

Development of the Forman Parkinson's Disease Symptom Checklist

Bushra Akram¹, Ivan Suneel²**Abstract**

Parkinson's disease (PD) is defined as a neurodegenerative disease which progresses slowly and adversely impacts the quality of life; although this disease is not fatal, however, it is quite debilitating not only for the patients but for the caregivers too (DeMaagd & Philip, 2015; Golbe et al., 2012). Approximately, there are above 600,000 individuals suffering from PD; number of cases remains undiagnosed because of lack of awareness in far flung areas and unavailability of culturally appropriate measuring tool (Mansoor, 2017). Considering the aforementioned, this research was conducted to develop culturally validated assessment tool on Parkinson's disease (PD). Moreover, the method section constituted of five steps (Zhou, 2019) which includes the detail of item generation, rating of the list by professionals and entering data in SPSS. Purposive sampling was done for the main study constituted of 100 patients suffering from PD (87% males and 13% females) between ages of 20-80 ($M=20$, $SD=14.04$). The factor analysis showed two factor solution through principal component analysis with rotation Direct Oblimin. The two factors were named as motor symptoms and non-motor symptoms respectively and had adequate psychometric properties.

Keywords: Parkinson's Disease (PD), Factor Analysis, Direct Oblimin, Psychometric Properties

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Introduction

Reportedly, Hussain et al. (2017) and Mansoor (2017) suggested in their study, there are 450,000 individuals suffering from PD in Pakistan and was highlighted as second most common neurodegenerative disease after Alzheimer (Mukhtar et al., 2018). It was reported in one of the studies that neurological disorders are considered as the fifth cause of death universally which would

get doubled by 2030. Moreover, it was explained that the ratio of number of neurologists working for the patients (1: 100,000) in Pakistan were far less than high income countries whereas treatment facilities at hospitals were inadequate (Correspondent, 2018; Ghulam et al., 2017; Tribune, 2018; Tufail, 2019). The researchers found that 117 individuals out of 10,786 were suffering from PD in the rural and urban areas of Karachi (Awan et al., 2019).

The neurological disorder consists of the death of neuron cells which varies from patient to patient (Ghulam et al., 2017; Tribune, 2018; Tufail, 2019) and its occurrence was significantly reported among the aged; 55 or more (Ghulam et al., 2017; Kruger et al., 2017; Rizek et al., 2016). However, 10% of the sufferers are below the age of fifty. It had been implied, PD is considered as the age of elderly, therefore, its symptoms had been misinterpreted by the

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physicians and the patients as the signs of old age.

Unfortunately, it had been highlighted that Pakistan lack data regarding frequency and occurrence of neurological disorders. Pakistan Medical and Research Council proposed to do research and they could not reach fruition because of the paucity of culturally validated tool. World Health Organization aimed to assess neurological disorders by devising simple questionnaires but those were not validated for Pakistan (Wasay & Ali, 2010). According to a report, Pakistan lack screening tool for assessing neurological disorders and whenever researches are conducted, non-validated neurological assessments are employed (Mahmood & Bashir, 2018; Naeem et al., 2016; Saad et al., 2017).

PD is defined as neurodegenerative disease which progresses slowly; constitutes of motor and non-motor symptoms (Faust et al., 2020; DeMaagd & Philip, 2015). The motor symptoms include resting tremors, rigidity, bradykinesia (slowness in actions) (Obeso et al., 2017) and postural instability whereas non-motor symptoms include pain, olfaction, low blood pressure, constipation, excessive sweating (Kruger et al., 2017; Obeso et al., 2017; Oliveira & Cardoso, 2021), drooling (Chen et al., 2020; Srivanitchapoom et al., 2014) and rapid eye movement sleep behavior disorder (Kim et al., 2007; Kruger et al., 2017). Moreover, non-motor symptoms also include mood related symptoms (anxiety and depression) and also tend to develop dementia (Kruger et al., 2017; Obeso et al., 2017).

Considering the previous studies (Correspondent, 2018; Naeem et al., 2016; Saad et al., 2017; Wasay & Ali, 2010), it is important to design a screening tool for assessing Parkinson's disease as non-standard assessment (Mini Mental Status Examination- MMSE) or the Western tools are implemented. The purpose of this

research is to construct a tool on PD by taking sample from different government facilities in Lahore.

Method

A comprehensive mix method model for scale development constituting of five steps (Zhou, 2019) was employed for this research. The first step (qualitative investigation of the scale construct) subsumed the discussion about item generation through deductive (analysis of literature review) and inductive methodology (interviewing the participants). The data was collected through purposive sampling and the purpose was to collect the data from the participants until the saturation point is reached; where no new information could be elicited. In order to gather data, three sources were consulted including the professionals (neurologists and psychiatrists), the caregivers and the patients. The professionals who had done MBBS (Bachelor of Medicine and a Bachelor of Surgery) and FCPS (Fellowship of College of Physicians and Surgeons) in neurosurgery, having other degrees in neurology, working as neurologist or psychiatrists either in private or government sectors were invited to be the part of study. Furthermore, the patients of any age and gender who had been given the confirmed diagnosis of PD were allowed to be the part of study. Those patients who were in the later stages of the disease and could not communicate with their caregivers were welcomed to be the part of study. Moreover, the patients who were suffering from other neurological diseases were excluded from the study. Furthermore, the information from those participants were included who used to speak Urdu in a comprehensible way.

This was followed by the second step (mixing phase) of converting interviews into the scale of items which was furthered by the third step (mixing validation); rating of the list of the items by professionals which ensures the content validity of the items. Moreover, the

pilot study was conducted to ensure face validity, which constituted of ten participants based on the study by Anthoine et al. (2014). Furthermore, fourth step constitutes the details of employment of main study by administering the finalized scale along with demographic form on the participants suffering from Parkinson's disease. The objective of implementing demographic form is to record the general information of the participants including age, gender, education, area to which they belong (rural or urban area), marital status, number of children, medical history (blood pressure, diabetes and cholesterol), past history of severe head injury and patient's care taker.

For the main study, sample size was hundred and collected through purposive sampling. According to Costello and Osborne (2005), the data from one hundred participants for scale development is adequate; however, the larger the better was advocated by other

studies (Cremers et al., 2012). The participants of any age, gender and Urdu speaking with only diagnosis of Parkinson's disease by the professionals were included in the study. Furthermore, the data had to be collected from healthy participants in order to determine the validity for the checklist. The fifth step was to enter the data in Statistical Package for the Social Sciences (SPSS) version 20 to run the analysis and calculated the descriptive and inferential statistics.

Results

Section I: Description of the sample (Table 1 & Table 2)

Section II: Factor analysis and psychometric properties of the scale (Table 3, 4, 5, 6, 7, 8, 9)

Section I

Description of the Sample

This section highlighted the descriptive statistics of the sample ($N=100$).

Table 1

Frequency Distribution of Study Variables ($N=100$)

Variables	<i>f</i>	%
Gender		
Male	87	87
Female	13	13
Age		
20-30	5	5
31-40	9	9
41-50	12	12
50+	74	74
Marital status		
Married	96	96
Unmarried	3	3
Divorced	1	1
Number of children		
No child	5	5
1-3	24	24
4-6	46	46
6+	25	25
Education		
uneducated	27	27

Under matriculation (primary/middle)	18	18
Matriculation	17	17
Intermediate	13	13
Higher education (UG/Grad/PG)	25	25
Place of living		
Rural	50	50
Urban	50	50
Medical history		
Not applicable (free of blood pressure, diabetes and cholesterol)	54	54
Blood pressure	33	33
Diabetes	12	12
Cholesterol	1	1
Occupation		
Not applicable (jobless)	26	26
Business	16	16
Private job	41	41
Government job	17	17
Monthly income		
Less than 40K	73	73
41K-60K	13	13
61K-81K	5	5
81K-1lac	9	9
Caretaker of patient		
No caretaker	6	6
Spouse	62	62
Children	24	24
Siblings	4	4
Others (parents/extended fam)	4	4s
Post injury onset of PD		
Not applicable (onset of PD without any head injury or accident)	87	87
Within 6 to 12 months	3	3
Within 12 to 24 months	1	1
More than 24 months	9	9

Note. *f* = Frequency, % = Percentage.

The Table 1 concluded the descriptive results of the sample showed that among the total participants ($N=100$), mostly aged above 50 (74%), there were mostly males (87%), married (96%), and most of the participants

were having children either in the range of 4-6 (46%) or more than 6 (25%). Moreover, most of the participants were having private jobs (41%) and earning less than 40K (73%). Furthermore, there were more participants

suffering from blood pressure (33%), mostly having spouses (62%) and children (24%) as caretakers. However, there was not much

significant finding regarding the place of living and post injury onset.

Table 2

Descriptive Statistics (N=100)

Variables	M	SD
Age	20	14.04
No. of Children	.00	2.41

Note. *M* = Arithmetic Mean, *SD* = Standard Deviation; Aforementioned variables were converted into categorical for further analyses

The Table 2 described the mean and standard deviation (SD) of the continuous variables including age and number of children. The

mean of age and number of children was 20 and .00 whereas their SD was 14.04 and 2.41 respectively.

Section II

Factor Analysis and Psychometric Properties of the Scale Adequacy of the Items

Preceding the factor analysis, an essential step to carry out is to do the assessment of

items which would help in making the item pool free from the ones with correlation <0.3. This would be done through item-total correlation (Field, 2013).

Table 3

Item Number and Item Total Correlation of Forman Parkinson's Disease Symptom Checklist (FPDSC) (N=100)

Item No.	Item-Total correlation	Item No.	Item-Total correlation	Item No.	Item-Total correlation
1	.50	11	.43	21	.34
2	.50	12	.56	22	.38
3	.34	13	.56	23	.52
4	.51	14	.63	24	.33
5	.56	15	.51	25	.27
6	.53	16	.51	26	.19
7	.31	17	-.06	27	.09
8	-0.3	18	.16	28	-.05

9	.47	19	.47	29	-.05
10	.42	20	.34	30	.28
				31	.44

Note. Items with <.3 correlation are highlighted.

From Table 3, it can be concluded that the items whose correlation was less than 0.3

were excluded in running further analysis as these items had less internal consistency.

Factor Analysis

A principal component analysis (PCA) was conducted on 22 variables with oblique rotation (direct oblmin). The Kaiser-Meyer Olkin was done to check the sample adequacy; KMO=.78 which was above 0.6. Also, the Bartlett's Test of Sphericity was also significant ($p=0.000$) Hence, it was proved that sample was adequate to run factor analysis (Pallant, 2016). Furthermore, in order to extract factors, total variance (eigen values with 1 or higher), scree plot and

parallel analysis were considered. However, according to Field (2013), results from parallel analysis are authentic, hence, three factors were extracted. While selecting the different rotations (preferably starting from Varimax, Oblimin and others) and setting the factors to extract three, cross loadings were appeared. However, with two factor extraction along with Oblimin rotation, very minimal cross loadings appear. For the correlation, items with values >0.3 were retained.

Table 4

Kaiser-Meyer-Olkin (KMO) and Bartlett's Test of Sphericity for Sample Adequacy (N=100)

Kaiser-Meyer-Olkin Measure of Sampling Adequacy			.78
Bartlett's Test of Sphericity	Approx. Chi-Square		861.97
	<i>df</i>		231
	<i>p</i>		.000

**** $p < 0.01$**

From Table 4, the value of KMO and Bartlett's Test of Sphericity was significant

which evidenced for the appropriateness of factor analysis.

Table 5

Total Variance Explained (N=100)

Components (factors)	Eigen values	% of Variance	Cumulative %
1	6.43	29.26	29.26
2	2.16	9.85	39.12
3	1.71	7.78	46.90
4	1.22	5.57	52.47

5	1.17	5.33	57.80
6	1.00	4.58	62.39

From the Table 5, it is concluded that six factors could be extracted and the rule of the extraction is the eigen value >1 . However, this rule extracts more factors than necessary and the ultimate goal of factor analysis is to

get optimal number of factors. This could be further confirmed by carrying out scree plot and parallel analysis (Pallant, 2016).

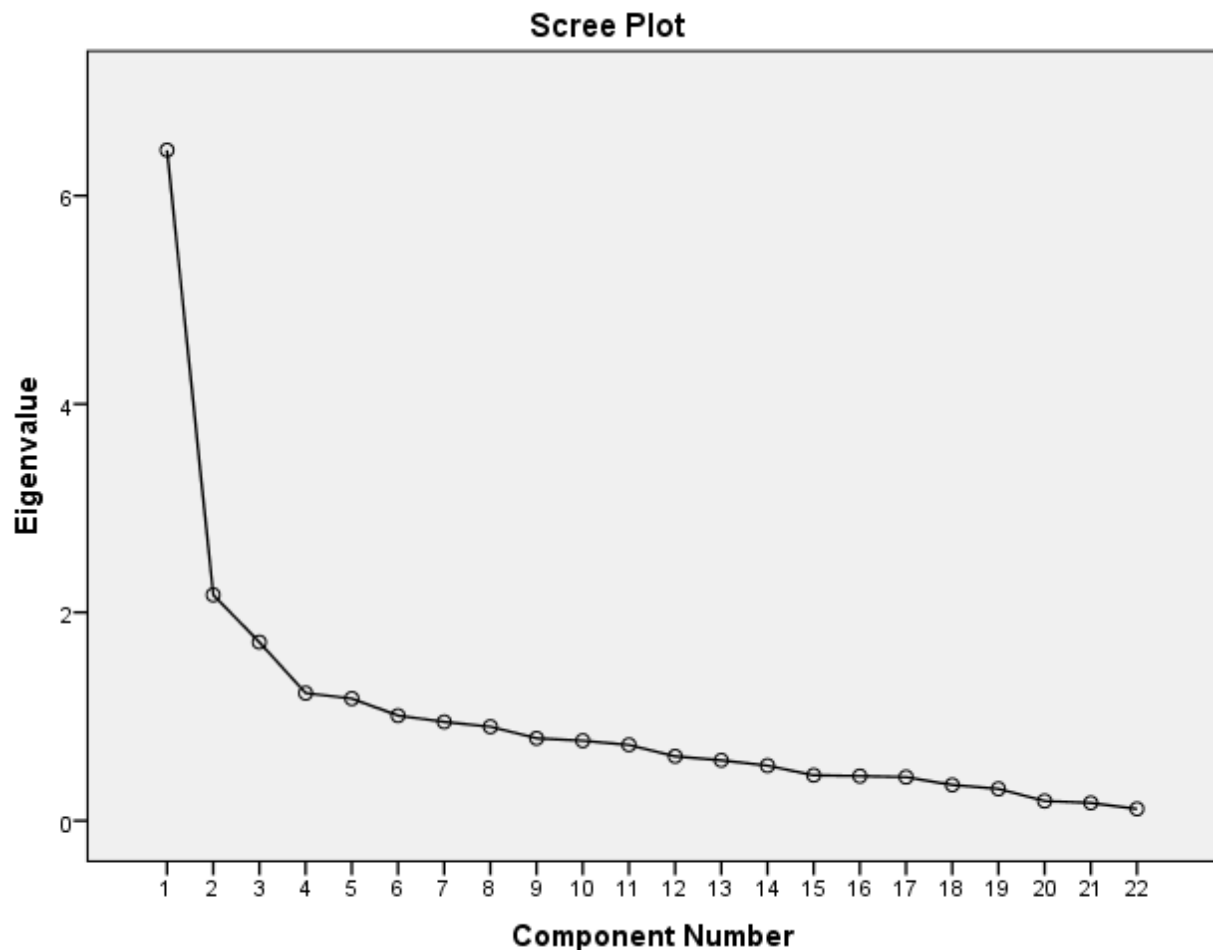


Figure 1

The figure 1 showed the Scree plot that there could be three factors extracted from the item pool. This was determined by considering the points until (before) the curve or the elbow shows up. Here, the elbow joint or breaking

point showed up at fourth point. Selection of the factors depends on the clinical judgment, literature and the opinion of the research investigator (Pallant, 2016).

Table 6

Comparison of Eigen Values from Principal Components Analysis (PCA) and the Corresponding Criterion Values obtained from Parallel Analysis (N=100)

Component Number	Actual Eigen Values from PCA	Criterion Value from Parallel Analysis	Decision
1	6.4	1.96	Accept
2	2.1	1.78	Accept
3	1.7	1.64	Accept
4	1.2	1.53	Reject

For the selection of the number of factors, parallel analysis was run which was likely scree plot. The Table 6 highlighted, if the eigen values > criterion value from parallel analysis is considered as a 'n' factor which showed that three factors could be extracted. Considering all the three statistics for factor extraction including eigen values, scree plot and Parallel Component Analysis (PCA),

there is contradiction in all of them regarding factors. The first two ways (total variance and scree plot) had been criticized for resulting in more factors as compared to PCA (Pallant, 2016). Furthermore, the rotation along with number of factors for extraction clarified the appropriate factor solution.

Table 7

The Pattern and Structure Matrix of the Items of Forman Parkinson's Disease Symptom Checklist with Direct Oblimin (N=100)

S. No.	Item No.	Items	Components			
			F1	F2	F1	F2
1	13	Difficulty in speech	.86	-0.97	.82	.28
2	12	Low volume voice	.80	-0.52	.78	.30
3	4	Difficulty in walk	.78	-0.96	.74	.24
4	1	Slowness in activities	.76	-0.86	.74	.35
5	5	Small steps during walk	.72	.03	.72	.25
6	6	Posture imbalance	.62	.06	.65	.33
7	2	Rigidity	.59	.09	.64	.35
8	15	Drooling	.40	.26	.52	.44
9	3	Resting tremors	.38	.09	.42	.25
10	23	Numbness in hands and feet	-.09	.77	.24	.73
11	16	Reduced sleep	-.02	.69	.28	.68
12	19	Restlessness in the legs	.01	.63	.28	.63
13	22	Burning sensation in the feet	-.08	.61	.57	.62
14	21	Needle pricking sensation in the limbs	-.12	.61	.18	.57
15	10	Repeated Urination	.07	.48	.14	.55
16	20	Memory problems	-.01	.46	.28	.51
17	14	Difficulty in swallowing	.37	.46	.47	.50
18	11	Urinary incontinence	.09	.45	.29	.50
19	7	Constipation	.03	.45	.23	.46

20	24	Nausea	.08	.37	.19	.46
21	9	Mask like expression	.31	.36	.39	.45
22	31	Sadness	.24	.34	.25	.41

Note. Items with correlation .3 or above showed up.

The first two columns of Table 7 showed the factor loadings, there were nine and thirteen items which were uploaded on the factor 1 and factor 2 respectively; named as motor and non-motor symptoms. On the basis of the literature and experts' opinion, item 13, 12 and 15 were also considered the items related to factor 2. Furthermore, there was a cross loading appeared on item 17 and 21 and were considered as the items of factor 2; on the basis of the higher correlation between the two factors. Moreover, the second two columns revealed the correlation between the factors and variables.

Factor Description

The two factors appeared as a result of factor analysis and they were named on the basis of the common themes shared by the items.

Factor 1

Motor Symptoms

The first factor of Forman Parkinson's disease (PD) symptom checklist (FPDSC) which appeared as a result of factor analysis was termed as motor symptoms. The motor symptoms are the primary symptoms of the Parkinson's disease which lead on to other symptoms. There were nine items which showed up on the first factor which were with the following titles; speaking difficulty, low volume voice, walking difficulty, slowness in activities, small steps while walking, posture imbalance, rigidity, drooling and resting tremors. On the basis of the previous literature and interviews with professionals,

It was revealed, factors extracted from eigen values, scree plot and parallel analysis would be six, three and three respectively. However, following Direct Oblimin as factor rotation, two factor solution turned out appropriate, which was contradicting to parallel analysis. While conducting rotation with three factors, the third factor revealed with three items; one of the items was with less than .3 correlation. According to Pallant (2016), the factor showed up with less than three items is discarded. Therefore, two factor solution with rotation Direct Oblimin was considered.

three items were found more appropriate in the other factor (non-motor symptoms) and those were as follows; speaking difficulty, low volume voice and drooling.

Factor 2

Non-motor Symptoms

The second factor of FPDSC was termed as non-motor symptoms. These non-motor symptoms appeared as a result of the motor symptoms or they could also be called as secondary symptoms. There were 13 items which were uploaded on the second factor and they were titled as numbness in hands and feet, reduced sleep, restlessness in the legs, burning sensation in the feet, needle pricking sensation in the limbs, repeated urination, memory problems, difficulty in swallowing, urinary incontinence, constipation, nausea, mask like facial expression and sadness.

Table 8

Means, Standard Deviations and Inter Factor Correlation of the Two Factors of Forman Parkinson's Disease Symptom Checklist (N=100)

Factors	F1	F2	M	SD
F1	-	.59**	16.64	5.51
F2	.59**	-	24.82	12.87

Note. *M* = Arithmetic Mean, *SD* = Standard Deviation

***p* < 0.01

From Table 8, it can be concluded that both the factors correlate significantly with each other.

Table 9

Cronbach Alpha, Mean Scores and Standard Deviation of the Total Score and Two Factors of Forman Parkinson's Disease Symptom Checklist (FPDSC) (N=100)

Scale	Number of items	α	M	SD
Motor symptoms	6	.79	16.64	5.51
Non-motor symptoms	16	.84	24.82	12.87
Forman Parkinson's disease (PD) symptom checklist	22	.88	41.46	16.74

Note. FPDSC = Forman Parkinson's Disease Symptom Checklist, *M* = Arithmetic Mean, *SD* = Standard Deviation.

From the Table 9, it was indicated that the internal consistency of the scale Forman Parkinson's disease (PD) symptom checklist was .88 and had 22 items whereas Cronbach *alpha* were determined for both the factors separately. According to Field (2013), value of reliability analysis (Cronbach alpha) can be in the range of .7 to .8. Here, for the individual factors and for their total, value of internal consistency is in the acceptable range i.e. .79, .84 and .88 respectively.

Split-half Reliability

Split half reliability was calculated by dividing the items of the scale into even and odd arrangement and it turned out to be .82.

Discussion

According to the previous studies (Mahmood & Bashir, 2018; Naeem et al., 2016; Saad et al., 2017; Tribune, 2018; Wasay & Ali, 2010), number of patients remain undiagnosed which resulted in the progress of the disease. Several researches could not

According to Field (2013), the larger the correlation between the two halves of the form will make the scale more reliable. The Cronbach alpha for two halves of FPDSC was .78 and .76 respectively.

Discriminant Validity

Discriminant validity was found out by determining the correlation between the same measure (Forman Parkinson's disease (PD) symptom checklist) administered on healthy and unhealthy participants. Bivariate analysis showed that the results were uncorrelated.

be conducted due to paucity of the culturally appropriate tool. This study aimed to construct checklist on Parkinson's disease considering the lack of culturally validated tool for Pakistani population.

The factor analysis was run through rotation (direct oblimin) and resulted in the formation

of two factors which were termed as motor and non-motor symptoms. There were nine factors showed up on the first factor (motor symptoms) which included the following items; difficulty in speech, low volume voice, difficulty in walk, slowness in activities, small steps during walk, postural imbalance, rigidity, drooling and resting tremors. Whereas, thirteen factors were uploaded on second factor (non-motor symptoms) which included numbness in hands and feet, reduced sleep, restlessness in the legs, burning sensation in the feet, needle pricking sensation in the feet, repeated urination, memory problems, difficulty in swallowing, urinary incontinence, constipation, nausea, masked expressions and sadness.

The motor and non-motor symptoms (Bronte-Stewart et al., 2002; Kruger et al., 2017; Pfeiffer, 2015) which had been aforementioned were similar to the symptoms reported in the studies (DeMaagd & Philip, 2015; Goetz, 2011; Obeso et al., 2017) conducted on Western population. While developing a PD checklist for Pakistani population, similar type of symptoms were found as had been reported in the literature, whereas, non-motor symptom specifically sexual problems had been rarely reported by males whereas not reported by any of the females. Its reason could be that sex talk could be considered as taboo in Pakistan (Ahmad & Zubair, 2016; Mukhtar et al., 2018). Therefore, item related to sexual problems was excluded because of low correlation from the finalized list of items.

Similarly, psychosis had been less reported by the participants which had been reported by the previous studies (Ahmad & Zubair, 2016; Mukhtar et al., 2018) conducted in Pakistan and its reason could be small sample size, however, not specified. Moreover, it had been reported (Correspondent, 2018) that several times research could not be completed because of absence of validated

tool on population of Pakistan. Therefore, the paucity of appropriate measurement tool was overcome through developing the checklist in an Urdu language, validated on Pakistani population. This could be administered in the future research rather than mini mental status examination or the other tools in English language (Naeem et al., 2016).

The result section revealed that after factor analysis (Table 3, 4, 5, 6, & 7), psychometric properties of the checklist (Table 8 & 9) were established through finding Cronbach alpha, doing split-half reliability and discriminant validity. The Cronbach alpha of both the factors was found individually and also as a sum of them; 0.79, 0.84 and .88 respectively. Furthermore, split half reliability was calculated by ordering the items into even and odd setting and it resulted in the higher correlation between the two halves of the scale; 0.82. Moreover, the discriminant validity was found by administering FPDSC on healthy (30 as sample size) and unhealthy (100 as sample size) participants which resulted in positive non-significant relationship between healthy and participants suffering from PD.

Implications

- Forman Parkinson's Disease Symptom Checklist (FPDSC) could be used as a screening tool at the hospitals. Moreover, it could also be used as a self-administered test by the caregivers under the supervision of medical personnel.
- FPDSC is a culturally appropriate tool and it could be administered in future researches.
- Masses could be aware about Parkinson's disease by arranging talks and making brochures in Urdu language.
- Forman Parkinson's Disease Symptom Checklist could indicate in which areas individual needs attention and improvement.

Therefore, it could be helpful in timely intervention.

- As the literature review and the interview of the caregivers highlight that they experience psychosocial burden. Therefore, counseling facilities could be provided to them. Furthermore, this finding also indicates that there is dearth of awareness regarding need for counseling as well as low ratio of trained neuropsychologists which opens an area for Pakistani psychologists to specialize in this field as there is higher need.

Further Research

The following could be done as a further research work:

- Collecting the data from different cities of Pakistan while focusing on the big sample size in order to make the data more generalized.
- Data could be collected from different private facilities.
- Confirmatory factor analysis (CFA) could be conducted in order to further confirm the results of exploratory factor analysis.
- Further researches could ascertain the relationship of caregivers' mental health or daily functioning with the patients' stage of the disease.
- Analyze the coping mechanisms used by the caretaker of the patients suffering from neurodegenerative diseases.

Conclusion

Parkinson's disease is a neurodegenerative disease which affects the person's daily functioning, although it is not a fatal disease; however, reduces the life expectancy. The factor analysis revealed two types of symptoms (motor and non-motor symptoms); similar as reported in the studies conducted on Western population. However, sexual problems were less reported which could be

due to social barrier. Similarly, psychosis was also rarely shared by participants and its reason could be small sample size, however, not specified. Forman Parkinson Disease Symptom Checklist (FPDSC) was developed in Urdu language and proved as a culturally validated tool.

Contribution of Authors

Bushra Akram: Conceptualization, Investigation, Data Curation, Formal Analysis, Writing - Original draft

Ivan Suneel: Conceptualization, Methodology, Formal Analysis, Writing-Reviewing & Editing

Conflict of Interest

There is no conflict of interest declared by authors.

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