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Validity and reliability testing of the Chinese (mainland) version of the 39-item Parkinson's Disease Questionnaire (PDQ-39)*

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Abstract: The 39-item Parkinson's Disease Questionnaire (PDQ-39) has been tested in many languages, but not in Chinese mainland. We aimed to assess the Chinese (mainland) version of the PDQ-39. Seventy-one subjects with Parkinson's disease (PD) completed the PDQ-39 and the Medical Outcomes Study 36-item Short Form Health Survey (SF-36). All subjects were retested with the PDQ-39 a week later. The united Parkinson's disease rating scale (UPDRS) and the Hoehn and Yahr (H & Y) scale were also used to evaluate the subjects. Reliability was assessed by Cronbach's α and intra-class correlation coefficient (ICC). Validity was examined in terms of agreement with SF-36, UPDRS, and H & Y scales. The Chinese (mainland) version of the PDQ-39 demonstrated acceptable reliability (Cronbach's α : 0.84–0.88; ICC: 0.56–0.82). The item-total correlations (0.33–0.88) and scaling success rates (77.56%) indicated satisfactory convergent and discriminant validity of the PDQ-39 items. The correlations between related constructs of the PDQ-39 and UPDRS (r=0.44–0.68) and between those of the PDQ-39 and SF-36 (r=(-0.46)–(-0.69)) were all statistically significant (P<0.01). Except for stigma, cognitions, and bodily discomfort, all other dimensions of the PDQ-39 significantly discriminated patients at different H & Y stages indicated by the H & Y scale. Although our observations indicate that some problematic subscales of this version of the PDQ-39 could be improved upon, this study suggests acceptable reliability and validity of the Chinese (mainland) version of the PDQ-39.

Key words: 39-item Parkinson's Disease Questionnaire (PDQ-39), Quality of life, Validity, Reliability **doi:**10.1631/jzus.B0900380 **Document code:** A **CLC number:** R741

1 Introduction

Parkinson's disease (PD) is a common degenerative neurological disease, characterized by tremor, rigidity, bradykinesia, and abnormal posture. Problems of physical mobility and non-motor symptoms all affect the quality of life of PD patients (Gomez-Esteban *et al.*, 2007). Extensive evaluation of a PD patient's quality of life is currently possible with a number of questionnaires. The Parkinson's Disease

Questionnaire (PDQ-39), developed by Peto *et al.* (1995), has been tested in many languages and widely used to evaluate the health-related quality of life (HRQOL) of PD patients in many western countries (Peto *et al.*, 1995; Martínez-Martín and Frades Payo, 1998; Bushnell and Martin, 1999; Katsarou *et al.*, 2001; Marinus *et al.*, 2008).

Recently, the PDQ-39 was translated into Chinese through standardized procedures, and tested in Hong Kong (China), Taiwan (China), and Singapore, (Tsang *et al.*, 2002; Luo *et al.*, 2005; Ma *et al.*, 2005). The results show satisfactory reliability and validity. In Chinese mainland, however, the reliability and validity of the PDQ-39 have not yet been tested. There are nearly two million PD patients living in

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Chinese mainland (Zhang et al., 2005). Therefore, the PDQ-39 must be formally validated for use in Chinese mainland, given the diversity of language, different living habits, different social systems and cultures among those living in Chinese mainland, Taiwan region, and Hong Kong region, and Singapore. The assessment of this instrument provides invaluable information about the psychometric properties of the PDQ-39 in Chinese mainland. Here, we evaluate its validity and reliability in Chinese mainland by comparing our preliminary data with previous studies assessing the PDQ-39 among other populations.

2 Methods

2.1 Preparation of the Chinese (mainland) version of the PDQ-39

We referred to the Chinese version of the PDQ-39 produced for Hong Kong (Tsang et al., 2002), for which back-translation work was completed. We then improved the language expression according to the language habits of Chinese mainland. We referred to the original questionnaire, however, in order to ensure that the meaning of the items was not changed. In order to prepare a version of the PDQ-39 for Chinese mainland, we designated a panel consisting of one statistics specialist who provided feedback on our methodology, two patients (one with elementary education and the other with junior education) to ensure that the language was easy to understand, and three neurologists who chose the patients from the clinic. This panel reviewed each item of the Chinese (mainland) version of the PDQ-39 provided by Taiwan (China), Hong Kong (China), and Singapore, making necessary language changes to produce a version of the PDQ-39 that was both understood by and relevant to patients in Chinese mainland. The two patients agreed on the final version of the PDQ-39.

2.2 Subjects

Seventy-one patients, diagnosed with PD according to Brain Bank Criteria (Hughes *et al.*, 1992), were recruited from the outpatient clinic for PD in the Department of Neurology at the Second Affiliated Hospital of School of Medicine of Zhejiang University. Each gave informed consent. Patients with dementia, as indicated by a mini mental state examination

(MMSE) score of less than 24 (range 0–30) (Cockrell and Folstein, 1988), were excluded. Bedridden patients were also excluded. This study was approved by the Institutional Review Board of the Hospital.

2.3 Procedures and measures

The subjects were evaluated using the united Parkinson's disease rating scale (UPDRS), the Hoehn and Yahr (H & Y) scale, and MMSE. Three residents from the Department of Neurology of the Second Affiliated Hospital were trained and calibrated to ensure rater concordance. The concordance results showed acceptable agreement on the evaluation of four patients among the three residents (Kendall's W=0.813, χ^2 =6.5, P=0.039).

Each research subject was encouraged to self-complete the PDQ-39 and the Medical Outcomes Study 36-item Short Form Health Survey (SF-36) in a random order. Those who were illiterate or otherwise incapable of filling out the questionnaires (due to significant hand tremor) were interviewed by a resident. Participants were asked to fill in the PDQ-39 a second time, one week after their initial appointment. Again, the patients who were able were asked to complete the questionnaire by themselves; those who were illiterate or physically unable completed their questionnaires with the help from their literate caregivers. The self-completed PDQ-39 was returned to us either upon their next visit to the clinic or via post.

The UPDRS includes 42 items in four subscales: (1) mentation, behavior, and mood; (2) activity of daily living (ADL); (3) motor examination (ME); and (4) complications of therapy (Fahn et al., 1987). A lower UPDRS score indicates better performance on the four subscales. The H & Y scale was used to evaluate the severity of PD, ranging from 1 to 5, with 1 indicating mild and 5 indicating severe (Hoehn and Yahr, 1967). The PDQ-39 contains eight dimensions, i.e., mobility, ADL, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort (Jenkinson et al., 1998). The SF-36 is a generic health questionnaire that can be used to assess global functioning and well-being in any subject (Ware and Sherbourne, 1992). The PDQ-39 and SF-36 are both self-administered questionnaires: a higher score of the SF-36 represents a better health condition while a lower PDQ-39 score indicates better health.

2.4 Data analysis

All PDQ-39 domains and general health status data were checked for floor and ceiling effects. Cronbach's α coefficients were calculated for each subscale in order to estimate the internal consistency. Cronbach's α values range between 0 and 1, and the minimum acceptable level is 0.7 (Nunnally, 1978). Test-retest reliability was assessed using the singlerating intraclass correlation coefficients (ICC), the preferred method for estimating reproducibility (Deyo et al., 1991). In general, a correlation of 0.70 is minimally acceptable, but a correlation above 0.80 is preferred (Aday, 1991). The item-total correlations were calculated by the correlation of the item with the score calculated by the remaining items in the same subscale (overlap-corrected correction). Spearman's rank correlation coefficient (r) was used to evaluate item-convergent validity, with a value equal to or above 0.4 considered acceptable (Fayers and Machin, 2000). Item-discriminant validity was present when an item had a significantly higher correlation with its own dimension, compared with the other dimensions (referred to as "scaling success").

Convergent validity involves a comparison of the PDQ-39 to other instruments. We examined the correlations between the related domains of the PDQ-39 and scales for the SF-36 and UPDRS by using Spearman's rank correlation coefficient (r). Correlation coefficients ranging from 0.00 to 0.25 indicate little or no relationship, those from 0.25 to 0.50 suggest a fair degree of relationship, 0.50 to 0.75 is considered moderate to good, and above 0.75 is considered good to excellent (Portney and Watkins, 2000). We hypothesized that the relevant scales from both measures would have a strong correlation: mobility (PDQ-39) with ADL (UPDRS), ADL (PDQ-39) with ADL, ME (UPDRS); mobility (PDQ-39) with physical function (SF-36), ADL (PDQ-39) with role-physical (SF-36); emotional well-being (PDQ-39) with mental health (SF-36); social support (PDQ-39) with social function (SF-36); and, bodily discomfort (PDQ-39) with bodily pain (SF-36). Finally, for discriminative validity, the Kruskal Wallis test was used to test whether the PDQ-39 could significantly discriminate among subjects at different H & Y stages. The threshold for statistical significance was set at 0.05. All statistical analyses were performed with SPSS 11.5 for windows.

3 Results

The study involved 71 subjects, among whom there were only 8 interviewed by a researcher and 63 completed the PDQ-39 by themselves. We chose to include a handful of patients who needed help filling out the questionnaire in order to include a broader segment of the patient population. The scores of the eight dimensions of the PDQ-39 were compared between the two groups (8 assisted subjects versus 63 non-assisted subjects, P: 0.188–0.940). There was no statistical difference between the data of these two group patients (P \geq 0.05). Table 1 summarizes the socio-demographic data for the 71 subjects.

Table 1 Socio-demographic data for the 71 patients

Variable	Value*
Age (year)	63.66±13.06 (32–84)
Sex	03.00±13.00 (32 04)
Male	44 (62.0%)
Female	27 (38.0%)
Education	27 (30.070)
None	6 (8.5%)
Primary school	17 (23.9%)
Junior secondary school	19 (26.8%)
Senior secondary school	16 (22.5%)
University	13 (18.3%)
Marital status	13 (10.570)
Single	8 (11.4%)
Married	56 (80.0%)
Separation	2 (2.9%)
Widowed	4 (5.7%)
Occupation	. (6.770)
Still working	8 (12.3%)
Retired	57 (87.7%)
Duration of disease (year)	6.00±4.16 (1-20)
SF-36	,
Physical function	59.44±26.76
Role-physical	38.73±40.71
Bodily pain	70.42 ± 23.23
General health	35.70±16.52
Vitality	50.00±20.44
Social function	55.56±28.36
Role-emotional	47.89±43.55
Mental health	62.48±18.15
UPDRS	
Mentation, behavior, and mood	4.00 ± 2.32
Activities daily living	14.97±7.66
Motor examination	31.24±15.24
Complications of therapy	1.93±2.33
MMSE	27.47±3.34

^{*} Values are expressed as n (%), mean±SD, or mean±SD (range)

All items were completed by 95.0% of the participants; five patients neglected four items. All data shown in Table 2, with the exception of test-retest reliability, were from the first time. In addition, Cronbach's α was acceptable for all the dimensions (0.84–0.88). Sixty-eight patients returned their retested questionnaires (PDQ-39) within roughly 7 d. The test-retest reliability was adequate for five dimensions (ICC: 0.71–0.82), but not for three dimensions (emotional well-being: 0.62; stigma: 0.67; social support: 0.56) (Table 2).

The item-total correlations from the first time were adequate for most of the items in Table 3 (r=0.33–0.88). Overall, 92.31% of all item-total correlations met the minimum acceptable item-convergent validity criteria (0.40). The average definite scaling success rate for tests of item-discriminant validity (showing that the item-to-own scale correlations exceed the item-to-other scale correlations) was 77.56%.

For convergent validity, the mobility dimension of the PDQ-39 correlated satisfactorily with the ADL subscale of the UPDRS (r=0.63), the ADL (PDQ-39) correlated significantly with the ADL subscale of the UPDRS (r=0.65), but not as high when measured

with motor skills (UPDRS) (r=0.44) (Table 4). The stigma (PDQ-39) did not correlate well, however, with all four subscales of the UPDRS. The following correlations were found to be acceptable between the PDQ-39 and SF-36 (Table 5): (1) correlations between the mobility of the PDQ-39 with physical function and role-physical of the SF-36 (r=-0.68; r=-0.69); (2) correlations between ADL of the PDQ-39 and physical function and role-physical of the SF-36 (r=-0.58; r=-0.53); (3) correlation between emotional wellbeing of the PDQ-39 and mental health of the SF-36 (r=-0.50); and (4) correlation between bodily discomfort (PDQ-39) and bodily pain (SF-36) (r=-0.63). The correlation was not high, however, between social support of the PDQ-39 and social function (SF-36) (r=-0.46), nor between stigma (PDQ-39) and all subscales of the SF-36. These correlations were negative because higher scores on the SF-36 represent a better condition while higher scores on the PDQ-39 represent a worse condition. Most of the dimensions of the PDQ-39 were able to discriminate patients at different H & Y stages (P<0.05), except for stigma, cognitions, and bodily discomfort dimensions of the PDQ-39, as shown in Table 6.

Table 2 Distribution and reliability of PDQ-39 scores^a

PDQ-39 dimension/index	Mean (SD) ^b	Median (inter-quartile) ^c	Floor/ceiling effect (%) ^d	Cronbach's α ^e	Test-retest ICC ^f	Success/ total	Scaling success rate (%) ^g
Mobility	33.73 (28.12)	30.0 (10.0, 52.5)	12.7/1.4	0.86	0.77	73/80	91.25
Activities daily living	28.35 (27.37)	20.8 (4.2, 41.7)	16.9/4.2	0.87	0.82	44/48	91.67
Emotional well-being	31.57 (22.29)	25.0 (16.7, 45.8)	4.2/0	0.87	0.62	42/48	87.50
Stigma	24.56 (27.49)	18.8 (0, 37.5)	32.4/1.4	0.88	0.67	29/32	90.63
Social support	19.48 (22.67)	16.7 (0, 33.3)	43.7/0	0.87	0.56	9/24	37.50
Cognitions	35.65 (21.74)	31.3 (18.8, 43.8)	2.8/2.8	0.87	0.71	8/32	25.00
Communication	28.64 (27.01)	16.7 (0, 58.3)	26.8/0	0.86	0.77	19/24	79.17
Bodily discomfort	35.09 (23.98)	25.0 (16.7, 50.0)	8.5/1.4	0.87	0.82	18/24	75.00
PDQ-39 summary index	29.63 (17.35)	29.1 (15.1, 39.6)	0/0	0.84	0.82		

^a All data, except for test-retest reliability, were from the first time; ^b Scores for all dimensions/summary indexes range from 0 to 100, with higher score indicating worse health-related quality of life (HRQOL); ^cThe first figure in the bracket is P₂₅ (the 25th percentile) and the second figure in the bracket is P₇₅ (the 75th percentile); ^d Percentage scoring 0 (floor) and 100 (ceiling) should not exceed 15%; ^e *n*=71; ^f *n*=68. Agreement model intra-class correlation coefficients (ICC) from scores of patients completing both administrations (7-d interval); ^g Percentage of occasions when items correlated significantly stronger with their proposed scale than with other scales

Table 3 Spearman's rank correlation coefficients (r) between the items and dimensions^a

PDQ-39 item and dimension	r	PDQ-39 item and dimension	r
Mobility		Stigma	
Had difficulty doing the leisure activities you would like to do	0.79	Felt you had to conceal your Parkinson's disease from people	0.58
Had difficulty looking after your home, e.g., doing it yourself (DIY), housework, cooking	0.84	Avoided situations which involve eating or drinking in public	0.67
Had difficulty carrying bags of shopping	0.72	Felt embarrassed in public due to having Parkinson's disease	0.82
Had problems walking 1 km	0.78	Felt worried about other people's reaction to you	0.76
Had problems walking 100 m	0.75	Social support	
Had problems getting around the house as easily as you would like	0.69	Had problems with your close personal relationships	0.42
Had problems getting around in public	0.88	Lacked support in the ways you need from your spouse or partner	0.56
Needed someone else to accompany you when you went out	0.70	Lacked support in the ways you need from your family or close friends	0.52
Felt frightened or worried about falling in public	0.67	Cognitions	
Been confined to the house more than you would like	0.69	Unexpectedly fallen asleep during the day	0.36
Activities of daily living (ADL) Had difficulty washing yourself	0.60	Had problems with your concentration, e.g., when reading or watching TV	0.44
Had difficulty dressing yourself	0.75	Felt your memory was bad	0.33
Had problems doing up buttons or shoe laces	0.79	Had distressing dreams or hallucinations	0.36
Had problems writing clearly	0.70	Communication	
Had difficulty cutting up your food	0.64	Had difficulty with your speech	0.78
Had difficulty holding a drink without spilling it	0.66	Felt unable to communicate with people properly	0.88
Emotional well-being		Felt ignored by people	0.51
Felt depressed	0.71	Bodily discomfort	
Felt isolated and lonely	0.72	Had painful muscle cramps or spasms	0.63
Felt weepy or tearful	0.63	Had aches or pains in your joints or body	0.65
Felt angry or bitter	0.65	Felt unpleasantly hot or cold	0.54
Felt anxious	0.78		
Felt worried about your future	0.57		

^a All data were from the first time, corrected for overlap (n=71)

Table 4 Correlations between PDQ-39 and UPDRS scores

PDQ-39 dimension/index	UPDRS dimension					
	Mentation, behavior, and mood	Activities of daily living	Motor	Complication of treatment		
Mobility	0.53	0.63	0.43	0.40		
Activities of daily living	0.34	0.65	0.44	0.16^{c}		
Emotional well-being	0.44	0.31^{a}	0.24^{b}	0.33		
Stigma	0.24 ^b	0.25 ^b	0.20^{c}	0.30^{a}		
Social support	0.48	0.35	0.17^{c}	0.21 ^c		
Cognitions	0.36	0.37	0.10^{c}	0.18^{c}		
Communication	0.50	0.54	0.31^{a}	0.21 ^c		
Bodily discomfort	0.45	0.45	0.30^{a}	0.22^{c}		
PDQ-39 summary index	0.64	0.68	0.45	0.37		

P<0.001 unless otherwise stated: ^a P<0.01; ^b P<0.05; ^c No statistical significance

SF-36 dimension PDQ-39 dimension/index Physical Role-**Bodily** General Social Role-Mental health function physical pain function emotional health Mobility -0.68-0.69-0.35-0.43-0.66-0.43 -0.35^{a} Activities of daily living -0.58-0.53 -0.08° -0.28^{b} -0.57-0.34 -0.31^{a} Emotional well-being -0.25^{b} -0.37 -0.24^{b} -0.25^{b} -0.43-0.33-0.50Stigma -0.28^{b} -0.32^{a} -0.22^{c} -0.16^{c} -0.43 -0.25^{b} -0.33^{a} Social support -0.35^{a} -0.33^{a} -0.38 -0.28^{b} -0.37 -0.31^{a} -0.46 -0.18^{c} Cognitions -0.28^{b} -0.28^{b} -0.23^{b} -0.32 -0.37^{a} -0.17^{c} Communication -0.43-0.34 -0.17^{c} -0.31^{a} -0.59 -0.32^{a} -0.37^{a} -0.09^{c} Bodily discomfort -0.43-0.34-0.63-0.37 -0.32^{a} -0.13^{c} PDQ-39 summary index -0.64-0.58-0.41-0.43-0.71-0.45-0.44

Table 5 Correlations between PDQ-39 and SF-36 scores using Spearmen's rank correlation coefficients

P<0.001 unless otherwise stated: ^a P<0.01; ^b P<0.05; ^c No statistical significance

Table 6 Chinese (mainland) version of the PDQ-39 in all stages of the disease by the categories of Hoehn and Yahr scale

PDQ-39 dimension —	H & Y scale ^a				
	Stage I (n=17)	Stage II (n=38)	Stage III (n=8)	Stages IV & V (n=8)	P^{b}
Mobility	15.74 (15.48)	32.11 (23.86)	38.44 (29.34)	75.00 (26.76)	0.000
Activities of daily living	17.40 (17.88)	24.78 (19.59)	16.67 (28.08)	80.21 (18.87)	0.000
Emotional well-being	19.36 (13.81)	34.43 (23.62)	35.42 (21.71)	40.10 (24.59)	0.048
Stigma	19.12 (26.65)	24.84 (23.94)	25.00 (24.55)	34.38 (46.05)	0.764
Social support	6.37 (13.98)	23.03 (21.17)	21.88 (24.37)	28.13 (33.91)	0.026
Cognitions	29.41 (17.51)	33.72 (18.01)	46.88 (28.93)	46.88 (32.73)	0.408
Communication	10.78 (14.06)	30.92 (26.77)	40.63 (29.69)	43.75 (30.78)	0.013
Bodily discomfort	28.43 (16.94)	34.43 (25.50)	31.25 (21.71)	56.25 (23.46)	0.064

 $^{^{\}rm a}$ Data are expressed as means (SD), $n{=}71;\,^{\rm b}$ Using Kruskal Wallis test

4 Discussion

Our study shows that the Chinese (mainland) version of the PDQ-39 has acceptable reliability and validity in our study population. In addition, we provide comparisons with those data from Taiwan (China), Hong Kong (China), and Singapore (Tsang et al., 2002; Luo et al., 2005; Ma et al., 2005). The Cronbach's α in our study ranged from 0.84 to 0.88, compared with those of Taiwan (α =0.58–0.96) and Hong Kong (α =0.54–0.90). Our results demonstrate that the internal consistency of the Chinese (mainland) version of the PDQ-39 is satisfactory. The item-total correlations ranged from 0.33 to 0.88, higher than those of both Singapore (r=0.15-0.79) and Hong Kong (China) (r=0.25–0.82). Three items had correlations less than 0.4, however, in the dimension of cognitions: 'unexpectedly falling asleep during the day' (r=0.36), 'felt your memory was bad' (r=0.33),

and 'distressing dreams or hallucinations' (r=0.36), which was similar to Singapore and Taiwan (China) (Luo et al., 2005; Ma et al., 2005). It may be that cultural differences were the reason why these items were difficult to translate accurately. The scaling success rate also indicated acceptable itemdiscriminant validity for the PDQ-39, except for cognitions (25.0%) and social support (37.5%). This suggests that the grouping of the items in these two dimensions is not good and they need be improved. For nearly half the scales, the floor effect was observed in social support (43.7%), communication (26.8%), and stigma (32.4%) dimensions, similar to Singapore and the UK (Peto et al., 1995; Luo et al., 2005). It should be noted that the floor effects are not related to the various translations. Large floor effects indicate that actual differences and changes, outside the range covered by these subscales, between those patients with minimum scores will not be detected. This implicates that these problematic subscales are not likely to be good choices as outcome measures and they should be changed or improved after further investigation.

The correlations between the PDQ-39 and UPDRS (Table 4) and between the PDQ-39 and SF-36 (Table 5) showed acceptable convergent validity. The correlation between emotional well-being (PDQ-39) and mental health (SF-36) (r=-0.50) was consistent with the result of a Spanish study, in which depression was found to correlate significantly with all scales of the PDQ-39 (P<0.01) (Katsarou et al., 2001). The discriminative validity of our study was acceptable, but not to the extent that was found in the Taiwan study (Tsang et al., 2002). Five dimensions of the PDQ-39 were able to distinguish patients at different H & Y stages with the exception of three dimensions: stigma, cognitions, and bodily discomfort. The PDQ-39 score trends were in the right direction, as the score increased with H & Y stages. In comparison, Taiwan only had one dimension (bodily discomfort) that could not reliably discriminate patients at different H & Y stages. One reason could be that the number of subjects was too small in stages III (n=8), IV, and V (n=8) to yield reliable data.

To date, this is the first study testing the reliability and validity of the PDQ-39 in Chinese mainland, providing comparisons of research results at an international level. We provided a foundation for evaluating PD patients with the PDQ-39 in countries with different language, cultures, and lifestyles. Our study has some limitations. First, we neglected to ask patients to record changes in their disease states during the 7 d. This is necessary in order to exclude patients with significant changes in their disease severity. Changes in disease severity, however, during this time frame are generally considered to be small, and thus may be disregarded. Nonetheless, our results demonstrated acceptable test-retest reliability. Second, the sample size may not be large enough to generalize to other study populations. There should be larger samples in future studies. Finally, our patients were not very severe and there were too small number of patients in H & Y stages III, IV, and V, which resulted in the PDQ-39 data in our study to be heavily skewed towards the less severe end. Our sample may pose some limitations to the generalizability of the results, but the sample represented similar ranges of disease

severity, duration, and ages with previous studies such as Taiwan (Ma *et al.*, 2005), suggesting it was fairly representative. The primary purpose of this study, however, was to assess its measurement properties for the Chinese (mainland) version of the PDQ-39 and provide data to inform further study of the PDQ-39 for PD patients in Chinese mainland. Future studies should include a balanced representation of patients from all stages of PD. In conclusion, this study suggests acceptable reliability and validity of the Chinese (mainland) version of the PDQ-39, specifically for PD patients with less severe symptoms.

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