Evaluation of the role of the Parkinson’s disease nurse specialist

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Record Status
This is a critical abstract of an economic evaluation that meets the criteria for inclusion on NHS EED. Each abstract contains a brief summary of the methods, the results and conclusions followed by a detailed critical assessment on the reliability of the study and the conclusions drawn.

Health technology
A service provided by Parkinson's Disease Nurse Specialists (PDNS) was examined. This was aimed at supporting patients and their families, by increasing awareness of Parkinson's disease (PD) through teaching and education; supporting regular monitoring of the illness; and encouraging early referral to specialist therapists.

Type of intervention
Other: nursing service.

Economic study type
Cost-effectiveness analysis.

Study population
The study population comprised patients with diagnosed idiopathic PD and without any evidence of dementia.

Setting
The setting was outpatient care. The economic study was carried out in the UK.

Dates to which data relate
No dates were reported. The price year was not given.

Source of effectiveness data
The effectiveness evidence was derived from a single study.

Link between effectiveness and cost data
The costing was undertaken prospectively on a subsample of patients used in the effectiveness analysis.

Study sample
Power calculations to determine the sample size were not performed. The patients were allocated to three study groups, reflecting the actual care in the study centres. The three groups were consultant neurologist only (group A), PDNS only (group B), and mainly PDNS with consultant follow-up (group C). Group A contained 85 patients with a mean age of 65.18 (+/- 8.23) years. Group B included 35 patients with a mean age of 68.47 (+/- 6.66) years. Group C comprised 65 patients with a mean age of 67.57 (+/- 6.64) years. However, the main comparison was between patients who received the PDNS care (group A) and those who received the consultant service (group B).

Study design
This was a randomised controlled trial carried out in three centres served by a specialist nurse, which had a large attendance of patients with PD, with new referrals and with the presence of a consultant neurologist. The patients were randomised within each centre, but the method of randomisation was not reported. All of the patients were seen at least twice during the study period (at the start of the study and at 12 months), with some being seen up to five times. The patients were followed up for one year. Of the initial sample of 185 patients, only 108 (58%) completed the study. Of these, 40 patients remained in group A, 17 in group B, and 41 in group C. A fourth group of patients was also included in the comparison (group D). This consisted of 10 patients who were referred by the consultant to PDNS.

It was stated that the control group was contaminated with patients who asked to be referred to the PDNS. It was unclear whether these patients were the 10 identified as group D. The authors also referred, in the 'Economic evaluation' section, to the design including a 6-month assessment and patients who missed this being counted as lost to follow-up. However, it was unclear what was intended to be measured at 6 months.

**Analysis of effectiveness**

The analysis of effectiveness was limited to patients who completed the follow-up assessment (treatment completers only). The primary health outcome assessed in the analysis was the patient's health state. This was measured using a questionnaire compiled at baseline and after every follow-up visit. The questionnaire was based on the Hospital Anxiety and Depression Scale, SF-36, Parkinson's Disease Questionnaire (PDQ), Functional Disability Questionnaire, and patient and care satisfaction survey. A small pilot study was performed to validate the methods used for data collection. The study groups were comparable at baseline in terms of the age and time since diagnosis (one-way analysis of variance test). A difference among the study groups was only found in terms of communication scores on the PDQ, out of the 22 dimensions measured.

**Effectiveness results**

The analysis of the outcomes showed that only 2 of the 22 dimensions assessed were statistically different between the study groups, (p less than or equal to 0.05), physical functioning and general health on the SF-36 scale. These favoured group B. There was no statistically significant difference between the study groups in terms of the remaining outcomes when comparing the baseline and follow-up data. The results were presented graphically. Qualitative data on comments made on the satisfaction survey showed that both patients and carers appreciated the PDNS service.

**Clinical conclusions**

The authors concluded that the two services were generally similar, with only 2 out of 22 health dimensions being statistically significantly different.

**Measure of benefits used in the economic analysis**

The health outcomes were left disaggregated and no summary benefit measure was used. A cost-consequences analysis was therefore carried out.

**Direct costs**

Discounting was irrelevant as the costs were incurred over a period of one year. The unit costs and the quantities of resources were not reported. A complete breakdown of costs was not given and the cost/resource boundary adopted was not stated. The primary analysis of the costs was based on patients who met the study criteria (47 patients). However, due to this small sample size, a secondary analysis including all patients who fulfilled the data requirement at 12 months (81 patients) was conducted. The source of the cost data was not reported. The dates during which the resources were collected were not reported. The price year was not given.

**Statistical analysis of costs**

Statistical analyses of the costs were not performed.
Indirect Costs
The indirect costs were not included in the analysis.

Currency
UK pounds sterling (GBP).

Sensitivity analysis
No sensitivity analyses were carried out.

Estimated benefits used in the economic analysis
See the 'Effectiveness Results' section.

Cost results
The primary analysis of 47 patients (30 in group A and 17 in group B) produced the following results.

During the first 6 months, the mean cost of care was £53.96 in group A and £4.76 in group B, (p=0.001). During the second 6 months, the mean cost was £66.77 in group A and £5.41 in group B, (p=0.001).

The median costs were £9.25 in group A and £1.50 in group B during the first 6 months, (p=0.001). During the second 6 months, the median costs were £9.46 in group A and £1.50 in group B, (p=0.001).

The secondary analysis of 81 patients (45 in group A and 36 in group B) also showed that the monthly cost was significantly higher in group A.

The mean cost of care was £53.76 in group A and £28.01 in group B during the second 6 months. This difference was statistically significant.

The median costs were £9.67 in group A and £1.50 in group B during the second 6 months, (p=0.001).

Synthesis of costs and benefits
Not relevant.

Authors' conclusions
The services carried out by Parkinson's Disease Nurse Specialists (PDNS) and consultant neurologists were similar in terms of the outcome measures. However, increased costs were associated with the PDNS service.

CRD COMMENTARY - Selection of comparators
The rationale for the choice of the comparators was clear. The consultant neurologist-led care was selected as it represented the routine service for patients with PD, while the PDNS service was first introduced in 1992. You should assess whether it represents a currently used service in your own setting.

Validity of estimate of measure of effectiveness
The authors noted some limitations of the study which could hinder the internal validity of the analysis. The initial sample size was quite small and power calculations were not performed. The effectiveness analysis was limited to an even smaller sample size of patients who provided complete data, due to difficulties in collecting the follow-up data. The scheduled assessment was not complied with for several patients included in the study. A further limitation was the lack of a control centre, resulting in possible confounding by the proximity of the PDNS and consultant.
Consequently, the study results may not be generalisable to all centres managing patients with PD.

The effectiveness results could have been easier to interpret had they been presented, not only graphically as baseline and end of study scores, but also as a table of differences between the baseline and end of study scores. It would also have been useful to have known the reasons for loss to follow-up, as these might have eventually led to bias in the final sample. Indeed, the only baseline characteristic to be statistically significantly different was the PDQ communication score, but this could be a crucial confounder.

**Validity of estimate of measure of benefit**

No summary benefit measure was used in the economic analysis since the health outcomes were left disaggregated. It would have been interesting had the authors used a summary measure reflecting the patients' preferences, which were already measured in the effectiveness analysis.

**Validity of estimate of costs**

The perspective from which the study was conducted was not stated. Few details of the cost analysis were reported. The unit costs and the quantities of resources were not reported since a complete cost breakdown was not given. The source of the cost data was not indicated. Statistical analyses of the costs and the quantities were not performed. However, the sample of patients used in the cost analysis was, as the authors acknowledge, an even more select group than that used for the effectiveness analysis. No price year was given, thus hindering any reflation exercises to other settings.

**Other issues**

The authors reported the results of published studies. The issue of the generalisability of the study results to other settings was not addressed. Also, sensitivity analyses were not carried out. Consequently, the external validity of the analysis is low. The authors did not report the study results in detail. A population of patients with PD was included in the study and this was reflected in the conclusions. The authors noted some limitations of their analysis, which have been outlined already.

**Implications of the study**

The authors state that the provision of PDNS services cannot be recommended solely on the basis of cost-effectiveness criteria. However, their conclusions regarding the cost-effectiveness must be treated with some caution due to the flaws in the design and presentation. A possible implication of the study is that, in terms of the two interventions, "complementing rather than substitution was seen as the way for the future, particularly for these patients who have such complex needs".

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