

THE MEDICAL, SOCIAL, AND FUNCTIONAL PROFILE OF PARKINSON'S DISEASE PATIENTS

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ABSTRACT

The study looked at the medical, social, and functional aspects of 34 patients with idiopathic Parkinson's Disease (PD). Eighty-five percent were above 55 years and 35% were over 70 years. Twenty-four (71%) were males.

Most patients had Stage II disease.

Overall functional state of the patient correlated closely with the stage of Parkinson's disease. Patients were likely to be dependent if their disease severity was stage III or more. Eighteen (53%) patients would require a carer to be present at least part of the day and 3 (9%) patients would require a carer most of the time.

Domestic chores such as meal preparation, housework, and shopping were also affected in most of those who were previously active in these tasks. Ten patients had given up work due to their Parkinson's disease.

The lack of knowledge of the disease was shown both in the carers and the patients. Twenty-nine of the patients had no knowledge of the disease, and only one carer had superficial knowledge of the disease. The major social problems associated with the disease were loss of social contact, behavioural problems, family members under strain and communication problems within the family.

Since Parkinson's Disease is a chronic illness, with associated disabilities, it is important that the physician should aim for a multi-disciplinary approach. Patient and carer education should be given emphasis, and the many everyday functional problems addressed. Advice on life-style management and aids to overcome disabilities may help improve quality of life of the patient and reduce carer's stress.

Keywords: Parkinson's disease, carer's stress, disability

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INTRODUCTION

The study of Parkinson's disease patients and their families was conducted in three areas, namely medical, functional and social. The study aimed to be an in-depth analysis on problems faced by Parkinson's patients and their family on the three aspects studied.

PATIENTS

A total of 103 patients were initially short-listed for the study. Only 45 patients were studied. The drop-outs were mainly due to unwillingness of patients and their family members to participate. Of the 45 patients seen, only 34 were found to have idiopathic Parkinson's disease.

METHOD OF ASSESSMENT

Questionnaires were completed via direct interviews with the

patients and their carers. Following the home visits, arrangements were made for the patients to be assessed by the physician and the occupational therapist at various centres. Where a patient was unable to go to the centre, home visit assessments were made by the doctor and the therapist.

Functional abilities were scored using the Katz index (Appendix I). This was then converted into descriptive terms when assessing overall functional status.

Appendix I - Katz index

Grading	
5	Normal performance
4	Adequate performance, but involvement noticeable and/or dependent on special apparatus, heights, weights, etc.
4-	Adequate performance but needs improvement, slow, awkward, etc.
3	Supervision needed to complete
2	Assistance needed to complete
1	Activity impossible

These were then divided into:

5:	Normal function
4-/4:	Independent with impaired performance
1-3:	Assistance required

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A 10-question mental status score (Appendix II)⁽¹⁾, was used for assessing the mental state of the patients.

In the assessment of functional status, each patient's general performance was taken into account rather than his presentation at the time of assessment. Where there was any doubt, the patient was seen again, often in the home environment. The level of disability was discussed at case conference and was a team decision.

RESULTS

Table I shows the age and sex distribution. Eighty-five percent were 55 years and 35% were over 70 years.

Appendix II – Mental status questionnaire

1. Where are we now?
2. Where is this place located?
3. What is the day of the month?
4. What month is it?
5. What year is it?
6. How are you?
7. When is your birthday?
8. In what year were you born?
9. Who is the Prime Minister of Singapore?
10. Who am I?

Table I – Sex and age distribution

Age range	Male	Female	Total
< 55	3 (9%)	2 (6%)	5 (15%)
55-69	14 (41%)	3 (9%)	17 (50%)
70 & >	7 (21%)	5 (15%)	12 (35%)
Total	24 (71%)	10 (29%)	34 (100%)

The severity of the disease was graded on the scale by Hohn & Yahr (Appendix III). Table II shows the severity of disease in relation to the duration of illness. As can be seen, most patients fall into stage II where balance was not impaired.

Appendix III –Hoehn and Yahr scale of clinical disability

Stage I	Unilateral involvement only, usually with minimal or no functional impairment.
Stage II	Bilateral or midline involvement, without impairment of balance.
Stage III	First sign of impaired righting reflexes. This is evident by unsteadiness as the patient turns or is demonstrated when he is pushed from standing equilibrium with feet together and eyes closed. Functionally the patient is somewhat restricted in his activities but may have some work potential depending on the type of employment. Patients are physically capable of leading independent lives, and their disability is mild to moderate.
Stage IV	Fully developed, severe disabling disease; the patient is still able to walk and stand unassisted but is markedly incapacitated.
Stage V	Confinement to bed or wheelchair unless aided.

Table II – Grading on Hohn & Yahr compared with duration of disease

Grading	No. of patients	Mean duration in months
I	4	63.8
II	14	71.4
III	10	77.3
IV	5	128.8
V	1	120

Medications

Thirty-one patients (91%) were on anti-parkinson's drugs. Three patients were not on any medication (2 had stage I disease and the other had stage III disease). Twenty-nine patients were taking L-dopa in the form of madopar or sinemet, either alone or in combination with other drugs (7 patients were on L-dopa alone). Three patients were on selegiline. Bromocriptine was given to 12 patients. Fifteen patients were on benzhexol.

Side effects

Fourteen patients experienced hallucinations. All were on L-dopa, 4 in combination with bromocriptine, 3 with artane, and one with artane and bromocriptine.

Other side effects were nightmares in 6 patients, athetosis in 3, nausea in 20, dry mouth in 10 and confusion in 9 patients. It was difficult to isolate the main drug causing these side effects as most of the patients were on a combination of treatments.

Mental and psychological status

Using a modified mental status questionnaire, 27 (79%) patients scored 8-10 (absent or mild chronic brain syndrome), 5 (15%) patients scored 5-7 (mild/moderate chronic brain syndrome) and 2 (6%) patients scored 4 and below (moderate/severe brain syndrome).

Psychological problems of anxiety was experienced by 7 (20.6%), paranoid symptoms by 4 (11.8%), confusion by 9 (26.5%), and depression by 2 (5.9%).

Most patients had more than one medical problems, with an average of 5 problems per patient. Common associated conditions were prostatomegaly, cataract, diabetes mellitus, osteoarthritis, stroke and hypertension.

Functional state in relation to severity of illness

Overall functional state (Table III) of the patients correlated closely with the stage of Parkinson's disease. Twelve patients with stage I or II disease had only mildly impaired function. Two patients with stage II disease had significantly altered approach to task and 3 patients with stage II disease required assistance most of the time. All 6 patients with stage IV or V disease, required some help or assistance most of the time. Of the 10 patients with stage III disease, 2 had mildly impaired performance, 3 had significantly altered approach to task, 5 required assistance most of the time.

It can be seen that patients were likely to be dependent if their disease severity was stage III and above. Thirty-one (91%) patients were receiving active treatment at the time of assessment and therefore their level of disability was based on their ability while on medication.

Table III – Overall functional status

Overall Functional Status of patient	Number (%) (n=34)
1. Carries out ADL at normal level	0
2. Mildly impaired performances	13 (38%)
a. required to adapt methods	
b. start using aids	
c. fatigues easily	
d. has recently given up work	
3. Significantly altered approach to task	6 (18%)
a. difficulty with ADL	
b. requires help around the house	
c. sometimes requires help with transfers	
4- Requires some help in ADL	12 (35%)
a. one helper present in house at least part of the day	
b. supervision required because of falls, stroke, balance.	
c. supervision required because of mental state	
4. Assistance required most of the time – presence of one person in the home, if person is not present, patient is in high risk category	3 (9%)
5. Severe dependency	0
a. help of 1 or 2 person most of the time	
b. patient only able to carry out light self care	

Mobility

Impaired mobility was observed in 32 (94%) of the patients. The degree of dysfunction varied from mild change in walking pattern, and reduction in stamina on longer walks to inability to walk at all (2 patients). Seven (20.6%) of the patients required aid or supervision in walking.

However, a greater disabling factor was the degree of difficulty in rising from sitting to standing whether from a chair, bed or toilet (Table IV). Difficulty turning in bed was experienced by 19 (55.9%) patients. Difficulty rising from the floor was seen in 25 (73.5%) and climbing up and down stairs in 23 (67.6%) patients.

Table IV – Transfers

	Assistance	Independent (impaired performance)	Normal
Ability on/off toilet	9 (26%)	23 (68%)	2 (6%)
chair (low)	14 (41%)	18 (53%)	2 (6%)
chair (high)	8 (24%)	23 (68%)	3 (8%)
bed	10 (29%)	22 (65%)	2 (6%)
in/out of car	16 (47%)	17 (50%)	1 (3%)

Activities of daily living (ADL)

The ability to carry out activities of daily living is shown in Table V. Domestic chores such as meal preparation, housework, and shopping were also affected in those who were previously active in these tasks (Table VI). Note that in this table, only patients who were active in these tasks prior to onset of Parkinson's disease were studied. Other problems included those who experienced problem with the elevator on a different level, 3 (8.8%), and those whose leisure activities were negatively affected by the disease, 10 (29.4%).

Table V – Activities of Daily Living

Ability in	Assistance	Independent (impaired performance)	Normal	Not Applicable
dressing	16 (47%)	16 (47%)	2 (6%)	
feeding	4 (12%)	27 (79%)	3 (9%)	
bathing	9 (26%)	23 (68%)	2 (6%)	
toilet	8 (24%)	24 (70%)	2 (6%)	
cutting nails*	9 (27%)	23 (70%)	1 (3%)	
hair combing	2 (6%)	25 (76%)	6 (18%)	
shaving	5 (15%)	17 (50%)	2 (6%)	10 (29%)

*information on one patient not available.

Table VI – Domestic chores

	Assistance	Independent (impaired performance)	Normal
Meal preparation	18 (75%)	5 (21%)	1 (4%)
Housework	19 (70%)	8 (30%)	0 (0%)
Shopping	21 (88%)	2 (8%)	1 (4%)

Communication

Speech was affected in the majority of the patients. However in the majority the change was mild and for most this was either reduced rate of delivery, 7 (20.6%); reduced volume, 5 (14.7%); or in 9 (26.5%) a combination of both these changes.

Atetoid movements of the tongue and jaw contributed in 2 cases to slurring of their words which improved as the effects of

medication wore off.

In writing, the majority of patients, 25 (73.5%) had some form of problem. Micrographia was the largest problem, with 10 (29.4%) exhibiting this phenomenon. Shaky writing was also felt to be a difficulty. Most patients in the elderly age group rarely wrote, few were in the habit of letter writing and the occasional signing of forms or cheques did not pose a problem. One patient who was a clerk gave up work because of writing difficulties and this was the first disability he noticed. Still for most being unable to write clearly was not a handicap which changed their lifestyle.

Thirteen patients (38%) were observed to have a poor level of communication, while 14 (41%) appeared to have no difficulty.

Social profile

Twenty-five (73.5%) of the patients were married, the other 9 (26.5%) were either single, divorced, widowed or separated.

The majority of the patients (23) stayed in flats. Nine stayed in houses and one in a bungalow. Information for one patient was not available.

Twenty (58.8%) of households had income of \$1000 or more, while 10 (29.4%) had less than \$500 per month.

The occupation of the patients were relatively well distributed amongst the various white-collar and blue-collar work. Relatively large number were housewives (9, 25%). Only 2 patients were working.

Ten (29%) of the patients quit work due to their disabilities. Looking at those over 55 years, 2.7% were working, contrasting with the national average in 1990 of 26.1%⁽²⁾. The study did not look at the number of care givers who gave up work to look after the patient. These were often the women.

Patient's knowledge of Parkinson's Disease

Only 2 (6%) of the patients were knowledgeable about the illness. Twenty-nine (85%) had no knowledge of the disease, and the rest 3 (9%) had superficial/mistaken beliefs of their illness. This poor understanding of the illness was also reflected in the family members. Only one family had superficial knowledge of the disease.

Profile of the carers

Carers consisted of mainly spouses 19 (56%), and family members 13 (38%). Two patients (6%) were looked after by maids.

Occupation of carers

A large number of carers were housewives (32%). Though the sample was small, a fairly even spread of occupations was registered among the carers.

Educational levels of the carers of the patients ranged from those who had not had any formal schooling to those who were tertiary institution graduates. Twenty (58.8%) had attained at least a secondary school education. Seven (20.5%) of the carers had only achieved up to primary school education and 7 (20.5%) of the carers did not have any formal education.

Forty-seven percent of the carers had been aiding the patients for a period of one to five years, 20.5% about 6 to 10 years, and 23.5% had been caring for the patients for more than ten years.

Attitude towards the patients

Fifty percent of family members expressed affection for the patients and 38% had feelings of filial piety. Nine percent expressed a tolerant attitude and only one family member (3%) was antagonistic towards the patient.

Patients and their carers experienced various types of social problems as listed in Table VII. Twenty-six (76%) had at least one of the stated problems. Of these, 8 (24%) had 5 or more problems.

Table VII – Social problems experienced by patients

Types of Social Problems	No.
Loss of social contact	15 (44%)
Fear of going outside	7 (21%)
Financial difficulties	3 (9%)
Behavioural problems	14 (41%)
Psychological problems	7 (21%)
Family members under strain	14 (41%)
Environmental factors	9 (26%)
Communication problems within the family	13 (38%)
Gave up work recently	8 (24%)

DISCUSSION

Parkinson's disease is a slowly progressive disorder affecting mainly the elderly population. Management difficulties are compounded by drug side-effects, associated medical conditions in the elderly, social and carer related problems.

The present study, although looking at a small and non-random sample of patients with Parkinson's disease, attempts an in-depth study of the problems encountered through a multi-disciplinary approach.

There are at present no local figures of the incidence and prevalence of Parkinson's disease in Singapore for comparison with our age and sex distribution. Comparison made with a similar study done in United Kingdom⁽³⁾ shows our sample to have a larger percentage of the young elderly (47% compared to 36% in the UK study for those aged 55-69) and a smaller prevalence of those over 70 years (42% compared to 58%). Our sample also reflected a higher percentage of male patients (71% compared to 50%).

The side-effects of Parkinson's treatment are shown clearly in this study, with the majority of the patients experiencing one or more side effects.

Also highlighted in this study is the large number of associated medical problems in these patients.

Looking at overall functional status, 18 (53%) were in group 3 or 4-, which means that this group of patients will require a carer to be present at least part of the day. Three (9%) patients required a carer most of the time. No patient had normal functional status or severe dependency. It is possible that these patients were amongst those who were unable or unwilling to participate.

The breakdown of the various functional tasks shown in the results emphasises the various day-to-day problems that were encountered by the patients. Looking at a specific example like dressing, a large number 16 (47%) needed help to complete this activity and certainly this number could be made smaller with

appropriate training and advice on types of garment and fastenings.

The data also highlighted some problems that need to be addressed:

- The lack of knowledge of the disease both in the carers and the patient. This lack of knowledge was reflected even in patients with secondary level of education.
- Social problems associated with the disease – the major ones being loss of social contact, behavioural problems, family members under strain and communication problems within the family.

Despite the difficulties of care and considering that most carers had been caring for a considerable length of time, it is heartening to note that 50% of the carers expressed affection for the patients and 38% had feelings of filial piety.

It has been found in specific studies on aids in Parkinson's disease that they have a very necessary function in enabling the person to carry out a variety of tasks unaided and with reduced help from others^(3,4).

Although objective studies to confirm the role of physical therapy, occupational therapy and speech therapy in the patient with Parkinson's disease are scarce, each of these therapy modalities can play a certain role in the management of the appropriate patient⁽⁵⁻⁸⁾.

There is a need to re-look at the way we manage patients with Parkinson's disease. Since Parkinson's disease is a chronic illness and many of our patients may have the disease for many years, it becomes particularly important that the physician should aim for a multi-disciplinary approach. Patient and carer education should be given emphasis, and the many everyday functional problems addressed. Advice on life-style management and aids to overcome disabilities may help improve quality of life of the patient and reduce carer's stress.

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