The Accuracy of a Death Certificate Checkbox for Diabetes: Early Results from New Jersey

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SYNOPSIS

Objectives. The rapid growth in diabetes prevalence has increased interest in measuring the burden of this disease. One response has been to add a checkbox for diabetes status to the death certificate, which New Jersey did in 2004. This study assessed the accuracy of the diabetes checkbox and its effect on cause-of-death coding. We analyzed whether a diabetes checkbox is a useful addition to the death certificate.

Methods. We examined the trend in cause-of-death coding for diabetes as an underlying and contributing cause of death by analyzing New Jersey mortality data between 1990 and 2005. We assessed the accuracy of the checkbox by examining inconsistencies between cause-of-death coding and checkbox status, and assessed sensitivity by analyzing linked hospital and death data for a cohort of decedents with diabetes.

Results. Between 2003 and 2005, there was approximately a 15% increase in the number of deaths listing diabetes as a contributing cause. The number of deaths where diabetes was listed as an underlying cause changed little. Approximately 10% of death certificates had an inconsistency between cause of death and checkbox status. The sensitivity analysis showed that approximately 40% of diabetic decedents had the appropriate checkbox status.

Conclusion. The addition of the checkbox was accompanied by a change in the reporting of diabetes as a contributing cause of death. Results from the sensitivity analysis raise questions about the accuracy of the checkbox as a measure of the diabetic status of decedents.

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Given the recent growth in the prevalence of diabetes, there is great interest in understanding the true health burden of this disease.[1,2] With respect to mortality, there is a widespread belief that the burden of diabetes is underestimated.[3,4] Because diabetes is not listed as either an underlying or contributing cause of death (COD) for many decedents who had the condition, the full potential impact of diabetes on mortality is not well understood. This notion has been confirmed in analyses of linked datasets, such as the National Health Interview Survey/National Death Index (NHIS/NDI) file, in which the COD codes are analyzed for decedents who had previously self-reported having diabetes. Approximately 60% of self-reported diabetics did not have any mention of diabetes on their death certificates, while about 14% listed diabetes as an underlying cause.[5] An earlier study found only 10% of diabetic decedents had diabetes listed as an underlying COD.[6]

One response to this potential undermeasurement of the mortality burden of diabetes has been to add a checkbox to the death certificate, which would indicate whether or not the decedent had diabetes. The purpose of this checkbox is to improve measurement of mortality among diabetics. This can occur in two ways: (*1*) by improving the quality of reporting of diabetes as an underlying or contributing COD, and (*2*) by providing a measure of the prevalence of diabetes among decedents regardless of COD, which would allow the calculation of mortality rates from all or selected causes by diabetic status.

In 1992, North Dakota was the first state to add a checkbox for diabetes to its death certificate.[7] Kentucky added two checkbox items in 2002, and New Jersey added a checkbox in 2004. While some diabetes advocacy groups support national adoption of the checkbox, this position has been opposed. There are general concerns about adding excessive numbers of checkboxes to the death certificate, as there are currently checkboxes for tobacco use and pregnancy status. Additionally, it is possible that the diabetes checkbox may not actually improve the quality of information about the mortality burden of diabetes.[5] This could occur if the presence of a checkbox led to increased inaccuracies in COD coding for diabetes (e.g., if the checkbox is mistakenly used in lieu of coding diabetes as a COD, or if the presence of the checkbox leads to excessive coding of diabetes as a COD), or if the diabetes checkbox proved to be an inaccurate measure of the prevalence of diabetes among decedents.

To determine whether a checkbox for diabetes is a desirable addition to death certificates, it is necessary to consider both its impact on COD reporting and its accuracy as a measure of the prevalence of diabetes among decedents. It is also important to examine whether the effect on COD reporting and the accuracy of the checkbox vary significantly by race/ethnicity, age, or gender to assess whether the addition of a checkbox is likely to enhance or distort our understanding of disparities in diabetes.

A diabetes checkbox would theoretically function to remind physicians filling out the death certificate to think about whether the decedent had diabetes. An expected result of adding a diabetes checkbox would be an increase in the number of deaths with any mention of diabetes. Yet, in the absence of a gold standard, it is difficult to know whether such a change would represent an improvement in quality. One paradoxical outcome is that the presence of a diabetes checkbox may lead certifiers to substitute the checkbox for the listing of diabetes as a COD, particularly in Part II of the death certificate. The checkbox is not an appropriate substitute for listing diabetes as a COD, as an affirmative response to the checkbox does not provide information on how or whether diabetes was a COD. Only items listed in Parts I and II of the death certificate are counted as CODs.

Kentucky added a checkbox that had two questions: one asked whether the decedent had diabetes, and a second asked whether diabetes was "an immediate, underlying, contributing cause of or condition leading to death." After introducing the checkbox, overall reporting of diabetes as a COD declined. Deaths reported in Part I increased slightly from 2002 to 2003 (1,487 to 1,562), while deaths reported in Part II declined significantly (1,711 to 1,488). This disparity seems largely due to the inclusion of the second question of the checkbox.[5] In North Dakota, which introduced a diabetes checkbox in 1992, but without the second question used in Kentucky, the reporting of diabetes as a contributing COD increased.[7]

Another argument for adding the diabetes checkbox to the death certificate is that it allows the calculation of death rates from various causes for diabetics. Using prevalence information estimated from surveys such as the Behavioral Risk Factor Surveillance System (BRFSS) or the NHIS as a denominator, it would be possible to examine whether rates of death from a variety of causes are higher among diabetics than non-diabetics. Better knowledge of the prevalence of diabetes, particularly among decedents, could lead to new understandings about the more general impact of diabetes on health.[8] For example, in North Dakota the checkbox has been used to analyze mortality among diabetics in several studies.[3,7] Yet, the value of such analyses depends largely upon the accuracy of the checkbox in measuring the prevalence of diabetes among decedents. An

examination of accuracy is an important aspect of assessing the usefulness of a checkbox for diabetes.

METHODS

New Jersey's diabetes checkbox is intended to be completed by the certifier, who is responsible for the other medical portions of the death certificate. The certifier must be a physician. The diabetes checkbox asks the question, "Did the decedent have diabetes?" Possible options for the checkbox are "yes," "no," and "unknown." The checkbox can also be left blank. To examine the potential effect of the addition of a checkbox for diabetes to the New Jersey death certificate on COD coding, we compared the New Jersey trend in diabetes death with the national trend. For this analysis, we used the National Center for Health Statistics' Multiple Cause of Death file for the years 1990–2005.

Additionally, we used two methods to estimate the sensitivity of the diabetes checkbox. We analyzed the consistency between the checkbox and COD coding for decedents with a mention of diabetes on their death certificates. This analysis used New Jersey death data from 2004 and 2005. We estimated sensitivity by calculating the proportion of decedents with any mention of diabetes who had a checkbox status of "yes." In this section, we estimated multivariate logistic regression to see whether sensitivity varied by gender, race/ethnicity, or place of death. Additionally, we calculated a measure of sensitivity by linking a cohort of hospitalized patients with a diagnosis of diabetes to their death certificates. For this analysis, we used New Jersey hospital discharge data (UB-92) to identify a cohort of patients hospitalized in 2004 and 2005 with a diagnosis related to diabetes, using International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code 250. We linked this cohort to their death certificates, and estimated sensitivity by calculating the proportion with a checkbox status of "yes."

RESULTS

Trend in diabetes as a COD

One way to examine the impact of the diabetes checkbox on COD coding is to compare trends in diabetes mortality in New Jersey with the U.S. as a whole. New Jersey used the checkbox for the first time in 2004. In that year, 2,595 deaths in New Jersey had diabetes coded as the underlying COD. This figure represents an increase of 111 deaths from 2003. In 2005, there were 2,540 deaths where diabetes was listed as the underlying COD. Table 1 shows age-adjusted mortality rates from diabetes by race/ethnicity in New Jersey between 1990 and 2005. As can be seen in Figure 1, the trend in diabetes mortality is essentially flat during the time period. The increase in the age-adjusted rate in New Jersey between 2003 and 2004 was 2.6%, and the rate declined by about 2.0% between 2004 and 2005. For the U.S. as a whole, the age-adjusted death rate from diabetes decreased by 3.6% between 2003 and 2004, from 25.3 to 24.5 (per 100,000). The rate remained relatively unchanged between 2004 and 2005 for the U.S. In New Jersey, rates increased slightly for males and females between 2003 and 2004, then continued to increase for males but declined for females between 2004 and 2005. The age-adjusted rate among white and Asian respondents rose slightly between 2003 and 2005, but decreased for black and Hispanic respondents.

It might be expected that the checkbox would have a greater impact on COD reporting in cases where the underlying COD is not diabetes, but where diabetes contributed to the death in some way. As Figure 2 and Table 2 show, there was an increase of more than 500 deaths overall between 2003 and 2004 in which diabetes was listed as a contributing but not underlying COD, representing an increase of nearly 16.0%. This increase was greatest among black, Hispanic, and Asian respondents; for these three groups, the change was statistically significant. This increase was concentrated in deaths reported in the first and second positions on the multiple-cause field. The increase was sharpest among those where diabetes was listed as the second contributing cause. There were 874 such deaths in 2003 and 1,060 such deaths in 2004, an increase of more than 20.0%. In 2005, the number of deaths coded with diabetes as a contributing but not underlying COD continued to increase, but at a much slower rate. The percent change between 2004 and 2005 was less than 3%, and the number of deaths coded with diabetes as contributing only rose slightly more than 100.

As seen in Table 2, increases were limited to deaths where diabetes was listed as the second or third contributing cause. Deaths with diabetes as the first contributing cause fell in 2005, after having increased in 2004. Overall, the trend data for New Jersey suggested that the checkbox may have functioned to increase coding of diabetes as a contributing COD, but had relatively little effect on the coding of diabetes as an underlying COD.

Sensitivity analysis

Ideally, the accuracy of the checkbox as a measure of the prevalence of diabetes among decedents should be assessed through conventional methods used to measure the usefulness of a diagnostic test, such as

Table 1. Age-adjusted diabetes death rates per 100,000 New Jersey residents, 1990–2005[a,b]

Year	Total	White non-Hispanic	Black non-Hispanic	Hispanic	API[c]	Male	Female
1990	27.4	NA	NA	NA	NA	29.2	25.8
1991	25.8	NA	NA	NA	NA	28.9	23.8
1992	27.3	NA	NA	NA	NA	31.7	24.1
1993	27.3	25.4	51.1	21.5	8.0	29.5	25.1
1994	27.5	24.8	52.8	23.1	16.9	29.2	25.8
1995	30.1	26.3	62.3	27.7	11.9	32.7	27.9
1996	29.1	25.3	62.4	29.5	13.8	31.8	27.2
1997	28.7	25.0	57.9	25.3	12.7	32.5	25.9
1998	27.4	24.9	50.1	28.3	17.2	32.1	24.0
1999	28.0	25.4	53.8	28.7	19.6	33.1	24.1
2000	28.2	25.8	54.6	29.7	20.3	34.0	24.1
2001	28.5	25.4	59.1	31.7	19.4	33.1	25.3
2002	27.8	25.4	52.0	27.1	17.7	31.4	24.9
2003	26.9	23.6	56.9	31.9	13.8	31.1	23.8
2004[d]	27.6	25.0	54.5	26.3	17.4	31.9	24.4
2005[d]	27.1	24.8	53.4	23.5	17.5	34.4	21.7

[a]Rates shown are for diabetes as an underlying cause of death.

[b]Rates from 1990–1998 were comparability modified because of the change from International Classification of Diseases (ICD), Ninth Revision and ICD, Tenth Revision. The comparability ratio = 1.008167.

[c]Rates for API do not meet standards of reliability or precision; based on fewer than 20 deaths.

[d]Bridged race data were used for 2004 and 2005 for comparability with 1990–2003 race/ethnicity classifications.

API = Asian/Pacific Islander

NA = not available

sensitivity or specificity. In the case of the diabetes checkbox, it is somewhat easier to calculate estimates of sensitivity, as it is possible to identify decedents known to have diabetes, yet more difficult to identify cohorts of decedents who definitively did not have diabetes. Following are some estimates of sensitivity; an analysis of specificity is planned for a future article.

Decedents with any mention of diabetes

The first estimate of the sensitivity of a checkbox used decedents with any mention of diabetes on their death certificates. For such decedents, we viewed a checkbox status other than "yes" as a false negative. A false negative is, of course, the alternative to a true positive, and the false negative rate is, thus, the converse of

Figure 1. Age-adjusted diabetes mortality rates in New Jersey and the United States, 1990–2005

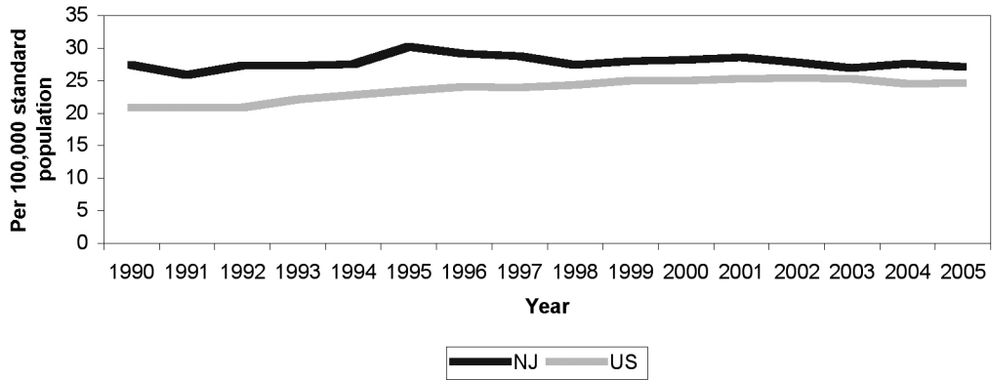
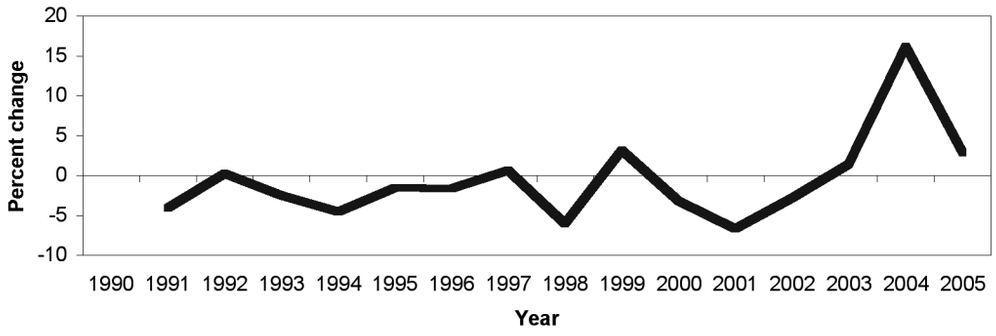


Figure 2. Percent change in deaths with diabetes as a contributing cause, New Jersey, 1991–2005



ssensitivity. Overall, the checkbox was checked "yes" in about 90% of deaths with any mention of diabetes as a COD. When "yes" was not checked, it was more likely that the "unknown" category was checked or that the checkbox was left blank than that "no" was checked.

Table 3 shows the proportion of decedents with the false negative error by gender, race/ethnicity, and place of death. We found no significant differences by age in checkbox status among decedents with any mention of diabetes. Overall, the prevalence of the false negative error declined somewhat between 2004 and 2005. Gender differences were minimal. We found black and Hispanic respondents to be somewhat more likely to have the false negative error than white and Hispanic respondents. Within certain racial/ethnic groups, we found significant differences by gender. For example, more than 15% of black males with a mention of diabetes as a COD did not have a "yes" on the diabetes checkbox, as compared with less than 10% of black females. Decedents who died at the scene or as inpatients were most likely to be false negatives, while those dying in hospice care were least likely to be false negatives. Multivariate logistic regression (not shown), which estimated the probability of the false negative error, has significant coefficients for male, black, and Hispanic decedents, as well as those who died at the scene.

These results are somewhat disconcerting, as the diabetic status of decedents with diabetes listed as a COD is clearly known at the time of death, and theoretically

Table 2. Deaths with diabetes as a contributing but not underlying cause of death: New Jersey, 1990–2005[a]

	Position of diabetes in contributing cause list								
	1	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*Total*
1990	2,887	907	270	67	13	5	1	0	4,150
1991	2,697	937	265	66	13	1	1	1	3,981
1992	2,766	887	260	60	12	4	0	0	3,989
1993	2,646	895	278	57	11	0	2	0	3,889
1994	2,519	891	236	52	9	4	0	0	3,711
1995	2,489	867	242	37	18	0	0	0	3,653
1996	2,463	830	249	38	10	4	0	0	3,594
1997	2,459	890	225	36	6	1	1	0	3,618
1998	2,308	822	216	46	6	1	0	0	3,399
1999	2,282	949	218	46	8	1	1	0	3,505
2000	2,233	893	216	42	7	1	1	0	3,393
2001	2,041	881	191	43	9	2	0	0	3,167
2002	1,954	865	211	33	11	3	0	0	3,077
2003	1,980	874	213	39	13	1	0	0	3,120
2004	2,268	1,060	230	54	10	1	0	0	3,623
2005	2,314	1,102	24	50	10	3	0	0	3,726

[a]Source: National Center for Health Statistics. Mortality data, multiple cause-of-death public-use data files [cited 2009 Apr 14]. Available from: URL: http://www.cdc.gov/nchs/products/elec_prods/subject/mortmcd.htm

Table 3. Prevalence of the false negative error, death certificates, New Jersey, 2004 and 2005[a,b]

	2004 (percent)	*2005 (percent)*	*Combined (percent)*
Total	11.4	9.9	10.7
Gender			
Male	12.2	9.5	10.9
Female	10.6	11.0	10.8
Race/ethnicity			
White	10.8	10.0	10.4
Black	12.5	11.9	12.2
Hispanic	14.7	10.7	12.7
Asian	13.3	6.7	10.0
Place of death			
Hospital inpatient	12.6	9.9	11.3
Hospital outpatient	11.3	7.2	9.3
Dead on arrival	17.9	9.1	13.5
Nursing home	10.5	10.4	10.5
Home	9.5	10.9	10.2
Hospice	6.8	6.1	6.5

[a]Source: Center for Health Statistics, New Jersey Department of Health and Senior Services. New Jersey health statistics [cited 2009 Apr 14]. Available from: URL: http://www.state.nj.us/health/chs/hlthstat.htm

[b]Percent of decedents with diabetes as an underlying or contributing cause of death who did not have "yes" checked on the diabetes checkbox

the same individual is completing both the COD section and the checkbox. Given the context in which it occurs, an error of this magnitude does not bode well for situations in which information about diabetic status may be less closely available at death, and raises questions about the usefulness of the diabetes checkbox as a measure of the diabetic status of decedents.

A hospitalized cohort

We obtained another estimate of sensitivity by matching to their death certificates a cohort of patients who were hospitalized with diagnoses that included a code related to diabetes (ICD-9-CM 250). We included patients hospitalized in 2004 or 2005. We limited the linkage to deaths occurring within one year of hospital discharge. Apart from that, the restriction included all deaths, regardless of location and cause. Some linkages for the 2005 cohort have not yet been made, due to the unavailability of 2006 mortality data at the time of the study. We linked approximately 8,000 patients from 2004 and 2005 to their death certificates. An analysis of their checkbox status is detailed in Table 4.

The results shown in Table 4 suggest that the sensitivity of the checkbox deteriorates as the distance between information about diabetic status and death increases. In other words, when diabetes was not listed as a COD, the probability that the diabetic status of the decedent would be reflected in the checkbox appeared to decline. For those decedents who had any mention of diabetes on their death certificate, approximately 90% received a checkbox status of "yes." This is consistent with the results described previously. However, for those with no mention of diabetes on their death certificate, less than 30% had the checkbox marked as "yes." Overall, only about 40% of these hospitalized decedents had their checkbox correctly checked as "yes," reflecting the fact that the majority of these decedents did not have a mention of diabetes on their death certificates. Conditional on whether there was any mention of diabetes, the place of death did not affect the checkbox status. However, as those with a mention of diabetes were more likely to die in the hospital, the checkbox status varied by place of death. We found little change between 2004 and 2005.

While this cohort of hospitalized decedents may not be representative of all decedents, these results suggest that the sensitivity of the checkbox declined substantially when the decedents had no mention of diabetes on their death certificates. Further analysis of the accuracy of the checkbox will involve finding more broadly representative cohorts with diabetes, in addition to cohorts who are known to not have diabetes. This latter addition will allow the calculation of specificity. Despite the limitations of these initial results, the sensitivity rate raises serious questions about the accuracy of the diabetes checkbox as a measure of the prevalence of diabetes among decedents.

DISCUSSION

This preliminary analysis of the diabetes checkbox in New Jersey showed that coding of COD seems to have changed somewhat since the introduction of the checkbox in 2004. While overall rates for diabetes have not changed significantly, the number of deaths with a contributing but not underlying COD of diabetes rose sharply in 2004 (approximately 16%) and somewhat more (approximately 3%) in 2005. In the absence of a true gold standard, it is not possible to know whether these changes in COD coding represent an improvement in accuracy. However, as the overall ranking of leading CODs is based on the underlying cause, the impact of the checkbox on conventional measurements of the mortality burden of diabetes in New Jersey appears to be negligible.

Further, the accuracy of the checkbox as a measure of diabetic status among decedents is questionable. One indicator of the potential accuracy of the checkbox, the false negative error, suggests that about 10% or 11%

Table 4. Estimate of the sensitivity of diabetes checkbox: checkbox status of a linked hospitalized cohort with diabetes-related diagnoses: New Jersey, 2004–2005[a]

	2004		2005	
	N	Percent	N	Percent
Percent in which checkbox = "yes"				
All deaths	8,227	41.4	8,291	39.3
Deaths occurring in hospital	6,204	49.4	6,050	47.9
Deaths occurring elsewhere	2,023	17.0	2,241	16.1
No mention of diabetes	6,502	28.3	6,877	28.8
Any mention of diabetes	1,725	90.9	1,414	90.4
Any mention—death in hospital	1,536	90.6	1,383	90.5
Any mention—death not in hospital	189	93.6	182	89.6

[a]Sources: Discharge data came from the Office of Health Care Quality Assessment, New Jersey Department of Health and Senior Services. Death data came from the Center for Health Statistics, New Jersey Department of Health and Senior Services.

of the time, decedents with a COD of diabetes do not have their checkboxes correctly recorded. These are situations in which theoretically certifiers are well aware of the diabetic status of the decedent, as they have listed diabetes as an underlying or contributing COD. Sensitivity of the checkbox should be at its highest with this subpopulation of decedents. Results from another sensitivity analysis using hospitalized decedents with a diagnosis of diabetes found a significant deterioration in accuracy, in that only 40% had the checkbox correctly noted as "yes." These preliminary findings raise concerns about the accuracy of the diabetes checkbox as a measure of the prevalence of diabetes among decedents.

Limitations

Our analysis had some limitations. We conducted the study after the diabetes checkbox had been in place in New Jersey for only two years. Some of the errors discussed may decline over time. Additionally, the hospitalized cohort used for the sensitivity analysis may not be representative of all decedents. Another planned study will use data from the Veterans Administration, which will include both inpatient and outpatient data. This will allow the calculation of both sensitivity and specificity in a somewhat more representative (though largely male) population.

CONCLUSION

There is great interest in accurately measuring the burden of chronic disease. Particularly in the case of diabetes, it is often claimed that death statistics do not fully capture the impact of the disease on mortality. However, this preliminary analysis suggests that a death certificate checkbox for diabetes is a problematic remedy for this situation. Increased education to certifiers about how to assign underlying and contributing CODs may improve the measure of the mortality burden of diseases such as diabetes. Additionally, alternative methods for measuring the burden of chronic disease, perhaps using hospitalization data or other measures of morbidity, should be explored.

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REFERENCES

1. Narayan KM, Boyle JP, Geiss LS, Saaddine JB, Thompson TJ. Impact of recent increase in incidence on future diabetes burden: U.S., 2005–2050. Diabetes Care 2006;29:2114-6.
2. Tierney EF, Gregg EW, Narayan KM. Leading causes of death in the United States. JAMA 2006;295:383.
3. Tierney EF, Cadwell BL, Engelgau MM, Shireley L, Parsons SL, Moum K, et al. Declining mortality rate among people with diabetes in North Dakota, 1997–2002. Diabetes Care 2004;27:2723-5.
4. Saydah SH, Eberhardt MS, Loria CM, Brancati FL. Age and the burden of death attributable to diabetes in the United States. Am J Epidemiol 2002;156:714-9.
5. Heron M, Anderson RN. Diabetes reporting on death certificates in Kentucky, 2002–2003 [cited 2007 Oct 3]. Available from: URL: http://www.cdc.gov/nchs/ppt/duc2006/heron_8.ppt
6. Bild D, Stevenson JM. Frequency of recording of diabetes on U.S. death certificates: analysis of the 1986 National Mortality Followback Study. J Clin Epidemiol 1992;45:275-81.
7. Tierney EF, Geiss LS, Engelgau MM, Thompson TJ, Schaubert D, Shireley LA, et al. Population-based estimates of mortality associated with diabetes: use of a death certificate checkbox in North Dakota. Am J Public Health 2001;91:84-92.
8. Miller DR, Safford MM, Pogach LM. Who has diabetes? Best estimates of diabetes prevalence in the Department of Veterans Affairs based on computerized patient data. Diabetes Care 2004;27(Suppl 2):B10-21.