The place of death in Parkinson's disease

SIR—In 2006, The National Institute for Health and Clinical Excellence (NICE) [1] recognised that patients with Parkinson’s disease (PD) have palliative care needs throughout their disease trajectory—needs which have been quantified in recent studies [2, 3]. It is now well established that the goal of reducing inequity and providing palliative care to patients with non-malignant conditions should be on a basis of need rather than diagnosis [4].

The National Health Service (NHS) End of Life Care (EOL) Programme (2004–07) [5] aimed to improve quality of care at the end of life for all patients and to enable more patients to live and die in the place of their choice. The proposed outcomes included:

- Greater choice for all patients in their place of care and place of death.
- Decreased numbers of emergency admissions for patients who would prefer to die at home.
- Decreased numbers of patients transferred from a care home to hospital in the last week of life.
- Generalists skilled in the use of care models to improve end of life care.

The End of Life Care Strategy (July 2008) [6] further established the implementation of the above outcomes. The strategy provided a framework on which local health and social care services can plan and coordinate care for all patients. It importantly highlighted a commitment at governmental level to enhance funding for EOL care services.

To date, no previous study has identified where patients with PD die. This information is vital in terms of signposting and informing optimal palliative care service provision, patient choice and advance care planning.

With recent national policy development and service planning in mind, the aim of this study was to identify the place of death in patients with idiopathic Parkinson’s disease (IPD).

Methods

Ethical approval was obtained from the NHS National Research Ethics Service (Gateshead and South Tyneside Local Research Ethics Committee) in April 2007.

Patients under the care of the Northumbria Parkinson’s Disease Service (NPDS) in the North Tyneside area, who died between 1 January 1999 and 1 January 2007, were identified from service records. Patients within the NPDS are followed up life long.

Inclusion criteria

Information on the database and in the medical notes was clarified in order to categorise the patients into those with idiopathic disease, as defined by the United Kingdom Parkinson’s Disease Society Brain Bank Clinical Diagnostic Criteria (UK Brain Bank Criteria) and those with other forms of Parkinson’s disease.


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of Parkinsonism [Progressive supranuclear palsy (PSP), multiple system atrophy (MSA), drug-induced Parkinsonism, cerebrovascular Parkinsonism and Lewy body dementia].

**Exclusion criteria**

Individuals were excluded if they did not have Parkinsonism, they died abroad or if insufficient information was available to confirm the diagnosis (e.g. missing notes and lack of available information on the database).

The Office for National Statistics (ONS) provided information relating to the place of death of all patients within the same community over the age of 65 years during the same time period. This provided a control population. Patients who had PD or Parkinsonism on the death certificate were excluded from this control population.

**Results**

Of the 219 patients registered with the North Tyneside Parkinson’s Disease Service, 143 patients had IPD, 26 had vascular Parkinsonism, 17 had Lewy body disease and 12 had either PSP or MSA. Of the remainder, 8 were excluded due to insufficient data (i.e. missing medical notes or incomplete database records), 12 were excluded because they did not have Parkinsonism (these patients mainly had essential tremor and one patient had a diagnosis of motor neurone disease). One further patient was excluded, having emigrated and died abroad.

Of the IPD patients, the average age of death was 81.5, with 68 female patients and 75 male.

**Place of death**

Place of death was categorised into home, hospital, care home or hospice. It was not possible to separate residential care from nursing care as dual care is provided at many sites. Only 9% of patients with IPD died in their own home compared to 17% of the general elderly population. Relatively more IPD patients died in a care home (36% vs 21%). Similar numbers of patients died in hospital compared to the control population (55% vs 59%). Of those that died in hospital, 63% were admitted from home. The mean length of hospital stay in the study group was 12.7 days, with 7% having an admission of <24 h, 44% of 1–7 days, 43% of 8–28 days and 4% of >28 days. Data on the length of stay for the control population was not available. None of the study patients died in a hospice compared with 3% in the control group.

**Discussion**

Our study includes patients under long-term follow-up with clearly defined IPD, as defined by the UK Brain Bank Criteria. This cohort is also representative of a community-based population—previous prevalence data has demonstrated that the NPDS cares for >85% of people with PD in this area [7].

**Preferred place of care**

There is little sound data to show where people would choose to die. Such information is limited because of the varying methods used to collect and collate the data and small sample sizes. These studies largely focus on those with a diagnosis of cancer. The evidence available, paradoxically, demonstrates that a significant number of people would prefer to die at home (53–90%), but the majority die in hospital (54%) [10–12]. There is no data on preferred place of care for patients with IPD. Further exploration is vital for appropriate service development.

**Study limitations**

Being a retrospective study there are no data relating to the wishes, perspectives and expectations of patients and their families in terms of end of life care. We were unable to
assess and compare other variables that may have influenced the place of death, such as the availability of carers for the study and control populations. For purposes of comparison, those patients cared for in ‘continuing care’ were grouped with those living in nursing and residential accommodation, as control data obtained from the ONS did not distinguish between different types of care facility.

**Key points**

- Patients with IPD most frequently die in hospital. They are more likely to die in a care home and less likely to die at home or in a hospice than the general elderly population.
- Further research is required to explore PD patients’ choice and experiences of care at the end of life.

**Conflicts of interest**

None.

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**References**


SIR—Epidemiological studies have widely demonstrated that in industrialised countries, the population is increasingly ageing. Since elderly people can be frail, disabled or dependent [1, 2], this phenomenon will result in significant social and financial burden. Thirty-five per cent of individuals aged over 65 years fall each year, and up to 10% of falls result in hip fracture [3]. Furthermore, in the elderly, falls and hip fracture are the most common causes of acute hospitalisation producing severe disability [3, 4]. These dramatic events are associated with morbidity, mortality, as well as poor quality of life [5, 6]. A growing number of people over 90 years of age will suffer from traumatic events and hip fractures that will need care and rehabilitation treatment, yet this advanced age is associated with increased mortality and poorer functional recovery [7–9]. Several reports [9–16] in the literature concern the recovery of the ‘oldest old’ [17] after hip fracture. However, few studies investigated elderly people aged 90 years or older [11–16] and only one followed the patients for >1 year [15]. Surgery and rehabilitation can be questionable in many of these very elderly [12, 18] who at the least may require a different approach as well as an inpatient setting for services [19, 20]. The purpose of the present study was to evaluate functional recovery in nonagenarian patients with hip fractures. The study focused on (i) functional outcome and recovery of gait after intensive rehabilitation treatment; (ii) rate of survival and (iii) maintenance of walking and functional ability in patients followed for almost 2 years.

**Survival and functional outcome in patients 90 years of age or older after hip fracture**

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