

# Perception of voice difficulties by individuals with Parkinson disease vis-à-vis their family members using Voice Handicap Index

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## Abstract

**Introduction:** Individuals with Parkinson disease (PD) experience difficulty in production of voice. Evidence also suggests a possible deficit in Parkinson's individuals' perception of their own speech loudness. Aim: This study aims to determine perception of voice difficulties in an individual with PD and obtain family members perspective of the same using Voice Handicap Index. **Methodology:** 31 individuals with PD and their respective family members ( $N=62$ ) were asked to fill Voice Handicap Index. Scores across three areas: emotional, functional and physical were compared. Two-way (factorial) ANOVA statistical test was used. **Results:** 64% of the individual with PD and 70% of the family members felt that a voice difficulty exists. The results of ANOVA indicated that the score of the PD differed from family on overall mean scores on VHI. Also, the impact of a voice problem is more noticeable by the family member as compared to the individual with PD. The family members have perceived that the individual with PD has become more restricted in their personal lives and avoid speaking situations due to their voice difficulties. On the other hand, the individual with PD notice the physical strain, effort and difficulty to produce the voice. **Conclusion:** Planning a treatment, which focuses on all these aspects, allows the PD and family members to get a healthy perspective of the voice difficulties and improve overall quality of life. In a country like India, that still has a close family structure, involving the family and obtaining their perspective for management of individuals with PD is of significant importance.

**Key words:** Family, Parkinson disease, perception, voice handicap index

## Introduction

"Words mean more than what is set down on paper. It takes the human voice to infuse them with deeper meaning."

Maya Angelo

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Communication is an important aspect for all stages of life. Humans communicate ideas to others through verbal and nonverbal interactions. However, communication is often constrained for individuals with Parkinson disease (PD). The prevalence of communication disorders is particularly high (89%) in the nearly seven million individuals worldwide with PD.<sup>[1]</sup> The reduced ability to communicate effectively is considered to be one of the most difficult aspects of an individual with PD by many people with the disease and their families.<sup>[2]</sup>

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One of the problems faced in communication is difficulty in production of voice. Voice disorders occur when quality, pitch, or loudness differs from voice characteristics of speakers with a similar gender, age, cultural background, and geographic location.<sup>[3]</sup> A study done on 23 Iranian PD patients with Voice Handicap Index (VHI) mentioned that Iranian individuals with Parkinson disorder show voice difficulties and the VHI scores exhibit a voice handicap which increases with increase in the severity of the PD.<sup>[4]</sup> It is common for individuals with PD to experience difficulty in breath control during speech and reduced volume of speech.<sup>[5]</sup>

Researchers have hypothesized that the features underlying voice disorders in people with PD can be due to (a) reduced amplitude of neural drive to the muscles of the speech mechanism that may result in a “soft voice that is monotone,” (b) difficulty in sensory perception which prevents a person with PD from accurately monitoring his/her vocal output, and (c) difficulty in independently generating the right amount of effort to produce adequate loudness.<sup>[6]</sup>

Evidence also suggests a possible deficit in Parkinson’s individuals’ perception of their own speech loudness.<sup>[7]</sup>

To the best of this researcher’s knowledge, there appear to be no studies on family member’s perception of voice and voice related difficulties in individuals with Parkinson’s.

In a country like India, that has a close knit family structure, involving the family and obtaining their perspective for the management of individuals with PD is of extreme importance.

Accepting and acknowledging the impact and reality of voice difficulties in Parkinson disorder initiates realistic expectations about its treatment and prognosis. After diagnosis, it is essential to focus treatment not only on the physical challenges of PD but also the emotional challenges. If not emphasized, it could leave the person with Parkinson’s, or family members, feeling confused and alone in coming to grips with the bigger picture of life plans.<sup>[8]</sup> Guimaraes emphasized the importance of supplementing the clinical decision-making process by providing an insight into the impact of the disease on the subject’s life from his/her own perspective.<sup>[9]</sup>

Hence, the purpose of this study is to determine awareness of the presence of voice difficulties in an individual with PD and obtain the family members perspective of the same. This would throw light on the PD and families perception of the voice difficulties.

Obtaining the family perception of the voice difficulties of PD can help to review the communication environment. This will lead to better understanding of the problem and perhaps the way family members can contribute in facilitating the treatment.

VHI is a perceptual tool used to identify self-perception of the presence and degree of voice difficulty.<sup>[10]</sup> In the present study, through the VHI original English version

1. The presence of voice disorder as perceived by individual with PD and family members was obtained
2. Perceptions of voice characteristics, the impact of the voice disorders on daily life and functional, physical, and emotional responses to the voice disorder were studied.

## Methodology

This is an exploratory, noninterventive, descriptive study with data collected from 62 individuals ( $N = 62$ ).

### Inclusion criteria

- Individuals with PD as diagnosed by neurologist
- Family members (spouses and/or children) living with the individual with PD.

### Exclusion criteria

- Individuals with PD with other associated neurological conditions
- Family members not living with the individuals with PD.

Thirty-one individuals with PD were taken for the study with adequate permission from the PD and Movement Disorder Society of Mumbai, at their centers across Mumbai. All the individuals are under medication for PD as prescribed by the neurologist. Twenty-nine were males, and two were females. The mean age of this group was 66.18 years (56–79 years). Only one was working (family business) the rest were retired, and both the females were homemakers. The minimum education of this group is matriculation passed and all the individuals could read English without difficulty.

The second group consisted of 31 respective family members - spouses and or the children of individuals with PD who are living with them.

The two groups were asked to read and fill the VHI, original English version. Any difficulty was verbally clarified by the author. The two groups were told to

separately and independently fill the questionnaire and were thus totally unaware of each other's responses.

The family members were instructed to provide their rating of the perceived voice difficulty as they feel individual with PD would face and mark on the VHI.

### Statistics

Software used for the statistical analysis was – SPSS Version 16.0. Released 2007. SPSS for Windows, Chicago, SPSS Inc.. In this study, the effect of two independent variables that is individuals with PD (term “patient” used for analysis) and family on the three dependent variable (VHI parameters - Physical, emotional, and functional aspect) was examined. This was studied using, two-way (factorial) ANOVA statistical test.

The assumptions underlying repeated measures ANOVA was checked by one-sample K-S test which reveals that the Z values were not statistically significant ( $P > 0.05$ ) for all the distributions. Thus, all the distributions were approaching normality.

## Results

Of the total 62, 20 individuals with PD (20 out of 31) and 22 family members (22 out of 31) felt that a voice difficulty exists from mild to a severe degree [Table 1].

The differences in the patient and family estimated means of the three aspects of VHI scores (functional, physical and emotional) are presented graphically in Figure 1.

**Table 1: Distribution of severity on the basis of voice handicap index scores**

Severity	Individual with PD	Family
No significant voice difficulty	11	9
Mild voice difficulty	3	5
Moderate voice difficulty	6	6
Severe voice difficulty	11	11

PD: Parkinson disease

As seen in Figure 1, the estimated mean score for a family is higher than for patient on functional and emotional aspects. On the contrary, on the physical aspect, the estimated mean score for a family is lower than for the patient.

Whether these differences are significant is assessed through simple effects (ANOVA) as shown in Table 2.

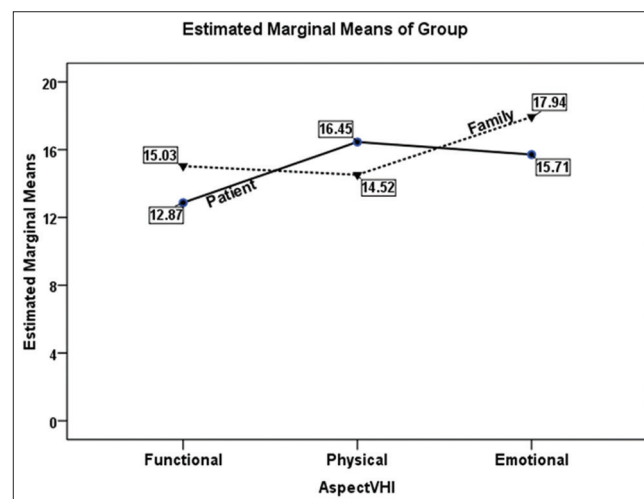
There is a significant main effect of group on scores of VHI,  $F(1,30) = 41.2$ . Thus, the score of the patients that is individuals with PD differed from family on overall mean scores on VHI.

### The main effect of group

The estimated marginal means for two levels of the group are presented in Table 3.

The estimated mean score for patient (mean = 15.01, Standard error = 12.22) is lower than for family (mean = 15.83, Standard error = 15.83).

The comparisons in Table 4 indicate that there is a significant effect of group on each aspect of VHI at  $P < 0.05$  [Table 4]. The family has higher estimated mean



**Figure 1:** Graphical presentation of the differences in the patient (Parkinson disease) and family estimated means for three aspects Voice Handicap Index

**Table 2: The results of ANOVA - tests of within-subjects effects: Voice Handicap Index score**

Source	Type IV sum of squares	df	Mean square	F	P
Group	31.054	1	31.054	41.20*	<0.0005
Error (group)	22.613	30	0.754		
Aspect VHI	255.903	2	127.952	19.42*	<0.0005
Error (aspect VHI)	395.43	60	6.591		
Group × aspect VHI	176.204	2	88.102	39.12*	<0.0005
Error (group × aspect VHI)	135.129	60	2.252		

\*F value significant at 0.05 level all effects are reported as significant at  $P < 0.05$ . VHI: Voice Handicap Index

scores than the patient; on functional and emotional aspects. However, on the physical aspect of VHI, patient has higher estimated mean score than family.

## Discussion

It was observed in this study that 64% of the individual with PD (20 out of 31) and 70% of the family members (22 out of 31) felt that a voice difficulty existed.

On VHI, the overall estimated mean scores of the family were higher than the overall estimated mean score of the individuals with PD. Thus, it was observed that the impact of a voice problem is more noticeable by the family member as compared to the individual with PD. This could be attributed to a distorted perception of own voice disorder in the individuals with PD.<sup>[6,7]</sup>

Furthermore, the family has higher estimated mean scores than the individuals with PD on functional and emotional aspects. However, on the physical aspect of VHI, the individuals with PD have higher estimated mean score than family.

Qualitative analysis of the VHI scores reveals the following observations:

On the functional aspect, the difficulties faced by the individual with PD were for the questions related to avoiding communication typically for phone call, in groups and talking to familiar people. The family members felt, overall the PD has a restricted personal life due to voice problems whereas, PD scored much lower in this same area. This implies that PD themselves are not aware of the fact that they are avoiding

communication, and their speech output is reduced. On the emotional aspect, the family members consistently mentioned that the individual with PD gets annoyed when asked to repeat and that they have become less outgoing. They have a higher score on these aspects as compared to the individual with PD.

On the physical aspect, the individual with PD predominantly mention that the amount of strain and effort required to produce a voice is more. The individuals with PD have rated this difficulty, which is on a personal level, higher than the family members. Thus, the physical impact and difficulty faced by the individual with PD and effort experienced by them may not be equally noticed by the family.

A further interesting point to note was that scores of a lesser value are marked on similar questions of emotional, functional, and physical aspects for the 11 individuals with PD and the 9 family members [Table 1], who scored in the lower ranges of VHI.

This suggests that these areas are affected even in the early stages but to a lesser degree.

Thus overall, the family members have perceived that the individual with PD has become more restricted in their personal lives and avoid speaking situations due to their voice difficulties.

Hence, when a diagnosis is made, a holistic approach which focuses the treatment on physical aspects, emotional and functional components is essential.

Thus, planning a treatment once the findings are explained, allows the individual with PD and family members to come to terms with the voice difficulties and make appropriate adjustments by getting an accurate perception of the situation.

It is a known fact that individuals with PD are confronted with physical, psychological, and psychosocial issues that impact the quality of life.<sup>[1]</sup> Therefore, focusing on the physical, emotional and functional aspects of voice and cohesively working to make reasonable and

**Table 3: Estimated marginal mean scores for two groups**

Group	Mean	SE	95% CI	
			Lower bound	Upper bound
Patient	15.01	1.37	12.22	17.81
Family	15.83	1.36	13.06	18.60

Patient - Group 1: Individual with PD; Family - Group 2: Family members; SE: Standard error; CI: Confidence interval; PD: Parkinson disease

**Table 4: The pair wise comparisons for two groups under each aspect of voice handicap index**

Aspect VHI	Group (I)	Group (J)	MD (I-J)	SE	P*	95% CI for differences	
						Lower bound	Upper bound
Functional	Patient	Family	-2.16*	0.325	<0.0005	-2.825	-1.498
Physical	Patient	Family	1.94*	0.371	<0.0005	1.178	2.693
Emotional	Patient	Family	-2.23*	0.31	<0.0005	-2.859	-1.593

Based on estimated marginal means. \*The mean difference is significant at the 0.05 level; \*Adjustment for multiple comparisons: Bonferroni. SE: Standard error; CI: Confidence interval; MD: Mean difference; VHI: Voice Handicap Index



realistic plans for the future would overall improve the quality of life.

## Conclusion

Individuals with PD experience a varied degree of difficulties in voice. In this paper, through the administration of VHI, it was observed that the family members notice the impact of voice problems more than the individual with PD. Furthermore, the family members feel that overall the individual with PD has a restricted personal life and have become less outgoing due to not only speech and other motor problems but also the voice problems. However, on the other hand, the individual with Parkinson notice the physical strain, effort, and difficulty to produce the voice.

Thus, planning treatment, which focuses on all these aspects, allows the PD and family members to get a healthy perspective of the overall voice difficulties and improve the overall quality of life. In a country like India, that still has a close-knit family structure, involving the family and obtaining their perspective for the management of individuals with PD is of significant importance.

## Limitations

The sample size is limited. A larger sample size would provide more substantial results of the comparison. The study does not differentiate the difficulty depending on the stage of PD. A hearing evaluation could not be conducted.

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## Conflicts of interest

There are no conflicts of interest.

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