Development and Validation of Quality of Life in Parkinson's Disease Instrument

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Abstract

Context: Parkinson's disease (PD) has devastating effects on quality of life (QoL), but there is no instrument that has been developed for Hindi-speaking persons with Parkinson's disease (PWP). **Objective:** The objective of this study was to develop and validate an instrument in Hindi language to measure health-related QoL (HRQoL) in PWP. **Subjects and Methods:** Literature review and interviews of stakeholders were done to create a pool of 68 items to develop a questionnaire. Self-rated global QoL item was also included in the questionnaire. Questionnaire was tested on 300 Hindi-speaking PWP. Item reduction was achieved through factor analysis and clinimetrics to finalize the QoL in PD (QLPD) instrument. Validity and reliability of the QLPD were tested. **Results:** "QLPD" is a 45-item instrument with nine subscales, namely, activities of daily living, mobility, psychological, fear, social, family, treatment, finance, and nonmotor symptom subscales. Internal consistency of QLPD's summary score and all subscales except treatment subscale was high ($\alpha = 0.74–0.94$). Intraclass correlation coefficient between summary score and global QoL was 0.79. Summary score and subscale scores were significantly different ($P < 0.0001$) for predefined five categories on global QoL (very good to very bad). QLPD subscales exhibited good convergent and divergent validity with subscales of 39-item PD questionnaire and short form-36 scale. Higher Hoehn and Yahr stage, lower monthly per capita income, and higher levodopa equivalent daily dosage were found to be independently associated with poor HRQoL. **Conclusion:** QLPD is a valid and reliable instrument to measure HRQoL in Hindi-speaking PWP.

Keywords: Development, Parkinson's disease, quality of life, questionnaire, validation

INTRODUCTION

Parkinson's disease (PD) is the second most common neurodegenerative disorder of the elderly creating devastating burden on patients, caregivers, and the state with substantial reduction in patients' quality of life (QoL).[1-4] Many generic and disease-specific QoL scales are in use for persons with Parkinson's disease (PWP). Generic scales lack disease-specific items and have limited sensitivity and responsiveness as compared to disease-specific health-related QoL (HRQoL) scales. Thirty nine –item Parkinson's Disease Questionnaire (PDQ-39);[5] Parkinson' s Disease Quality of Life Questionnaire;[6] Parkinson's Disease Quality of Life Scale,[7] and Scales for Outcomes in Parkinson's Disease-Psychosocial[8] are widely used disease-specific HRQoL scales for PWP. Educational, socioeconomic, and cultural diversity in developing countries such as India poses challenges in adopting and translating these scales that have been developed for the Western population.[9,10] Den Oudsten *et al*.[11] have criticized these scales pronouncing them health status scales and not HRQoL scales. These scales lack domains on financial implication, efficacy of current treatment, and nonmotor symptoms (NMS). Keeping these aspects in mind, we present the development of Quality of Life in Parkinson's disease (QLPD) instrument in Hindi language, in the present communication.

SUBJECTS AND METHODS

This study was done at a tertiary care teaching hospital in India after approval of IRB/EC of the hospital. We developed QLPD, following the principles laid down for patient-reported outcome measures.[12-14]

Item pool generation

Literature review and semi-structured interviews of stakeholders with native language as Hindi created the item pool in Hindi language. After obtaining informed consent, 28 cognitively preserved (Mini–Mental State Examination score >24) PWP diagnosed on the basis of UK PD Brain Bank Clinical Diagnostic Criteria[15] without any other disabling disease, six caregivers of PWP, eight movement disorder specialists, and one psychiatrist were interviewed by the same researcher (RA). The interviews were audio recorded with due permission and consent. The demographics; age, gender, duration of symptoms, family type (joint or nuclear), disease severity (as per Hoehn and Yahr stage) and socio-economic status (as per Kuppuswamy scale)[16] of recruited PWP were recorded.

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An expert panel consisting of four neurologists, one physiotherapist, one biostatistician, and one psychiatrist conceptualized and defined HRQoL in PD[17] and identified 68 items from content analysis of interviews and literature review after several levels of deliberations to develop a questionnaire. An item on person's overall self-perception of their QoL (global QoL) based on 0–100 visual analog scale with five categories was also added in the questionnaire [Appendix 1]. Recall period for answering was kept at 4 weeks. (All items were translated from Hindi to English language for publication by translators fluent in English language: Appendix 1.)

Pilot testing of the questionnaire was done on 19 PWP who were recruited to fill the questionnaire followed by cognitive interview for its face validity, content validity, language, format, and options. Four neurologists and a psychiatrist also reviewed the questionnaire. At this stage, no item was considered for removal.

After pilot testing, the questionnaire was subjected for field testing on 300 consecutive PWP from the the same institution. Demographics, per capita monthly income (PCMI) and Levodopa equivalent daily dosage (LEDD) of these PWP were recorded. In addition to the questionnaire, all participants were requested to fill either PDQ-39[5] or 36-item short-form scale (SF-36).[18] PDQ-39 is most commonly used PD specific scale to assess HRQoL in PWP. PDQ-39 contains 8 domains: Mobility, Activities of daily living, Emotional well being, Stigma, Social support, Cognitions, Communication and Bodily discomfort. Items of PDQ-39 assess how often PWP experiences difficulty using 5 point ordinal range where 0 means never and 4 means always. Each domain provides a domain score ranging from 0 to 100. Lower score reflects better QoL. SF-36 is most commonly used generic HRQoL for PWP that contains 36 items in 8 subscales: Physical function (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social function (SF), role emotion (RE) and mental health (MH). For each subscale, items are coded, summed and transformed on to a scale from 0 (worst HRQoL) to 100 (Best HRQoL) using a software provided by Optum® outcomes. SF-36 also provides two summary scores viz. Physical component summary score (PCS) and Mental component summary score (MCS). Scores are norm based: mean (SD) = 50 (10). Score interpretation: 50 is average; 0 to 49 are below average and 51 to 100 are above average (higher the score better will be QOL).

Proxies were used for collection of response in participants in advanced stage, who could not respond reliably due to infirmity/severe tremor. Questionnaires were reviewed for missing responses and participants were encouraged to answer all items before leaving.

Item reduction and construction of scales

Item-level analysis of data from field testing was done to find floor and ceiling effects and mean response of each item. We calculated impact of each item by multiplying mean response of the item with frequency of that item. Exploratory factor analysis of 68 items was done. Domains with eigenvalue >1 were retained and subjected to maximum likelihood method, followed by orthogonal varimax rotation to improve loading of items around domains. Items that loaded more than 0.4 were considered relevant. Before dropping an item, the remaining items were reviewed in relation to content validity of the questionnaire. The fate, frequency, mean response, and impact of all 68 items have been shown in Appendix 1. Extracted domains were subjected to confirmatory factor analysis to assign subscales. These subscales and global QoL item constituted QLPD [Appendix 2]. Cronbach's alpha (α) and item-scale correlation were used for internal consistency. Subscale scores and summary score were created on 0–100 scale with higher score representing poor HRQoL as follows:

1. Subscale score = aggregate of observed scores of items in the subscale/maximum possible total score of that subscale × 100
2. Summary score = aggregate of observed scores of items in all subscales/maximum possible total score of all subscale × 100.

Single-item QoL scales are valid and reliable tool for measuring QoL,[19,20] so considering global QoL, a close approximation of true QoL, we did intraclass correlation (ICC) between summary score and global QoL score. For discriminative validity, we compared mean summary score and subscale scores for five categories of participants on the basis of global QoL (0–20, very bad; 21–40, bad; 41–60, neither good nor bad; 61–80, good; and 81–100, very good) using one-way analysis of variance. Multitrait–multimethod correlation matrix was used for convergent and divergent (discriminant) validity of QLPD subscales with subscales of PDQ-39 and SF-36. We attributed strong correlation when Spearman's correlation coefficient (ρ) was ≥0.6 between two subscales, moderate correlation for $0.4 \leq \rho < 0.6$, while low correlation for $\rho < 0.4$. Strong correlation coefficients between similar subscales of QLPD and PDQ-39 and/or SF-36 were considered evidence of convergent validity while divergent validity was assumed when a subscale of QLPD had the highest correlation with similar subscales of PDQ-39 and/or SF-36, i.e., lower correlation with other unrelated subscales of PDQ-39 and/or SF-36. We did regression analysis to determine the effect of demographics and clinical severity on HRQoL. For this purpose, we divided participants into two groups Group 1: Hoehn and Yahr [H and Y] stage ≤ 2.5; and Group 2: H and Y stage ≥3. We did multivariate linear regression of summary score as dependent variable and age at onset of symptoms, duration of symptoms, H and Y stage, PCMI, and LEDD as explanatory variables. STATA version 9.0 (Statacorp, 4905 Lakeway drive, College station, Texas 77845 USA) and SPSS version 16.0 (SPSS Inc. 233 South Wacker Drive, 11th Floor Chicago, IL 60606-6412 USA) software were used for statistical analysis.

RESULTS

Demographic summary of PWP who participated in the study is shown in Table 1. Mean (range) clinical experience of nine interviewed specialists was 19.2 (8–32) years for treating PWP. The duration of interviews ranged from 15 to 45 min.

Table 1: Characteristics of persons with Parkinson's disease who participated in the development of quality of life in Parkinson's disease

Characteristics	Stage of QLPD development		
	Item pool generation	Pilot testing	Field testing
n	28	19	295
Age (years), mean±SD (range)	54.2±9.2 (40-74)	55±8.1 (42-72)	57±10.7 (23-85)
Male gender (%)	71	53	73
Duration of symptoms (years), mean±SD (range)	6.3±3.3 (1-15)	8.9±6.7 (1-26)	7.2±5.4 (0.3-32)
Family joint: Nuclear (%)	50:50	58:42	52 : 48
H and Y stage (%)			
1	3.5	5.3	13.9
1.5	3.5	10.5	18
2	0	10.5	19
2.5	25	26.3	13.2
3	54	31.6	22.4
4	14	15.8	10.5
5	0	0	3
Socioeconomic status# (%)			
Upper	11	10.5	15.4
Upper middle	36	42.1	33.0
Lower middle	28	31.6	38.7
Upper lower	21	15.8	11.2
Lower	4	0	1.9

#Based on Kuppuswami scale.[16] H and Y stage=Hoehn and Yahr stage, QLPD=Quality of life in Parkinson's disease instrument, SD=Standard deviation

In the pilot testing of initial questionnaire, face validity and content validity of the questionnaire were graded as very good as the stakeholders did not suggest any new item. From 300 PWP for field testing, five treatment-naive persons were excluded from the study, as questions regarding treatment satisfaction and/or expenditure were irrelevant for them. Final analysis was done on data collected from 295 PWP. Out of 295 PWP, 136 also filled PDQ-39 scale while 114 filled SF-36 scale. Item-level analysis of data revealed that only 0.85% of data was missing which was replaced with item's mean value.[21] The mean response of all items was in the range of 0.18–2.88 (maximum possible = 4) while the impact of items ranged from 0.01 to 2.11 (maximum possible = 4). Exploratory factor analysis of 68 items yielded eight domains with eigenvalue >1 that accounted for 80.3% variance of the data. After applying maximum likelihood with eight domains and orthogonal varimax rotation, 41 items loaded >0.4 in seven domains. These domains were motor, financial, fear and social, psychological, NMS, treatment, and family with variance 46%, 10%, 6%, 5%, 4%, 3%, and 3%, respectively. None of the items in the 8th domain reached benchmark of 0.4 and accounted for only 2.9% variance and so it was dropped. Of the remaining 27 items with loading <0.4, 11 causal items on tremor, family disturbance, consistency of effects of medicine, constipation, fatigue, sleep, body aches, sensory symptoms, swallowing, restless leg syndrome, and sexual satisfaction were retained, as these do not follow psychometric principles. These 11 items were distributed among seven domains on the basis of their face validity. The remaining 16 items were deleted as they neither were causal items nor loaded >0.4. This left us with 52 items. To further reduce items, seven more items on social embarrassment, family responsibilities, spat in family, dependency on medication, vision-related problems, and weird dreaming were removed as they were either not applicable to large population, or their content was already represented in other items in different domains. Hence, the final questionnaire contained 45 items.

Confirmatory factor analysis of financial, psychological, treatment, and family domains revealed single dimensionality. Motor domain was divided into activities of daily living (ADL) and mobility domain. 'Fear and social' domain was divided into two separate social and fear domains. NMS domain did not show single dimensionality on confirmatory factor analysis as it consisted of causal items. We decided to retain all NMS items, though they did not comply with factor analysis and an item on overall health satisfaction into NMS domain. These nine domains formed nine subscales. Finally, we had 45 items in nine subscales plus one global QoL which constituted QLPD [Appendix 2].

Internal consistency (reliability) and scoring of quality of life in Parkinson's disease

Cronbach's alpha (α) of QLPD was 0.94 while α of eight subscales was in the range of 0.74–0.91 [Table 2]. Item-scale correlations of subscales found only four items that did not correlate with their subscales as α improved after removing these items. These four items were retained considering content validity. Subscale scores were widely distributed and had full range of scores from 0 to 100 in all subscales except NMS (0–86) [Table 2]. Mean (standard deviation [SD], range) summary score of QLPD ($n = 295$) was 35.3 (16.6, 1–83). Reliability testing of summary score with global QoL revealed ICC coefficient, 0.79 (95% confidence interval [CI]; 0.74–0.83; $P < 0.0001$). Discriminant validity was demonstrated as mean summary score and subscale scores had statistically significant difference ($F[4, 290] = 55.1$ $P < 0.0001$) across five global QoL categories [Table 3].

Multitrait–multimethod correlation matrix showed good convergent and divergent validity. Table 4 shows the Spearman's correlation coefficient among subscales of the QLPD ($n = 295$), QLPD versus SF-36 ($n = 114$), and QLPD versus PDQ-39 ($n = 136$). For convenience, the subscales of QLPD and PDQ-39 were prefixed with q and p, respectively. All subscales of QLPD had low-to-moderate correlation with other subscales of QLPD except qADL with qmobility and qNMS, and qsocial with qfear. Summary score had high correlation with global QoL. In regression analysis model, univariate analysis of age at onset of symptoms, duration of symptoms, PCMI, and LEDD with summary score as dependent variable explained variance of 2%, 8%, 12%, and 14%, respectively. Younger age at onset (β: −0.23 [95% CI: −0.41–−0.06]; $P < 0.05$), longer duration of symptoms (β: 0.88 [95% CI: 0.53–1.22]; $P < 0.001$), lower PCMI (β: −0.68 [95% CI: −0.89–−0.47], $P < 0.001$), and higher LEDD (β: 0.03 [95% CI: 0.02–0.04]; $P < 0.001$) were associated with higher summary score (poor HRQoL). Clinical severity of disease (H and Y stage) explained 18% variance. Mean (SD) summary scores for Group 1 (H and Y ≤2.5) and group 2 (H and Y ≥3) were 30 (14.8) and 44.7 (15.7), respectively. Higher staging of H and Y stage (β: 14.7 [95% CI: 11.09–18.34], $P < 0.001$) revealed poor HRQoL. In combined model, to know the significant determinant of HRQoL, multivariate linear regression showed that higher H and Y stage, lower PCMI, and higher LEDD (adjusted $R^2 = 0.37$) were associated with poorer HRQoL.

Table 2: Subscales of quality of life in Parkinson's disease instrument: Internal consistency and their scores tested on 295 persons with Parkinson's disease

Subscale	Number of items	Cronbach's coefficient (α)	Mean±SD scores	Range
ADL	6	0.82	39.4±19.7	0-100
Mobility	4	0.83	31.1±22.8	0-100
Psychological	4	0.78	30.3±25.6	0-100
Fear	4	0.80	39.3±26.8	0-100
Social	4	0.78	30.4±25.3	0-100
Family	3	0.74	36.7±29.5	0-100
Treatment	3	0.42	54.6±24.1	0-100
Finance	3	0.91	33.0±31.8	0-100
NMS	14	0.83	32.5±17.8	0-86

ADL=Activities of daily living, NMS=Nonmotor symptoms, SD=Standard deviation

DISCUSSION

We developed QLPD instrument, a disease-specific HRQoL instrument for Hindi-speaking Indian PD population. From literature review and interviews of stakeholders involved in the care of PWP, comprehensive coverage of all relevant items related to HRQoL was ensured, but item reduction was a challenge. It was difficult to ascertain the cutoff line for inclusion of items on the basis of impact. Second, many items on NMS and falls had low impact due to the lower prevalence in our population due to the differential representation of various stages, but when present, they significantly and adversely affected QoL. Keeping content validity in mind, clinimetrics based on clinical sensibility; and psychometrics based on factor analysis guided us to finalize items. We made it a point to include patients of varied background and all severity of disease, so that the instrument would be relevant to all categories of Indian PWP. Our sample for field testing was a heterogeneous group of PWP, including persons of both gender, wide age range (23–85 years), wide duration of illness (3 months–32 years), and wide severity of PD as gauged by H and Y stage of disease (1-5).

QLPD is comprehensive in approach with all relevant domains of HRQoL in PWP. QLPD gives emphasis on NMS in addition

Table 3: Mean summary score and subscale scores across the global quality of life categories of quality of life in Parkinson's disease instrument

QLPD	Global QoL categories					$F^{\#}$
	Very bad (n=22)	Bad (n=61)	Neither good nor bad (n=109)	Good (n=77)	Very good (n=26)	
Summary score	59.7	46.6	34.8	25.6	18.9	55.1*
ADL	63.3	48.5	40.0	29.1	25.8	26.6*
Mobility	52.3	41.3	32.4	20.9	14.4	19.0*
Psychological	56.8	41.4	27.1	22.9	17.1	14.9*
Fear	60.2	53.7	39.4	28.1	20.2	17.8*
Social	59.1	40.6	29.5	20.9	14.2	18.7*
Family	76.9	51.8	35.3	24.4	9.9	32.9*
Treatment	68.9	66.5	55.5	45.1	38.5	13.6*
Financial	67.4	51.9	31.2	18.6	9.9	25.9*
NMS	53.8	42.1	31.8	24.5	18.5	27.7*

$^{\#}F$=Statistics for testing equality of mean scores across five categories of Global QoL, *$P<0.0001$. QoL=Quality of life, QLPD=Quality of life in Parkinson's disease instrument, ADL=Activities of daily living

Table 4: Spearman's correlation coefficient "ρ" between subscales of quality of life in Parkinson's disease instrument, Parkinson's disease questionnaire-39, and short form-36

	qADL	qMobility	qPsycho	qfear	qsocial	qfamily	qtreat	qfinance	qNMS	qtotal	qglobal
qADL	1										
qMobility	0.71	1									
qPsycho	0.46	0.43	1								
qfear	0.34	0.35	0.57	1							
qsocial	0.50	0.47	0.49	0.64	1						
qfamily	0.60	0.53	0.54	0.50	0.56	1					
qtreat	0.33	0.30	0.32	0.40	0.34	0.32	1				
qfinance	0.28	0.25	0.32	0.42	0.37	0.43	0.30	1			
qNMS	0.66	0.56	0.49	0.41	0.47	0.57	0.28	0.40	1		
qtotal	0.78	0.72	0.70	0.69	0.73	0.77	0.50	0.56	0.83	1	
qglobal	−0.51	−0.48	−0.40	−0.46	−0.43	−0.54	−0.40	−0.50	−0.51	−0.65	1
pmob	0.72	0.65	0.48	0.45	0.51	0.64	0.34	0.32	0.68	0.76	−0.64
pADL	0.71	0.50	0.42	0.29	0.40	0.60	0.17	0.24	0.58	0.64	−0.52
pEmotion	0.57	0.52	0.75	0.63	0.59	0.63	0.37	0.41	0.61	0.78	−0.56
pstigma	0.29	0.26	0.43	0.56	0.65	0.45	0.28	0.35	0.24	0.49	−0.37
psocial	0.28	0.19	0.38	0.43	0.41	0.43	0.17	0.35	0.29	0.43	−0.27
pcog	0.51	0.47	0.41	0.44	0.49	0.50	0.30	0.36	0.65	0.66	−0.48
pcomm	0.59	0.51	0.39	0.39	0.53	0.48	0.25	0.22	0.57	0.62	−0.44
pboddis	0.33	0.26	0.45	0.41	0.32	0.42	0.37	0.31	0.49	0.54	−0.40
PF	−0.50	−0.53	−0.27	−0.16	−0.22	−0.31	−0.34	−0.11	−0.42	−0.48	0.41
RP	−0.38	−0.40	−0.35	−0.31	−0.20	−0.37	−0.25	−0.20	−0.46	−0.49	0.30
BP	−0.50	−0.45	−0.39	−0.42	−0.47	−0.51	−0.31	−0.27	−0.52	−0.64	0.33
GH	−0.32	−0.25	−0.41	−0.38	−0.34	−0.33	−0.27	−0.23	−0.44	−0.47	0.40
VT	−0.46	−0.41	−0.50	−0.37	−0.43	−0.40	−0.41	−0.37	−0.44	−0.59	0.51
SF	−0.57	−0.57	−0.51	−0.40	−0.53	−0.62	−0.38	−0.33	−0.49	−0.69	0.41
RE	−0.33	−0.37	−0.36	−0.3	−0.23	−0.34	−0.24	−0.35	−0.42	−0.48	0.32
MH	−0.36	−0.36	−0.68	−0.55	−0.46	−0.43	−0.27	−0.33	−0.5	−0.63	0.33
PCS	−0.51	−0.49	−0.24	−0.24	−0.28	−0.40	−0.35	−0.13	−0.49	−0.54	0.41
MCS	−0.41	−0.42	−0.65	−0.52	−0.46	−0.51	−0.32	−0.44	−0.54	−0.67	0.41

Prefix "q" has been used for subscales of QLPD. qADL=Activities of daily living, qMobility=Mobility, qPsycho=Psychological, qfear=Fear, qsocial=Social, qfamily=Family, qtreat=Treatment, qfinance=Finance, qNMS=Nonmotor symptoms, qtotal=Summary score, qglobal=Global quality of life rating by the patient. Prefix 'p' has been used for subscales of 39-item PDQ-39. pmob=Mobility, pADL=ADL, pEmotion=Emotional, pstigma=Stigma, psocial=Social, pcog=Cognition, pcomm=Communication, pboddis=Bodily discomfort, SF 36=36 item short form scale, PF=Physical function, RP=Role physical, BP=Body pain, GH=General health, VT=Vitality, SF=Social function, RE=Role emotion, MH=Mental health, PCS=Physical component summary, MCS=Mental component summary, QLPD=Quality of life in Parkinson's disease, PDQ-39=39-item Parkinson's disease questionnaire

to motor function as it has 13 items on NMS while 10 items on motor functions. This makes it more relevant and holistic as it takes in account both motor and NMS to measure QoL, since past studies[22-24] have shown higher impact of NMS on HRQoL.

Treatment and finance are two unique subscales in QLPD. Successful management of symptoms and meeting the patients' expectations has direct relationship with patients' HRQoL.[25] Regularly, new technologies[26] for the management of PD are emerging. HRQoL has been recommended as an important end point for efficacy measurement of any new treatment strategy;[27] therefore, it is required that PD-specific HRQoL instruments should be sensitive to treatment efficacy as well as patients' satisfaction. Financial implication of the disease is of paramount importance for PWP, especially in low-income countries in the absence of medical insurance. The direct cost of treatment due to expenditure on medications, consultations, and visits to the hospital as well as indirect costs in the form of loss of wages of self and caregiver also impact overall well-being.[2] Lower PCMI was found to be associated with poor HRQoL in this study. Similar results have been published by Ray *et al*.[28]

We chose 5-point Likert scale as it covers good range of possible responses with adequate scope for change in score with change in status of the patient while keeping a balance between precision and responsiveness.[29] To develop subscale scores and summary score, we did not use weights as it has not been shown to be better method than nonweighted system.[30]

The internal consistency of QLPD and its subscales except treatment subscale was very good. Low internal consistency of treatment subscale may be attributed to its three items with wide-ranging content. The presence of ceiling or floor effects indicates that scale will have poor discrimination resulting in reduced sensitivity and responsiveness.[29] Summary score and subscale scores in our cohort of PWP were widely distributed without any floor or ceiling effect.

Validity of a scale implies ability of the scale to measure what it intends to measure. An ICC of 0.79 between global QoL and summary score in QLPD supports the patient's overall perceived QoL which is highly correlated with estimated QoL from nine subscales. Interpretability of the QLPD is good as it provides a scale profile on 0–100 scales that includes a summary score, nine subscale scores, and one global QoL item.

Construct validity of quality of life in Parkinson's disease and its subscales

The convergent validity of QLPD's subscales with similar subscales and divergent validity with unrelated subscales of SF-36 and PDQ-39 were good. ADL subscale of QLPD had high correlation with mobility, family and NMS subscales of QLPD, and ADL and mobility subscales of PDQ-39. High correlation between ADL and mobility subscales may be attributed to items of these subscales which are largely motor features whereas high correlation between ADL and NMS subscales of QLPD may be due to parallel deterioration of motor as well as NMS with advancing disease. Fulfilling family responsibilities largely depends on patient's ability to move and ability to do household chores and/or occupational works that are primarily dependent on physical abilities that may explain high correlation of ADL subscale with family subscale. Psychological subscale of QLPD has high correlation with emotion subscale of PDQ-39, mental health, and mental component summary of SF-36 that primarily consists of items on anxiety and depression, hence highly correlated to each other. Fear subscale of QLPD had high correlation with emotion and stigma subscales of PDQ-39 and mental health subscale of SF-36. Patients who are apprehensive and worrying in nature (neuroticism trait)[31] curtail their social participation affecting their social life. The common elements among these subscales were fearfulness, worrying nature, stigma, and emotional issues.

Treatment and finance subscales contributed around 14% of total variability in the data and had low-to-very low correlations with most of the subscales of QLPD, PDQ-39, and SF-36. The items of these two subscales are unique and are not available in other scales. In QLPD, global QoL item is moderately (0.4–0.6) correlated with all subscales of QLPD which suggests that all subscales of QLPD contribute to overall QoL in PD.

The development of QLPD had many limitations and challenges. Being a single-center study has its own strength, as it ensures uniformity of data collection and assessment. The number of participants in Stage 5 was low (3%) as patients who are very disabled do not like to visit hospitals due to obvious reason. This was observed in many of the studies published earlier.[22,28] Despite these limitations, QLPD is the first disease-specific HRQoL instrument that has been developed after defining HRQoL and conceptualization of QoL and does not measure just frequency and severity of different symptoms but actually measures the perception of persons about impact of the disease on their lives. QLPD is an improvement over other known HRQoL questionnaires as it has finance, treatment, family, and NMS subscales that have not been considered in earlier PD-specific scales. QLPD also includes global QoL item that is instrumental in estimation of patient's self-perception about his/her overall QoL.

CONCLUSION

We have developed QLPD, a new HRQoL instrument for Hindi-speaking PWP. QLPD has good internal consistency, construct validity, precision of scores, and interpretability. It will be useful if it can be translated into other Indian languages and tested in PWP conversant with those languages.

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Conflicts of interest

There are no conflicts of interest.

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APPENDICES

Appendix 1: Item pool and global quality of life

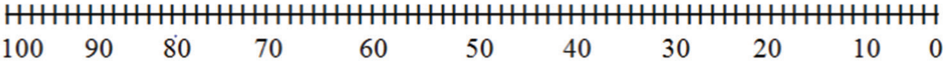
n	Item	Fate of item#	Frequency	Mean response	Impact
q1	Do you take more time in daily routine activities (such as bathing, dressing, and taking food.) compared to predisease state?	ADL	0.89	1.74	1.55
q2	To what extent your tremors disturb you?	ADL	0.89	2.15	1.91
q3	Is there any change in your voice?	ADL	0.84	1.45	1.21
q4	Do you have difficulty in turning in bed or taking blankets?	ADL	0.75	1.45	1.08
q5	Do you have difficulty in daily routine activities such as toileting, brushing teeth, bathing, dressing, and eating?	ADL	0.82	1.43	1.17
q6	Do you feel difficult in getting up from chair?	ADL	0.70	1.23	0.86
q7	Do you feel difficulty in walking?	Mobility	0.91	1.64	1.48
q9	Do you feel difficulty in turning while walking?	Mobility	0.71	1.29	0.92
q10	Do you feel that your feet get glued (freeze) to the floor while walking, making a turn or initiate walking?	Mobility	0.63	1.42	0.90
q11	Do you fall while walking?	Mobility	0.37	0.63	0.24
q12	Do you get angry?	Deleted	0.83	1.63	1.36
q13	Do you feel weepy?	Psychological	0.53	0.93	0.49
q14	Do you feel like living alone?	Deleted	0.37	0.66	0.25
q15	Do you feel excited to start any new task?	Deleted	0.72	2.06	1.48
q16	Do you feel ignored (people neglect you)?	Deleted	0.49	0.90	0.44
q17	Do you feel anxious/tensed?	Psychological	0.74	1.60	1.18
q18	Do you feel that it's better to die than this sort of life?	Psychological	0.41	0.89	0.37
q19	Do you feel you are sad?	Psychological	0.72	1.43	1.02
q20	Do you have difficulty in concentration?	Deleted	0.66	1.35	0.89
q21	Do you worry for progression of the disease?	Fear	0.86	2.05	1.76
q22	Does the changed attitude of others due to the disease, disturb you?	Fear	0.58	1.21	0.70
q23	Is it difficult for you to accept the disease?	Fear	0.66	1.47	0.98
q24	Are you afraid of what's there in your destiny?	Fear	0.64	1.56	0.99
q25	Do your unusual behavior like suspecting others without any reason, disturb you?	Deleted	0.39	0.80	0.31
q26	Have you ever tried to commit suicide?	Deleted	0.05	0.18	0.01
q27	Is there any change in your self-confidence?	Deleted	0.73	1.24	0.90
q28	Is there any change in religious faith due to disease?	Deleted	0.44	0.82	0.36
q29	Do you feel embarrassed/ashamed while eating/drinking in front of strangers?	Deleted	0.56	1.17	0.65
q30	Due to disease, do you feel embarrassed/ashamed in the society?	Social	0.58	1.24	0.72
q31	Is it difficult for you to ask help from others?	Social	0.60	1.29	0.78
q32	Do you feel difficulty in talking to strangers?	Social	0.51	1.10	0.56
q33	Is your family disturbed because of you?	Family	0.50	1.21	0.61
q34	Do you have become dependent on others due to disease?	Family	0.63	1.46	0.92
q35	Can you fulfill your family responsibilities?	Family	0.68	1.73	1.18
q36	Do you get support (as expected by you) from your family?	Deleted	0.38	0.78	0.29
q37	Can you do your business or job-related work?	Deleted	0.75	2.22	1.65
q38	Can you do your household chores (such as cooking, washing clothes, and dusting)?	Deleted	0.75	2.22	1.67
q39	Do you have spat/brawl in family due to disease?	Deleted	0.40	0.68	0.27
q40	Is there any change in your social outings/meetings?	Social	0.68	1.23	0.83
q41	What is the change in your life with Parkinson's disease medication?	Treatment	0.89	2.15	1.91
q42	Does dependency on medication disturb you?	Deleted	0.73	1.74	1.27
q43	Shortly after taking the medicine, is the medicine less effective or ineffective?	Treatment	0.73	2.88	2.11
q44	Do side effects of the drugs are a problem for you?	Deleted	0.58	1.32	0.76
q45	Dyskinesia (movement of your body against your desire) is a problem for you?	Deleted	0.67	1.68	1.13
q46	The loss of appetite or weight loss is a problem for you?	Deleted	0.42	0.91	0.38
q47	Do you see something (such as someone is sitting in the room), which does not really exist?	NMS	0.28	0.61	0.17

Contd...

Appendix 1: Contd...

n	Item	Fate of item#	Frequency	Mean response	Impact
q48	Do visit to hospital, meeting doctors, and treatment-related work is a problem for you?	Deleted	0.53	1.21	0.65
q49	Are you satisfied with your treatment?	Treatment	0.69	1.53	1.06
q50	Due to disease, is there any effect on yours or your family's income?	Financial	0.57	1.10	0.62
q51	Due to disease, have you or your spouse declined anything related to financial benefit such as promotion and project?	Deleted	0.23	0.88	0.20
q52	Due to disease, have you or your spouse left his/her business or job?	Deleted	0.22	0.84	0.18
q53	To what extent expenditure on treatment bothers you?	Financial	0.66	1.58	1.05
q54	Is there any effect on important works of family (such as education of children, marriage, and construction of house) due to increase in expenditure on treatment?	Financial	0.54	1.28	0.70
q55	Is there any change in your memory?	NMS	0.68	0.95	0.64
q56	In the last 4 weeks, how much you were bothered due to constipation (No bowel movement for 3 days)?	NMS	0.57	1.38	0.78
q57	Do you feel helpless due to fatigue?	NMS	0.83	1.87	1.56
q58	Are you bothered due to drooling of saliva?	NMS	0.48	0.95	0.46
q59	Are you disturbed due to sleep?	NMS	0.55	1.23	0.68
q60	Are you disturbed with body aches due to disease?	NMS	0.72	1.66	1.20
q61	Are you disturbed due to coldness, burning or numbness of hands and feet?	NMS	0.63	1.38	0.87
q62	Are you bothered due to urinary problem (going frequently or soiling of clothes)?	NMS	0.63	1.36	0.85
q63	Do you feel difficulty in swallowing food?	NMS	0.33	0.59	0.19
q64	Are you bothered due to vision-related problems (double vision, appearance of lights or flashes)?	Deleted	0.41	0.77	0.31
q65	While sleeping, do you grumble or move your hands and legs, like you are acting a dream?	NMS	0.53	1.13	0.60
q66	Do you feel restlessness or fidgety in legs while sitting idle or lying which gets relieved with leg mobility?	NMS	0.56	1.14	0.64
q67	Do you get hold of weird dreams?	Deleted	0.49	0.97	0.47
q68	Are you satisfied with your sexual life?	NMS	0.60	1.56	0.93
q69	Are you satisfied with your health?	NMS	0.84	2.38	2.00

The following scale has been created for measuring the quality of your life, where 100 means the happiness, joy in your life (no compromise on the quality of life) if Parkinson's disease had not been there in your life, and 0 means the worst possible state of your life, which you can imagine. Based on the past 4 weeks of your life please rate your quality of life on the line

Global QOL item	Very good	Good	Neither good nor bad	Bad	Very bad
Overall how will you evaluate your quality of life?	 100 90 80 70 60 50 40 30 20 10 0				

#Shows the subscales of quality of life in Parkinson's disease instrument in which item pool's items were retained otherwise deleted. Frequency=Fraction of patients who have been affected by the item, mean response=Average of all response for the item, Impact=Frequency×mean response, QoL=Quality of life, ADL=Activities of daily living subscale, NMS=Nonmotor symptom subscale

Appendix 2: Quality of life in Parkinson's disease (QLPD) instrument - Hindi

QLPD - Hindi

भारतीय पारकिन्सन रोग जीवन गुणवत्ता पैमाना

पारकिन्सन रोग का आपके जीवन की गुणवत्ता (क्वालिटी ओफ लाइफ) पर प्रभाव जानने के लिए यह प्रश्नावली तैयार की गई है। कृप्या सभी प्रश्नों का उत्तर आप दिए गए संभावित उत्तर में से किसी एक पर कर दें, जो कि आप के हिसाब से सबसे उचित हो। संभवतयाः यह उत्तर वह हो सकता है, जो आपके दिमाग में सबसे पहले आया हो।

इस प्रश्नावली में कुछ प्रश्न ऐसे हो सकते हैं जो आप पर लागू नहीं होते, तो भी आप उन प्रश्नों का जवाब दिए गए संभावित उत्तरों में से चुनें।

आपका जवाब दवा के प्रभाव में तथा दिन प्रतिदिन के हिसाब से अलग-अलग हो सकता है, परन्तु **आप अपना जवाब उस स्थिति के आधार पर दें जो स्थिति पिछले 4 सप्ताह में ज्यादातर समय रही।**

नाम **आयु/लिंग** **पंजीकरण क्रमांक ------------------------------**
फोन न. **दिनांक ------------------------------**

01	**क्या आपको दैनिक कार्यो (जैसे नहाना, कपड़े पहनना, भोजन करना आदि) में बीमारी से पहले की अपेक्षा ज्यादा समय लगता है ?**	
	नहीं	**0**
	थोड़ा ज्यादा समय लगता है	**1**
	तकरीबन दो गुना समय लगता है	**2**
	तकरीबन 4-3 गुना समय लगता है	**3**
	मैं कोई काम नही कर पाता/ पाती हूँ	**4**
02	**किस हद तक कंपन आपको परेशान करता है ?**	
	मुझे कोई कंपन नहीं है	**0**
	कंपन मुझे परेशान नहीं करते हैं	**1**
	कंपन मुझे कभी कभी परेशान करते हैं	**2**
	कंपन मुझे रोजमर्रा के काम करने में परेशान करते हैं	**3**
	कंपन के कारण मैं कोई काम नही कर पाता/ पाती हूँ	**4**
03	**क्या बीमारी से पहले की अपेक्षा आपकी आवाज मे कुछ बदलाव आया है ?**	
	बिल्कुल नहीं	**0**
	थोड़ी धीमी हो गई है, परन्तु समझी जा सकती है	**1**
	काफी धीमी हो गई है, परन्तु ज्यादातर लोग समझ जाते हैं	**2**
	बहुत ज्यादा धीमी हो गई है, समझाने के लिए कई बार दोहराना पड़ता है	**3**
	मेरी आवाज कोई नही समझ पाता है	**4**

		नहीं	**थोड़ा ज्यादा समय लगता है**	**मुश्किल से कर पाता/ पाती हूँ परन्तु स्वयं कर लेता/ लेती हूँ**	**पूरी तरह नहीं कर पाता/ पाती हूँ, किसी दूसरे व्यक्ति की सहायता लेनी पड़ती है**	**बिल्कुल भी नहीं कर पाता/ पाती हूँ**
04	**क्या आपको बिस्तर पर करवट लेने अथवा चादर या रजाई ओढने में परेशानी होती है ?**	**0**	**1**	**2**	**3**	**4**
05	**क्या आपको कोई भी दैनिक दिनचर्या के कार्य (जैसे शौच, दाँत साफ करना, नहाना, कपड़े पहनना, खाना खाने) में परेशानी होती है ?**	**0**	**1**	**2**	**3**	**4**

06	क्या कुर्सी पर से बैठ कर खड़े होने में आपको परेशानी महसूस होती है ?	0	1	2	3	4

		बिल्कुल नहीं	थोड़ी बहुत	काफी ज्यादा	बहुत ज्यादा	मैं चल नहीं सकता/ सकती
07	क्या आपको चलने में परेशानी होती है ?	0	1	2	3	4
08	क्या चलते समय मुड़ने में आपको परेशानी होती है?	0	1	2	3	4

		कभी नहीं	कभी कभार (महीने में एक बार या उससे भी कम)	काफी बार (महीने में एक से अधिक बार परन्तु रोजाना नहीं)	अधिकतर (रोजाना/ प्रतिदिन)	मैं चल नहीं सकता/ सकती
09	जब भी आप चलते हैं या मुड़ते हैं या चलना शुरू करते हैं, तो क्या आपको लगता है कि आपके पैर जमीन से चिपक गए हैं?	0	1	2	3	4
10	क्या चलते हुए आप गिर जाते हैं?	0	1	2	3	4

		कभी नहीं	कभी कभार (महीने में एक बार या उससे भी कम)	काफी बार (महीने में एक से अधिक बार परन्तु हर सप्ताह नहीं)	बहुत बार (सप्ताह में एक बार या उससे अधिक)	हमेशा (तकरीबन रोज)
11	क्या आपका रोने को मन करता है ?	0	1	2	3	4
12	क्या आप चिन्तित रहते हैं?	0	1	2	3	4
13	क्या आपको लगता है कि आप उदास रहते हैं?	0	1	2	3	4
14	क्या आपको लगता है कि ऐसे जीने से तो मर जाना बेहतर है?	0	1	2	3	4

		बिल्कुल नहीं	बहुत थोड़ा	थोड़ा बहुत	काफी ज्यादा	बहुत ज्यादा
15	क्या आपको बीमारी के बढने का डर लगता है ?	0	1	2	3	4
16	क्या आपकी बीमारी के कारण दूसरे लोगो का नजरिया आपको परेशान करता है ?	0	1	2	3	4
17	क्या बीमारी को स्वीकार करना आपके लिए मुश्किल है ?	0	1	2	3	4
18	क्या आपको इस बात का डर लगता है कि पता नहीं मेरे भाग्य में क्या लिखा है?	0	1	2	3	4

		कुछ बदलाव नहीं है	कुछ कम हो गया है	काफी कम हो गया है	बहुत कम हो गया है	बिल्कुल खत्म हो गया है
19	क्या आपका बाहर के लोगो से मिलना जुलना में कुछ बदलाव आया है?	0	1	2	3	4

		बिल्कुल नहीं	बहुत थोड़ा	थोड़ा बहुत	काफी ज्यादा	बहुत ज्यादा
20	बीमारी के कारण क्या आप समाज में शर्मिन्दगी महसूस करते हैं?	0	1	2	3	4
21	दूसरों से सहायता माँगना क्या आपके लिए मुश्किल होता है?	0	1	2	3	4
22	क्या आपको अजनबी लोगों से बात करने में मुश्किल होती है?	0	1	2	3	4
23	क्या आपकी बीमारी के कारण आपका परिवार परेशान रहता है?	0	1	2	3	4
24	क्या आप बीमारी के कारण दूसरो पर निर्भर हो गए हैं?	0	1	2	3	4

		पूरी तरह से	बहुत हद तक	काफी हद तक	कुछ हद तक	बिल्कुल नहीं
25	**क्या आप अपनी पारीवारिक जिम्मेदारियाँ निभा पाते हैं?**	0	1	2	3	4

क्या आप पारकिन्सन रोग की कोई दवा लेते हैं, यदि हाँ तो नीचे लिखे प्रश्न संख्या 28 से 30 का उत्तर दें, अन्यथा प्रश्न संख्या 31 पर जाएँ।

26	**पारकिन्सन रोग की दवा लेने से आपके जीवन में क्या बदलाव होता है?**	
	मैं पूरी तरह से सामान्य/ठीक हो जाता/जाती हूँ	0
	मैं ज्यादातर ठीक हो जाता/जाती हूँ	1
	मैं काफी हद तक ठीक हो जाता/जाती हूँ	2
	मैं थोड़ा बहुत ठीक हो जाता/जाती हूँ	3
	दवा लेने से मुझे कोई फायदा नहीं होता	4
27	**दवा लेने के बाद और अगली दवा के बीच में**	
	दवा का प्रभाव एक समान रहता है	0
	निश्चित समय पर दवा का प्रभाव कम हो जाता है	1
	निश्चित समय पर दवा का प्रभाव समाप्त हो जाता है	2
	अचानक से कभी भी दवा का प्रभाव कम हो जाता है	3
	अचानक से कभी भी दवा का प्रभाव समाप्त हो जाता है	4

		पूरी तरह से	बहुत हद तक	काफी हद तक	कुछ हद तक	बिल्कुल नहीं
28	**क्या आप अपने ईलाज से संतुष्ट हैं?**	0	1	2	3	4

		बिल्कुल नहीं	कुछ कम हो गई है	काफी कम हो गई है	बहुत कम हो गई है	बिल्कुल खत्म हो गई है
29	**क्या बीमारी की वजह से आपकी या आपके परिवार की आमदनी पर फर्क पड़ा है?**	0	1	2	3	4

		बिल्कुल नहीं	बहुत थोड़ा	थोड़ा बहुत	काफी ज्यादा	बहुत ज्यादा
30	**ईलाज पर खर्चा आपको किस हद तक परेशान करता है?**	0	1	2	3	4
31	**क्या आपके ईलाज पर खर्चा बढने से परिवार के जरूरी कामों (जैसे बच्चों की पढाई, शादी अथवा घर बनाना) पर फर्क पड़ा है?**	0	1	2	3	4

पिछले 4 सप्ताह में निम्नलिखित समस्या ने आपको कितना परेशान किया

		बिल्कुल नहीं	बहुत कम	थोड़ा बहुत	काफी ज्यादा	बहुत ज्यादा
32	**कब्ज**	0	1	2	3	4
33	**थकावट के कारण खुद को असहाय महसूस करना**	0	1	2	3	4
34	**मुँह से थूक अथवा लार गिरना**	0	1	2	3	4
35	**नींद की समस्या**	0	1	2	3	4
36	**बीमारी के कारण शरीर में दर्द**	0	1	2	3	4
37	**हाथ पैरों में ठंडापन, जलन अथवा सुन्नपन**	0	1	2	3	4
38	**पेशाब की वजह (जैसे बार बार जाना, कपड़ों में निकल जाना) से परेशानी**	0	1	2	3	4
39	**खाना निगलने में परेशानी**	0	1	2	3	4

		कुछ बदलाव नहीं है	कुछ कम हो गई है	काफी कम हो गई है	बहुत कम हो गई है	बिल्कुल खत्म हो गई है
40	क्या आपकी याददाश्त पर कुछ फर्क पड़ा है?	0	1	2	3	4

		कभी नहीं	कभी कभार (महीने में एक बार या उससे भी कम)	काफी बार (महीने में एक से अधिक बार परन्तु हर सप्ताह नहीं)	बहुत बार (सप्ताह मैं एक बार या उससे अधिक)	हमेशा (तकरीबन रोज)
41	ऐसा कुछ दिखाई देना (जैसे कमरे में कोई बैठा है), जो वास्तव में नहीं होता	0	1	2	3	4
42	क्या सोते हुए आप बड़बड़ाते हैं अथवा हाथ पाँव चलाते हैं जैसा लगे आप किसी सपने का अभिनय कर रहे हैं	0	1	2	3	4
43	क्या खाली बैठे/लेटे/सोते हुए आप पैरों में बेचैनी या हड़कन होती है जिसमें पैरों को चलाने से आराम मिलता है।	0	1	2	3	4

		पूरी तरह से	बहुत हद तक	काफी हद तक	कुछ हद तक	बिल्कुल नहीं
44	क्या आप अपनी सेक्सुअल जिन्दगी से संतुष्ट हैं?	0	1	2	3	4
45	क्या आप अपने स्वास्थय से संतुष्ट हैं?	0	1	2	3	4

यदि आपके जीवन की गुणवत्ता को मापने के लिए एक पैमाना बनाया जाए, जिसमें **100 का मतलब है कि आपके जीवन में अगर यह पारकिन्सन रोग न होता तो जो खुशियाँ, आनन्द होता** तथा **0 का मतलब है कि आपके जीवन की सबसे खराब स्थिति** जिसकी आप कल्पना कर सकते हैं तो पिछले 30 दिनों के आधार पर आप अपने जीवन का मुल्यांकन इस नीचे बनाई गई रेखा पर अंकित कीजिए।

		बहुत अच्छी	अच्छी	न अच्छी न खराब	खराब	बहुत खराब
46	आप अपने जीवन की गुणवत्ता का कैसे मुल्यांकन करेंगें?	100 90	80 70	60 50	40 30	20 10 0

47	6 महिने पहले की तुलना में अब आप आमतौर पर अब अपने स्वास्थय को कैसा पाते हैं?	6 महिने पहले की तुलना में अब बहुत बेहतर	6 महिने पहले की तुलना में अब काफी बेहतर	6 महिने पहले की तुलना में अब कुछ बेहतर	तकरीबन 6 महिने पहले जैसा ही	6 महिने पहले की तुलना में अब कुछ बदतर	6 महिने पहले की तुलना में अब काफी बदतर	6 महिने पहले की तुलना में अब बहुत बदतर
		1	2	3	4	5	6	7

क्या प्रश्नावली भरने में आपकी किसी ने सहायता की, यदि हाँ तो उनका परिचय(नाम/संबंध्द) दें।

आपको प्रश्नावली भरने में तकरीबन कितना समय लगा ___________मिनट

आपके सहयोग के लिए धन्यवाद।