

Reporting of diabetes on death certificates of 1872 people with type 2 diabetes in Tayside, Scotland

J. M. M. Evans¹, K. N. Barnett¹, M. E. T. McMurdo², A. D. Morris²

Background: It has been suggested that diabetes is under-recorded on death certificates. **Methods:** We examined the death certificates of 1,872 people with type 2 diabetes in Tayside, Scotland, to determine how frequently diabetes was recorded. **Results:** Diabetes was mentioned on the certificates of 42.8% and was the underlying cause of death for 6.4%. There was mention of diabetes for 51.3% of the 811 people for whom cardiovascular disease was the underlying cause of death. Being male was associated with less frequent mention of diabetes, with more frequent mention associated with increasing duration of diabetes, increasing age and underlying cardiovascular cause of death. **Conclusions:** This study highlights the limitations of using routine mortality data for monitoring the burden of diabetes in populations.

Keywords: diabetes, death certificates, routine data

Introduction

Routine data sources such as death certificates may be used to monitor the burden of morbidity on a population, but the limitations of such data must be recognized. It has been suggested that the under-reporting of diabetes on the death certificates of diabetic people in different countries means that the true impact of diabetes is being under-estimated.^{1,2} This may result in necessary resources not being allocated to prevention and treatment. Evidence shows that the proportion of death certificates with any mention of diabetes has remained consistently low over the past few decades, with analysis of temporal trends showing no improvement.³ In the United Kingdom Prospective Diabetes Study (UKPDS), 42% of death certificates of diabetic people mentioned diabetes;⁴ the figure was 36% in a London hospital.⁵ In the United States, 38% of deaths of 428 diabetic people between 1965 and 1974 had a mention of diabetes,⁶ the proportion was 38% in a sample from 1986,⁷ and still only 39% in a recent study.⁸ More frequent mention of diabetes has been associated with increased duration of diabetes and insulin treatment,⁸ and also increasing age, social class and a cardiovascular underlying cause of death.⁴ In this study, we evaluated recording of diabetes on death certificates among people in Tayside, Scotland (population ~388 000) who had had type 2 diabetes for up to 12 years.

Methods

We carried out this study using the data sources of the DARTS/MEMO Collaboration for the population of Tayside, in Scotland.⁹ This collaboration has developed the record linkage of routine health care databases in Tayside for epidemiological and health services research. The DARTS database is a register of every patient with type 1 and type 2 diabetes in Tayside, with detailed clinical information. Data on death

certification from the General Register office for Scotland is also available. This study was granted ethical approval from the Tayside Committee on Medical Research Ethics.

As part of a larger cohort study on mortality in diabetes, we examined the electronic recording of death certificates of people with type 2 diabetes who died between January 1994 and February 2005. They were from a cohort of people who were diagnosed with type 2 diabetes between January 1994 and December 2001. We determined the proportion of death certificates with diabetes or a complication of diabetes [International Classifications of Disease (ICD) 9 code 250; ICD10 codes E10–E14] as the underlying cause of death, the proportion with any mention of diabetes, and the proportion with cardiovascular disease as the underlying cause of death that had any mention of diabetes. For the death certificates coded with ICD10 codes, we also examined whether there were any instances of type 2 diabetes misclassified as type 1 diabetes (type 1 and type 2 diabetes are not classified separately using ICD9 codes).

We examined whether these proportions of mentions increased between 1993 and 2005. In a logistic regression analysis, we investigated whether the following variables were associated with any mention of diabetes on the death certificate: year of death, age at diagnosis, duration of diabetes, sex, underlying cause of death and an area-based measure of material deprivation (the Carstairs index).¹⁰ This measure was available for 1813 diabetic people only. If they were statistically significant (or borderline) univariately (with $P < 0.05$), variables were entered in to the final model. Analyses were performed using SPSS version 12.0.

Results

There were 11 125 people newly diagnosed with type 2 diabetes between 1994 and 2001. Of these, 1872 (16.8%) died in the follow-up period to February 2005. Diabetes or a complication of diabetes was noted as the underlying cause of death for 120 people (6.4% of total deaths). There was mention of diabetes for 682 of the people for whom diabetes was not the underlying cause of death (36.4%). In total, therefore, diabetes was mentioned on 42.8% of death certificates of all those who died. There were 811 people for whom cardiovascular disease was the underlying cause of death. Diabetes was mentioned on the death certificates of 416 (51.3%).

1 Division of Community Health Sciences, University of Dundee, Dundee, DD2 4BF, Scotland, UK

2 Division of Medicine and Therapeutics, University of Dundee, Dundee, DD1 9SY, Scotland, UK

Correspondence: Josie M. M. Evans, Section of Public Health, Division of Community Health Sciences, Mackenzie Building, Kirsty Semple Way, Dundee, DD2 4BF, Scotland, UK, tel: 01382 420108, fax: 01382 420101, e-mail: j.m.m.stansfield@dundee.ac.uk

Table 1 Results of logistic regression (mention of diabetes on death certificate is dependent variable)

	N	Total (%) with mention of diabetes	Unadjusted odds ratio (95% confidence intervals)	Adjusted odds ratio^a (95% confidence intervals)
Sex				
Females	883	398 (45.1)	1.00	1.00
Males	989	404 (40.8)	0.84 (0.70, 1.01)	0.84 (0.69, 1.01)
Age at diagnosis				
<45 years	26	5 (19.2)	1.00	1.00
45–54 years	100	42 (42.0)	3.04 (1.06, 8.72)	3.09 (1.06, 8.98)
55–64 years	322	130 (40.4)	2.84 (1.05, 7.73)	2.67 (0.97, 7.34)
65–74 years	628	288 (45.9)	3.56 (1.33, 9.55)	3.33 (1.23, 9.05)
>74 years	796	337 (42.3)	3.08 (1.15, 8.26)	2.85 (1.05, 7.71)
Duration of diabetes				
0–2 years	933	369 (39.5)	1.00	1.00
3–5 years	592	256 (43.2)	1.17 (0.95, 1.44)	1.31 (1.05, 1.65)
6–8 years	271	134 (49.4)	1.50 (1.14, 1.96)	1.67 (1.24, 2.24)
9+	76	43 (56.6)	1.99 (1.24, 3.19)	2.34 (1.42, 3.85)
Year of death				
1993–95	206	103 (50.0)	1.00	1.00
1996–98	281	113 (40.2)	0.67 (0.47, 0.97)	0.59 (0.40, 0.86)
1999–2001	475	201 (42.3)	0.73 (0.53, 1.02)	0.62 (0.44, 0.89)
2002–05	910	385 (42.3)	0.73 (0.54, 0.99)	0.58 (0.41, 0.81)
Underlying cause of death (UCD) cardiovascular				
No	1061	386 (36.4)	1.00	1.00
Yes	811	416 (51.3)	1.84 (1.53, 2.22)	1.82 (1.51, 2.20)
Deprivation category				
1 least deprived	90	36 (40.0)	1.00	–
2	351	144 (41.0)	1.04 (0.65, 1.67)	–
3	492	208 (42.3)	1.10 (0.70, 1.74)	–
4	206	104 (50.5)	1.53 (0.93, 2.53)	–
5	231	99 (42.9)	1.13 (0.69, 1.85)	–
6	297	121 (40.7)	1.03 (0.64, 1.67)	–
7 most deprived	146	61 (41.8)	1.08 (0.63, 1.84)	–

a: Adjusted for sex, age at diagnosis, duration of diabetes, year of death, whether UCD cardiovascular

In total, 1156 death certificates were coded with ICD10 codes. Of these, there were only two instances of the underlying cause of death coded as type 1 diabetes, and 17 instances of other mentions of diabetes misclassified as type 1 diabetes.

Table 1 shows the proportions of death certificates with a mention of diabetes, stratified by patient characteristics. The results of the logistic regression (with whether diabetes was mentioned on the death certificate as the dependent variable) are also shown. No association was found for deprivation category, and there was no evidence of a trend (χ^2 -test for trend $P=0.60$), so this was the only variable not entered in the final model. Men were less likely to have a mention of diabetes than women, with later year of death also associated with less frequent mention. The most frequent recording was noted for the earliest time period (1993–95). Mention of diabetes was independently associated with an increasing duration of diabetes, whether the underlying cause of death was cardiovascular, and with increasing age of diagnosis.

Discussion

This study shows that less than half of patients with type 2 diabetes in Tayside, Scotland, have any mention of diabetes on their certificate. This is not necessarily due to incomplete or incorrect recording. If, as Lu *et al.* pointed out,¹¹ diabetes does not contribute to the cause of death, it is not appropriate to include diabetes on the death certificate. Yet even among people with cardiovascular disease as the underlying cause of death, diabetes is only mentioned on half of certificates. Given the central importance of diabetes as a contributory risk factor to cardiovascular mortality, this does suggest that diabetes is being under-recorded, and there is no evidence of any

improvement over the past two decades. Note though that misclassification of type 2 diabetes as type 1 diabetes was not common on these death certificates.

This study was carried out among all patients with diabetes in a defined geographical population using validated data sources, and we are confident it is accurate. However, there were no patients in our study who had had diabetes for >12 years. This might explain why the proportion of people with an underlying cardiovascular cause of death was lower (43%) than that for the 981 participants of the UKPDS (56%).⁴ However, our results were similar to analyses of the certificates of these 981 people, with being male independently associated with decreased proportions of certificates mentioning diabetes. We also found that longer duration of diabetes was associated with more frequent mentions of diabetes, as were older age and a cardiovascular underlying cause of death. An association with duration was not evaluated in the UKPDS study but has been reported elsewhere.^{8,12}

This study therefore draws attention to groups for whom prevalence of diabetes might be under-estimated if relying on routine data sources such as death certificates. In particular, although the numbers involved were small, we noted low proportions of certificates mentioning diabetes where age of diagnosis was <45 years (worthy of note given the importance of monitoring the increasing incidence of type 2 diabetes among young people) and for patients with diabetes of short duration. It is essential that users of routine mortality data have a clear understanding of the concepts of cause of death coding. This study therefore adds to the body of evidence to guide public health practitioners in recognizing the limitations of death certification data to characterize diabetes and its mortality in populations.

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Conflicts of interest: None declared.

Key points

- The proportion of death certificates of diabetic people that have no mention of diabetes as a cause of death is high.
- Analyzing death certificates to estimate the burden of diabetes in a population is problematic.
- Recording of type 2 diabetes is particularly low among young people, and those who have been recently diagnosed.
- Public health practitioners must understand the limitations of routine data sources for monitoring the burden of disease in populations.

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