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## The "Missing Cases" of Pleural Malignant Mesothelioma in Minnesota, 1979-81: Preliminary Report

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### Synopsis .....

*Malignant mesothelioma is a sentinel neoplasm for population exposure to asbestiform fibers. Public health officials may be alerted to temporal or spatial clustering of malignant mesothelioma*

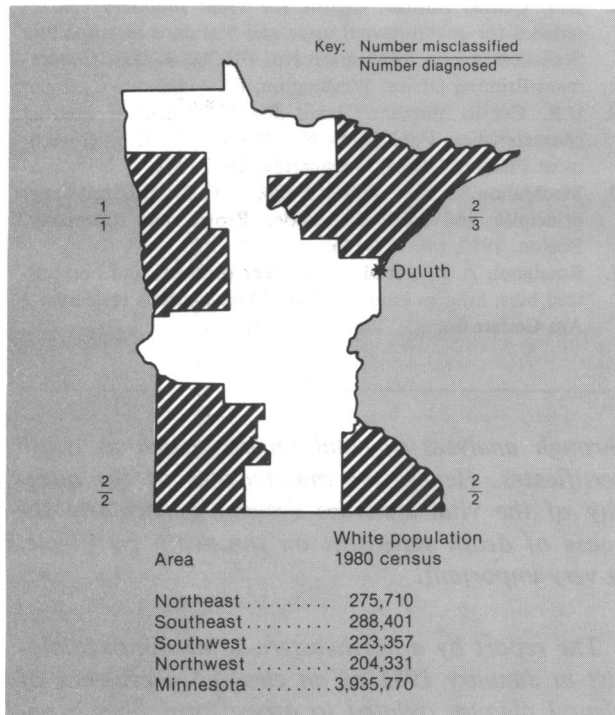
*through analyses of vital records, such as death certificates. Hence, the maintenance of the integrity of the vital statistics system, particularly the cause of death statement on the death certificate, is very important.*

*The report by a northeastern Minnesota radiologist in January 1985 of an elevated prevalence of pleural plaques (related to asbestiform fiber exposure) to the Minnesota Department of Health resulted in an investigation of pleural malignant mesothelioma mortality trends in that area and in three other similar areas in the State. In that study, we noted that in several instances malignant mesothelioma (either intrathoracic or unspecified site) was listed on the death certificate in such a manner as to imply that the neoplasm was either a lung cancer or a malignancy of an unspecified site. The effect of this misclassification is to underestimate the mortality from malignant mesothelioma by fourfold to eightfold. Given the importance of malignant mesothelioma as a proxy for past asbestos exposure, it is necessary to determine the extent of such misclassification for all deaths in the United States.*

**I**N THE PAST 25 YEARS, MUCH EPIDEMIOLOGIC and laboratory data have accumulated relating exposure to asbestos fibers with subsequent incidence of malignant mesothelioma (1). Although other causes of some malignant mesotheliomas are suspected, this relationship (asbestos-malignant mesothelioma) is very specific (2). Hence, it is valuable to public health officials as an index of past asbestos exposure. They can, in turn, prepare

health resources needed to contend with the variety of health effects associated with such exposure, such as asbestosis, pleural thickening, lung cancer, and gastrointestinal cancers (1,3). The specificity of the asbestos-malignant mesothelioma association can also be used by such officials to assess reports of clusters of asbestos-associated diseases (such as pleural thickening). If a population had been exposed to asbestos in the past, one would expect

Distribution of deaths caused by pleural malignant mesothelioma and number of misclassified causes of death, in four study areas of Minnesota, 1980-81



to find an increase in the incidence of and mortality from malignant mesothelioma in that population.

On January 25, 1985, the Minnesota Department of Health received a report of an unusually high prevalence of pleural thickening from a radiologist in Virginia, MN (a town of about 10,000 population on the Iron Range, in the northeastern section of the State). As part of its investigation of this report, staff at the Minnesota Department of Health reviewed the trends in mortality from several diseases, including lung cancer and malignant mesothelioma.

Specifically, computer tapes of the coded mortality certificates for 1950-51, 1959-61, 1969-71, and 1979-81 were reviewed for deaths among Minnesota residents generally, and from the northeastern, northwestern, southwestern, and southeastern sections of the State, specifically. The analytic procedures followed in that investigation are detailed subsequently. It was recognized that prior to 1979-81, few (if any) cases of malignant mesothelioma would be noted on the death certificate. However, since the investigation was initiated in response to a report of an asbestos-associated condition, it was felt that malignant mesothelioma mortality should be examined for the period 1979-81 to provide a baseline for future investiga-

tions. During this review an irregularity in mortality reporting for cases of pleural malignant mesothelioma was discovered that we believe is national in scope.

## Materials and Methods

The geographic area of interest in this study was the northeastern section of Minnesota, where the presumed asbestos exposure had occurred. This area had a population in 1980 of approximately 275,000, one-third to one-half of whom resided in the Duluth metropolitan area. For comparative purposes, three sections of the State, each with an urban area and a 1980 population of approximately 275,000, were identified in the northwestern, southwestern, and southeastern corners of Minnesota (see figure). Nonwhites were not included in the study since they were a small segment (fewer than 1,000 persons) of the 1980 population in the four study areas. The mortality trends by underlying cause of death for all causes of death, all cancers, lung cancer, and malignant mesothelioma (both pleural and peritoneal) were examined for the period 1950-81. For each of the four areas, the sex-specific death rate for each of these causes for 1950-51, 1959-61, 1969-71, and 1979-81 were calculated, and the trends in mortality were then compared among the four sections.

In Minnesota, all demographic and epidemiologic data are coded from the death certificate by nosologists according to the protocol developed by the National Center for Health Statistics (4). These nosologists, in the Minnesota Department of Health, are trained and certified by the National Center for Health Statistics. The coded data are then placed onto magnetic tapes. The magnetic tapes for the years 1979, 1980, and 1981 (a census year and 1 year before and after) were reviewed for deaths with pleural malignant mesotheliomas listed as the underlying cause (ICD-9 rubrics 163.0 through 163.9) (5). Peritoneal malignant mesothelioma deaths (ICD-9 rubrics 158.8-158.9) were also identified in the same manner.

The initial listing of such cases for all four study areas contained only one death from pleural malignant mesothelioma; this number was markedly smaller than the nine deaths expected, based on SEER data (6). The single observed death from peritoneal malignant mesothelioma was, however, approximately equal to the 1.6 deaths expected. For each of the four areas, the sex-specific, age-adjusted death rate for each of these causes for 1950-51, 1959-61, 1969-71, and 1979-81 were

Table 1. Stated causes of death in northeastern, northwestern, southeastern, and southwestern Minnesota for cases of pleural malignant mesothelioma, 1980-81

Year, case number, sex, and race	Section	Age (years)	Stated underlying cause of death	ICD-9
<i>1980</i>				
1. White male .....	Northeast.....	68	"Mesothelioma" .....	199.1 = cancer, not otherwise stated.
<i>1981</i>				
2. White male .....	Southeast .....	67	"Mesothelioma with metastases-site was probably lung, possible secondary to asbestos exposure."	162.9 = lung cancer
3. White male .....	Southwest .....	58	"Mesothelioma R Lung c̄ metastases" .....	162.9 = lung cancer
4. White male .....	Southeast .....	52	"Mesothelioma" .....	199.1 cancer, not otherwise stated.
5. White male .....	Southwest .....	74	"Malignant mesothelioma right lung" .....	162.9 = lung cancer
6. White female....	Northeast.....	76	"Pleural mesothelioma" .....	163.9 = pleural malignancy
7. White male .....	Northwest .....	78	"Malignant mesothelioma of right chest" .....	195.1 = intrathoracic malignancy, not further specified.
8. White male .....	Northeast.....	69	"Mesothelioma, lung, with metastases" .....	162.9 = lung cancer

calculated, and the trends were then compared among the four sections. It was possible that some deaths occurred with pleural malignant mesothelioma listed as a "co-existing condition" or as a "contributing cause," but not the underlying one; however, the magnitude of the observed discrepancy could not be attributed to such possibilities. Rather, we wondered whether there were "missing" cases of pleural malignant mesothelioma.

Subsequent discussions with the Minnesota Department of Health staff indicated that some cases of pleural malignant mesothelioma may have been coded with the ICD-9 rubrics 162.2-162.9 (malignant neoplasm of bronchus or lung), 195.1 (malignant neoplasms of other and ill-defined sites of thorax), or 199.1 (malignant neoplasm without specification of site), rather than the "usual" codes of 163.0 through 163.9. We evaluated this hypothesis by retrieving the death certificate identification numbers from the magnetic tapes for 1979 through 1981 for deaths in which a malignancy of respiratory organs (ICD-9 rubrics 160.0-165.9), or a malignancy of ill-defined site in the thoracic cavity (ICD-9 rubric 199.1) was listed as the underlying cause. The corresponding records were located. A copy of each certificate was reviewed individually and independently by both authors. For malignancies not stating the site as being intrathoracic (two cases), the attending physician

(or clinic) was contacted for confirmation of a pleural neoplasm. The number of cases with a pleural malignant mesothelioma as an underlying cause of death in each of the four regions was tabulated, as was the number of those malignancies coded as ICD-9 rubrics 163.0-163.9.

## Results

The total number of death certificates from 1979 that were reviewed was 405, from 1980, 446, and from 1981, 474. The number of deaths due to pleural malignant mesotheliomas for 1980 through 1981 in the four areas was eight. No such deaths occurred in 1979. The distribution of these deaths and their reported cause is shown in the figure. No variation in the misclassification is seen for the four areas. The stated causes of death are presented in table 1. Given the small numbers of deaths observed, no statistical tests were performed.

## Discussion

The distribution of cases in the figure does not suggest a pattern either in the occurrence of malignant mesothelioma or in the number of cases misclassified as lung cancer. We have hypothesized that physicians, in their statements of the cause of

Table 2. Numbers of malignant mesothelioma cases diagnosed in the Third National Cancer Survey by primary site, histologic confirmation, race, and sex, 1969-71

Primary site	Microscopically confirmed									Not microscopically confirmed
	All races			White			Black			
	Total	Male	Female	Total	Male	Female	Total	Male	Female	
Total .....	154	105	49	148	101	47	6	4	2	4
Appendix .....	1	1	...	1	1	...	...	...	...	...
Retroperitoneum, omentum, mesentery .....	19	9	10	19	9	10	...	...	...	1
Lung, bronchus, and trachea .....	11	10	1	11	10	1	...	...	...	1
Other respiratory system .....	101	73	28	97	70	27	4	3	1	2
Soft tissues .....	4	2	2	3	1	2	1	1	...	...
Ovary .....	4	...	4	3	...	3	1	...	1	...
Testis .....	1	1	...	1	1	...	...	...	...	...
Other male genital system .....	4	4	...	4	4	...	...	...	...	...
Unknown primary site .....	9	5	4	9	5	4	...	...	...	...

SOURCE: Reference 7.

*'Indeed, if the degree of misclassification prevalent in Minnesota extends to the entire United States, pleural malignant mesothelioma mortality could be underestimated by fourfold or greater.'*

death, specify the site of a malignant mesothelioma as being the lung (or other nonpleural intrathoracic sites abutting the lung). In approximately 25 percent of the cases, the site was not specified at all, that is, it was simply a "mesothelioma." The standard National Center for Health Statistics protocol states that a malignant neoplasm of the lung is coded under the general ICD-9 rubric 162 (specified site of the malignant neoplasm-lung) (4). The fact that the neoplasm is a malignant mesothelioma is ignored in this process; it is viewed as the tumor's histology. The histology of any lung cancer (for example, adenocarcinoma) would be so ignored (4,5).

Given the importance in the current nosology of diseases of the site of a neoplasm, this approach is usually satisfactory. When a physician specifies a malignant mesothelioma as occurring at the chest wall, as in table 1, the cause of death is coded under rubric 195. This creates a distinct impediment to data utilization by public health officials insofar as it decreases their ability to discern regions where increases in pleural malignant

mesothelioma (rubric 163) incidence and mortality are occurring. Indeed, if the degree of misclassification prevalent in Minnesota extends to the entire United States, pleural malignant mesothelioma mortality could be underestimated by fourfold or greater.

The present study is not the first dataset to disclose the current difficulties in ascertaining the site (and, therefore, rubric) for a malignant mesothelioma. Data collected in the Third National Cancer Survey (TNCS), in which cancer incidence was studied for a 10 percent sample of the 1969-71 U.S. population, demonstrate that histologically confirmed morbidity data for malignant mesothelioma have the same weaknesses that were discussed previously. Table 2, adapted from the TNCS report (table 46 in reference 7), shows the stated site of both histologically confirmed and not confirmed cases of malignant mesothelioma. These data suggest that our findings are not an aberration specific to Minnesota, nor are they the result of poor training of the nosologists. Rather, the reported findings result from misstated sites of malignant mesothelioma incidence.

We believe that consideration should be given by the appropriate national officials to a policy whereby all U.S. physicians would specify all occurrences of intrathoracic malignant mesotheliomas on the death certificates as being pleural, unless autopsy data indicated a different site of origin for the malignancy. An alternative approach would be modifying the nosological convention to account for the histology of tumors. It should be remembered that similar difficulties with vital statistics in the past have suggested epidemics of disease where none, in fact, existed (8). The

particular problem disclosed in our State is an excellent illustration of the basis for a 1929 quotation attributed to Sir Josiah Stamp:

The government (statisticians) are very keen on amassing statistics—they collect them, add them, raise them to the nth power, take the cube-root and prepare wonderful diagrams. But what you must never forget is that every one of these figures comes in the first instances from the . . . village watchman, who puts down what he damn pleases.

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## The Nationalization of a Disease: a Paradigm?

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**Synopsis**.....

*The early history of the Federal involvement in Hansen's Disease reflects the history of the Public Health Service itself. As a young and aggressive institution, the Public Health Service sought out contagious, infectious diseases that threatened the public health. National resources and national coordination were needed to fight the likes of malaria, hookworm, or smallpox. The customary attack would consist of a field study, determination of the etiology, the method of transmission, and, then, perhaps, preventive measures. An eradication campaign would follow.*

*Leprosy fit perfectly into the model—a disease of unknown etiology, an unknown method of transmission, thought to be highly contagious, and no known cure. The United States launched a major investigation in Hawaii, where the disease was prevalent and its victims conveniently segregated.*

*The investigation failed. The Public Health Service then turned toward segregation and isolation as a way to fulfill its public health role. A bureaucracy was established around the idea that victims of leprosy must be incarcerated for the good of the public.*

*The institutionalization of the Public Health Service and the philosophy upon which its treatment of leprosy was based proved difficult to change when researchers in the field made major scientific breakthroughs in the 1940s. The realization that the disease was only feebly contagious, activities of patient organizations, and pressure from the media and the Congress did not achieve as dramatic results as the sulfone drugs did. The Public Health Service moved, but slowly. What are the lessons in all of this?*

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**I**N MARCH 1916, THE CONGRESS of the United States had before it a proposal to nationalize a disease (*1a*). Never before had the Federal Government moved so boldly in the name of public

health. That the disease was leprosy made such a move all the more dramatic.

Leprosy was largely misunderstood in 1916, shrouded in mystery, its victims suffering as much