Care requirements of a prevalent population of people with idiopathic Parkinson's disease

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Abstract

Background: Parkinson's disease (PD) is the second most common neurodegenerative condition in the UK. Care needs increase as the disease progresses, but there are very few published data in relation to this.
Objective: the aim of this study was to elicit the care requirements for a prevalent PD population and compare these to a similarly aged background population.
Methods: all people diagnosed with idiopathic PD from within a defined area of north-east England were asked to participate in this study. Those who agreed to participate were assessed using a number of standard rating scales including Hoehn and Yahr stage, Unified Parkinson's Disease Rating Scale (UPDRS), Hospital Anxiety and Depression Scale, Parkinson's Disease Questionaire-39 and Mini-Mental State Examination (MMSE). In addition, participants were asked whether they had experienced hallucinations. Social and demographic information (e.g. age, sex and place of abode) was also recorded.
Results: from all cases ($n=161$), 135 people (83.8%) agreed to participate. Of these, 19 (14.1%) were living in residential or nursing homes, representing 1.6% of the total nursing/residential home residents in the study area. Participants had a mean age of 74.8 years and disease duration of 5.6 years. Those in care were significantly older and had significantly poorer Hoehn and Yahr, MMSE and UPDRS scores.
Conclusion: PD patients in institutional care have poorer cognitive function, are older, have later stage disease and worse functional ability than those living at home.

Keywords: *Parkinson's disease, accommodation, service use, care requirements, elderly*

Introduction

Parkinson's disease (PD) is a progressive, fluctuating, neurological condition with a range of motor and non-motor symptoms. These symptoms can give rise to complex care requirements. PD affects around 1 in 1,000 of the UK population, and the prevalence increases with age, affecting around 1 in 200 in those over 75 years old [1]. The economic impact of PD on the UK is large, estimated to be up to £3.3 billion annually [2, 3]. Of this, the largest direct economic cost of PD in the UK is nursing home care and hospital in-patient admission.

However, most PD patients live in their own homes and receive a combination of informal support from family and friends, alongside more formal home-care packages where appropriate [4]. In a hospital-based German study, 15% of PD patients lived alone, 66% with their families and 19% in a nursing home, though results may not be generalised to the wider PD population [5]. We are not aware of any reliable reports from the UK regarding place of abode for people with PD or of any comparisons with non-PD populations. Indeed, it is not known exactly how many people living in residential care settings in the UK have PD, although an American-based study suggests a figure of 5–10% [6]. Interestingly, Aarsland *et al.* [7] demonstrated that both motor and neuropsychiatric symptoms contributed to institutionalisation of PD patients, with the presence of hallucinations the strongest predictor of care home placement.

A study of the accommodation requirements of PD patients is important for a number of reasons. In broad terms, institutional care is much more costly than care at home [8]. Direct costs of PD care increase with Hoehn and Yahr stage and can rise fivefold on admission to residential care [8]. This may have financial implications for patients and their families as well as healthcare providers. Outcomes for PD

patients who are admitted to residential care may also be worse than those who are able to stay at home, with a lack of knowledge and understanding of the condition by staff resulting in sub-optimal care [9].

The aim of this study was to compare the type of accommodation and level of service use of PD patients with that of a broadly comparable background population and to compare the demographics and disease characteristics of patients in care with those living in the community.

Methods

In a previously published study, we identified 161 eligible cases of PD from a study population of 108,597 within the North Tyneside area of north-east England [1]. All cases identified were invited to complete a questionnaire as part of a semi-structured interview, at which the diagnosis of PD was re-confirmed using the UK PD Brain bank criteria [10]. This gave a crude prevalence estimate of 148 cases per 100,000 (95% CI, 124–174) and 284 cases within the entire North Tyneside area (population, 191,659) [11].

Participants in this study were recruited from those people identified as having PD from the prevalence study. Those consenting to participate were asked to complete questionnaires recording social and demographic information, including type of accommodation and service use. PD specific information was also recorded, including Hoehn and Yahr stage (degree of disability and functional limitation) [12], Unified Parkinson's Disease Rating Scale (UPDRS) score [13] and the 39-item Parkinson's Disease Questionnaire (PDQ-39) score [14]. Cognition was assessed using the Mini-Mental State Examination (MMSE) [15], and mood was assessed using the Hospital Anxiety and Depression (HAD) score [16]. Finally, patients were asked whether or not they had experienced hallucinations and to describe these events.

Cases were classed as having mild/moderate PD if they had a Hoehn and Yahr stage of I–III and severe if they had progressed to stage IV or V. A MMSE score of ≤24 was used to identify patients with significant cognitive impairment. Ten participants were identified with such a degree of cognitive impairment that they were not thought capable of accurately completing the HAD scale or of reliably reporting the presence of visual hallucinations. Consequently, for the parts of the study involving these items, the results of only 125 patients were included.

The findings for the type of accommodation and level of care service use were compared to UK National Health Service (NHS) statistics for the population of persons over the age of 65 in the North Tyneside area.

The study received ethical approval from the local research ethics committee and satisfied the Caldicot requirements for handling patient identifiable information. Dr Bob Porter was funded as a teaching and research fellow by Northumbria Healthcare NHS trust for carry-

ing out the prevalence study. Miss Sarah R. Henry carried out this work in partial fulfilment of the requirements of a medical degree at the University of Newcastle-upon-Tyne.

Statistics

The data were quantitative in nature and collected at a nominal, ordinal and interval/ratio level. They were analysed using standard statistical software, SPSS-16 for windows (SPSS, Chicago, IL, USA). With the exception of age and UPDRS score, all predictor variables were found to be non-normally distributed (Kolmogorov–Smirnov test) and so did not meet parametric assumptions. No obvious outliers or influential cases were identified. Spearman's correlation test was used to assess whether scores from one predictor were associated with scores from other predictors (multicollinearity) as part of a preliminary screening of the data. Accommodation type was dichotomized into institutional care or non-institutional care (community-dwelling), and a point biserial correlation test was used to assess association with other variables. Logistic regression analysis was used to identify independent predictors of accommodation type.

Results

Of the 161 cases identified, 135 (83.8%) agreed to complete the study questionnaire, 65 males and 70 females. The mean age was 74.8 years (SD, 8.50; range, 50–96 years), and the mean disease duration was 5.6 years (SD, 4.64; range, 1–28). Eighty-two (60.7%) were living in a house, 19 (14.1%) in a bungalow, 8 (5.9%) in a flat, 7 (5.2%) in sheltered accommodation, 12 (8.9%) in a residential home and 7 (5.2%) in a nursing home. Therefore, 14.1% of the cohort was living in residential or nursing care homes. Of the 116 not living in a residential or nursing home, 78 (67.2%) were living with a partner, 32 (27.6%) lived alone and 6 (5.2%) were living with another family member.

At the 2001 census, there were 34,284 people aged over 65 in the North Tyneside area, of whom 1,761 (5.1%) were living in residential (*n*=1,108, 3.2%) or nursing (*n*=653, 1.9%) home care [17]. Assuming that the vast majority of those in care homes were above the age of 65 and that there are ~284 persons with PD in the North Tyneside area [1], then ~1.6% of those living in nursing or residential care in North Tyneside have PD.

Furthermore, within the North Tyneside catchment area, between 1 April 2001 and 31 March 2002 (the time of the prevalence study), a number of services were provided to those over 65 years old (*n*=34,284) due to physical or sensory disability. One thousand three hundred twenty people (5.9% of those over 65 years old) received meals at home, 300 (1.3%) received day care, 2,790 (12.4%) received home help and 370 (1.6%) received respite care [17]. In compari-

Table 1. Comparison of PD patients with regard to accommodation, disease severity and hallucination

			Age	Disease duration	Hoehn and Yahr stage	MMSE score	PDQ-39 score	UPDRS score	Total HAD Score
Accommodation	Community dwelling	Mean	73.3	5.5	2.4	27.3	41.7 (n=115)	28.7	10.4 (n=114)
	(n=116, 85.9%)	SD	7.715	4.710	0.9228	3.996	23.781	12.857	5.975
	58 males, 58 females	Range	50–95	1–28	1–5	6–30	8–122	4–60	0–32
		95% CI	71.8–74.7	4.6–6.3	2.2–2.5	26.6–28.0	37.4–46.0	26.3–31.0	9.3–11.5
	Institutional care	Mean	83.9	6.0	3.8	14.4	55.6 (n=12)	50.6	11.8 (n=11)
	(n=19, 14.1%)	SD	7.322	4.249	1.1220	10.673	18.461	16.962	5.474
	7 males, 12 females	Range	67–96	1–16	1–5	0–27	14–86	21–89	3–22
		95% CI	80.7–87.2	4.1–8.0	3.3–4.3	9.6–19.2	45.1–66.0	43.0–58.2	8.6–15.0
Disease severity	Mild/moderate	Mean	73.4	5.0	2.1	27.0	38.1 (n=106)	26.6	10.0 (n=105)
	(n=108, 80.0%)	SD	8.265	4.398	0.6987	4.542	20.789	11.296	5.977
	55 males, 53 females	Range	50–95	1–28	1.0–3.0	6–30	8–95	4–60	0–32
		95% CI	71.8–74.9	4.2–5.8	2.0–2.3	26.2–27.9	34.2–42.1	24.5–28.9	8.9–11.2
	Severe	Mean	80.3	7.7	4.2	19.2	67.8 (n=21)	52.2	13.2 (n=20)
	(n=27, 20.0%)	SD	7.120	5.005	0.4466	10.896	21.831	12.681	4.969
	10 males, 17 females	Range	67–96	1–22	4.0–5.0	0–30	39–122	37–89	6–25
		95% CI	77.6–83.0	5.9–9.6	4.1–4.4	15.1–23.3	58.4–77.1	47.5–57.0	11.0–15.4
Hallucinations	Formed visual hallucination	Mean	75.0	8.0	2.9	26.0	54.9	38.9	12.6
	(n=23, 18.4%)	SD	7.796	3.570	0.9869	4.674	23.938	13.612	5.829
	9 males, 14 females	Range	53–96	1–28	1.5–5	10–30	10–95	5–60	5–25
		95% CI	71.1–79.0	5.0–11.0	2.5–3.3	24.3–27.8	47.4–62.3	33.8–43.9	10.2–15.1
	No formed visual hallucination	Mean	74.4	4.8	2.4	27.0	40.2	28.7	10.1
	(n=102, 81.6%)	SD	9.651	7.261	1.0407	4.374	18.261	12.400	5.944
	52 males, 50 females	Range	50–95	1–17	1–5	0–30	1–122	4–67	0–32
		95% CI	72.9–75.9	4.1–5.5	2.2–2.6	26.1–27.9	35.5–44.8	26.1–31.4	9.0–11.3

son, for people diagnosed with PD, 3 (2.2%) received meals at home, 2 (1.5%) received day care, 22 (16.3%) received home help and 5 (3.7%) received respite care.

Table 1 compares those PD patients living in institutional care with those living in the community. Of the 125 cases who were able to complete the HAD scale, 114 were living in the community and 11 living in institutional care. Age (r=0.439, P<0.001), Hoehn and Yahr score (r=0.462, P<0.001), MMSE (r=−0.642, P<0.001) and UPDRS score (r=0.495, P<0.001) were all significantly correlated with accommodation type.

Of the 135 patients, 108 (80.0%) had mild/moderate disease and 27 (20.0%) had severe disease. Those with severe disease are compared to those with mild or moderate disease in Table 1. Patients with severe disease were older (r=0.329, P<0.001), had higher UPDRS scores (r=0.666, P<0.001), longer disease duration (r=0.236, P=0.002), lower MMSE scores (r=−0.447, P<0.001) and higher PDQ-39 scores (r=0.468, P<0.001) compared with those with mild/moderate disease.

Thirty-one patients (23.0%) were identified as having significant cognitive impairment (MMSE score ≤ 24), of whom 14 (45.2%) were in care. In contrast, of the remaining 104, only five (4.8%) were in care. Patients with cognitive impairment were older (r=0.242, P=0.005), had higher UPDRS scores (r=0.367, P<0.001) and were more likely to be living in either a residential or nursing home (χ^2=32.157 (1), P<0.001) when compared to those with higher cognitive function.

All patients completing the questionnaire were asked whether they had had any visual or auditory disturbances in the 3 months prior to assessment. In total, 67 (53.6%) of 125 patients reported some form of visual disturbance, 35 (28.0%) of whom reported more than one type of visual disturbance. Twelve patients reported flashes of light, 7 reported spots in front of the eyes, 5 had difficulty identifying correct colours, 47 reported a sensation of something in the periphery of vision, 16 reported seeing objects changing shape, and there were 31 reports (13 during the day and 18 at night) of seeing something that was known not to be there.

The visual disturbances were classified as minor hallucinations/illusions in 44 (35.2%) patients and as formed visual hallucinations in 23 (18.4%) patients. Table 1 compares the 23 patients with formed visual hallucinations (three in care) to the remaining 102 patients (10 in care). Patients with formed visual hallucinations had significantly higher Hoehn and Yahr scores (r=0.187, P=0.037), PDQ-39 scores (r=0.288, P=0.001) and UPDRS scores (r=0.298, P=0.001) than those that did not. There was no higher frequency of care home placement in hallucinating patients when compared to non-hallucinating patients (χ^2=0.211 (1), P=0.706).

A logistic regression model was constructed in which age, UPDRS score and MMSE score were independent predictors of those requiring institutional care, see Table 2. The model appears robust with little interaction between predictors. MMSE score is the strongest single predictor in the model with a unit change in the score (scored from 0–30) resulting in a 0.729 change in the odds of institutional care

Table 2. Regression model predicting care home placement or community-dwelling

	B	SE	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)	
							Lower	Upper
Age	0.294	0.087	11.410	1	0.001	1.342	1.131	1.591
MMSE	−0.316	0.109	8.329	1	0.004	0.729	0.588	0.904
UPDRS	0.120	0.045	7.185	1	0.007	1.128	1.033	1.231
Constant	−22.801	7.097	10.322	1	0.001	0.000		

placement. Using Nagelkerke's method $r^2 = 0.793$ for the model, indicating that it predicts almost 80% of the variation in the outcome.

Discussion

We have shown that UK PD patients are more likely to be in care than a similar population without PD. The figure of 1.6% of nursing/residential home residents having PD is lower than the 5–10% estimated in an American study, though their study may have included patients with diagnoses other than idiopathic PD, such as parkinsonism, or dementia with Lewy bodies [6]. Moreover, our study reveals that those people with PD who were in either nursing or residential care were significantly older, had significantly greater cognitive dysfunction and had significantly greater disease severity and progression than those who were community-dwelling. Indeed, UPDRS score and MMSE score, together with age, are independent predictors of residential care placement. PD patients were more likely to require nursing care, residential care, home care, day care or respite care than the general population of elderly people from the same catchment area.

Previous work carried out in the North Tyneside area has shown that when people with PD are admitted to hospital, their length of stay is longer than other medical patients of a similar age [18]. Furthermore, after hospital admission, there is an increase in those requiring nursing home care. Indeed, it is often an admission to hospital that precipitates care home placement.

Those in care appear to have more complicated symptoms and may find attending hospital clinics difficult. Therefore, ideally, PD services should be able to review these patients in the care home and provide support to on-site carers, clinicians and general practitioners. In this respect, the role of the PD nurse specialist is vital. When providing a service to PD patients, there must be access to residential and nursing homes. Furthermore, care home staff should have training in relation to PD. Nevertheless, more than five out of every six patients live in their own home, which may be of solace to newly diagnosed patients who often have an unnecessarily pessimistic opinion on how they will fare in the years to come.

We have previously shown that despite the fact that many PD patients live at home, most people with idiopathic PD die in hospital (55%) or institutional care (36%), with only 8%

dying at home, compared with 59, 21 and 16% respectively from an age-matched general population within the same catchment area [19]. It is likely that for many individuals, their preferred place of care at end of life would be at home, though there are no published studies addressing this issue.

Significant cognitive impairment was seen in 23.0% of the study population and was associated with more marked disease severity, older age and an increased risk of care home placement. With regard to hallucinations, the information relied on patients' recall of events; this may have resulted in some inaccuracy in the results. Not all hallucinations will necessarily be due to PD, particularly minor hallucinations. Indeed, elderly patients in particular may report visual hallucinations as part of a delirium or as a consequence of visual impairment [20, 21]. For this reason, only formed visual hallucinations were considered clinically significant within the cohort. Previous studies have identified the presence of visual hallucination as a strong predictor of need for institutional care in people with PD [7]. The reason why hallucinations were not associated with care home placement in our cohort is not clear, although relatively small numbers of patients with formed visual hallucinations ($n = 23$), and exclusion of 10 patients with significant cognitive impairment, who may be more likely to hallucinate, may help to explain the lack of significance. Furthermore, the NHS trust serving the North Tyneside area has a comprehensive PD service, and therefore our cohort may have received more proactive treatment for neuropsychiatric symptoms than previous study populations, enabling them to remain community-dwelling for longer.

Limitations of this study

In this study, the results are obtained from assessing a prevalent population. This helps reduce the risk of sampling errors and helps ensure the results are more applicable to the wider UK PD population. However, the authors accept that the prevalence estimate is only a minimum estimate and that not all cases of PD will necessarily have been identified. In addition, it is accepted that as patients with marked cognitive impairment ($n = 10$) were excluded from some parts of the analysis, this may have resulted in bias, particularly in relation to hallucinations. The ages of the comparison population for accommodation and service use were restricted to those over 65, whilst the mean age of those completing the PD prevalence questionnaire was 74.7 years (range, 50–96). Although this is not a direct comparison, it is nevertheless valuable.

Key points

- PD patients are more likely to live in nursing/residential care than the general population.
- Among those in residential or nursing home accommodation, 1.6% may have PD.

- The proportion of people requiring residential/nursing care increases as severity of disease and cognitive impairment increases.
- Patients reporting hallucinations were no more likely to be in care than those without hallucinations.

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Conflicts of interest

There were no conflicts of interest.

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