



Under-reporting of diabetes on death certificates among a population with diabetes in Otago Province, New Zealand

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Abstract

Aims To estimate the degree of under-reporting of diabetes on death certificates, and to describe the population of patients enrolled on the Otago Diabetes Register known to have died during the 6-year period to 31 December 2003.

Methods The Otago Diabetes Register was established in 1998, as part of the Otago Diabetes Project, to monitor and evaluate diabetes care in the Otago region, New Zealand. Demographic and clinical data, including vital status, type of diabetes and year of diagnosis, diabetes complications, diabetes medication and clinical examination, and biochemistry test results were collected annually from general practice medical records. Copies of death certificate information were obtained from the national Births, Deaths and Marriages office, Department of Internal Affairs for 508 enrolled diabetic patients known to have died before 31 December 2003. Causes of death were coded using ICD-10. Date, place, and causes of death were added to the Otago Diabetes Register.

Results The mean age at death was 78 years (SD=9.7) and the average duration of diagnosed diabetes was 12.1 (SD=8.6) years. Diabetes was mentioned on the death certificates of just over half (55.1%) of the 508 diabetic patients. More of those using insulin only, or oral hypoglycaemic and insulin therapies combined, before death had diabetes mentioned on their death certificate, 67.8% and 81.0%, respectively, compared with those taking oral hypoglycaemics only (55.7%) or diet only treatment (38.0%). Almost 50% of deaths were due to a circulatory system disorder, either cardiovascular or cerebrovascular disease. Five men with type 1 diabetes, all aged less than 50 years, died from diabetic ketoacidosis or hypoglycaemia.

Conclusion Diabetes is under-reported on death certificates in New Zealand. Improvements in the completion of death certificates are necessary, if the impact of the diabetes epidemic on mortality is to be monitored appropriately.

Diabetes prevalence is increasing worldwide, and studies have consistently shown excess death rates amongst diabetic populations compared with the general population.^{1,2,3} However, the impact of increasing diabetes prevalence on mortality rates is difficult to determine. Death certificates are the only routine source of mortality information with which to monitor the national burden of diabetes-related deaths, but it has been repeatedly shown that diabetes is under-reported on death certificates worldwide.^{1,4,5} Thus, the contribution of diabetes to cause of death is usually underestimated.⁶

The degree of under-reporting of diabetes on death certificates varies between countries,^{1,5,7} as does death certificate coding practices, although the same World Health Organization (WHO) rules and guidelines are usually used.^{8,9} This partly stems from differences in opinion about the causal role of diabetes when it is associated with

other conditions such as cardiovascular disease.^{8,10} Also, coding practices have changed over time resulting in inconsistent time trends. For example, in Australia, higher death rates attributable to diabetes were reported in the 1940s compared with the 1950s and 1980s¹¹—and in the Oxford region, England, diabetes mortality rates based on underlying cause decreased stepwise between the 1984-92 and 1993-99 study time periods.¹² Thus, the validity of comparisons of diabetes mortality rates between countries and over time is questionable.

In New Zealand, there is only one published report estimating the degree of under-reporting of diabetes on death certificates.⁵ For this recent Christchurch-based study, it was necessary to link several health information sources to identify deceased diabetic patients. The Otago Diabetes Register, established in 1998, enables diabetes-related data for enrolled individuals to be directly linked with death certification information.

The purpose of this study was to use data from the Otago Diabetes Register to estimate the degree of under-reporting of diabetes on death certificates, and to describe the population of enrolled patients known to have died during the 6-year period to 31 December 2003.

Methods

The Otago Diabetes Register was established as part of the Otago Diabetes Project to monitor and evaluate diabetes care in the Otago region of New Zealand. The project also involved establishing or updating general practice diabetes registers, organising education sessions for general practitioners (GPs) and practice nurses and developing and implementing guidelines for the management of core aspects of diabetes care. Details of how general practice registers and the regional diabetes register were established have been previously described.¹³

Briefly, a project nurse established or updated general practice diabetes registers for participating GPs (about 95% of all GPs in the region). Identified diabetic patients were sent an invitation from their GP to participate in the project, along with an explanatory pamphlet, a consent form and a stamped addressed envelope for return of the form. Consent was also obtained opportunistically, when patients attended their general practice or the local retinal screening programme.

Data (including demographic details, type of diabetes and year of diagnosis, dates and results of retinal and foot examinations, diabetes complications, diabetes medication, and dates and results of biochemistry tests) were collected annually from general practice medical records. For patients who had attended Dunedin Hospital's Outpatient Diabetes Clinic or Eye Department, checks were made for missing data. If patients' diabetes type was uncertain, this was checked with the local specialist diabetes clinic.

Those patients who had died during the previous 12 months were noted as such on the regional register. The vital status of the 279 patients who had moved from the Otago region or had changed to a non-participating GP during the 6-year study period was not known. Between 1998 and 2003, the annual number of enrolled alive diabetic patients living in the Otago region increased from 1693 to 3387, which was about 71% of the estimated 4800 people with diagnosed diabetes in the province.

Copies of death certificate information were obtained from the national Births, Deaths and Marriages office, Department of Internal Affairs for patients known to have died. ICD-10 was used to code all diseases recorded on the death certificate.¹⁴ The date of death, place of death, and causes of death were added to the Otago Diabetes Register—a Microsoft Access-based program developed by the project.

Means and standard deviations, or frequencies and percentages based on the patients' last review, were calculated for variables of interest. Student's *t*-tests, Chi-squared tests, or Fisher's exact test (as appropriate) were used to examine differences between men and women.

Ethical approval was obtained from the Southern Regional Health Authority Ethics Committee.

Results

At 31 December 2003, 4320 diabetic patients had ever been enrolled on the Otago Diabetes Register, of whom 509 (11.8%) were known to have died. Death certificate information was matched for 508 enrolees who had died, of whom 253 were females and 255 were males. Most people (96.1%) were of European descent, with 3.0% self-identifying as Maori. Of the 508 with matched death certificate information, 17 had type 1 diabetes, 482 had type 2 diabetes, and 9 had diabetes secondary to another condition or steroid medication. More than one-half (57.1%) of the patients died in a hospital. The proportion of males who died at their own home (22.4%) was higher than for women (13.0%). Other places of death were rest homes (17.9%), hospices (6.3%), and the community (1.0%).

For those with type 1 diabetes, 4 were females and 13 were males. Five people, all males, were aged less than 50 years at death and died in their own home. The immediate cause of death for three of these five males was diabetic ketoacidosis and the other two died from a hypoglycaemic event.

Table 1. Characteristics of patients with type 2 diabetes or diabetes secondary to another condition or steroid medication

Variable	Females (n=249)	Males (n=242)	Total (n=491)	Difference between males and females
	Mean (SD) or %	Mean (SD) or %	Mean (SD) or %	P value
Age at death (yrs)	78.6 (9.6)	77.5 (9.8)	78.1 (9.7)	0.21
Age at diagnosis (yrs)*	66.2 (12.4)	65.3 (11.6)	65.8 (12.0)	0.41
Duration diagnosed diabetes (yrs)*	12.4 (9.0)	11.8 (8.1)	12.1 (8.6)	0.44
Current smoker (%)	9.2	9.5	9.4	0.92
Ex-smoker (%)	36.9	71.5	54.0	0.00
<i>Treatments</i>				
Diet only (%)	25.7	26.9	26.3	0.77
OAs only (%)	50.2	46.3	48.3	0.39
Insulin only (%)	19.3	23.1	21.2	0.30
OAs and insulin (%)	4.8	3.7	4.3	0.55
ACE inhibitor (%)	55.0	52.9	54.0	0.64
Lipid lowering (%)	14.5	17.4	15.9	0.38
Other antihypertensives (%)	27.7	16.1	22.0	0.002

*Year of diagnosis values were missing for 16 females and 22 males; SD=standard deviation.

The characteristics of the 491 patients with type 2- or secondary-diabetes are shown in Table 1. Overall, the mean duration of diagnosed diabetes was about 12 years. Females were slightly older at both the time of diagnosis of diabetes and time of death compared with males. About one-quarter used insulin treatment prior to death, and a further one-quarter were being treated with diet only. Over one-half were prescribed an ACE inhibitor during the review year prior to death. A further 48 people (9.8%) had previously been prescribed an ACE inhibitor, but were no longer taking it. (Reasons for stopping their ACE inhibitor therapy were not recorded on the Otago Diabetes Register.) A statistically significant higher proportion of females were

prescribed antihypertensive treatments (excluding ACE inhibitors) compared with males ($p=0.0002$).

Diabetes was mentioned on the death certificates of 55.1% of all 508 diabetic patients. For seven people, diabetes was listed as the immediate cause of death. Diabetes was not recorded anywhere on the death certificate of one person with type 1 diabetes. People who died in hospital or their own home were more likely to have diabetes mentioned on their death certificate, 59% and 62% respectively, compared with those who died at other places: rest home (50%), hospice (31%), and community (40%).

Table 2 shows the clinical characteristics of those who had diabetes mentioned on their death certificate compared with those who did not have diabetes mentioned on their death certificate. Overall, the group with diabetes mentioned on their death certificate were younger at the time of diagnosis and duration of diabetes was about 5 years longer than those where diabetes was not mentioned. A significantly higher proportion of the group who did not have diabetes mentioned on their death certificate were using diet only treatment for glycaemic control compared with the group who had diabetes mentioned ($p=0.0$). The reverse was observed for insulin treatment ($p=0.001$). Similar proportions of each group used oral hypoglycaemic treatments.

Table 3 shows the immediate causes of death by major disease category as recorded on the death certificate. Almost 50% of deaths were due to a circulatory system disorder, either cardiovascular or cerebrovascular disease. Respiratory diseases and neoplasms were also frequent causes of death. A neoplasm was the cause of death for a significantly higher proportion of the group with no diabetes mentioned on the death certificate compared with the group with diabetes on the death certificate.

Table 2. Clinical characteristics of the group with diabetes mentioned on their death certificate and the group without diabetes mentioned on their death certificate

Variable	Diabetes on death certificate (n=280)		Diabetes <i>not</i> on death certificate (n=228)		Difference
	Number	Mean (SD) or number (%)	Number	Mean (SD) or number (%)	P value
Age at death (yrs)	280	77.6 (9.7)	228	77.4 (11.2)	0.82
Age at diagnosis (yrs)*	263	62.3 (14.8)	207	66.8 (12.8)	0.001
Diabetes duration (yrs)*	263	15.0 (11.5)	207	10.3 (7.5)	0.00
Diet only (%)		49 (17.5)		80 (35.1)	0.00
OH only (%)		132 (47.1)		105 (46.1)	0.93
Insulin only (%)		82 (29.3)		39 (17.1)	0.001
OH and insulin (%)		17 (6.1)		4 (1.8)	0.015
Diastolic BP (mmHg)†	274	74.3 (11.3)	222	75.5 (10.8)	0.23
Systolic BP (mmHg)†	274	134.5 (21.2)	222	137.3 (21.2)	0.15
HbA1c (%)†	264	7.4 (1.5)	216	7.0 (1.5)	0.004
Total cholesterol (mmol/L)†	160	5.3 (1.2)	136	5.5 (1.3)	0.20
HDL-cholesterol (mmol/L)†	158	1.06 (0.31)	134	1.2 (0.52)	0.002
Triglycerides (mmol/L)†	159	2.3 (1.6)	134	2.0 (1.2)	0.03

*Age at diagnosis was not recorded for 38 patients; †For some patients clinical measures or blood tests were not completed during the 12 months prior to death. OH=oral hypoglycaemics; BP=blood pressure; HDL=high-density lipoprotein; SD=standard deviation.

Table 3. Causes of death by major category for those with and without diabetes mentioned on the death certificate

Cause of death	Diabetes on death certificate (n=280)		Diabetes <i>not</i> on death certificate (n=228)		Total (n=508)		Difference
	N	(%)	N	(%)	N	(%)	P value
Infectious and parasitic	14	(5.0)	9	(3.9)	23	(4.5)	0.57
Neoplasms	22	(7.9)	45	(19.7)	67	(13.2)	0.00
Endocrine	7	(2.5)	0	(0.0)	7	(1.4)	0.02
Cardiovascular disease	111	(39.6)	90	(39.5)	201	(39.6)	0.97
Cerebrovascular	26	(9.3)	16	(7.0)	42	(8.3)	0.36
Respiratory	46	(16.4)	25	(11.0)	71	(14.0)	0.08
Gastrointestinal	10	(3.6)	13	(5.7)	23	(4.5)	0.25
Genitourinary	13	(4.6)	3	(1.3)	16	(3.1)	0.03
Other	35	(12.5)	23	(10.1)	58	(11.4)	0.40

Discussion

Under-reporting of diabetes on death certificates was recognised worldwide some time ago,⁴ but this practice continues.⁷ This study found that 45% of people with documented diabetes had no mention of diabetes on their death certificate. While this is consistent with a recent Christchurch study,⁵ some studies have found that as many as 73% of diabetic patients have diabetes mentioned at any level on the death certificate, but this was amongst an insulin treated diabetic population,¹ whereas other studies have found as few as 36% of death certificates amongst a diabetic population mention diabetes.⁷

The proper completion and accuracy of death certificates has been questioned in several countries, including New Zealand.^{15,16,17} Clinical diagnoses may be erroneous, but often little can be done about incorrect or unknown diagnoses. For known diseases, the sequence of events leading to death may be entered incorrectly on the certificate or important events omitted.⁹ Guidelines and calls to ensure that doctors complete certificates correctly have been made in many countries.^{16,17} In New Zealand, directions for completing death certificates are included on the front cover of each book of certificates, and detailed in a booklet published by NZHIS.¹⁸ As diabetes is not always the immediate, underlying, or contributing cause of death it will correctly not be recorded on the death certificate, but this is unlikely to be the explanation for the absence of diabetes on all 45% of the 508 death certificates that we examined.

The range of diseases known or thought to be associated with diabetes, including some cancers such as pancreatic, liver and more recently bowel cancer,^{19,20} may not always be recognised, and this may contribute to the under reporting of diabetes on death certificates. There may be other explanations. Nevertheless, because of the complex nature of diabetes, it has been suggested that diabetes should always be recorded on the death certificate of all those with this condition, regardless of whether it is considered to be the underlying or contributing cause of death.⁴

The most recent published mortality data for New Zealand shows that for the year 2000, 1455 people died in the Otago DHB region.²¹ From this study, it is known that

in 2000, at least 115 people with diabetes died (8% of the total number of deaths in the Otago region). This proportion could be an underestimate, as not all people with diabetes are enrolled on the Otago Diabetes Register and hence were not included in this study, and generally up to 50% of people with diabetes have not had the condition diagnosed.

The median age at death for this diabetic study population (79.6 years for females and 78.2 years for males) compares favourably with the median age at death for the general New Zealand population. For the 2000-2002 period, half of female deaths occurred at ages 81 years and over, and half of male deaths occurred at ages 75 years and over.²² A similar observation was noted using data from the Skaraborg Diabetes Registry, Sweden, where diabetic patients aged over 80 years had a survival similar to that of the background population,²³ as did a group of Scottish men who were aged over 65 years at the time type 2 diabetes was diagnosed.²⁴ This supports the suggestion that the onset of diabetes at an older age may not decrease life expectancy.²⁵ However, quality of life may be reduced, particularly if diabetes related complications are present. At the other end of the age spectrum, the deaths of 5 males with type 1 diabetes aged less than 50 years from diabetic ketoacidosis or hypoglycaemia was surprising and concerning.

The higher proportion of females prescribed antihypertensive medication (compared with males) was an unexpected finding, but it is consistent with results of the most recent New Zealand Health Survey which found that the prevalence of self reported hypertension was higher amongst females than males in the 65-74 and 75+ age groups.²⁶ Also, among patients aged over 60 years registered at Swedish primary health centres males had generally better blood pressure control (defined as less than 140 mmHg systolic and/or 85 mmHg diastolic) than females.²⁷

Cardiovascular disease was not unexpectedly the most common cause of death. While this study did not compare cardiovascular mortality rates between diabetic and general or non-diabetic populations, many studies have found that the death rate for cardiovascular disease (particularly ischaemic heart disease) is higher among diabetic populations compared with the general population.^{1,3,28} There is no reason why this would not be the case for the Otago region.

Diabetes prevalence is increasing worldwide, yet the impact on mortality cannot be accurately monitored. Under-reporting of diabetes on death certificates was recognised more than two decades ago, and this study found that this practice continues. If the impact of the diabetes epidemic on mortality is to be monitored appropriately in New Zealand, attention needs to be given to improving the completion of death certificates, including always recording diabetes when it is present, irrespective of whether it is considered to be the underlying or a contributing cause of death.

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Acknowledgements: The Otago Diabetes Project was funded through contracts with the following health funders: Southern Regional Health Authority, Health Funding

Authority, and Otago District Health Board. Additional funds were received from Novo Nordisk Pharmaceuticals Ltd to undertake this study.

We acknowledge the invaluable assistance of Phillipa Mann (Research Assistant), Claire Lamb (Project Nurse, Otago Diabetes Project), and Jane Smith (Team Leader, Medical Records and Coding, Dunedin Hospital). We thank all GPs, practice nurses, and diabetic patients who participated in the Otago Diabetes Project.

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References:

1. Riley MD, McCarty DJ, Couper DJ, et al. The 1984 Tasmanian insulin treated diabetes mellitus prevalence cohort: an eight and a half year mortality follow-up investigation. *Diabetes Res Clin Pract.* 1995;29:27–35.
2. Brown LJ, Scott RS, Moir CL. All-cause mortality in the Canterbury (New Zealand) insulin-treated diabetic registry population. *Diabetes Care.* 2001;24:56–63.
3. Roper NA, Bilous RW, Kelly WF, et al. Cause-specific mortality in a population with diabetes: South Tees diabetes mortality study. *Diabetes Care.* 2002;25:43–8.
4. Fuller JH, Elford J, Goldblatt P, Adelstein AM. Diabetes mortality: new light on an underestimated public health problem. *Diabetologia.* 1983;24:336–41.
5. Chen F, Florkowski CM, Dever M, Beaven DW. Death certification and New Zealand Health Information Service (NZHIS) statistics for diabetes mellitus: an under-recognised health problem. *Diabetes Res Clin Pract.* 2004;63:113–8.
6. Balkau B, Papoz L. Certification of cause of death in French diabetic patients. *J Epidemiol Community Health.* 1992;46:63–5.
7. Will JC, Vinicor F, Stevenson J. Recording of diabetes on death certificates. Has it improved? *J Clin Epidemiol.* 2001;54:239–44.
8. Jouglu E, Papoz L, Balkau B, et al. Death certificate coding practices related to diabetes in European countries--the 'EURODIAB Subarea C' Study. *Int J Epidemiol.* 1992;21:343–51.
9. Balkau B, Jouglu E, Papoz L and the Eurodiab Subarea C Study Group. European study of the certification and coding of causes of death of six clinical case histories of diabetic patients. *Int J Epidemiol.* 1993;22:116–26.
10. Lu TH, Walker S, Huang CN. It is not appropriate to record diabetes on death certificates for every patient. *Diabetes Res Clin Pract.* 2004;65:293–95.
11. Whittall DE, Glatthaar C, Knuiman MW, Welborn TA. Deaths from diabetes are under-reported in national mortality statistics. *Med J Aust.* 1990;152:598–600.
12. Goldacre MJ, Duncan ME, Cook-Mozaffari P, Neil HA. Trends in mortality rates for death-certificate-coded diabetes mellitus in an English population 1979-99. *Diabet Med.* 2004;21:936–39.
13. Coppel K, Manning P for the Otago Diabetes Team. Establishing a regional diabetes register and a description of the registered population after one year. *N Z Med J.* 2002;115(1160). URL: <http://www.nzma.org.nz/journal/115-1160/146>
14. ICD-10. International Statistical Classification of Diseases and Related Problems. Tenth Revision. World Health Organization; 1992.
15. Gwynne JF. Death certification in Dunedin Hospitals. *N Z Med J.* 1977;86:77–81.
16. Kircher T, Anderson RE. Cause of death. Proper completion of the death certificate. *JAMA.* 1987;258:349–52.

17. Brown SH, Frankovich M. How accurate are New Zealand death certificates? *N Z Med J*. 1998;111:321–22.
18. New Zealand Health Information Service. *A Guide to Certifying Causes of Death. A guide for doctors and coroners on the provision of information on deaths to the New Zealand Health Information Service*. Wellington: Ministry of Health; 2001.
19. Coughlin SS, Calle EE, Teras LR, et al. Diabetes mellitus as a predictor of cancer mortality in a large cohort of US adults. *Am J Epidemiol*. 2004;159:1160–7.
20. Khaw KT, Wareham N, Bingham S, et al. Preliminary communication: glycated hemoglobin, diabetes, and incident colorectal cancer in men and women: a prospective analysis from the European prospective investigation into cancer-Norfolk study. *Cancer Epidemiol Biomarkers Prev*. 2004;13:915–9.
21. New Zealand Health Information Service. *Mortality and Demographic Data 2000*. Wellington: Ministry of Health; 2004. Available online. URL: <http://www.nzhis.govt.nz/publications/mortality00.pdf> Accessed December 2004.
22. Statistics New Zealand. *New Zealand Life Tables 2000-2002 Commentary*. Available online. URL: <http://www2.stats.govt.nz/domino/external/pasfull/pasfull.nsf/7cf46ae26dcb6800cc256a6200a2248/4c2567ef00247c6acc256e660082356b?OpenDocument> Accessed December 2004.
23. Berger B, Stenstrom G, Sundkvist G. Incidence, prevalence, and mortality of diabetes in a large population. A report from the Skaraborg Diabetes Registry. *Diabetes Care*. 1999;22:773–8.
24. Tan HH, McAlpine RR, James P, et al. Diagnosis of type 2 diabetes at an older age: Effect on mortality in men and women. *Diabetes Care*. 2004;27:2797–9.
25. Croxson SCM, Price DE, Burden M, et al. The mortality of elderly people with diabetes. *Diabet Med* 1994;11:250–2
26. Ministry of Health. *A Portrait of Health: Key results of the 2002/03 New Zealand Health Survey*. Wellington: Ministry of Health; 2004. Available online. URL: <http://www.moh.govt.nz/moh.nsf/0/3d15e13bfe803073cc256eeb0073cfe6?OpenDocument> Accessed December 2004.
27. Nilsson PM, Theobald H, Journath G, Fritz T. Gender differences in risk factor control and treatment profile in diabetes: a study in 229 Swedish primary health care centres. *Scand J Prim Health Care*. 2004;22:27–31.
28. Morgan CL, Currie CJ, Peters JR. Relationship between diabetes and mortality. A population study using record linkage. *Diabetes Care*. 2000;23:1103–7.