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Reporting of clinically diagnosed dementia on death certificates: retrospective cohort study

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Abstract

Background: mortality statistics are a frequently used source of information on deaths in dementia but are limited by concerns over accuracy.
Objective: to investigate the frequency with which clinically diagnosed dementia is recorded on death certificates, including predictive factors.
Methods: a retrospective cohort study assembled using a large mental healthcare database in South London, linked to Office for National Statistics mortality data. People with a clinical diagnosis of dementia, aged 65 or older, who died between 2006 and 2013 were included. The main outcome was death certificate recording of dementia.
Results: in total, 7,115 people were identified. Dementia was recorded on 3,815 (53.6%) death certificates. Frequency of dementia recording increased from 39.9% (2006) to 63.0% (2013) (odds ratio (OR) per year increment 1.11, 95% CI 1.07–1.15). Recording of dementia was more likely if people were older (OR per year increment 1.02, 95% CI 1.01–1.03), and for those who died in care homes (OR 1.89, 95% CI 1.50–2.40) or hospitals (OR 1.14, 95% CI 1.03–1.46) compared with home, and less likely for people with less severe cognitive impairment (OR 0.95, 95% CI 0.94–0.96), and if the diagnosis was Lewy body (OR 0.30, 95% CI 0.15–0.62) or vascular dementia (OR 0.79, 95% CI 0.68–0.93) compared with Alzheimer's disease.
Conclusions: changes in certification practices may have contributed to the rise in recorded prevalence of dementia from mortality data. However, mortality data still considerably underestimate the population burden of dementia. Potential biases affecting recording of dementia need to be taken into account when interpreting mortality data.

Keywords: *older people, dementia, mortality, death certification*

Introduction

Reliable information on deaths and their causes is essential to monitor disease burden and trends, to assess public health programmes, to guide policy and to decide priorities for research. In most countries, a legal requirement to register deaths means that death registries achieve complete population coverage. Adherence to World Health Organisation standards on recording the causes of death allows international comparison [1].

Dementia is a global health priority, and the number of people living with dementia is predicted to double by 2030 [2]. The use of death registration data to monitor the burden of dementia has been limited by long-standing concerns over the level of recording in death certificates [3–6]. Despite this, mortality statistics remain a frequently used source of information on patterns of mortality from dementia [7–11]. In the USA, the Centre for Disease Control and Prevention (CDC) lists Alzheimer's disease as the sixth leading cause of death [12], and in England, dementia is now reported as being the leading cause of death for women, having overtaken cancer and cardiovascular disease [13]. However, it is unclear how much of this reported increase in the population burden of dementia, which is derived from mortality data, relates to increases in prevalence or detection and how much to changes in death certification practices. The aim of this study was to investigate the frequency with which clinically diagnosed dementia

is recorded on death certificates, including time trends and other predictive factors.

Methods

Ethics statement

The source database is approved for secondary analysis by the Oxfordshire Research Ethics Committee C (reference 08/H0606/71+5).

Study setting and data source

A retrospective observational study was conducted using data from the South London and Maudsley NHS Foundation Trust (SLAM) Biomedical Research Centre (BRC) Case Register and the Clinical Record Interactive Search (CRIS) data extraction tool. This data resource has been described in detail [14, 15] and has supported a range of analyses [16–18]. In summary, it provides researcher access to full anonymised copies of electronic medical records from SLAM, one of Europe's largest mental healthcare providers covering a geographic catchment of 1.2 million residents in four boroughs of south London and delivering a comprehensive range of services, including dementia assessment and treatment. Data are currently archived on over 250 000 cases with a range of mental disorders.

Study cohort

Records were retrieved from the SLAM BRC Case Register of all patients with a diagnosis of dementia recorded in SLAM between 1st January 2000 and 16th December 2013 and who were aged 65 or over at diagnosis. Diagnosis of dementia was determined from structured fields in the source record where clinicians are required to enter ICD-10 codes (using F00x-03x categories), supplemented by a bespoke natural language processing algorithm using General Architecture for Text Engineering (GATE) software [19]. This applies information extraction to unstructured text data within clinical records (including correspondence and case notes), returning text strings associated with diagnostic statements [20, 21, 14]. CRIS data have been linked with Office for National Statistics (ONS) mortality and death certification data, and this linkage was used to identify cohort members who had died, restricting the analysis to this group. Four patients were excluded as their age at death could not be determined.

Covariates

CRIS was used to extract data on age, gender, ethnicity (European, Asian, African Caribbean or other) and recorded dementia sub-type. Socioeconomic status was estimated from the 2010 Index of Multiple Deprivation (IMD) applied to the lower super output area for the patient's most recent address. Dementia severity was estimated from the most recently recorded Mini Mental State Examination (MMSE) score, drawn from a structured field in the source record and a further GATE information extraction application [18, 14]. The most recent Health of the Nation Outcome Scale (HoNoS) was also ascertained from the source record. HoNoS is a standard instrument applied routinely in mental health care comprising 12 subscales each rated 0 (no problem) to 4 (severe or very severe problem). We dichotomised the HoNoS scores (scores of 0 and 1 were grouped as no or minor problems, scores of 2, 3 and 4 represented mild to severe problems) to facilitate interpretation.

Linkage with ONS mortality data provided information on date of death, place of death, and recorded cause(s) of death. The place of death was categorised as private residence/own home, hospice, hospital, care home (including residential and nursing homes) and 'other' (for example, prisons, street). Place of death was categorised from free text provided by ONS by one author (G.P.) and independently checked by a second author (K.S.). Where there were discrepancies these were discussed and a category was agreed. The time intervals (in months) between the last face-to-face contact by a SLAM staff member and death, and between the first dementia diagnosis and death were determined using the date of death from ONS mortality data.

The primary outcome was a recording on the death certificate of dementia (ICD-10 codes F00*-03* and G30*) as either the underlying cause of death or a contributory cause of death.

Statistical analysis

The study population was described initially in terms of demographic and clinical variables, followed by logistic regression analyses of dementia recorded as a cause of death on the death certificate. For the multivariable model, explanatory variables were selected according to a priori hypotheses and significance in unadjusted analyses ($P < 0.1$). The HoNoS cognitive problems sub-scale (which measures problems of memory, orientation and understanding) was excluded from the multivariable model because of correlation with MMSE. In light of missing data for HoNoS and MMSE, a sensitivity analysis was run with these variables removed. Analyses were performed using STATA version 13.

Results

In the analysed cohort, 7,115 deceased patients with a previous clinical diagnosis of dementia were identified. Descriptive data on the sample are summarised in Table 1. The mean age at death was 85.5 years (SD 7.0), and the majority of the sample (60.6%) was women. Most patients (81.3%) were European, 8.7% were African Caribbean and 2.6% Asian; 41.3% had Alzheimer's disease as the most recent dementia diagnosis. The mean interval between the last SLAM face-to-face contact and death was 14.4 months (SD 18.5), and the mean interval from first diagnosis of dementia to death was 28.6 months (SD 24.5). 50.6% of the cohort died in hospital, and 39.8% died in care homes;

Table 1. Characteristics of the sample

Study characteristics	Total sample (n = 7,115)	Dementia recorded on the death certificate	
		No (%) (n = 3,300)	Yes (%) (n = 3,815)
Age at death			
Mean (SD)	85.5 (7.0)	84.9 (7.3)	86.1 (6.7)
65–69	105 (1.5)	70 (2.1)	35 (0.9)
70–74	405 (5.7)	230 (7.0)	175 (4.6)
75–79	926 (13.0)	471 (14.3)	455 (11.9)
80–84	1,150 (16.2)	555 (16.8)	595 (15.6)
85–89	2,376 (33.4)	1,059 (32.1)	1,317 (34.5)
90 and over	2,153 (30.3)	915 (27.7)	1,238 (32.5)
Gender			
Female	4,314 (60.6)	1,938 (58.7)	2,376 (62.3)
Male	2,801 (39.4)	1,362 (41.3)	1,439 (37.7)
Most recent dementia diagnosis			
Alzheimer's disease	2,941 (41.3)	1,145 (34.7)	1,796 (47.1)
Dementia in other diseases	219 (3.1)	123 (3.7)	96 (2.5)
Lewy body dementia	54 (0.8)	39 (1.2)	15 (0.4)
Mixed dementia	108 (1.5)	34 (1.0)	74 (1.9)
Unspecified dementia	1,818 (25.6)	1,021 (30.9)	797 (20.9)
Vascular dementia	1,975 (27.8)	938 (28.4)	1,037 (27.2)
Ethnicity			
European	5,783 (81.3)	2,648 (80.2)	3,135 (82.2)
Asian	184 (2.6)	93 (2.8)	91 (2.4)
African Caribbean	617 (8.7)	296 (9.0)	321 (8.4)
Other	531 (7.5)	263 (8.0)	268 (7)
Mean deprivation score (SD)	27.4 (11.1)	27.6 (11.1)	27.2 (11.2)
Year of death[a]			
2006	479	288 (60.1)	191 (39.9)
2007	699	388 (55.5)	311 (44.5)
2008	844	466 (55.2)	378 (44.8)
2009	807	366 (45.4)	441 (54.6)
2010	1,018	480 (47.2)	538 (52.8)
2011	1,018	434 (42.6)	584 (57.4)
2012	1,177	481 (40.9)	696 (59.1)
2013	1,073	397 (37.0)	676 (63.0)
Most recent MMSE score			
Mean (SD)	16.1 (6.8)	17.5 (6.5)	14.9 (6.9)
<10	949 (13.3)	304 (9.2)	645 (16.9)
10–20	2,929 (41.2)	1,328 (40.2)	1,601 (42)
21–24	924 (13.0)	512 (15.5)	412 (10.8)
25 and over	608 (8.5)	369 (11.2)	239 (6.3)
Missing	1,705 (24.0)	787 (23.8)	918 (24.1)
Time since last face-to-face SLAM contact			
Mean number of months (SD)	14.4 (18.5)	11.8 (16.1)	16.6 (20.0)
Time since first dementia diagnosis			
Mean number of months (SD)	28.6 (24.5)	22.3 (21.6)	34.1 (25.5)
Place of death			
Hospital	3,600 (50.6)	1,928 (58.4)	1,672 (43.8)
Nursing home, care home or residential care home	2,829 (39.8)	981 (29.7)	1,848 (48.4)
Private residence	592 (8.3)	323 (9.8)	269 (7.1)
Hospice	85 (1.2)	60 (1.8)	25 (0.7)
Other	9 (0.1)	8 (0.2)	1 (0.0)
HoNOS			
Missing all subcomponents	1,063 (14.9)	531 (16.1)	532 (13.9)
Problem HoNoS scores (sub-scale scores 2–4)[b]			
Agitated behaviour	1,524 (21.4)	603 (18.3)	921 (24.1)
Self-injury	84 (1.2)	39 (1.2)	45 (1.2)
Problem drinking/drugs	105 (1.5)	73 (2.2)	32 (0.8)
Physical illness	4,377 (61.5)	2,045 (62)	2,332 (61.1)
Hallucinations	719 (10.1)	344 (10.4)	375 (9.8)
Depressed mood	752 (10.6)	384 (11.6)	368 (9.6)
Relationship problems	1,226 (17.2)	547 (16.6)	679 (17.8)
Daily living problems	4,854 (68.2)	2,156 (65.3)	2,698 (70.7)
Living conditions problems	778 (10.9)	392 (11.9)	386 (10.1)
Occupational problems	2,227 (31.3)	1,008 (30.5)	1,219 (32)

[a]Percentages given by row.
[b]Apart from missing all HoNoS in certain patients, some patients had few subcomponents missing and those were excluded when calculated percentages.

8.3% died in a private residence, and 1.2% died in an inpatient hospice unit.

The annual sample size increased over the observation period from 479 (2006) to 1,073 (2013). Previous MMSE score was available for 76.0% deaths, and the most recently recorded mean score was 16.1 (SD 6.8). Information on HoNoS score was available for 85.1% of deaths.

Dementia was included on the death certificate in 3,815 (53.6%) deaths. The proportion of cases where dementia was mentioned on the death certificate increased over the study period from 39.9% (2006) to 63.0% (2013). In unadjusted logistic regression models, older age, agitated behaviour and daily living problems were associated with increased likelihood of certification of dementia. Female gender, problems with drinking/drugs, physical illness and depressed mood were associated with decreased likelihood of death certification of dementia. Lower cognitive function (MMSE), more recent year of death, and dying in a care home or hospital were associated with increased recording of dementia on the death certificate, as were longer time since last SLAM contact, or since first dementia diagnosis. Lewy body dementia, vascular dementia, unspecified dementia and dementia in 'other' diseases were associated with decreased likelihood of dementia certification (compared with Alzheimer's disease) (Table 2).

In multivariable logistic regression (Table 3), the following factors remained significantly and independently associated with recording of dementia on the death certificate: older age, female gender, agitated behaviour, longer time since first dementia diagnosis, and death in a care home or hospital compared with death at home. Recording of dementia was less likely for those with drinking or drug problems on the relevant HoNoS sub-scale and in those with higher scores on their most recent MMSE assessment. Recording of dementia became more likely each year over the study period. Recording of dementia was less likely for people with diagnoses of Lewy body, vascular, unspecified or 'other' dementia compared with Alzheimer's disease.

A sensitivity analysis where HoNoS and MMSE scores were removed gave similar results, except female gender no longer remained significant (Supplementary data, Table 1, available in *Age and Ageing* online).

Table 2. Unadjusted logistic regression model of dementia recorded in the death certificates of people with a previous diagnosis

Covariates (separately entered)	Association with dementia recorded on death certificate	
	Odds ratio	*P*-value
Age at death (per year increment)	1.02 (1.02 to 1.03)	<0.001
Female gender	0.86 (0.78 to 0.95)	<0.001
Area-level deprivation (per unit increment)	1.00 (1.00 to 1.01)	0.14
Ethnicity		
European	Ref.	
Asian	0.83 (0.62 to 1.10)	0.20
African Caribbean	0.92 (0.78 to 1.08)	0.30
Any other/mixed ethnic groups	0.86 (0.72 to 1.03)	0.10
Most recent dementia diagnosis		
Alzheimer's disease	Ref.	
Dementia in other diseases	0.50 (0.38 to 0.66)	<0.001
Lewy body	0.25 (0.13 to 0.45)	<0.001
Mixed	1.39 (0.91 to 2.10)	0.12
Unspecified dementia	0.50 (0.44 to 0.56)	<0.001
Vascular dementia	0.70 (0.63 to 0.79)	<0.001
Year of death (per unit increment)	1.13 (1.11 to 1.16)	<0.001
Problem HoNoS scores (sub-scale scores 2–4)		
Agitated behaviour	1.40 (1.24 to 1.58)	<0.001
Self-injury	0.97 (0.63 to 1.50)	0.90
Problem drinking/drugs	0.36 (0.24 to 0.55)	<0.001
Physical illness	0.87 (0.77 to 0.97)	0.01
Hallucinations	0.91 (0.78 to 1.06)	0.24
Depressed mood	0.78 (0.67 to 0.91)	<0.001
Relationship problems	1.06 (0.94 to 1.20)	0.35
Daily living problems	1.30 (1.14 to 1.48)	<0.001
Living condition problems	0.81 (0.69 to 0.94)	0.54
Occupational problems	1.06 (0.95 to 1.18)	0.46
One unit increase in MMSE score	0.95 (0.94 to 0.95)	<0.001
Time since last face-to-face SLAM contact (per month increment)	1.01 (1.01 to 1.02)	<0.001
Time since first dementia diagnosis (per month increment)	1.02 (1.02 to 1.02)	<0.001
Place of death		
Private residence/own home	Ref.	
Hospice	0.57 (0.31 to 0.82)	<0.001
Hospital	1.24 (1.03 to 1.65)	0.03
Nursing home/care home	2.26 (1.89 to 2.71)	<0.001
Other	0.15 (0.02 to 1.21)	0.08

Table 3. Multivariable logistic regression investigating independent predictors of dementia recording in death certificates in people with a previous diagnosis

Covariates (simultaneously entered)	Association with dementia recorded on death certificate (n = 4,690)	
	Odds ratio	*P*-value
Age at death (per year increase)	1.02 (1.01–1.03)	<0.001
Female gender	1.15 (1.01–1.31)	0.04
Most recent dementia diagnosis		
Alzheimer's disease	Ref.	
Dementia in other diseases	0.56 (0.38–0.81)	<0.001
Lewy body	0.30 (0.15–0.62)	<0.001
Mixed	1.54 (0.95–2.51)	0.08
Unspecified dementia	0.59 (0.50–0.69)	<0.001
Vascular dementia	0.79 (0.68–0.93)	<0.001
Time of death (per year increment)	1.11 (1.07–1.15)	<0.001
Problem HoNoS scores (sub-scale scores 2–4)		
Agitated behaviour	1.27 (1.09–1.47)	<0.001
Problem drinking/drugs	0.42 (0.25–0.69)	<0.001
Daily living problems	1.15 (0.98–1.35)	0.09
Depressed mood	0.98 (0.81–1.19)	0.71
Physical illness	1.03 (0.89–1.19)	0.73
MMSE score (per unit increment)	0.95 (0.94–0.96)	<0.001
Time since last face-to-face SLAM contact (per month increment)	1.00 (0.99–1)	0.72
Time since first dementia diagnosis (per month increment)	1.02 (1.01–1.02)	<0.001
Place of death		
Private residence/own home	Ref.	
Hospice	0.84 (0.44–1.57)	0.58
Hospital	1.14 (1.03–1.46)	0.04
Nursing home/care home	1.89 (1.50–2.40)	<0.001
Other	0.29 (0.03–2.65)	0.28

Discussion

In this retrospective cohort study, just over half of decedents who had a clinical diagnosis of dementia were certified with dementia as a cause of death, although this proportion increased over the study period. Independent of their degree of cognitive impairment, people who died in care homes or in hospitals were more likely to be certified with dementia than those who died at home.

Studies from Europe, the USA, Canada and Australia have previously shown variable certification of dementia [3, 5, 22–27]. In our study, dementia was listed as a cause of death for just 53.6% of patients overall, confirming that mortality statistics considerably underestimate the population burden of dementia. The increase over time in the proportion of death certificates which included dementia as a cause of death suggests that changes in certification practices are likely to be an important contributor to the increase in population prevalence of dementia identified using mortality data [13]. However, additional contributions of biological variation or improved detection cannot be ruled out.

One of the strongest factors associated with death certification of dementia in this study was the place in which the person died: dementia was more likely to be written on the death certificate for people who died in care homes compared with those who died at home. A similar association has been shown elsewhere [22, 28]. In England, up to two-thirds of care home residents have dementia [29], and it may be that physicians with care home responsibilities better recognise dementia as a terminal illness. Longer time since diagnosis, as well as associations with cognitive function and agitation, indicate that more advanced and disabling dementia prior to death is more likely to be recorded as a cause. Although these factors were independent predictors in the final model, it is important to bear in mind that time intervals between assessments and death were lengthy in many cases and it is conceivable that all reflect an underlying dimension of dementia severity. The negative association with previously identified

alcohol/drug problems might reflect the fact that a certifying physician may be less likely to be aware of or record co-existing dementia for patients with substance use disorders. On the other hand, dementia was more likely to be recorded in cases where the diagnosis was of Alzheimer's disease compared with other aetiologies such as vascular and Lewy body dementia.

To our knowledge, this is the largest study to have examined the likelihood of death certification among people with a clinical diagnosis of dementia and to have included an examination of trends over time. Use of a detailed clinical database allowed exploration of the factors associated with death certification, and the specialist care records enabled severity of cognitive impairment to be taken into account in analyses, a measure that is frequently unavailable in administrative healthcare databases (e.g. those derived from acute or primary care). We chose as our primary outcome any mention of dementia on the death certificate because of previous findings in England that dementia is infrequently recorded as the underlying cause of death [30].

Considering limitations of our study, the data, although comprehensive and unique in scale and depth, were drawn from a single service provider with active memory assessment services and the generalisability of findings needs to be established. The increase in size of the cohort over the study period reflects the growth of the database over this time [14], though changes in prevalence or identification of dementia cannot be excluded. The cohort was derived from a defined geographic catchment, although outcomes would have been captured irrespective of where the death occurred (within the UK). The cohort was identified using both structured data (ICD-10 codes F00–F03) and unstructured text; ICD-10 codes G30* were not used as these are used rarely in the SLAM database. As mentioned above, predictive factors were primarily limited to those measured during specialist care contacts. Finally, it is also important to note that failure to mention dementia in 46.4% of death certificates does not necessarily imply inaccurate certification: for some of these cases, dementia may have been present and recognised, but may not have been felt to have contributed to the patient's death.

Conclusions

Reliable mortality data are essential to understand the global burden of disease. Our study provides evidence that changes in certification practices in dementia are likely to have contributed to the increase in the prevalence of dementia identified using mortality data. Even so, the burden of dementia measured using mortality data remains an underestimate, with only 63.0% of deaths in the most recent year studied (2013) including mention of dementia on the death certificate. In addition, there are clearly important potential biases affecting whether dementia is recorded or not, which need to be taken into account when interpreting mortality data. Under-reporting, and biased reporting, may be a result of a persisting lack of awareness of dementia as a terminal illness. Alternatively, they may reflect uncertainty and varying practice regarding the recorded contribution of chronic degenerative diseases to individual deaths. In light of ageing populations with increasing co-morbidity, alternative systems that facilitate recording of chronic conditions would improve the epidemiological value of mortality data. This could be achieved by the routine recording of all chronic conditions present at the time of death, in addition to those that directly contribute to and cause death, on the death certificate, or through enhanced and routine linkage of mortality data with disease registries.

Key points

- Just over half of patients with clinically diagnosed dementia had dementia included on their death certificate.
- People who died in care homes and hospitals were more likely have dementia as a cause of death than people who died at home.
- Death certification of dementia was more likely in people with Alzheimer's disease than in people with Lewy Body, vascular or other causes of dementia.
- The frequency of death certification of dementia increased over the time period.

Authors' contributions

G.P., K.S. and R.S. conceived the idea for this study and designed the analysis plan with input from all authors. G.P. implemented the analysis plan, with input from K.S., R.S. and I.J.H. The manuscript was drafted by K.S. and G.P. with input from R.S., I.J.H. All authors read and approved the final manuscript.

Supplementary data

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

Conflicts of interest

None declared.

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References

1. Davies JM, Gao W, Sleeman KE *et al*. Using routine data to improve palliative and end of life care. BMJ Support Palliat Care 2016. [Epub ahead of print].
2. Dementia: A Public Health Priority. World Health Organization, 2012. http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1 (21 April 2016, date last accessed).
3. Jorm AF, Henderson AS, Jacomb PA. Regional differences in mortality from dementia in Australia: an analysis of death certificate data. Acta Psychiatr Scand 1989; 79: 179–85.
4. Macera CA, Sun RK, Yeager KK, Brandes DA. Sensitivity and specificity of death certificate diagnoses for dementing illnesses, 1988-1990. J Am Geriatr Soc 1992; 40: 479–81.
5. Martyn CN, Pippard EC. Usefulness of mortality data in determining the geography and time trends of dementia. J Epidemiol Community Health 1988; 42: 134–7.
6. Gillum RF, Yorrick R, Obisesan TO. Population surveillance of dementia mortality. Int J Environ Res Public Health 2011; 8: 1244–57.
7. Chandra V, Bharucha NE, Schoenberg BS. Conditions associated with Alzheimer's disease at death: case-control study. Neurology 1986; 36: 209–11.
8. Desesquelles A, Demuru E, Salvatore MA *et al*. Mortality from Alzheimer's disease, Parkinson's disease, and dementias in France and Italy: a comparison using the multiple cause-of-death approach. J Aging Health 2014; 26: 283–315.
9. Gillum RF, Obisesan TO. Differences in mortality associated with dementia in U.S. blacks and whites. J Am Geriatr Soc 2011; 59: 1823–8.
10. Chandra V, Bharucha NE, Schoenberg BS. Patterns of mortality from types of dementia in the United States, 1971 and 1973-1978. Neurology 1986; 36: 204–8.
11. Chamandy N, Wolfson C. Underlying cause of death in demented and non-demented elderly Canadians. Neuroepidemiology 2005; 25: 75–84.
12. Kochanek KD, Murphy SL, Xu J, Arias E. Mortality in the United States, 2013. NCHS Data Brief 2014; 178: 1–8.
13. Deaths Registered in England and Wales (Series DR), 2013. Office for National Statistics, 2014. http://webarchive.nationalarchives.gov.uk/20160105160709/; http://www.ons.gov.uk/ons/dcp171778_381807.pdf (21 April 2016, date last accessed).
14. Perera G, Broadbent M, Callard F *et al*. Cohort profile of the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) Case Register: current status and recent enhancement of an Electronic Mental Health Record-derived data resource. BMJ Open 2016; 6: e008721.
15. Stewart R, Soremekun M, Perera G *et al*. The South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLAM BRC) case register: development and descriptive data. BMC Psychiatry 2009; 9: 51.
16. Chang CK, Hayes RD, Perera G *et al*. Life expectancy at birth for people with serious mental illness and other major disorders from a secondary mental health care case register in London. PLoS One 2011; 6: e19590.
17. Hayes RD, Chang CK, Fernandes A *et al*. Associations between substance use disorder sub-groups, life expectancy and all-cause mortality in a large British specialist mental healthcare service. Drug Alcohol Depend 2011; 118: 56–61.
18. Perera G, Khondoker M, Broadbent M, Breen G, Stewart R. Factors associated with response to acetylcholinesterase inhibition in dementia: a cohort study from a secondary mental health care case register in london. PLoS One 2014; 9: e109484.
19. Cunningham H. GATE, a general architecture for text engineering. Comput Hum 2002; 36: 223–54.
20. Taylor CL, Stewart R, Ogden J, Broadbent M, Pasupathy D, Howard LM. The characteristics and health needs of pregnant women with schizophrenia compared with bipolar disorder and affective psychoses. BMC Psychiatry 2015; 15: 88.
21. Fok ML, Stewart R, Hayes RD, Moran P. The impact of co-morbid personality disorder on use of psychiatric services and involuntary hospitalization in people with severe mental illness. Soc Psychiatry Psychiatr Epidemiol 2014; 49: 1631–40.
22. Ganguli M, Rodriguez EG. Reporting of dementia on death certificates: a community study. J Am Geriatr Soc 1999; 47: 842–9.
23. Thomas BM, Starr JM, Whalley LJ. Death certification in treated cases of presenile Alzheimer's disease and vascular dementia in Scotland. Age Ageing [Research Support, Non-U.S. Gov't] 1997; 26: 401–6.
24. Kay DW, Forster DP, Newens AJ. Long-term survival, place of death, and death certification in clinically diagnosed presenile dementia in northern England. Follow-up after 8–12 years. Br J Psychiatry [Research Support, Non-U.S. Gov't] 2000; 177: 156–62.
25. Romero JP, Benito-Leon J, Louis ED, Bermejo-Pareja F. Under reporting of dementia deaths on death certificates: a systematic review of population-based cohort studies. J Alzheimers Dis 2014; 41: 213–21.
26. James BD, Leurgans SE, Hebert LE, Scherr PA, Yaffe K, Bennett DA. Contribution of Alzheimer disease to mortality in the United States. Neurology 2014; 82: 1045–50.
27. Romero JP, Benito-Leon J, Mitchell AJ, Trincado R, Bermejo-Pareja F. Under reporting of dementia deaths on death certificates using data from a population-based study (NEDICES). J Alzheimers Dis 2014; 39: 741–8.
28. Olichney JM, Hofstetter CR, Galasko D, Thal LJ, Katzman R. Death certificate reporting of dementia and mortality in an Alzheimer's disease research center cohort. J Am Geriatr Soc 1995; 43: 890–3.
29. Dementia UK: Second Edition. Alzheimer's Society, 2014. https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2759 (21 April 2016, date last accessed).
30. Sleeman KE, Ho YK, Verne J, Gao W, Higginson IJ. Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001–2010. BMC Neurol 2014; 14: 59.

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