EREDETI KÖZLEMÉNY

ORIGINAL ARTICLE

Factors influencing the level of stigma in Parkinson's disease in western Turkey

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Background and purpose – Stigma is a widespread phenomenon in Parkinson's disease (PD) and has been shown to affect the quality of life of individuals. This study aims to assess the level of stigma and identify the factors contributing to stigma in patients with PD in Turkey.
Methods – A total of 142 patients diagnosed with PD between June 2022 and March 2023 were included in the study. Sociodemographic data including age, gender, marital status, education level, and duration of PD were collected using a sociodemographic information form. Motor symptom severity was assessed using the Unified Parkinson's Disease Rating Scale (UPDRS part III). The disease stage was determined using the Hoehn and Yahr scale. Participants were classified as PIGD (postural instability/gait difficulty) or TD (tremor dominant) based on the UPDRS score. Patients with a UPDRS ratio greater than or equal to 1.5 were classified as TD, while subjects with a ratio less than or equal to 1.0 were classified as PIGD. Ratios between 1.0 and 1.5 were classified as mixed type. Depression was assessed using the Hamilton Depression Rating Scale (HAM-D), while stigma was measured using the Chronic Illness Anticipated Stigma Scale (CIASS) and the stigma sub-scale of the 39-item Parkinson's Disease Questionnaire (PDQ-39 stigma sub-scale).
Results – The mean score on the stigma sub-scale of the PDQ-39 was 7.60±4.39, while the mean total stigma score on the CIASS was 1.37±0.39. Our results indicated that stigma was more prevalent among patients with PD with the TD motor subtype, younger age, shorter disease duration, higher level of disability, and presence of depression symptoms.

A Parkinson-kóros betegekkel kapcsolatos stigma szintjét befolyásoló tényezők Nyugat-Törökországban
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Háttér és cél – A Parkinson-kórban (PD) szenvedők gyakran találkoznak előítélettel és szembesülnek stigmatizálással, ami bizonyítottan rontja életminőségüket. E tanulmány célja a stigmatizáltság szintjének felmérése, és a stigmához hozzájáruló tényezők azonosítása törökországi PD-betegek körében.
Módszerek – A vizsgálatba összesen 142, 2022 júniusa és 2023 márciusa között Parkinson-kórral diagnosztizált beteget vontunk be. A szociodemográfiai adatokat, köztük az életkort, a nemet, a családi állapotot, az iskolai végzettséget és a PD időtartamát egy szociodemográfiai adatlap segítségével gyűjtöttük össze. A motoros tünetek súlyosságát a Mozgászavar Társaság-féle Egyesített Parkinson-kór Pontozó Skála (UPDRS III. rész) segítségével értékeltük. A betegség stádiumát a Hoehn–Yahr-skála segítségével határoztuk meg. A résztvevőket az UPDRS-pontszám alapján PIGD (posturalis instabilitás/járási nehézség) vagy TD (tremordomináns) kategóriába soroltuk. Az 1,5-nél nagyobb vagy azzal egyenlő UPDRS-aránnyal rendelkező betegeket TD-nek, míg az 1,0-nél kisebb vagy azzal egyenlő arányúakat PIGD-nek minősítettük. Az 1,0 és 1,5 közötti aránnyal bírókat vegyes típusba soroltuk. A depressziót a Hamilton Depresszió Pontozó Skála (HAM-D), míg a stigmát a Krónikus Betegségekben Anticipált Stigma Skála (CIASS) és a 39 tételes Parkinson-kór Kérdőív stigmaalskálája (PDQ-39 stigmaalskála) segítségével mértük.
Eredmények – A PDQ-39 stigmaalskála átlagos pontszáma 7,60 ± 4,39 volt, míg a CIASS teljes stigmapontszámának átlaga 1,37 ± 0,39 volt. Eredményeink azt mutatják, hogy a stigma gyakoribb a TD motoros altípusú, fiatalabb, rövidebb betegségtartamú, nagyobb fokú fogyatékossággal élő és a depressziós tünetekkel rendelkező PD-betegekkel szemben.

Conclusion – Our study highlights the association between stigma and disease progression, duration, and depressive symptoms in patients with PD in western Turkey.

Következtetés – Tanulmányunk rávilágít a stigmatizáltság és a betegség progressziója, időtartama és a depressziós tünetek közötti összefüggésre a nyugat-törökországi PD-betegek körében.

Keywords: Parkinson's disease, stigma, tremor

Kulcsszavak: Parkinson-kór, stigma, tremor

Parkinson's disease (PD) is the second most common neurodegenerative disease, affecting approximately 1% of people over the age of 60[1]. Although the exact prevalence of PD in Turkey is not known, a study conducted in western Turkey found the prevalence to be 1.2%[2]. While motor symptoms such as tremor, rigidity, bradykinesia, and postural instability are traditionally associated with PD, non-motor symptoms, psychiatric issues, and social problems also contribute to the disability experienced by patients with PD[1].

Stigmatization, characterized by condemnation, humiliation, devaluation, labeling, and social isolation, is a significant factor that negatively affects the quality of life and psychosocial well-being of people with chronic diseases[3]. Stigma strongly influences the social identity of stigmatized individuals[4]. In neuropsychiatric disorders, stigma can lead to avoidance of medical diagnosis, treatment, and support, reduced quality of life, and increased suicide rates[4, 5]. Stigma is a common concept among people with PD and should be carefully considered[6, 7].

Previous studies have shown that more than half of patients with PD attempt to conceal their diagnosis[8]. In addition, highly stigmatized patients with PD may attempt to hide their clinical symptoms. Several factors contribute to the experience of stigma in patients with PD. Among the motor symptoms, the presence of a masked facial symptom affects social interactions and may lead to stigmatization, even by healthcare professionals, similar to the general population[9]. In addition, cardinal symptoms such as tremor, bradykinesia, and gait difficulties, as well as PD-specific difficulties such as medication fluctuations (i.e., motor off periods) and motor complications such as dyskinesia, have important psychosocial consequences such as stigma[7, 9]. Invisible stigma can lead to social isolation among people with PD, which may result in disability[10].

Previous studies have reported a higher incidence of stigma in patients with PD with severe motor symptoms, significant impairment in activities of daily living, younger age, and higher levels of depression[11–13]. However, in addition to clinical manifestations, socio-cultural factors may also influence the stigma experienced by patients with PD. This study aims to assess the level of stigma and the factors influencing stigma among people with PD in western Turkey.

Methods

Ethical approval for this study was obtained from the local ethics committee. Informed consent was obtained from all participants enrolled in the study.

Participants

The study was conducted with 142 patients who were admitted to the neurology department of Kocaeli Acıbadem Hospital with PD between June 2022 and March 2023. Inclusion criteria were as follow: (1) patients with PD according to UK Brain Bank criteria; (2) participants aged ≥ 40 years; (3) patients with Hoehn and Yahr stage 4 and below. Exclusion criteria were: (1) patients with severe physical defects due to another disease; (2) mild, moderate, and severe cognitive problems by cognitive assessment. Cognitive assessment of patients was performed by clinical evaluation and the standardized Mini-Mental State Examination (MMSE) (patients with a cut-off score of 23 or less were considered to have dementia); (3) medication-refractory psychiatric disorders (major depression, psychosis, and mood disorders); (4) age < 40 years (diagnosed as juvenile PD); (5) Hoehn and Yahr stage 5 (bedridden due to PD and unable to participate in the surveys due to speech impairment); and (6) patients who refused to participate in the study.

Patients were evaluated in person, and the sociodemographic form, including age, gender, marital status, education level, and duration of PD, was completed by the same neurologist. The Unified Parkinson's Disease Rating Scale (UPDRS part III) was used to assess motor symptoms of PD[14]. The disease stage was assessed using the Hoehn and Yahr scale. PD motor symptom subtype was calculated as the ratio of mean tremor to mean postural instability/gait difficulty (PIGD) symptoms. UPDRS Part III ratios greater than or equal to 1.5 were classified as tremor-dominant TD, whereas subjects with ratios less than or equal to 1.0 were classified as PIGD. Ratios between 1.0 and 1.5 were classified as mixed type[15].

Depression was assessed with the Hamilton Depression Rating Scale (HAM-D). The HAM-D is a 17-item test that physicians can use to measure the severity of depression. It consists of 17 items about symptoms of depression experienced in the past week. Items related to difficulty falling asleep, waking up in the middle of the night, waking up early in the morning, somatic symptoms, genital symptoms, weakness, and insight are scored on a range of 0-2, and the other items are scored on a range of 0-4. The maximum score is 53[16]. Its Turkish reliability and validity study was conducted by *Akdemir* et al[17].

Stigma was assessed using the Chronic Illness Anticipated Stigma Scale (CIASS) and the Stigma sub-scale of the 39-item Parkinson's Disease Questionnaire (PDQ-39 Stigma sub-scale). The 5-point Likert-type Chronic Illness Anticipated Stigma Scale (CIASS) was developed by *Earnshaw* et al.[3], and its Turkish validation study was conducted by *Tunerir* et al. in 2019[18]. The scale consists of 3 sub-scales, including expected stigma from family and friends, colleagues, and healthcare professionals. The first 4 items of the scale aim to measure expected stigma from family and friends, the other 4 items aim to measure expected stigma from people at work, and the last 4 items aim to measure expected stigma from healthcare professionals. Each item is scored on a 5-point Likert scale.

The Parkinson's Disease Questionnaire is a 39-item scale for assessing the quality of life in PD. Each item is scored from 0 to 4. Items 23-26 are used to assess stigma and are defined as the PDQ-39 Stigma sub-scale. The PDQ-39 stigma sub-scale is assessed with the following items: 23: Do you feel that you have to hide your PD from people? 24: Have you avoided situations where you have to eat or drink outside your home where others are present? 25: Have you felt embarrassed in public because of your PD? 26: Have you worried about other people's reactions to you? Participants responded as (0: never, 4: always) and scores ranged from 0-16[19]. The Turkish validity study of this scale was conducted in 2018 by *Kayapınar* et al.[20].

All raters were trained before the start of the study. The inter-rater concordance of all ratings was greater than 0.8.

Statistical analysis

The SPSS 21.0 program was used for the statistical analysis of the results obtained in the study. The normality of the distribution was tested using the Kolmogorov-Smirnov test to determine the tests used in comparisons. Since the data were not normally distributed, non-parametric tests were used. Descriptive statistics, Cronbach's alpha coefficient, and Spearman correlation analysis were used to evaluate the research data. SPSS was used to evaluate the results with a 95% confidence interval, and $p<0.05$ was accepted as statistically significant.

Table 1. *General characteristics of patients with PD*

Variables	*Mean*±SD.
Age	62.98±10.45
Duration of illness (years)	5.03±1.72
The stigma dimension PDQ-39	7.60±4.39
CIASS Family Relations Stigma	1.18±.28
CIASS Work Life Stigma	2.02±.28
CIASS Healthcare Professionals Stigma	1.01±.08
CIASS Total Stigma	1.37±.39
Hoehn and Yahr	1.78±.65
UPDRS part III	36.17±14.92
HAM-D	12.88±7.65
Gender	*n (%)*
Male	57 (40.1)
Female	85 (59.9)
PD Motor Subtypes	*n (%)*
TD	54 (38)
PIGD	52 (36.6)
Mixed-Type	36 (25.4)

Results

Table 1 shows that the mean age of the participants was 62.98±10.45 years, the mean disease duration was 5.03±1.72 years, 40.1% were male and 59.9% were female. The mean Hoehn and Yahr score was 1.78±0.65, the mean UPDRS part III score was 36.17±14.92, and the mean HAM-D score was 12.88±7.65. It was found that 38.0% of the patients had TD, 36.6% had PIGD, and 25.4% had mixed-type PD.

Among the stigma scales, the mean PDQ-39 Stigma sub-scale score was 7.60±4.39, the mean CIASS Family Relations Stigma score was 1.18±0.28, the mean CIASS Work Life Stigma score was 2.02±0.96, the mean CIASS Healthcare Professionals Stigma score was 1.01±0.08, and the mean CIASS Total Stigma score was 1.37±0.39.

According to the results of Spearman correlation analysis, PDQ-39 Stigma sub-scale scores were positively correlated with Hoehn and Yahr at a low level ($r=0.191$, $p=0.023$) and positively correlated with CIASS Total Stigma and HAM-D at a high level ($r=0.957$, $p=0.000$). Highly significant negative correlations were found between age and PDQ-39 Stigma sub-scale ($r=-0.700$, $p=0.000$), CIASS Work Life Stigma ($r=-0.749$, $p=0.000$), and CIASS Total Stigma ($r=-0.734$, $p=0.000$), and moderate negative correlations were found with CIASS Family Relations Stigma ($r=-0.465$, $p=0.000$). Moderately significant negative correlations were found between disease duration and the PDQ-39 Stigma sub-scale ($r=-0.644$, $p=0.000$), CIASS Family Relations Stigma ($r=-$

Table 2. *Regression analysis results for predicting the stigma dimension PDQ-39 scores*

Model	B	Std. Error	β	t	R	R^2_{ad}	F
Constant	26.153	1.619	–	16.149	.70	.49	134.848
Age	–.295	.025	–.700	–11.612			
Constant	15.870	.876	–	18.111	.64	.41	99.472
Duration of Illness	–1.645	.165	–.644	-9.974			
Constant	5.303	1.060	–	5.004	.19	.03	5.318
Hoehn and Yahr	1.291	.560	.191	2.306			
Constant	.518	.212	–	2.450	.96	.92	1511.005
HAM-D	.550	.014	.957	38.872			

0.430, p=0.000), CIASS Work Life Stigma (r=-0.663, p=0.000), and CIASS Total Stigma (r=-0.643, p=0.000).

As a result of the simple linear regression analyses conducted to predict PDQ-39 Stigma sub-scale scores (shown in **Table 2**), it was observed that there is a decrease in PDQ-39 Stigma sub-scale scores with increasing age and disease duration and an increase in PDQ-39 Stigma sub-scale scores with increasing Hoehn and Yahr and HAM-D scores.

As a result of the simple linear regression analyses conducted to predict CIASS stigma scores, it was observed that there is a decrease in CIASS stigma scores as age and disease duration increase and an increase in CIASS stigma scores as HAM-D scores increase **(Table 3)**.

When the results of the "one-way analysis of variance (ANOVA)" were analyzed, it was found that there was a statistically significant difference in PDQ-39 Stigma (F=7.183, p=0. 001), CIASS Family Relations Stigma (F=5.551, p=0.005), CIASS Work Life Stigma (F=6.529, p=0.002), and CIASS Total Stigma (F=6.776, p=0.002) scores according to the subgroups of PD motor findings **(Table 4)**. According to the post hoc (Scheffe) results performed to determine the origin of the difference, the mean scores of the patients with TD were found to be significantly higher than those of the PIGD and mixed-type patients in all variables in which there was a difference.

Discussion

The present study revealed a higher prevalence of stigma among patients with the PD-TD motor subtype, younger age, shorter disease duration, greater disability, and the presence of depression. These findings suggest that effective management of motor symptoms, particularly tremor, and treatment of psychiatric issues, such as depression, could potentially reduce stigma.

Our study found a positive correlation between stigma scale scores and Hoehn and Yahr scores, indicating that stigma levels increase with greater disability as measured by the Hoehn and Yahr scale. However, in contrast to previous research, no significant correlation was found between UPDRS Part III parameters and stigma scores. We propose that this discrepancy may be due to the fact that stigma is influenced by the level of disability as assessed by the Hoehn and Yahr scale, whereas the UPDRS Part III assesses different motor symptoms that may vary depending on different cultural factors. When considering only the TD and PIGD scores, we found positive correlations between these scores and levels of stigma. However, when we conducted more in-depth analyses, it became clear that the TD score had a more pronounced influence on the level of stigma.

In this study, we found a positive correlation between

Table 3. *Regression analysis results for the prediction of CIASS stigma scores*

Model	B	Std. Error	β	t	R	R^2_{ad}	F
Constant	3.084	.136	–	22.724	.73	.54	163.068
Age	–.027	.002	–.734	–12.770			
Constant	2.101	.077	–	27.210	.64	.41	98.876
Duration of Illness	–.145	.015	–.643	–9.944			
Constant	.816	.033	–	24.808	.86	.73	389.869
HAM-D	.043	.002	.858	19.745			

Table 4. *Comparison results of stigma scales according to PD motor subtypes*

	Parkinson's	n	X	SD	F	p	Difference
The stigma dimension PDQ-39	TD[a]	54	9.30	4.25	7.183	.001	a>b,c
	PIGD[b]	52	6.73	4.21			
	Mixed-type[c]	36	6.31	4.17			
CIASS Family Relations Stigma	TD[a]	54	1.27	.35	5.551	.005	a>b
	PIGD[b]	52	1.10	.21			
	Mixed-type[c]	36	1.13	.24			
CIASS Work Life Stigma	TD[a]	54	2.38	1.00	6.529	.002	a>b,c
	PIGD[b]	52	1.78	.90			
	Mixed-type[c]	36	1.82	.87			
CIASS Healthcare Professionals Stigma	TD[a]	54	1.00	.00	.864	.424	
	PIGD[b]	52	1.02	.14			
	Mixed-type[c]	36	1.00	.00			
CIASS Total Stigma	TD[a]	54	1.52	.42	6.776	.002	a>b,c
	PIGD[b]	52	1.28	.34			
	Mixed-type[c]	36	1.29	.33			

the Hoehn and Yahr score and stigma levels. However, we also found that stigma levels increased as disease duration decreased. We hypothesize that this phenomenon may be due to the lack of a consistent correlation between disease duration and the Hoehn and Yahr score. It is possible that as disease duration increases, the propensity to accept and adapt to the condition increases, in contrast to the early stages. At the same time, the stigma levels observed in younger individuals may be due to the shorter disease duration.

PD-specific motor subscores may have a direct and significant impact on stigma. Resting tremor, bradykinesia, and postural and gait disturbances attract public attention, lead to changes in body image, and evoke in patients feelings of shame, embarrassment, and isolation[21, 22].

In addition, *Hermanns* et al. reported that the masked face symptom, which results in impaired speech and difficulty with nonverbal communication in participants with PD, leads to social isolation and stigma[9]. Another multicenter study conducted in the USA and Taiwan reported that the masked face symptom caused prejudice against patients with PD even among healthcare professionals, but this prejudice was more prevalent in the USA than in Taiwan due to cultural factors[10]. In our study, similar to the study conducted in China[13], tremor in particular was found to be important in the stigmatization of patients. In the Chinese study, when the authors interviewed patients with Parkinson's disease, they found that patients increased the doses of the medications they used to stop tremors and that the reason of their desire to stop tremors was to break other people's prejudices against them. In addition, we suggest that the higher stigma scores observed in PD patients with TD compared to PD patients with PIGD may be due to the inability of patients to reduce their tremors. In contrast, PIGD patients may be adept at concealing their symptoms (e.g., by adopting a seated position during periods of increased stability and gait difficulties), resulting in lower stigma. Nonetheless, postural instability/gait difficulties can potentially lead to an increased risk of falls and traumatic injuries, which indirectly contribute to stigma. In our study, both stigma scale scores increased in parallel with Hoehn and Yahr scores. Conversely, no positive correlation was found between UPDRS Part III scores and stigma scores, which differs from findings in other studies. We hypothesize that this discrepancy is due to the increase in stigma relative to PD-related disability as quantified by the Hoehn and Yahr scale. On the contrary, the UPDRS Part III parameters encompass a variety of motor manifestations, and their diversity varies according to cultural factors.

Depression causes social withdrawal in addition to motor symptoms such as tremors, gait disturbances, and falls in patients with PD. Depressed patients experience more shame, hopelessness, and anxiety due to PD, which directly and indirectly increases perceived stigma in patients[11–13]. *Salazar* et al. reported that depression was an important predictor of stigma in patients with PD, and the level of depression significantly affected stigma and activities of daily living[11]. Another study conducted in China reported that the level of stigma score increased with

increasing HAM-D score in patients with PD[13]. A study conducted in the United Kingdom reported that about half of patients with PD retired early within 5 years of disease onset, causing economic crisis and psychological pressure[23]. Consistent with the literature, our study found that the level of stigma increased as the level of depression increased and that the level of depression was a predictor of stigma in patients with PD. The change in social roles and social interactions in patients with PD may affect the quality of life and psychology of these patients and their families[24]. Moreover, as stigma is a very important socio-cultural factor, it is important to recognize the social significance of PD and PD-related symptoms, and for this reason, we anticipate that targeted treatment of depression in patients with PD is important to reduce stigma.

Our study found a positive association between younger age and increased stigma among people with PD. The experience of being diagnosed with a neurodegenerative disease at a relatively young age may be qualitatively different from that of being diagnosed at an older age, as it may significantly affect one's familial, social, and occupational self-perceptions and expectations[25, 26]. In addition, the uncertainty surrounding the ability to slow or halt the progression of PD in younger individuals may contribute to psychological distress, while the prolonged duration of the disease may impose limitations on social and daily activities, potentially leading to social isolation[27].

Several limitations of this study should be acknowledged. First, the cross-sectional nature of the study design precludes the establishment of causal relationships between the independent variables and outcomes. Second, the assessment of the quality of life was limited to the stigma-related items of the PDQ scale and did not include a comprehensive assessment of the overall quality of life. Third, the study did not investigate other social determinants such as income, education, and occupation. Finally, the sample size was limited to a single hospital and did not include severely affected patients, which limits the generalizability of the findings.

In conclusion, this study assessed levels of stigma against Parkinson's patients with different motor subtypes and at different stages of the disease. Our study showed that stigma is associated with disease progression, disease duration, and depression in patients with PD in western Turkey. We anticipate that the implementation of multiple approaches will reduce stigma and improve the quality of life of people with PD as a result of studies that evaluate the effects of different predictors with more centers, more patients, and participants from different regions.

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CONFLICT OF INTEREST STATEMENT – There are no conflicts of interest.

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