Parkinson's disease as community health problem: study in Norwegian nursing homes

J P Larsen and the Norwegian Study Group of Parkinson's Disease in the Elderly

Abstract

Objective—To examine the extent of under-diagnosis and overdiagnosis of Parkinson's disease and to determine quality of treatment in a defined population.

Design—Clinical evaluation of an elderly population.

Setting—40 Norwegian nursing homes.

Subjects—3322 residents of nursing homes, of whom 500 were selected by nursing staff for evaluation on the basis of a structured information programme on Parkinson's disease and 269 were examined in detail by neurologists.

Main outcome measures—Patients' scores on clinical rating scales, diagnosis of parkinsonism, and effect of changing drug treatment.

Results—169 (5.1%) patients were found to have clinical idiopathic Parkinson's disease, 31 of whom had not had the disease diagnosed previously. In addition, 31 patients without the disease were taking antiparkinsonian drugs unnecessarily. Eighty patients were judged to be receiving "optimal" treatment. In the remaining 58, the treatment was changed, and 36 patients showed a definite functional improvement after a 12 week observation period.

Conclusions—The quality of life of many elderly patients with Parkinson's disease could be improved by increasing medical and neurological services.

Introduction

Parkinson's disease is a neurodegenerative disorder that usually presents in old or late middle age. Major advances have been made by studying the pathophysiology and treatment of the disease over the past decades.¹

Despite substantial epidemiological data on the disease,^{2,3} few studies have tried to establish the importance of the disease as a community health problem. Knowledge of the true incidence of the disease in well defined populations of elderly people could help answer this important question. Data on the incidence of the disease, quality of diagnosis, and the quality of medical treatment should also have an impact on the medical and neurological services made available to this group of patients.

Reports from the United Kingdom have indicated that Parkinson's disease is not a large problem in nursing homes⁴ and that the main problem is over-diagnosis in elderly people.⁵ In a pilot study in Norwegian nursing homes, however, we found 30 patients with the disease among 589 residents.^{6,7} Eleven had the disease diagnosed during the observation period and a definite improvement in function was achieved in 14 of the 30 parkinsonian patients by introducing or changing drug treatment. The median age of patients in Norwegian nursing homes is about 80

years and they represent a high risk population for parkinsonism. We report here the prevalence of and the quality of diagnosing and treating Parkinson's disease in a representative selection of people in nursing homes throughout Norway.

Subjects and methods

We studied 3322 residents in 40 nursing homes located in 14 municipalities all over Norway; all the homes were within one hour's travelling distance from a department of neurology. Most of the people in these homes are elderly and have reduced physical or mental ability such that they are unable to live alone or with their family in their homes. Sixteen neurologists participated in the study, and all examinations were performed at the nursing homes.

The nursing staff at the homes were given an information programme which included both oral and written information and a video programme. On the basis of this educational material the staff, primarily the head nurse in each section of the nursing home, selected patients with presumed or possible Parkinson's disease. In most of the nursing homes the selection was performed in cooperation with the consulting physician in charge of the medical services at the institution.

The neurologists conducted an informal screening of the selected patients and then examined those with suspected parkinsonism more closely. For each of these patients a diagnosis was made and recorded. Demographic and clinical details were obtained for patients with idiopathic Parkinson's disease and their condition was assessed by clinical rating scales.

Parkinsonism was defined as the presence of two or more of the following signs: resting tremor, rigidity, akinesia, and postural abnormality (flexed posture or impaired postural reflexes).⁸ Clinical idiopathic Parkinson's disease was diagnosed if a patient with parkinsonism had no other probable alternative cause of the syndrome. In the differential diagnostic process several alternative diagnoses were considered. Parkinsonism in patients who had used neuroleptic drugs within the past three months was classified as drug induced. A mild parkinsonism in patients with a dominating dementia of the Alzheimer type was considered to be due to Alzheimer's disease. Multiple system atrophy was diagnosed in patients with a parkinsonism unresponsive to levodopa and with additional signs and symptoms of autonomic failure and coexisting evidence of cerebellar or pyramidal features. Conditions such as progressive supranuclear palsy and multiple infarct dementia were also evaluated. As the mild extrapyramidal signs often seen in very old people may be difficult to distinguish from symptoms of Parkinson's disease the response to levodopa in these patients was an important guide to diagnosis.

Parkinsonian signs and disability were clinically

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evaluated with the Hoehn and Yahr scale⁹ and Webster's clinical rating scale.¹⁰ Performance of daily activities and dementia were evaluated by using two subscales of the Gottfries, Brne, Gullberg, and Steen dementia rating scale (GBS).¹¹ The motor subscale (GBS-M) was used to estimate patients' ability to perform activities such as dressing, eating, personal hygiene, and physical activity and the subscale of intellectual functions (GBS-I) to evaluate dementia. The GBS-I scale scores 11 variables from 0-6; a mean score of less than one indicates no dementia, a score between one and two mild dementia, between two and three moderate dementia, and more than three severe dementia. The antiparkinsonian drug treatment used by the neurologists in this study followed international recommendations.¹² In this population of elderly patients levodopa was the main drug and bromocriptine the main adjuvant used to keep the dose of levodopa as low as possible or to deal with the long term problems of treatment with levodopa.

The primary clinical evaluation in patients with possible parkinsonism was followed by examinations six and 12 weeks later to adjust drug doses and evaluate any change in functional ability. At the follow up examinations patients' functional ability was scored by the clinical rating scales and by a subjective evaluation by the neurologist and the nurse in charge of the patient. The possible change in function was scored as worse, unchanged, perhaps improved, slightly improved, markedly improved, or much improved, the last two categories being considered as a definite improvement in daily functioning.

Results

On the basis of the information programme nursing staff selected nearly 500 of the 3322 patients for an informal screening by the neurologists, and 269 of them were evaluated by the protocol. Clinical idiopathic Parkinson's disease was diagnosed in 169 patients (5.1% of the study population). The mean (SD) duration of disease was 9.3 (6.3) years.

In 31 patients Parkinson's disease was first diagnosed through this study. Table I shows their demographic details and clinical rating scores before and after treatment. Eighteen patients had experienced a definite improvement in their functional impairment after 12 weeks of treatment. This improvement was also recognised by the patients. Eight patients showed some improvement in motor function, but because of other handicaps their overall function was not substantially changed. Of the remaining five patients, one died, one was severely demented, one had a hip fracture and reduced general medical condition, one was judged not to benefit from drugs in this phase of the disease, and one had to stop treatment because of side effects.

The GBS-I dementia rating scale showed that 22 of the 31 newly diagnosed patients had no or only mild dementia. After 12 weeks 19 of the patients took only levodopa, and the mean daily dose was 391 mg. Nine

patients took levodopa and bromocriptine, two patients took no drugs, and one had died.

Of the 138 patients who had had Parkinson's disease diagnosed before the study, 80 were judged to have been receiving "optimal" drug treatment. Fifteen of them had a well controlled parkinsonism. In 41 the neurologist did not expect any improvement because of severe dementia or parkinsonism in its end stage. In 24 patients recent adjustments of treatment had caused side effects that outweighed the functional improvement. Fifty two patients took levodopa alone and only two patients took an anticholinergic drug. Eight patients were not receiving drug treatment. Table I shows the clinical details of these patients.

Fifty eight patients with previously diagnosed Parkinson's disease had their drug treatment changed; 36 patients showed improvement and 22 showed no improvement. Twenty of the 36 (56%) patients who showed improvement had no dementia or only mild dementia compared with nine of 22 (41%) who showed no improvement. Among the 22 patients whose condition did not improve after changing treatment, in six this was attributed to treatment failure, in six to side effects, and in five to deterioration of general medical condition; in five patients the dosage was reduced because the initial doses were too high.

Most of the patients who showed improvement had had their treatment changed to a combination of levodopa and bromocriptine. Five patients took anticholinergics before drug adjustments and none thereafter.

Among the 100 patients without Parkinson's disease, 31 were receiving antiparkinsonian drugs unnecessarily (table II). The mean age of these 31 patients was 80.7 years (17 women and 14 men). Six patients were taking antiparkinsonian drugs and did not have parkinsonism. Three of these patients had a benign essential tremor, two had polyarthrosis, and one had a chorea of unknown cause.

TABLE II—Diagnosis in patients with suspected parkinsonism found not to have Parkinson's disease

Diagnosis	Total No of patients	No who had drugs withdrawn
Drug induced parkinsonism	44	9
Alzheimer's disease	23	6
Multiple system atrophy	12	7
Progressive supranuclear palsy	2	0
Multiple infarct dementia	4	3
No parkinsonism	15	6
Total	100	31

Discussion

We found Parkinson's disease in 5.1% of residents of Norwegian nursing homes. Thirty one patients had not had the disease diagnosed before this study. Most of these patients had no or only mild dementia, and onset of disease had often occurred after admission to the home. For most of the new cases and for 36 of the

TABLE I—Demographic details and clinical rating scores before and after 12 weeks of treatment in patients with Parkinson's disease in Norwegian nursing homes

	No of patients (men/women) n=169 (54/115)	Mean (SD) age (years)	Mean (SD) duration of disease (years)	Mean (SD) Hoehn and Yahr score (0-5)**		Mean (SD) Webster score (0-30)††		Mean (SD) GBS-M score (0-36)‡‡	
				0 Week	12 Weeks	0 Week	12 Weeks	0 Week	12 Weeks
Parkinson's disease first diagnosed in study	31 (7/24)	81.0 (7.3)	2.7 (1.4)	3.8 (0.9)	3.6 (0.9)	17.1 (4.6)	12.7 (5.0)	18.4 (9.2)	13.7 (8.2)
Already receiving optimal treatment	80 (23/57)	81 (6.7)	10.3 (6.5)	4.2 (0.9)		18.2 (5.7)		21.4 (9.8)	
Treatment changed:									
Functional improvement	36 (13/23)	77 (7.1)	9.9 (6.5)	4.4 (0.7)	3.7 (1.0)	20.3 (4.2)	14.6 (4.6)	22.4 (7.4)	16.6 (7.7)
No functional improvement	22 (11/11)	79 (7.2)	14.5 (8.9)	4.4 (0.8)	4.3 (0.8)	19.9 (4.9)	18.3 (5.0)	23.0 (9.8)	21.5 (9.9)

*Scale measures disease progression (0=no disease, 5=wheelchair dependent).

†Scale measures clinical signs and symptoms of disease (0=no disease, 30=end stage disease).

‡Scale measures daily activities (0=independent, 36=fully incapacitated).

previously diagnosed patients a definite functional improvement was obtained by introducing or adjusting drug treatment. We also found 31 patients who had been misdiagnosed and who could successfully stop treatment.

The diagnosis of Parkinson's disease in typical patients is usually not difficult. Many patients, however, are not typical and re-evaluation of the diagnosis over time is important. Several differential diagnoses must be considered.^{8,13} In this study drug induced parkinsonism, Alzheimer's disease, and multiple system atrophy were the commonest diagnoses in patients who had parkinsonism due to causes other than Parkinson's disease. The differential diagnostic process based on clinical symptoms and signs carries a potential for erroneous diagnostic classification of the cause of parkinsonism and may also lead a specialist to both overdiagnose and underdiagnose Parkinson's disease. For instance, some of the 44 patients we found with drug induced parkinsonism may have had idiopathic Parkinson's disease that was unmasked by neuroleptic drugs, thus making the prevalence even higher. On the other hand, alternative causes for parkinsonism may become evident in the future in some of the patients in whom we diagnosed Parkinson's disease. Croxson examined 63 patients in Britain who were taking antiparkinsonian drugs and withdrew drugs from 16.⁵ In our study drugs were stopped successfully in 31 patients.

Satisfactory recognition of Parkinson's disease in elderly patients and those in continuous care has consequences not only for the individual patients but for the health authorities planning medical and neurological services. In a report from eastern England only 12 patients with Parkinson's disease were identified in the continuous care wards of Liverpool Health Authority.⁶ This represented approximately 1% of the estimated number with parkinsonian syndromes in the area. In Norway a high estimate of the number of people with Parkinson's disease is 8000. Our study included nearly 10% of all residents at nursing homes in Norway, suggesting that about 20% of patients with Parkinson's disease are living in nursing homes.

The advanced age and relatively high proportion of dementia in our patient population restricted the possibilities for effective drug treatment. Furthermore, as our study was not blinded the evaluation of response to changes in drug treatment has obvious limitations. Nevertheless, treatment was changed in 58 patients, stopped in 31, and started in a further 31, and 36 of the 58 patients whose treatment was changed showed a definite improvement in function and obtained a better quality of life and motor activity. Thus our findings indicate that many elderly patients with Parkinson's disease can experience an improvement in quality of life with simple adjustments of drug treatment, and the availability of medical and neurological services to these patients should therefore be increased.

Accurate diagnosis of Parkinson's disease has

important implications for individual patients and for epidemiological research. Epidemiological data from defined populations have shown an increasing prevalence of the disease with increasing age.¹⁴⁻¹⁶ The age-specific incidences, however, show an increase up to 75 to 80 years of age and then a decrease in incidence. This proposed fall in the incidence of Parkinson's disease in the oldest patients has been supposed to provide clues to the pathogenesis of the disease.³ Most of these data, however, are based on known cases of Parkinson's disease¹⁴⁻¹⁶ or registries of antiparkinsonian drugs¹⁷ and could be biased by incomplete case ascertainment. A door to door survey of all residents in Copiah County, Mississippi, found that the low prevalence among black people was probably caused by unrecognised cases of Parkinson's disease.¹⁸ Our study underlines the difficulties of case ascertainment in elderly people and should at least question the validity of the incidence among the oldest members of the community.

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