

## Short Communication

# Parkinson Matters

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**Abstract.** Recent epidemiological observations have drawn attention to the rapid rise in the burden caused by Parkinson's disease over the past years, emphasizing that Parkinson's disease is a matter of serious concern for our future generations. A recent report by Public Health England corroborates this message, by providing new insight on trends in deaths associated with neurological diseases in England between 2001 to 2014. The report indicates that mortality associated with Parkinson's disease and related disorders increased substantially between 2001 and 2014. This trend is partially explained by increased longevity in the population. However, it is possible that changes in exposure to risk factors, recent improvements in multidisciplinary care (leading to prolonged survival), and improved diagnostic awareness or improved registration also influenced the observed trend. Furthermore, patients with Parkinson's disease and related disorders were found to die at an advanced age, and the majority die in a care home or hospital, despite a preponderant preference for many patients and their families to spend their last days at home. To combat these concerning observations, future efforts should be focused on providing resources for vulnerable elderly Parkinson patients, avoiding unplanned hospital admissions and out-of-home deaths as much as possible. Possible solutions include a community-based network of specifically trained allied health therapists, personal case managers for Parkinson patients, dedicated Parkinson nursing homes, and improved centralised support services from university clinics to regional community hospitals aimed at facilitating optimal wide-scale care delivery.

**Keywords:** Parkinson's disease, mortality, trends, epidemiology

## INTRODUCTION

At population level, the burden caused by Parkinson's disease (PD) has recently increased, leading some to label this as a Parkinson "pandemic" [1, 2].

Scrutiny of temporal trends in causes of death can offer useful complementary information in this regard. Here, we draw attention to a recently published report by Public Health England on trends in deaths associated with neurological diseases in England between 2001 to 2014, [3] which contains several interesting observations concerning Parkinson's disease and related disorders (PDRD). (Box 1) We will summarise these findings, and address some implications for future healthcare needs. Specifically,

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 Box 1. Key observations in the Public Health England report
 

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1. Mortality associated with Parkinson's disease and related disorders (PDRD) increased substantially between 2001 and 2014; this trend appears to be partially explained by increased longevity.
  2. PDRD patients generally die at an advanced age.
  3. The majority of PDRD patients die in a care home or hospital.
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we focus on the frequency, age and place of deaths associated with PDRD, as well as on temporal trends in the frequency of these deaths.

### CAUSES OF DEATH IN THE AGEING POPULATION: THE PUBLIC HEALTH ENGLAND REPORT

In the United Kingdom, it has long been a legal requirement to report deaths to the Office of National Statistics, yielding near-complete mortality data on a population-wide scale (<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths>). For each deceased individual, health-care professionals register a single underlying cause of death, as well as up to 15 contributory conditions on the death certificate. Conditions are coded in line with the International Statistical Classification of Diseases and Related Health Problems.

According to the Public Health England report, [3] 6,590,453 individuals aged 20 years and over died in England between 2001 and 2014. Of these deaths, 366,728 (6%) were associated with at least one neurological condition (listed as the underlying cause or a contributory cause of death). The report also contains data on deaths associated with seven specific groups of neurological conditions: epilepsy; motor neurone disease and spinal muscular atrophy; multiple sclerosis and inflammatory disorders; neuromuscular diseases; traumatic brain and spine injury; tumours of the nervous system; and PDRD. The latter group comprised all disorders characterized by parkinsonism (including atypical parkinsonisms), other extrapyramidal disorders (including chorea), or tic disorder. Of note, dementia (including dementia with Lewy bodies) and stroke were not among the groups of neurological conditions analysed in the above-referenced report, however, they could be

recorded as the underlying cause of death on a death certificate.

### COMMON CAUSES OF DEATH

The group that was most commonly listed on death certificates between 2001 and 2014 was PDRD; these were mentioned on 31% of deaths associated with a neurological condition as the underlying cause, the contributory cause, or both. PD was the most commonly recorded underlying neurological cause of death (14% of deaths associated with a neurological condition). Remarkably, falls (6%) and pneumonia (3%) were among the 10 most common underlying causes of deaths associated with a neurological condition, while Alzheimer's disease, vascular dementia and unspecified dementia were each recorded on only 1% of death certificates. Falls and pneumonia may have occurred as a complication of parkinsonism or dementia (including dementia with Lewy bodies) in some patients, which implies that the report may have underestimated how often these diseases are the underlying cause of death. Indeed, falls and fall-related injuries are very common in Parkinson patients, and hip fractures in this population are associated with high mortality rates [4, 5]. Aspiration pneumonia secondary to dysphagia is also a common cause of death for Parkinson patients [6]. On the other hand, some misclassification of a diagnosis of PD may have occurred, as a previous study showed that almost one in six patients with a diagnosis of PD in the population did not fulfil strict clinical criteria for the disease [7].

Taken together, these data demonstrate that deaths associated with PDRD are common in the population.

### AGE AND PLACE OF DEATHS

Deaths associated with PDRD were the only group of neurological conditions for which the mean age at death was higher than the overall mean age at death in the population (82 vs. 78 years, data reported for the 2012–2014 period). PD is not exclusively diagnosed in the very elderly, [8] and the high age at death suggests that PD patients live for long periods of time with this condition. Considering the projected rise in life expectancy globally, more resources will be needed to take care of elderly patients with PD.

Care homes were the most common place of death among patients with PDRD, occurring in 43% of cases. Notably, healthcare professionals working in

these institutions frequently lack Parkinson-specific expertise [9]. Perhaps dedicated Parkinson nursing homes or Parkinson-specific training programs could help to reduce some preventable deaths. Aside from care homes, 41% of deaths associated with PDRD were recorded in hospitals, 14% occurred at home, and 2% in other places. By comparison, 23% of all-cause deaths and 18% of deaths associated with neurological conditions occurred at home. These data suggest that, despite recent improvements, [9, 10] the end-of-life for PD patients is often unplanned and occurring in hospitals or care homes. Although there are undeniably instances when dying in a hospital is more appropriate than dying at home, most patients indicate a preference for dying at home [10]. Family caregivers also typically indicate their own home as the preferred place of care for their relatives towards the end-of-life [11]. Furthermore, the vast majority of hospital admissions of PD patients are unplanned, resulting from either complications of the disease or its treatments or comorbidities [12, 13].

Parkinson-specific training of professionals working in the community might prevent some of these unscheduled admissions. For instance, care delivery by physiotherapists with specific expertise in Parkinson management was associated with fewer hospital admissions due to fractures, other orthopaedic injuries or pneumonia, as compared to regular care by a generically trained therapist [14]. Further gains may be made by introducing intensive case management for community-dwelling Parkinson patients, entailing a personalised, collaborative plan of care, not only for but also with patients and their families. Also, closer collaboration between university clinics and regional community hospitals may improve delivery of optimal patient care, with an emphasis on care delivered close to the patient's home whenever possible, but with seamless access to more remote specialized care whenever needed. Specific areas of collaboration may include peer-to-peer support (e.g., university centres supporting community-based colleagues with less expertise), diagnostics in university clinics for unclear cases, shared education programs for patients and professionals, and improved regional guideline development.

## TEMPORAL TRENDS

The number of all-cause deaths per year gradually declined between 2001 and 2006 and remained

relatively stable between 2007 and 2014. Compared to 492,205 deaths in 2001, there were 464,556 in 2014, representing a 6% decline. By contrast, the yearly number of deaths associated with a neurological condition increased steadily from 23,051 in 2001 to 31,925 in 2014, representing a 39% increase over this relatively short time period. The number of deaths associated with PDRD increased from 6,963 to 10,067 during the study period, indicating a marked 45% rise. There were even steeper relative rises in mortality associated with neuromuscular diseases (+83%), epilepsy (+70%), and traumatic brain and spine injury (+64%). Ageing of the population did not fully account for the observed rise in mortality associated with a neurological condition, since age-standardised mortality for deaths associated with a neurological condition only increased by 12%. Age-standardised mortality of deaths associated with PDRD rose by 10%.

The increase in mortality associated with PDRD may be reflective of a rise in the incidence, a longer survival after diagnosis, an increased awareness of coding these conditions on death certificates in England, or a combination thereof. Temporal trends in the incidence of parkinsonism, including its most common cause PD, have varied substantially across populations around the world [15–18]. It is possible that differential temporal changes in exposure to risk factors (e.g., exposure to airborne pollutants, toxins such as pesticides, heavy metals or solvents) have resulted in discrepant trends in the incidence of parkinsonism across populations. Furthermore, we consider the possibility that survival after diagnosis among parkinsonism patients may have increased as a result of improvements in multidisciplinary care during the last decade [14, 19, 20]. Future studies are warranted to elucidate to what extent such changes may have affected the observations in the Public Health England report.

Interestingly, age-standardised mortality of almost every group of neurological conditions increased throughout the study period. This suggests that an improved awareness of neurological conditions or a more complete registration of contributory causes on death certificates by healthcare professionals over time may have contributed to the observed rise in mortality associated with PDRD. Unfortunately, it is not clear whether the number of contributory conditions listed on death certificates changed during the study period. We also note that some individuals who were diagnosed with dementia but not with PDRD may have had an alpha-synucleinopathy, suggesting that

the observed mortality rate associated with PDRD reflects an underestimate of the mortality rate associated with alpha-synucleinopathies. Conversely, it is possible that not all individuals with PDRD had an alpha-synucleinopathy.

## IMPLICATIONS FOR FUTURE HEALTHCARE NEEDS

Health care planning should properly anticipate a possible further rise in mortality associated with PDRD. Efforts should particularly be focused on providing resources for vulnerable elderly patients with these disorders, avoiding unplanned hospital admissions and out-of-home deaths as much as possible. Possible solutions include a community-based network of specifically trained allied health therapists, personal case managers for Parkinson patients, dedicated Parkinson nursing homes, and improved centralised support services from university clinics to regional community hospitals aimed at facilitating optimal wide-scale care delivery.

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## CONFLICT OF INTEREST

The authors declare no potential conflicts of interest.

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