Diabetes Reporting as a Cause of Death

Results from the Translating Research Into Action for Diabetes (TRIAD) study

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OBJECTIVE — To determine the frequency of reporting of diabetes on death certificates of decedents with known diabetes, define factors associated with reporting of diabetes, and describe trends in reporting over time.

RESEARCH DESIGN AND METHODS — Data were obtained from 11,927 participants with diabetes who were enrolled in the Translating Research Into Action for Diabetes study, a multicenter prospective observational study of diabetes care in managed care. Data on decedents ($n = 540$) were obtained from the National Death Index. The primary dependent variable was the presence of ICD-10 codes for diabetes on the death certificate. Covariates included age at death, sex, race/ethnicity, education, income, duration of diabetes, type of diabetes, diabetes treatment, smoking status, and number of comorbidities.

RESULTS — Diabetes was recorded on 39% of death certificates and as the underlying cause of death for 10% of decedents with diabetes. Diabetes was significantly less likely to be reported on the death certificates of decedents with diabetes dying of cancer. Predictors of recording diabetes anywhere on the death certificate included longer duration of diabetes and insulin treatment. Longer duration of diabetes, insulin treatment, and fewer comorbidities were associated with recording of diabetes as the underlying cause of death.

CONCLUSIONS — Diabetes is much more likely to be reported on the death certificates of diabetic individuals who die of cardiovascular causes. Reporting of diabetes on death certificates has been stable over time. Death certificates underestimate the prevalence of diabetes among decedents and present a biased picture of the causes of death among people with diabetes.

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Death certificates are commonly used to rank leading causes of death, estimate all-cause and cause-specific mortality, and describe trends in mortality over time (1–3). Each year the National Center for Health Statistics publishes a report on the leading causes of death in the U.S. and years of life lost (4–6). These data are used by agencies such as the National Institutes of Health and the Centers for Disease Control and Prevention to define the burden of disease in the U.S. and to determine funding levels (7).

There are three ways that diabetes can be recorded on a death certificate (8). In part I, diabetes may be recorded as either the underlying cause of death or as an antecedent condition, and in part II, diabetes may be recorded as a significant condition contributing to death but not resulting in the underlying cause given in part I (10). National mortality estimates are based on a simple analysis of the underlying cause of death listed on death certificates.

There are many problems related to the reliability and validity of cause-of-death information on death certificates. These problems arise from inaccuracy of diagnosis, variation in interpreting causal sequences and conditions contributing to death, changing perceptions of the causal role of diseases, variations in nosological coding, lack of training in death certificate completion, and improper completion of death certificates (8,9). Coding of cause of death is especially problematic when a decedent has multiple chronic conditions because a single disease may not adequately describe the cause of death.

Clearly, not everyone with diabetes dies of diabetes. Studies dating back to the 1970s have shown that diabetes is often not recorded as a cause of death for people with diabetes (8,9,11–21). For decedents with a history of diabetes, diabetes was listed anywhere on the death certificate only 38% of the time in 1986 and 36% of the time in 1993 (16,17).

Individuals who have diabetes recorded as a cause of death may not be representative of all decedents with diabetes. For example, in the National Health and Nutrition Examination Survey I Epidemiologic Follow-up Study, diabetes was recorded as an underlying cause of death among women with diabetes (21%) more frequently than among men with diabetes (7%) (22). Hispanic or Latino heritage may also be associated with more frequent recording of diabetes on death

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Abbreviations: NDI, National Death Index; TRIAD, Translating Research Into Action for Diabetes.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

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certificates, especially when the death is due to cardiovascular disease (8,23).

Will et al. (17) have hypothesized that diabetes reporting on death certificates may improve because of the increasing prevalence of diabetes, highly publicized results of major clinical trials, and increased media coverage of diabetes. To determine the frequency of reporting of diabetes on death certificates of decedents with known diabetes, the factors associated with more complete reporting of diabetes, and whether recording practices have changed over time, we examined the reporting of diabetes on death certificates in the Translating Research Into Action for Diabetes (TRIAD) study, a multicenter prospective observational study of diabetes care in managed care.

RESEARCH DESIGN AND METHODS

— TRIAD has been described in detail elsewhere (24). In brief, six Translational Research Centers collaborated with 10 managed care health plans and 68 provider groups that serve ~180,000 people with diabetes. The health plans are geographically and ethnically diverse (Hawaii, California, Texas, Indiana, Michigan, Pennsylvania, and New Jersey). The TRIAD study population consists of a stratified, random sample of adults with diabetes from the patient populations of these health plans. Study participants were ≥18 years of age, were community-dwelling, were not pregnant, were English- or Spanish-speaking, and had been continuously enrolled in the health plan for at least 18 months and had made at least one claim for health services during the previous 18 months. Participants were sampled from provider groups that had at least 50 participants with diabetes enrolled in the health plan. Recruitment began in 1999 and was completed in September 2001. The study protocol was reviewed and approved by the institutional review boards at all six Translational Research Centers. All participants provided informed consent.

We used a survey to collect information from TRIAD participants. The survey was administered by computer-assisted telephone interview or in writing by mail. We also reviewed medical records. We obtained information on TRIAD decedents from National Death Index (NDI) Plus searches (25). All deaths were verified by matching name, social security number (available for ~52% of participants), date of birth, and sex of the decedent with data supplied by the NDI. The sensitivity of NDI has been shown to range from 87 to 98% (26). Different combinations of identifiers excluding social security number correctly identify 83–92% of deceased individuals and 92–99% of living individuals, making NDI an accurate source of ascertaining vital status even without social security number (27).

Vital status was determined for all TRIAD participants (n = 11,927) as of 1 January 2003. All information regarding ICD-10 codes for the underlying and contributing causes of death were derived from the NDI file. For our analyses, we included all TRIAD participants (n = 11,927), 540 (4.5%) of whom were identified through NDI, as having died before 1 January 2003.

Main outcome measures and covariates

We used the American Heart Association definitions to group causes of death according to underlying cause (28). We investigated two dichotomous dependent variables: the presence of diabetes as defined by ICD-10 codes E10–E14 on the death certificates as either the underlying cause of death or as a cause appearing anywhere on the death certificate. Covariates included age at death, sex, race/ethnicity, education, income, age at diagnosis of diabetes, duration of diabetes, type of diabetes, diabetes treatment, smoking status, and number of comorbidities. Type 1 diabetes was defined by insulin use (without the use of oral antidiabetic agents) and age at diagnosis of diabetes ≤30 years; all others were defined as having type 2 diabetes (29). Number of comorbidites was defined using the Charlson index, a weighted measure of comorbid conditions associated with mortality (30). The Charlson Index has been extensively studied and provides an accurate and valid measure of comorbidity (31).

Statistical analyses

Bivariate analyses were performed for all-cause mortality and separately for cardiovascular (ICD-10 codes I00–I99) and noncardiovascular mortality (all other ICD-10 codes). Unadjusted odds ratios were constructed using each variable singularly in a logistic model predicting either diabetes as the underlying cause of death or diabetes listed anywhere on the death certificate.

To simultaneously adjust for covariates that predict the recording of diabetes on death certificates, we constructed multivariable models. We modeled diabetes as the underlying cause of death, and diabetes listed anywhere on the death certificate separately. We also modeled diabetes listed anywhere on the death certificate separately for cardiovascular and noncardiovascular causes. Single imputations were generated for missing values for covariates from the TRIAD patient survey using the transcan function in S-PLUS edition 6.1 (Insightful, Seattle, WA). Variables obtained through chart review were not imputed. For multivariable analyses, we excluded all TRIAD decedents who did not consent to medical record review (n = 173, 32%, excluded). Those who were excluded from the multivariable models were more likely to be nonwhite, to have less education, and to not use insulin for diabetes treatment. Before constructing the models, we assessed a correlation matrix with exposure variables. Age at diagnosis of diabetes, duration of diabetes, type of diabetes, and age at death were correlated at Spearman's r >0.5. To decrease colinearity between predictors in the multivariable models, we only included duration of diabetes because it had the strongest bivariate association with each outcome. Although education and income were correlated at Spearman's r >0.5, we included both in the multivariable models because they may have different predictive properties when modeling health-related outcomes (32).

In constructing the models, we used multivariable logistic regression, first including the variables that were found to be significant in bivariate tests of association between predictors and outcomes. For models of diabetes listed anywhere on the death certificate, we had a large sample size and were able to include variables that were significantly associated with mortality in previous studies (sex and race/ethnicity) (22,23,33) and variables that might explain the differences previously seen in mortality by race/ethnicity (education and income) or variables that might account for the differences seen in bivariate tests of association (Charlson index and smoking). For models of diabetes as the underlying cause of death and for models of diabetes as any listed cause separated by cardiovascular and noncardiovascular causes, sample size was smaller and we included only duration of diabetes, treatment for diabetes, and Charlson Index. All models included variables for TRIAD site to account for possible geo-

Table 1—*Distribution of underlying causes of death for TRIAD decedents (n = 540) and odds ratio (95% CI) of recording diabetes anywhere on the death certificate using cardiac causes as the reference group, 2000–2002*

Underlying cause of death	ICD-10 codes	Percent of deaths by underlying cause of death	Odds ratio of having diabetes recorded anywhere	Lower 95% CI	Upper 95% CI
Cardiac	I00–09, I11, I13, I20–25, I27, I30–52	36%	1.00	—	—
Cancer	C00–99	21%	0.43*	0.25	0.73
Other	all other	12%	0.56	0.30	1.03
Diabetes	E10–14	10%	—	—	—
Cerebrovascular disease	I60–69	6%	0.71	0.32	1.59
Respiratory	J00–09, J19–99	5%	0.89	0.54	2.33
All other cardiovascular disease	I10, I12, I14–19, I28–29, I53–59, I70–99	3%	1.16	0.42	3.25
Accidents, suicide, assault	V00–99, W00–99, X00–99, Y00–99	2%	0.27	0.06	1.26
Infections	A00–99, B00–99	2%	0.27	0.06	1.26
Renal failure	N17–19	2%	0.33	0.07	1.58
Influenza and pneumonia	J10–18	1%	0.75	0.13	4.18

$^*P \leq 0.05$.

graphic or organizational differences in reporting diabetes on death certificates. In separate analyses, we used hierarchical logistic regression models (SAS GLIMMIX Macro with penalized quasi-likelihood estimation method [34]) with random intercepts for health plans and provider groups to account for the clustered study design (health plan, provider group, and participant levels) and the correlation among participant characteristics within health plans and provider groups. We did not find significant clustering at any level, so the results are not shown.

All analyses were performed using SAS version 8.02 (Research Triangle Institute, Research Triangle Park, NC).

RESULTS — Ten percent of decedents had diabetes recorded as the underlying cause of death, and 39% had diabetes recorded anywhere on their death certificates. Table 1 shows the distribution of underlying causes of death and the odds of recording diabetes anywhere on the death certificate by underlying cause of death. Compared with dying of cardiac disease, diabetes was recorded more frequently for those who died of all other cardiovascular disease, although this difference was not statistically significant. The more frequent recording of death due to all other cardiovascular disease was driven by those who died of hypertension or hypertensive renal disease, of whom 80% had diabetes recorded on the death certificate. For all other causes of death, diabetes was reported less frequently than it was for cardiac disease. This result was statistically significant only when the cause of death was cancer (Table 1).

The unadjusted characteristics associated with recording diabetes as the underlying cause of death were treatment with insulin and having fewer comorbidities (Table 2). The only factors that were significantly associated with recording diabetes anywhere on the death certificate were treatment with insulin and diabetes duration 5–14 years and ≥15 years (Table 2).

When we looked only at those who died of cardiovascular causes, no unadjusted characteristics were significantly associated with recording of diabetes anywhere on the death certificate. Among people who died of noncardiovascular causes, only treatment with insulin was significantly associated with recording of diabetes.

In multivariable analyses of underlying cause of death, longer duration of diabetes and having fewer comorbidities were associated with the recording of diabetes (Table 2). In multivariable analyses of all-cause mortality, we found that recording of diabetes anywhere on the death certificate was only associated with longer duration of diabetes (Table 2).

In models of cardiovascular mortality, no variables predicted recording of diabetes anywhere on the death certificate. In models of noncardiovascular mortality, longer duration of diabetes was associated with the recording of diabetes anywhere on the death certificate (Table 2).

CONCLUSIONS — Attribution of death to diabetes is often a subjective judgment on the part of certifying physicians (10). Physicians may not record diabetes on the death certificates of decedents because they may not have known that the decedent was diagnosed with diabetes before death, may not have believed that diabetes contributed to the decedent's death, or may not have listed diabetes because of space constraints. The standard death certificate includes only three to four lines for part I and one to two lines for part II. People with diabetes may have multiple chronic conditions such as hypertension, dyslipidemia, cardiovascular disease, and renal disease, which may compete with diabetes for space on the death certificate.

The results of our study that used knowledge of physician-diagnosed diabetes to determine diabetes status are consistent with those of previous studies that used data from the 1986 and 1993 National Mortality Follow-Back Survey and information from next of kin or personal informants. We found that 10% of diabetic decedents had diabetes recorded as the underlying cause of death, and 39% had diabetes recorded anywhere on their death certificates. Earlier studies found that 10 and 11% of diabetic decedents had diabetes recorded as the underlying cause of death, and 38 and 36% had diabetes recorded anywhere (16,17). Al-

Table 2—*Factors associated with the recording of diabetes on death certificates and ORs and their associated 95% CIs in the TRIAD decedent population, 2000–2002*

Characteristic	Entire cohort of deceased subjects	Diabetes listed as the underlying cause of death on death certificate (%)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Diabetes listed anywhere on death certificate (%)	Unadjusted OR (95% CI)	Fully adjusted OR (95% CI)	Adjusted OR (95% CI) for those who died of CVD causes predicting diabetes listed anywhere on death certificate	Adjusted OR (95% CI) for those who died of non-CVD causes predicting diabetes listed anywhere on death certificate
n	540			367			367	164	203
Age at death (mean)	70.3	—	0.99 (0.96–1.01)	†	—	1.01 (0.99, 1.02)	*	†	†
Sex (Referent: Male)									
Female	47	8	0.71 (0.40–1.27)	†	37	0.88 (0.62–1.24)	0.77 (0.49–1.23)	†	†
Race (referent: white)				†				†	†
Hispanic	14	11	1.16 (0.50–2.69)		38	0.98 (0.57–1.67)	0.74 (0.33–1.65)		
Black	23	13	1.39 (0.71–2.71)		40	1.09 (0.71–1.69)	1.32 (0.70–2.48)		
Other	16	6	0.58 (0.22–1.58)		37	0.94 (0.57–1.55)	1.62 (0.69–3.82)		
Education (referent: some high school or less)				†				†	†
High school graduate	26	10	1.23 (0.60–2.53)		39	1.08 (0.69–1.68)	0.98 (0.54–1.77)		
College	35	11	1.24 (0.63–2.41)		41	1.18 (0.78–1.76)	1.08 (0.59–2.00)		
Income (referent: <$15,000)				†				†	†
$15,000-$40,000	34	7	0.65 (0.33–1.28)		37	0.91 (0.61–1.34)	0.84 (0.49–1.44)		
≥$40,000	18	13	1.21 (0.59–2.50)		40	1.04 (0.64–1.67)	1.54 (0.75–3.15)		
Age at diabetes diagnosis (referent: <30 years)				†			*	†	†
≥30 years	93	10	0.92 (0.31–2.70)		38	0.85 (0.44–1.66)			
Duration of diabetes (referent: <5 years)									
5–14 years	42	11	1.87 (0.74–4.73)	5.68 (1.26–25.55)	41	1.90 (1.14–3.18)	2.31 (1.16–4.59)	0.74 (0.27–2.03)	6.50 (2.27–18.65)
15+ years	39	11	1.93 (0.76–4.89)	4.16 (0.88–19.73)	42	1.94 (1.16–3.37)	2.12 (1.02–4.40)	0.77 (0.28–2.14)	5.53 (1.80–17.03)
Type of diabetes (referent: type 2 diabetes)				†			*	†	†
Type 1 diabetes	4	14	1.56 (0.45–5.50)		62	2.70 (1.10–6.63)			

Diabetes treatment (referent: non-insulin)													
Insulin (any)	43	13	1.84(1.04–3.26)	1.22	(0.59–2.53)	45	1.65(1.16–2.34)	1.46	(0.91–2.36)	1.44	(0.71–2.92)	1.44	(0.76–2.76)
Smoker (referent: nonsmoker)				†						†		†	
Yes	19	9	0.87(0.41–1.84)			33	0.76(0.48–1.20)	0.82	(0.46–1.46)				
Charlson index (mean)	4.02	—	0.80(0.67–0.97)	0.78	(0.65–0.95)	—	0.95(0.87–1.04)	0.94	(0.85–1.04)	0.94	(0.80–1.09)	0.94	(0.82–1.08)
R^2				0.0614				0.0605		0.0318		0.1055	
Hosmer-Lemeshow goodness-of-fit *P* value				0.0856				0.4638		0.1258		0.2946	

*Not included in the fully adjusted model due to high collinearity with other variables in the model. †Not included in the adjusted model because of small cell sizes. CVD, cardiovascular disease; OR, odds ratio.

though those studies hypothesized that the frequency of recording of diabetes on death certificates would increase, results from our study suggest that the frequency of recording has remained constant despite an increase in the prevalence of diabetes since 1986 (17).

In our study, we were able to ascertain more factors from the decedents and from their medical records before death to investigate predictors of recording. These factors included race/ethnicity, education, income, diabetes treatment, smoking status, and number of comorbidities. Using these in multivariable models, we found that longer duration of diabetes consistently predicted recording diabetes as the underlying cause of death and as a cause of death anywhere on the death certificate for both all-cause mortality and noncardiovascular causes of death. Insulin treatment and having fewer comorbidities were also associated with the reporting of diabetes. This finding suggests that more severe diabetes and having fewer comorbidities are likely to trigger the physician to list diabetes as a cause or contributor to death.

Recording of diabetes on death certificates was most frequent when the cause of death was cardiac, highlighting the well-recognized association between diabetes and cardiovascular disease. Nevertheless, only 39% of diabetic patients dying of cardiovascular disease had diabetes recorded anywhere on their death certificates. Diabetes was significantly less likely to be recorded on death certificates when the cause of death was cancer. National statistics that have used the recording of diabetes on death certificates as an indicator of comorbid diabetes in patients with cancer suggest that individuals with diabetes do not die of cancer as frequently as individuals without diabetes. In a recent publication, Coughlin et al. (35) demonstrated that diabetes may contribute to the development of cancer and that diabetes is an independent predictor of mortality from cancer of the colon, pancreas, female breast, and, among men, of the liver and bladder. Our results, and the realization that death certificates of decedents with cancer are less likely to report diabetes, highlight the need for careful studies of cancer in people with diabetes.

Certainly diabetes is not a cause of or a contributor to death in all decedents with diabetes. Death certificates are intended to record and count events, but people often use them as a tool to measure the burden of disease (3,5,7). Unfortunately, diabetes mortality rates based on death certificates fail to account for all deaths among people with diabetes. Using death certificates to define whether a decedent had diabetes thus underestimates mortality in all people with diabetes and presents a biased perspective on causes of death in people with diabetes. These problems are less of an issue in cohort studies that define diabetes status before death and so cohort studies may be the preferred design for studying diabetes mortality.

At least two limitations were present in our study. First, we limited our multivariable analyses to decedents who consented to medical record review, which excluded 32% of decedents. Those who were excluded from the multivariable models were more likely to be nonwhite, have less education, and not use insulin for diabetes treatment. When multivariate models were run for all decedents but excluded variables obtained from the medical record review, the results were not substantially changed. Second, we studied only managed care enrollees, and our findings may not extend to other populations. Indeed, our finding that <50% of diabetic subjects died of cardiac, cerebrovascular, or other cardiac disease (compared with 65% in other studies [8]) may reflect better access to care and better risk factor control in managed care.

Adding a series of check boxes for common conditions of interest (similar to those on a clinical encounter form) would likely improve recording of diabetes as a coexistent condition on death certificates (9). Without such an intervention, death certificates alone are not a good source of data to estimate the strength of associations between the presence of diabetes and specific causes of death. Similarly, death certificates probably do not provide a valid basis for determining the effect of diabetes on life expectancy, since the average age at death may differ by causes for which the completeness of recording of diabetes may differ. In conclusion, death certificates underestimate the prevalence of diabetes among decedents and present a biased picture of the causes of death among people with diabetes.

APPENDIX

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Significant contributions to this study were made by members of the TRIAD study group (see APPENDIX). The authors acknowledge the participation of our health plan partners.

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