Journal of the Neurological Sciences 347 (2014) 188–192

Contents lists available at ScienceDirect

Journal of the Neurological Sciences

journal homepage: www.elsevier.com/locate/jns

Under-reporting of Parkinson's disease on death certificates: A population-based study (NEDICES)

Julián Benito-León [a,b,c,*], Elan D. Louis [d,e,f], Alberto Villarejo-Galende [a,b], Juan Pablo Romero [a,b,g], Félix Bermejo-Pareja [a,b,c]

[a] Department of Neurology, University Hospital "12 de Octubre", Madrid, Spain
[b] Centro de Investigación Biomédica en Red sobre Enfermedades Neurodegenerativas (CIBERNED), Spain
[c] Department of Medicine, Complutense University, Madrid, Spain
[d] Taub Institute for Research on Alzheimer's Disease and the Aging Brain, College of Physicians and Surgeons, Columbia University, New York, NY, USA
[e] Department of Epidemiology, College of Physicians and Surgeons, Columbia University, New York, NY, USA
[f] Mailman School of Public Health, Columbia University, New York, NY, USA
[g] Faculty of Biosanitary Sciences, Francisco de Vitoria University, Pozuelo de Alarcón, Madrid, Spain

ARTICLE INFO

Article history:
Received 16 June 2014
Received in revised form 7 August 2014
Accepted 23 August 2014
Available online 2 October 2014

Keywords:
Death certificates
Elderly
Epidemiology
Parkinson's disease
Population-based study
Under-reporting

ABSTRACT

Background: Parkinson's disease is frequently omitted as a cause of death from death certificates. A limitation of previous studies that attempted to assess the validity of death certificates is that population-dwelling cases, with milder, undiagnosed Parkinson's disease were likely excluded. As a result, those studies likely overestimated the validity of death certificates because they did not include these milder cases. We assessed the validity of death certificates in a prospective population-based study (NEDICES), which includes previously undiagnosed Parkinson's disease cases detected during the assessment.
Methods: 3926 community-dwelling elderly subjects with and without Parkinson's disease were followed during a median of 12.6 years, after which the death certificates of those who died were examined. We calculated the proportion of cases of clinically diagnosed Parkinson's disease for whom a diagnosis of Parkinson's disease was certified as the basic cause of death on death certificates.
Results: 1791 (45.6%) of the 3926 participants died over a median follow-up of 7.1 years, including 82 (73.9%) deaths among 111 participants with Parkinson's disease. Parkinson's disease was rarely certified as the basic cause of death (14.6%). Gender, disease stage and the period during which the study was conducted (i.e., 1994 to 2007) did not influence the likelihood that Parkinson's disease would be reported.
Conclusions: Our findings reinforce the notion that the reporting of Parkinson's disease on death certificates remains poor. This suggests a lack of awareness of the importance of Parkinson's disease as a cause of death.

© 2014 Elsevier B.V. All rights reserved.

1. Introduction

The burden of neurodegenerative diseases in high income countries is increasing, as the mean age of these populations increases. Parkinson's disease (PD) is one of the most common neurodegenerative disorders. With an increase in the prevalence of older people in recent decades, epidemiological and clinical information on PD becomes even more essential [1]. Two of the most relevant public health indicators are mortality rate and the cause of death. Death certificates have often been used as a source of data in order to understand the incidence, prevalence, and the mortality of PD [2–6], as well as the causes of death associated with PD [7,8]. However, the utility of such data may be limited [9,10]. Often, death certificates do not accurately reflect the mortality of PD [9]. Previous studies have shown that PD is frequently omitted from the death certificate, even in cases with clear and long-standing PD [9,11–16].

A limitation of previous studies is that population-dwelling cases may not have been included. Therefore, it is likely that those studies overestimated the validity of death certificates because they did not include these milder cases [9,11–16]. Our aim was to assess the validity of death certificates in a prospective population-based study (NEDICES), which includes previously undiagnosed Parkinson's disease cases detected during the assessment.

* Corresponding author at: Avda. De la Constitución 73, portal 3, 7° Izquierda, E-28821 Coslada, Madrid, Spain.
E-mail address: jbenitol67@gmail.com (J. Benito-León).

http://dx.doi.org/10.1016/j.jns.2014.08.048
0022-510X/© 2014 Elsevier B.V. All rights reserved.

2. Methods

2.1. Study population

Data for these analyses were derived from the Neurological Diseases in Central Spain (NEDICES) study, a longitudinal, population-based survey of the prevalence, incidence, mortality, and determinants of major age-associated conditions of the elderly, including PD, essential tremor, stroke, and dementia [17–27]. Detailed accounts of the study population and sampling methods have been published [28–30].

The survey area consisted of three communities: Margaritas (approximately 14,800 inhabitants), a working-class neighborhood in Getafe (Greater Madrid); Lista (approximately 150,000 inhabitants), a professional-class neighborhood in Salamanca district (Central Madrid), and Arévalo (approximately 9000 inhabitants), the agricultural zone of Arévalo County (125 km northwest of Madrid). Up-to-date lists of residents were generated from population registers. In each community, survey eligibility was restricted to residents aged 65 years or older who were present there on December 31, 1993, or during 6 or more months of 1993. Eligible persons who had moved away from the survey area were not traced. In Margaritas and Arévalo, every eligible subject was to be screened. Because of the large number of elderly residents in Lista, proportionate stratified random sampling was used to select subjects for screening. All procedures were approved by the ethical standards committees on human experimentation at the University Hospitals "12 de Octubre" (Madrid) and "La Princesa" (Madrid). Written (signed) informed consent was obtained from all enrollees.

2.2. Study evaluation

Briefly, at the time of their baseline assessment (1994–1995), 5278 elderly subjects were interviewed using a 500-item screening questionnaire that assessed demographic factors and medical conditions. The face-to-face interview included data collection on demographics, current medications (including drugs that affect the central nervous system), and medical conditions.

A short form of the questionnaire was mailed to subjects who declined or were unavailable for face-to-face interview, or telephone screening. This form collected data on demographic characteristics, several neurological disorders (essential tremor, stroke, dementia, and parkinsonism), current medications, and also requested the name of the subjects' family doctor.

The screening protocol for parkinsonism included three questions: (1) previous diagnosis of PD or parkinsonism, (2) complaint of tremor, and (3) complaint of slowness [17,18]. Participants were considered to have screened positive for parkinsonism if they responded positively to one or more question. Persons who screened positive for PD underwent a neurological examination, which was composed of a general neurological examination and the motor portion of the Unified Parkinson's Disease Rating Scale (UPDRS) [31]. The neurological examination was performed by one of eight senior neurologists who met at the inception of the study to establish standardized methods to perform and interpret the examination (J. B.-L., F. B.-P., and see http://www.ciberned.es/estudio-nedices). For subjects who could not be examined, medical records were obtained from their general practitioners, from in-patient hospitalizations, and from neurological specialists (if they had visited one). We defined parkinsonism based on four cardinal signs: resting tremor, rigidity, bradykinesia, and impaired postural reflexes [17,18]. Parkinsonism was diagnosed when at least two signs were present in a subject not receiving anti-parkinsonian therapy, or when at least one sign was present in a patient specifically treated [17,18]. Among subjects fulfilling these criteria, the etiologic subgroups were defined as follows.

Drug-induced parkinsonism was defined as an entity following the use of antidopaminergic drugs in the six months preceding onset of symptoms, along with a previously negative history for the parkinsonian signs. The diagnoses were confirmed if the parkinsonian symptoms disappeared or subsided six months after stopping the drug, whenever it was possible [17,18].

Vascular parkinsonism was defined by the presence of at least two of the following findings: history of repeated strokes with abrupt onset and stepwise progression of parkinsonism features, hypertension, emotional incontinence and pseudobulbar palsy, broad-based rigid gait, and widespread pyramidal signs [17,18].

Parkinsonism with associated features, or due to other etiologies, such as nervous system infection, severe head trauma, brain tumor, dementia, or other neurological diseases that possibly affected the basal ganglia, was defined by routine clinical diagnosis [17,18]. This type of parkinsonism also included Parkinson-plus syndromes [17,18].

Subjects were diagnosed as having definite PD or idiopathic parkinsonism after the exclusion of all other possible causes of parkinsonism. Unspecified parkinsonism was that for which clinical information was insufficient to reach an etiologic classification. A Hoehn and Yahr stage was assigned to each case [32].

During the second (i.e., follow-up) evaluation (1997–1998), the same methods were used. Follow-up data on death were collected until May 1, 2007. The date of death was obtained from the National Population Register of Spain (*Instituto Nacional de Estadística*). In all Spanish communities (including those studied here), deceased individuals receive the same death certificate, completed by a doctor, at the time of death. In accordance with the recommendations of the World Health Organization, the classification of causes of death is based on the basic cause of death [33]. This is defined as the illness or injury which started the chain of pathological events which directly led to death [33]. The certificate is then sent to the local authority in the municipality where the person had been living, and the information is collected in the National Register. The cause of death (using the International Classification of Diseases — ICD — 9th Revision for deaths that occurred prior to 1999, and the ICD 10th Revision for deaths occurring thereafter) was divided into six primary categories: dementia, cerebrovascular disorders, cardiovascular disorders (pulmonary embolism, congestive heart failure, myocardial infarction, heart or aortic rupture, and asystole), respiratory diseases, cancer, and other causes (infections, trauma, genitourinary or gastrointestinal disorders) [33].

2.3. Statistical analyses

Data analyses were performed in SPSS Version 21.0 (SPSS, Inc., Chicago, IL). Unadjusted (bivariate) analyses were performed using the *t* test to compare mean ages and chi-square tests to determine associations between categorical variables.

We calculated the proportion of cases of clinically diagnosed PD for whom a diagnosis of PD was listed as the primary cause of death on the death certificate. To further determine whether PD was more likely to be certified in distinct subgroups of PD patients, we characterized the sample by age, gender, and PD stage.

To identify the subject characteristics that were associated with having PD reported on death certificates, we performed a stepwise multiple logistic regression model with the dependent (outcome) variable being presence or absence of PD on the death certificate. Independent (predictor) variables eligible for inclusion in the model were gender (women [reference] vs. men), year of death (May 1, 1994 [reference] to September 30, 2001 vs. October 1, 2001 to May 1, 2007), and Hoehn and Yahr stage (<3 [reference] vs. ≥ 3). These analyses generated odds ratios (OR) with 95% confidence intervals (CI).

3. Results

Of the 5278 participants screened for neurological disorders at baseline (1994–1995), we detected 81 prevalent PD cases, leaving 5197 participants without baseline PD (Fig. 1). Of these 5197

Download English Version:

https://daneshyari.com/en/article/8276684

Download Persian Version:

https://daneshyari.com/article/8276684

Daneshyari.com