Linkage of Hospital and Death Records Increased Identification of Dementia Cases and Death Rate Estimates

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Key Words

Dementia · Data linkage · Case-finding methods · Epidemiologic methods · Vital records · Mortality statistics

Abstract

Background/Aim: To use health record data linkage to improve case ascertainment and death rate estimates of deaths with dementia. **Methods:** Retrospective population study. Western Australians older than 20 years who died between 1990 and 2005 with a dementia diagnosis in Western Australian hospitals and/or death records using the Western Australian Data Linkage System were classed as having a lifetime history of dementia. Cases with dementia documented on death certificates were classified as having dementia as a contributory cause of death (COD). Age-standardized death rates (ASDR) were estimated. **Results:** 29,884 decedents were identified with a lifetime history of dementia. 88.2% had hospital records and 55.9% had death records indicating dementia. The ASDRs for dementia as a contributory COD increased from 50 to 81 per 100,000 person-years from 1990 to 2005. ASDR for lifetime history of dementia increased from 80 to 140 per 100,000 person-years over the same time period. In 2005, 50.1% (95% confidence interval: 47.2–53.1) of all females and 39.2% (35.8–42.7) of all males aged 85+ years died with dementia. **Conclusion:** Data linkage nearly doubled case ascertainment of deaths with dementia because people hospitalized with dementia often lacked dementia

documentation at death. These results have important implications for strategic healthcare planning. Data linkage methodology could improve studies of hospitalisation trends in dementia.

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Introduction

The ageing phenomenon has established the burden of dementia as a top priority for the development of healthcare policy and resource allocation in Australia and internationally [1–3]. While strategic policy development and resource allocation require accurate data on dementia, there is no single source of data which can be relied upon for the estimates about the prevalence of dementia, the characteristics and needs of people with dementia or the range of services that they are receiving. There is concern that current methods to identify persons with dementia may significantly underestimate the size of this population, which in turn could have major implications for healthcare planning, policy and resource allocation. This concern is particularly fuelled by reports that death record data underestimate the identification of dementia [4–6].

In Australia, estimates of the prevalence of dementia rely on applying international, mainly European, age-specific prevalence rates [2] onto Australian population

estimates. These prevalence estimates, which contain considerable uncertainty, have contributed towards calculating the economic and healthcare burden of dementia [7, 8]. It has been estimated that in 2005 over 200,000 Australians (about 1% of the population) were living with dementia and that as a consequence of Australia's ageing population there will be a four-fold increase in the dementia prevalence by 2050; the so-called 'dementia epidemic' [9, 10].

In the absence of a national dementia registry, analysis of morbidity and mortality data is important for assessing the burden of dementia and developing healthcare policy initiatives targeted at dementia management. Published information on the impact of dementia in Australia has been based, in part, on national hospital morbidity data [11]. These data capture patient diagnostic and demographic information for each hospital separation and were used to report on the use of hospital services by persons with dementia. However, dementia is often a co-morbid condition and not the primary diagnosis for admission to hospital and, while primary diagnoses are usually accurately coded, co-morbid conditions are not. A chart review of the Western Australia Hospital Morbidity Data System (HMDS) data found that, whilst specificity was good for identifying dementia, sensitivity was low [12]. Consequently, reports based exclusively on HMDS data may significantly underestimate the burden that dementia places on the healthcare system.

Mortality statistics can be compiled using underlying cause-of-death (COD) data or contributory COD data recorded in the Australian Bureau of Statistics Mortality Data System (MDS). The underlying COD is the disease or condition that initiated the series of events that led to death [13]. Contributory COD data include both the underlying COD and any other contributory condition reported on the death certificate. The importance of including contributory COD in reports on mortality statistics for dementia is evidenced by the finding that in 2001, the Australian death rate of dementia as the contributing COD was more than twice as great as the rate for dementia as the underlying COD [11]. However, in the USA only 11–12% of deaths with a known history of Alzheimer's disease or dementia had it documented on the death certificate [4, 5]. Given this, it is likely that published Australian age-standardized death rates (ASDR) for dementia based exclusively on death certificate records contained within the MDS significantly underestimate the burden of dementia for the population [11]. This has important implications for health policy development and resource allocation.

The Western Australian Data Linkage System (WADLS) is an internationally renowned, population-based, validated and ongoing data linkage system that creates links among a number of state health administrative data sets and covers the entire state population of approximately 2 million people [14, 15]. This system has made it possible to link together successive records relating to the same person and has been used in studies of disease aetiology and health outcomes [15–19]. The purpose of our study was to determine whether using the WADLS to link records of all hospital morbidity and state mortality records could improve case ascertainment of persons dying with a diagnosis of dementia. Specifically, the study aimed to estimate how many Western Australians died between 1990 and 2005 with a lifetime history of dementia (i.e. documentation of dementia in HMDS and/or death records) and then compare the lifetime history death rates with those derived exclusively from the MDS.

Methods

Study data were obtained in December 2006 from the WADLS following institutional ethics approval and confidentiality clearance through the Health Department of Western Australia. International Classification of Disease (ICD) codes and the text terms 'dementia' and 'Alzheimer' were used by the WADLS to provide a de-identified extraction of all in-patient Hospital Morbidity Data, Mental Health Information System (MHIS) and MDS records pertaining to any person who died in the period 1 January 1990 to 31 December 2005. The HMDS records all discharge summaries from all WA acute hospitals (private and public) and day surgery clinics; the MHIS is the database of contacts with mental health services (including psychiatric hospitals). The MDS data provided by the WADLS contained all the text information from both part 1 and part 2 of the death certificate, in addition to an ICD code for the underlying COD. Part 1 includes the disease/condition directly leading to death as well as the antecedent causes (i.e. any morbid condition giving rise to the disease or condition directly leading to death). The underlying COD is the cause that is deemed to have started the morbid train of events that led to death. Part 2 of the death certificate documents other significant conditions that have contributed to death, but which are not considered to be part of the morbid train of events leading to death. The MDS did not separate part 1 and part 2 text fields prior to March 2003, thereby limiting our ability to discriminate between antecedent causes and other significant conditions.

A case was defined as any person, aged 20 years or older, who died between 1990 and 2005 and had a dementia diagnosis as an in-patient in the MHIS, HMDS or MDS databases. Dementia cases were identified using the following ICD-9, ICD-9-CM, ICD-10-AM codes: Alzheimer's dementia 331.0, F00, G30; vascular dementia 290.4, F01; fronto-temporal dementia 331.1, F02.0, G31.0; Creutzfeldt-Jakob disease 046.1, F02.1, A81.0; Huntington's disease 333.4, G10, F02.2; Parkinson's dementia F02.3; non-specific dementia 290.0, 290.1, 290.2, 290.3, 290.8, 290.9, 294.1, 294.8,

Table 1. Summary characteristics of Western Australians (1990–2005) identified with dementia as the underlying COD (n = 5,445), dementia as a contributory COD (n = 16,706), with dementia identified exclusively in hospital records (n = 13,181) and for those with a lifetime history of dementia (n = 29,884)

	Underlying COD		Contributory COD		Hospital		Lifetime history	
	n	%	n	%	n	%	n	%
Sex								
Male	1,822	33.5	6,152	36.8	5,560	42.2	11,711	39.2
Female	3,623	66.5	10,554	63.2	7,621	57.8	18,173	60.8
Age								
20–54	32	0.6	52	0.3	64	0.5	116	0.4
55–59	25	0.5	65	0.4	49	0.4	114	0.4
60–64	74	1.4	168	1.0	146	1.1	314	1.1
65–69	139	2.6	371	2.2	328	2.5	699	2.3
70–74	309	5.7	934	5.6	765	5.8	1,699	5.7
75–79	633	11.6	1,971	11.8	1,778	13.5	3,749	12.5
80–84	1,082	19.9	3,682	22.0	3,033	23.0	6,713	22.5
85+	3,151	57.9	9,463	56.6	7,018	53.2	16,480	55.1
Total	5,445	100.0	16,706	100.0	13,181	100.0	29,884	100.0
Hospital diagnosis								
Yes	4,295	78.9	13,174	78.9	13,181	100.0	26,259	87.9
No	1,147	21.1	3,532	21.1	–	–	3,625	12.1
Follow-up								
All cases	2.0	0.1–4.7	1.4	0.1–3.9	1.3	0.3–3.2	1.4	0.2–3.6
Hospital Dx	3.1	1.2–5.5	2.4*	0.8–4.6	1.3*	0.3–3.2	1.8	0.5–3.9

n = Number of cases identified; hospital diagnosis includes cases with at least 1 dementia diagnosis in hospital records; follow-up is time in years (interquartile range) from first dementia diagnoses until death.

* p < 0.001: duration of follow-up of cases with dementia documented in both hospital and death records was significantly longer than for cases with only a hospital diagnosis of dementia.

331.2, F02.8, F03, F05.1, G31.1, G31.8, G31.9. To improve case ascertainment, the text terms for the aforementioned dementia types were searched for in the MDS in addition to the following alternative medical terms for dementia: multi-infarct dementia, arteriosclerotic dementia, frontotemporal lobe dementia, primary progressive dementia, corticobasal dementia, and Picks dementia. Cases with drug-, alcohol- or HIV-related dementias in the absence of a specific dementia diagnosis were excluded, as was senility without mention of psychosis.

Decedents were grouped into three categories. The first, dementia as the underlying COD, was limited to those cases with a dementia ICD COD code in the MDS. The second, dementia as a contributory COD, included cases with a dementia ICD code and/or a dementia text term in the MDS. The third, lifetime history of dementia, includes cases with any record of a dementia diagnosis in either MDS and/or HMDS/MHIS records identified using data linkage. Follow-up time for cases with a diagnosis of dementia in HMDS/MHIS records was calculated from date of first admission to hospital with a diagnosis of dementia until death date. International Shortlist for Hospital Morbidity Tabulation categories were used to categorise all underlying COD codes into 20 diagnostic categories based on ICD-10 chapters [20]. ICD-9 codes 480–487 and ICD-10 codes J10–J18 were used to identify cases with pneumonia and influenza as the underlying COD.

ASDR (per 100,000 person-years) were computed by the direct method using the total resident population of Australia in 2001 as the standard population. ASDR were also computed using the WHO World Standard Population [21] to enable international comparison. Sex- and age-specific death rates were calculated using the appropriate Western Australian population as denominator. The proportions of deaths with dementia were calculated as a percentage of the total number of Western Australian deaths for each age and sex category. Poisson analysis was undertaken using SPSS version 15.0 for Windows (SPSS Inc., Chicago, Ill., USA) to estimate adjusted-rate ratios and 95% confidence intervals (95% CIs) for each of the covariates entered into the models: year, age group and sex. Age groups less than 55–59 years were excluded from the Poisson analyses due to small numbers. The Mann-Whitney test was used to test for a difference in follow-up time.

Results

Case Ascertainment

Linkage of hospital and death records identified 29,884 Western Australian decedents (1990–2005) with a lifetime history of dementia. Of these cases, 55.9% had

Fig. 1. a Yearly ASDR (standardized to Australian 2001 population) for persons with dementia as the underlying COD (▲) with dementia as the contributory COD (●) and a lifetime history of dementia (■). Yearly ASDR (standardized to WHO World Standard Population) for persons with underlying COD (dotted line),

b Yearly ASDR for males (▲, ●, ■) and females (△, ○, □) for underlying COD, contributory COD and lifetime history of dementia, respectively. Error bars are 95% CI.

dementia coded as a contributory COD and the remaining 44.1% had no dementia documented on their death certificate (table 1). Dementia was coded as the underlying COD in 18.2% of those with a lifetime history. Table 1 provides a sex and age breakdown of these cohorts.

The median length of follow-up from time of first hospital admission with a record of dementia to death varied according to cohort (table 1). Follow-up for cases with dementia as underlying COD was 3.1 years (IQR 1.2–5.5). Follow-up was significantly longer for the 13,174 cases with dementia as a contributory COD who also had hospital documentation of dementia than for the 13,181 cases who only had dementia documented in hospital records [median 2.3 years (IQR: 0.8–4.6) vs. 1.3 years (0.3–3.2); $p < 0.001$].

The top 5 International Shortlist for Hospital Morbidity Tabulation categories for underlying COD for persons with dementia as a contributory COD were: circulatory system (36.7%), nervous system (18.6%), mental disorders (17.9%), respiratory system (7.2%) and neoplasms (6.3%). For persons without dementia documentation on their death certificates, the top 5 underlying CODs were: circulatory system (52.5%), neoplasms (13.1%), respiratory system (12.5%), endocrine diseases (4.2%) and digestive system (3.8%). Pneumonia was the underlying COD for 2.8% of cases with dementia documented as a contribu-

tory COD, 4.3% of cases with a lifetime history of dementia and 6.1% of cases who did not have dementia on their death records but had dementia documented in their hospital records.

Death Rates

In 1990, the ASDR per 100,000 person-years (adjusted to 2001 Australian census) for persons with underlying COD, contributory COD and lifetime history were estimated to be 19.6 (95% CI: 16.9–22.3), 50.1 (45.7–54.4) and 79.4 (74.0–84.8), respectively. By 2005, these rates had increased to 25.5 (23.2–27.7), 81.1 (77.1–85.1) and 144.6 (134.9–145.3) (fig. 1a). To enable international comparison, the ASDR adjusted to WHO World Standard Population are also shown in figure 1; the 2005 ASDR for persons with underlying COD, contributory COD and lifetime history were estimated to be 13.2 (95% CI 12.0–14.4), 41.5 (39.5–43.6) and 72.3 (69.6–75.0), respectively. Over the 16 years of the study, the ASDR for those with a lifetime history of dementia were on average 1.8-fold higher than the ASDR for contributory COD. Table 2 shows the sex- and age-specific death rates for underlying COD, contributory COD and lifetime history. Adjusted rate ratios indicate that for each 5-year increment in age there was an approximately 3-fold increase in death rates. Using Poisson analysis, it was estimated that, after adjustment for age and sex, the relative annual increase in de-

Table 2. Sex- and age-specific death rates, for time-periods 1990–1997 and 1998–2005, for Western Australians identified with dementia as the underlying COD, dementia as a contributory COD and for those with a lifetime history of dementia

Time period	Age group	Underlying COD		Contributory COD		Lifetime history	
		male	female	male	female	male	female
1990–1997	55–59	1.4	1.8	5.9	4.3	9.0	6.8
	60–64	5.5	6.8	17.0	15.6	28.0	22.0
	65–69	14.8	14.7	42.2	32.0	83.1	55.7
	70–74	39.8	36.5	133.9	90.0	249.7	152.2
	75–79	121.4	95.4	365.2	262.3	735.0	459.1
	80–84	304.9	262.3	1,013.1	842.8	1,946.1	1,417.7
	85+	821.5	1,020.8	2,574.4	2,972.1	4,625.6	4,747.5
1998–2005	55–59	1.7	2.3	5.0	3.8	9.8	7.1
	60–64	6.6	7.1	15.9	11.3	33.5	26.1
	65–69	14.9	13.1	46.3	32.8	91.7	58.2
	70–74	38.6	40.1	140.0	107.1	267.6	188.2
	75–79	106.9	100.1	393.6	297.1	792.3	538.0
	80–84	267.0	269.4	1,011.3	900.9	1,911.8	1,645.0
	85+	855.4	1,165.8	2,984.2	3,342.8	5,628.3	5,866.8
Adjusted RR							
		RR	95% CI	RR	95% CI	RR	95% CI
1990–1997	Year	1.02	1.00–1.03	1.07	1.06–1.08	1.07	1.07–1.09
	Male	1.00		1.00		1.00	
	Female	1.04	0.95–1.14	0.95	0.90–1.00	0.83	0.80–0.86
	Age group	2.89	2.79–2.99	2.95	2.88–3.01	2.89	2.84–2.93
1998–2005	Year	1.02	1.01–1.04	1.02	1.01–1.03	1.01	1.01–1.02
	Male	1.00		1.00		1.00	
	Female	1.20	1.11–1.29	0.98	0.94–1.02	0.91	0.88–0.94
	Age group	2.98	2.89–3.08	3.03	2.98–3.09	2.98	2.94–3.02

Adjusted rate ratios (RR) show the different effects of year, sex and age on death rates within each time period. Rates are per 100,000 person-years. Rate ratios were calculated using Poisson regression with year, sex and age category entered into the model. Referent group for sex is male.

mentia death rate from 1990 to 1997 was 7% for both contributory COD and lifetime history, but from 1998 onwards, the annual increase fell to 2 and 1%, respectively (table 2).

Figure 1b shows the effect of sex on the ASDR over time. After adjustment for age and year, the relative death rate for underlying COD between 1998 and 2005 was estimated to be 20% higher for females whereas males with a lifetime history had a 9% higher death rate than females. After adjustment, the dementia rates for contributory COD were not different between males and females (table 2).

In 2005, an estimated 6.4% (95% CI: 4.3–8.6) of all Western Australian male deaths (aged 65–69 years) and 7.8% (4.5–11.1) of all female deaths (aged 65–69 years) had

a lifetime history of dementia; for the 85+ age group, the proportions were 39.2% (35.8–42.7) and 50.1% (47.2–53.1) for males and females, respectively. After adjustment for sex and year of death, it was estimated that for each 5-year increment in age there was a 56% (95% CI: 54–58) increase in the proportion dying with a lifetime history of dementia. This increase in risk due to age group was similar in magnitude for contributory COD and underlying COD (table 3). Table 3 gives the breakdown of the average age- and sex-specific proportion of deaths with dementia for periods 1990–1997 and 1998–2005.

Hospital Use

In the last year of life, 67% of all decedents with a lifetime history of dementia were admitted to a Western

Table 3. Proportion (%) of Western Australian deaths, for time-periods 1990–1997 and 1998–2005, identified with dementia as the underlying COD and with dementia as the contributory COD and for those with a lifetime history of dementia

Time period	Age group	Underlying COD		Contributory COD		Lifetime history	
		male	female	male	female	male	female
1990–1997	55–59	0.2	0.4	0.8	1.0	1.2	1.6
	60–64	0.4	1.0	1.3	2.2	2.1	3.1
	65–69	0.7	1.3	1.9	2.8	3.7	4.8
	70–74	1.1	1.8	3.8	4.5	7.0	7.6
	75–79	2.0	2.8	6.1	7.7	12.2	13.4
	80–84	3.1	4.4	10.3	14.0	19.9	23.6
	85+	4.7	7.2	14.7	21.1	26.4	33.7
1998–2005	55–59	0.3	0.7	0.9	1.2	1.8	2.2
	60–64	0.7	1.3	1.7	2.1	3.6	4.8
	65–69	0.9	1.5	2.9	3.7	5.7	6.6
	70–74	1.4	2.6	5.1	6.9	9.7	12.0
	75–79	2.3	3.7	8.4	11.0	16.9	19.8
	80–84	3.4	5.2	13.0	17.5	24.5	32.0
	85+	5.5	9.3	19.1	26.6	36.0	46.7
		Adjusted RR					
		RR	95% CI	RR	95% CI	RR	95%CI
1990–1997	Year	1.02	1.00–1.04	1.07	1.06–1.08	1.08	1.07–1.09
	Male	1.00		1.00		1.00	
	Female	1.51	1.38–1.66	1.37	1.30–1.44	1.21	1.16–1.25
	Age group	1.59	1.53–1.64	1.62	1.59–1.65	1.59	1.57–1.62
1998–2005	Year	1.04	1.03–1.06	1.04	1.03–1.05	1.03	1.03–1.04
	Male	1.00		1.00		1.00	
	Female	1.66	1.55–1.80	1.36	1.30–1.61	1.27	1.23–1.31
	Age group	1.55	1.51–1.60	1.59	1.56–1.61	1.56	1.54–1.58

Adjusted rate ratios (RR) show the effects of year, sex and age on the proportion of deaths with dementia within each time period. Proportion (%) is dementia deaths per Western Australian deaths expressed as a percentage. Rate ratios were calculated using Poisson regression with year, sex and age category entered into the model. Referent group for sex is male.

Australian hospital (77% of males and 61% of females); 84% in the last 3 years of life and 98% in the last 10 years of life. There were 3,529 cases (11.8% of all cases) with dementia as a contributory COD who had no dementia diagnoses in their hospital records; 32.8% of these had been admitted to hospital in the last year of life, 54.0% had been admitted in the 3-year period prior to death and 6.7% (n = 238) had no record of prior admission to any Western Australian hospital.

Thirty-one percent (95% CI: 30.4–31.4) of all deaths occurred in hospital; 35.3% (34.5–36.1) of cases aged 65–84 years and 27.2% (26.5–27.9) of cases aged 85+ years died in hospital. 21.8% of cases with dementia as a contributory COD died in hospital and 42.3% of all the cases who could only be identified as having dementia from

hospital records died in hospital. Logistic regression analysis found that, after adjustment for age, sex and year of death, cases that could only be identified as having dementia from hospital records were found to have greater odds of dying in hospital than cases with dementia documented on the death certificate (odds ratios 2.6; 95% CI: 2.4–2.7).

Discussion

Using data linkage of hospital and death records this study identified close to 30,000 Western Australians who died between 1990 and 2005 with documentation of dementia by a physician. A substantial proportion (44%) of

these cases with a lifetime history of dementia could not be identified as having dementia from their death records. Consequently, we estimate that the ASDR for those dying with dementia were approximately 80% higher than estimates that rely on death certificates alone. Just as in the USA, where the method of case ascertainment greatly influenced the magnitude of the problem [6], dementia was found to be an extremely common cause of morbidity and mortality, with 50% of females and 40% of males aged over 84 years dying with dementia. In the absence of a compulsory Australian dementia registry and while dementia continues to be sub-optimally documented on death certificates, the use of linked health record data sets is useful for providing a more complete and inclusive examination of dementia-related deaths.

It has been shown previously that ASDR are higher for females than males, whether from underlying COD, contributory COD, or from follow-back surveys [22]. While we also found that females had a higher dementia death rate for underlying COD, males were found to have a higher lifetime history of dementia death rate. This difference may be explained, in part, by hospital admission patterns for the elderly Western Australian population. To clarify, those aged over 84 years of age have been shown to use less in-patient resources in the last year of life than those aged between 65 and 84 [16]. As Australian males have a shorter life expectancy and as dementia is strongly associated with age [23], males are more likely to be hospitalized in the last years of life than females. Consequently, our method of identifying cases with a lifetime history of dementia is biased towards capturing a greater proportion of males. While this bias affects lifetime history of dementia death rates for the sexes, the data linkage of hospital and death records provides an opportunity to assess hospitalization rates more accurately in the last year of life for patients with dementia. More than 75% of males and 60% of females with dementia are hospitalized in their last year of life. The increasing demand on hospital services that ageing Australians with dementia will place on the healthcare system requires consideration for future healthcare planning and resource allocation.

Meta-analyses have found that from 60 years of age onwards the prevalence rates of dementia double with every 5 years of age [23, 24]. In our study, the age-specific death rates for dementia tripled every 5 years. We recognise that prevalence rates do not equate with death rates and also acknowledge that the methodologies for determining prevalence rates were different from the data linkage methodology employed in our study. Even within our study, the choice of denominator affected the magnitude

of the effect of age, there being only a 50- to 60-percent increase with every 5-year age increase in the proportion of deaths. However, regardless of which death rate we examined, our rate data support the steep (exponential) rise in the incidence and prevalence of dementia with increasing age that has been shown by others [23, 24].

The median follow-up time from the first hospital documentation of dementia and time to death for the more than 13,000 cases identified solely from hospital records was estimated to be less than 16 months. No doubt, a proportion of these deaths was totally unrelated to dementia: for example, 13% had cancer documented as the underlying COD. However, to have qualified for an ICD code of dementia during their stay in hospital 16 months prior to death, the dementia had to be severe enough to affect their management. Due to their advanced age, less than 1% of cases were likely to have had reversal of their dementia [25]. Therefore, the relatively short follow-up time between admission to hospital with dementia and time of death suggests that dementia probably contributed to death in many cases. The true contributory COD rates for dementia probably fall in between estimated death rates for underlying COD and lifetime history. While guidelines for physicians in completing death certificates exist [13], our results suggest that specific physician training aimed at more inclusive documentation of the contributing COD could reduce the current underestimate of dementia based on death data.

Severe dementia affects the process of swallowing and can thereby predispose the person with dementia to both acquire and die from pneumonia [4, 26, 27]. However, while the immediate COD may be pneumonia, the underlying COD (i.e. the cause that started the morbid train of events) for dementia patients with swallowing difficulties should be dementia or perhaps another condition that impairs the immune system. In our study, pneumonia was the underlying COD in 3% of cases with dementia documented on the death certificate. It is possible, therefore, that the misclassification of pneumonia as the underlying COD may partially explain the underestimate of dementia as the underlying COD in mortality statistics.

Between 1990 and 1997 there appears to have been some improvement in the recognition of dementia. In that period, the ASDR increased by 7% annually. In the absence of any biologically plausible explanation, these increases may be due to changes in either diagnosing and/or coding for dementia and/or changes in the practice of completing death certificates. While this improvement is commendable, studies still need to be conducted to de-

termine the extent of under-reporting of dementia in hospital administrative records.

The study had a number of limitations. We could not estimate the number of dementia patients who were not documented in hospital discharge summaries or death records. Nor could we determine which dementia criteria were used by the diagnosing physician and the onset, duration and severity of dementia. It is, however, more than likely that the dementia was moderate to severe at the time of either death or hospitalization to warrant documentation. Changes occurred in the classification and processing of Australian mortality data that may also have influenced the mortality trends demonstrated in the present study. The introduction of the multi-cause Automated Coding System in 1997 was shown to assign fewer deaths to Alzheimer's disease than the previous manual coding method [28] and ICD-10, introduced in 1999, identifies more Alzheimer's disease deaths than the ICD-9 coding system [29]. We minimized the impact of these changes by searching for dementia types in the text of death certificates and searched both death and hospital records for dementia-related ICD codes. While this study was able to investigate the prevalence of dementia at the time of death, we could not confirm whether dementia was a contributory and/or underlying cause of death in all cases with a lifetime history of dementia.

This comparison study has also been useful in demonstrating the importance of using sources other than just

data derived from death certificates in determining the prevalence of diseases other than just dementia, as in many longitudinal epidemiologic studies. It is possible that case ascertainment through just death data review could be underestimated for a wide variety of fatal conditions without review of additional source documents.

Conclusion

Linkage of hospital and death report data considerably improved case ascertainment and substantially increased population estimates of deaths in patients with dementia. Given that improved measures are central to refining our ability to forecast associated demand on health systems, this method is likely to be important for healthcare planners. Future studies employing data linkage methodology to assess use of in-patient hospital services of persons with dementia are needed to prepare for the healthcare needs of this growing population.

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