Original Articles

# Partner perception of affective, behavioral, and cognitive reactions to voice use in people with Parkinson's disease

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## ARTICLE INFO

## ABSTRACT

*Introduction:* People with Parkinson's disease (PWPD) experience negative feelings, thoughts, and coping behaviors due to the experienced communication challenges. This study aimed to compare the perceptions of PWPD with those of proxies for the affective, behavioral, and cognitive reactions specific to voice production during communicative interactions.

*Methods:* The Behavior Assessment Battery – Voice (BAB-Voice) was administered to 31 PWPD and their close communication partner/proxy. The BAB-Voice contained four subtests: Speech Situation Checklist – Emotional Reaction (SSC-ER), Speech Situation Checklist – Speech Disruption (SSC-SD), Behavior Checklist (BCL), and Communication Attitude Test for Adults (BigCAT). The scores for each of these subtests were calculated and statistically analyzed.

*Results:* A repeated measures MANOVA did not find statistically significant differences between the subscores of PWPD and proxies (Pillai's trace = 0.25, $F[4] = 2.22$, $p = .094$, $\eta_p^2 = 0.25$). Fair to excellent agreement between the PWPD and proxies was found. The highest agreement was found on the BigCAT ($ICC = 0.80$). The SSC-SD ($ICC = 0.77$) and SSC-ER ($ICC = 0.71$) still showed excellent agreement, while only fair agreement was found for the BCL ($ICC = 0.57$).

*Conclusion:* Proxies were able to identify the affective, behavioral, and cognitive reactions to voice use in PWPD. Communication partners close to the PWPD could, therefore, provide valuable information regarding the assessment and treatment of hypophonia in PD.

## 1. Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease and affects basal ganglia function [1]. On top of the typical motor symptoms (rest tremor, bradykinesia, rigidity, and postural instability) and non-motor symptoms (autonomic dysfunction, sleep disturbances, neuropsychiatric issues, etc.) [1], the majority of the people with Parkinson's disease (PWPD) will also experience communication difficulties [2,3]. The neuromotor impairments associated with communication deficits in PD are referred to as hypokinetic dysarthria and affect all subsystems of speech. Hypokinetic dysarthria is characterized by changes in all the subsystems of speech: hypophonia (soft voice), dysphonia (typically a harsh and breathy voice quality),

hypokinetic articulation, hypoprosodia (monoloudness and monopitch) as well as disfluencies and tremor [2,4,5]. The phonatory changes arising from hypokinetic dysarthria are hypophonia and dysphonia, with potentially a vocal tremor as well: PWPD's voices can present with reduced loudness, changed pitch, monotone pitch and loudness, harsh and breathy voice quality, and tremor [5,6]. Along with these speech and vocal changes, PWPD also often present with language deficits, which may be of cognitive origin [7]. However, these were not considered for this study.

The communication difficulties experienced by PWPD extend beyond hypokinetic dysarthria alone, as there is also a negative impact on their psychosocial wellbeing [8–10]. This psychosocial impact expresses itself in a variety of ways. PWPD commonly experience negative

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feelings, such as anxiety, stress, and embarrassment when communicating [8–10]. PWPD feel impacted in maintaining relationships, communicating with strangers, or talking in specific situations (such as noisy locations or on the phone) [3,8–10]. They can also start avoiding certain situations and people, or take less initiative in conversation [8,10]. Overall, these communication changes lead to a loss of participation [3]. Interestingly, the psychosocial impact experienced by PWPD is independent of motor status, cognitive status, and disease duration [11]. To measure aspects of psychosocial impact, the literature has proposed several tools for use in PWPD. Examples are the Communicative Effectiveness Survey [12], the Communication Participation Item Bank [13], and the Dysarthria Impact Profile [14].

Most tools designed to assess the psychosocial burden of voice are self-rated by the patient. However, it has been noted that PWPD can struggle with self-perception. One of those areas affected by misperception in PD is speech [15]. PWPD seem not fully aware of the presence or extent of their speech deficits. They overestimate their vocal loudness and are less accurate in interpreting emotion [15]. Sapir [16] hypothesizes that the misjudgment of their voice could be a causal factor in the hypokinetic dysarthria in PD. One possible solution to this problem of perception is the use of close communication partner or proxy judgment.

Close communication partners of the PWPD are directly involved in the communication process and thus could provide the clinician with valuable information. For other impacted dimensions in PD, partner judgment has been used previously. For example, when considering quality of life measures, Fleming et al. [17] found a trend that proxies rated the quality of life of the PWPD as more impaired, though their ratings were not necessarily statistically significantly different. Other authors found no significant differences between PWPD and proxy ratings with moderate to strong agreement between the scores [18–20]. Both Fleming et al. [17] and Martínez-Martín et al. [18] found more disagreement between PWPD and proxies in the later, more severe stages of the disease as well as in participants with depression. Specifically for speech-related measures, Parveen and Goberman [21] compared ratings of the speech-related quality of life using the Voice Handicap Index in PWPD and communication partners. They found little agreement between the ratings and found that communication partners tended to rate the speech-related quality of life more positively. However, no significant differences between the ratings were found [21]. Similarly, Miller et al. [11] reported that when they asked participants to rate communication using adjective pairs, communication partners rated communication more positively than PWPD. Once again these differences were not statistically significant [11]. When employing the Communicative Effectiveness Survey [12,22], Dykstra et al. [23] found no differences between PWPD and communication partner rating. On the other hand, Donovan et al. [22] did find significant differences: using the Communication Effectiveness Survey [12,22] where proxies rated the PWPD as having higher communicative effectiveness than the PWPD themselves. Given the conflicting findings of previous research, it is unclear how well proxy judgments agree with those of PWPD when describing the psychosocial consequences of communication associated with hypokinetic dysarthria.

The Behavior Assessment Battery (BAB) is a standardized and normed tool that was originally developed to assess the affective, behavioral, and cognitive reactions in people who stutter [24]. An adapted version of the BAB, the Behavior Assessment Battery-Voice (BAB-Voice), was developed to assess these psychosocial domains in populations with voice disorders. The BAB-Voice has been used in individuals with spasmodic dysphonia [25–27], and more recently in PWPD [28]. The BAB-Voice consists of four subtests that provide a holistic description of the affective, behavioral, and cognitive reactions to voice use difficulty: Speech Situation Checklist – Emotional Reaction (SSC-ER), Speech Situation Checklist – Speech Disruption (SSC-SD), Behavior Checklist (BCL), and Communication Attitude Test for Adults (BigCAT) [25–27]. Of the four BAB-Voice subtests, the Speech Situation Checklist – Emotional Reaction (SSC-ER) and Speech Situation Checklist

– Speech Disruption (SSC-SD) both comprise the same list of 38 different speech situations (e.g., "talking on the phone", "talking to a stranger"). For each of those situations, the participant has to consider the experienced negative emotion (SSC-ER) or the experienced voice difficulty (SSC-SD). They can rate their negative emotion and voice difficulty on a scale from 1 ("not at all") to 5 ("very much"). Thus, the subtest scores of both the SSC-ER and SSC-SD can range between 38 and 190, with higher scores indicating more negative emotions and voice difficulties, respectively. The Behavior Checklist (BCL) includes 34 different coping behaviors (e.g., "avoiding eye contact", "taking a deep breath before speaking"). The participant can indicate if they utilize these behaviors (scored as 1) or not (scored as 0), resulting in a possible score from 0 to 34, with higher scores indicating more coping behaviors. The Communication Attitude Test for Adults (BigCAT) contains 34 statements reflecting either a positive or negative speech-related attitude. A statement reflecting a negative attitude is scored as 1, whereas a statement reflecting a positive attitude is scored as 0. For instance, replying "yes" to the statement "There is something wrong with my voice" would be rated as 1. The BigCAT subtest score ranges between 0 and 34, with higher scores indicating a more negative speech-related attitude.

Moreover, the BAB has been modified to proxy assessment before [29]. Svenning et al. [29] found that PWS and communication partners rated the PWS's communication experience similarly, though significant differences between PWS and their communication partners were found on the SSC-ER and SSC-SD. Given the agreement between the ratings those results still support the notion that the BAB-Voice may be an appropriate tool for proxy assessment when evaluating the communication challenges of PWPD. Therefore, the current study aimed to describe and compare the ratings of PWPD and close communication partners for the PWPD's negative emotions and experienced voice difficulty in specific speech situations, their use of coping behaviors, and negative speech-associated attitude as assessed by the BAB-Voice.

## 2. Methodology

Recruitment: The study was approved by the first author's university Institutional Review Board. To participate in the study, PWPD needed to have a diagnosis of PD by a neurologist through a motor and neurological clinical examination identifying the cardinal motor symptoms of PD (bradykinesia with rigidity and/or rest-tremor) as well as non-motor symptoms. Participants could not have any other neurological disorders associated with conditions other than PD and have self-reported hearing within normal limits for their age with or without amplification. The recruited sample was on average 71.23 (SD = 9.09) years of age, with an average PD duration of 8.02 (SD = 5.13).

Communication partners of the PWPD (proxies) had to communicate orally (real-life conversation or video/phone conversation) with the PWPD daily, as assessed by self-report. They also were required to have self-reported hearing within normal limits. Dyads consisting of a PWPD and a proxy were contacted primarily in the Dallas-Fort Worth area (United States) using an existing volunteer database, PD support groups, and social media. Additional PWPD-proxy dyads were recruited throughout the United States using PD support groups and social media.

Instrumentation: Prior to filling out any questions, informed consent was obtained from the PWPD and their communication partners. PWPD responded to demographic questions (age, gender, PD status, time they had known the proxy) as well as questions associated with the four subtests of the BAB-Voice. Example communicative situations noted in the BAB-Voice questions were adapted so that they were relevant to PD. Other than that, the BAB-Voice was administered as outlined in the Introduction.

The proxy communication partners responded to similar demographic questions and also completed the four subtests of the BAB-Voice. Their responses on the BAB-Voice were associated with their perceptions of the difficulties experienced by the partner with PD. The questions and scoring of the BAB-Voice were identical for PWPD and

proxies. However, each question was rephrased so the proxy could answer from the PWPD's perspective (e.g., "Is your communication partner anxious…", "Does your communication partner think…"). The questionnaires for the PWPD and the proxy were integrated into one big survey to allow for paired data analysis.

Data collection and analysis: Data collection was completed virtually through the survey software Qualtrics, with or without guidance from one of the researchers. All analyses employed a significance level of $\alpha = 0.05$ unless otherwise noted. Outliers falling outside three times the interquartile range were removed prior to the inferential analyses. The data from PWPD and their proxies were considered paired. The data were visualized and analyzed descriptively using mean, standard deviation, median and interquartile range. The subtest scores of BAB-Voice were compared and analyzed subsequently. To determine the differences between the ratings on each BAB-Voice subtest, a repeated-measures MANOVA was applied using rater (self – proxy) as the within-subject independent variable and the four subtest scores as dependent variables. As follow-up analysis, paired t-tests with Bonferroni correction were employed. The agreement between the scores of the PWPD and proxies was determined using two-way mixed, absolute agreement, single measures Intra Class Correlations (ICC).

## 3. Results

Thirty-one dyads of a PWPD and proxy were recruited. The characteristics of the dyads are described in Table 1. The majority of PWPDs were male (58%) while the majority of communication partners were female (61%). However, a McNemar test showed that the proportions of gender difference between PWPDs and their communication partners were not statistically significant ($\chi^2 = 0.89$, $p = .345$). The PWPDs were about 2 years older than their communication partners ($71.23 \pm 9.09$ years vs $69.74 \pm 9.35$ years), a difference that was not statistically significant as shown by a Wilcoxon Signed Rank Test ($Z = 122.50$, $p = .177$).

The subtest scores of the BAB-Voice can be found in Table 2. The PWPD's mean ratings of the SSC-ER, SSC-SD, BCL, and BigCAT were

**Table 1**
Descriptive data of the sample of PWPD and proxies.

|  |  | PWPD (n = 31) | Proxy (n = 31) |
|---|---|---|---|
| Gender | Male (%) | 18 (58.1%) | 12(38.7%) |
|  | Female (%) | 13 (41.9%) | 19 (61.3%) |
| Chronological Age (years) | Mean (SD) | 71.23 (9.09) | 69.74 (9.35) |
|  | Median (IQR) | 73.00 (65.00–78.00) | 71.0 (66.00–76.00) |
| PD duration (years) | Mean (SD) | 8.02 (5.13) |  |
|  | Median (IQR) | 7.33 (4.00–10.75) |  |
| PD treatment | Treated | 31 (100%) |  |
|  | - Medication | - 30 (96.8%) |  |
|  | - DBS | - 6 (19.4%) |  |
|  | - Other | - 7 (22.6%) |  |
| SLT in past | SLT in past | 12 (38.7%) |  |
|  | SLT currently | 2 (6.5%) |  |
| Time of acquaintance | Mean (SD) | 38.45 (17.94) |  |
|  | Median (IQR) | 43.08 (20.00–55.00) |  |

Note. Categorical data are presented with the absolute and percent frequencies. Continuous data are presented with mean, standard deviation, median, and interquartile range.
Abbreviations PWPD, people with Parkinson's Disease PD, Parkinson's disease SLT, speech-language therapy.

**Table 2**
The Scores of the Sample of PWPD and Proxies on the BAB-Voice.

|  |  | PWPD (n = 31) | Proxy (n = 31) | Bivariate analysis |
|---|---|---|---|---|
| SSC-ER | Mean (SD) | 83.0 (46.8) | 72.6 (39.6) | $F(1) = 3.29$, $p = .080$, $\eta_p^2 = 0.10$ |
|  | Median (IQR) | 60.0 (50.0–124.0) | 57.0 (44.0–84.0) |  |
| SSC-SD | Mean (SD) | 77.3 (40.2) | 74.4 (38.2) | $F(1) = 0.36$, $p = .553$, $\eta_p^2 = 0.01$ |
|  | Median (IQR) | 65.0 (48.0–96.0) | 63.0 (44.0–93.0) |  |
| BCL | Mean (SD) | 7.2 (5.8) | 7.1 (6.3) | $F(1) = 0.02$, $p = .900$, $\eta_p^2 = 0.01$ |
|  | Median (IQR) | 7.0 (2.0–9.0) | 7.0 (2.0–10.0) |  |
| BigCAT | Mean (SD) | 16.3 (11.7) | 13.7 (11.5) | $F(1) = 4.03$, $p = .054$, $\eta_p^2 = 0.12$ |
|  | Median (IQR) | 13.0 (6.0–27.0) | 12.0 (2.0–24.0) |  |

Note. The average and median scores for each subtest are represented for both groups, along with the results of the bivariate follow-up analysis.
Abbreviations. PWPD, people with Parkinson's Disease; BCL, Behavior Checklist; BigCAT, Communication Attitude Test for Adults; SSC-ER, Speech Situation Checklist – Emotional Reaction; SSC-SD, Speech-Situation Checklist – Speech Disruption.

$83.0 \pm 46.8$, $77.3 \pm 40.2$, $7.2 \pm 5.8$, and $16.3 \pm 11.7$, respectively. This indicated the presence of moderate negative emotional reaction and voice disruption in the queried speech situations as well as mild to moderate use of coping behaviors and moderate negative speech-related attitudes as measured by the BAB-Voice. The scores of the proxies tended to be lower than the scores of the PWPD, indicating less perceived psychosocial impact.

The difference between the ratings of the PWPD and proxies was calculated. The repeated-measures MANOVA revealed that no significant effect of rater (PWPD vs. proxy) on the combined subtest scores of the BAB-Voice was found (Pillai's trace $= 0.25$, $F[4] = 2.22$, $p = .094$, $\eta_p^2 = 0.25$), suggesting the ratings of the PWPD and their communication partners did not differ significantly on any of the four subset BAB-Voice scores. Follow-up analysis confirmed there were no differences between the different subtests (see Table 2).

The ICC values calculated the agreement between the PWPD and proxy ratings and can be found in Table 3. Using Cicchetti's [30] criteria, we found fair to excellent agreement between the PWPD and proxies for each subtest. The ratings of both groups were most similar on the BigCAT ($ICC = 0.80$), followed by the SSC-SD ($ICC = 0.77$) and SSC-ER ($ICC = 0.71$). The least similar ratings were found in the BCL ($ICC = 0.57$), which were only fair.

## 4. Discussion

The current study investigated the agreement between PWPD and

**Table 3**
Intraclass correlation between participant and communication partner judgment for the subtests of the BAB-Voice.

|  | Intraclass Correlation | 95% Confidence interval | Judgment based on Cichetti (1994) |
|---|---|---|---|
| SSC-ER | 0.71 | 0.48–0.85 | Good |
| SSC-SD | 0.77 | 0.57–0.88 | Excellent |
| BCL | 0.57 | 0.28–0.77 | Fair |
| BigCAT | 0.80 | 0.61–0.90 | Excellent |

Note. The two-way mixed, absolute agreement, single measures Intraclass Correlations were reported.
Abbreviations. BCL, Behavior Checklist; BigCAT, Communication Attitude Test for Adults; SSC-ER, Speech Situation Checklist – Emotional Reaction; SSC-SD, Speech-Situation Checklist – Speech Disruption.

communication partners on ratings of affective, behavioral, and cognitive reactions to voice use during communicative situations using the BAB-Voice instrument. No statistically significant differences in the ratings of the four BAB-Voice subset scores were found between the two groups. Moreover, a strong degree of agreement between self-ratings (PWPD) and proxy ratings (communication partner) was found for all four BAB-Voice subtests.

The lack of difference between the ratings of the PWPD and proxies indicated that the dyads perceived the psychosocial burden the PWPD experienced similarly. A mild to moderate psychosocial impact related to voice use was reported. However, a slight tendency for the communication partner to rate the PWPD as less impaired was noted. In other published studies on the psychosocial impact of communication changes in PWPD, similar results have been found. Using different instruments, Miller et al. [11], Parveen and Goberman [21], and Dykstra et al. [23] all found no statistically significant differences between the judgment of communication partner and PWPD. Miller et al. [11] and Parveen and Goberman [21] did describe that communication partners tended to rate communication more positively than did the PWPD themselves, which is also aligned with our current findings. Donovan et al.'s [22] study was the only one to find that communication partners rated communication statistically significantly more positively than PWPD. Overall, the literature indicates that while communication partners tend to underestimate the communicative psychosocial burden of PWPD, they can still provide a largely accurate description of both the presence and severity of the psychosocial burden associated with voice use in PWPD.

The judgment of communication partners/proxies could have been influenced by additional factors, such as the non-phonatory characteristics of the hypokinetic dysarthria or the overall changes to the communication between the PWPD and the communication partner. PWPD's communication deficits likely exceed those of the dysarthria alone and could include difficulties with higher-order linguistic and pragmatic communication [31,32]. Moreover, aspects of the communication partner's speech (such as speech rate, non-verbal communication) could also influence the communication process [32]. Studies have shown that PWPD provide less feedback after utterances of their communication partners [31], are less efficient to repair communication difficulties [33], and may experience word-finding difficulties on top of already altered communication strategies [34]. These changes can result in very unintelligible speech. On the other hand, communication partners enunciate more clearly, speak more slowly [35] and use more specific repair sequences during communicative difficulty [32]. The communicative changes on both the PWPD's and communication partner's end highlight the importance of a broad assessment including the communication partner when mapping out the communication deficits of PWPD in both the clinic and research.

Our findings also showed fair to excellent agreement between PWPD and their communication partners, which is somewhat consistent with previous BAB research in PWS. Svenning et al. [29] also found that for the SSC-ER and SSC-SD the life partners of the PWS underestimated the psychosocial impact of stuttering. While these differences were significant, there was still a moderate positive correlation between their judgments, indicating that the life partners were able to gauge the emotional impact of stuttering. On the other hand, the BigCAT scores of the life partners and PWS were nearly identical, and once again correlated with one another [29]. In the current study, the strongest agreement was found for the BigCAT as well, an indication that communication partners close to the PWPD can accurately assess the negative communication attitude experienced by PWPD. A less robust agreement, but still excellent to good, was found for the SSC-ER and SSC-SD. In all comparisons, the ratings of the PWPD and proxies did not differ significantly.

Interestingly, the weakest agreement between PWPD and their proxies was found on the BCL. The BCL was not included in Svenning et al.'s [29] study making a comparison with the current study impossible. It is somewhat surprising that the agreement was least on the BCL,

as it considers the use of coping behaviors that are often visible or audible. For motor-related behaviors, it has been suggested that agreement between proxies and participants is larger when considering outwardly perceptible behaviors. This supposition has sometimes proven ambiguous [17,18]. Speech-related quality of life can be considered more personal and subjective than the more visible motor behaviors [21]. Proxies likely are not aware of all consequences of the disordered communication [11,21]. In the current study, the BCL inquired about the use of avoidance and escape behaviors specifically performed to help the participant overcome voice disruptions. It is possible that proxies may have noted the presence of coping behaviors, but were unaware of the fact that the PWPD used them to overcome voice disruption. This could explain the lack of agreement between both groups.

Despite the BAB-Voice indicating an impact on PWPD's psychosocial wellbeing, these results need to be interpreted carefully, as the instrument was not standardized in PWPD. Previous research has shown that PWPD rated themselves more negatively indicating more voice difficulty and negative emotions in speech situations, more coping behaviors, and more negative attitudes towards voice compared to healthy adults of a similar age [28]. Nevertheless, standardizing the BAB-Voice in PWPD should be considered for future research projects.

Some other limitations should be noted within the current study. Speech samples or data on the neuropsychological status and disease status of the PWPD could not be collected due to data collection during the initial months of the COVID-19 pandemic when human contact was limited, and could therefore not be included in the analysis. The current study focused on voice use, disregarding other speech or language impairments in PWPD. While an explanation of voice use was provided, PWPD and/or communication partners possibly considered communication as a whole (and thus the speech and language impairments as well) while filling out the instrument. Future research projects could include and control for this information. Given that some of the participants filled out the questionnaire online at home, it could not be verified that all PWPD and communication partners filled out the questionnaire separately and independently. Future research should take these considerations into account.

Despite the limitations, the current study did indicate that communication partner judgment can provide valuable supplemental or augmentative during the diagnostic and therapeutic process for PWPD. While the PWPD themselves remain the most important source of information for clinical assessment [21], the communication partner can be used as an alternative source of information, especially in situations where the PWPD is incapable of providing appropriate information, for example, due to physical or cognitive constraints, [11,21,23]. Moreover, including communication partners in the treatment process of PWPD may be beneficial. Miller et al. [11] suggested that communication partners may be able to facilitate communication in PWPD and lessen some of the experienced difficulty. In other neurological disorders, such as aphasia, communication partners are employed in some therapy approaches. A systematic review found that skilled communication partners can help improve functional communication, participation, and even well-being in people with aphasia [36]. Focusing on language abilities, Forsgren et al. [37] performed a pilot study on communication partner training in PWPD. They found that a communication partner training program may work well in PWPD with some adjustments [37]. The potential of involving partners in the treatment of voice disorders and their psychosocial consequences in PD remains to be investigated.

## 5. Conclusion

The purpose of this study was to determine the agreement between PWPD and communication partners in assessing the behavioral, cognitive, and emotional reactions to voice difficulty associated with communication in PD. We found a strong agreement and no significant differences between the judgments of the PWPD themselves and proxies.

This suggests that proxies are able to perceive the communication difficulties experienced by PWPD and thus may provide valuable information for the assessment and treatment planning of voice-related impairment associated with PD.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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