Exploring Vocal Challenges In Individuals With Parkinson's Disease: Insights From The Social And Family Sphere

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Abstract:

Background: *Parkinson's disease (PD) is a multifaceted neurodegenerative condition manifesting in adulthood, characterized by a spectrum of motor and non-motor symptoms. The alteration in the voice of individuals with PD can significantly impact their communication dynamics with the surrounding environment, influencing the perceptions of those around them.*
Objective: *This study aims to assess the perception of vocal difficulties in individuals with Parkinson's disease from the perspective of their socio-family environment.*
Methodology: *A cross-sectional descriptive observational study was conducted involving 17 relatives of individuals with Parkinson's disease, comprising family members and friends acting as primary caregivers in the city of Lahore. Data were collected through in-person surveys, utilizing an adapted version of the VHI-30 questionnaire.*
Results: *Of the participants, 71.2% were aged over 40, with 76.5% being women, and spending more than 5 hours daily with their family members afflicted by PD. A significant 76.4% acknowledged a specific impact related to vocal difficulties in their PD-affected family member, considering functional, physical, and emotional criteria. Within this group, 29.4% reported mild to moderate difficulties, while 47% reported severe to very severe difficulties.*
Conclusion: *Family members and caregivers exhibit varying degrees of perception regarding the vocal challenges faced by individuals with Parkinson's disease. Recognizing the impact on functional, physical, and emotional aspects is crucial. Inclusive therapeutic interventions that involve*

CC License CC-BY-NC-SA 4.0	*the socio-family environment are essential for effectively addressing the challenges posed by the disease.* ***Keywords: Parkinson's Disease, Voice Disorders, Speech, Family.***

INTRODUCTION:

Parkinson's disease (PD) is a complex neurodegenerative process that appears mainly in adulthood, constituting the second most common neurodegenerative disease after Alzheimer's dementia. Parkinson's disease is clinically characterized by a motor triad composed of akinesia or slowness of movements, tremors at rest and rigidity. Globally, the prevalence of Parkinson's disease has doubled over the past 26 years, rising from 2.5 million people to 6.1 million in 2016 (Kaplan, Barkan-Slater, Zlotnik, & Levy-Tzedek, 2024).

In Pakistan, the prevalence is 190 cases per 100,000 inhabitants, accounting for 1% of the population over 60 years of age. Pakistan is the South Asian country with the highest rates of this pathology. The above information is directly related to the rate of older adults in Pakistan; according to the 2023 census, the life expectancy / average age of male is 66.8 years and female is 71.6% and average age from 15-64 is 56%, 65 and above is 3.7%. Although it is not an exclusive disease of advanced age, it is undeniable that it has a greater incidence among older people, worrying and frightening those affected and their families(Bayés & Hernandez-Vara, 2024).

Speech in EP is characterized by monotonous loudness and intensity, low tone and poor prosody, which tends to fade at the end of phonation. It also manifests in slow attacks and significant pauses for breathing between words and syllables, reducing fluidity and verbal rhythm. The alterations are similar to those that occur in depressive states, and it is not for nothing that these patients suffer from them frequently and are affected by the changes that naturally occur as a result of the physiological changes produced in their phonatory system: changes in the larynx, alterations in the respiratory system, in the resonance cavities and the articulatory organs, resulting from the deterioration of muscles, cartilage, joints, ligaments and laryngeal mucosa (Bartolomeu Pires, Kunkel, Kipps, Goodwin, & Portillo, 2024)

Parkinson's disease produces hypokinetic dysarthria that affects all aspects of speech, such as breathing, phonation, articulation, prosody, and resonance. Almost 90% of patients have oral communication disorders, but the voice is affected more and earlier than other language subsystems. One-third of Parkinson's patients suffer from dysphonia, with a cracked and hoarse voice being the most debilitating deficit (Chen & Sidits, 2024).

The production of reduced loudness (hypophonia), altered vocal quality (dysphonia), flattened pitch inflexion (monotony), and loss of accent (single loudness) is also described. Other observations are insufficient airflow for phonation, decreased vocal intensity, difficulty in photorespiratory coordination, hoarseness, harsh voice, swollen voice, vocal fatigue and increased nasality (Rahman et al., 2024).

Voice and articulation disorders occur in between 40% and 80% of people diagnosed with Parkinson's disease. As regards the voice, professionals and experts in the sector state that the voice volume is altered in these people, which is the first complaint of patients suffering from this condition. They report that their voice becomes weaker and that other people cannot hear them. The voice is part of a person's identity because, without our voice changing, the perception of our environment concerning us changes because by producing a different voice, people will no longer have the body image they had of the subject before their voice changes, which could affect the two-way communication of the person with PD and with his family since you will no longer have the same motivation to communicate in the same way as before with your environment (Tueth et al., 2024).

Speech and communication problems lead the person with personality disorder to limited communicative participation, as well as often feeling ashamed for what he says. This is why individuals, in general, feel they have lost control of communication, have less self-confidence, feel frustrated and less independent, often avoiding participating in communication(Zogaan et al., 2024).

A study highlights the importance of the family as a fundamental pillar in coping with Parkinson's. All patients agree in indicating that without the unconditional support of the family, this disease would be complicated to deal with, both physically and psychologically, since in the bad moments of the disease, family support is essential for them (Kluger et al., 2024).

Caregivers play a crucial role in maintaining an adequate quality of life for a person with Parkinson's, and their presence is believed to reduce morbidity and mortality. This role is usually filled by a family member, partner, or close friend. As a natural evolution of Parkinson's disease, patient care becomes the caregiver's main

activity. Since their caregivers regularly live with the person with PD, they ultimately become valid interlocutors in characterizing the communication difficulties they present (Beauchamp et al., 2024).

Another study conducted in the United Kingdom in 2007 showed that family members and friends of people with Parkinson's disease have difficulty understanding them in more than 50% of cases. Therefore, it is essential to include the family in the understanding process of therapy and also know their perception of how Parkinson's disease affects and impacts the person, since in this way, it is possible to provide care that is more focused on the person and their family and not on an isolated subject, increasing the improvements, the progress of the therapy and the quality of life of the person with PD (Shah-Zamora, Anderson, Barton, & Fleisher, 2024).

Since the 1990s, Pakistan has started reforming its healthcare system, considering demographic and epidemiological changes and educational, family, community and social changes. Therefore, within the framework of the 2004 healthcare reform, the Pakistani Ministry of Health proposes a change in the existing care model to improve the primary healthcare (PHC) strategy. Thus, based on biopsychosocial and systemic approaches, the Family Health Model (MSF) was born, emphasizing the person and their family and social context (Garg et al., 2024).

There are currently no studies in Pakistan that focus on the perception of family members regarding the difficulties presented by people who have Parkinson's disease, hence the need to investigate and generate knowledge, especially when, as a country, we promote global family-centred care. In consideration of this, the aim of the present study is to evaluate the perception of vocal difficulties in subjects suffering from PD from the point of view of the family environment (Sahoo & Choudhury, 2024).

METHODOLOGY:

The study design was observational, descriptive in scope, and cross-sectional. The population was made up of family members of users affected by PD who attend the People with Parkinson's Disease Group of Lahore. The final sample was made up of 17 relatives and caregivers, selected through a non-probability convenience sampling and who had to meet the following inclusion criteria: being a family member or caregiver of a person with Parkinson's disease who attends the group, residing in Lahore; guarantee daily coexistence with the person suffering from PD (MARTÍN-PALOMO, GONZÁLEZ-CALO, Lucchetti, & Badanta, 2024).

Evaluation Tool:
To collect the necessary data, a tool called "Vocal Disability Index" was used from the point of view of the socio-family environment, which was adopted by the research group using the "Vocal Disability Index" tool in its version as a basis of 30 questions (VHI-30), whose original objective is the evaluation of the damage associated with dysphonia that the person perceives based on three domains or dimensions: physical, functional and emotional (Jiang et al., 2024).

This survey is of the Likert type, with values ranging from 0 (when the questioned characteristic never occurs) to 4 (when the questioned characteristic always occurs). This Score was In the instrument adapted and used, these questions maintain their affirmative formulation towards the interviewee but expressed based on his perception of the family member affected by PD, i.e. using the "third person singular". For greater clarity, we report an example with question n°1: In the original survey, it says, "People have difficulty hearing their voice", while in the adapted survey, it changed to "People have difficulty hearing their voice" (Çetin, Kılınç, & Çakmaklı, 2024). After making this modification, the instrument was subjected to the judgment of 4 experts in the academic and clinical area of voice, who determined its validity according to content, relevance, pertinence and writing criteria (de Graaf et al., 2024).

Procedures:
At first, authorization was requested from the group's president, illustrating the project and its aims. Subsequently, the list of members was requested to whom it was explained what the study consisted of, the existence of family members and the healthcare workers who lived with them daily was verified, and their contact information was requested (Almutawa et al., 2024).

Subsequently, a meeting was coordinated with the family members and caregivers of the users suffering from PD in a comfortable place where the study's details were explained and doubts clarified. It is essential to underline that the emphasis was placed on explaining that when they answered the questionnaire, they always did so thinking about how they perceived this difficulty in their family member affected by PD. Finally, the "Vocal Disability Index from the Family Perspective" assessment tool was applied physically and in person (Liu et al., 2024).

The present study complied with the ethical standards provided by the Scientific Ethics Committee of the Speech Therapy Program of the Autonomous University of Pakistan, Lahore. It received its approval through the validation code FONOAU0089. Each participant expressed his or her authorization by signing an informed consent form voluntarily and intentionally (Xue, Lu, Zhang, Guo, & Gao, 2024).

Statistic Analysis:

The information collected from the applied surveys was tabulated and statistically processed in a Microsoft Office Excel 2016 spreadsheet. Considering the descriptive scope of this research and that the responses of the instrument correspond to quantitative categorical variables, the analysis carried out was frequency and percentage (Ramati, 2024).

RESULTS:

The main results tables will be presented below, as well as an explanatory graph. Each element then has a narrative description of its content.

DIMENSION	DESCRIPTOR	FREQUENCY	PERCENTAGE
Participants	-	17	100%
Age	< 40 years	5	29.4%
	between 40 and 60 years	6	35.3%
	>60 years	6	35.3%
Sex	Man	4	23.5%
	Women	13	76.5%
Daily contact time with the person with PD	>5 hours	13	76.5%
	<5hours	4	23.5%

Table 1: Sample characterization.

In Table 1, it is possible to see a characterization of the sample (n=17) about age, gender and time spent in daily coexistence with the user suffering from PD. As regards the first item, 5 are under 40 years old (29.4%), 6 are between 40 and 60 years old (35.3%) and 6 are over 60 years old (35.3%). As regards the second item, 4 participants were men (23.5%) and 13 women (76.5%). Finally, in the third item, 13 declared that they spend more than 5 hours a day with their family member suffering from PD (65.5%). In contrast, 4 declared that they spend less than 5 hours a day with their family member suffering from PD (23.5%) (Pragadeeswaran & Kannimuthu, 2024).

DOMAIN	SEVERITY	FREQUENCY	PERCENTAGE
Perception Of Functional Impact	Normal	6	35.3%
	Mild Disability	4	23.5%
	Severe Disability	5	29.4%
	Moderate Disability	2	11.8%
Perception Of Physical Impact	Normal	3	17.6%
	Mild Disability	8	47.1%
	Severe Disability	3	17.6%
	Moderate Disability	3	17.6%
Perception Of Emotional Impact	Normal	6	35.3%
	Mild Disability	4	23.5%
	Severe Disability	4	23.5%
	Moderate Disability	3	17.6%
Overall Score	Normal	4	23.5%
	Mild Disability	4	23.5%
	Moderate Disability	1	5.9%

Table 2 presents an analysis of the stages by severity based on the scores obtained in the vocal disability index from the family perspective.

For domain, the "normal" category is established when the Score is less than 5; "mild disability" when the Score is between 6 and 20; "moderate disability" when the Score is between 21 and 30; and "severe disability" when the Score is between 31 and 40. As regards the overall Score, the categorization is as follows: "normal" when the Score is less than 10; "mild disability" when the Score is between 11 and 30; moderate disability" when the Score is between 31 and 60; "severe disability" when the Score is between 91 and 120 (Teo, Bird, Wang, & Zheng, 2024).

It can, therefore, be observed in the "Perception of functional impact" domain that 6 people (25.3%) evaluate their family member with PD with normal voice, 4 people (23.5%) with mild vocal disability, 2 people (11.8%) with moderate vocal disability and 5 people (29.4%) with severe vocal disability. Regarding the domain "Perception of physical impact", it is shown that 3 people (17.6%) classified their relative affected by PD as having a normal voice, 8 people (47.7%) as having a mild disability vocal, 3 people (17.6%) in the context of a moderate vocal disability and 3 (17.6%) in the context of a severe vocal disability (Roche & Longacre, 2024). In the last domain, corresponding to the "Perception of the emotional impact", 6 people (25.3%) rated their family member as having a normal voice, 4 people (23.5%) with a mild vocal disability, 3 people (17.6%) with a moderate vocal disability and 4 (23 .5%) had severe vocal impairment. Finally, regarding the global Score, 4 research participants (23.5%) rated their family member affected by PD as having a normal voice, 4 (23.5%) as having a mild vocal disability and 1 (5 .9%) as having a disability. Moderate vocal disability: 5 people (29.4%) have a severe vocal disability, and 3 people (17.6%) have a severe vocal disability (Auccahuasi et al., 2024).

DOMAIN	DESCRIPTOR	QUESTION NUMBER	SCORE
Perception Of Functional Impact	> Domain Score	Question 2	38
	< Domain Score	Question 5	20
Perception Of Physical Impact	>Domain Score	Question 6	37
	< Domain Score	Question 3	8
Perception Of Emotional Impact	> Domain Score	Question 7	34
	< Domain Score	Question 2	9

Table 3: Maximum and minimum score of the questions based on each area of the applied survey

Table 3 shows the item or question that scored the highest and the one that scored the lowest based on the applied survey domain. Regarding the functional domain, question 2, corresponding to "People do not understand you in noisy places", obtained the highest Score (38). In contrast, question 5, corresponding to "You tend to avoid meetings because of your voice", got the highest Score (38). lowest Score (20). Regarding the physical domain, question 6, "Are you embarrassed because of your voice problem?" obtained the highest Score (37). In contrast, question 3, corresponding to "People ask you, what Is there something wrong with your voice?" obtained the lowest Score (8). Finally, in the emotional area, question 7, "Do you feel uncomfortable when people make you repeat yourself?" obtained the highest Score (34). In contrast, question 2, corresponding to "People seem irritated by your voice", received the lowest Score. (9) (Pendl, Glatz, & Gasteiger-Klicpera, 2024).

ANALYSIS AND DISCUSSION:

The objective of this research was to describe the perception of vocal difficulties in the family environment of people with Parkinson's disease, analyzing the sex and the daily contact time of the family member and caregiver with the person with Parkinson's disease. A more significant number of female caregivers were to spend more than 5 hours a day with their family. This coincides with the findings where 75% of participants were women (most in a blood or marital relationship), plus an average caregiving dedication of 18 ± 8 hours per day. They have identified a marked social construct that associates the female gender with care tasks, which could also be highlighted in our research (Kapoor, Sharma, Sharma, Sahu, & Gupta, 2024; Karande & Kulkarni, 2024).

As regards the perception of family members in the area of "functional impact", the highest Score could be highlighted among all the tools applied (question 2, "People do not understand you in noisy places"), with a total of 38 points, which suggests that the socio-familial environment of users with PE finds it challenging to understand them in these contexts. The above is related to other research indicating that one of the main complaints of Parkinson's disease patients is that their voice has become weak. They cannot be heard in noisy environments, and their families often complain. They correct them, asking them to speak louder, which generates frustration and makes them more introverted (Amuthan, Jyothi, & Samy, 2024).

The two lowest scores observed in the entire instrument are presented about the other two domains of the guideline. In the "physical impact" domain, question 3 scored 8 points ("People ask you: "What is wrong with your voice?"), and in the "emotional impact" domain, question 2 scored 9 points ("Do people seem irritated by your voice"). These questions directly involve aspects of the perception of the environment. As mentioned by some studies, due to their vocal difficulties, these patients avoid conversations with strangers and have a more restricted social life, relating only to their closest environment; they are already familiar with the problems they present. Similarly, the study conducted by them mentions that people suffering from disease usually isolate themselves in their homes out of fear, shame, or to hide their symptoms, while another study conducted states that the people around them minimize their symptoms or are the object of ridicule (Karande & Kulkarni, 2024; O'Connor, 2024).

Also, analyzing the overall results obtained from the instrument and classifying them by stage of severity, it is clear that the majority of family members can perceive some vocal alteration in the person with PD, from a mild to a severe level, corresponding to a cumulative value of 76, 4%, which is consistent with another study in which the perception of family members was compared with that of the PD patient about vocal difficulties: 70% of the first group felt that there was a vocal difficulty. VHI scores in functional and emotional aspects were also higher than those of the same PD patients. As a research group w, we believe it could be essential to delve deeper into this comparative aspect regarding the perceptions of the sample studied(Pham, Holmes, Zou, Patel, & Coulthard, 2024).

Finally, one of the main limitations of this research is the sample size, which allows local analyses but makes it difficult to do them in a more global way, as well as being limiting at the time of sampling because some participants expressed poor availability of time to respond. At the same time, a significant prejudice is not knowing the stage of evolution of the disease in which one is found (Lopez-Soto, 2024).

CONCLUSION:

Patients with Parkinson's disease (PD) may or may not experience voice changes. As a result, they may become less outgoing and avoid public speaking. Close family members or caregivers can discern how the illness affects the patients' voices. For this reason, they can offer us vital information to help us plan our treatments and assist the patients in managing their condition, particularly in light of Pakistan's recently established health system, family-centred systemic and biopsychosocial health.

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