

Research Report

PDQ-8: A Simplified and Effective Tool Measuring Life Quality in Progressive Supranuclear Palsy

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Abstract.

Background: The self-reported quality of life (QoL) should be carefully listened to in progressive supranuclear palsy (PSP) from the patient-centered perspective. However, there was still a lack of short QoL measurement tool in atypical parkinsonism.

Objective: We aimed to test whether the short Parkinson's Disease Questionnaire-8 (PDQ-8) was effective in assessing QoL in PSP, comparing with Progressive Supranuclear Palsy Quality of Life Scale (PSP-QoL) and Parkinson's Disease Questionnaire-39 (PDQ-39).

Methods: 132 patients with clinical diagnosed PSP, including PSP-Richardson syndrome (RS) subtype ($n=71$) and PSP-non-RS subtype ($n=61$) were recruited for clinical evaluation including QoL assessment. The detailed QoL profiles and possibility of using PDQ-8 were systemically analyzed. The determinants to the QoL were then calculated by multivariate linear regression analysis.

Results: The PSP-QoL total score summary index (SI) was 22.8 (10.1, 41.1), while the PDQ-8 and PDQ-39 total SI score were 28.1 (12.5, 46.9) and 29.5 (15.4, 49.4). Mobility, activities of daily life, cognition and communication were the main affected QoL subdomains (median SI: 40.0, 31.3, 25.0 and 25.0 respectively). PSP-RS subtype showed more severe damage physically ($p<0.001$) and mentally ($p=0.002$) compared to other subtypes. More importantly, the strong relevance of PDQ-8 and recommended PSP QoL tools were confirmed ($p<0.001$). In addition, disease severity, depression and daytime sleepiness were proved to be critical determinants for QoL in PSP.

Conclusions: PDQ-8 could be an easy, reliable, and valid tool to evaluate QoL in patients with PSP. Besides motor symptoms, more attention should be paid to non-motor impairment such as depression in PSP.

Keywords: Health-related quality of life, PDQ-8, PSP-QoL, progressive supranuclear palsy

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INTRODUCTION

Progressive supranuclear palsy (PSP) is a progressive neurodegenerative disorder, characterized by supranuclear vertical gaze palsy, repeated falls, levodopa-unresponsive parkinsonism, and cognitive disturbances [1]. Without effective therapy, these motor and non-motor symptoms severely impair the life quality of the patients. Therefore, the self-reported quality of life (QoL) should be carefully listened to and considered before making clinical assessments and therapeutic explorations, from the patient-centered perspective.

So far, the most commonly used tools on QoL in PSP include the Progressive Supranuclear Palsy Quality of Life Scale (PSP-QoL) [2], the Parkinson's Disease Questionnaire-39 (PDQ-39) [3], and the EuroQol instrument (EQ-5D) [4, 5]. PSP-QoL scale was designed as a specific measure of health status in PSP, including physical and mental domains [2]. PDQ-39, though designed specifically for Parkinson's disease (PD) [6–9], was also used in atypical parkinsonism including PSP [2, 3, 10, 11], to compare QoL among different diseases sometimes. However, both questionnaires take long time to complete, limiting their clinical practice, especially in the severely ill patients, online consultations and longitudinal follow-ups [12]. Finding an appropriate simplified QoL questionnaire was also badly in need to follow up chronic and progressive diseases during COVID-19 period.

As far as we know, there has been no short QoL context specially designed for PSP yet. PDQ-8, which is composed of eight representative questions from PDQ-39 [13], is the only available and widely used short QoL tool related to parkinsonism. Because PDQ-8 could shorten the filling time and increase the completion rate, it is preferred in the use of mobile app and follow-up in PD [14]. It has also been put into use as the vital endpoint in diverse PD clinical experiments [15–19]. Nevertheless, whether PDQ-8 could be used in assessing the QoL in PSP has not been assessed yet.

In this study, we explored the detailed profiles and related determinants of QoL in PSP by several QoL measurements in a relatively large cohort. Furthermore, we aimed to validate whether PDQ-8, the only simplified QoL tool in Parkinsonism, could be applied in assessing the QoL in PSP.

METHODS

Participants

Patients with clinically diagnosed PSP were from Progressive Supranuclear Palsy Neuroimage Initiative (PSPNI) and consecutively recruited from January 2020 to January 2022 in the Movement Disorders Clinic, Department of Neurology, Huashan Hospital, Fudan University (Shanghai, China). All the patients were diagnosed and divided into PSP-Richardson syndrome subtype (PSP-RS) and PSP-non-RS subgroups (including PSP-pure akinesia with gait freezing subtype, PSP-parkinsonism subtype, PSP-postural instability subtype, PSP-speech/language disorders subtype, and PSP-ocular motor dysfunction subtype) in accordance with the 2017 Movement Disorder Society (MDS) diagnostic criteria [20]. The study protocol conforms to the national and international regulations and the ethical guidelines set forth by the Helsinki declaration. The study was approved (KY2016-214 and KY2020-1160) and supervised by the Ethics Committee of Huashan Hospital. All subjects provided written informed consent before entering the study.

Clinical assessments

Demographic information and clinical characteristics of the patients, including age (years), sex, disease duration (months), education (years), and levodopa equivalent daily dose (LEDD, mg), were systematically collected. Disease severity was evaluated using PSP rating scale (PSPrs). PSP-QoL was answered by patients with PSP or their caregivers to assess quality of life, composed of physical and mental domains. PDQ-39 was also applied at the same time, including eight domains of mobility, activities of daily life (ADL), emotional well-being, stigma, social support, cognition, communication, and physical discomfort. PDQ-8 was extracted from each domain of PDQ-39 [13]. Original PSP-QoL, PDQ-39, and PDQ-8 scores were standardized to summary index (PSP-QoL SI, PDQ-39 SI and PDQ-8 SI), dividing the raw scores by the maximum possible raw score, and multiplying by 100 (range from 0 to 100). The higher scores indicated the worse QoL. Non-motor symptoms were assessed by Non-motor Symptoms Scale (NMSS), cognitive function was assessed using Mini-Mental State Examination (MMSE), depression was assessed by Geriatric Depression (GDS),

and daytime sleepiness was assessed by Epworth Sleepiness Questionnaire (ESS). The questionnaires were provided to the participants in the Chinese version.

Statistical analysis

Data were tested for normality by Kolmogorov-Smirnov test. Descriptive statistical analysis was performed for the demographic and clinical information of patients with PSP as mean \pm SD (standard deviation) or median (inter-quartile) whereas appropriate depending on normality. Comparisons of clinical variables among different subgroups were compared by student's t test for normally distributed data, or Mann-Whitney U test for the data that were not. Categorical data were compared by chi-square. Correlations among QoL and baseline clinical parameters were assessed using Spearman's rho correlation coefficient. The internal consistency reliability of questionnaire was evaluated by Cronbach's alpha. The intraclass correlation coefficient was also made between PDQ-8 and other QoL instruments. The multivariate linear regression analysis was performed on these variables to ascertain the predictors of composite scores of the PSP-QoL and PDQ-8. Statistical analysis was performed using SPSS software (Version 17.0; SPSS, Inc. Chicago, IL). Statistical significance was set at $p < 0.05$.

RESULTS

Demographic and clinical information

In the current study, 132 patients with PSP were finally included, with 71 patients as PSP-RS, and 61 patients as PSP-non-RS (26 PSP-PGF patients, 31 PSP-P patients, 1 PSP-PI patient, 1 PSP-SL patient, and 1 PSP-OM patient specifically). Among them, 114 patients were diagnosed as probable PSP, 14 patients as possible PSP, and 4 PSP patients as s.o. PSP (suggestive of PSP). The detailed demographic information and clinical characteristics of the participants were shown in Table 1. As for the comparison between PSP-RS and PSP-non-RS, patients with PSP-RS suffered more from the motor and non-motor symptoms, as reflected by heavier disease severity (PSP-rs scores, $p < 0.001$), cognition impairments (MMSE scores, $p < 0.01$), and depression (GDS scores, $p < 0.05$).

The quality of life in PSP

The PSP-QoL total score SI in the PSP cohort was 22.8 (10.1, 41.1), and the QoL VAS score was 70.0 (50.0, 85.0). Regarding PDQ-8 and PDQ-39, the total SI score was approximate (median: 28.1 and 29.5), with the domains in PDQ-39 of mobility, ADL, cognition and communication most critically impaired respectively (Table 2). There was only one patient with PSP-P reported 0 in PSP-QoL assessment (QoL VAS score: 100). Moreover, patients with PSP-RS reported worse QoL than those with PSP-non-RS physically and mentally as reflected by all the QoL tools. In detail, QoL scores in PSP-RS was higher than that in PSP-non-RS especially in the PDQ-39 domains of mobility ($p < 0.05$), ADL ($p < 0.05$), emotional well-being ($p < 0.05$) and cognition ($p < 0.05$) (Table 2).

Strong relevance of PDQ-8 and well-acknowledged PSP QoL measurement tools

To examine the use possibility of simplified QoL tool, the spearman correlation was made between PDQ-8 and the specific-designed QoL tool (PSP-QoL) in pooled PSP patients and different PSP subtypes (Table 3). The great relevance remains in both patients with shorter and longer disease duration (divided by 36 months) as shown in Supplementary Table 1. Apart from the strong relevance of different QoL tools ($p < 0.001$), the validity and reliability of PDQ-8 in assessing QoL of PSP was also taken into consideration in Supplementary Table 2. Each of the PDQ-8 items showed strong correlations with total PDQ-8 SI scores, total PDQ-39 SI scores and their own dimensional SI scores in PDQ-39 (item convergent validity); and the correlation to their own dimensional SI scores was higher than those with other items (item discriminant validity). There was also a strong relevance of PDQ-8 SI with each item of PSP-QoL (Supplementary Table 3). The internal reliability of the 8 items of PDQ-8 calculated by Cronbach's alpha statistic was 0.836. The intraclass correlation coefficient between PDQ-8 and PSP-QoL was 0.764, which between PDQ-8 and PDQ-39 was 0.955.

Clinical correlations with QoL in PSP

In our total cohort, the clinical factors correlating with the PSP-QoL SI scores included the disease duration ($r = 0.369$, $p < 0.001$), PSP-rs scores

Table 1
Demographic and clinical information of PSP patients

	PSP, <i>n</i> = 132	PSP-RS, <i>n</i> = 71	PSP-non-RS, <i>n</i> = 61	<i>p</i>
Age (y)	66.4 ± 6.5	67.1 ± 6.0	65.1 ± 7.2	0.259
Sex (M/F)	71/61	36/35	35/26	0.443
Disease Duration (mo)	35.0 (18.3, 61.5)	34.0 (19.0, 47.0)	44.0 (17.5, 72.0)	0.153
Education (y)	9.0 (8.0, 12.0)	9.0 (6.0, 12.0)	11.0 (8.0, 12.0)	0.119
LEDD (mg)	400.0 (150.0, 555.0)	400.0 (150.0, 537.5)	400.0 (140.6, 600.0)	0.714
PSPPrs	30.0 (21.0, 40.0)	35.0 (28.0, 43.0)	23.0 (16.3, 29.8)	<0.001***
NMSS	35.0 (20.3, 74.5)	40.0 (21.0, 88.0)	32.0 (12.0, 59.0)	0.069
MMSE	25.0 (21.0, 27.0)	23.0 (18.3, 27.0)	26.5 (24.0, 28.0)	0.001**
GDS	10.0 (6.0, 19.0)	13.5 (8.0, 21.3)	9.0 (5.0, 17.5)	0.011*
ESS	6.0 (3.0, 11.0)	8.0 (3.0, 12.0)	5.0 (3.0, 10.0)	0.112

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. PSP-RS, progressive supranuclear palsy-Richardson's syndrome; PSP-non-RS, other PSP subtypes except progressive supranuclear palsy-Richardson's syndrome; LEDD, levodopa equivalent daily dosage; PSPPrs, PSP rating scales; NMSS, Non-motor symptoms scale; MMSE, Mini-Mental State Examination; GDS, Geriatric Depression Scale; ESS, Epworth Sleepiness Questionnaire.

Table 2
Quality of life in PSP assessed by PSP-QoL, PDQ-8 and PDQ-39 in PSP

	PSP, <i>n</i> = 132	PSP-RS, <i>n</i> = 71	PSP-non-RS, <i>n</i> = 61	<i>p</i>
PSP-QoL SI	22.8 (10.1, 41.1)	32.2 (16.1, 47.8)	16.1 (7.2, 31.1)	<0.001***
Physical Subscore SI	30.5 (14.3, 48.8)	36.0 (22.0, 58.0)	20.0 (8.0, 36.0)	<0.001***
Mental Subscore SI	16.5 (4.0, 35.0)	23.0 (10.0, 45.0)	9.0 (2.0, 24.5)	0.002**
QoL VAS score	70.0 (50.0, 85.0)	60.0 (50.0, 80.0)	80.0 (50.0, 90.0)	0.080
PDQ-8 SI	28.1 (12.5, 46.9)	34.4 (12.5, 53.1)	21.9 (9.4, 35.9)	0.009*
PDQ-39 SI	29.5 (15.4, 49.4)	37.2 (17.9, 55.8)	20.5 (10.9, 34.6)	0.001**
Mobility SI	40.0 (17.5, 72.5)	47.5 (30.0, 82.5)	25.0 (10.0, 60.0)	0.001**
Activity of daily living SI	31.3 (16.7, 58.3)	41.7 (16.7, 66.7)	20.8 (10.4, 37.5)	0.003**
Emotional well-being SI	16.7 (4.2, 37.5)	20.8 (4.2, 45.8)	8.3 (2.1, 25.0)	0.006**
Stigma SI	18.8 (0.0, 43.8)	18.8 (0.0, 43.8)	18.8 (0.0, 31.3)	0.612
Social support SI	0.0 (0.0, 25.0)	8.3 (0.0, 33.3)	0.0 (0.0, 16.7)	0.099
Cognition SI	25.0 (12.5, 37.5)	31.3 (18.8, 50.0)	18.8 (6.3, 28.1)	0.001**
Communication SI	25.0 (8.3, 50.0)	25.0 (8.3, 58.3)	16.7 (0.0, 50.0)	0.042
Physical discomfort SI	16.7 (0.0, 47.9)	16.7 (0.0, 50.0)	16.7 (4.2, 41.7)	0.702

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. PSP-RS, progressive supranuclear palsy-Richardson's syndrome; PSP-non-RS, other PSP subtypes except progressive supranuclear palsy-Richardson's syndrome; PSP-QoL, Progressive Supranuclear Palsy Quality of Life Scale; VAS, visual analogue scale; PDQ-8, Parkinson's Disease Questionnaire-8; PDQ-39, Parkinson's Disease Questionnaire-39; SI, summary index.

Table 3
Correlation between PDQ-8 SI, PSP-QoL SI and PDQ-39 SI in pooled PSP and different PSP subtypes

	PSP-QoL SI	PSP-QoL Physical SI	PSP-QoL Mental SI	PDQ-8 SI
PSP total (<i>n</i> = 132)				
PDQ-8 SI	0.811***	0.767***	0.719***	/
PDQ-39 SI	0.819***	0.799***	0.711***	0.950***
PSP-RS subgroup (<i>n</i> = 71)				
PDQ-8 SI	0.806***	0.777***	0.709***	/
PDQ-39 SI	0.804***	0.812***	0.682***	0.945***
PSP-non-RS subgroup (<i>n</i> = 61)				
PDQ-8 SI	0.788***	0.714***	0.676***	/
PDQ-39 SI	0.786***	0.722***	0.683***	0.951***

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. The spearman correlation is made among different quality of life questionnaires. PSP-RS, progressive supranuclear palsy-Richardson's syndrome; PSP-non-RS, other PSP subtypes except progressive supranuclear palsy-Richardson's syndrome; PSP-QoL, Progressive Supranuclear Palsy Quality of Life Scale; PDQ-8, Parkinson's Disease Questionnaire-8; PDQ-39, Parkinson's Disease Questionnaire-39; SI, summary index.

($r = 0.759$, $p < 0.001$), MMSE scores ($r = -0.411$, $p < 0.001$), NMSS scores ($r = 0.657$, $p < 0.001$), GDS scores ($r = 0.642$, $p < 0.001$), and ESS scores ($r = 0.330$, $p < 0.001$) (shown in Supplementary Table 4). When assessing the life quality using PDQ-8 and PDQ-39, similar correlations could also be confirmed with disease duration ($p < 0.01$), PSPrs scores ($p < 0.001$), MMSE scores ($p < 0.01$), NMSS scores ($p < 0.001$), GDS scores ($p < 0.001$), and ESS scores ($p < 0.001$). Although the correlation results may be diverse in different subtypes, they remained similar among several QoL tools. There was also a trend of correlation between PDQ-8 and diagnostic certainty ($r = 0.141$, $p = 0.113$) while great relevance of PSP-QoL with diagnostic certainty ($r = 0.230$, $p = 0.009$).

Determinants of life quality

Multivariate linear regression ($R^2 = 0.763$, with great regression effect) was performed on the above variables (including age, disease duration, sex, PSPrs, NMSS, ESS, GDS, MMSE) to reveal their relative impact on PSP-QoL total score SI as shown in Table 4. For patients with PSP, PSPrs ($\beta = 0.497$, $p < 0.001$) was the most important determinant of life quality, followed by depression as assessed by GDS ($\beta = 0.348$, $p < 0.001$), longer disease duration ($\beta = 0.183$, $p < 0.001$) and daytime sleepiness (ESS, $\beta = 0.106$, $p < 0.05$). Furthermore, through the multivariate linear regression analysis ($R^2 = 0.591$, with great regression effect) with same variables clinically important or correlated with PDQ-8 SI entered, the determinants of life quality in PSP consist of GDS ($\beta = 0.324$, $p < 0.001$), non-motor symptoms (NMSS, $\beta = 0.249$, $p < 0.05$), PSPrs ($\beta = 0.235$, $p < 0.05$), ESS ($\beta = 0.202$, $p < 0.01$) were confirmed again (Table 4).

DISCUSSION

In our relatively large PSP cohort, three major findings on the QoL in patients with PSP were reported. First, the patients with PSP showed more or less impairment in quality of life physically and mentally evaluated by PSP-QoL, presenting a multiple-domain lesion pattern in PDQ-39, with mobility, ADL, cognition and communication most severely involved. Second, as the only widely accepted short QoL measurement tool in PD [15–19] and related disorders, PDQ-8 was comparable to PSP-QoL in assessing the QoL in PSP, which could be further used in the future clinical practices. Last but not least, the disease severity (PSPrs), depression (GDS) and daytime sleepiness (ESS) may be critical determinants on the QoL burdens (assessed by PSP-QoL or PDQ-8) in PSP. This study may provide useful information in assessing the quality of life and treatment response in PSP.

In the current study, there were no floor effect in all the QoL tools. Although a broad spectrum of clinical manifestation could contribute to individual variation in QoL impairment, we found almost every patient reported physical and mental problems from PSP-QoL. Meanwhile, all the patients with PSP reported at least one QoL domain impaired evaluated by PDQ-39, most severely impaired in the domains of mobility, ADL, cognition and communication, in contrast to PD with physical discomfort and stigma domains mainly affected [21]. These findings were also similar to our previous report in MSA-P [21] and other report in PSP [3] respectively. Furthermore, the patients with PSP-RS reported more severe QoL lesions than the PSP-non-RS ones physically and mentally, also shown in the PDQ-39 domains of mobility, ADL, emotional well-being and cognition.

Table 4
Impact of clinical features on PSP-QoL total score SI
and PDQ-8 SI based on linear regression in PSP

	Unstandardized β	Standardized β	<i>p</i>
Dependent variable = PSP-QoL SI Adjusted $R^2 = 0.763$			
Age (y)	0.078	0.015	0.749
Disease duration (mo)	0.208	0.183	<0.001***
Sex	2.754	0.040	0.414
PSPrs	1.251	0.497	<0.001***
MMSE	0.544	0.089	0.169
NMSS	0.096	0.128	0.081
GDS	1.490	0.348	<0.001***
ESS	0.620	0.106	0.042*
Dependent variable = PDQ-8 SI Adjusted $R^2 = 0.591$			
Age (y)	-0.014	-0.004	0.949
Disease duration (mo)	0.071	0.093	0.145
Sex	5.531	0.118	0.065
PSPrs	0.398	0.235	0.025*
MMSE	0.354	0.086	0.310
NMSS	0.127	0.249	0.010**
GDS	0.935	0.324	<0.001***
ESS	0.794	0.202	0.004**

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. Multivariate linear regression was made on these variables to ascertain the predictors of composite scores of the PSP-QoL SI and PDQ-8 SI. PSP-QoL, Progressive Supranuclear Palsy Quality of Life Scale; PDQ-8, Parkinson's Disease Questionnaire-8; SI, summary index; PSPrs, PSP rating scales; MMSE, Mini-Mental State Examination; NMSS, Non-motor symptoms scale; GDS, Geriatric Depression Scale; ESS, Epworth Sleepiness Questionnaire.

The findings in the self-reported QoL were in consistent with the results from physicians-evaluated motor and non-motor scales, and they were supported by the idea that PSP-RS was the final stage with most severe lesions in the clinical trajectories of PSP [1, 22].

It is noteworthy that here not only did we use the specific-designed PSP-QoL in the cohort, but we also applied the PDQ-39 questionnaire to acquire more specific information of QoL subdomains impairment, as a few of other publications did [2, 3, 10, 11]. In addition, we and other reports [2] proved a strong correlation between PDQ-39 and PSP-QoL subscales (physical and mental). Crucially, we admitted that PDQ-39 was not designed for PSP. Some frequently experienced symptoms in PSP, such as ocular motor dysfunction, muddled thinking, confusion and apathy are not precisely addressed in this PD-specific life quality questionnaire [23]. Therefore, if time and conditions permit, the quality of life of PSP patients should be evaluated by the more specialized PSP-QoL [2, 24]. However, it was impossible for some advanced patients (e.g., with dementia or failing to express themselves) to complete the 30-min questionnaires [12], not to mention those patients in the remote follow-up, which was common during COVID-19 period.

In that case, we aimed to find a valid, simple, quick to complete and easy to score QoL instrument, which was still a vacancy in PSP. As a simplified questionnaire of PDQ-39, PDQ-8 was easy for patients to understand, with high completion rate. Therefore, it was preferred in the longitudinal follow-up and online self-report consultations [15–19]. Nevertheless, it has not been proved to be valid and reliable in patients with PSP, which was necessary. Currently, we preliminarily validated the effectiveness of PDQ-8 in assessing QoL in PSP and different subtypes through item-to-dimension correlations. The profiles of QoL burden assessed by PSP-QoL and PDQ-39, could also be successfully recaptured by PDQ-8 in our cohort. Therefore, we supported that PDQ-8 could be carefully and effectively used in PSP.

In further analysis, disease severity, depression and daytime sleepiness were classified as critical determinants to the QoL (evaluated either by PSP-QoL or PDQ-8) in PSP. Our data were in consistent with the previous reports of great association between PSPrs and PSP-QoL [24], while verified that non-motor symptoms also play an important role in the quality of life [25–28]. In particular, depression may impose a heavy QoL burden on the patients with PSP [29–31]. It has been previously reported that depression should be carefully evaluated, as it was a common determi-

nant to QoL in neurodegenerative disorders, such as PD [21, 32] and MSA [3, 5, 33]. In general, patients with PSP are more prone to depression than MSA [4, 5]. Additionally, depression has been identified as a possible predictor of shorter survival in PSP [34], emphasizing the importance of paying attention to mental health and administering antidepressant therapy. The depressive symptoms may be related not only to disease-related changes in brain function, but also to the functional consequences of the disease. As for sleep disturbance, it has been reported as a most severe non-motor symptoms in PSP [35], with more sleep architecture abnormalities and insomnia than other neurodegenerative disorders. Such sleep disturbances may be due to the atrophy of pontine tegmental nuclei [35].

In our previous study, we validated the use of PDQ-8 in Chinese patients with PD [36], and adopted it as a primary endpoint in the multi-center real-world study (clinical trials ID: NCT03649503). Moreover, we developed a PAWEI remote medical system/app for the longitudinal follow-up in PD, in which the PDQ-8 was adopted. This telemedicine system was successfully run for the remote medical consultation during this COVID-19 pandemic time. After the current validation, we will further explore the use of PDQ-8 in telemedical system for assessing QoL in PSP. We also look forward to the invention of PSP-specific simplified QoL instrument or the improved PDQ-8 in the future. We believe this timely feedback from patients can serve as a reminder for physicians and their caregivers, which could also be carefully considered as the endpoint of clinical trials in PSP.

As we know, this was the first study validating the application of PDQ-8 in a relatively large PSP cohort. Some limitations should be admitted here. First, despite the large sample size, this cohort was in the single hospital with all Asian patients included. Second, the nature of the QoL assessment was self-reported, so we could not rule out the participants-related bias to the study. Third, the diagnosis of PSP was made cross-sectionally, and the longitudinal follow-up will be helpful for validating our findings. In addition, we should always keep in mind the PDQ-8 was not specifically designed for PSP. The exact effectiveness of using PDQ-8 in PSP and the development of modified short-version of PSP-QoL need to be further explored in the future. Last but not least, we raised the possibility of using PDQ-8 to assess QoL through the PAWEI telemedicine system. However, we should be aware of its limitation in some aspects that are different

between patients with PD and patients with atypical parkinsonism.

Conclusion

PDQ-8, which could recapture the severity and determinant factors to QoL, was a valid and reliable instrument to assess QoL in PSP. Our work provided evidence for future application of PDQ-8 in QoL assessment in PSP, especially in the remote telemedicine system.

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CONFLICT OF INTEREST

The authors declare that this research was conducted in the absence of any commercial or financial relationships that could be perceived as a potential conflict of interest.

DATA AVAILABILITY

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <https://dx.doi.org/10.3233/JPD-223553>.

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