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

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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, physiotherapy, and occupational therapy, and visits to day centres and hospital outpatients.[4 5] Surveys show that up to 70% of patients with Parkinson's disease have no regular contact with consultants and rely entirely on their general practitioners for medical care.[6–8]

The role of nurses specialising in Parkinson's disease has developed over the past 10 years.[9] 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 1), but their effectiveness has not been evaluated comprehensively.[10 11] A small controlled study based in a tertiary hospital clinic for Parkinson's disease evaluated the effect of two community based nurse specialists undertaking two home visits to patients with Parkinson's disease and having five telephone contacts over a six month period.[12] The nurses had a positive impact on provision of information and were subjectively valued but had no detectable benefit on patients' psychosocial functioning. The effect of nurse specialists on health outcome or cost of care was not assessed.[12]

We evaluated the effects of nurse specialists working with general practitioners on the health outcomes and healthcare costs of patients with Parkin-

Box 1: 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

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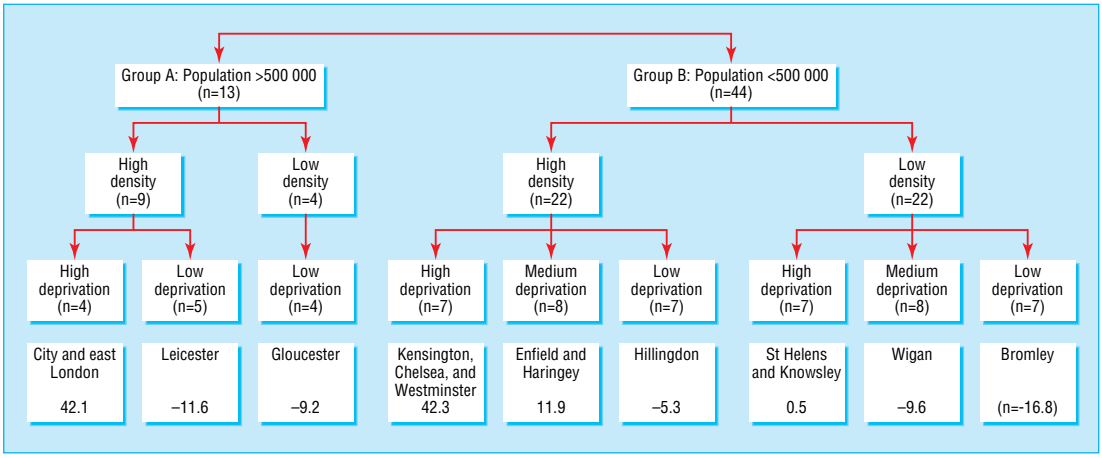

Fig 1 Selection of health authority areas. Numbers with names of health authorities are amended underprivileged area scores (excludes under 5s component)

Table 1 Geographical distribution of nurse specialists in Parkinson's disease and participants

Health authority	No of patients randomised (n=1859)	UPA score*	No of patients per nurse	No of nurses (n=9)	No of patients	
					Nurse group (n=1041)	Control group (n=818)
Bromley	194	−16.8	135	1	135	59
Leicestershire	406	−11.6	146	1.4	204	202
Wigan	206	−9.6	124	1	124	82
Gloucestershire	443	−9.2	139	1.6	223	220
Hillingdon	106	−5.3	114	0.5	57	49
St Helens and Knowsley	159	0.5	95	1	95	64
Enfield and Haringey	156	11.9	94	1	94	62
City and east London	102	42.1	68	0.9	61	41
Kensington, Chelsea, and Westminster	87	42.3	80	0.6	48	39

*Amended underprivileged area score (excludes under 5s component); higher score is socially more deprived.

son's disease. We tested the null hypothesis that there would be no difference in health outcomes or in net healthcare costs between patients who received community based care from a nurse specialist and those who received standard care from their general practitioner.

Methods

Recruitment

Our sampling frame included all English health authorities coterminous with local authorities in 1995 (to ensure optimal relations between health carers and social services) that did not already have well developed community based services of nurse specialists in Parkinson's disease. We stratified the health authorities by three factors that influence service organisation and accessibility: size, population density (an indicator of rurality), and area deprivation score.[13 14] We allocated the 57 eligible authorities to one of nine strata, from each of which we randomly chose one authority area (fig 1). The nine initially selected health authorities all agreed to participate. Recruitment of practices was difficult in one area so we approached the second randomly selected health authority in that stratum, which agreed to participate. We received approval for our trial from each relevant local research ethics committee.

We approached all the general practices in the nine areas and asked them to identify from their own information sources, disease registers, and prescribing data patients with a diagnosis of Parkinson's disease from their doctor or 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. Written consent was obtained in each case. 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

The statistical power of our study could be reduced by internurse variability which, if present, would increase the variance of any nurse effect in the intervention arm. To minimise this variability we equated the workload of the nurse specialists by having different randomisation ratios in each health authority area, from a 50:50 ratio of nurse specialist to control group in Gloucestershire to a 70:30 split in Bromley. In each health authority area the randomisation ratio was determined by the number of patients recruited, deprivation, geographical factors such as the time taken for the nurse to travel and ease of parking, and the number of whole time equivalent nurses who could be made available to a health area (table 1). Most areas were allocated one nurse specialist, but Leicestershire and Gloucestershire shared three, and Kensington, Chelsea, and Westminster, City and East London, and Hillingdon shared two nurses between them.

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. We randomised 1836 patients, 1028 (56%) to the nurse specialist group and 808 (44%) to the control group.

Randomisation was performed centrally between January and March 1996 by an independent social survey organisation. Patients were randomised within practice by using block randomisation lists that reflected the randomisation ratio of the health authority area. Where numbers permitted, patients were stratified within practice by age (<70, 70-77, >77), sex, and duration of disease (<5, 5-9, >9 years), separate lists being used in each stratum.

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.[15] 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 1) 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 were employed by the independent survey organisation, Social and Community Planning Research (now the National Centre for Social Research), to interview participants in their place of residence and to collect information relevant to health outcome and costs at baseline and at one and two years (box 2). Before each interview the patients were sent a questionnaire eliciting information about self perceived health status. Questionnaires were also sent to carers, the results of which will be reported elsewhere.

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 (score range −0.59 to +1: higher value represents better quality).[16–19] The PDQ-39 is a disease specific measure, which scales patients' responses (score range 0-100: higher score represents worse function) to aspects of morbidity known to be affected by Parkinson's disease: mobility, activities of daily living, emotional wellbeing, self perceived stigma, social support, cognition, communication, and bodily discomfort.

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 single value was derived representing an individual's change in health over the two year period (fig 2). 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 (age, sex, social class, employment, income, and household circumstances). 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 seconds (dot in square test), a measure of visuomotor coordination influenced by tremor and bradykinesia.[20] The Columbian rating scale was used to test patients' ability to rise from a chair with a hard seat to allow "push off."[21] Results were classified as able to stand up normally, slowly, or needing two attempts (group 1), fell back or took more than two

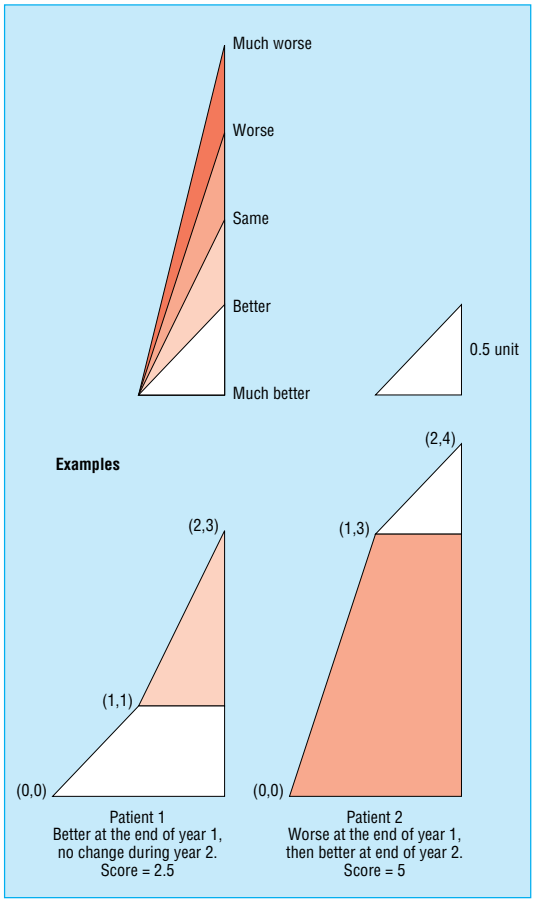

Fig 2 Area under curve method used to combine global question responses. Participants at intersection (0,0) at baseline. Participant moves one unit along x axis during year 1. Movement on y axis determined by global health response (for example, "much better" stays on axis (1,0), "better" goes up by one unit (1,1). During year 2 participants move another unit along x axis, with movement on y axis defined same as year 1. Participant much better in each year therefore stays on x axis, moving from (0,0) to (2,0) and has an area under curve of 0 units. Participant "much worse" in each year moves from (0,0) to (2,8) and has an area under curve of 8 units. Participants getting much better in year 1 and staying same in year 2 arrive at same point (2,2) as someone staying same and then getting much better. Former patient will have higher score, however, reflecting earlier benefit

Box 2: Source of information for trial outcomes

Primary outcome
Clinical
Stand-up test group—patient interview
Dot in square score—patient interview
Mortality—NHS Central Registry
Proportion sustaining fracture—patient interview

Patient wellbeing
PDQ-39 questionnaire—patient completed
Euroqol—patient interview
Global subjective wellbeing question—patient completed

Healthcare costs
Institutional, respite, hospital, day care, medication, community and general practitioner care, social security benefits, home aids and adaptations—patient interview
Nurse specialists in Parkinson's disease—costs based on NHS scales

Secondary outcome
Medication
Median dose levodopa—patient interview
Proportion of patients on levodopa controlled release preparation—patient interview
Proportion of patients receiving more than monotherapy—patient interview

Referral
Proportion of patients referred to ancillary therapy—patient interview
Proportion of patients referred to specialist for Parkinson's disease—patient interview

attempts, but eventually got up without help (group 2), and could not rise without holding on to something, or unable to stand up (group 3). Adverse events such as fractures were also recorded, together with information relevant to secondary outcomes (box 2).

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 costs[22]; drugs were priced from the *Monthly Index of Medical Specialities* 1996 net ingredient costs.[23] 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). Further details of the methods are given elsewhere.[24]

Statistical analysis

We compared the nurse and control groups for outcomes at the end of the two year trial. 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. We initially included terms to model variability between nurses, but we found them unnecessary and removed them.

For each patient we calculated the changes in healthcare cost (excluding costs for carer and social security benefit) over the two years. We compared differences in the mean change of the nurse and control groups by using unpaired t tests. We report parametric confidence intervals for differences. Data were highly skewed, and we checked all results by using 2000 bootstrapped samples[25]; we found no major differences between the two methods of analysis. We did not include costs of apomorphine in the main analysis, but they are reported separately; their extreme annualised values pertain to a small number of patients taking it on an "as required basis," which leads to wide fluctuations in its frequency of use, making a cost analysis unreliable.

Results

Participant flow and follow up

Of the 863 eligible practices, 438 (50.8%) agreed to participate. These practices ascertained 3392 registered patients with Parkinson's disease; 3124 were eligible for study of whom 1859 (59.5%) agreed to participate (fig 3). Twenty three patients died during recruitment, leaving 1836 patients when the intervention began. Seventeen of the 1836 patients were not traced at the NHS central registry and are therefore not included in mortality analyses. Follow up in both groups was comparable. No noticeable differences were observed between treatment groups at baseline for age, sex, accommodation, social class, disease duration, disease severity, or drugs (table 2).

Comparative data are not available for participants and those who declined to take part. However the study sample as a whole was representative of the population of England and Wales with Parkinson's disease in terms of disease duration and age, except for slight under-representation of patients aged 85 or more, probably the result of the exclusion criterion for cognitive impairment.[24]

Patients showed a decline in health status (table 3). After two years, patients were significantly more likely

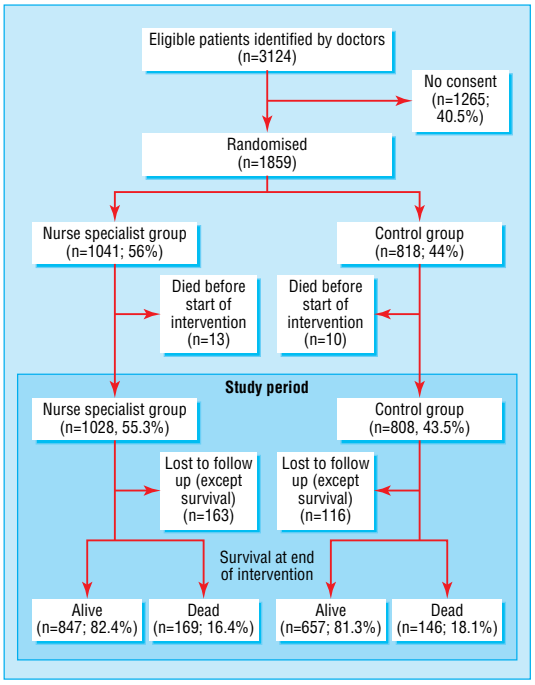

Fig 3 Participant flow through study

to perform poorly in the stand-up and dot in square tests, and scores in the Euroqol and each item of the PDQ-39 also indicated a worsening of health. At the end of the study, the average self perceived health score as assessed by the global health question was 4.89, another indicator of deterioration; unchanged self perceived health over 2 years would score 4 on this question (fig 2).

Primary outcomes

Objective measures of health

At two years' follow up the severity of Parkinson's disease was not significantly different between the two groups, as shown by the stand-up and dot in square tests (table 4). No differences were detected in the proportion of each group sustaining a fracture during the trial. Mortality at two years' follow up was 17.3%, with no differences between the two groups overall; four years after randomisation there was no between group difference in mortality (table 4).

Patient wellbeing

No differences were observed in Euroqol scores or in any dimension of the PDQ-39 at the end of the study (table 5). However, when 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 progressive nature of Parkinson's disease is reflected in the increased total cost of health care (institutional, respite, hospital, day care, drugs (excluding apomorphine), community care, and cost of nurse specialists) during the study. 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 6). 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. At baseline, 16 of 1836 patients were taking apomorphine, at an average cost of £6900 per patient; at the end of the study 20 of 1254 patients were taking the drug at the increased average cost of £54 700 each.

Table 2 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.

Secondary outcomes

Medical treatments

The median daily dose of levodopa increased from 300 mg to 400 mg during the study, but with no significant difference between groups. The proportion of patients taking a controlled release form of levodopa increased differentially, from a third of each treatment group at

Table 3 Deterioration of participants during study—within people differences. Values are means (SDs) unless stated otherwise

	Baseline (n=1254)	Two years (n=1254)	Change (95% CI)	P value
No (%) in stand-up group:				
1, no problems	606 (48.3)	469 (37.4)		<0.001
2, without holding on	242 (19.3)	196 (15.6)		
3, unable or had to hold on	391 (31.2)	576 (46.0)		
Dot in square best hand score	47.6 (21.9)	45.6 (21.1)	−2.6 (−3.7 to −1.5)	<0.001
Euroqol tariff*	0.47 (0.35)	0.38 (0.35)	−0.10 (−0.12 to −0.08)	<0.001
PDQ-39†:				
Mobility	49.9 (33.4)	60.5 (32.3)	11.7 (10.2 to 13.1)	<0.001
Activities of daily living	42.2 (28.4)	52.1 (29.2)	10.8 (9.5 to 12.1)	<0.001
Emotional wellbeing	31.2 (23.8)	34.6 (25.2)	4.1 (2.9 to 5.3)	<0.001
Stigma	29.4 (27.9)	30.7 (28.0)	1.7 (0.4 to 3.1)	0.013
Social support	11.6 (18.8)	15.0 (21.5)	3.5 (2.0 to 4.9)	<0.001
Cognition	34.8 (22.7)	38.7 (23.8)	4.8 (3.7 to 5.9)	<0.001
Communication	22.5 (22.8)	28.6 (24.7)	6.8 (5.6 to 7.9)	<0.001
Bodily discomfort	43.1 (25.5)	44.6 (25.0)	1.7 (0.4 to 3.0)	0.011

*High score good.
†High score bad.

Table 4 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.

Table 5 Quality of life measures at end of study. Values are means (SDs) unless stated otherwise

	Nurse group (n=696)	Control group (n=558)	Difference (95% CI) (nurse *v* control)	P value
Global health*	4.79 (1.50)	5.02 (1.38)	–0.23 (–0.40 to –0.06)	0.008
Euroqol tariff†	0.37 (0.35)	0.39 (0.35)	–0.02 (–0.06 to 0.02)	0.30
Parkinson's disease questionnaire*:				
Mobility	61.1 (31.9)	59.8 (32.9)	1.38 (–2.57 to 5.34)	0.49
Activities of daily living	52.4 (28.6)	51.7 (29.9)	0.71 (–2.73 to 4.14)	0.69
Emotional wellbeing	34.7 (24.7)	34.5 (25.8)	0.21 (–2.79 to 3.20)	0.89
Stigma	30.6 (27.5)	30.8 (28.7)	–0.14 (–3.44 to 3.16)	0.93
Social support	15.9 (22.1)	13.7 (20.8)	2.21 (–0.66 to 5.08)	0.13
Cognition	39.3 (23.2)	38.0 (24.4)	1.30 (–1.52 to 4.11)	0.37
Communication	28.6 (24.4)	28.7 (25.1)	–0.10 (–3.02 to 2.82)	0.95
Bodily discomfort	45.4 (24.8)	43.7 (25.3)	1.68 (–1.26 to 4.62)	0.26
PDQ-39 summary index	39.7 (21.2)	39.2 (22.1)	0.47 (–2.72 to 3.66)	0.77

*High score bad.
†High score good.

baseline to 52.5% of the nurse group and 45.3% of the control group (P=0.016) (data not shown). Also apparent was a greater tendency for patients in the nurse group to discontinue taking their selegiline: among 581 patients with complete follow up who were taking selegiline at baseline, 71.8% of those in the nurse group had discontinued use after two years compared with 54.8% in the control group ($P < 0.001$). No differences were found between the two groups in the proportion of patients taking anticholinergics, dopamine agonists, or apomorphine, nor in the average number of different types of drugs prescribed for Parkinson's disease. The proportion of patients in each group referred to hospital outpatients or to ancillary therapists during the intervention period did not vary significantly between the two groups.

Table 6 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 (3.74)
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.

Nurse activity

The time use study showed that the nurse specialists assessed an average of 13.7 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

The provision of community based nurses specialising in the care of patients with Parkinson's disease has little effect on clinical progression of the disease when compared with patients receiving standard care from their general practitioner. However, responses to the global health question, a measure of patients' perception of changes in wellbeing, showed that the nurse specialists helped preserve patients' sense of wellbeing. The benefit in subjective wellbeing in the nurse group was significant, but the confidence interval around this difference in benefit was relatively wide, approached zero at the lower end, and was not accompanied by

positive changes in health status, judged by differences in the disease specific PDQ-39 or by Euroqol score. Healthcare costs of patients with Parkinson's disease were comparable to those of other studies.[26] The lack of differences in use of health services between the nurse and control groups resulted in no significant differences in net health costs.

Our study is the largest carried out to date and the only one to be based in primary care. However, our findings mostly agree with those of an earlier hospital based study, which found that patients with Parkinson's disease subjectively valued nurse specialists although their psychosocial functioning did not improve.[12] Our study also mostly agrees 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.[27]

In December 1995, close to the start of our trial, the UK Parkinson's Disease Research Group published a finding of excess mortality in patients taking combined levodopa and selegiline.[28] Since then use of selegiline has decreased, a trend observed by us. The reduction in use of selegiline over two years was significantly greater in the nurse group than in the control group, suggesting that the nurses were more responsive than doctors to emerging scientific evidence. The greater increase in the use of controlled release levodopa among the nurse group also suggests a heightened awareness of current best practice among the nurse specialists.

As with any trial of randomisation within general practice, contamination of controls from the spill over effects of the intervention cannot be entirely excluded. The nurse specialists had a lot of contact with members of primary care teams but were rigorous in avoiding any contact with, or conversation about, patients other than those allocated to their care. 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 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.

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

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.[29] The benefit in subjective wellbeing is an important finding, especially in a condition such as Parkinson's disease where decline is generally relentless.[30] This improvement was achieved without an increase in healthcare costs.

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1 Mutch WJ, Dingwall-Fordyce I, Downie AW, Paterson JG, Roy SK. Parkinson's disease in a Scottish city. *BMJ* 1986;292:534-6.
2 Ben-Shlomo Y, Sieradzan K. Idiopathic Parkinson's disease: epidemiology, diagnosis and management. *Brit J Gen Pract* 1995;45:261-8.
3 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.
4 Calne DB. Treatment of Parkinson's disease. *N Engl J Med* 1993;329:1021-7.

5 Münchau A, Bhatia KP. Pharmacological treatment of Parkinson's disease. *Postgrad Med J* 2000;76:602-10.
6 Mutch WJ, Strudwick A, Roy SK, Downie AW. Parkinson's disease: disability, review, and management. *BMJ* 1986;293:675-7.
7 College of Health. *The needs of people with Parkinson's disease*. London: College of Health, 1994.
8 Ridsdale L. Community care for patients with idiopathic Parkinson's disease. *Brit J Gen Pract* 1995;394:226-7.
9 Parkinson's Disease Society. *Parkinson's disease and the nurse*. London: Parkinson's Disease Society, 1999.
10 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.
11 Wilson-Barnett J, Beech S. Evaluating the clinical nurse specialist. A review. *Int J Nurs Stud* 1994;31:561-71.
12 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.
13 Jarman B. Identification of underprivileged areas. *BMJ* 1983;312:1705-9.
14 Jarman B. Underprivileged areas: validation and distribution of scores. *BMJ* 1984;289:1587-92.
15 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.
16 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.
17 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.
18 Jenkinson C, Fitzpatrick R, Peto V. *The Parkinson's disease questionnaire*. Oxford: Health Services Research Unit, Department of Public Health, University of Oxford, 1998.
19 Williams A. *The measurement and validation of health: a chronicle*. York: Centre for Health Economics, University of York, 1995. (Discussion paper 136.)
20 Gerstenbrand F, Grunberger J, Schubert H. Quantitative testmethoden zur objecktivierung des effekts einer L-Dopalangzeittherapie beim Parkinson-syndrom. *Nervenarzt* 1973;44:428-33.
21 Wade DT. *Measurement in neurological rehabilitation*. Oxford: Oxford University Press, 1994.
22 Netten A, Denett J. *Unit costs of health and social care*. Canterbury: Personal Social Services Research Unit, 1996.
23 *The monthly index of medical specialities 1996 net ingredient costs*. London: Haymarket Medical, 1996.
24 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.
25 Thompson SG, Barber A. How should cost data in pragmatic randomised trials be analysed? *BMJ* 2000;320:1197-200.
26 MacMahon DG, Findley L, Holmes J, Pugner K. The true economic impact of Parkinson's disease: a research survey in the UK. *Movement Disorders* 2000;15(suppl 3):178. (Poster No 861.)
27 Reynolds H, Wilson-Barnett, Richardson G. Evaluation of the role of the Parkinson's disease nurse specialist. *Nurs Stud* 2000;37:337-49.
28 Lees AJ. On behalf of the Parkinson's Disease Research Group of the United Kingdom. Comparison of therapeutic effects and mortality data of levodopa and levodopa combined with selegiline in patients with early, mild Parkinson's disease *BMJ* 1995;311:1602-7.
29 Peto V, Jenkinson C, Fitzpatrick R. Determining minimally important differences for the PDQ-39 Parkinson's disease questionnaire. *Age Ageing* 2001;30:299-302.
30 Marsden CD. Parkinson's disease. *J Neurol Neurosurg Psychiatry* 1994;57:672-81.

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