Use of Death Certificates for Mesothelioma Surveillance

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Synopsis

Data from the Massachusetts Cancer Registry and death certificates were linked for mesothelioma cases reported to the registry from 1982 through 1987 to determine the extent to which the cause of death information that is given on the death certificate is useful in identifying mesothelioma cases for disease surveillance. Only 12 percent of all persons reported with mesothelioma who had died were detected using underlying cause of death codes for cancers of the peritoneum and pleura, which are commonly used to identify mesothelioma cases. The rate increased to 83 percent when death certificates were reviewed manually for any mention of mesothelioma. Surveillance using only the coded cause of death data currently available will result in a large underascertainment of mesothelioma cases.

THE USE of death certificates for mesothelioma surveillance purposes is problematic since there is currently no specific ICD code (International Classification of Diseases, 9th Revision) (*1*) to identify these deaths (*2*). Mesothelioma, cancer of the lining of the lung and other organs, whose only known cause is asbestos, is defined by morphology (cell type) and not by the site of occurrence. Since morphology information is not routinely coded on death certificates, mesothelioma cases are commonly identified for surveillance purposes by using primary site codes for cancers of the peritoneum (ICD 158.8, 158.9) and pleura (ICD 163.0, 163.1, 163.8, 163.9) (*3,4*).

This study was undertaken to determine the extent to which these ICD codes are useful for identifying deaths caused by mesothelioma for disease surveillance. The Massachusetts Cancer Registry and death certificate files were linked to examine the reported cause of death for known cases of mesothelioma.

Methods

The Massachusetts Cancer Registry collects information on all malignant neoplasms diagnosed by Massachusetts hospitals and licensed clinics. Primary site and morphology information are coded by tumor registrars at the hospital of diagnosis according to the ICD-O (International Classification of Diseases for Oncology) system (*5*).

All cases of mesothelioma (ICD-O morphology 9050-9053) reported to the registry during the years 1982-87 were identified and matched to the Massachusetts death certificate file by name and date of birth. Cause of death information was examined for all persons with mesothelioma in the registry who had died by December 31, 1989, and had a Massachusetts death certificate on file. Cause of death information is coded by State nosologists according to the multiple cause of death system (Automated Classification of Medical Entities) using ICD-9 codes, and the underlying cause of death is assigned by computerized algorithms developed by the National Center for Health Statistics.

For purposes of the analysis, mesothelioma cases reported to the Massachusetts Cancer Registry were considered "true" cases of mesothelioma. The utility of using death certificate data for mesothelioma surveillance was measured by computing a detection rate, as suggested by Percy (*6*). The detection rate was calculated by dividing the number of persons with mesothelioma in the registry who had died and been assigned underlying cause

Table 1. Death certificate diagnoses for persons with mesothelioma reported to the Massachusetts Cancer Registry in 1982–87 who had died by December 31, 1989

ICD–9	Underlying cause of death	Primary site of cancer registry diagnosis			Mesothelioma mentioned on certificate
		Pleura	Peritoneum	All sites	
	All causes	231	22	299	248
140–208	Malignant neoplasms	210	19	266	232
158.9	Peritoneum, unspecified[1,2]	1	3	6	4
162.9	Bronchus, lung unspecified	44	0	57	38
163.9	Pleura, unspecified[1,3]	29	0	30	30
195.1, 195.2	Other and ill defined sites	3	2	7	6
199.0, 199.1	Site unspecified	131	10	160	152
	Other site	2	3	6	2
390–459	Diseases of the circulatory system	9	0	15	7
460–519	Diseases of the respiratory system	8	0	11	7
	Other causes	4	3	7	2

[1] Causes of death commonly used as indicators of mesothelioma.
[2] None of persons with mesothelioma who had died were assigned underlying cause of death codes for specified parts of the peritoneum (ICD 158.8).
[3] None of persons with mesothelioma who had died were assigned underlying cause of death codes for specified parts of the pleura (ICD 163.0, 163.1, 163.8).
NOTE: Detection rate using coded underlying cause of death indicators of mesothelioma = 36 ÷ 299 = 12 percent. Detection rate using literal cause of death information = 248 ÷ 299 = 83 percent.

Table 2. Number and percent of pleural and peritoneal cancer deaths with Cancer Registry or death certificate evidence of mesothelioma, Massachusetts residents, 1983 through 1987

ICD–9	Underlying cause of death	Total	Number reported as mesothelioma		Registry or death certificate	
			Registry	Death certificate only	Number	Percent
	Malignant neoplasm of:					
158.8	Peritoneum, specified parts	7	0	0	0	0
158.9	Peritoneum, unspecified	26	5	3	8	31
163.9[1]	Pleura	43	25	5	30	70

[1] There were no deaths assigned underlying cause of death codes for specified parts of the pleura (ICD 163.0–163.8) in 1983 through 1987.

of death codes for cancer of the peritoneum or pleura (ICD 158.8, 158.9, and 163) by the total number of deceased persons with mesothelioma. It measures the extent to which "true" cases of mesothelioma are identified using death certificate primary site information only and is a measure of sensitivity.

For all persons with mesothelioma reported to the registry who had died, all causes of death and significant conditions listed on the death certificate were reviewed for any mention of mesothelioma. A second detection rate was computed by dividing the number of deceased persons with mesothelioma identified using this literal information by the total number of persons with mesothelioma reported to the registry who had died. In addition, Massachusetts death certificates and, when available, the Massachusetts Cancer Registry records for all deaths of residents due to pleural or peritoneal cancer from 1983 through 1987 were examined to determine what proportion of these deaths were persons diagnosed and reported as having mesothelioma.

Results

There were 367 newly diagnosed cases of mesothelioma reported to the Cancer Registry in 1982–87. The diagnosis of mesothelioma was microscopically confirmed in 97 percent of these cases. Of the 367 persons, 299 had died by December 31, 1989, and had a Massachusetts death certificate on file. Death certificate diagnoses for all persons reported with mesothelioma who had died and detection rates are shown in table 1. The detection rate using underlying cause of death codes for cancers of the peritoneum and pleura is disturbingly low, only 36 in number (12 percent). (The rate improved only slightly, 14 percent, using codes for all mentions of these cancers on the death certificates). Approximately 157 (53 percent) of the mesothelioma deaths were attributed to neoplasm of unspecified site, not disseminated (ICD 199.1). The detection rate increased to 248 (83 percent) when literal information on the death certificate was used.

Although the actual number of "true" cases of mesothelioma detected using coded cause of death information is low, it is possible that a large proportion of deaths assigned to ICD-9 codes 158.8, 158.9, and 163 are caused by mesothelioma, and that these codes can still be used to identify at least some of these deaths. However, examination of the Massachusetts Cancer Registry and death certificate records for 1983 through 1987 for deaths of residents due to pleural or peritoneal cancer found no evidence of mesothelioma for a substantial proportion of these deaths. Only 50 percent of these deaths had been reported to the Massachusetts Cancer Registry as mesothelioma cases or had mesothelioma recorded anywhere on the death certificates. As shown in table 2, this proportion varied by site: 0 percent for specified parts of the peritoneum (ICD 158.8), 31 percent for peritoneum, unspecified (ICD 158.9), and 70 percent for pleura, unspecified (ICD 163.9). The extent to which these proportions reflect the capture of other cancers in these ICD categories or underdiagnosis and underreporting of mesothelioma is not known.

Discussion

This study clearly shows that using coded cause of death data to identify mesothelioma cases will result in a large underestimate of these cases. Only 12 percent of persons with mesothelioma reported to the registry who died were identified as mesothelioma deaths using underlying causes of death codes for pleural and peritoneal cancers. This figure is notably lower than the 23–24 percent reported by Connelly and coworkers (*7*), suggesting that relative differences in pleural and peritoneal mortality rates by geographic region may reflect regional differences in diagnostic and reporting practices as well as differences in the underlying incidence of mesothelioma. Estimates can be greatly improved using literal information available on the death certificate, although this would entail manual review of a large number of certificates.

The majority of true mesothelioma deaths are currently coded as cancer of unspecified site, not disseminated ICD 199.1 (53 percent) or cancer of the bronchus and lung, unspecified ICD 162.9 (19 percent). This finding is consistent with coding conventions which assign ICD 199.1 to mesothelioma with no site specified and ICD 162.9 to "mesothelioma of the lung." Identification of mesothelioma cases through review of all death certificates with these ICD codes would be inefficient, since very few of these deaths are due to mesothelioma. It is more feasible to review the relatively small number of deaths attributed to cancers of the peritoneum and pleura (ICD 158.8, 158.9, and 163). The finding that only 50 percent of these deaths have evidence of mesothelioma on the death certificate or Cancer Registry reports suggests that even these cancers, particularly peritoneal cancer, may not be good indices of mesothelioma.

The problem of underascertainment may be alleviated to some degree in the future when literal cause of death information is included in computerized death files. This will make review of a large number of death certificates much easier. Also, the tenth revision of the International Classification of Diseases (ICD–10) will include specific codes for mesothelioma. When this revision is implemented, sometime in the mid-1990s, all States will be able to include mesothelioma in their mortality statistics.

According to this study, use of ICD–10 codes will allow identification of about 80 percent of all persons who died of mesothelioma. Until these codes are implemented, the problems inherent in conducting mesothelioma surveillance with mortality data should be kept in mind. Cancer registries, where available, are the best alternative for estimating mesothelioma incidence.

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