Quality of Life in Parkinson's Disease - Indian Scenario

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Abstract

The subjective sense of well being is central to the concept of quality of life (QoL) and a good QoL should be the ultimate goal to any therapeutic measure. In Parkinson's disease (PD), several rating scale are in vogue to measure the QoL, namely PDQ-39, PDQ-8, SF-36, Likert scale etc. Parkinson's Impact Scale (PIMS) has been used in this study to assess the QoL which includes 10 items.

Methodology : thirty two patients of Parkinson's disease satisfying the UK Parkinson's disease brain bank diagnostic criteria, ranging from HY stage I to IV have been recruited. UPDRS was also administered to them. Statistical analysis was performed using Spearman rank correlation and multivariate stepwise regression analysis using SPSS for windows.

Result : seventy two percents were male, all getting levodopa, 72% got anticholinergics. Monthly income varied from Rs.800 (US$ 17.10) to Rs.15,000(US$ 320) pm. Eighty eight percent belonged to HY II-III.UPDRS score ranged from 3-85 (40.4±18.6).PIMS total score ranged from 1-22 (10.4±6.1).

Discussion and Conclusion : The QoL deteriorates with H-Y staging, the UPDRS score, not with advancing age as seen in other studies. It is also significantly influenced by duration of the disease and financial security. Surprisingly, the family and community relations were not significantly affected with advancing disease, perhaps due the close family and social tie up among Indians. So, measurement of QoL should be made an essential part to the routine assessment of PD patients to get a complete scenario of the problem. PIMS can serve as a comprehensive tool for the same suitable for use in the OPD. ©

INTRODUCTION

The sense of well being is central to the concept of quality of life (Qol) but there is no universally accepted definition for the same. It refers to the patient's own evaluation of the impact of the disease. Medicine has myopically focused on medical outcome, viewing symptoms and signs with laboratory studies from the physician's perspective but the patient's own view often takes a backseat in both routine patient care and clinical studies.[1] Experience suggests that patients are inherently biased – lacking awareness in medical terminology, classification, outcome and their opinions are heavily linked with expectation and desire. But they know how they feel! This subjective well being is the ultimate goal of any therapeutic measure. The disease impact on various aspects of life depends entirely on patient's life style, occupation, pre-morbid personality etc. For example, a mild action tremor may be acceptable to a manual worker but disabling to a writer or surgeon.

A better quality of life is a natural demand of most of

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the patients irrespective of their basic illness. So, while treating a chronic illness, a broader perspective of the disease needs to be considered than focusing on physical ailments only. Like any other chronic neurological disease, Parkinson's disease (PD) has got a major impact on individual's physical, psychological and socio-economic spheres and its measurement is of paramount importance in evaluating research outcome and in cost benefit analysis.[2] There are numerous reasons for impairment of the QoL in PD and many of these problems go unnoticed in routine clinical evaluation. Only QoL assessment allow them to be rated. Growing interest in this field has initiated a number of studies for assessment of QoL in PD. Some of them applied general health questionnaire like Nottingham health profile (NHP), 5 point Likert scale, SF-36 etc.[3-6] However, these generic instruments are designed for a wide range of diseases and may lack items of particular relevance to PD.[6] This is precisely the reason why a disease-specific instrument is essential in assessment of QoL. PDQ-39 (39 item questionnaire for PD), PDQL-37 are widely used and accepted disease-specific tool.[6] Parkinsonism Impact Scale (PIMS) has been validated in a Canadian study in 1996 but it has not been widely used till date.[7]

In India, there are no published data to date on QoL in patients with PD and it is more important to know the quality of life of Indian patients considering the long term treatment needed , use of costly drugs and the role of family members. In the present study, PIMS has been used as a disease specific instrument of QoL. It deals with the interpersonal relations, social and emotional aspects of life affected by the disease. It was intended to see the impact of PD on these aspects and other physical variables in the study.

AIMS AND OBJECTIVES

1. Assessment of the impact of the disease in patients suffering from PD in terms of their physical disability as well as the overall QoL.
2. To determine the correlation between different variables of physical disability and QoL.

METHODOLOGY

Thirty-two patients of PD undergoing regular treatment at the Movement Disorder Clinic, Bangur Institute of Neurology, Kolkata have been recruited over a period of one year.

Inclusion Criteria

1. Patients diagnosed as Parkinson's disease as per the UK Parkinson's Disease Society Brain Bank Diagnostic Criteria.
2. Patient's suffering for more than one year and had significant and persistent improvement with Levodopa for at least one year.
3. Patients who are attending the Movement Disorder Clinic regularly for more than one year and following the treatment schedule as advised.

Exclusion Criteria

1. Patients with secondary Parkinsonism and other Parkinsonian plus syndrome.
2. Patients who had minimal improvement with Levodopa.
3. Patients having severe hypertension, diabetes mellitus, heart disease or other chronic illness which may otherwise affect the overall quality of life and interferes with assessment of patients with PD.
4. Patients with significant cognitive impairment.

All the patients have been examined thoroughly after taking the detailed clinical history. The study period extended from July 1998 to September 1999. The cognitive function were assessed by Mini-mental status examination (MMSE) and patients with score less than 24 out of 30 were excluded form the study. The staging of PD was done with Hoehn and Yahr staging. Unified Parkinson's disease rating scale (UPDRS) has been administered to evaluate the mentation, activities of daily living (ADL), motor functions and side effects.

The QoL has been assessed by administering the Parkinsonism Impact Scale (PIMS). It's a 10 item scale and the score in each point varies from zero to four. Total score varies from zero to forty. The scores indicate the impact of PD on one's life – zero refers to no impact and four indicate severe impact (Fig . 1). Each of the items in PIMS has been explained to the patients and the responses were kept optional.

Statistical Analysis

The correlations between the UPDRS total and itemized score, HY staging, patient's age, disease duration, monthly income, overall PIMS score and scores between individual items of PIMS have been analyzed using Spearman's rank correlation co-efficient. A non-parametric multivariate analysis was performed using a stepwise regression analysis to find out the association between different explanatory and dependant variables. The dependant variables are the PIMS score (total), the individual items. The explanatory variables are UPDRS score, H-Y score, the disease duration, monthly income, family and community relations.

The statistical computing was performed with the Statistical package for social sciences (SPSS) for windows.

RESULTS

Thirty-two patients have been assessed in this study. Twenty-eight percents are below 50, 66% are between 50-70 and six are above 70 years of age. There are 23 (72%) male and 9(28%) female patients. 90% of them are married. Ten (30%) patients are suffering for less than 5 years, 16 (50%) for 5-10 years and 6(20%) for over 10 years (Table 1).

Treatment included Levodopa in all patients, anticholinergics in 23(72%), selegeline in 8 (25%) and dopa-agonists in 5 (18%). Their monthly income varies from Rs. 800.00 (US$ 17.10) per month (p.m.) to Rs. 15,000 (US$ 320.00) p.m. (Mean Rs.5613 ±3674= US$ 120± 78) and in 14 (44%) patients it is within Rs. 2,000.00 (US$ 43.00) to 5,000.00 (US$ 106.00) p.m. Only 3 (9%) patients have monthly income above Rs.10,000 (US$ 212.00). Monthly expenditure for the treatment varies from Rs. 300.00 (US$ 6.38 to Rs.2,000.00(US$ 43.00) (Rs. 616.40± 360.00= US$ 13.11±7.65). Eleven patients spend less than Rs.500.00 (US$ 10.63) pm and 18 (53%) patients between Rs.500.00 (US$ 10.50) to 1,000.00 (US$ 23.00) p.m.

Among the co-morbid conditions, 10 (31%) have mild hypertension, 1 patient had coronary artery disease, all

Table 1

	Mean	Standard Deviation
Age (In Years)	54.27	12.50
Duration of disease (Years)	07.15	04.5
Monthly Income (Rupees/US$)	5613(120)	3674(79)
Monthly Expenditure (Rupees/US$)	616(13)	360(7.5)
MMSE	29.25	1.07
H-Y	2.46	0.5

are well controlled with drugs. Sixteen (50%) patients belonged to H-Y stage II, 12(38%) is in stage III, 3(9%) is stage I and one patient was in stage IV. Their cognitive functions have been assessed with MMSE (29.25±1.07). The UPDRS total score ranged form 3 to 85 (40.4±18.6). Scores of the different items of UPDRS (Mean ± SD) are as follows: Mentation 2.77±1.4, ADL 9±1.29, Motor 23.6±12.66, side effects 3.41±2.41(Table 2).

The QoL has been assessed with Parkinsonism Impact Scale (PIMS). The 10 points of PIMS are grouped into four broad categories like "Psychological factors" (includes self feeling, leisure, safety, sexuality), "Social factors" (family, community), "Physical factors" (work, travel) and "Economic factors" (financial security) (Fig. 1.).

PIMS total score ranged from 1 to 22 (10.4±6.1). Among the individual points in PIMS, self positive, self –negative, work, leisure, travel, safety were affected in 65-90% of patients but family and community relationships were affected in only 10-12 cases. Only 8

Table 2 : UPDRS

	Mean	Standard Deviation
Mentation	2.77	1.4
ADL	9	1.29
Motor	23.6	12.66
Side Effects	3.41	2.41
Total	40.4	18.6

Table 3 : Parkinsonism Impact Scale

PIMS	Mean	Standard deviation
Self (Positive)	1.65	1.12
Self (Negative)	1.71	0.88
Family Relationship	0.18	0.64
Community relationship	0.15	0.44
Work	1.37	1.21
Leisure	1.56	1.21
Travel	1.5	1.16
Safety	1.34	1.18
Financial Security	1.06	2.13
Sexuality	1.37	1.30
Total PIMS score	10.4	6.1

Table 4 : Spearman's Rank Correlation

Variables	Correlation Coeff (R)	Significance (P)
Age & QoL	-0.1548	0.398
Disease Duration & QoL	0.0003	0.999
Monthly income & QoL	-0.1629	0.373
MMSE & QoL	-0.1168	0.524
UPDRS & QoL	0.4408	0.012
UPDRS (Mental) & QoL	0.3120	0.082
UPDRS (ADL) & QoL	0.3464	0.052
UPDRS (Motor) &Qol	0.3003	0.095
UPDRS(Side Effects) & QoL	0.4614	0.00
HY staging & QoL	0.4264	0.015
Financial security & QoL	0.5700	0.001

PARKINSON'S IMPACT SCALE   **PIMS**
NAME: DATE:

☐ Please indicate by a number (0-4) what impact Parkinsonism has had on your life.
0 = no change 1 = slight 2 = moderate 3 = moderately severe 4 = severe
☐ Use the definitions below to help you measure impact.
Self : (Positive) Refers to how positive you feel about yourself (self-worth, happiness, optimism)
Self : (Negative) Refers how negative you feel about yourself (level of stress, anxiety or depression)
Family Relationships : Refers to your spouse, partner, children and relatives that you consider part of your immediate family.
Community Relationships : Refers to your neighbours, friends, people you work with and those who provide you with services (store clerk, doctor, pastor, etc.)
Work : Refers to your job and/or the running of your home and your ability to support yourself and your family.
Travel : Refers to your ability to reach your destinations ie : work and/or social
Leisure : Refers to your ability to continue enjoyable activities (hobbies, sports, Volunteering
Safety : Refers to your ability to do what you want without injuring yourself or others (driving, being outdoors, in the kitchen, in the bathroom, etc.)
Financial Security : Refers to your ability to support yourself and your family and pay your medical costs
Sexuality : Refers to your ability to maintain a satisfactory sexual relationship
☐ If your symptoms are stable complete column 1
☐ If your symptoms fluctuate complete columns 2a and 2b (best and worse)

Column	1	2a (Best)	2b (Worst)
1. Self-positive			
2. Self-negative			
3. Family Relationships			
4. Community Relationships			
5. Work			
6. Travel			
7. Leisure			
8. Safety			
9. Financial Security			
10. Sexuality			

Parkinson's Impact Scale (PMIS) Parkinsonism and Related Orders, 1996 Vol. 2, No. 2, pp 55-61.

Fig. 1 : Showing the PIMS scale.

(25%) patients responded to the question regarding sexuality and among them 5 had changes (Table 3).

The 2-talied significance by Spearman rank correlation shows statistically significant correlation between UPDRS (total score), UPDRS side effects, HY staging, Financial security and QoL (Table 4).

Multivariate stepwise regression analysis was made with dimensions of PIMS as dependant variables and UPDRS (Total and itemized score), duration of the disease, monthly income, HY staging as explanatory variables (Table 5). It shows that higher PIMS score is obtained with longer duration of disease, lesser monthly income, more severe motor affection as seen in UPDRS and HY staging. The ADL affects the PIMS (work). The PIMS (leisure and financial security) is also affected by HY staging.

Table 5 : Results of the multivariate stepwise regression analysis with the QoL and its different points as dependent variables and duration of disease, monthly income, ADL and motor section of UPDRS, HY staging as explanatory variables.

Variables	Constant	Coefficient	P-value
PIMS score (Total)			
Step 1. Duration of disease	-1.4829	0.877	<0.50*
Step 2. Monthly income	4.177004	6.00317	0.0433
Step 3. UPDRS (Motor)	6.090625	0.172409	0.4388
Step 4. HY staging	-0.440767	4.393728	0.0288*
PIMS (Work)			
Step 1. ADL	0.661650	0.082112	0.0347*
PIMS (Leisure)			
Step 1. HY Staging	2.177112	0.186649	0.0161*
PIMS (Financial Security)			
Step 1. HY Staging	1.638489	-1.67936	0.0014*

DISCUSSION

In general, health is considered to be an essential part of QoL and diseases are known to be more prevalent with advancing age. In the present study, the mean age was below 60 years and it did not affect the QoL significantly though in other studies the advancing age had adversely affected the QoL.[8] The UPDRS score had a significant correlation with QoL. It is seen in other studies that UPDRS has significant correlation with physical mobility, emotional reaction, stress and isolation.[9] The UPDRS (side effects) are also significantly correlated with QoL. It indicates when the disease or treatment related side effects start appearing the QoL deteriorates steadily and significantly. The HY staging has significant correlation to QoL, which implies an advanced disease has direct impact on the QoL. In the multivariate stepwise regression analysis, the dependant variables are the PIMS total and itemized scores and the explanatory variables are the duration of the disease, monthly income, UPDRS(Motor) and HY staging. The score of PIMS for QoL was significantly affected by the duration of the disease, as the longer duration is more complicated with motor fluctuations, loss of efficacy of L-dopa or dopa-related side effects. Monthly income also affects the QoL significantly. A secured income is more comfortable to the patient, which ensures a good quality of treatment and better quality of life at the same time. Financial difficulties due to premature retirement and complex benefit system were found to deteriorate QoL.[10] The ADL has adversely affected the PIMS (work) as it depends on the physical ability of the patient. The leisure of the patient was significantly altered by the disease severity as indicated by the HY staging which in advanced stages also affects the financial security. The QoL as measured by other tools like PDQ-39, EQ-5D and physical summary of SF-36, deteriorated significantly with increasing disease severity as indicated by HY staging.[11]

One interesting finding in this study is the minimal alteration of family and community relationship. Possibly a good family bondage among Indians or a close social tie-up is responsible for this. One Japanese study has shown that patients who have a supportive caregiver are as twice satisfied as those who do not[12]. Another important finding in this study is that very few patients (25%) responded to the questions regarding changes in sexual functions. The inherent shyness of Indian patients to discuss about their sexual life might have contributed to it.

CONCLUSION

In the present study, it is seen that severity of the disease, indicated by the HY staging and the UPDRS score, has significantly altered the QoL as shown in the PIMS score. This is the first study on QoL among Indian patients suffering from PD. An reasonable monthly income and eventually the financial security has a significant positive impact on the QoL. In the later part of the disease, when motor fluctuations and other complications appear, the QoL deteriorates significantly. The PIMS addresses the different aspects in assessment of QoL which are not entirely modifiable by improving the physical symptomatology with drug treatment alone. Family and community relationship with supporting caregivers can enhance the QoL. Support from the employer and other sources could provide a better financial security and a better quality. Proper utilization of the leisure times with the help of the family members or the community makes life easier.

So it is important to realize that while treating a patient of Parkinson's disease, it must be borne in mind that we should look beyond the physical disabilities. Assessment of QoL should be combined with the routine examination, which helps to get a complete scenario of the problem. In this regard, PIMS may serve as a comprehensive and easy-to-administer tool in OPD basis. No scale for the assessment of depression has been administered in this study because a point on self-negativism has been included in PIMS and inclusion of another rating scale on PD would make the process of evaluation lengthier and unsuitable for use on OPD basis. The point on self-negativism has would bring out the factors adversely affected by the disease which are often overlooked in routine clinical examination. Those factors have definite impact on QoL and need to be addressed separately. Thus a multidisciplinary approach is warranted along with the medical treatment of PD which involves psychotherapists, occupational therapists, financial advisors, and the clinicians with the sympathetic approach to the family members and friends. It will certainly help the patient to cope with the protracted illness adding life to years rather years to life only.

No study is perfect and our study suffers from a small number of sample size. But this preliminary finding will

go a long way to undertake similar studies in different ethnic and cultural groups in India which might be useful factors for improvement of quality life in long term sufferers.

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Book Review

Neurological Practice - An Indian Perspective

Prof Noshir H. Wadia

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17-A/1, Main Ring Road, Lajpat Nagar-IV,
New Delhi – 110 024.

Prof. Wadia is one of the founding peers of neurology not only in India but in the tropics. For almost close to 5 decades he has very carefully studied with astute detail what is truly Indian in manifestations of the nervous system. He has also mentored several students who are now taking his clinical legacy to the next generation technology savvy nerve specialists armoured with fancy drugs. This master piece is illustrates how art of medicine merges with science of medicine. An ardent observer and sound record keeper allowed him to conduct quality research in a resource poor but clinically fertile environment from the corridors of the 4th floor of Government's Sir JJ Group of Hospitals and Grant Medical College prior to his shifting to high-tech Jaslok Hospital.

The book presents an exhaustive exposition of the prevalence and management of neurological disorders in India. It comprehensively covers various infections – viral, bacterial, prions and parasitic. It also covers epilepsy, vascular diseases, degenerative and environmental diseases, nutritional deficiency disorders, paediatric neurology, imaging of CNS infections, and other disorders of the nervous system. Each chapter begins with a short historical account of the disease, followed by a critical evaluation of the epidemiological and/or hospital based data. This is then compared with the data of other global populations. A clinical description of the disease is then presented and variations in India from the standard description are highlighted. The chapter then, discusses the related pathology, basic mechanism and patient management, and suitably emphasizes the specific variations in India.

This book would serve as a reference text for residents and clinicians in neurology, neuroradiology, neuropathology as well as for neurosurgeons. I feel every physician should have this masterpiece which shows all of us how disorders are studied in the Indian context.

Shashank R Joshi
Hon. Editor

Parkinson's disease (PD) is a chronic progressive neurodegenerative syndrome that impacts both motor and non-motor domains.[1] Treatment of PD is largely symptomatic and much of the focus has been on improvement of function and health-related quality of life (HRQL).[1] PD treatment frequently targets the motor symptoms including tremor, rigidity, slowness, and gait impairment. Data source. The National Parkinson Foundation (NPF) prospectively compiles and maintains long-term clinical outcomes of people with PD drawn from fifteen Centers of Excellence within and outside of the United States as part of the NPF Quality Improvement Initiative clinical study (NPF-QII). Patients who consent to enrollment are annually examined in-person.