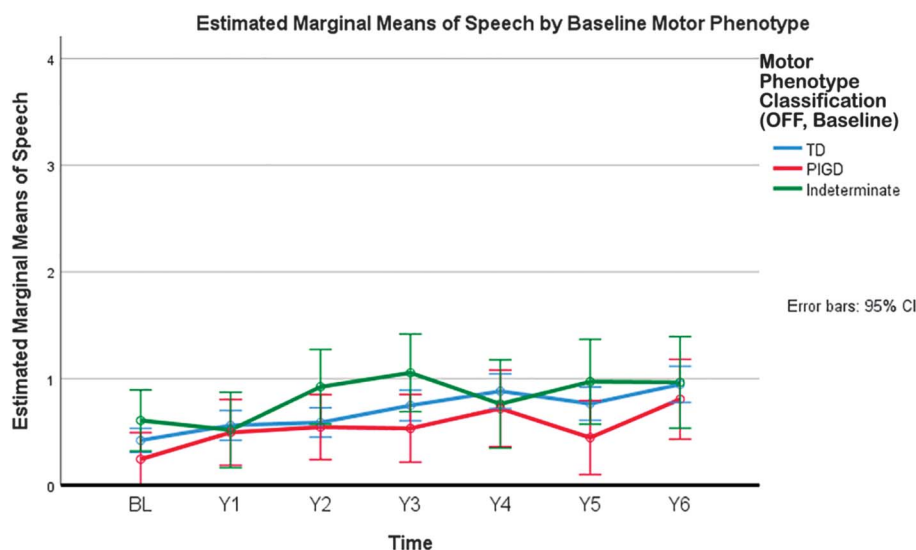
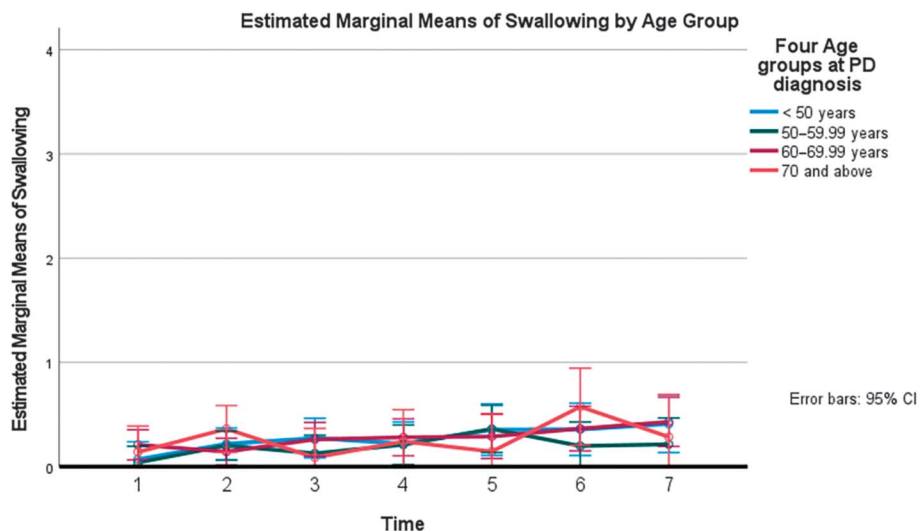


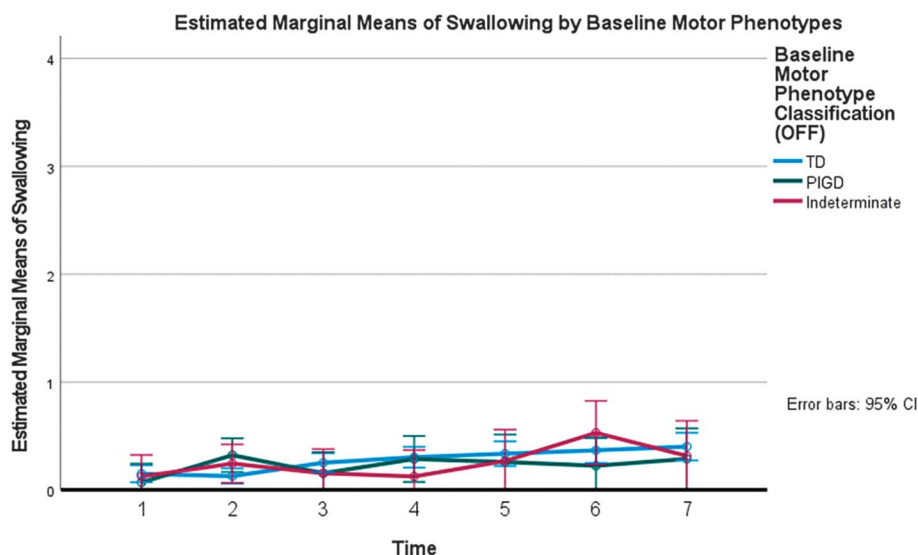
Figure 6. Patterns of progression in self-perceived swallowing impairment as a function of age at diagnosis. PD = Parkinson's disease; CI = confidence interval.



the disease (Miller, 2017; Ramig et al., 2004; Schalling et al., 2017), the nature of progression within the early stages of the disease has not been well established. This study found that across the first 6 years after diagnosis, the perception of speech impairment severity does change significantly in a progressive pattern, albeit remaining within a mild level of severity for most individuals. These findings support the need for early postdiagnosis assessment and possible early intervention for speech and swallowing function in PWP, even in light of individuals perceiving impairments as mild.

The second research question sought to determine if self-perceptions of swallowing impairment changed across a 6-year period in people who were newly diagnosed with PD. We found that self-perceptions of swallowing impairment were judged to be less severe than those of speech impairment across the first 6 years after diagnosis. These findings are aligned with previous studies which have reported both longer latencies to perceived dysphagia compared with dysarthria in PWP (Müller et al., 2001) and the reduced saliency of dysphagia impairment in people with PD when compared with instrumental confirmation of swallowing impairments (Kalf

Figure 7. Patterns of progression in self-perceived swallowing impairment as a function of motor phenotype. TD = tremor dominant; PIGD = postural instability/gait dominant; CI = confidence interval.



et al., 2012). Results of this study indicate that some PWP in the early disease stages do perceive dysphagia symptoms, the perceived impairments change significantly over time, although across the first 6 years after diagnosis, the severity of those impairments remains mild. A possible explanation for the difference in perceived severity of swallowing compared with speech in newly diagnosed PD is that PWP are able to compensate for impairments of swallowing in a way that is different from how they might compensate for impairments of voice and speech (Ertekin et al., 2002). This supposition has been supported when comparing cerebral activity, tongue pressures, and laryngeal muscle contraction amplitude during swallowing between PWP and healthy older controls, which have found to differ (J. Kim & Watts, 2020; Pitts et al., 2018; Suntrup et al., 2013). Taken together, the changes over time in perceived speech and swallowing severity further strengthen the argument that early assessment and intervention may be justified for a number of PWP.

The third research question of this study sought to determine if the patient-centered factors of age at diagnosis and motor phenotype had an effect on changes in perceptions of speech and swallowing impairment over time. Results indicated that there were no statistically significant main effects for these factors in either the speech or swallowing data sets. That is, age at diagnosis and motor phenotype did not affect the degree of change in perceived speech or swallowing severity ratings across the 6-year period. While some authors have indicated that age at diagnosis is strongly associated with overall motor impairment and disability level (Post et al., 2008) and that PD motor phenotype can effect laryngeal function (Burk & Watts, 2019), PD remains a largely heterogeneous disease with varied degrees of severity in symptomatology across individuals (Ryden & Lewis, 2019). At later and terminal stages of the disease, characteristics of speech and swallowing impairment severity are more consistent from one individual to the next and impairments in those stages likely account for the classic descriptions of dysarthria and dysphagia associated with PD. In newly diagnosed patients at early stages of the disease, this investigation also found that perceived speech and swallowing impairments remained within a mild range of severity for most participants over a 6-year period, as illustrated in Figures 3–6, which accounted for the lack of statistical significance in age of diagnosis and motor phenotype.

While changes in self-perceptions of speech and swallowing impairment were not affected over a 6-year period in this sample of newly diagnosed PWP, it is important to consider that mild levels of impairment were perceived in both functions. Although age at diagnosis and motor phenotype did not predict the degree of change over time at these early disease stages, changes in overall motor impairment (including factors in addition to speech and swallowing) as measured by UPDRS subscale scores (i.e., section total scores; total tremor scores, etc.) has

been predicted by biological factors in this same sample of PWP. For example, Ye et al. (2021) found that the protein neurofilament light chain (NFC) predicted motor decline across the first 8 years postdiagnosis based on UPDRS Section III (clinical exam) and total UPDRS scores. Their report also indicated that NFC predicted greater motor decline in nontremor motor phenotypes. Lee et al. (2019) found that dopamine transporter deficits as measured via single-photon emission computerized tomography imaging were significantly different in TD phenotypes compared with participants with an IND motor phenotype at 4 years postdiagnosis. The collective evidence suggests that, while overall motor decline is progressing across the first 4–8 years postdiagnosis, and that certain motor phenotypes may progress at different rates, changes in speech and swallowing are not progressing at the same rate in different motor phenotypes during these early disease stages as compared with other underlying biological factors.

There are a number of limitations associated with this study that should be taken into account when generalizing findings. Firstly, the self-perception of speech and swallowing impairment were assessed using self-rated items in the MDS-UPDRS, while MDS-UPDRS is suggested to be insensitive in detecting differences of motor signs of PD (Regnault et al., 2019). Secondly, with only 50% (211/422) of the patients having the full 6-year assessment, it is possible that attrition bias may limit the generalizability of the study. Thirdly, while strong reliability of MDS-UPDRS measures has been documented in previous studies, data have been based on total UPDRS scores, which pooled patient reported data and trained rater data from the clinical examination. Some studies have indicated that reliability for the UPDRS Section II (ADL, reported by the patient) manifests less robust reliability (i.e., see Evers et al., 2019). Lastly, based on the baseline information, patients in the PD cohort were relatively young, overwhelmingly non-Hispanic White, and highly educated, which also limits generalizability. It is also worth noting that the traditional repeated measure ANOVA done in general linear modeling may only capture the differences over time at an overall level as explored by our research questions. A more sophisticated statistical modeling such as hierarchical linear modeling is desirable when the research interest is the growth rate and/or at the individual level.

Conclusions

This study found that self-perceptions of speech and swallowing impairment, as measured via the MDS-UPDRS across six consecutive years, change significantly over time in newly diagnosed PWP. This change was linear in the direction of increasing severity, although for both speech and

swallowing, the change in severity level remained in the mild range. Self-perceptions of speech impairments were rated as more severe than those of swallowing impairments, and the degree of change in severity across 6 years was also greater for speech impairments. Changes in the perceptions of speech and swallowing impairments over time were not affected by age of diagnosis or motor phenotype, reflecting the large degree of heterogeneity associated with PD especially in the early stages of the disease. These findings reveal that even in the early years postdiagnoses, PWPDP are experiencing changes to speech and swallowing function, albeit within the mildly severe range. The presence of self-perceived speech and swallowing impairments in the initial years postdiagnosis, even though perceived as mild, may support the need for intervention to improve and or sustain function over time.

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