Behind the Mask: A Study on the Clinical Course, Psychopathology and Impact on Quality of Life in Idiopathic Parkinson’s Disease

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Introduction

Parkinson’s disease is by no means an uncomplicated disorder. It is one of the commonest neurological conditions to affect older people with an overall incidence of 10-20 cases per 1 lakh population per year and a prevalence of about 160 cases per lakh. It was first described by James Parkinson, the well known neurologist in his ‘An Essay on The Shaking Palsy’ in 1871 as “involuntary tremulous motion with lessened muscular power in the parts not in action and even when supported with a propensity to bend the trunk forward, and to pass from a walking to a running pace, the senses and the intellect being unimpaired.” (Parkinson 1967).

Subsequent studies, have however reported psychiatric symptoms and organic brain changes associated with the disorder (Brown et.al. 1990, Aarsland et.al. 1999). Depression, psychosis and cognitive impairment have been extensively studied in these patients (Mindham 1970, Mayeux et.al 1981). Sudden extreme and occasional unpredictable changes in disability are a characteristic feature of untreated and treated Parkinson’s disease which manifest as freezing or paradoxic kinesis. These variables have been greatly accentuated by the introduction of levodopa. (Barbeau, 1971).

Mood fluctuations have been reported in up to two thirds of patients with Parkinson’s disease who experience motor fluctuations. Most researchers indicate that mood fluctuations are decreased when the patient is in the ‘on’ (mobile) state and increased when the patient is in the ‘off’ (immobile) state (Richard et.al 2001). Similarly anxiety (Richard et.al, 1996, Stein et.al. 1990) and obsessive compulsive symptoms have also been reported. Dementia is known to affect 40% of the patients with Parkinsonism and the incidence of dementia in these patients is 6 times that of the normal population (Emre, 2003).

Though the more apparent effects of parkinsonism are on the motor system, non motor problems also contribute to the overall impact of the condition. It is important therefore that assessment covers the physical, mental and social domains (Meara, 2001). The disorder has no doubt a detrimental effect on the quality of life of the patient. The impact of the disorder may hamper one’s ability to earn a source of livelihood due to the paralyzing motor disability with causes and concern for safety due to involuntary movements and gait problems (Damiano et.al., 1999).

Parkinson’s disease has always been the neurologist’s domain, but it is essential to study the psychological effects and the various psychiatric manifestations that may ensue as a result of the neurological problem.

Aims and Objectives

1. To assess the impact of Parkinson’s disease on mentation, activities of daily living and motor activity.
2. To study the psychopathology in patients of Parkinson’s disease having stable and fluctuating symptoms.
3. To assess the level of disability caused by Parkinson’s disease in both the groups.
4. To compare the quality of life in patients of Parkinson’s disease having both stable and fluctuating symptoms.
5. To correlate motor symptoms with disease severity, activities of daily living (ADL), disability, duration of illness, psychopathology and impact on quality of life of both the groups.

Material and Method

Sample - The sample consisted of 54 patients of ‘Idiopathic Parkinson’s Disease’ diagnosed as per criteria of the UK

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Parkinson’s Disease Society Brain Bank (Hughes et.al., 1992) diagnosed by a Neurologist, and attending the Movement Disorders Clinic at the Neurology and Neurosurgery OPD of a general municipal tertiary hospital.

Inclusion Criteria

1. All patients having idiopathic Parkinson’s disease.
2. Patients of all ages, both the sexes and language compatibility were selected for the study.
3. Patients were screened by the Mini Mental Status Examination to rule out any cognitive decline.

Exclusion Criteria – Patients having:

1. Parkinson’s disease due to other causes eg. drugs, arteriosclerosis etc.
2. Cognitive decline and dementia.
3. Any other medical or surgical complications.
4. Language incompatibility.
5. Any sensorimotor difficulty that would impair testing on scales.

The study was approved by the institutional ethics committee, and the patients were explained about the nature of the study and its application and voluntary consent was obtained from each patient.

Method

All the patients were initially screened by Mini Mental State Examination (MMSE) (Folstein, et.al., 1975) to rule out cognitive decline or dementia. The MMSE has a range of 0-30 and only those patients having a score of 19 and above were considered in the study (Crumm et.al. 1993). 4 patients out of the sample of 54 had a lower score on the MMSE and so were excluded from the study. All the patients were examined and assessed on all the scales in the ‘off’ state on the same day.

A proforma was designed in the form of a semi-structured interview to obtain information on demographic variables, disease history and drug therapy.

The clinical examination consisted of:

1. A complete Unified Parkinson’s Disease Rating Scale (UPDRS) (Fahn & Elton, 1987) assessment that had the following sections –
   - Mentation, behaviour and mood (range 0-16 and highest disease severity indicated by 16),
   - Activities of daily living (range 0-52 and highest disability indicated by 52),
   - Motor section (range 0-56 and highest disease severity indicated by 56),
   - The Hoehn and Yahr scale for parkinsonism (range 0-5 and highest disease severity indicated by 5),
   - The Schwabe and England disability scale (range 0-100% and the greatest independence indicated by 100%).

Clinical Groups

The scores of the motor section of the UPDRS with the questions pertaining to tremor, rigidity, bradykinesia, gait, postural instability, ‘on’ and ‘off’ states, presence or absence of falls and dyskinesias were taken into account to divide the patients into two groups –

- Group A – Patients of Parkinson’s disease having fluctuating symptoms. (N = 34)
- Group B – Patients of Parkinson’s disease having stable symptoms. (N = 16)

Psychiatric Assessment

The psychopathology was assessed by the Symptom Checklist-90 (SCL-90) (Derogatis et.al. 1970) that is composed of 90 items (each rated on a 5 point lickert type scale of distress) and 9 primary symptom dimensions believed to underline the large majority of symptom behaviours as under –

I - Somatization.
II - Obsessive Compulsive.
III - Interpersonal Sensitivity.
IV - Depression.
V - Anxiety
VI - Hostility.
VII - Phobic Anxiety.
VIII - Paranoid Ideation.
IX - Psychoticism.

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Quality of Life
The impact of idiopathic parkinsonism on the patient’s emotional, social and economic status was assessed by the Parkinson’s Impact Scale (PIMS) (Calne et al. 1996) across 10 items. Self, feelings, family, community, work, travel, safety, leisure, financial security and sexuality were the items assessed. The item was scored from 0-4 with 0 indicating no change and 4 the most severe.

Data Analysis
The following scores were obtained after administration of the scales –

1. UPDRS – scores on the mentation, motor activity and activities of daily living subscales along with a total score. The Hoehn and Yahr staging along with percentage of disability was also obtained.

2. PIMS – scores in form of a global(weighted) score obtained by summation of all the items.

3. SCL-90 – raw scores on all the symptom dimensions of the SCL-90 were obtained and the global score of General Symptomatic Index (GSI) was calculated as per the formula.

Statistics
Non parametric tests were chosen because of the ordinal nature of the scales. Group differences were analysed by the Mann Whitney U tests (Seigal, S. & Castellan Jr., N.J., 1988) and the direction and magnitude of the associations between scale variables with Spearman rank correlation. Two tailed p values were obtained for all statistical analyses.

Results and Discussion
As shown in Table 1, the sociodemographic profile revealed the mean age to be 60 ± 9.87 years and 63.12 ± 10.13 years in groups A and B respectively. Males outnumbered females in both the groups. Nearly 82% of the patients were married in both the groups, the remaining being widowed or single. 73% of the patients in Group B had achieved secondary plus higher education as compared to 55.8% in Group A. There was also a higher frequency of illiterates in Group A i.e. 23.52%, as compared to Group B. There are certain studies which have found patient’s educational status to improve life satisfaction in Parkinsonism (Cubo et al. 2002). However there were no significant differences seen in the socio-economic strata or the employment status of both groups.

Patients with Parkinson’s disease eventually develop a fluctuating response along with involuntary movements (dyskinesias) on medication. The scores of the motor section of UPDRS were considered for dividing the patients into 2 groups (Table 2). A significant difference was noted with patients in Group A having more rigidity, tremors, bradykinesia, postural instability, on-off fluctuations and dyskinesias.

On assessing mentation, behaviour and mood an extremely significant difference (p < 0.0001) was noted in both the groups. Patients having fluctuating symptoms experienced more problems with cognition, periods of sadness, thought disorder and poor motivation. There are several studies that report mood fluctuations in patients who are having motor fluctuations especially in the “off” state. (Richard et al., 2001). These minor depressions are more likely to remit (Mayeux et al., 1981) and may be closely related to disability (Starkstein et al., 1990) which has been corroborated in our study.

Patients having motor fluctuations begin to lose control of their daily life as their ability to work or perform their daily activities may fluctuate with response to medication and the involuntary movements may interfere with activities (Adler, 2002). This has also been seen in our study with a significant difference (p < 0.01) noted on ADL in both the groups. Patients in Group A reported significant difficulty in handling their daily routine with respect to eating, swallowing, hygiene, cutting things, falling etc. Thus patients having fluctuating symptoms had problems in all areas on evaluation of the UPDRS (p < 0.001) as compared to those without motor impairment.

When both the groups were compared for disability on the Schwabe & England Disability Scale a significant difference (p < 0.04) was seen (Table 3). This is in keeping with the results seen in the study (Dural et al., 2003) where motor and musculoskeletal impairments correlated with the disability scores.

The symptomatic profile of all the patients (chart 1) revealed depressive symptoms to be more marked in both the groups followed by anxiety and somatization. This is in keeping with studies by Gottam et al. (1986), Cummings (1992), Walsch et al. (2001) and Schiffer et al. (1988). The depression in Parkinson’s disease includes a high rate of anxiety symptoms, little guilt feelings of failure or punishment and a low suicide rate (Huber et al. 1990). Obsessive compulsive symptoms and interpersonal sensitivity were more marked in Group A than Group B whereas psychoticism rated the least in both the groups.
Table 1

AGE AND SEX PROFILE OF BOTH GROUPS

| Variable          | Grp A (N = 34) | Grp B (N = 16) |
|-------------------|---------------|---------------|
| Age               | Mean Age (Years) 60 ± 9.87 | 63.125 ± 10.1 |
| Sex               | Males 22 (64.7%) | 12 (75%) |
|                   | Females 12 (35.3%) | 4 (25%) |
| Religion          | Hindu 29 (85.29%) | 15 (93.75%) |
|                   | Muslim 5 (12.54%) | 1 (6.25%) |
| S.E. Status       | Low 16 (47.06%) | 5 (31.25%) |
|                   | Middle 18 (52.94%) | 7 (43.75%) |
|                   | Upper Middle 0 | 4 (25%) |
| Marital Status    | Married 28 (82.35%) | 13 (81.25%) |
|                   | Single 1 (2.94%) | 2 (12.5%) |
|                   | Widowed 5 (14.7%) | 1 (6.25%) |
| Education         | Illiterate 8 (23.52%) | 1 (6.25%) |
|                   | Primary 6 (17.64%) | 3 (18.75%) |
|                   | Secondary 15 (44.12%) | 9 (56.25%) |
|                   | Graduate 4 (11.76%) | 3 (18.75%) |
| Employment        | Retired 19 (55.88%) | 8 (50%) |
|                   | Employed 5 (14.71%) | 5 (31.25%) |
|                   | Unemployed 10 (29.41%) | 3 (18.75%) |

Table 2

CLINICAL EVALUATION OF PARKINSON’S DISEASE

| U.P.D.R.S. Sectors | Group A (N = 34) (Sum of Ranks) | Group B (N = 16) (Sum of Ranks) | 2 Tailed P Value |
|--------------------|---------------------------------|---------------------------------|-----------------|
| Motor              | 985.5                           | 286.5                           | 0.0119*         |
| Mentation & Behaviour | 1053.5                        | 221.5                           | 0.0001**        |
| Activities Of Daily Living | 990.5                        | 284.5                           | 0.0105*         |
| Total Score        | 1025                            | 250                             | 0.001**         |

* Significant  ** Very Significant.

Table 3

DISABILITY IN PATIENTS WITH PARKINSON’S DISEASE

| VARIABLE                  | Group A (N = 34) (Sum of Ranks) | Group B (N = 16) (Sum of Ranks) | 2 Tailed P Value |
|---------------------------|---------------------------------|---------------------------------|-----------------|
| Schwabe & England Disability Scale | 770                            | 505                             | 0.044*          |

* significant.

When psychopathology was compared in both the groups on different dimensions it however revealed a significant difference on interpersonal sensitivity, phobic anxiety, psychoticism and depression (Table 4). This could be due to the fact that patients having motor disability have feelings of personal inadequacy and inferiority in comparision to other especially during interpersonal interactions.

Phobic anxiety represents agoraphobia on this measure. Fear to travel away from home or in public places or conveyance would therefore seem probable in these patients having fluctuating symptoms. Phobic disorder, social phobia and agoraphobia has been identified in patients with Parkinson’s disease. (Lauterbach, 1991, Stein, et.al., 1990, Menza et.al., 1993). There have been some studies which have formed a temporal relationship between the on-off phenomenon and panic attacks which is also documented in our study. (Stein et.al. 1990, Menza et.al. 1990, Siemers et.al. 1993).
Table 4

| SCL-90 DIMENSIONS | Group A (N = 34) (Sum of Ranks) | Group B (N = 16) (Sum of Ranks) | 2 Tailed P Value |
|-------------------|---------------------------------|---------------------------------|-----------------|
| Somatization      | 942.5                           | 332.5                           | 0.118           |
| Obsessive Compulsive | 954                             | 321                             | 0.07            |
| Inter-Personal Sensitivity | 967                             | 308                             | 0.03            |
| Depression        | 967.5                           | 307.2                           | 0.037*          |
| Anxiety           | 912                             | 326                             | 0.153           |
| Hostility         | 951.5                           | 323.5                           | 0.08            |
| Phobic Anxiety    | 993                             | 282                             | 0.009**         |
| Paranoia          | 934.5                           | 340                             | 0.163           |
| Psychoticism      | 298.5                           | 0.02*                           |                 |
| Additional        | 961.5                           | 313.5                           | 0.05            |
| General Symptomatic Index (Gsi) | 954                             | 321                             | 0.07            |

* significant. ** very significant

Psychoticism refers to behaviour viewed as oblique with items reflecting Schneiderian first rank symptoms. Studies by Aarsland et al. 1999 and Sanchez-Ramos et al. 1996 reported hallucinations and delusions in patients with Parkinson’s disease which correlated with levels of akinesia and rigidity. Similar results were noted in our sample of patients.

Thus a wide range of neuropsychiatric disturbances were seen which have also been noted in other studies.

However when the general symptomatic index was compared for distress no significant difference was noted in both groups.

Idiopathic Parkinson’s disease being a chronic progressive neurodegenerative disorder with onset of motor complications after levodopa therapy for 3-5 years results in a tremendous impact on QOL, with a reduced health related QOL when fluctuations are present (Table 5). In our study all the dimensions of QOL viz. psychological (self, feelings, leisure and safety), social (community, family, sexuality), physical activities (work, travel) and economic dimension (financial security) were significantly affected in patients with raving motor fluctuations. An item analysis revealed community relationships (p < 0.006) and travel (p < 0.003) to be more significantly affected than others. This could be due to the constraints of motor disability and dyskinesias that hampered the patient’s mobility and social interactions. Thus overall QOL suffers in patients having motor fluctuations. (Adler, 2002, Schrag, 2000). A higher economic burden has been studies in patients of motor fluctuations with a definite increase in healthcare expenditure (Dodel et al. 2001) which has also been seen in our study. The questions on sexuality was optional because though answered by all did not reveal a significant difference between the two groups.

As shown in table 6 when the motor UPDRS scores of both the groups were correlated with different variables like disease severity (Hoehn and Yahr staging), ADL, Schwabe and England disability scale, duration of illness, psychopathology (SCL-90) and impact on QOL (PIMS) for significance then a definite correlation was obtained on ADL (r = 0.6491, p < 0.0001, r = 0.5163 and p < 0.0406) and PIMS (r = 0.4739 and p < 0.004, r = 0.5239 and p < 0.03) which is in both groups respectively which is in keeping with several studies (Adler, 2002, Dodel et al. 2001 and Durel et al., 2003). However disability (r = 0.62 and p < 0.0101) and psychopathology (r = 0.5269 and p < 0.036) could be correlated only in the stable group, thus not confirming to the hypotheses that patients having motor fluctuations are at a lower risk of developing neuropsychiatric disturbances and disability. This could be due to the fact that though they are having Parkinson’s disease, they are leading relatively normal lives as motor fluctuations have not yet developed. They may therefore respond to various other stressors as they are not hampered by motor disability. A study by Aarsland et al. (1999) gave no correlation between neuropsychiatry symptoms and level of disability caused by on-off fluctuations and dyskinesias. The psychopathology in these groups of patients could also be neurobiologically mediated. The duration of illness or disease severity however did not have a significant correlation with motor fluctuations.
Conclusions

Idiopathic Parkinson’s disease is a chronic progressive neuropsychiatric disorder affecting people over 60 years of age. It results in motor complications seen with levodopa treatment. 68% of patients in our study (n = 34) had motor fluctuations when these patients were compared with those who were stable (n=16). For impact of Parkinson’s disease a significant difference was seen on mentation, behaviour, mood, ADL and motor disability. Patients having motor fluctuations also exhibited high levels of interpersonal sensitivity, phobic anxiety, depression and psychoticism. Health related QOL was also significant in patients with motor fluctuations with community relationships and travel being severely hampered. A distinct correlation of ADL and QOL with motor symptoms were seen in both groups whereas psychopathology and level of disability could be correlated only with the stable patients. This may well mean that patients with fluctuating symptoms are often the ones who may be disease oriented mentally and may thus not be bothered about various social factors and community participation, while those with stable symptoms try to achieve some kind of social role and community participation that results in the actual psychopathology and disability coming to the fore. It is therefore of critical importance that there is a forward planning to put in place strategies and services that would effectively address the needs of this population to maintain their mental well being and QOL. A study of this sort would thus be a stepping stone in this regard.

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