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The effect of swallowing disorder on quality of life in patients with Parkinson's disease

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ABSTRACT

Objectives: The aim of this study is to evaluate the severity of dysphagia in Idiopathic Parkinson's Disease (IPD) using both self-assessment and clinical assessment tools, to investigate the correlation between these methods, and to examine the effect of dysphagia on quality of life.

Methods: Patients diagnosed with IPD who applied to the Movement Disorders Clinic of the Neurology Department of Istanbul University Faculty of Medicine between 2020-2021 were included in the study. Dysphagia severity was assessed using the Eating Assessment Tool (EAT-10), Dysphagia Disability Index (DHI), and Gugging Swallowing Screening (GUSS). The effect of dysphagia on quality of life was assessed using the Turkish Swallowing Quality of Life Questionnaire (T-SWAL-QOL).

Results: A total of 38 patients, 24 (63.2%) of whom were male, were included in the study. There was a moderate correlation between GUSS and EAT-10 scores (r: -0.548; P<0.01). All areas of the quality of life questionnaire were negatively affected, with the most prominent problems being fatigue, sleep, and communication problems. The questionnaire scores showed a moderate correlation with EAT-10 scores (r: -0.583; P<0.01), a high correlation with DHI scores (r: -0.751; P<0.01)

Conclusions: This study demonstrates that dysphagia in IPD negatively impacts quality of life in several ways. The similar results obtained from self-assessment scales and clinical measures suggest that the clinician may include the results of self-assessment scales when screening for swallowing disorders.

Keywords: Dysphagia, swallowing disorder, Parkinson's disease, quality of life

Idiopathic Parkinson's disease (IPD) is a progressive neurodegenerative disease characterized by motor symptoms such as resting tremor, rigidity, bradykinesia, and postural instability, as well as non-motor symptoms [1]. Dysphagia is a common symptom in patients with IPD, and its prevalence varies between 11% and 82% depending on the stage, duration, and assessment method [2, 3]. It can limit or prevent safe oral feeding, reduce the patient's full capacity in society, and cause social, psychological, and economic

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problems for the individual [4]. Aspiration pneumonia, especially due to swallowing disorders, has been reported to be one of the leading causes of death in IPD [5]. Since it is not directly related to the stage of the disease and the perception of dysphagia usually develops much later, the presence of dysphagia should be investigated from the very early stages [2]. Health-related quality of life has been defined as “the patient's own perception and self-assessment of the effects of a disease and its consequences on his or her life” [6]. Quality of life is an important factor to be considered in the management of chronic, progressive and complex diseases such as IPD and is affected by a wide range of clinical features including both motor and non-motor symptoms in IPD (5). There are studies in the literature showing that swallowing disorders in IPD negatively affect quality of life; however, these studies evaluated swallowing disorders with screening scales and did not use clinical measurement tools applied by clinicians [7-10]. Although there are various studies in our country that include voice and swallowing evaluations in IPD, studies examining swallowing-related quality of life are limited [11, 12]. Dysphagia can be reported subjectively by patients or their caregivers, as well as objectively with instrumental tools. Since dysphagia is frequently seen in Parkinson's disease, it is important to determine whether the patient is at risk for dysphagia in order to determine whether instrumental evaluation is needed. In the literature, it is a matter of debate whether self-assessment scales provide accurate results in terms of detecting swallowing disorders in Parkinson's patients. For these reasons, in our study, swallowing severity in IPD was screened with clinical measurement tools as well as self-assessment scales and the effects of both methods on quality of life were investigated by looking at their relationships with each other. The aim of this study was to determine the reliability of using self-assessment methods and scales used by clinicians in screening swallowing disorders in Parkinson's patients as a practical screening for clinicians in the evaluation by examining the relationship between each other.

METHODS

Participants

This descriptive study included 38 consecutive patients who applied to the Movement Disorders Polyclinic of the Neurology Department of Istanbul University, Istanbul Faculty of Medicine between 2020-2021 and were diagnosed with Idiopathic Parkinson's disease according to the UK Brain Bank criteria [13]. In the study, all evaluations were performed with all patients during the "on" period of the drug cycle. The research plan was scientifically and ethically approved by the Istanbul Medipol University Non-Interventional Clinical Research Ethics Committee and was conducted in accordance with the Declaration of Helsinki (Date: 26.10.2021, Number: 1060). All subjects included in the study were informed about the purpose, duration, and evaluations to be performed. All subjects were included in the study after the "Informed Voluntary Consent Form" approved by the Istanbul Medipol University Non-Interventional Clinical Research Ethics Committee was approved. The number of participants included in the study was limited to 38 people due to the ongoing Covid-19 pandemic and the decrease in the number of patients applying to the outpatient clinic.

Inclusion Criteria

Our study planned to include patients who did not have a diagnosis of dementia, did not have any additional neurological diseases (Stroke, ALS, Multiple Sclerosis, etc.), did not have other disorders that could affect swallowing function (e.g. head and neck cancer), had at least five years of education, and were diagnosed with Idiopathic Parkinson's Disease according to the UK Brain Bank criteria [13].

Demographic Data of the Sucjects

The name, surname, gender, age, educational status, and duration of illness of the patients who voluntarily participated in the study were questioned.

Data Collection

In order to clinically evaluate the severity of swallowing disorder, Gugging Swallowing Screening Test (GUSS), Dysphagia Handicap Index (DHI) and Eating Assessment Tool (EAT-10) scales were administered when the patients were alert in terms of motor findings. Dysphagia Handicap Index and EAT-10 scales measure the severity of swallowing disorder by the individual's answers to the questions in the scale. The Gugging Swallowing Screening Test scale involves a

speech and language therapist trained in swallowing to clinically evaluate the individual's swallowing with various consistencies. In addition to these scales, the T-SWAL-QOL, designed to assess swallowing-related quality of life, was administered to determine the effect of swallowing disorder and symptoms related to swallowing disorder on quality of life. The scales were administered in the examination room and took an average of 20 minutes for each participant. The researcher read the questionnaire items and answer options aloud to each patient to guarantee correct answers and reduce the possibility of misinterpretation due to low levels of education or visual impairments. The aim of this methodology was to increase the comprehensibility of the questionnaire and minimize the possibility of deceptive answers. By administering the questionnaires in the same way to each participant, consistency was maintained and any bias in the data collection process was avoided.

Scales Used

Eating Assessment Tool (EAT-10)

It measures the severity of swallowing disorder, quality of life and treatment effectiveness. The scale consists of 10 questions and the questions are scored between 0 and 4 (0=no problem, 4=severe problem). A total score of 3 or above indicates a risk for swallowing disorder. A higher total score indicates a higher severity of swallowing disorder. Turkish validity and reliability of the study was performed [14].

Dysphagia Handicap Index (DHI)

It is an assessment questionnaire consisting of 25 questions developed to evaluate the effects of swallowing disorder on the person's life and the severity of swallowing. The questions are divided into three groups. The aim of the groups is to evaluate the patient's swallowing quality from physical, emotional and functional perspectives. Turkish validity and reliability was performed by Çiyiltepe *et al*. [15]. Each question has three answers: "never", "occasionally" and "always". During scoring, "never" is scored as 0, "sometimes" as 2 and "always" as 4. As a result of the questionnaire, a score between 0-100 is obtained [15]. A higher total score indicates a higher severity of swallowing disorder.

Gugging Swallow Screening Test (GUSS)

It is one of the bedside swallowing screening tests with proven reliability and is used in clinical practice. A Turkish adaptation study of GUSS was also conducted by Umay *et al*. [16] in 2018. Like many bedside swallowing tests, it starts with fluid and the screening process is terminated early when aspiration is suspected. The GUSS consists of 2 stages, indirect assessment and direct assessment, and is a 20-point test in total. The first part consists of the ability to maintain wakefulness for 15 minutes, to cough and/or clear the throat voluntarily at least twice, and to swallow saliva successfully without change in voice or drooling. Patients who pass this first part of the GUSS with 5 full points pass to the second stage, which is a 15-point direct swallowing test to be evaluated with semi-solid, liquid and solid foods, respectively. Patients who score less than 20 full points as a result of the test are referred to instrumental swallowing evaluation for further clinical evaluation [17].

Turkish Swallowing Quality of Life Questionnaire (T-SWAL-QOL)

The T-SWAL-QOL was used to assess patients' swallowing-related quality of life. The T-SWAL-QOL assesses the impact of swallowing disorder on quality of life from the patient's perspective. It consists of 44 questions assessing different dimensions of quality of life. The questions are scored between 1 and 5 (1=completely true, 5=not true at all). A higher score indicates a higher quality of life. The questionnaire has 11 headings including general complaints, desire to eat, time of eating, social, food choice, fear of eating, sleep, fatigue, communication, mental health, and symptom frequency. Turkish validity and reliability study was conducted [18].

Statistical Analysis

Data were analyzed using the Statistical Package for Social Sciences (SPSS) Version 26.0 (IBM SPSS Inc., Chicago, IL, USA). The "Shapiro Wilk Test" was used to determine whether the data conformed to normal distribution. Parametric tests were used to analyze the data conforming to normal distribution and non-parametric tests were used to analyze the data not conforming to normal distribution. In the statistical analysis of the study, continuous variables were defined as mean (Mean), standard deviation (SD), median, minimum and maximum values and categorical

Table 1. Demographic and clinical characteristics of patients (n=38)

Characteristics	Data
Age (years)	64.61±12.6
Sexuality, man, n (%)	24 (63.2%)
Disease duration (year), n (%)	8.38±5.38
1 year	1 (2.63%)
<5 year	7 (18.41%)
5-10 year	19 (49.97%)
<10 year	23 (60.49%)
10-30 year	14 (36.82%)
>30 year	1 (2.63%)
Education status, n (%)	
Primary education	20 (52.6%)
Middle school	3 (7.8%)
High school	8 (21.1%)
University	7 (18.4%)
EAT-10	4.05±7.6
DHI	11.89±17.7
GUSS	19.76±0.7
T-SWAL-QOL	82.14±16.4

Data are shown as mean±standard deviation or n (%). EAT-10=Eating Assessment Tool-10, DHI=Dysphagia Handicap Index, GUSS=Gugging Swallowing Screen, T-SWAL-QOL=Turkish Swallowing Quality of Life Questionnaire, SD=Standard Deviation

variables were defined as number (n) and percentage (%). The correlation analysis of the non-normally distributed data was performed using Spearman Correlation Analysis. The direction of the relationship level was determined according to whether the Spearman correlation coefficient "r" value was positive or negative, while the strength was determined according to the magnitude of the "r" value. All statistical analyses were performed at 95% confidence interval and significance was evaluated at P<0.05 level.

RESULTS

The study included 38 participants. Of the participants, 24 (63.2%) were male and 14 (36.8%) were female. The mean age of the participants was 64.61±12.6 years and the mean duration of illness was 8.38±5.38 years. The duration of the disease was less than 10 years for 60.52% of the participants, between 10-30 years for 36.84% and more than 30 years for 2.63%. The mean scores of the participants from the scales

Table 2. Results of the relationship between GUSS total score and EAT-10 and DHI total scores

		EAT-10 total score	DHI total score
GUSS total score	r	-.548	-.490
	P value	**0.0004****	**0.002****
	n	38	38

EAT-10=Eating Assessment Tool-10, GUSS=Gugging Swallowing Screen, DHI=Dysphagia Handicap Index
**P<0.01 were considered significant

Table 3. Results of the relationship between T-SWAL-QOL total scores and EAT-10, DHI and GUSS total scores.

		EAT-10 total score	DHI total score	GUSS total score
T-SWAL-QOL total score	r	-.583	-.751	0.393
	P value	**0.0001****	**0.0001****	**0.015***
	n	38	38	38

EAT-10=Eating Assessment Tool-10, DHI=Dysphagia Handicap Index, GUSS=Gugging Swallowing Screen, T-SWAL-QOL=Turkish Swallowing Quality of Life Questionnaire

*P<0.05, **P<0.01 were considered significant.

used were EAT-10: 4.05±7.6, DHI: 11.89±17.7, GUSS: 19.8±0.7, and T-SWAL-QOL: 82.14±16.4, respectively. Demographic and clinical characteristics of the patients are presented in Table 1.

The results of the correlation between the screening test in which the clinician evaluates the patient's swallowing and the scales in which the patient evaluates his/her own swallowing are shown in Table 2.

There was a statistically significant, negative, moderate, statistically significant, negative, moderate correlation between the GUSS total scores and EAT-10 scores (r:-0.548; P=0.0004) and a statistically significant, negative, low correlation between the DHI scores (r:-0.490; P=0.002) (Table 2.). All three methods indicating the severity of swallowing disorder are correlated with each other.

The results of Parkinson's disease patients' swallowing disorder scores obtained by clinical evaluation and scales and swallowing-related quality of life scores are presented in Table 3.

There was a statistically significant, negative, medium level (r:-0.583; P=0.0001), statistically significant, negative, high level (r:-0.751; P:0.0001) and statistically significant, positive, low level (r:0.393; P=0.015) correlation between T-SWAL-QOL total scores and EAT-10 score, DHI score and GUSS score (Table 3.). As a result, it was observed that quality of life deteriorated more as the severity of swallowing disorder increased.

The sub-fields of the quality of life questionnaire were examined to determine how the quality of life of Parkinson's patients was affected by the swallowing disorder they experienced, and it was observed that all areas were negatively affected, the most in the areas

Table 4. T-SWAL-QOL subscores and total scores (n=38).

	Median	Min-Max	Mean±SD
Fatigue	58.30	0-100	56.77±31.6
Sleep	68.75	0-100	61.51±39.6
Communication	75	0-100	70.39±34.4
Eating time	100	12.5-100	82.57±28.1
Symptom frequency	92.31	34.62-100	86.34±14.8
Fear of eating	100	25-100	86.68±25
Desire to Eat	100	25-100	88.58±21.4
Mental health	100	0-100	91.28±23.1
Food choices	100	50-100	92.11±17.3
General complaints	100	0-100	92.43±23.5
Social life	100	25-100	94.87±18
T-SWAL-QOL total	86.25	3.6-100	82.14±16.4

T-SWAL-QOL=Turkish Swallowing Quality of Life Questionnaire, Min=minimum, Max=maximum, SD=standard deviation

of fatigue, sleep and communication, and the least in the areas of social and food selection (Table 4).

DISCUSSION

Motor and non-motor findings are observed in patients with Idiopathic Parkinson's disease and may negatively affect the quality of life [6]. Dysphagia, which is frequently observed in the course of the disease, also has a negative effect on quality of life and may lead to social and psychological problems for the individual [4].

Various studies in the literature have examined the effect of swallowing disorder on quality of life in individuals with swallowing disorder and found that swallowing-related quality of life decreased with increasing severity of swallowing disorder [19-21]. This study examines the effect of severity of swallowing disorder on swallowing-related quality of life in patients with idiopathic Parkinson's disease. As a result of our study, a statistically significant, negative correlation was found between EAT-10 total scores and DHI total scores and T-SWAL-QOL total scores of patients with idiopathic Parkinson's disease in accordance with the literature. The presence of a statistically significant, negative correlation between these two values indicates that patients with less severity of swallowing disorder have a higher quality of life, and as the severity of swallowing disorder increases, the quality of life is negatively affected.

Similar studies in the literature have evaluated the swallowing-related quality of life of patients with idiopathic Parkinson's disease using scales in which the patients evaluated their swallowing disorder themselves [7-10]. However, studies in which the swallowing disorder of Parkinson's patients was also evaluated by a clinician are limited. Therefore, the GUSS scale, which allows the clinician to evaluate the severity of the patient's swallowing disorder, was included in this study. At the end of the study, a statistically significant negative correlation was found between the GUSS scale and the EAT-10 and DHI scales, and a statistically significant positive correlation was found between the GUSS scale and the T-SWAL-QOL scale. The relationship between the GUSS scale and other scales shows that scales in which the therapist evaluated the patient's swallowing yield similar results and scales in which the patient evaluated his/her own swallowing. In this study, similar to other studies examining the relationship between the GUSS scale and swallowing evaluation scales, significant results were obtained, consistent with the literature [22]. This result shows that including scales in which the patient evaluated himself/herself in the evaluation may be consistent with the clinician's evaluation. It is important for clinicians to have scales that they can use in the clinic to determine whether a patient is at risk for swallowing disorders so that they can evaluate the patient correctly.

Although similar studies are very limited in the literature, Bengisu *et al*. used the EAT-10 scale, which includes self-assessment of swallowing disorders, and the Videofluoroscopic Swallowing Study (VFSS), which is an instrumental swallowing assessment method, but observed inconsistency between the results of the two methods [23]. In our study, scales including the clinician's assessment and scales including the patient's self-assessment gave consistent results. This may Dysphagia may accompany IPD in varying degrees of severity from the early stages of its course. This study shows that screening for swallowing disorders using self-assessment scales or clinical measurement tools yields correlated results and negatively affects quality of life in many ways in proportion to its severity. This suggests that the use of self-assessment scales may also be useful in situations where rapid assessment is required, such as in outpatient clinic settings. However, using this assessment together with a subjective or objective assessment by the clinician will increase the reliability of the result.

A study comparing the results of the self-assessment scales used in this study with the results of an instrumental assessment method may provide more reliable information to the literature about the reliability of self-assessment scales.

Ethical Statement

This study was approved by the İstanbul Medipol University Non-Interventional Clinical Research Ethics Committee (Date: 26.10.2021, Decision No: 1060) and informed written consent was obtained from all participants.

Authors' Contribution

Study Conception: ST, SB, DB; Study Design: ST, SB, DB; Supervision: ST, SB, ZT; Funding: ZT, ENB, HAH; Materials: ZT, ENB, HAH; Data Collection

and/or Processing: DB, END; Statistical Analysis and/or Data Interpretation: ZT, HAH; Literature Review: ST, SB, DB; Manuscript Preparation: ST, SB, DB and Critical Review: ST, SB, DB.

Conflict of interest

The authors disclosed no conflict of interest during the preparation or publication of this manuscript.

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Editor's note

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