



The full version of this article appears on bmj.com

Effects of community based nurses specialising in Parkinson's disease on health outcome and costs: randomised controlled trial

Brian Jarman, Brian Hurwitz, Adrian Cook, Madhavi Bajekal, Alison Lee

Department of Primary Health Care and General Practice, Centre for Primary Care and Social Medicine, Imperial College of Science, Technology, and Medicine, London W6 8RP

Brian Jarman
emeritus professor

Brian Hurwitz
professor

Adrian Cook
research analyst
Madhavi Bajekal
honorary research fellow

Alison Lee
research analyst

Correspondence to:
B Hurwitz
b.hurwitz@ic.ac.uk

BMJ 2002;324:1072-5

Abstract

Objective To determine the effects of community based nurses specialising in Parkinson's disease on health outcomes and healthcare costs.

Design Two year randomised controlled trial.

Setting 438 general practices in nine randomly selected health authority areas of England.

Participants 1859 patients with Parkinson's disease identified by the participating general practices.

Main outcome measures Survival, stand-up test, dot in square test, bone fracture, global health question, PDQ-39, Euroqol, and healthcare costs.

Results After two years 315 (17.3%) patients had died, although mortality did not differ between those who were attended by nurse specialists and those receiving standard care from their general practitioner (hazard ratio for nurse group *v* control group 0.91, 95% confidence interval 0.73 to 1.13). No significant differences were found between the two groups for the stand-up test (odds ratio 1.15, 0.93 to 1.42) and dot in square score (difference -0.7, -3.25 to 1.84). Scores on the global health question were significantly better in patients attended by nurse specialists than in controls (difference -0.23, -0.4 to -0.06), but no difference was observed in the results of the PDQ-39 or Euroqol questionnaires. Direct costs for patient health care increased by an average of £2658 during the study, although not differentially between groups: the average increase was £266 lower among patients attended by a nurse specialist (-£981 to £449).

Conclusions Nurse specialists in Parkinson's disease had little effect on the clinical condition of patients, but they did improve their patients' sense of wellbeing, with no increase in patients' healthcare costs.

Introduction

Parkinson's disease has a prevalence of about 1.6 per 1000 in the United Kingdom, therefore the average UK general practitioner with 1900 patients will care for only three patients with the condition.¹⁻³ Its management is complicated by a widening range of drug types and by patients with advanced disease requiring a multiplicity of aids and therapies, including adaptations to the home, referral for speech therapy, physio-

therapy, and occupational therapy, and visits to day centres and hospital outpatients.^{4,5}

The role of nurses specialising in Parkinson's disease has developed over the past 10 years.⁶ These nurse specialists were initially promoted by consultants with an interest in Parkinson's disease in response to the need for coordination of their patients' education, monitoring, and care (box), but their effectiveness has not been evaluated comprehensively.⁷⁻⁹ We evaluated the effects of nurse specialists working with general practitioners on the health outcomes and healthcare costs of patients with Parkinson's disease.

Methods

Recruitment

Our sampling frame included all English health authorities coterminous with local authorities in 1995 that did not already have well developed community based services of nurse specialists in Parkinson's disease. After random selection, we recruited nine health authorities (see bmj.com).

We approached all the general practices in the nine areas and asked them to identify patients with a diagnosis of Parkinson's disease from their doctor or

Role of nurse specialists in Parkinson's disease

- Counselling and educating patients and carers about Parkinson's disease in their homes, at health centres and general practitioner clinics, in hospital outpatients, and on the telephone
- The provision of information on drugs to patients under the auspices of general practitioners and consultants
- Monitoring clinical wellbeing and response to treatment (minimum of two assessments per year), reporting to general practitioners and consultants where appropriate
- Instigating respite and day hospital care where appropriate; seeing patients in hospital if admitted, and liaising with hospital staff when the patient is discharged
- Assessing entitlement to social security benefit
- Liaison with local multidisciplinary primary care teams for ongoing assessment and therapy where appropriate

hospital. Eligible patients were those taking one or more antiparkinsonian drugs. They were invited to take part by letter from either their doctor or us. We excluded patients aged 17 years or less or those with severe mental illness or cognitive impairment sufficient (in the view of their doctor) to preclude valid informed consent.

Statistical power and randomisation

With an expected dropout rate of 15% in each year of the trial, we determined a total initial sample size of 1600 patients could detect a 10% change in a categorical outcome having an initial prevalence of 50%, with 80% power at the 5% significance level. Patients were randomised within practice by using block randomisation lists that reflected the randomisation ratio of the health authority area (see bmj.com).

Nurse intervention

Nine nurses were employed by the university and trained at the Nursing and Midwifery School, University of Sheffield. They completed a course on meeting the special needs of people with Parkinson's disease and their carers.¹⁰ In the trial their clinical position in the community was advisory to the general practitioner rather than clinically autonomous. Each nurse was supplied with a leased car and a mobile phone and assumed areas of responsibility (box) under the guidance of a nurse manager. Their working pattern was characterised by a time use study in which the nurses kept a diary of their daily work over two one week periods. Patients in the control group were not provided with additional services until the end of the two year intervention, when they were offered one assessment from a nurse specialist.

Baseline and follow up assessments

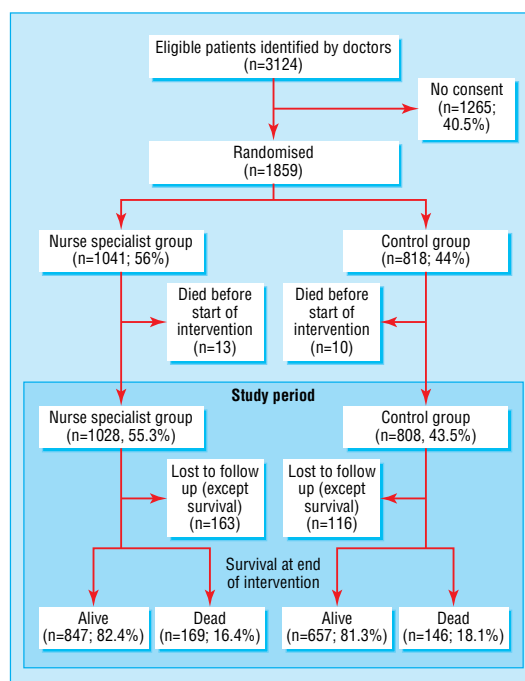
Trained lay interviewers collected information relevant to health outcome and costs at baseline and at one and two years. Before each interview the patients were sent a questionnaire eliciting information about self perceived health status.

Self completed questionnaire

The questionnaire included a validated instrument for measuring the functioning and wellbeing of patients with Parkinson's disease, the PDQ-39, and the Euroqol, a health related quality of life measure.¹¹⁻¹⁴ The questionnaires at one and two years also included a self perceived global health question asking patients about change in their general health over the preceding 12 months. This question is used by clinicians specialising in Parkinson's disease to gauge patient perception of changes in wellbeing between visits to hospital clinics. The five possible responses to this question were much better (score 0), better (1), same (2), worse (3), and much worse (4). Because the response in the second year depends on the response in the first year, a score was derived representing an individual's change in health over the two year period (see bmj.com). The score ranged from 0 (best) to 8 (worst).

Interviews

Face to face interviews covered three broad groups of questions: assessment of clinical outcome measures, use of health and social services, and personal characteristics. Clinical assessment included questions relating to duration and severity of disease and a test of patients' ability to put dots in a grid of 90 squares within 30 sec-



Participant flow through study

onds (dot in square test).¹⁵ The Columbian rating scale was used to test patients' ability to rise from a chair with a hard seat to allow "push off."¹⁶ Adverse events such as fractures were also recorded.

Costs

Services, aids, and adaptations to the home were valued by using data compiled by the Personal Social Services Research Unit and priced at 1996 costs¹⁷; drugs were priced from the *Monthly Index of Medical Specialities* 1996 net ingredient costs.¹⁸ For all these elements average costs were calculated by summing the unit cost per patient, annualising where appropriate, and dividing the total by the number of patients in the study. Costs incurred by carers are not reported here.

The interviews were repeated at one and two years. Follow up of mortality continued for 4 years (to 31 December 1999).¹⁹

Statistical analysis

We estimated between group differences using ordinal logistic regression for progression on stand-up test, logistic regression for bone fracture, ordinary linear regression for dot in square scores and quality of life measures, and Cox regression for mortality. For each patient we calculated the changes in healthcare cost (excluding costs for carer and social security benefit) over the two years.

Results

Participant flow and follow up

Of the 863 eligible practices, 438 (51%) agreed to participate and 1859 patients with Parkinson's disease were randomised (figure). No noticeable differences were observed between treatment groups at baseline (table 1).

At the end of the study, patients showed a decline in health status (see bmj.com). The average self perceived health score as assessed by the global health question was 4.89, another indicator of deterioration;

Table 1 Characteristics of participants at beginning of study, by treatment group. Values are numbers (percentages) unless stated otherwise

	Nurse group (n=1028)	Control group (n=808)
Sociodemographic characteristics		
Age (years):		
<70	354 (34.4)	256 (31.7)
70-77	359 (34.9)	290 (35.9)
>77	315 (30.6)	262 (32.4)
Male	588 (57.2)	456 (56.4)
Accommodation:		
Free living	916 (89.1)	716 (88.6)
Sheltered	47 (4.6)	41 (5.1)
Institution	65 (6.3)	51 (6.3)
Free living, with main carer	631 (61.4)	489 (60.5)
Manual social class	462 (44.9)	382 (47.3)
Health measures		
Years since diagnosis*:		
0-4	517 (50.3)	400 (49.5)
5-9	211 (20.5)	183 (22.6)
>9	247 (24.0)	187 (23.1)
Stand-up group†:		
1, no problems	453 (46)	344 (42.6)
2, without holding on	187 (18.2)	155 (19.2)
3, unable or had to hold on	353 (34.3)	299 (37.0)
Bone fracture in past 12 months	55 (5.4)	50 (6.2)
Mean (SD) best hand score‡	45.6 (21.7)	45.0 (21.8)
Drugs:		
Levodopa	869 (84.5)	695 (86.0)
Levodopa and anticholinergic	98 (9.5)	62 (7.7)
Levodopa and dopamine agonist	84 (8.2)	45 (5.6)
Levodopa (mg daily), median (quartiles)	300 (150, 550)	300 (150, 500)
Mean (SD) Euroqol score	0.43 (0.35)	0.43 (0.36)
Mean (SD) PDQ-39 summary score	37.9 (21.8)	38.2 (21.8)

*Missing data as some patients unaware of time since diagnosis.

†Missing data as some patients refused test.

‡Dot in square test.

unchanged self perceived health over 2 years would score 4 on this question.

Primary outcomes

Objective measures of health

At two years' follow up the severity of Parkinson's disease, the proportion of each group sustaining a fracture, and mortality was not significantly different between the two groups (table 2).

Patient wellbeing

No differences were observed in Euroqol scores or in any dimension of the PDQ-39 at the end of the study (see bmj.com). However, when the patients were asked about change in general health in the global health

question, the combined scores from years 1 and 2 differed between groups, with the nurse group doing significantly better than the control group (difference in means -0.23 , 95% confidence interval -0.4 to -0.06).

Costs

The mean annual cost among the nurse group increased from £4050 in the year preceding the study to £5860 in the second year of the study and from £3480 to £5630 among the control group, the difference in mean increase between groups not being significant (table 3). The mean costs of different components of health care were also similar in each group during the second year; the provision of nurse specialist care cost £200 per patient per year.

Nurse activity

The time use study showed that the nurse specialists assessed an average of 14 patients per week, 75% at home, 14% at general practices, and 11% in hospital consultant clinics. Patients in the nurse group received on average eight assessments by the nurse per year. In a typical week the nurses made five visits to general practitioners, two to carers, and one to a consultant to discuss patient care. Apart from face to face contact, considerable amounts of nurse time were spent each week on administration, letter writing, telephoning patients (6 hours), and travelling (8.4 hours).

Discussion

An earlier hospital based study found that patients with Parkinson's disease subjectively valued nurse specialists although their psychosocial functioning did not improve.⁹ Our study, the largest carried out to date and the only one to be based in primary care, mostly agrees with that study as well as with the recent hospital based randomised trial of 185 patients with Parkinson's disease, which found no evidence of a nurse specialist effect on a range of self reported health outcomes.²⁰

As with any trial of randomisation within general practice, contamination of controls from the spill over effects of the intervention cannot be entirely excluded. Evidence of contamination was sought, but not found, from analysis of within patient changes in the mobility dimension of the PDQ-39. One nurse specialist and one control patient were randomly selected from each participating practice and their scores regressed on practice size (on the assumption that the larger the number of study patients from each practice the

Table 2 Clinical outcomes at end of study. Values are numbers (percentages) unless stated otherwise

	Nurse group (n=696)	Control group (n=558)	Odds ratio (95% CI) (nurse v control)	P value
Stand-up group*:				
1, no problems	248 (35.6)	221 (39.6)		
2, without holding on	114 (16.4)	82 (14.7)	1.15 (0.93 to 1.42)	0.19
3, unable or had to hold on	329 (47.3)	247 (44.3)		
Bone fracture during study	92 (13.2)	62 (11.1)	1.20 (0.85 to 1.69)	0.31
Mean (SD) best hand score†	45.3 (21.2)	46.0 (21.1)	-0.70 (-3.25 to 1.84)‡	0.59
Mortality:				
	(n=1016)	(n=803)		
Died by 1 January 1998 (2 years)	169 (16.6)	146 (18.2)	0.91 (0.73 to 1.13)§	0.38
Died by 1 January 2000 (4 years)	353 (34.7)	307 (38.2)	0.89 (0.76 to 1.03)§	0.12

*Missing data as some patients refused test.

†Dot in square test.

‡Regression coefficient and confidence interval from linear regression model.

§Hazard ratio.

greater the likelihood contamination would occur), but no significant difference was found between the nurse and control groups.

The trial intervention used nurses who had only recently trained in nursing patients with Parkinson's disease. They were therefore on a professional learning curve and may not be representative of experienced nurse specialists. Another limitation of our pragmatic trial was the reliability of case ascertainment when based on general practice records and information systems. A recent cross sectional prevalence survey of idiopathic Parkinson's disease in 15 general practices across London showed that 54 of 241 (22%) patients whose records contained either a diagnosis of Parkinson's disease or parkinsonism, prescription of antiparkinsonian drugs, or mention of tremor after the age of 50 years had no form of parkinsonism.³ Although it is likely that some patients with non-Parkinson's disease entered our trial, randomisation minimised the likelihood of bias by distributing such patients proportionately in both arms.

Conclusion

Although our study found no significant differences in health outcome between patients receiving care from a nurse specialist and those receiving standard care from their general practitioner, there was a significant improvement in subjective wellbeing of patients cared for by a nurse. Our study was of sufficient size to detect important changes, and the measured decline of health in the group as a whole confirms that the instruments used were appropriate.²¹ The benefit in subjective wellbeing is an important finding, especially in a condition such as Parkinson's disease where decline is generally relentless.²² This improvement was achieved without an increase in healthcare costs.

We thank the participants and doctors; Ruth Jones, Debbie Hart, and Chris Leigh of the research team; the nurse specialists (Jane Stewart, Janet Barton, Elizabeth Carter, Jaqueline Chamberlain, Joanne Evans, Katherine Gray, Karen Harris, Kate Madden, Lynne Osborne, and Katie Richards); Susan Purdon, Julie Barber, and Caroline Dore for statistical advice and comments on earlier drafts of the paper; Nish Chaturvedi, Konrad Jamrozik, and Sasha Shepperd for comments on later drafts; Gerald Stern, Doug MacMahon, and Niall Quinn for advice on Parkinson's disease; and the Parkinson's Disease Nurse Specialist Steering Group, in particular, Mary Baker, Leslie Findley, Beverley Castleton, David Hutchinson, and James Cornford.

Contributors: see bmj.com

Funding: Paul Hamlyn Foundation, the Parkinson's Disease Society, and Britannia Pharmaceuticals.

Competing interests: Britannia Pharmaceuticals, manufacturer of apomorphine and former distributor of selegiline, part funded this research.

- Mutch WJ, Dingwall-Fordyce I, Downie AW, Paterson JG, Roy SK. Parkinson's disease in a Scottish city. *BMJ* 1986;292:534-6.
- Ben-Shlomo Y, Sieradzan K. Idiopathic Parkinson's disease: epidemiology, diagnosis and management. *Brit J Gen Pract* 1995;45:261-8.
- Schrag A, Ben-Shlomo Y, Quinn NP. Cross sectional prevalence survey of idiopathic Parkinson's disease and parkinsonism in London. *BMJ* 2000;321:21-2.
- Calne DB. Treatment of Parkinson's disease. *N Engl J Med* 1993;329:1021-7.
- Münchau A, Bhatia KP. Pharmacological treatment of Parkinson's disease. *Postgrad Med J* 2000;76:602-10.
- Parkinson's Disease Society. *Parkinson's disease and the nurse*. London: Parkinson's Disease Society, 1999.
- MacMahon DG, Thomas S. Practical approach to quality of life in Parkinson's disease: the nurse's role. *J Neurol* 1998;245(suppl 1):19-22S.
- Wilson-Barnett J, Beech S. Evaluating the clinical nurse specialist. A review. *Int J Nurs Stud* 1994;31:561-71.
- Jahanshahi M, Brown C, Whitehouse C, Quinn N, Marsden CD. Contact with a nurse practitioner: a short-term evaluation study in Parkinson's disease and dystonia. *Behav Neurol* 1994;7:189-96.

Table 3 NHS and local authority costs (in £000s), excluding benefits. Values are mean (maximum)

	Nurse group (n=1028)	Control group (n=808)
Year preceding study*	4.05 (55.4)	3.48 (35.0)
Year 2†	5.86 (39.1)	5.63 (33.1)
Individual mean increase‡	2.54 (34.6)	2.80 (31.6)‡
Cost components in year 2†		
Nurse specialist	0.20	
Institutional cost	2.86 (20.6)	3.31 (20.6)
Respite care	0.09 (12.8)	0.08 (7.98)
Hospital cost	0.79 (17.9)	0.74 (22.3)
Primary health care	0.15 (6.34)	0.19 (6.34)
Therapy	0.10 (4.33)	0.10 (4.71)
Drugs§	0.70 (25.3)	1.12 (37.4)
Home help	0.34 (2.50)	0.30 (2.50)

*All patients entering study.

†Patients at end of study.

‡P value 0.47 (difference -0.26, -0.98 to 0.45) (unpaired *t* test with unequal variances). P value and 95% confidence interval checked with 2000 bootstrapped samples.

§Excludes apomorphine.

What is already known on this topic

Most patients with Parkinson's disease have no regular contact with consultants specialising in the condition

Contact by nurse specialists of patients attending hospital increases provision of information and is subjectively valued

It has not been shown whether nurse specialists improve psychosocial functioning

What this study adds

Provision of community based nurses specialists in Parkinson's disease does not slow clinical progression of the condition

Nurses specialists help to preserve patients' sense of wellbeing

Healthcare costs are not increased

- School of Nursing and Midwifery. *Knowledge based practice for people with Parkinson's disease and their carers*. Sheffield: School of Nursing and Midwifery, Northern General Hospital, 2000.
- Peto V, Jenkinson C, Fitzpatrick R, Greenhall R. The development and validation of a short measure of functioning and well-being for individuals with Parkinson's disease. *Qual Life Res* 1995;4:241-8.
- Jenkinson C, Peto V, Fitzpatrick R, Greenhall R, Hyman N. Self-reported functioning and well-being in patients with Parkinson's disease: a comparison of the short-form health survey (SF-36) and the Parkinson's disease questionnaire (PDQ-39). *Age Ageing* 1995;24:505-9.
- Jenkinson C, Fitzpatrick R, Peto V. *The Parkinson's disease questionnaire*. Oxford: Health Services Research Unit, Department of Public Health, University of Oxford, 1998.
- Williams A. *The measurement and validation of health: a chronicle*. York: Centre for Health Economics, University of York, 1995. [Discussion paper 136.]
- Gerstenbrand F, Grunberger J, Schubert H. Quantitative testmethoden zur objektivierung des effekts einer L-Dopalanalgetherapie beim Parkinson-syndrom. *Nervenarzt* 1973;44:428-33.
- Wade DT. *Measurement in neurological rehabilitation*. Oxford: Oxford University Press, 1994.
- Netten A, Denett J. *Unit costs of health and social care*. Canterbury: Personal Social Services Research Unit, 1996.
- The monthly index of medical specialities 1996 net ingredient costs*. London: Haymarket Medical, 1996.
- Hurwitz B, Bajekal M, Jarman B. Evaluating community-based Parkinson's disease nurse specialists—rationale, methodology and representativeness of patient sample in a large randomised controlled trial. In: Stern G, ed. *Parkinson's disease. Advances in neurology*. Volume 80. Philadelphia: Lippincott, Williams, and Wilkins, 1999:431-9.
- Reynolds H, Wilson-Barnett, Richardson G. Evaluation of the role of the Parkinson's disease nurse specialist. *Nurs Stud* 2000;37:337-49.
- Peto V, Jenkinson C, Fitzpatrick R. Determining minimally important differences for the PDQ-39 Parkinson's disease questionnaire. *Age Ageing* 2001;30:299-302.
- Marsden CD. Parkinson's disease. *J Neurol Neurosurg Psychiatry* 1994;57:672-81.

(Accepted 15 January 2002)