Death rates from dementias and neurodegenerative disorders in England and Wales and the USA, 1993–97

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The aim of the study was to examine and to compare death rates from dementias and neurodegenerative disorders in people aged 15 years and over in England and Wales and the USA from 1993 to 1997. There has been an increase in death rates from dementias and neurodegenerative disorders in both England and Wales and the USA from 1993 to 1997. The USA showed higher death rates for all dementias and neurodegenerative disorders and also had the largest increase in the death rate from 1993 to 1997. Death rates from dementias and neurodegenerative disorders among people aged 15–34 years showed no increase, and the increase in all dementias and neurodegenerative disorders was mainly due to an increase in rates among the elderly.

Introduction

Diseases of the brain that lead to a deterioration in intellectual functions and cognition are very important for patients, carers, and society. Medically, such conditions are collectively termed dementias and neurodegenerative disorders. This group of disorders includes many diseases including senile dementia, Alzheimer's disease and Creutzfeldt-Jakob disease. As well as leading to intellectual impairment, such disorders can also affect the personality of an individual and their behaviour.[1] Patients with these disorders often have complex health needs, which can lead to difficulties for both carers and for health and social services. The prevalence of these disorders increases with age and they are rare among the younger age groups.[2,3] Because of the increasing number of elderly people in the population, and the subsequent increase in the number of people suffering from dementia, primary care and community services will have to care for more patients with dementia in the future.[4]

One cause of dementia is Creutzfeldt-Jakob disease (CJD), which can exist in several forms. In Britain, a new type of CJD, variant CJD, was first reported in 1996.[5] The new form of CJD differed in many ways from the traditional sporadic form of CJD. In particular, it affected a younger age group than sporadic CJD and is mainly confined to Britain. There is increasing evidence that variant CJD is caused by exposure to the prion that causes bovine spongiform encephalopathy (BSE), a disease that affects the central nervous system of cattle.[6,7] In 1989, to try to limit the risk of BSE to people, the use of cattle brain and spinal cord for human consumption was banned (the specified bovine offal ban). However, large numbers of people would have been exposed to BSE-infected material before the introduction of the specified bovine offal ban and because of this, there are concerns that Britain may experience a large epidemic of variant CJD. Until now, there has only

been a small increase in the death rate from both sporadic and variant CJD.[8,9] However, although CJD remains rare, there is enormous public health interest in CJD both in Britain and elsewhere.

Both sporadic and variant Creutzfeldt-Jakob disease are difficult to diagnose and can only be diagnosed with certainty after neuropathological examinations. It is therefore possible that cases of sporadic and variant Creutzfeldt-Jakob disease have occurred in Britain that were not correctly diagnosed because histological examination was not performed.[10] In such cases, patients could have been diagnosed as dying from a different neurological disorder. This would have increased mortality from other dementias and neurodegenerative disorders and led to under-ascertainment of death from Creutzfeldt-Jakob disease in England and Wales.

In this paper, we examine the death rates from dementia and neurodegenerative disorders for men and women aged 15 years and over in England and Wales and the USA from 1993 to 1997. Death rates from dementia have been rising in the UK for many years and a comparison to the USA will help show if this increase is unique to the UK or whether it has also been observed in other countries.

Methods

The number of deaths for residents of England and Wales from selected dementias and neurodegenerative disorders were obtained from data held by the Office for National Statistics, in people aged 15–34, 35–64, 65–74, 75–84 and 85 years and over during 1993 to 1997. The causes of death selected and their respective codes in the ninth version of the International Classification of Diseases (ICD9), are shown in Box one. The disorders in Box one were selected after discussion with specialists at the UK National CJD Surveillance Unit. The number of deaths for residents in the USA were obtained for the same age groups, time frame and ICD codes from the National Centre for Health Statistics in the USA.

The annual numbers of deaths in each age group in England and Wales and the USA were used together with population estimates for the two countries to calculate age-sex specific death rates for each year and each cause of death between 1993 and 1997. Direct age-standardisation to the European Standard population was used to adjust for any changes in overall death rates within each country and, also, for differences in the age structure in the population of England and Wales and the USA. To enable an easier comparison of the results, the causes of death were grouped into three main categories: senile &

Box one

Dementias and neurodegenerative disorders: preferred terms and their corresponding codes in the ninth revision of the International Classification of Diseases (ICD9).

Group 1. Senile & presenile organic psychotic conditions

290.0	Senile dementia, simple type
290.1	Presenile dementia
290.2	Senile dementia, depressed or paranoid type
290.3	Senile dementia with acute confusional state
290.4	Arteriosclerotic dementia
290.8	Senile dementia, other
290.9	Senile dementia, unspecified
331.2	Senile degeneration of the brain

Group 2. Alzheimer's disease

331.0	Alzheimer's disease

Group 3. Other dementias and neurodegenerative disorders

046	*Slow virus infection of central nervous system*
046.1	Creutzfeldt-Jakob disease
046.2	Subacute sclerosing panencephalitis
046.3	Progressive multifocal leucoencephalopathy
046.8	Other
046.9	Unspecified
298	*Other non-organic psychoses*
298.0	Depressive type
298.1	Excitative type
298.2	Reactive confusion
298.8	Other and unspecified reactive psychosis
298.9	Unspecified psychosis
323	*Encephalitis, myelitis and encephalomyelitis*
323.5	Encephalitis following immunization procedures
323.8	Encephalitis, myelitis and encephalomyelitis, other
323.9	Encephalitis, myelitis and encephalomyelitis, unspecified
331	*Other cerebral degenerations*
331.1	Pick's disease
331.3	Communicating hydrocephalus
331.4	Obstructive hydrocephalus
331.8	Other cerebral degeneration
331.9	Other cerebral degeneration, unspecified
333	*Other extrapyramidal disease and abnormal movement disorders*
333.0	Other degenerative diseases of the basal ganglia
333.1	Essential and other specified forms of tremor
333.2	Myoclonus
333.3	Tics of organic origin
333.4	Huntington's chorea
333.5	Other choreas
333.6	Idiopathic torsion dystonia
333.7	Symptomatic torsion dystonia
333.8	Fragments of torsion dystonia
333.9	Other and unspecified
334	*Spinocerebellar disease*
334.0	Friedreich's ataxia
334.1	Hereditary spastic paraplegia
334.2	Primary cerebellar degeneration
334.3	Other cerebellar ataxia
334.8	Other
334.9	Unspecified

presenile organic psychotic conditions (ICD9 290 &331.2); Alzheimer's disease (ICD9 331.0); and all other dementias and neurodegenerative disorders. No tests of statistical significance were carried out because with the size of the populations being studied (around 50 million in England and Wales and 250 million in the USA) even very small differences in rates would be highly statistically significant.

Results

Senile & pre-senile organic psychotic conditions

England and Wales

The number of deaths from senile & pre-senile organic psychotic conditions in people aged 15 years and over in England and Wales increased by 19% from 5,683 in 1993 to 6,745 in 1997. Age-standardised death rates increased by 9% during the same time period from 85 to 93 per million. The number of deaths in men increased by 19% from 1,637 to 1,953. The number of deaths in women increased by 18% from 4,046 to 4,792. Age-standardised death rates increased by 9%, from 77 to 84 per million in men, and by 12%, from 86 to 96 per million in women.

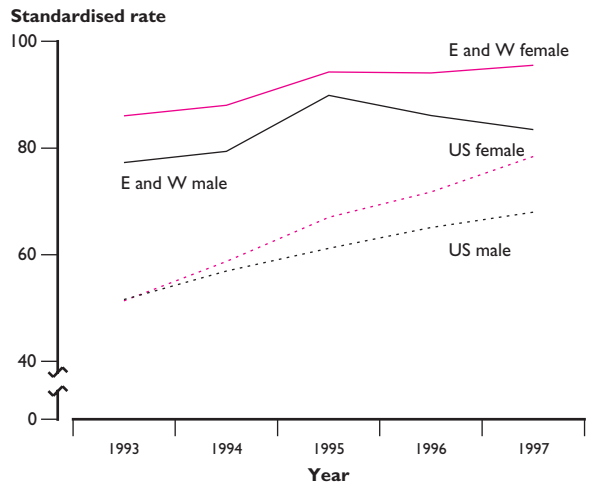
USA

The number of deaths from senile & pre-senile organic psychotic conditions in people aged 15 years and over in the USA increased by 61% from 13,714 in 1993 to 22,100 in 1997. Age-standardised death rates increased by 46% during the same time period from 52 to 76 per million. The number of deaths in men increased by 49% from 4,527 to 6,752. The number of deaths in women increased by 67% from 9,187 to 15,348. Age-standardised death rates increased by 31%, from 52 to 68 per million in men and by 53%, from 51 to 78 per million in women.

Comparison between England and Wales and USA

Women from England and Wales had the highest death rates from senile & pre-senile organic psychotic conditions during the 5 year period from 1993 – 97 (Figure 1). Men from England and Wales had the second highest rate, followed by US-women, and US-men showed the lowest death rate during 1993 – 97. However, women from the USA showed the largest increase in the death rate from senile and pre-senile organic psychotic conditions, followed by US-men compared to a smaller increase in the death rate shown by women from England and Wales. Men from England and Wales showed a big increase from 1994 to a peak in 1995, but decreased after that until 1997.

Figure 1 **Comparison of directly age standardised death rates per million from senile and presenile organic psychotic conditions for men and women aged 15 years and over between England and Wales and USA, 1993–97**



Alzheimer's disease

England and Wales

The number of deaths from Alzheimer's disease in people aged 15 and over in England and Wales increased by 48% from 1,473 in 1993 to 2,185 in 1997. Age-standardised death rates increased by 38% during the same time period from 23 to 31 per million. The number of deaths in men increased by 36% from 488 to 664. The number of deaths in women increased by 54% from 985 to 1,521. Age-standardised death rates increased by 24%, from 23 to 28 per million in men, and by 45%, from 23 to 33 per million in women.

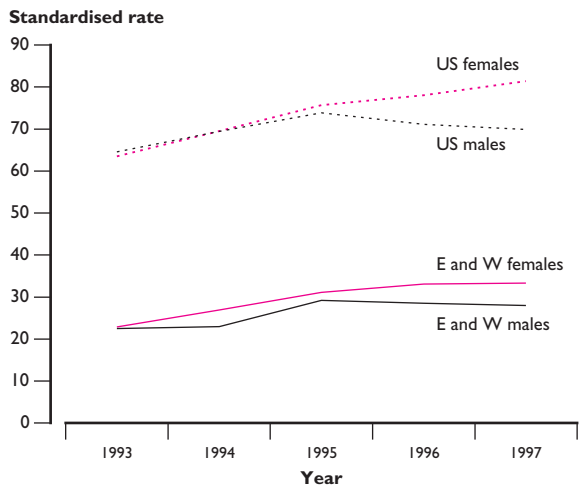
USA

The number of deaths from Alzheimer's disease in people aged 15 years and over in the USA increased by 34% from 16,753 in 1993 to 22,473 in 1997. Age-standardised death rates increased by 21% during the same time period from 64 to 78 per million. The number of deaths in men increased by 21% from 5,820 to 7,036. The number of deaths in women increased by 41% from 10,933 to 15,437. Age-standardised death rates increased by 9%, from 65 to 70 per million in men, and by 28%, from 64 to 81 per million in women. This increase occurred mainly during 1993 to 1995, and from 1995 onwards, rates were relatively stable.

Comparison between England and Wales and USA

Death rates from Alzheimer's disease were much higher in the USA than in England and Wales between 1993 and 1997 (Figure 2). Women from the USA showed the highest death rates, followed closely by US-men. Women from England and Wales had constantly higher death rates than men from England and Wales and they also had the largest increase in the death rate from Alzheimer's disease from 1993 to 1997. Men from England and Wales had the lowest death rates.

Figure 2 **Comparison of directly age standardised death rates per million from Alzheimer's disease for men and women aged 15 years and over between England and Wales and USA, 1993–97**



Other dementias and neurodegenerative disorders

England and Wales

The number of deaths from other dementias and neurodegenerative disorders in people aged 15 years and over in England and Wales increased by 24% from 1,786 in 1993 to 2,216 in 1997. Age-standardised death rates increased by 17% during the same time period from 30 to 35 per million. The number of deaths in men increased by 25% from 665 to 830. The number of deaths in women increased by

23%, from 1,131 to 1,386. Age-standardised death rates increased by 17%, from 31 to 36 per million in men, and by 20%, from 28 to 34 per million in women.

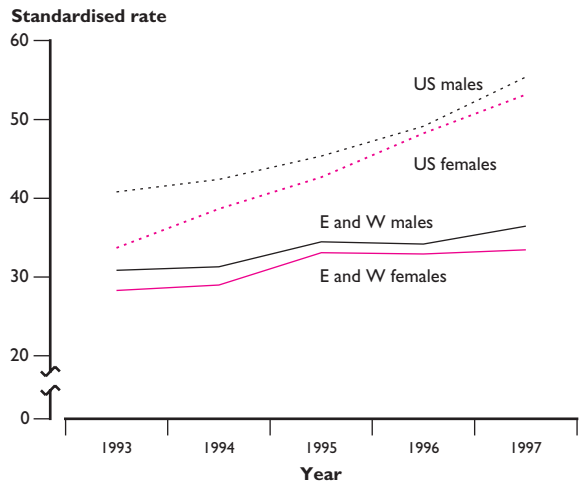
USA

The number of deaths from other dementias and neurodegenerative disorders in people aged 15 years and over in the USA increased by 68% from 9,124 in 1993 to 15,295 in 1997. Age-standardised death rates increased by 49% during the same time period from 37 to 55 per million. The number of deaths in men increased by 51%, from 3,642 to 5,482. The number of deaths in women increased by 79%, from 5,482 to 9,813. Age-standardised death rates increased by 35%, from 41 to 55 per million in men, and by 57%, from 34 to 53 per million in women.

Comparison between England and Wales and the USA

Death rates from other dementias and neurodegenerative disorders were higher in the USA than in England and Wales between 1993 and 1997 (Figure 3). US-men had the highest death rates from 1993 till 1997, followed by US-women. Women from the USA showed the largest increase in the death rates during that 5-year period. Men and women from England and Wales showed low death rates during that time period and also had very small increases in the death rate from 1993 to 1997 from other dementias and neurodegenerative disorders.

Figure 3 **Comparison of directly age standardised death rates per million from other dementias and neurodegenerative disorders for men and women aged 15 years and over between England and Wales and USA, 1993–97**



All dementias and neurodegenerative disorders

England and Wales

The number of deaths from all dementias and neurodegenerative disorders in people aged 15 years and over in England and Wales increased by 25% from 8,942 in 1993 to 11,146 in 1997. Age-standardised death rates increased by 16% from 137 to 159 per million. The number of deaths in men increased by 24%, from 2,780 to 3,447. The number of deaths in women increased by 25%, from 6,162 to 7,699. Age-standardised death rates increased by 13%, from 131 to 148 per million in men, and by 18%, from 137 to 162 per million in women.

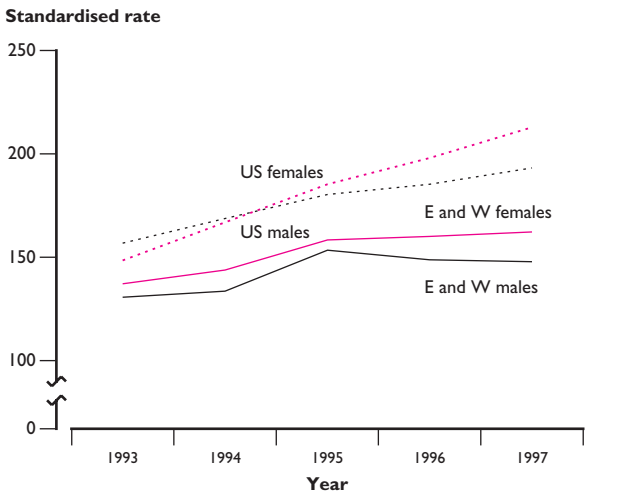
USA

The number of deaths from all dementias and neurodegenerative disorders in people aged 15 years and over in the USA increased by 51% from 39,591 in 1993 to 59,868 in 1997. Age-standardised death rates increased by 36% from 153 to 208 per million. The number of deaths in men increased by 38% from 13,989 to 19,270. The number of deaths in women increased by 59% from 25,602 to 40,598. Age-standardised death rates increased by 23% from 157 to 193 per million in men and by 43% from 149 to 213 per million in women.

Comparison between England and Wales and USA

The USA had higher death rates than England and Wales during the entire 5-year period from 1993 to 1997 (Figure 4). The USA also showed a larger increase in death rates from 1993 to 1997. US-women had the highest death rates from 1994 until 1997. Women from the USA also showed the largest increase in the death rate between 1993 and 1997. US-men had the second highest death rate, except in 1993 when they showed the highest death rate. Women from England and Wales had lower death rates than both US men and women during the entire time period, and men from England and Wales had the lowest death rates between 1993 and 1997.

Figure 4 **Comparison of directly age standardised death rates per million from all dementias and neurodegenerative disorders for men and women aged 15 years and over between England and Wales and USA, 1993–97**



There were large differences in the death rates for both men and women in England and Wales and the USA between the different age groups (Table 1) and, as expected, death rates increased in the older age groups. Among 15 to 34 year olds, England and Wales had a higher death rate during 1993 to 1997 than the USA (Figure 5). However, there was no evidence of any increase in death rates among this age group from the selected neurological disorders examined in either the USA or England and Wales.

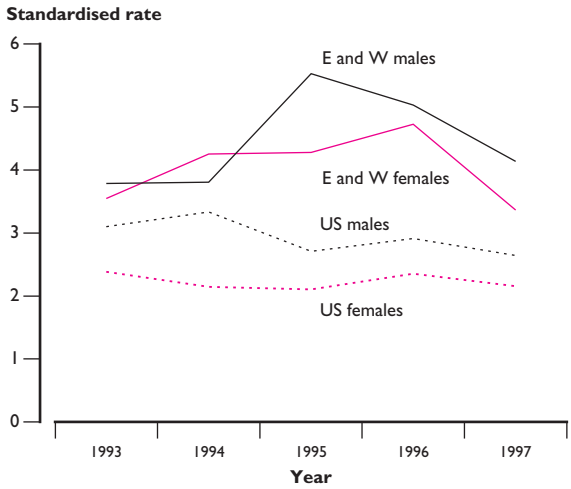
Discussion

The study has shown that there has been an increase in death rates from dementia and neurodegenerative disorders in England and Wales and in the USA from 1993 to 1997. Overall, the USA showed higher death rates from all dementias and neurodegenerative disorders during the entire 5 year period from 1993 to 1997 than England and Wales. The USA also showed the largest increase in the death rates. The death rates from all dementias and neurodegenerative disorders increased by 16% in England and Wales, and by 36% in the USA from 1993 to 1997. However, when analysed by age groups, men and women in England and Wales showed higher death rates for all dementias and neurodegenerative disorders among 15-34 year olds. Although 15-34 year old men and women from England and Wales experienced a

Table 1 **Age- and sex-specific death rates per 100,000 from all dementias and neurodegenerative disorders for women and men aged 15 years and over in England and Wales and the USA, 1993–97**

	15–34		35–64		65–74		75–84		85 and over	
	F	M	F	M	F	M	F	M	F	M
England and Wales										
1993	0.35	0.38	1.27	2.03	17.54	20.94	120.20	118.27	526.98	427.99
1994	0.43	0.38	1.81	1.84	18.93	21.96	127.81	123.92	524.11	434.25
1995	0.43	0.55	1.71	2.15	20.67	25.17	136.34	138.30	603.73	506.87
1996	0.47	0.50	1.71	1.81	21.39	23.45	144.13	136.08	587.01	503.42
1997	0.34	0.41	1.69	1.82	21.15	22.17	138.51	132.88	626.81	517.07
USA										
1993	0.24	0.31	1.37	1.73	18.28	25.44	123.70	145.40	599.12	533.73
1994	0.21	0.33	1.40	1.81	21.92	26.91	137.35	151.78	675.44	592.54
1995	0.21	0.27	1.62	1.73	22.77	27.39	154.46	165.48	753.62	643.74
1996	0.24	0.29	1.57	1.78	23.54	28.40	161.50	169.13	827.25	662.39
1997	0.22	0.26	1.48	1.78	24.89	28.61	170.41	174.21	911.85	708.06

Figure 5 **Comparison of directly age standardised death rates per million from all dementias and neurodegenerative disorders for men and women aged 15–34 years, between England and Wales and the USA, 1993–97**



decrease in the death rates from 1995 for men and from 1996 for women until 1997, the death rate in this age group was still higher in England and Wales from 1993 to 1997 than in the USA.

People in England and Wales had constantly higher death rates from senile and pre-senile organic psychotic conditions than people in the USA during 1993 to 1997. However, women and men from USA showed consistently higher death rates from Alzheimer's disease and from other dementias and neurodegenerative disorders. This finding seems to imply that in England and Wales conditions that are coded to senile and pre-senile organic psychotic conditions are more widely used when diagnosing the cause of a dementia death, whereas in the USA more doctors certified Alzheimer's disease or other dementias and neurodegenerative disorders as the cause of death. The findings may be due to differences in the two health care systems, as a definite diagnoses of Alzheimer's disease can only be made after post-mortem or neuropathological examination of brain samples. The American health care system uses more neuropathological investigations and this may therefore result in more people who suffered from dementia being diagnosed as having died of Alzheimer's disease.[10,11,12,13,14,15]

Alzheimer's disease is the most prevalent form of dementia. It affects about 57%- 88% of all cases of dementia in people aged 75 years and over.[16] Like the other dementia related illnesses, the incidence of Alzheimer's disease increases with age.[17,18] Death rates will underestimate the burden of disease caused by diseases such as dementia. Studies that estimate the prevalence of dementia might be better in estimating the burden of disease. However, prevalence studies might offer very different estimates of the burden of disease, depending on the diagnostic criteria used to diagnose dementia.[19]

Women had slightly higher death rates than men for senile & pre-senile organic psychotic conditions and for Alzheimer's disease. Men showed higher death rates for other dementias and neurodegenerative disorders. For all dementias and neurodegenerative disorders, women also had the higher death rates. However, sex differences in death rates were generally not very large in this study. As expected, there was a marked increase in the death rates with increasing age. This is the case for every category of disease and for both, men and women, from England and Wales and from the USA.

It is difficult to draw conclusions about trends over time in the incidence of dementia from mortality data. Age-standardised death rates increased between 1993 and 1997 in England and Wales and in the USA, but it is not clear whether this was due to a true increase in incidence, or to a greater recording of dementias and neurodegenerative disorders on death certificates by doctors, or to a combination of both. However, there is no evidence that the death rates in England and Wales are increasing at a faster rate than in the USA.

Dementia and neurodegenerative disorders have a different impact on health and social services when they occur in a young person than in an elderly person. Young people are also more likely than the elderly people to have a post-mortem or neuropathological examination after a dementia-related death. The diagnosis of a certain dementia at death in a young person is therefore more likely to be a true diagnosis and a representation of the true incidence of dementia in young persons. A recent study on misclassification at death of CJD in England from 1979 to 1996 showed that there were no undetected cases of CJD found in people aged 15–44, who had died of a dementia or a neurodegenerative disorder.[20] This implies that surveillance and histological examination in the younger age-groups was good, and that CJD in this age-group had not been missed or misclassified. The likelihood of a histological examination of brain tissue or a post-mortem being carried out in a young person that suffered from dementia or a neurodegenerative disorder is much higher than the same examination being carried out on

an older person.[10] Therefore it is more likely that cases of dementia and neurodegenerative disorders may have been missed or misclassified among the elderly.

Further monitoring of dementia trends in England and Wales, as well as further comparisons of dementia death rates between England and Wales and other countries will be important for health and social service providers, and also for an early detection of a possible epidemic of variant CJD.

Key findings

- Age-standardised death rates from dementias and neurodegenerative disorders increased in both the USA and England and Wales from 1993 to 1997. However, there was no evidence that rates were increasing more quickly in England and Wales than in the USA.
- Except among people aged 15–34 years, death rates from dementias and neurodegenerative disorders were higher in the USA than in England and Wales.
- England and Wales had a higher death rate from senile & pre-senile organic psychotic conditions than the USA.
- The USA had a much higher death rate from Alzheimer's disease than England and Wales.

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