

Malignant Mesothelioma Surveillance:

A Comparison of ICD 10 Mortality Data with SEER Incidence Data in Nine Areas of the United States

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With the implementation in 1999 of ICD-10 death certificate coding in the United States, mortality data specific to malignant mesothelioma became readily available on a national basis. To evaluate the accuracy and completeness of diagnosis and coding for mesothelioma on the death certificate, mortality information was compared with incidence data. A mortality/incidence ratio was calculated for each of the nine areas covered by the SEER Program, using National Vital Statistics mortality data from 1999 and 2000, and the SEER incidence data for 1998 and 1999. The mortality/incidence ratio for the two years combined for all areas was 0.82. Only two areas (Connecticut and Atlanta) had ratios <80%. The overall correlation coefficient between mortality and incidence rates was 0.96. Thus, mortality data coded using ICD-10 can be a valid source for mesothelioma surveillance and can be instituted without major cost if a national mortality statistics program based on ICD-10 is in place, making it feasible even for developing countries. *Key words:* mesothelioma; mortality; incidence; surveillance; death certificates; ICD-10; epidemiology.

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Malignant mesothelioma is a rare tumor that arises from mesothelial cells. The pleura is the most common site, but mesothelioma can also occur in the peritoneum and pericardium.¹ Exposure to asbestos or other fibrous minerals such as zeolite (erionite)² is considered the most important cause of malignant mesothelioma.³ Other factors, such as SV40 virus (a contaminant of polio vaccines in the late 1950s and early 1960s)⁴ and radiation,³ have also been implicated.

In the United States, asbestos has been mined and used commercially since the 1800s. Consumption increased substantially during World War II and subse-

quent decades, though it has declined sharply from a peak in the mid-1970s.⁵ Currently, approximately 1.3 million employees are estimated to be exposed directly or indirectly to asbestos in many industries and activities, such as shipyards, steel mills, construction, and manufacturing asbestos products (textiles, friction products, insulation, and other building materials).⁶ The problem is not exclusively occupational, but is also an important environmental concern because the inhalation of small amounts of the fiber can cause the tumor. The U.S. Environmental Protection Agency estimates that asbestos-containing materials can be found in most of the nation's approximately 107,000 primary and secondary schools and 733,000 public and commercial buildings.⁶

The average annual incidence of malignant mesothelioma in the United States was reported as 11.4 cases/million/year for males and 2.8 for females in the 1973-1984 period.⁷ Mortality is expected to increase in many countries, with a projected peak incidence between 2020 and 2030.^{8,9}

Until recently, there was no specific International Classification of Diseases (ICD) code for this tumor. With the recent adoption of the 10th revision (ICD-10) of this classification system for coding causes of death in the United States, mesothelioma has a unique code—C45; this should improve the usefulness of vital records for mesothelioma surveillance.¹⁰ The object of the present study was to compare vital-statistics-system mesothelioma mortality data coded using ICD-10 with available incidence data.

METHODS

Incidence Data

Incidence data for 1998 and 1999 were acquired from the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute,¹¹ which monitors cancer incidence in about 10% of the U.S. population. The SEER Program covers nine regions: New Mexico, Connecticut, Utah, San Francisco-Oakland, Seattle (Puget Sound), Detroit (metropolitan), Atlanta (metropolitan), Iowa, and Hawaii.

Age-adjusted incidence rates were calculated with SEER*Stat 5.0 using data from the November 2002 sub-

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TABLE 1. Mesothelioma Incidences in Nine SEER Areas, 1998–1999

SEER Area	1998		1999	
	Cases (n)	Rate (per Million)	Cases (n)	Rate (per Million)
Seattle (Puget Sound)	65	23.30	63	22.49
San Francisco–Oakland	61	20.31	48	15.74
New Mexico	23	18.28	20	14.93
Connecticut	42	14.48	41	14.17
Utah	16	13.42	15	12.64
Detroit (metropolitan)	32	10.51	43	13.95
Iowa	16	6.45	28	10.94
Atlanta (metropolitan)	8	4.96	11	7.00
Hawaii	4	4.49	6	5.87
All areas combined	267	13.89	275	14.18

mission,¹² and adjusted to the Year 2000 U.S. Standard Population. The rates were expressed as cases per 1 million population.

Mortality Data

The Surveillance Branch of the Division of Respiratory Disease Studies at the National Institute for Occupational Safety and Health (NIOSH) maintains a mortality surveillance system for malignant mesothelioma and other respiratory diseases of occupational interest. The data are drawn from annual National Center for Health Statistics mortality files, which include all deaths in the United States. From 1999 and 2000 files, cases were selected in which any of the ICD-10 codes for mesothelioma—pleura (C45.0), peritoneum (C45.1), pericardium (C45.2), other sites (C45.7), unspecified site (C45.9)¹³—was listed as either the underlying or a contributing cause of death.

Mortality data were abstracted for the same nine areas covered by SEER (see above) using county or city of residence codes for decedents. Age-adjusted mortality rates were calculated using the Year 2000 U.S. Standard Population for each SEER area, for all nine SEER areas combined, and for the entire United States. Rates were expressed as cases per 1 million population.

Comparison of Mortality and Incidence

On the assumption of an average one-year expectation of life after diagnosis of mesothelioma, we related the incidence rate for 1998 to the mortality rate for 1999, forming a mortality/incidence rate ratio. We repeated this for 1999 and 2000, and also derived the two-year ratio by the same process. Correlation coefficients between mortality and incidence were also calculated.

RESULTS

In 1998 and 1999, 542 incident cases of mesothelioma were reported in the nine SEER areas, accounting for incidence rates of 14.81 in 1998 (*n* = 267 cases) and 13.22 in 1999 (*n* = 275 cases). Seattle (Puget Sound), San Francisco–Oakland, and New Mexico had the highest incidence rates, and Hawaii the lowest (Table 1).

In 1999 and 2000 combined, the number of mesothelioma deaths in the nine SEER areas was 447 (*n* = 214 in 1999; *n* = 233 in 2000). The highest mortality rates were found in Seattle in both years (Table 2). The age-adjusted mortality rates for the nine SEER areas combined were 11.08 in 1999 and 11.90 in 2000, whereas the national age-adjusted mortality rates were 11.65 in 1999 and 11.64 in 2000.

TABLE 2. Mesothelioma Mortality in Nine SEER Areas, 1999–2000

SEER Area	1998		1999	
	Cases (n)	Rate (per Million)	Cases (n)	Rate (per Million)
Seattle (Puget Sound)	54	19.28	58	20.13
San Francisco–Oakland	44	14.26	43	13.82
New Mexico	17	13.05	20	15.29
Connecticut	33	11.60	18	6.29
Utah	9	7.52	20	16.58
Detroit (metropolitan)	23	7.23	40	12.95
Iowa	21	7.92	23	9.07
Atlanta (metropolitan)	8	5.91	7	5.28
Hawaii	5	4.95	4	3.97
All areas combined	214	11.08	233	11.90

TABLE 3: Mesothelioma Mortality/Incidence Ratios in Nine SEER Areas, Allowing for a One-year Survival

SEER Area	Mortality 1999/ Incidence 1998	Mortality 2000/ Incidence 1999	Mortality 1999–2000/ Incidence 1998–1999
Seattle (Puget Sound)	0.83	0.92	0.88
San Francisco–Oakland	0.72	0.90	0.80
New Mexico	0.74	1.00	0.86
Connecticut	0.79	0.44	0.61
Utah	0.56	1.33	0.94
Detroit (metropolitan)	0.72	0.93	0.84
Iowa	1.31	0.82	1.00
Atlanta (metropolitan)	1.00	0.64	0.79
Hawaii	1.25	0.67	0.90
All areas combined	0.80	0.85	0.82

The mortality/incidence ratio for the two-year period in all SEER areas combined was 0.82; corresponding values by area ranged from 0.61 in Connecticut to 1.00 in Iowa (Table 3). Mortality and incidence rates of the nine areas for the combined two-year period were highly correlated ($r = 0.96$; $p < 0.05$). Connecticut was the only outlier, with mortality rates much lower than incidence rates (Figure 1).

DISCUSSION

The SEER Program is considered the “gold standard” for quality among cancer registries around the world.¹¹ Studies are conducted every year in the SEER areas to evaluate the quality and completeness of the data being reported. In some studies, a sample is reabstracted to confirm the accuracy of each of the data elements collected from the medical records.¹¹ For mesothelioma and some other tumors, the data cover nine geographic areas, representing 10% of the U.S. population.

Several studies have addressed the representativeness of these areas with regard to demographic and epi-

demologic factors. In general, SEER data have been shown to be representative of the entire United States.¹⁴ However, Walker et al. claimed that due to the high number of shipyards in the SEER areas, the national incidence of mesothelioma can be overestimated when based on SEER data.¹⁵ On the other hand, Nicholson suggested that national mesothelioma incidence based on SEER data could be underestimated, because manufacturing and construction in large urban areas are underrepresented.¹⁶ In our study, mesothelioma mortality rates for the combined SEER areas proved to be very similar to overall U.S. mesothelioma mortality rates, suggesting that the combined SEER areas are likely to be quite representative of the overall United States with respect to mesothelioma.

The highest mesothelioma incidence and mortality rates in this study were found in the Seattle area. This has also been noted by Hinds, who attributed the findings to the presence of large shipyards in the area.¹⁷ Several other studies have also demonstrated the link between exposure to asbestos in shipyards and high mesothelioma incidence and mortality.^{7,18,19}

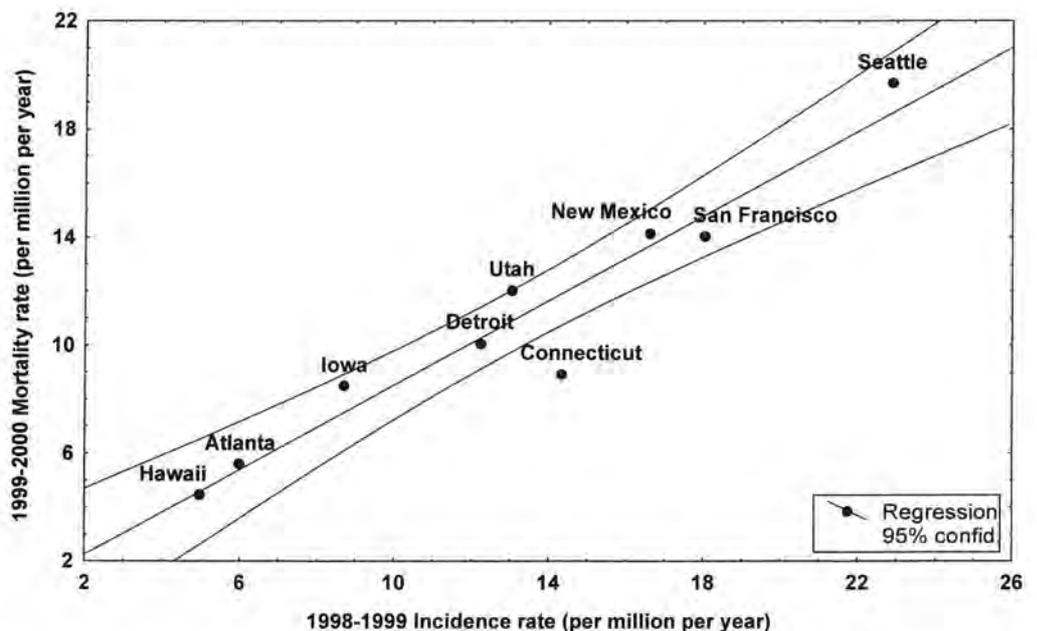


Figure 1—Scatterplot showing the correlation between mortality and incidence rates for malignant mesothelioma in nine SEER areas, allowing for a one-year survival.

Previous studies using data from SEER^{17,20,21} showed lower incidence rates in the past than we report for recent years. This is consistent with projections for an increase in asbestos-related diseases associated with heavy use of asbestos during the World War II era.^{8,15} Connelly et al. reported 3.1 deaths/million/year for white males in the 1973–1984 period.⁷ After taking differences in Standard Populations into consideration (data not shown), our mesothelioma mortality rate for white males is almost six times higher.

Vital statistics mortality data prior to 1999 did not permit analyses of specific data for mesothelioma, as there was no specific ICD-9 code for this tumor. Mesothelioma studies based on ICD-9 were limited. From 1979 to 1981, only one of eight cases of pleural malignant mesothelioma was coded as a malignant pleural tumor in the vital records of Minnesota.²² Likewise, only 12% of the malignant mesothelioma cases reported in the Massachusetts Cancer Registry between 1982 and 1987 were later identified on death certificates using underlying cause-of-death codes for pleural and peritoneal tumors.¹⁰ In Brazil, a review of death-certificate data from 1979 to 1994 showed that 34% of the codes indicating pleural tumors were miscodes.²³

Davis et al. predicted that approximately 80% of mesothelioma deaths would be detected using death certificates with the implementation of ICD-10 codes.¹⁰ That prediction compares quite well with our finding of an overall mortality/incidence ratio of 82%, which was based on mesothelioma incidence data from 1998 and 1999 and, allowing for a one-year survival, mesothelioma mortality data from 1999 and 2000. Mortality/incidence ratios substantially lower than 80% were found in only one of the nine SEER areas—Connecticut (0.61). The two one-year mortality/incidence ratios for Connecticut were 0.79 and 0.44, the latter representing the lowest one-year ratio observed in our study.

A difficulty with our analysis is that it essentially follows the ecologic approach—that is, it did not involve direct linkage between individuals, but compared data from two time periods for the same geographic units. The natural variability in mesothelioma occurrence and survival times gives rise to random variation in incidence and mortality counts from year to year, and thus impacts our ratios. This problem is exacerbated by the small numbers brought about by having only two years of data. Another possible difficulty with our methods could be in- and out-migration. For instance, incident cases might come to an urban center to seek treatment, but die outside that area. Or cases might move back to families elsewhere after diagnosis. Overall, these two factors would tend to artifactually affect incidence and/or mortality rates.

In the past, the use of mortality data to study mesothelioma was much more problematic, but with the implementation of ICD-10 it is now possible to assess specific mortality data for this tumor. Neverthe-

less, even using ICD-10, our findings suggest that for nearly 20% of mesothelioma cases, “mesothelioma” is not mentioned on the death certificate or, if mentioned, is miscoded. Regardless, the diagnosis of this tumor remains a challenge, demanding experienced pathologists and modern immunohistochemical techniques. Diagnostic difficulty can contribute to underdiagnosis, which can, in turn, influence both mortality and incidence data.

The experience from the NIOSH Surveillance Program demonstrates that national surveillance for mesothelioma based on mortality data can be instituted without major cost, making it feasible even for developing countries if an ICD 10-coded national vital statistics mortality system is already in place. It can be used to document the burden of this occupational and environmental disease, to evaluate the impact of prevention measures taken in the past, and to describe demographic and geographic patterns of the disease, which can potentially lead to the identification of unusual etiologic exposures. Surveillance findings regarding malignant mesothelioma can be an important basis for generating hypotheses and developing asbestos-related prevention strategies in many countries. NIOSH has begun tracking mesothelioma deaths and has recently published several summary tables and figures concerning mesothelioma in the United States.²⁴

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