Accuracy of the Cancer Death Records*

ELEANOR J. MACDONALD, F.A.P.H.A.

Epidemiologist, Division of Adult Hygiene, State Department of Public Health, Boston, Mass.

THE challenge to statisticians to prove that data upon which extensive biometrical methods are used and from which conclusions are drawn are basically accurate enough to warrant this expenditure of effort or to justify the conclusions drawn, suggested the need for appraisal. This study is concerned with the soundness of the data contained in the cancer death records.

The general use of autopsy for exact verification of doubtful diagnoses does not seem imminent. Only about 12 per cent of the cancer deaths at the present time come to autopsy, and these in no sense represent a cross-section of the cancer population. With the limitation in autopsies, the method employed in this study furnishes a reasonable evaluation of the cancer death records.

The late Robert B. Greenough advised checking the accuracy of the information on the cancer death records by interviewing those who were related to or associated with the deceased. The state-wide interest in the cancer program, in effect in Massachusetts since 1926, with the consequent rational attitude toward the disease as an entity, would presuppose a coöperative attitude toward the study. It was an extensive undertaking, financed in part by the Rockefeller Foundation, and coöperated

in enthusiastically in practically every instance by that portion of the population interviewed—approximately 15,000 individuals. Whether, in view of the state cancer program in operation for the past 10 years, the findings in Massachusetts could be applied to other states is problematical.

The death records were first copied on a special card prepared for the purpose. In addition to the name and address of the individual, the death record contains information concerning the cause of death, date of birth and death, nativity, date of first recognizable symptoms, the operative history, the place of death, any associate cause of death, the record of an autopsy if one were performed, and the name of the individual who signed the certificate.

Comparable information was obtained from the family, every physician employed, hospitals attended, and social workers who knew the case.

There were 6,153 deaths from cancer in Massachusetts in 1932. Since several interviews were required for every completed case record, it was necessary to sample the deaths rather than to attempt to obtain information on every single death for the calendar year. It was predetermined that completed records of one-third of the total deaths should be secured. This necessitated at least one visit to the residences of about one-half of the individuals who had died of cancer in Massachusetts in 1932. The family was visited first in every instance. From this source the

names of the physicians employed, as well as the hospitals attended, the social workers, and others familiar with the case could usually be obtained. When the family and physicians of one of these cases could not be reached, the case was not followed further. This caused the rejection of approximately 1,000 records after one or more contacts had been made, since records with insufficient data were discarded.

An attempt was made to draw the true picture of the life of the cancer patient from the material thus obtained, and to note differences between this picture and that furnished by the death record itself. While it is realized that in some instances accurate details may not have been obtained, it is believed that in most cases the verified data represent the actual facts.

The sample of cancer deaths surveyed was 32.9 per cent of the total for 1932. That the sample was representative by site of cancer is evidenced by the fact that the distribution in the surveyed population of the several sites studied shows no significant difference by chi-square test from the distribution by site in the total Massachusetts cancer deaths for 1932 (chi-square = 4.9 and n = 8). This shows that this sample is representative of the Massachusetts cancer deaths by site for 1932. The geographical fairness of the sample had been assured by having the surveyors collect a certain number of records from each part of the state.

The verified data were in complete agreement with the death records on the question of sex, as was to be expected. Discrepancies as to age were so slight as to be practically negligible. Only an occasional case differed more than a year from the recorded data. Nativity was correct in over 99 per cent of the records. One may assume that the age, sex, and nativity information furnished by the death record is accurate.

The question of operations was reasonably accurate with agreement occurring in 93.7 per cent of all cases. A reasonable accuracy was present in the associate cause of death with agreement occurring in 92.0 per cent of all cases.

The duration of cancer is the least reliable information on the death record. Agreement between the death records and the facts learned in the survey occurred in only 22.8 per cent of the records. This item of information is frequently entirely omitted from the record, and was missing in 53.7 per cent of the cases studied. When the average duration of these cases in which information was available was compared with the verified duration, the true figure was nearly twice as large as that obtained from the death records—13.6 months on the death records and 23.8 months in the survey. From these facts, it is evident that little reliance can be placed on the importance of duration in cancer as determined by the death records.

The most important item from the standpoint of the student of cancer statistics is the value of the record certified as being cancer. The number of cures prevents cancer mortality from being an index of cancer morbidity. With accurate cancer mortality, accurate duration of disease, and a reasonably accurate estimate of the percentage of cures, morbidity can be approximated from mortality data. A death is either certified as being due to cancer or not. The statistician wishes to know how many of those so certified are correct, and how many of those not so certified should have been classified as cancer.

Another problem which is increasing in importance with improved methods of handling statistical data and with better knowledge of the disease is that of the exact primary location of the cancer. The present-day statistician not only wants to know whether or not the patient died of cancer, but also

TABLE I

Comparison of Actual and Death Record Diagnosis

Location of Cancer	Official Death Record Diagnosis	Verified Diagnosis		Complete Agreement	Percentage Agreement with Death Record	Author's Estimate of Percentage Agreement
Buccal Cavity	79	74		66	83.5	84.0
Digestive Tract	1,028	792		776	75.5	80.0
Respiratory Tract	64	53		44	....	....
Uterus	213	191		172	80.8	83.0
Other Female Genital Organs	43	57	(89.0%)	33	....	....
Breast	225	246		222	98.7	99.0
Male Genitourinary Organs	169	157		141	83.4	86.0
Skin	28	29		16	....	....
Other and Unspecified Organs	180	209		120	66.7	68.0
Doubtful—Probably Cancer	0	66	(3.2%)	0	....	....
Doubtful—Possibly Cancer	0	75	(3.7%)	0	....	....
Doubtful—Probably Not Cancer	0	47	(2.3%)	0	....	....
Non-Cancer	4	37	(1.8%)	0	....	....
Total	2,033	2,033	(100.0%)	1,590	78.2	83.0

where the primary lesion originated. The data obtained in the death record survey furnish an answer to all these questions with the exception of the size of the group classified as dying of other diseases that should have been classified as cancer. Inasmuch as only cancer deaths were verified, additional data were obtained to determine the volume of this particular group.

Table I shows the official diagnosis compared with the verified diagnosis, subdivided by broad types of location of cancer. Four cancer cases were not recorded in the official cancer classification because other diseases which the individual had were given precedence over cancer. While these individuals had cancer, they were classified as follows:

1. Sudden death under ether anesthesia preparatory to operation for extensive carcinoma of the stomach
2. Hypostatic pneumonia following a fracture of the left femur; associate cause, cancer of the prostate gland
3. Shock following fracture of the right hip; associate cause, cancer of the lung
4. Shock due to pathological fracture of right femur and left humerus; metastatic lesions from cancer of the breast

While these cases are classified as dying of accident, they all had extensive cancers, and from the point of view of cancer epidemiology might well have been classified under cancer.

A group of 66 cases was probably malignant, although conclusive evidence was lacking. In most of these cases the diagnosis had been based on observation of clinical symptoms by one or more physicians and although the physician or physicians had not had the advantages of consultation, they had treated the patient over a considerable length of time and did not base their opinions solely on observations of the patients in a moribund condition.

A second group comprising 75 cases was classified as possibly malignant. A physician might state he believed this case to be malignant from the symptoms, but because the patient refused sufficient examination or study of the case, he was not certain. An example of this type of case was the woman who refused examination and whose family refused to permit examination of the body even after death, when all the symptoms pointed toward cancer of

the uterus. Another type of case included in this group of 75 was of those individuals who, although they went to a hospital, refused other than palliative treatment, and whose hospital records read "question of malignancy." A third type of case was of those individuals to whom a physician was summoned only a week or so before death. His opinion had to be based on a superficial examination of a moribund individual.

Forty-seven cases were viewed in which the evidence was presumptive of non-malignancy, but not sufficiently strong to warrant a positive statement. Several of the physicians signing records in this group made the statement that their diagnosis of cancer was only a guess. In other cases the hospital records stated positively that the case was non-malignant, while the local physician was equally positive that it was malignant.

Thirty-seven additional cases were definitely not cancer. Several of them at autopsy were found to be other conditions, and the death certificates were evidently written before the report of the autopsy findings. Others had been biopsied a short time before death with negative findings for malignancy. In one case in which the patient died of heart disease, the physician had written on the certificate that this patient was operated on for cancer of the bladder several years previous to that time and had had no recurrence. The fact that cancer appeared on the death certificate caused this to be certified as a cancer death rather than heart disease. In all of these 37 cases the evidence collected from the family, physician, hospital, and autopsy records seemed sufficiently strong to make the dogmatic statement that none of these cases was cancer.

This analysis of the presence or absence of cancer disregarding location indicates that the presence of cancer as measured by the death certificate is accurate to somewhere between 89 per cent and 98 per cent. This may be even more closely approximated by the assumption that the probable cancers were cancers, and the probable non-cancers were not cancers. This is a reasonably safe assumption as errors in either of the classifications may well be balanced by the other. This would place the actual figure between 92 per cent and 96 per cent.

An exhaustive analysis of those cases classified as "possible cancer" leads one to believe that approximately three-fourths of the cases were cancer. An estimate that cancer as a disease was accurately diagnosed in 95 per cent of the total cases is felt to be a sound one.

A comparison of the diagnosis of the official death record by broad classification of site of cancer with the verified diagnosis disclosed complete agreement in 78.2 per cent of the total cases. If similar assumptions are made regarding the doubtful cases as were made with total cancer, this figure would be increased to 83 per cent. Frequently, the site of metastasis was given rather than the site of the primary lesion. When these cancers were allocated to the correct site, a decrease was found in the number of cases of cancer of the buccal cavity, of the digestive tract, of the respiratory tract, of the male genito-urinary organs, and of the uterus. An increase was apparent in other female genitals, breast, and cancer of other and unspecified organs. Cancer of the skin was practically the same. From Table I the inference is drawn that site of cancer is not particularly well defined on the death record.

This is even more graphically shown in Table II where the broad classifications are subdivided into smaller units. Complete agreement was present in 70.9 per cent of the total cases. If the same assumption as was made above is repeated, this figure may be as high as

TABLE II

Comparison of Actual and Death Record Diagnosis

Location of Cancer	Official Death Record Diagnosis	Complete Agreement	Percentage Agreement with Death Record	Author's Estimate of Percentage Agreement
Lip	7	7	....	....
Tongue	18	11	....	....
Mouth	14	5	....	....
Jaw	17	13	....	....
Other Buccal	20	12	....	....:
Pharynx	3	1	....	....
Esophagus	38	33	....	....
Stomach	379	292	77.0	80.0
Intestines	290	211	72.8	75.0
Rectum and Anus	109	78	71.6	75.0
Liver, Biliary, Gall-bladder	126	22	17.5	20.0
Pancreas	57	44	....	....
Peritoneum	2	0	....	....
Other Digestive	27	0	....	....
Larynx	12	7	....	....
Lungs and Pleura	45	32	....	....
Other Respiratory	7	0	....	....
Uterus	213	174	81.7	85.0
Ovarian and Fallopian Tube	39	27	....	....
Vagina and Vulva	4	3	....	....
Breast	225	223	99.1	99.0
Male Kidney	14	11	....	....
Male Bladder	53	30	....	....
Prostate	98	85	86.7	90.0
Testes	1	1	....	....
Scrotum	1	1	....	....
Others of This Class	2	2	....	....
Skin	28	16	....	....
Female Kidney	14	8	....	....
Female Bladder	21	14	....	....
Brain	13	11	....	....
Bones except Jaw	9	8	....	....
Others and Unspecified	123	60	48.8	50.0
Non-Cancer	4	0	....	....
Total	2,033	1,442	70.9	75.0

75 per cent. The greatest discrepancy appeared in cancer of the liver, biliary passages, and gall-bladder where complete agreement occurred in only 17.5 per cent of the cases. Again, repeating the previous assumption, this figure may be as high as 20 per cent. This is due to the practice, which is still common although far less so than previously, of certifying a death record as being cancer of the liver rather than cancer of the original site.

These findings warrant conservatism in any discussion of cancer by location of organs affected in which mortality figures are used, but are much better than one would be led to believe by reviewing some of the literature.

These figures indicate a more accurate record diagnosis than was shown by Lund and Hoffman [1] in their study from 1918 to 1930. They found 31 per cent of mouth cases recorded as dying of cancer outside the buccal cavity. In

this study 16.5 per cent were found. While this sample of buccal cavity can-. cer is smaller and subject to more statistical fluctuation, the great differ-ence would indicate that certification in 1932 was far better than the sample of Lund and Hoffman with the median year of death 1921. This points toward an improvement.

A compilation from the literature of 6 studies on autopsies in which the data have been reported so that comparison is possible has been combined in Table III with a review of records from the Massachusetts General Hospital of au-topsies performed from January, 1928, to July, 1937, inclusive. This table shows the cases that were clinically diagnosed as cancer, those that were erroneously diagnosed as cancer, and the missed cases that were found only at autopsy. The percentage of errone-ously diagnosed cancers varied from 2.2 in Lubarsch's study[2] to 12.0 in that of Bilz.[2] The Massachusetts General Hospital figure of 8.4 is in close agreement with 3 of the other studies and is also the median for the series. While attempts are made at the Massa-chusetts General Hospital to obtain autopsies on as many bodies as possible, the fact that this hospital receives ma-

terial which is difficult to diagnose clinically from all New England, makes its autopsy series a specialized group. Moreover, the cancers by location differ from a cross-section of cancer deaths, and if adjustments were made for these two items alone the rate for erroneously diagnosed cases would not differ greatly from the estimate made from the survey.

This strengthens the belief that 5 per cent erroneously diagnosed cases is close to the correct figure.

The number of missed cases per 100 erroneously diagnosed cases at the Massachusetts General Hospital was 230. In 2 of the other studies this figure was 244 and 264 respectively. The records of the Massachusetts state-aided cancer clinics show 220 originally diagnosed as non-cancer and later changed to cancer, to every 100 first diagnosed as cancer and later changed to non-cancer. Inasmuch as the Massa-chusetts state-aided cancer clinic cases are followed from first attendance at clinic to death of the patient and are in close agreement with the majority of the autopsy studies, this figure seems suitable to use in estimating the per-centage of missed cases. There would thus be between 9 and 18 per cent

TABLE III

Measurement of the Accuracy of Clinical Diagnosis by Autopsy

	Clinically Diagnosed Cancer	Erroneously Diagnosed (Clinically Diagnosed Cancer— Found to be Non-cancer at Autopsy)	Missed Cases (Clinically Diagnosed Non-cancer— Found to be Cancer at Autopsy)	Percentage of Erroneously Diagnosed Cancer	Missed Cases per 100 Erroneously Diagnosed Cancer
Wells [2]	400	33	178	8.2	539
Lubarsch [2]	7,426	163	1,312	2.2	805
Bilz [2]	600	72	60	12.0	83
Ritterhaus [2]	405	13	48	3.2	369
Riechelmann [2]	613	58	156	9.5	264
de Vries [2]	1,102	102	249	9.3	244
Current Study—Massa-chusetts General Hospital	677	57	131	8.4	230

missed cases, the most probable figure being 11 per cent.

The total error in the number of cancer cases reported would be about 6 per cent (11 per cent missed cases minus the 5 per cent erroneously diagnosed cases). If 6 per cent were added to the number of recorded deaths in Massachusetts, a figure would be obtained which would closely approximate the actual cancer mortality.

The analysis of these data indicates that in Massachusetts identification of cancer deaths is sufficiently accurate to warrant statistical compilations on age, sex, nativity, and the disease as a whole. There is a considerable error in exact location of cancer and a large error in duration of disease, and the statistician should not draw conclusions on these data without making corrections for errors known to exist.

REFERENCES

1. Lund, Charles C., and Hoffman, Virginia. The Accuracy of Death Certificate Diagnoses in Cases of Buccal Carcinoma. *New Eng. J. Med.*, 209, 15:719–722 (Oct. 12), 1933.
2. de Vries, W. M. The Prevalence of Cancer as Revealed by Mortality Returns and at Autopsy. Pp. 217–246 of *Cancer Control Report of an International Symposium held under the Auspices of the American Society for the Control of Cancer, Lake Mohonk, New York, U. S. A., September 20–24, 1926.* Surgical Publishing Co., Chicago, 1927.

Tobacco, Alcohol, and Longevity

. . . The net result is obvious. In this group of nearly 7,000 men the smoking of tobacco was associated definitely with an impairment of life duration, and the amount or degree of this impairment increased as the habitual amount of smoking increased. The contrast between the life tables relative to the implied effects upon longevity of moderate smoking, on the one hand, and the moderate use of alcoholic beverages, on the other hand, is very striking. The moderate smokers in this material are definitely shorter lived than the total abstainers from tobacco; the moderate drinkers are not significantly worse or better off in respect of longevity than the total abstainers from alcohol.

Heavy indulgence in either tobacco or alcohol is associated with a very poor life table, but the life table for heavy smokers is definitely worse than that for heavy drinkers up to about age 60. Thereafter to the end of the life span the heavy smokers do a relatively better job of surviving than the heavy drinkers. But neither group has anything to boast about in the matter of longevity.—The Search for Longevity, by Prof. Raymond Pearl, *Sci. Month.*, May, 1938, p. 480.