Tuberculosis Surveillance Using Death Certificate Data, New York City, 1992

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SYNOPSIS

Objective. To determine the accuracy and frequency of reporting tuberculosis as either the contributing or underlying cause of death on death certificates in New York City during 1992.

Methods. Death certificates from 1992 that listed tuberculosis were matched with the New York City tuberculosis registry. For those persons who had tuberculosis listed as a cause of death, but who were not listed in the registry, medical records were reviewed. The frequency of reporting tuberculosis on death certificates in patients who died with active tuberculosis was evaluated in the second part of this study. Death certificates of patients with active tuberculosis (persons who died within six months of starting anti-tuberculosis medications)in 1992 were reviewed.

Results. Tuberculosis was listed on 635 death certificates; 377 (59%) were confirmed cases based on registry data. Reviews of medical records were possible for 230 (89%) of the remaining 258 patients and confirmed only two additional tuberculosis cases. Of 310 persons who died with active tuberculosis in 1992 (second part of the study), only 104 (34%) had tuberculosis listed on their death certificates.

Conclusion. In New York City, a diagnosis of tuberculosis on death certificates is an inaccurate measure of tuberculosis burden.

Data from death certificates are used to determine disease-specific and overall mortality rates. The major uses for these rates include assessment of the relative public health importance of particular diseases and the efficacy of available treatments.

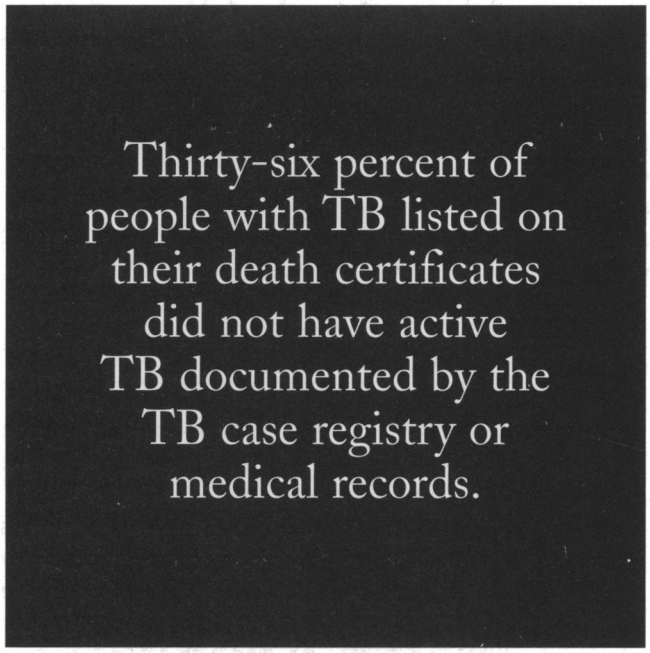
From 1986 through 1992, tuberculosis (TB) mortality rates in New York City (NYC) remained stable at approximately 3 per 100,000 persons despite a sustained rise in reported TB case rates during this same period (fig.).

Information listed in the NYC TB registry is verified by NYC Department of Health staff, but death certificate data do not undergo similar review. To determine the accuracy of death certificate TB listings, we reviewed the medical records of all patients whose 1992 death certificates listed TB and reviewed all death certificates of patients known to have died with active TB during 1992.

Methods

Accuracy of death certificate TB diagnoses. In general the underlying causes of death listed on death certificates by the certifying physicians are used to determine mortality rates. Although we were primarily interested in TB as the underlying cause of death, we also wanted to evaluate the accuracy of all TB diagnoses listed on death certificates. Therefore, we reviewed 1992 NYC death certificates that listed TB as either the underlying or contributing cause of death.

The *International Classification of Diseases, Ninth Revision (ICD-9)* codes 010.0 through 018.9 identify TB as the underlying cause of death.[1] New York City's death certificate has a unique coding section for a limited number of outcomes such as TB, human immunodeficiency virus (HIV) infection, and injuries. TB listed as underlying cause of death receives the appropriate ICD-9 code; if TB is listed elsewhere on the death certificate as a contributing cause, that is noted in the special coding area.



Match with TB registry. We performed computer-assisted queries of the NYC TB registry for all persons with TB listed as the underlying or contributing cause of death on their death certificates; criteria for matching included patient name, age, sex, date of birth, address, and social security number. The reviewer made a determination of the matching outcome for each case. For each query, a match required the same name and one of the following: *(a)* age or date of birth; *(b)*address; or *(c)* social security number. Patients with TB confirmed by the registry were considered to have an accurate TB diagnosis. To determine the accuracy of death certificate TB diagnoses, we reviewed the] medical records of those with TB diagnoses on their death certificates but who were not listed in the NYC TB registry.

Individuals are included in the NYC TB registry only if they are confirmed to have positive cultures for *Mycobacterium tuberculosis* or clinical confirmation of active disease. A clinically confirmed case is defined by surveillance case definition for the NYC TB registry as the presence of signs and/or symptoms consistent with TB in an individual who was treated with two or more anti-TB medications.[2,3] Since we evaluated the records of patients who died, the TB diagnosis for those not listed in the TB registry was based on bacteriologic or pathologic data; autopsy results were reviewed when available.

The gold standard used to confirm or refute TB disease status was documentation of active TB in case reports or the medical record. Medical records were reviewed for the following information: demographic data; clinical and laboratory information; and TB risk factors such as HIV infection, homelessness, and injectable drug use. Those whose TB treatment was completed before death and who had no clinical, bacteriologic, or histologic evidence of active TB at time of death were considered to have a prior history of TB (inactive). When we found records with incomplete laboratory data, we contacted the laboratories for details. When we did not find sufficient data to substantiate a TB diagnosis, we tried wherever possible to review previous medical records.

Frequency of reporting TB on death certificates. In the second part of the study, we determined how often TB is recorded on death certificates of those who died with active TB. We reviewed copies of the death certificates of people listed in the TB registry as having died with active TB in 1992 to determine if TB was given as either the underlying or contributing cause of death. Active TB was defined as death that occurred less than six months after beginning treatment for TB.[4] Characteristics of patients with active TB at time of death whose TB disease was not recorded on the death certificate were evaluated and compared with those whose TB disease was recorded on the death certificate.

The chi-square test, Fisher's exact test, or chi-square analysis for linear trend in proportions were used as appropriate.[5]

Results

Accuracy of death certificate TB diagnoses. In 1992 in NYC, 635 death certificates listed TB as either the underlying or contributing cause of death. Of these, 377 (59%) had been reported to the NYC Bureau of TB Control and confirmed as TB cases. Medical records were available for 230 (89%) of the 258 patients who were not confirmed by the TB registry.

Of these 230 patients, 114 (50%) had no evidence of current active TB (most of their medical records mentioned the need to "rule out" TB), and 85 (37%) were infected with nontuberculous mycobacteria (mostly *Mycobacterium avium* complex). Eighteen (8%) of these 230 had a history of inac-

Table 1. Accuracy of death certificate tuberculosis diagnoses, New York City, 1992[a]

			Confirmed TB[b]				
	Number	Percent	Number	Percent	RR	CI	PPV
TB listed as underlying cause	193	30	129	67	1.31	1.04, 1.64	60
TB listed as contributing cause	442	70	250	57		(379/635)	
Total	635	100	379	100			

[a]In New York City, 635 death certificates listed tuberculosis as either underlying cause or contributing cause of death in 1992.
[b]Confirmation based on TB registry information and medical record reviews.
NOTE: TB = tuberculosis; RR = relative risk; CI = confidence interval; PPV = positive predictive value (of a TB listing anywhere on the death certificate).

tive TB (2 to 50 years previously) at time of death; an additional 11 (5%) had a history of TB infection, had no active disease, and were on preventive therapy. Thus, 228 (36%) of 635 persons with TB listed on their death certificates did not have TB. Only two (1%) of the 230 patients with a death certificate TB diagnosis were confirmed as having active TB based on medical record reviews. One of these two was cared for by a private physician who submitted the patient's specimen to an out-of-state laboratory; the physician and laboratory failed to report this case of culture-confirmed TB to the NYC Department of Health. In the other instance, TB was diagnosed at autopsy based on the pathologist's findings and neither the pathologist nor the patient's physician reported this case to the NYC Department of Health.

TB was listed as the underlying cause of death in 193 of the 635 patients. We were able to confirm the diagnosis of TB for only 129 (67%) of these 193] based on TB registry information and medical record reviews (table 1). The rest did not have TB or the records were incomplete. Patients with TB listed as the underlying cause were more likely to have the diagnosis confirmed than those with TB listed as a contributing cause of death (67% [129/193] versus 57% [250/442]; p = 0.02). The positive predictive value of a listing of TB anywhere on the death certificate was 60% (379/635).

TB Reporting on death certificates. In 1992, 310 people were identified by the TB registry as having had active TB disease at time of death. Of these, 104 (34%) had TB listed on the death certificate as the underlying or contributing cause of death, which included 41 (13%) for whom TB was listed as the underlying cause.

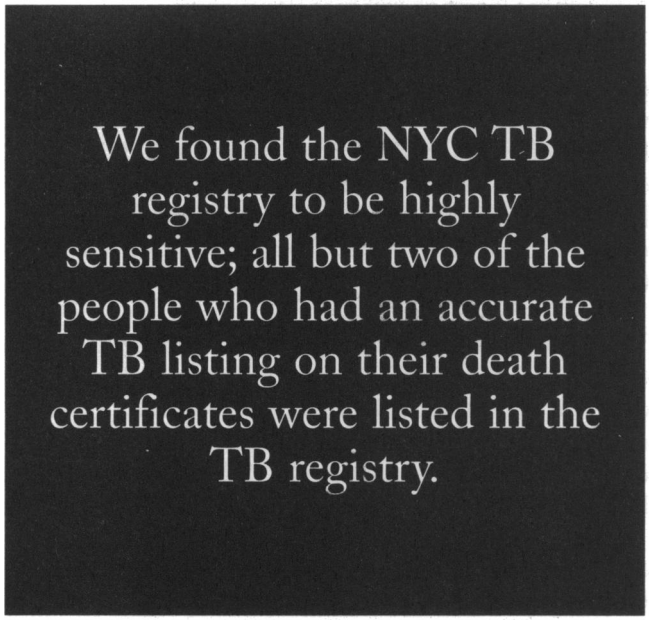
Table 2 lists the most frequent underlying causes of death for those with confirmed TB for whom TB was not listed on the death certificate. Of the 206 patients with TB omitted from the death certificate, 112 (54%) had HIV/AIDS listed as the underlying cause of death. HIV

Table 2. Most frequent underlying causes of death listed for 206 people who died with active TB but for whom TB was not listed on the death certificate, New York City, 1992

Death certificate diagnosis	ICD-9 code	N=206	% of total
AIDS/HIV	042–044	112	54
Chronic ischemic heart disease	414	20	10
Chronic liver disease and cirrhosis	571	10	5
Pneumonia, unspecified organism	486	9	4
Malignant neoplasm of trachea, bronchus, lung	162	5	2
Hypertensive heart disease	402	4	2
Septicemia	038	4	2
Pneumococcal lobar pneumonia	481	4	2
Other diseases of lung	518	4	2
Gastrointestinal hemorrhage	578	4	2
Other disorders of kidney and ureter	593	4	2
Unspecified infectious and parasitic disease	136	3	1
Other	—	23	11

NOTE: Because of rounding, percentages do not total 100.

status was known for 214 (69%) of the 310 people who died with TB disease in 1992. The majority of those with a known HIV status were HIV-positive; HIV-positive people were more likely to have TB omitted from their death certificates than those who were HIV-negative (135/206 [66%] versus 2/8 [25%]; RR = 2.6; 95% CI 0.8 to 8.7). However, when HIV-positive persons were compared with persons who either had an unknown HIV status or were HIV-negative, HIV status was not associated with omission of a TB diagnosis from the death certificate (135/206 [66%] versus 71/104 [68%]; RR = 1.0; 95% CI 0.8 to 1.1) (Table 3).



Increasing age was associated with the omission of a TB diagnosis from the death certificate (chi-square for linear trend $P = 0.03$). The type of hospital did not affect the likelihood of omission of a death certificate TB diagnosis. Of the 310 people who died with TB disease, 67 (22%) died at municipal hospitals; 28 (42%) of these had TB listed on their death certificates. Of the remaining 243, 228 died at private hospitals, 8 died at nonmunicipal long-term care facilities, and 7 died at private residences; 167 (69%) did not have TB listed on their death certificates (p = 0.11). Race, ethnicity, sex, and homelessness were not associated with an omission of TB from the death certificate.

Table 3. Characteristics of 310 patients who died with active TB disease, New York City, 1992

Characteristic	Died with active TB[a]	TB omitted from death certificate	
		Number	Percent
Age group[b]			
0–19	6	3	50
20–44	171	107	63
45–54	60	40	67
55–64	21	17	81
≥65	52	39	75
Race			
Black	161	111	69
White	139	88	63
Asian	10	7	70
Ethnicity			
Hispanic	86	56	65
Non-Hispanic	224	150	67
Sex			
Male	225	145	64
Female	85	61	72
Homelessness			
Yes	56	33	59
No	254	173	68
Disease site			
Extrapulmonary[c]	63	49	78
Pulmonary	247	157	64
HIV status			
Positive	206	135	66
Negative or unknown	104	71	68
Municipal hospital			
Yes	67	39	58
No	243	167	69

[a]Persons with TB who died within six months of starting anti-TB treatment.
[b]chi-square for trend $P = 0.03$.
[c]$P = 0.04$.

Discussion

Studies have shown that death certificates are often inaccurate, particularly in patients with infectious diseases.[6–12] We found that in NYC during 1992, the peak year of the recent resurgence of TB,[13] TB diagnoses recorded on death certificates were often inaccurate; 36% of people with TB listed on their death certificates did not have active TB documented by the TB case registry or medical records. In addition, approximately two-thirds (66%) of the people who died with active TB did not have this diagnosis listed on their death certificate.

A listing of TB on the death certificate was often nonspecific. Most of those whose death certificates had an erroneous listing of TB were undergoing diagnostic evaluations to rule out TB at the time of their death. Many were diagnosed with nontuberculous mycobacterial infections. In some of these cases, by the time of death a laboratory report documenting acid-fast bacilli from patient specimens had been received but mycobacterial culture results and identifi-

cation were still pending. In other cases, there appeared to be confusion on the part of treating medical staff; TB diagnoses were used interchangeably with nontuberculous mycobacterial diagnoses in the medical records.

We found the NYC TB registry to be highly sensitive; all but two of the people who had an accurate TB listing on their death certificates were listed in the TB registry. The current investigation suggests that TB reporting in New York City is relatively complete. In the second part of the study, we determined how often TB was listed on death certificates of those who died with active TB. We looked at the frequency of reporting TB on death certificates, not the validity of TB as a contributing or underlying cause of death. The clinical relevance of TB to the cause of death was likewise not investigated; we did not determine if the patient died from their TB or if TB contributed to their death. Persons in older age groups were more likely to have had TB omitted from their death certificates. As the population ages, it is more likely that multiple disease processes are present. Because death certificates provide limited space to enter diagnoses, TB may not be listed. In addition, TB among the elderly is often not diagnosed before death, partly because of atypical presentation and physicians' failure to "think TB."[14,15]

A possible explanation for the stable TB mortality rate while case rates were rising in NYC is that because most TB deaths were HIV-associated, TB may have been listed more often as contributing than underlying cause compared to previous years. So, even though the number of persons dying with active TB may have been increasing, particularly among those who were HIV-positive, that fact was not reflected in the mortality statistics.

Our analysis demonstrates that the NYC TB registry is more accurate and reporting is more complete than physicians' diagnoses on death certificates; almost all persons who died with active TB disease had already been reported to the TB registry. Thus, TB registry data rather than death certificate diagnoses should be used to measure the burden of TB in NYC, and death certificate data should be interpreted with caution.

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