



Recording of Diabetes on Death Certificates of Decedents With Type 1 Diabetes in DCCT/EDIC

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Diabetes is frequently not recorded on the death certificates of decedents with type 2 diabetes (1). Less is known about the recording of diabetes for decedents with type 1 diabetes (2–4). We describe the recording of diabetes on death certificates for decedents with type 1 diabetes who participated in the Diabetes Control and Complications Trial (DCCT)/Epidemiology of Diabetes Interventions and Complications (EDIC) (ClinicalTrials.gov reg. nos. NCT00360815 and NCT00360893, respectively).

We investigated whether the word(s) “diabetes,” “diabetes mellitus,” “type 1 diabetes,” “type 2 diabetes,” or their abbreviations appeared as the underlying cause of death (last listed cause of death in part I of the death certificate) or anywhere on the death certificate. We defined end-stage renal disease, chronic renal failure, and diabetic ketoacidosis as diabetes-related underlying causes of death. Covariates included age and duration of diabetes at death, sex, race/ethnicity, education, last recorded treatment group, BMI, and smoking status at baseline. Study coordinators at each DCCT/EDIC site determined whether the person who signed the death certificate was the decedent’s primary care physician (PCP). The *t* test and χ^2 test were used to identify variables associated with recording diabetes.

By April 2016, 134 DCCT/EDIC participants had died. Death certificates were available for 95 (71%), and 91 recorded a cause of death. The characteristics of the 43 decedents without death certificates did not differ from the 91 with death certificates that recorded a cause of death. The characteristics of decedents are shown in Table 1.

Forty-four percent of decedents had diabetes recorded anywhere on the death certificate, and 16% had diabetes recorded as the underlying cause of death. Underlying causes of death are shown in Table 1. Diabetes was recorded anywhere on the death certificates for 57% of decedents who died of cardiovascular disease. When the underlying cause of death was cancer, none of the death certificates recorded diabetes. When suicide/accident/injury and “other” were the underlying causes of death, 18% and 17% of death certificates, respectively, recorded diabetes.

Older decedents were less likely to have diabetes recorded anywhere on the death certificate (Table 1). Seventy-five percent of decedents <40 years of age, 41% of those 40–49, 48% of those 50–59, and 13% of decedents ≥ 60 had diabetes recorded anywhere ($P = 0.0137$), and 50% of decedents <40 years of age, 13% of those 40–49, 15% of those 50–59, and

none who were ≥ 60 had diabetes recorded as the underlying cause ($P = 0.0044$).

If the PCP was the certifying physician, diabetes was more likely to be recorded on the death certificate (Table 1). The credentials of the certifier, place and time of death, and performance of an autopsy were not associated with recording of diabetes (Table 1).

Of decedents with diabetes recorded anywhere, 64% did not specify diabetes type, 33% had type 1 diabetes specified, and 3% had type 2 diabetes incorrectly specified. Only 27% of decedents with diabetes recorded as the underlying cause of death had type 1 diabetes specified.

In summary, diabetes was recorded anywhere on the death certificate for 44% of decedents with long-standing type 1 diabetes and as the underlying cause of death for 16% of decedents. These results are similar to those from a meta-analysis that assessed decedents with type 1 and type 2 diabetes (1) but lower than those from previous studies that focused on decedents with insulin-treated diabetes (58% of such decedents in the U.K. had diabetes recorded anywhere and 15% had diabetes recorded as the underlying cause of death) (2) and type 1 diabetes (84% of such decedents in Tasmania had diabetes recorded anywhere and 47% had diabetes recorded

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Table 1—Characteristics of DCCT/EDIC decedents with type 1 diabetes according to whether or not diabetes was recorded anywhere on the death certificate

	All decedents with T1D	Decedents with diabetes recorded anywhere	Decedents with diabetes not recorded anywhere	P value
Number (%)	91 (100)	40 (44)	51 (56)	
Underlying cause of death†				<0.0001
Cardiovascular	28 (31)	16 (57)	12 (43)	
Cancer	21 (23)	0 (0)	21 (100)	
Diabetes-related	18 (20)	18 (100)	0 (0)	
Suicide/accident/injury	11 (12)	2 (18)	9 (82)	
Respiratory/infection/sepsis	7 (8)	3 (43)	4 (57)	
Other	6 (7)	1 (17)	5 (83)	
Age at death (years)	51 ± 9	48 ± 8	54 ± 9	0.0032*
Duration of diabetes at death (years)	28 ± 8	26 ± 7	29 ± 8	0.1711
Sex				0.6799
Female	34 (37)	14 (35)	20 (39)	
Male	57 (63)	26 (65)	31 (61)	
Race/ethnicity				0.2008
White	87 (96)	37 (93)	50 (98)	
Nonwhite	4 (4)	3 (8)	1 (2)	
Education				0.3304
< College	54 (59)	26 (65)	28 (55)	
≥ College	37 (41)	14 (35)	23 (45)	
Cigarette smoker	26 (29)	14 (35)	26 (65)	0.2293
BMI at baseline (kg/m ²)	24 ± 3	23 ± 3	24 ± 3	0.1030
Last recorded treatment method				0.4262
Pump	12 (13)	4 (10)	8 (16)	
Injections	79 (86)	36 (90)	43 (84)	
PCP as certifier				0.0325*
No	67 (89)	24 (80)	43 (96)	
Yes	8 (11)	6 (20)	2 (4)	
Certifier type				0.3978
Physician	42 (56)	18 (55)	24 (57)	
Medical examiner	25 (33)	13 (39)	12 (29)	
Coroner	8 (11)	2 (6)	6 (14)	
Medical examiner contacted				0.8990
No	28 (44)	12 (43)	16 (44)	
Yes	36 (56)	16 (57)	20 (56)	
Place of death				0.3290
Residence	28 (38)	13 (37)	15 (39)	
Hospital	30 (41)	17 (49)	13 (34)	
Other	15 (21)	5 (14)	10 (26)	
Time of death				0.8213
8 A.M.–5 P.M.	29 (48)	13 (50)	16 (47)	
5 P.M.–8 A.M.	31 (52)	13 (50)	18 (53)	
Autopsy performed				0.8484
No	51 (74)	24 (75)	27 (73)	
Yes	18 (26)	8 (25)	10 (27)	

Data are frequency (percent) or mean ± SD, unless otherwise indicated. T1D, type 1 diabetes. **P* < 0.05. †When stratified by recording of diabetes anywhere, row percents are shown.

as the underlying cause of death) (3). A German study reported that 71% of decedents with physician-diagnosed type 1 diabetes had diabetes recorded anywhere (4).

As in our study, prior studies have found that diabetes is recorded more frequently when cardiovascular disease

is the underlying cause of death and less frequently when the underlying cause of death is cancer (2,4). None of the previous studies examined whether type 1 diabetes was correctly specified. We found that when diabetes is recorded, type 1 diabetes is correctly specified only 33% of the time. Consistent with our previous study

of decedents with type 2 diabetes (5), we found that PCP certifiers are more likely to record diabetes, suggesting that they are more familiar with the decedents' medical histories.

While diabetes is known to be underreported on death certificates, we did not find that diabetes was more likely to be recorded for decedents with type 1 diabetes. Because of this substantial underreporting, analyses of death certificates alone will underestimate mortality among people with type 1 diabetes. Cohort studies are most appropriate to describe mortality in people with type 1 diabetes.

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such, had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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