



Research article

Is PDQ-39 a reliable measure of quality of life of patients at advanced stages of Parkinson's disease considered for Deep Brain Stimulation

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ABSTRACT

Purpose: Parkinson's disease (PD) significantly impedes, especially at its advanced stages, the health-related quality of life (QoL) of patients. The Parkinson's disease questionnaire (PDQ-39) is a widely-used measure assessing the impact of the disease on the patients' QoL. To date, the reliability of PDQ-39 has not been selectively evaluated for patients at a particular delineated stage of the PD progression. Against this backdrop, the study aimed firstly to evaluate comprehensively the internal consistency reliability of PDQ-39 and the constituent scales specifically for patients at the advanced stages of PD who were candidates for Deep Brain Stimulation (DBS) surgery, and secondly, to compare the Cronbach's alpha coefficients with those reported in other studies conducted with patients across all stages of the PD progression.

Methods: The sample included 36 Bulgarian patients (29 men and 7 women) at advanced stages of PD (Hoehn and Yahr stage 4), PD duration, $M = 11.06$, $SD = 3.50$). The internal consistency reliability of the questionnaire and the constituent scales was assessed using three criteria: Cronbach's alpha coefficients, inter-item and item-total correlations.

Results: The internal consistency reliability indicators were satisfactory for the entire instrument and for most of the scales and similar to those reported in previous studies. None of the scales had low internal consistency reliability results across the three criteria. Except for the Communication scale, seven of the eight scales had Cronbach's alpha values that were satisfactory or marginally below the cut off score. All scales had acceptable inter-item correlations. Three of the scales (Emotional Well-Being, Cognition and Communication) contained more than one item with non-satisfactory item-total correlations. With minor exceptions, the removal of the items with low item-total correlations either did not improve or improved marginally or even decreased the Cronbach's alpha coefficients of the respective scale. The Communication scale was the only scale with a Cronbach's alpha coefficient that was both low and comparatively different to other studies and had as well low item-total correlations for all constituent items, thus showing non-satisfactory results on two of the three internal consistency reliability estimates. In contrast, the Mobility scale met all three internal consistency reliability criteria.

Conclusion: PDQ-39 is a reliable tool for assessing the QoL of patients at advanced stages of PD across multiple health-related domains. The questionnaire can be recommended for inclusion in

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1. Introduction

1.1. Parkinson's disease

Parkinson's disease (PD) is the second most common neurodegenerative disorder after Alzheimer's disease and is characterized by a range of motor and non-motor symptoms that progressively increase over time and greatly affect a person's quality of life (QoL) [1, 2]. PD prevalence worldwide is estimated to be about 1 % in people after 60 years of age, and about 3 % after 80 years of age [3]. Approximately 10 % of them are in the advanced stage [4], during which the debilitating impact of the disease is most pronounced.

The concept of health-related QoL emphasizes individual experiences of patients in relation to their clinical symptoms, physical and social functioning, role performance, and emotional well-being [5]. As a progressive degenerative disorder PD has a significant debilitating impact on the mobility, activities of daily living, physical, social and emotional well-being of patients. Common motor symptoms include resting tremor, rigidity, loss of postural stability, bradykinesia (slowness of movement), akinesia [1,6], which affect physical mobility and influence patients' every-day personal and professional life. Stiffness, shuffling gait, and loss of dexterity are frequently experienced by patients as embarrassing in social situations. Speech disturbances (e.g., difficulties talking or monotonous speech) and impassive facial expression could cause communication difficulties and could lead to self-isolation [5]. The non-motor symptoms encompass an array of cognitive impairments along with emotional and behavioural dysregulation. Depression, anxiety, apathy, fatigue, and in some instances hallucinations and psychosis are also integral features of the disease. Autonomic dysfunction like excessive sweating, urine incontinence, constipation, and bodily discomfort (e.g., stiffness, pain, headaches) may pose additional psychological burden on the daily living and QoL of people with PD [6,7].

1.2. Advanced stages of Parkinson's disease

Clinical progression of PD is typically assessed on the 5-stage Hoehn and Yahr (H&Y) scale [8] according to which stages 3 and 4 are considered middle to advanced, respectively. Mild to moderate disability occurs in stage 3, typically manifested following a 7-year median duration of PD. Severe disability takes place in stage 4, emerging after around a 9-year median duration of PD [8]. The time period for a patient to enter into the advanced stage varies substantially depending on individual characteristics of disease progression and the patient's age, but typically it is more than 10 years since clinical onset [9,10]. Though widely used [11–17], the limitations of the H&Y scale, particularly for determining patients' eligibility for device-aided therapies, have been addressed and a more comprehensive assessment paradigm for disease progression was outlined within the Delphi-panel approach [18]. The key criteria adopted in the present study for determining patients' advanced PD (APD) were in accordance with this approach and compliant with the recommendations stipulated in the National Consensus on the Diagnostics and Treatment of PD in Bulgaria [19], informed by this approach.

With the advancement of the neurodegenerative processes, motor, as well as cognitive, and emotional functions gradually decline causing increased dependence, loss of employment, and communication difficulties. In advanced stages, some somatic manifestations of depression including psychomotor retardation, altered appetite and weight, and sleep disturbances can also be present. The exacerbation of motor and non-motor symptoms lead to further social isolation and embarrassment, emotional issues, reactive depression, frustration, apathy, anxiety [11], all of which have a significant debilitating effect and considerably worsen the patients' QoL. To date, the impact of non-motor symptoms, including cognitive impairment [20–24] and depression [25–27] has been specifically highlighted. As shown by Rahman et al. [7] in their evaluation of the relative contribution of motor, cognitive, psychiatric, and PD medication-related symptoms, depression, anxiety, disability, difficulty in turning, and shuffling gate together accounted for 78.9 % of the variance in the QoL of the participants ($n = 38$ in H&Y stage 4 or 5 and a mean duration of PD = 9.28 years, SD = 6.48). Given that the progressive increase in medication may become ineffective for symptom alleviation and/or produce aggravating side effects [4], device-aided therapies like Deep Brain Stimulation (DBS) can be beneficial to patients who have transitioned to the advanced stages of the disease.

1.3. Deep Brain Stimulation (DBS)

DBS surgery can provide significant long-term alleviation of motor symptomatology, thus greatly improving the QoL of patients with PD, and is reportedly the most effective treatment at advanced stages of PD [4]. The success of DBS treatment is based on the careful selection of the candidates in compliance with the criteria for APD [18] and the guidelines stipulated in the Core Assessment Program for Surgical Interventional Therapies in Parkinson's disease (CAPSIT-PD) [12], taking into account the accumulated experience in the field [4]. In addition, the thorough evaluation of which particular areas of a patient's life are most compromised by PD is deemed relevant for selecting the optimal individual treatment and is frequently included in the protocol for clinical assessment of candidates for DBS treatment [4,12].

1.4. Parkinson's disease questionnaire - PDQ-39

The Parkinson's disease questionnaire (PDQ-39) is a widely used self-report questionnaire designed to measure the disease-specific QoL of patients with PD from their own perspective. The instrument was originally designed and validated in the UK in 1995 [16] and a total score/summary index (SI) was introduced in a follow up study by Jenkinson et al. [17]. The initial development and validation of the questionnaire [16] was done in three stages whereby the mean duration of PD of the patients participating in Stage 2 of the study was 9.4 years, and the mean duration of PD of the patients in Stage 3 was 8.6 years.

Since its introduction PDQ-39 has consistently shown good test-retest reliability, internal consistency, content and construct validity. Over the years the instrument has been translated into many languages, validated and widely used in different countries and cultures [13], including Bulgaria [14]. In some of the psychometric evaluations, for instance, with samples in China [28], Japan [29], South Korea [2], Spain [29,30], and the US [29,31], the reliability estimates for the Social Support scale were non-satisfactory, thus informing the suggestion that this scale might be the least reliable within PDQ-39 [29]. Among the limitations of the extant studies is that the samples included patients who were at different stages (early, middle, and advanced) of the PD progression and were unequally spread across these stages, with a relatively small proportion falling into the advanced stages. In one of the pioneering validations [17], only 20 of the 127 participants were in H&Y stage 3, and 18 – in stage 4 and 5 combined. In later studies [32–34], including the Bulgarian studies, the sample distributions were similar. For instance, 28 (70 %) of the 40 participants in Todorova et al. study [14] were at H&Y stage 1 or 2 and just 12 participants (30 %) were at stage 3 or 4. In a subsequent, larger-scale Bulgarian study ($n = 866$), the participants were also spread across different H&Y stages, with the majority of them being at stage 3 [35].

The psychometric properties of rating scales depend to a great extent on the context of their application and sample characteristics, and PDQ-39 was not originally developed for use with a particular subgroup of patients with PD [36]. Furthermore, as the patients' QoL changes greatly with the progression of PD, it would be appropriate to ascertain the psychometric soundness, and particularly the internal consistency reliability of the instrument, separately for patients who are either at early, middle, or advanced stages of PD. A methodologically strong approach, which the present study adopted for addressing these considerations, entails the application of multiple, exhaustive, and complementary psychometric criteria outlined below.

1.5. Aims

The aim of the present study was two-fold: firstly, to evaluate comprehensively the internal consistency reliability of PDQ-39 (Bulgarian translation) and the constituent scales specifically for patients at the advanced stages of PD who were candidates for DBS surgery, and secondly, to compare the Cronbach's alpha coefficients with those reported in other studies conducted with patients across all stages of the PD progression.

2. Participants

The participants in the study ($N = 36$; 29 men and 7 women) were patients at the University Multiprofile Hospital for Active Treatment UMBAL "St. Ivan Rilski", Sofia, Bulgaria, who had prior diagnosis of idiopathic PD and were candidates for DBS surgery. The disease progression of all participants was compliant with the criteria for APD, and compatible with H&Y stage 4. Twenty-nine candidates proceeded with the clinical evaluations for DBS and twenty-three patients (63.89 %) of the total sample ($N = 36$) underwent implantation.

3. Materials and methods

3.1. Materials

All participants completed PDQ-39 (Bulgarian translation) [14] as part of the neuropsychological assessment included in the standard procedure for evaluating the patients' candidacy for DBS surgery. The instrument consists of 39 items divided into eight scales that measure different health-related areas of life affected by PD to a various degree. The eight scales are: Mobility (10 items), Activities of Daily Living (6 items), Emotional Well-Being (6 items), Stigma (4 items), Social Support (3 items), Cognition (4 items), Communication (3 items), and Bodily Discomfort (3 items). Responses to questions are based on each person's individual experiences within the last month and are marked on a 5-point Likert scale (0 = never; 1 = occasionally; 2 = sometimes; 3 = often; 4 = always). The SI shows the overall impact of PD on a person's QoL. Higher scale or SI scores reflect greater impact of PD on the respective area of life or on the overall life experience. The data were collected in the period mid-2020 to mid-2022 with consecutive patients who had provided written informed consent upon their admission at the hospital.

3.2. Methodological considerations: criteria for internal consistency reliability of a scale

Internal consistency reliability of a psychometric scale refers to the degree to which the items are intercorrelated [37]. The most common criteria of internal consistency reliability applied across various investigations of PDQ-39 [16,28,31,32,38,39] are Cronbach's alpha coefficient, inter-item correlation, and item-total correlations. Cronbach's alpha coefficient above 0.70 is traditionally considered an indicator for good internal consistency [40] and for short scales with less than ten items, a value above 0.50 is deemed acceptable [41]. The eight scales of the PDQ-39 have consistently met these criteria, with the Cronbach's alpha coefficients found to

have ranged between 0.66 and 0.95 [16].

Since Cronbach's alpha value can be increased by merely adding more items to a scale, the inter-item correlation is considered a comparatively better indicator of internal consistency reliability [37] and should therefore be reported as well. The optimal mean inter-item correlation is recommended to be between 0.15 and 0.20 for broader constructs and within the range of 0.40–0.50 for narrower constructs [37]. Considering that the PDQ-39 scales tap both narrower and broader constructs, inter-item correlations ranging between 0.15 and 0.50 would be acceptable and would reflect the complexity of the constructs while not restricting them to too specific constituents.

Item-total correlation is another important criterion of internal consistency reliability. It refers to the correlation between an item score and the total scale score and shows if an item within a questionnaire scale measures the same construct as other items in that scale. Item-total correlation coefficient above 0.40 is considered good [42]. If it is less than 0.40, that particular item might measure a different construct and a Cronbach's alpha rerun without it should determine whether its removal results in an improvement of the Cronbach's alpha coefficient. Negative item-total correlations might indicate inconsistency of an item with others in the same scale or that it does not measure the same construct [43].

3.3. Statistical analyses

The internal consistency reliability of PDQ-39 was assessed using Cronbach's alpha coefficients of the SI and the scales, as well as the mean inter-item correlations and Spearman's rank item-total correlations for each of the scales. The Cronbach's alpha coefficients for the SI and for the eight scales were compared with those reported in the initial UK psychometric evaluation (PDQ-39-UK-1995) by Peto et al. [16,44] and in the Bulgarian validation (PDQ-39-BG-2005) by Todorova et al. [14]. Detailed item-total correlation data are reported in few studies. Among these are the initial UK study (PDQ-39-UK-1995) by Peto et al. [16], and the subsequent investigation in the US (PDQ-39-US-1999) by Bushnell and Martin [31], both with participants in a postal survey. These two studies were referred to for comparatively analyzing the item-total correlations obtained in the present investigation. The comparative analyses were conducted using the Cocron software package, version 1.0–1 [45]. All other statistical analyses were performed using SPSS, version 26.0 for Windows.

4. Results

4.1. Cronbach's alpha coefficients

The Cronbach's alpha coefficients for the overall questionnaire and for each of the eight scales are presented in Table 2 below.

Comparative figures refer to the UK study (PDQ-39-UK-1995) by Peto et al. [16,44], $N = 227$; and to the Bulgarian study (PDQ-39-BG-2005) by Todorova et al. [14], $N = 40$.

The Cronbach's alpha coefficient of the entire questionnaire was excellent ($\alpha = 0.90$) and on a par with the values reported in both the initial psychometric evaluation ($\alpha = 0.84$) in the UK [44], and in the subsequent psychometric evaluation ($\alpha = 0.82$) in Bulgaria [14]. The Cronbach's alpha coefficients for the Mobility, Activities of Daily Living, Emotional Well-Being, and Stigma scales were also excellent, ranging from 0.91 to 0.71. As seen in Table 2, even though the Cronbach's alpha coefficients for these four scales were significantly lower in comparison with the values in the PDQ-39-UK-1995 study, there was no statistically significant difference when compared with the Bulgarian study (PDQ-39-BG-2005) [14], except for the Emotional Well-Being scale, for which the Cronbach's alpha coefficient, though acceptable ($\alpha = 0.71$), was significantly lower in comparison to both the UK and the Bulgarian studies.

With the exception of the Communication scale, the Cronbach's alpha values for the rest of the scales (Social Support, Cognition, and Bodily Discomfort) were marginally below the acceptable level of 0.70 (ranging from 0.60 to 0.68) and were not significantly different from those generated in the UK and Bulgarian comparison studies (refer to Table 2). The Communication scale showed a Cronbach's alpha coefficient of just 0.39, which was not satisfactory with reference to the criterion suggested in previous research, of at least 0.50 for short scales [41] and was also significantly lower than the values in the PDQ-39-UK-1995 ($\alpha = 0.76$) and the PDQ-39-BG-2005 ($\alpha = 0.83$) studies.

Table 1
Demographic and clinical characteristics of the participants.

	N	Range	Min	Max	Mean	SD
Age	36	31.75	45.41	77.16	64.36	8.43
Education	36	13.0	8.0	21.0	13.78	3.21
PD duration	36	13	5	18	11.06	3.50
MMSE total	36	14	16	30	26.72	3.13
MDS-UPDRS III OFF	29	68	20	88	53.41	15.68
PDQ-SI	36	58.96	8.96	67.92	40.58	12.86

The patients' demographic and clinical characteristics (see Table 1) were similar to those reported in previous studies conducted with samples of patients at advanced stages of PD, in terms of age ($M = 66.2$, $SD = 8.8$ [15]) education ($M = 13.2$, $SD = 2.2$ [46]), PD duration ($M = 11.9$, $SD = 5.1$ [46]), MMSE ($M = 26.8$, $SD = 2.5$ [47]), MDS-UPDRS ($M = 48.4$, $SD = 14.3$ [48]), and PDQ-SI scores ($M = 39.6$, $SD = 17.5$ [7]).

Table 2

Cronbach's alpha coefficients for PDQ-39 (SI) and for the constituent scales obtained in the present study (PDQ-39-BG-2022), in the UK validation study (PDQ-39-UK-1995), and in the Bulgarian validation study (PDQ-39-BG-2005).

PDQ-39 scales	Number of Items	Cronbach's α Coefficients		
		PDQ-39-BG-2022	PDQ-39-UK-1995	PDQ-39-BG-2005
Mobility	10	0.91	0.95 ^a	0.95
Activities of Daily Living	6	0.81	0.90 ^a	0.90
Emotional Well-Being	6	0.71	0.88 ^b	0.90 ^b
Stigma	4	0.73	0.86 ^a	0.83
Social Support	3	0.63	0.66	0.69
Cognition	4	0.60	0.74	0.75
Communication	3	0.39	0.76 ^b	0.83 ^b
Bodily Discomfort	3	0.68	0.72	0.72
All items (SI)	39	0.90	0.84	0.82

Note.

^a $p \leq .05$.

^b $p \leq .01$.

4.2. Mean inter-item correlations

The mean inter-item correlations for all eight scales were all within the optimal range of 0.15–0.50 (see Table 3 below).

4.3. Item-total correlations

Table 4 below includes the Cronbach's alpha coefficients resulting from the deletion of an item, as well as the item-total correlations obtained in the present study and in the comparison studies.

As shown in Table 4, no negative values were obtained for any of the scales suggesting that the items within each scale were consistent with each other. The item-total correlations were all good within the Mobility and the Bodily Discomfort scales, ranging between 0.84 and 0.43. For the other six scales either one or more items had item-total correlations below the acceptable level of 0.40 indicating that those items might have a weaker relevance to the construct underlying the respective scale. The items with low item-total correlation were: item 14 (“problems writing clearly”) in the Activities of Daily Living scale; item 18 (“felt isolated and lonely”), item 20 (“felt angry or bitter”) and item 22 (“felt worried about the future”) in the Emotional Well-Being scale; item 24 (“avoided eating or drinking in public”) in the Stigma scale; and item 28 (receiving “support from spouse or partner”) in the Social Support scale. Importantly, all items in the Communication scale and three of the four items in the Cognition scale (item 30 “fallen asleep during day”, item 32 “felt your memory was bad”, and item 33 experiencing “distressing dreams or hallucinations”) had non-satisfactory item-total correlations. The items with the lowest item-total correlations were item 36 (“felt ignored by people”) in the Communication scale ($\rho = 0.12$) and item 20 (“felt angry or bitter”) in the Emotional Well-Being scale ($\rho = 0.15$).

The re-run of the Cronbach alpha coefficients without the items with low item-total correlations ($\rho < 0.40$) indicated that a substantial improvement was achieved with reference to four items only. These were: item 14 (“problems writing clearly”) in the Activities of Daily Living scale (increased from $\alpha = 0.81$ to $\alpha = 0.85$); item 20 (“felt angry or bitter”) in the Emotional Well-Being scale (increased from $\alpha = 0.71$ to $\alpha = 0.74$); item 24 (“avoided eating or drinking in public”) in the Stigma scale (increased from $\alpha = 0.73$ to $\alpha = 0.77$); and item 36 (“felt ignored by people”) in the Communication scale (increased the most, from $\alpha = 0.39$ to $\alpha = 0.50$). The removal of the other items with item-total correlations less than 0.40, either did not result in any change (items 22, 33); or resulted in a marginal increase of not more than 0.02 (item 28); or led to a decrease of the Cronbach's alpha coefficient of the respective scale (items 18, 30, 32, 34, 35). Thus, removing items might be tentatively considered only for items: 14, 20, 24, and 36.

4.4. Summary of the results

Table 5 below contains a summary of the results for the three internal consistency reliability criteria.

As seen in Table 5 above, none of the scales had low internal consistency reliability results across the three criteria. Except for the

Table 3
Mean inter-item correlations obtained in the present study (PDQ-39-BG-2022).

PDQ-39 scales	Mean inter-item correlation
Mobility	0.49
Activities of Daily Living	0.41
Emotional Well-Being	0.30
Stigma	0.41
Social support	0.36
Cognition	0.27
Communication	0.18
Bodily discomfort	0.42

Table 4

Cronbach's alpha coefficients for PDQ-39-BG-2022 and item-total correlations for PDQ-39-BG-2022, PDQ-39-UK-1995 and PDQ-39-US-1999.

		Cronbach's α if item deleted			
		Item-Total Correlation Coefficients (ρ -values)			
PDQ-39 Scales' items		PDQ-39-BG-2022	PDQ-39-BG-2022	PDQ-39-UK-1995	PDQ-39-US-1999
Mobility ($\alpha = 0.91$)					
1.	difficulty doing leisure activities	0.91	0.47	0.75	0.74
2.	difficulty looking after your home	0.90	0.62	0.80	0.86
3.	difficulty carrying shopping bags	0.90	0.67	0.82	0.88
4.	difficulty walking half a mile	0.89	0.78	0.85	0.75
5.	difficulty walking 100 yards	0.90	0.56	0.84	0.88
6.	difficulty getting around the house	0.90	0.71	0.85	0.88
7.	difficulty getting around in public places	0.89	0.84	0.88	0.92
8.	needed to be accompanied when out	0.89	0.73	0.82	0.79
9.	frightened or worried about falling in public	0.90	0.63	0.72	0.77
10.	confined to the house more than liked	0.90	0.67	0.81	0.76
Activities of Daily Living ($\alpha = 0.81$)					
11.	difficulty washing yourself	0.76	0.67	0.84	0.72
12.	difficulty dressing yourself	0.76	0.69	0.87	0.77
13.	problems doing up buttons or laces	0.75	0.71	0.84	0.81
14.	problems writing clearly	0.85	0.22	0.67	0.63
15.	difficulty cutting up food	0.77	0.60	0.84	0.75
16.	difficulty holding a drink	0.79	0.54	0.72	0.58
Emotional Well-Being ($\alpha = 0.71$)					
17.	felt depressed	0.60	0.63	0.78	0.84
18.	felt isolated and lonely	0.70	0.37	0.74	0.84
19.	felt weepy or tearful	0.61	0.63	0.71	0.68
20.	felt angry or bitter	0.74	0.15	0.73	0.71
21.	felt anxious	0.62	0.63	0.75	0.72
22.	felt worried about the future	0.71	0.32	0.73	0.65
Stigma ($\alpha = 0.73$)					
23.	felt you had to conceal PD	0.67	0.54	0.70	0.63
24.	avoided eating or drinking in public	0.77	0.33	0.77	0.59
25.	felt embarrassed about having PD	0.59	0.66	0.88	0.79
26.	felt worried about others' reactions to you	0.64	0.61	0.82	0.82
Social Support ($\alpha = 0.63$)					
27.	problems with close relationships	0.34	0.56	0.79	0.16
28.	support from spouse or partner	0.65	0.35	0.79	0.41
29.	support from friends or family	0.53	0.44	0.79	0.42
Cognition ($\alpha = 0.60$)					
30.	fallen asleep during day	0.55	0.37	0.73	0.64
31.	problems with concentration	0.37	0.58	0.80	0.69
32.	felt your memory was bad	0.58	0.32	0.68	0.62
33.	distressing dreams or hallucinations	0.60	0.29	0.69	0.55
Communication ($\alpha = 0.39$)					
34.	difficulty with speech	0.27	0.25	0.87	0.74
35.	unable to communicate properly	0.10	0.34	0.91	0.76
36.	felt ignored by people	0.50	0.12	0.73	0.52
Bodily Discomfort ($\alpha = 0.68$)					
37.	muscle cramps or spasms	0.61	0.48	0.85	0.57
38.	aches and pains	0.47	0.58	0.85	0.70
39.	felt unpleasantly hot or cold	0.67	0.43	0.75	0.42

Note.

The comparative data refer to the UK study (PDQ-39-UK-1995) by Peto et al. [16], $N = 359$; the US study (PDQ-39-US-1999) by Bushnell and Martin [31], $N = 75$; and the current study (PDQ-29-BG-2022), $N = 36$.

Communication scale, seven of the eight scales had Cronbach's alpha values that were satisfactory or marginally below the cut off score. All scales had acceptable inter-item correlations. Three of the scales (Emotional Well-Being, Cognition and Communication) contained more than one item with non-satisfactory item-total correlations. The Communication scale manifested non-satisfactory results on two of the three internal consistency reliability estimates (Cronbach's alpha and item-total correlation). In contrast, the Mobility scale met all three internal consistency reliability criteria.

5. Discussion

The first aim of the present study was to evaluate comprehensively the internal consistency reliability of PDQ-39 and the constituent scales specifically for patients at the advanced stages of PD who were candidates for DBS surgery. Each of the scales met at least one of the adopted criteria for internal consistency reliability. In particular, the Cronbach's alpha coefficient was excellent for the entire instrument; it was very good for four of the scales (Mobility, Activities of Daily Living, Emotional Well-Being, and Stigma); marginally below the cut off score for three of the scales (Social Support, Cognition and Bodily Discomfort) and non-satisfactory for one

Table 5
Summary of the internal consistency reliability criteria of the PDQ-39 scales obtained in the present study (PDQ-39-BG-2022).

PDQ-39-BG-2022 Scales	Number of items	Scale's Cronbach's α	Scale's Mean Inter-item correlation	Item-total correlation	
				Satisfactory ^a	Non-satisfactory ^f
Mobility	10	Satisfactory ^a	Satisfactory ^d	All items	
Activities of Daily Living	6	Satisfactory	Satisfactory		Item 14
Emotional Well-Being	6	Satisfactory	Satisfactory		Items 18, 20, 22
Stigma	4	Satisfactory	Satisfactory		Item 24
Social Support	3	Marginally below the cut-off ^b	Satisfactory		Item 28
Cognition	4	Marginally below the cut-off	Satisfactory		Item 30, 32, 33
Communication	3	Non-satisfactory ^c	Satisfactory		All items
Bodily Discomfort	3	Marginally below the cut-off	Satisfactory	All items	

Note.

^a Cronbach's $\alpha > .70$.

^b Cronbach's $\alpha < .70$ and $> .50$.

^c Cronbach's $\alpha < .50$.

^d Inter-item correlation coefficient within the range of $.15-.50$.

^e Item-total correlation coefficient $\rho > .40$.

^f Item-total correlation coefficient $\rho < .40$.

scale (Communication). All scales met the inter-item correlation criterion, revealing that the items within each of the eight scales are neither too similar (which would point to a redundancy), nor too different from each other, and as such, tap a distinct, yet unified construct underlying each scale. In contrast, the item-total correlation criterion was met for two of the eight scales (Mobility and Bodily Discomfort). Three of the scales (Activities of Daily Living, Stigma, and Social Support) had single items with low item-total correlations, and three of the scales (Emotional Well-Being, Cognition and Communication) contained a wider range of items with low item-total correlation coefficients. Possible confounding factors underlying the non-satisfactory item total correlations of three of the four items in the Cognition scale might be related to the advancement of PD, which is associated with a significant, yet individually highly variable decline of a wide range of neuropsychological functions [1]. Furthermore, as argued by Jones et al. [49], this scale may be more relevant to a mood-related construct (e.g., depression or arousal/sleep efficiency) rather than to cognition per se.

In the Emotional Well-Being scale, the three of the six items with non-satisfactory item-total correlations denote related but separable emotional conditions (i.e., anger, loneliness and worry about the future). As such, these items likely tap more pronounced heterogeneity and/or multidimensionality of the underlying construct [50], evolving in the advanced stages of PD, in conjunction with fluctuations in patients' clinical/emotional functioning inherent to the disease progression [10]. In the Communication scale, the non-satisfactory item-total correlations of all three constituent items suggest that for this group of patients the scale's underlying construct is insufficiently coherent.

With minor exceptions, the removal of the items with low item-total correlations across all scales either did not improve or improved marginally or even decreased the Cronbach's alpha coefficients of the respective scale. In particular, in the Cognition scale even though three of the four items had non-satisfactory item-total correlations, the removal of those items was inconsequential for the Cronbach's alpha coefficient of the scale. Within the other scales the removal of only four of the items with low item-total correlations (see Table 5) resulted in a more notable improvement of the Cronbach's alpha coefficient of the respective scale. These were: item 14 ("problems writing clearly") in the Activities of Daily Living scale; item 20 ("felt angry or bitter") in the Emotional Well-Being scale, item 24 ("avoided eating or drinking in public") in the Stigma scale and item 36 ("felt ignored by people") in the Communication scale.

The responses on some of these items might have been influenced by either the specific characteristics of the sample or by contextual variables. For example, item 14 ("problems writing clearly") in the Activities of Daily Living scale might be irrelevant for patients at the advanced stages of PD, bearing in mind that in our sample the majority of such patients reported that they had been avoiding writing for a considerable period of time due to the typically severe motor symptomatology they endured. Item 20 (feeling "angry or bitter") in the Emotional Well-Being scale might be inconsistent with the scale's total score because of a social-desirability bias when being a candidate for DBS surgery. Item 24 ("avoiding eating or drinking in public") in the Stigma scale might not be applicable to the advanced stage of PD for two main reasons. Firstly, due to the exacerbated motor difficulties manifested at the advanced stage of the disease [11,28,34], many patients refrain from going to public places. Secondly, at the time of the data collection, public places and restaurants were closed for most of the time due to the Covid-19 restrictions and hence "eating or drinking in public" was not a feasible activity for anyone. Item 36 ("felt ignored by people") in the Communication scale appears to have been inconsistent for the patients in the present study with the notion of communication, and perhaps more relevant to their emotional experiences.

It is also acknowledged that the particular non-satisfactory internal consistency indicators (see Table 5) identified in the present study are likely to have been additionally influenced by intensification of the PD symptoms, occurring in some instances during instrument completion, due to the wearing off of medication and related impediment of patients' overall functionality at the time.

The analysis across the three criteria for internal consistency reliability showed that the Mobility scale met all of them. In particular, this scale had the highest Cronbach's alpha coefficient, and each of the constituent items had satisfactory inter-item and item-total correlation coefficients. The Activities of Daily Living, Emotional Well-Being and Stigma scales met two criteria – Cronbach's alpha and inter-item correlation coefficients. The Bodily Discomfort scale also met two criteria – the inter-item and item-total

correlation coefficients. The Social Support and Cognition scales met one criterion (the inter-item correlation) but given that their Cronbach's alpha values were just marginally below the cut off score, their internal consistency reliability was not deemed problematic. The Communication scale also met one criterion (the inter-item correlation), however, it had a non-satisfactory Cronbach's alpha coefficient.

Thus, the only scale that showed non-satisfactory results with reference to several reliability indicators was the Communication scale. Firstly, the scale had the lowest Cronbach's alpha coefficient among the eight scales, and its value was significantly different from those reported in the comparison studies. Secondly, the item-total correlations for all of the scale's items were lower than the acceptable level, and lastly, the scale's internal consistency improved when one of the items (item 36, feeling "ignored by other people") was removed. Therefore, for patients at advanced stages of PD the assessment data yielded on this scale should be interpreted with caution.

Overall, the results confirmed satisfactory internal consistency reliability of the entire PDQ-39 and for seven of the eight scales. With minor exceptions, the removal of items with low item-total correlations was inconsequential for the Cronbach's alpha coefficients of the respective scales. The findings with reference to each and all criteria for assessing the internal consistency reliability suggest that PDQ-39 and the constituent scales can be considered reliable measures for assessing QoL of patients at advanced stages of PD. It is reasonable to further evaluate the reliability indicators for the Communication scale, for which the results were equivocal and point to an insufficient coherence of the scale's construction and/or item formulations for this group of patients.

The second aim of the present study was to compare the Cronbach's alpha coefficients of PDQ-39 obtained with patients at advanced stages of PD with those reported for patients across all stages of the progression of the disease. The results showed that the Cronbach's alpha coefficient of the entire instrument was excellent and not significantly different from the comparison studies conducted by Peto et al. [44] in the UK and Todorova et al. [14] in Bulgaria. The same applies to the Social Support, Cognition, and Bodily Discomfort scales. In contrast, the Mobility, Activities of Daily Living, Emotional Well-Being, Stigma, and Communication scales had Cronbach's alpha coefficients that were significantly lower than either one or both of the comparison studies (see Table 2). Nevertheless, the Cronbach's alpha coefficients for these scales were within the acceptable levels, except for the Communication scale, which displayed low internal consistency reliability across two of the three internal consistency reliability criteria.

It is noted that in the comparative evaluations of reliability estimates, the Cronbach's alpha coefficients for some of the scales (Mobility, Activities of Daily Living and Stigma) though acceptable, differed primarily in relation to PDQ-39-UK-1995 study, rather than the PDQ-39-BG-2005. This suggests that these differences likely reflect contextual and sample characteristics, the role of which has been recognized in cross-cultural psychometric evaluations of reliability estimators [51,52]. In the present study, the homogeneity of the sample, yielding low variance of items scores, along with contextual variables (language, culture, conditions of instrument completion, time, socio-historical specificity), might have been contributing to the comparative lowering of the Cronbach's alpha values for the scales denoted in Table 2.

There were several limitations of the present study. Firstly, the sample was relatively small, though compatible with the comparison study by Todorova et al. [14] (N = 40, with 30 % (n = 12) at H&Y stage 3 and 4) and other validation studies (e.g., Jenkinson et al. [17], N = 127, n = 18 at stages 4 and 5; Lj Ziropadja et al. [53], N = 102, n = 2 at H&Y stage 4; Martinez-Martin et al. [30], N = 435, with 8.05 % (n = 35) in stage 4). It would be useful to replicate the study with a larger sample of patients with APD. Secondly, it would be valuable to assess the psychometric properties of PDQ-39 for such patients when their health-related QoL is not potentially impacted by the world-wide and nation-wide elevated rates of Covid-19. Thirdly, the sample consisted predominantly of men. Although PD affects more men than women [54], a more balanced gender distribution of the participants might contribute to the generalizability of the results.

6. Conclusion

The reliability evaluation of the PDQ-39 (Bulgarian translation) with reference to three criteria (Cronbach's alpha, inter-item correlation and item-total correlation coefficients) indicated excellent reliability of the questionnaire. The Mobility scale met all three reliability criteria. In contrast, the Communication scale showed relatively poor internal consistency reliability and should thus be used with caution. In summary, the entire questionnaire and seven out of the eight scales had good reliability results. It is concluded that PDQ-39 is a reliable tool for assessing the QoL of patients at advanced stages of PD across multiple health-related domains. The questionnaire can be recommended for inclusion in the best practice guidelines for evaluating DBS candidacy and the efficacy of DBS treatment for patients' QoL.

Statements and Declarations

The authors declare that no funds, grants, or other support were received during the preparation of this manuscript.

Ethics approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of the University Multiprofile Hospital for Active Treatment UMBAL "St. Ivan Rilski", Sofia, Bulgaria (December 22, 2019; No. 4).

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Data availability statement

Due to the sensitive nature of the clinical evaluation procedures and heightened vulnerability of the participants in this study, they were assured that the data collected are confidential and that only aggregated data will be made available for scientific purposes.

CRediT authorship contribution statement

Maria Damianova: Writing – review & editing, Writing – original draft, Validation, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Desislava Gancheva:** Writing – review & editing, Writing – original draft, Validation, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Kaloyan Gabrovski:** Validation, Resources, Investigation, Data curation. **Petar Karazapryanov:** Validation, Resources, Investigation, Formal analysis, Data curation. **Yoana Milenova:** Validation, Resources, Investigation, Formal analysis, Data curation. **Ivo D. Popivanov:** Methodology, Conceptualization. **Krasimir Minkin:** Writing – review & editing, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

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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