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Original Article

Development, reliability and validity of the psychosocial adaptation scale for Parkinson's disease in Chinese population

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Abstract: Objective: To develop psychosocial adaptation scale for Parkinson's disease (PD) in Chinese population and evaluate its reliability and validity. Methods: The items were designed by literature review, expert consultation and semi-structured interview. The methods of corrected item-total correlation, discrimination analysis and exploratory factor analysis were used for items selection. 427 valid scales from PD patients were collected in the study to test the reliability and validity. Results: The scale incorporated six dimensions: anxiety, self-esteem, attitude, self-acceptance, self-efficacy and social support, a total of 32 items. The scale possessed good internal consistency. The test-retest correlation coefficient was 0.99 and average content validation rate was 0.97. The Hoehn and Yahr stage were correlated with total score of the scale. Conclusions: The psychosocial adaptation scale in this study showed good reliability and validity, it can be used as a reliable and valid instrument to evaluate the psychosocial adaptation of PD objectively and effectively.

Keywords: Parkinson's disease, psychosocial adaptation, scale, reliability, validity

Introduction

Parkinson's disease (PD) is a degenerative disorder of the central nervous system. In the early course of the disease, the most obvious symptoms were the movement-related, which included rigidity, tremor, bradykinesia and postural instability. And in the advanced stage, thinking and behavioral problems might arise, as well as sensory, sleep and emotional problems. The prevalence is estimated to be 100 to 200 cases per 100,000 and the annual incidence is 20 cases per 100,000 in the world [1-3], and increased with higher age. In China, the incidence of PD were 2 per 100,000 and 797 per 100,000 person-years, and for the populations more than 80 years old, the prevalence as high as 1,663 per 100,000 [4]. As a developing country with a huge population and rapid speed in aging societies, China might face an increased social burden associated with PD.

For people with PD, the disease had a considerable impact on their quality of life (QoL). QoL was a concept to describe the patient own evaluation on the impact of disease, it covered the physical, psychological, spiritual and socioeconomic status [5]. But in medicine, more attentions were paid on the health-related quality, and ignored their individual's self-perception on the disease, as well as the comprehensive evaluation on the status of psychology and society. Due to the slight chance to recovery for this chronic progressive illness, the induced problems of adjustments should not be neglected [6]. However, there was not a clear definition of the concept in medicine. From other researches [7, 8], the psychosocial adaptation can be regarded as a process of change in patient's reactions and subjective experience triggered by the disease. In the face of changes and pressures brought by the disease, most of the patients showed bad psychosocial adaptation, the lack of attention and support of psychosocial issues to PD patients might influence their therapy, prognosis [9]. Hence, the considerable impact of PD on their psychosocial functioning should be evaluated.

The psychosocial measurements on PD were usually evaluated with generic or disease-specific health-related QoL instruments [10]. These instruments were effective tools in clinical studies, but they did not concentrate on the psychosocial aspects of PD. Some researchers used the combination of generic and PD-specific QoL measurement [11-13], however, they were hard to acquire the specific problems of psychosocial adjustment on PD patients. Recently, some specific instruments were developed, such as the psychosocial questionnaire Belastungs-fragebogen Parkinson kurzversion (BELA-P-k) [14], scales for outcomes in parkinson's disease-psychosocial questionnaire (SCOPA-PS) [10]. They were tested to be valid and useful in assessing the psychosocial issues in PD.

In an integrated approach, psychological counseling and interventions were indispensable. It has been revealed that the psychological factors [9], including the stage of the disease, the age and marital status of the patient and/or caregiver, and the coping styles of the patient and their family members, could seriously influence the quality of life and the ability to cope with psychosocial stress in PD patients [15, 16]. Psychological status should be regarded as an important variable in the management of PD patients, as well as the focus of the clinical investigations. Mastering their psychological status and helping them to cope with the everyday situations might contribute to the improvement of the serious illness. However, there were no definite clinical indexes for the poor psychological status. Nowadays, scale evaluation is becoming an important tool to solve these problems. However, there was no unified, generally accepted scale to assess the extent to which the patient is bothered by the psychosocial problems or psychosocial levels specifically for PD in China. Herein a PD-specific psychosocial adaptation instrument which only focused on the psychosocial impact was conducted. The aim of this study was to develop a psychosocial adaptation scale for PD patients, and to evaluate its reliability and validity.

Participants and methods

Development of the psychosocial adaptation scale

The study was a Measurement development study. The characteristics of psychosocial adaptation with PD were the basis for the development of scale. In order to ensure a broad scope of symptoms were involved in the initial scale, the information was collected from a semi-structured interviews with PD patients about the areas of their lives that had been influenced. Other items were added by the literature review concerning the problem of psychosocial adaption for PD [10, 17, 18] and referred to the former psychosocial scales [7, 10, 19, 20], as well as the advices/suggestions of specialists specialised in psychology, neurology and nursing (n = 12).

The initial generated scale consisted of 43 items, totally six dimensions. The participants were asked to complete the scale with the use of 4-point Likert scale, each item with the answers "completely inappropriate" "a little appropriate" "mostly appropriate" and "entirely appropriate" scored as 1, 2, 3 and 4 points, respectively.

Sample

From July 2014 to February 2015, patients with idiopathic PD treated/hospitalized at the Department of Neurology, the First Affiliated Hospital of Dalian Medical College were enrolled in study. All participants met the following inclusion criteria: (1) aged over 18 years old, (2) diagnosed with an idiopathic PD, (3) ability to understand all the items in the scale, and were willing to be interviewed. The exclusion criteria were as follows: (1) severe cognitive impairment or mental disorders, (2) serious cardiovascular disease or other diseases that seriously affect QoL, (3) Parkinsonism-Plus. All the eligible patients singed the informed consent. The study was approved by the institutional review board at The First Affiliated Hospital of Dalian Medical University. At last, a total of 427 persons responded, including 218 male and 209 female. The sample in the age range of 46-87 years old and their Hoehn and Yahr Staging was 1-3.5 according to the modified H&Y Staging Scale [21]. The scale was completed by patients themselves or with the nurse's assistances for the illiterate ones. Assessment was performed in a quiet room away from disturbance and time consumed within 20 minutes.

Validity, reliability and statistical analysis

SPSS 19.0 software was used for data entry and analyzing. The item reduction and scale generation was completed with multiple meth-

Table 1. Demographic data of the study population (*n* = 427)

Variable	Case	Percentage (%)
Age		
<50	16	3.7
50-60	123	28.8
60-70	130	30.5
≥70	158	37.0
Gender		
Male	218	51.1
Female	209	48.9
Modified H&Y grade		
1	50	11.7
1.5	37	8.6
2	161	37.8
2.5	97	22.7
3	79	18.5
3.5	3	0.7
Education		
Junior high school or below	250	58.6
High school/Technical secondary school	89	20.8
Junior college or above	88	20.6
Monthly family income (RMB)		
≤1000	102	23.9
1000-3000	190	44.5
3000-5000	109	25.5
5000-10000	26	6.1
Marital status		
Married	377	88.3
Unmarried	3	0.7
Live separate and apart	1	0.2
Widowed	35	8.2
Divorced	11	2.6
Living status		
Living alone	9	2.1
Living with others	418	97.9
Living partners		
Spouse	363	85.0
Others	64	15.0
Medical payment		
Self-paying	86	20.1
Chronic disease medical insurance	244	57.2
Basic medical insurance	82	19.2
Others	15	3.5

ods, (1) corrected item-total correlation: calculated the correlation coefficient between the score on the item and the sum on all items, elected the ones with *P* value less than 0.05; (2) the degree of dispersion analysis: the interquartile range of each scale was calculated and selected the ones with the value ≥ 1; (3) exploratory factor analysis: the items had a factor loading of 0.4 or greater were elected. The items met the above requirements were screened out and listed as the final items.

The internal consistency of the scale was estimated with Cronbach's α coefficient. The test-retest reliability was assessed by asking the participants to conduct a second measurement after 15 days.

Validity is a quantitative assessment of how well it measures what it claims to measure [11]. Content validity was supported by the judgement of specialists in psychology and nursing. In the criterion-related validity test, self-rating anxiety scale (SAS), general self-efficacy scale (GSES) and self acceptance questionnaire (SAQ) were adopted as criterions, to calculate the Pearson's correlation coefficients. SAS was a 20-item self-report assessment device to quantify the level of anxiety [22]. GSES measured the strength of an individual's belief in his/her own ability to respond to novel or difficult situations and to deal with any associated obstacles or setbacks [23]. SAQ was a scale to evaluate the features of self-esteem, self-abased and self-acceptance [24]. Confirmatory factor analysis (CFA) was performed to assess the goodness of fit of the model to the data. Variance analysis was used to compare the total scores of patients in different stages and test the discrimination validity of the scale.

Results

The structure of the scale

Valid scales were collected from July 2014 to February 2015, a total of 427 idiopathic PD patients, including 51.1% male. The mean age was 66.9 years old. Demographic characteristics of the participants were shown in **Table 1**.

Table 2. Item to total correlations and factor loadings of the elected items in the psychosocial adaptation scale

Items	Item to total correlation		Loading
	r	P	
Anxiety			
Felt isolated and lonely	0.507	0.00424	0.594
Felt anxious and cannot calm down	0.768	0.00000	0.632
Felt tired to do anything	0.515	0.0036	0.508
Emotional states varied with symptoms	0.691	0.00002	0.631
Felt weepy or tearful	0.542	0.00196	0.571
Sleep difficulties	0.488	0.00627	0.434
Felt worried about the future	0.734	0.00000	0.627
Self-esteem			
Being content with yourself	0.566	0.00111	0.502
I felt I like a loser	0.764	0.00000	0.721
Felt there are nothing to be boasted	0.619	0.00027	0.724
Felt uneasy when talk about your illness	0.719	0.00001	0.557
Attitude			
Unstable in emotion	0.742	0.00000	0.671
Unsatisfied with yourself	0.695	0.00002	0.624
Keep your problems locked up inside	0.587	0.00065	0.578
Accept your illness and face the changes positively	0.427	0.01853	0.418
Persuaded yourself that life is not worth living	0.622	0.00024	0.715
Can not accept the fact of illness	0.514	0.00363	0.603
Self-acceptance			
Wonder why I became sick	0.513	0.00375	0.609
I can not do something as before	0.447	0.01320	0.493
I lost my own individuality	0.357	0.05263	0.534
My mind is limited seriously	0.521	0.00313	0.589
Self-efficacy			
Felt impossible to become better by myself	0.651	0.00010	0.436
Felt there is little to do for recovering	0.450	0.01251	0.430
Felt there is little to do for smooth life in future	0.539	0.00212	0.498
Hard to hold on my temper	0.476	0.00780	0.532
Social support			
Short of sense of security	0.667	0.00006	0.710
Felt isolated from others	0.750	0.00000	0.731
Your circle of friends is shrinking	0.655	0.00008	0.601
Do not participate in group activities regularly	0.715	0.00001	0.583
Became quietly at home behind closed doors	0.516	0.00353	0.515
Can not sure what kind of help I need	0.712	0.00001	0.580
Felt nobody understand my situations	0.506	0.00438	0.594

The initial item pool contained 43 items, after item reduction, 32 items were screened out to form the scale. **Table 2** showed the correlations of items to total scale and factor loadings of the elected items. The scale consisted of six dimensions. *Anxiety* (seven items) addressed the problems of anxiety/depression, "inability to relax, restlessness, feeling tense, worrying thoughts" were prominent anxiety symptoms in PD [25]. *Self-esteem* (four items) addressed the problems of their lower self-esteem and confidence. *Attitude* (six items) addressed the problems of their attitude towards to the changes arising from the disease. *Self-acceptance* (four items) addressed various problems of their negative attitude. *Self-efficacy* (four items) reflected the problems of their own confidence or faith on whether they had ability to cope with life. *Social support* (seven items) reflected the support perceived from social relationship. A higher score represented a better psychosocial adaptation.

Reliability

Table 3 showed the value of Cronbach's α coefficients and test-retest reliability of psychosocial adaptation scale. The Cronbach's α coefficient for the overall psychosocial adaptation questionnaire was 0.938, while those for each dimension were 0.784, 0.757, 0.78, 0.683, 0.666 and 0.835, respectively. Test-retest reliability of the scale was calculated from the responses of 30 patients who were selected randomly and remeasured after 15 days. Good rest-retest reliability was obtained,

Table 3. Internal reliability (Cronbach's alpha) and test-retest reliability of scale (n = 427)

	Cronbach's alpha	Test-retest reliability
Anxiety	0.784	0.988
Self-esteem	0.757	0.978
Attitude	0.780	0.944
Self-acceptance	0.683	0.970
Self-efficacy	0.666	0.995
Social support	0.835	0.881
Total	0.938	0.990

Table 4. Correlations between the self-rating anxiety scale (SAS), general self-efficacy scale (GSES) and self acceptance questionnaire (SAQ)

Criterions	Correlations	P
SAS	0.711	<0.001
GSES	0.499	<0.001
SAQ	0.563	<0.001

Table 5. The scores of Psychosocial Adaptation Scale of patients in different PD stages

H&Y stage	Average total score	SD	*F*	P
1-1.5	100.11	20.78	11.761	<0.001
2-2.5	80.96	21.90		
3-3.5	81.72	19.67		

the correlation coefficients with the scale and six dimensions of two measurements were 0.990, 0.988, 0.978, 0.944, 0.970, 0.995 and 0.881.

Validity

Twelve specialists and ten PD patients evaluated the content validity and face validity of the scale. The content validation rate was in the range of 0.8-1.0, and the average rate was 0.97±0.21. The PD patients judged that the content in the scale were appropriate, comprehensive and in a good description. The correlations between psychosocial adaptation scale and SAS, GSES, SAQ were analyzed by Pearson coefficients, they were 0.711, 0.499 and 0.563 (**Table 4**). The results revealed good criterion validity.

Construct validity was examined by means of CFA. CFA allows hypothesized structures, based on the associations among the items, to be drawn up and then tested for goodness of fit to the actual data [26]. Comparative fit index (CFI) was a comparative goodness-of-fit index. The analysis of the scale produced CFI value of 0.664, and a X^2 of 2936.251 (P<0.01). The Hoehn and Yahr staging was used to evaluate the severity of PD, a higher stage showed greater levels of functional disability [27] Participants were classified according to their different modified H&Y staging [21]. The scores of patients in different PD stages differed significantly (**Table 5**). The mean score for group 1 (H&Y 1 and 1.5) was 100.11 (SD = 20.78), and that for group 2 (H&Y 2 and 2.5) and 3 (H&Y 3 and 3.5) was 80.96 (21.92) and 81.72 (19.67). From the results of the least significant difference (LSD) pairwise multiple comparison test, the differences of the scores were not significant in stage 1-1.5 and stage 2-2.5, but were significant with stage 3-3.5 (P<0.01).

Discussion

Parkinson's disease is a common neurodegenerative disease in middle-aged and elderly people, which may affect their quality of life. In the previous surveys, more attentions were paid on the improvement of PD symptoms, sign index and dyskinesia, while neglected the nonmotor features such as depression, apathy, mood changes. Faced with the abnormalities brought by disease, most of the patients were shown in an inadaptable situation when facing their daily life, and even affected their treatment, prognosis of the disease. Even worse, the psychosocial consequences of PD was rarely evaluated separately and in-depth [28]. Hence, it was of great importance to assess the psychosocial adaptation on PD patients.

In this study, we develop a suitable psychosocial adaptation scale for PD. The internal consistency of the scale was acceptable (with Cronbach's α coefficient 0.938). A previously designed instrument, scales for outcomes in Parkinson's disease-psychosocial questionnaire (SCOPA-PS) had been transformed into several versions in different languages/cultures. Results from similar studies on SCOPA-PS revealed that the internal consistency was in the range of 0.83-0.90 [19]. This reflected a good internal consistency of psychosocial adaptation scale in this study. The correlation coefficient between test and retest after 15

days was 0.990, which indicated the test-retest reliability was high.

Content validity referred to the extent which the measure represented a given objective. In the development of the scale, based on the consultations of experts and feedbacks from interviews with different patients, the scale had typical and common characteristics. Other scales SAS, SAQ and GSES were chosen as outside criterion to get the criterion validity of the scale, the moderate correlations were found. This probably because SAS, SAQ and GSES were specific to psychological evaluations in normal population, some special items for PD, such as "I wondered why I became sick" were not reflected. Thus, the three scales and adaption scale for PD were not closely associated. For CFI, value of 0.90 or higher were recommended as a standard to judge the adequacy [29]. In this study, the fitting effect was not well, which reflected the need of further improvement in the current scale. Furthermore, according to our results, patients with higher H&Y stages had more problems with their psychosocial function. Psychosocial adaptation scale scores was able to discriminate between H&Y 1-2.5 and H&Y 3-3.5, but H&Y 1-1.5 and H&Y 2-2.5 were indistinguishable. It might due to the subtle difference with the respect to physical function and disease symptoms between these stages.

The comprehensive scale measured the anxiety, self-esteem, attitude, self-acceptance, self-efficacy and social support to a total of six dimensions. The item-total correlation coefficients of the items were in the range of 0.246 to 0.768. The highest correlation score (0.768) referred to item 2 "I always felt anxious and cannot calm down". Dissanayaka [25] reviewed on the prevalence of anxiety in PD, and pointed out that anxiety added to the burden of disease. The occurrence of depression was a psychogenic reaction to this chronic disease, some social events such as retirement and loss of spouse contributed or exacerbated their depression. Self-esteem and self-acceptance were closely related, self-acceptance was a self-attitude formed on their assessment and was the essential feature of self-esteem. Self-esteem with higher item-total correlations, low self-esteem meant more depressive and anxious emotions, which went against their relief to conquer diseases. Some PD patients could not accept the fact of their illness, they felt shame for the changes accompanied with the disease, while the ones with high self-acceptance could accommodate the changes properly. The ways to react the disease could directly affect their QOL and survival. Pan [30] found that a positive way and attitude of acceptance contributed to the higher QOL. Self-efficacy was the confidence or faith that people needed in achieving behavior target in specific field. Previous studies revealed that PD patients with higher self-efficacy achieved higher level of psychological health [31]. The social support acquired for the patients were also closely related to their health status. It was proven [32] that the importance of adequate social support to PD patients in helping them to cope with current stress.

Conclusion

The scale established in the current study was an appropriate, rational and convenient tool in measuring psychosocial problems in PD patients. It has been shown to be reliable and valid. The level of psychosocial adaptation could be evaluated comprehensively. Further evidence of the reliability and validity of this scale will be accumulated over time as the scale is administered to more PD patients. Other limitations in this scale will be improved, for instance, the negatively feelings might influence their objective choice in face of some items, the patients in H&Y grade 4-5 stayed at home were not enrolled in this study. Further research is required to overcome the potential drawbacks.

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Disclosure of conflict of interest

None.

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