A BRIEF ORIGINAL CONTRIBUTION

Validation of Cause-of-death Certification for Outpatient Cancers: The Contrasting Cases of Melanoma and Mycosis Fungoides

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The reported incidence of cancers typically diagnosed in the outpatient setting may underestimate their true frequency, but the validity of mortality estimates from many of these causes has not been studied in detail. The authors sought to evaluate the validity of mortality estimation from death certificates for two such cancers, melanoma and mycosis fungoides (a cutaneous lymphoma), using routinely collected cancer registry data for 1973–1994 from the Surveillance, Epidemiology, and End Results program. Their method estimates that 93% of the deaths attributable to melanoma were certified as due to melanoma but that only 60% of the deaths attributable to mycosis fungoides were so certified. Evaluation of the accuracy of cause-of-death certification in this manner is helpful in the interpretation of mortality statistics. Am J Epidemiol 1998;148:1184–6.

depth certificates; melanoma; mortality; mycosis fungoides; registries

Monitoring trends in cancers typically diagnosed on an outpatient basis has become a more difficult enterprise. Several studies have now demonstrated a degree of underregistration of melanoma in otherwise high-quality, comprehensive, population-based cancer registries (1–4), such as the Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute (5), as well as state cancer registries unaffiliated with the national program (6, 7). Similar degrees of underregistration have been noted for mycosis fungoides, the most common form of cutaneous lymphoma (M. A. Weinstock and B. Gardstein, unpublished manuscript). This problem has been attributed to changes in the delivery of health care in the United States during recent years.

Both of these malignancies may lead to death in a substantial proportion of their victims (10-year relative survival of cases diagnosed 1973–1983: 76 percent for melanoma and 63 percent for mycosis fungoides (M. A. Weinstock, unpublished data)), and the above-mentioned limitation in measurement of incidence underscores the importance of the assessment of mortality in monitoring overall progress in the control of these disorders. This has been a particularly prominent feature of efforts aimed at understanding and controlling the burden of melanoma (8–18) and has also been used for evaluation of treatment and for etiologic inference in mycosis fungoides (19–21). However, the validity of death certification for melanoma has received little attention, and even less attention has been paid to documenting the validity of certification of cutaneous lymphoma deaths. Deaths attributed to another cutaneous malignancy, squamous cell carcinoma, have been demonstrated to be substantially misclassified (22, 23). In the case of melanoma, the cause-of-death information has generally been assumed to be accurate, and the meager published evidence supports that assumption (24).

The purpose of this report is to evaluate the validity of the cause-of-death certification for these two diagnoses. We are unaware of previous use of this method for this purpose.

MATERIALS AND METHODS

The data used for these analyses derive from the system of population-based cancer registries maintained by the SEER program of the National Cancer Institute. These registries seek to include all malignancies (other than basal and squamous cell carcinomas of the skin) diagnosed among residents of their respective geographic areas, which are the metropolitan areas of Atlanta, Georgia; Detroit, Michigan; San Francisco,
we preferred to use the entire period of excess mortality to estimate a certification proportion that would be most useful in the interpretation of cause-specific mortality statistics.

RESULTS

For melanoma, 8,200 deaths were observed among cases diagnosed during 1973–1983. Of these, 48 were excluded due to unknown race, six due to "other" race (as defined by SEER detailed race coding), and 49 due to ascertainment by death certificate or autopsy, for a total of 103 excluded cases (1.3 percent of the deaths). The final analysis included the remaining 8,097 cases. The expected number of deaths for this group (based on life tables) was 3,860, so the remaining 4,237 were attributable to melanoma. According to the cause-of-death coding, 3,946 were actually attributed to melanoma, which represents 93 percent of the number attributable to this cause.

For mycosis fungoides, 430 deaths were observed among cases diagnosed during 1973–1983. Of these, three were excluded due to unknown race, two due to other race, and two due to ascertainment by death certificate or autopsy only. In total, seven (1.6 percent of deaths) were excluded; hence, 423 were available for analysis. The expected number of deaths in this group was 178, so 245 were attributable to mycosis fungoides. However, according to the cause-of-death coding, only 146 deaths were due to this cause, which represented 60 percent of the number attributable to this cause (the certification proportion). An additional 39 deaths (16 percent of the total) were classified as due to lymphomas of other or unspecified types; therefore, the total number of lymphoma deaths was 185, 76 percent of the number attributable to mycosis fungoides. Among these 39 deaths, the registry data had no record of another malignancy either prior to or subsequent to the mycosis fungoides for 28 cases (72 percent). Fifty-seven (24 percent) of the nonlymphoma deaths were listed as due to malignancy, of which lung cancer (21 deaths), colorectal cancer (six deaths), and leukemia (six deaths) were the only sites responsible for more than five deaths. Other major categories were circulatory disorders (including cardiovascular and cerebrovascular disease), which were responsible for 76 deaths, pneumonia (11 deaths), chronic obstructive pulmonary disease (nine deaths), and sepsis (five deaths). We examined the distribution of the certification proportion by category of age, gender, race, and year of diagnosis, but found no major differences among these categories.

DISCUSSION

We have described a method for assessment of the validity of cause-of-death certification for malignan-
cies by using cancer registry data, but not involving rereview of medical records. We used this method to assess the validity of cause-of-death certification for two cancer sites commonly diagnosed on an outpatient basis, for which registry data may underestimate incidence. Our analyses suggest that melanoma deaths are accurately certified, but that a substantial proportion of mycosis fungoides deaths are misclassified as due to another cause.

The source of error in the certification of mycosis fungoides deaths is unclear, and several possibilities must be considered. Some of the error appears to be due to misclassification of the advanced stages of this disease as some other or unspecified form of lymphoma. The possibility that some nonlymphoma malignancies may have been induced by the mycosis fungoides or the therapy for it cannot be ruled out. However, we must also consider the likelihood that the disease or its therapy may have reduced the survivability of (or perhaps induced) other conditions that were ultimately responsible for death among patients with this generally relatively indolent disorder.

We must also consider a methodological component to some of the discrepancy noted. In particular, since our method is indirect, we could have been misled if the types of people who develop mycosis fungoides were otherwise likely to have a life expectancy greater than that of the general population. However, we believe this to be quite unlikely, given the magnitude of the observed differences for mycosis fungoides and the absence of a similar difference for melanoma, even though the latter is directly associated with socioeconomic status.

Our analyses pertain to the United States, and we would be reluctant to apply our conclusions to other countries. It would be worthwhile to determine the extent to which these findings can be generalized.

We now consider the confidence previously placed in the use of melanoma mortality statistics to be reinforced, but that mycosis fungoides mortality must be interpreted more cautiously, since a substantial minority of deaths may be missed by routine cause-of-death certification. More-detailed investigation into the cause of this inaccuracy would be worthwhile.

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REFERENCES