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ACCURACY OF DEATH CERTIFICATES AND MORTALITY STATISTICS IN VICTORIAN TESTIS CANCER DEATHS 1950-1977

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Abstract

426 death certificates relating to testicular cancer in Victoria, from 1950 to 1977, were examined for inaccuracies in cause of death narrative and coding for cause of death statistics. The narrative was inaccurate in major diagnosis in 33 certificates (21 false positives and 12 false negatives) and 17 accurately written certificates were mis-coded (12 false positives and 5 false negatives). Review of the pathological terms used revealed 10 lymphomas incorrectly ascribed to germ cell malignancy. The term "seminoma" seems to have been employed as a generic term for testis tumour, only 50 per cent of the tumours so designated being confirmed as seminoma. It is concluded that although Victorian figures relating to mortality from testis cancer are reasonably accurate (for 337 cases for which relevant records were available the detection rate was 95%, the confirmation rate 96% and concordance 91%), little reliance can be placed on the recorded pathological sub-type.

Introduction

A medical practitioner in completing a death certificate (DC) is fulfilling a legal requirement. But the subsequent use made of the information on these certificates, and the mortality statistics derived from them, engage the interests of a diverse audience in public health, health services, epidemiological research and other workers in health and social science fields.

Mortality data are frequently the only long term and population-based statistics available. When the subject of study is malignant neoplasms, central cancer registries can be of value, but they are of comparatively recent establishment in Australia. Mortality statistics continue to be a primary source, particularly for investigations of time trends. They are also a vital source of follow-up information for clinicians and others, and provide a valuable check on the completeness of studies whose data are ascertained by other methods.[1]

Whatever the field of interest of a user, he or she will need to rely on the accuracy of the information on the Death Certificate (DC) and published mortality statistics. Of course, users have differing requirements as to degree of accuracy. As Glasser points out, epidemiologists studying relatively rare diseases will be exacting in their requirements, whereas community health planners may only need to know the relative ranks or magnitudes.[2] The reliability of the data for the proposed purpose cannot be determined in the absence of information on the accuracy of the routinely collected statistics to be used.

Research on the subject of accuracy of DCs in Australia is sparse. Two studies have examined them in relation to autopsy results but give little information on the accuracy of certificates in cancer deaths.[3,4] Nairn and her colleagues compared DCs with the outcome of a review of clinical, pathological and coronial data, with a view to clarifying the accuracy of the DC narrative and subsequent cause of death code.[5] The authors found 77 per cent agreement on cause of death for malignant neoplasms as a group, but gave no information for specific sites.

Only a limited number of overseas studies have examined DCs for malignancies in detail. They demonstrated a wide variation in accuracy according to primary site, as well as factors such as age.[6-8] The overall error in certification of breast cancer is comparatively small, estimated at 4 per cent in England and 7 per cent in Sweden.[9,10] Colo-rectal cancer in Exeter (England) was considered under-estimated by about 5 per cent.[11] DCs and hospital records for malignancies of the pancreas and lung were found to be concordant in 73 per cent and 78 per cent of cases respectively[12], but a detailed study of tonsil carcinoma found a concordance of only 59 per cent.[13]

As part of a survey into the incidence of testis cancer in the State of Victoria, we examined the cause of death narrative on relevant DCs. There are many characteristics of this tumour which should result in a high quality of certification. The majority of patients are young men and have been treated in hospital. The condition is readily diagnosed and the testis is not a common site of metastasis from other organs. Most patients

undergo orchidectomy, resulting in histological information upon which to base accurate diagnosis of the primary site.

This paper compares the cause of death, as recorded on the certificates, with hospital and other medical records, examines the effect of errors on published cause of death data and reviews the accuracy of specific histological terms given on the death certificates.

Materials and Methods

To determine the incidence of testicular cancer in Victoria between 1950 and 1978, a survey was made of all the records available for that time. Records in all pathology laboratories (except one which had ceased operation), public hospital clinical records, private radiotherapists' case notes and death certificates were meticulously searched, resulting in a series of 1562 cases.

The present paper is based on Victorian DCs acquired for this study. A list of registration numbers for the 364 DCs assigned to testis cancer for the years 1950-1977 was supplied by the Australian Bureau of Statistics (ABS) and copies of the certificates were then requested from the Victorian Registry of Births, Deaths and Marriages. Two certificates were not supplied, one whose registration number was unknown and one for unknown reasons, resulting in 362 certificates which had been the basis for cause of death statistics, as published in the ABS publications "Demography" (before 1963) and "Cause of Death" (1963 and after).

In order to detect any valid testis cancer deaths not recorded by the ABS ("false negatives"), we obtained DCs for all remaining men in our survey who had died in Victoria. The resulting 64 certificates were perused to identify those which failed to state a death medically confirmed as due to testis cancer (12), and those in which death was stated to be due to testis cancer yet which did not appear on the ABS list (5). The other 47 certificates were excluded from the remainder of the study.

Figure 1 categorises the total case material according to the nature of the medical data available. Where the histological specimen was available it was reviewed in the Pathology Department of the Peter MacCallum Cancer Institute. The histological system used was that of the British Testicular Tumour Panel.[14] Terms from other systems on pathology reports or DCs were converted into the British equivalent.

Calculations of measures of accuracy of DCs were carried out on 337 cases for which both DCs and other medical records were available and at least one gave testis cancer as cause of death. The study of pathological terms was restricted to 246 cases where such terms were used on the DC and histological review had produced a reliable diagnosis.

Figure 1: Nature of medical data available for Victorian testis cancer death certificates

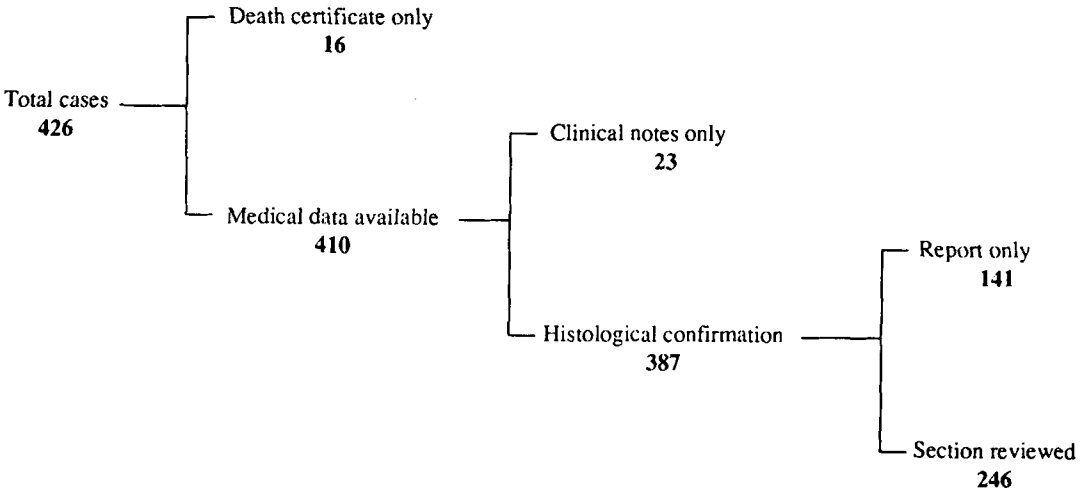

Table 1

Errors in narrative on Victorian testis cancer death certificates

Nature of Error	False Positives	False Negatives
Site of malignancy inaccurate	8	7 *
Confirmed testis cancer, intercurrent cause of death	2	-
Diagnosis changed on review	4	5
Insufficient detail - lymphomas	1	-
Diagnosis changed on review - lymphomas	6	-
Total	21	12

* Includes two cases which were confirmed as testis cancer, had no testis cancer recorded on the DC, yet appear in cause of death statistics.

Results

Table 1 shows the nature of 33 errors made in the cause of death narrative, as determined by review of available records, resulting in 21 false positives and 12 false negatives. Of the false positives there were eight cases where medical records revealed the death to be due to malignancy at another site: kidney (2), the male breast (1), paratesticular organs (3), one non-testicular germ cell primary and one metastasis to the testis from an unknown primary site. There were two further patients with a history of testicular cancer who died of intercurrent causes (cancers of pancreas and lung) and whose DC wrongly ascribed death to testicular neoplasm. In four cases the cause of death on the DC was consistent with concurrent records, however our subsequent review process resulted in change of diagnosis to non-testicular germ cell primaries (2), one metastasis to the testis from an undetermined site and one with no malignancy seen in the testis at post-mortem. The remaining seven false positives were cases of testicular lymphoma and are discussed below.

The twelve false negatives fell into two categories. Seven DCs failed to record death as due to confirmed testicular malignancy – two stated generalised cancer only, two gave other sites (epididymis, bronchus) and three gave only non-malignant conditions. Five other cases were determined upon review to have died due to malignancies originating in the testis. Their DCs stated primary unknown (3) or other sites (kidney, retroperitoneal teratoma).

For the eighteen cases (11 false positives and 7 false negatives) in which it appears that a mistake had been made by the certifying medical officer, a check was made on where the patient died to see whether full information should have been available to the physician. Ten died in hospital, two probably did and one certificate had been written by the coroner. The other five were probably certified by the local medical officer who may not have been in possession of all medical reports.

Ten of the false negatives do not appear in the list of DCs supplied by the ABS which corresponds to published cause of death statistics. The other two were included in spite of the DCs failure to state known testicular malignancy, presumably due to a follow-up query during the recording process at the ABS (as outlined by Nairn and colleagues[5]).

Table 2 shows the 17 errors made in coding of DCs at the ABS, resulting in a further 12 false positives and five false negatives. The false positives include three DCs whose narratives gave other conditions (one metastatic cancer, two non-malignancies) and four cases where the DC noted pre-existing testicular malignancy but ascribed death to intercurrent causes. The DCs of the three non-testicular germ cell primaries clearly stated the site of the tumour. In accordance with the rules of the International Classification of Disease (ICD)[15] requiring that coding be by site, these should have been assigned to that site. The two lymphomas are discussed below. The five false negatives consisted of DCs stating death as due to malignancies of testicular origin yet not coded to that category.

Table 2

Errors in cause of death data derived from Victorian testis cancer death certificates

Nature of Error	False Positives	False Negatives
DC* records correct site of malignancy	1	5
DC records no malignancy	2	-
DC records intercurrent cause of death	4	-
DC records non-testicular germ cell primary	3	-
DC records lymphoma	2	-
Total	12	5

* DC = Death Certificate

Table 3

Concordance, detection and confirmation rates for Victorian testis cancer death certificates

A.	No. of cases with diagnosis of testis cancer following review	323
B.	No. of cases with testis cancer as cause of death on Death Certificate	322
C.	No. of cases in agreement	308
D.	Total cases in A and/or B	337

Detection $\frac{C}{A} = \frac{308}{323} = 95\%$ Confirmation $\frac{C}{B} = \frac{308}{322} = 96\%$ Concordance $\frac{C}{D} = \frac{308}{337} = 91\%$

Primary lymphomas of the testis present some difficulties. ICD rules require tumours of lymphatic tissue to be coded by morphology rather than site. In seven cases of primary lymphoma of the testis the DC was inaccurate (in six of these the diagnoses were revised on review). In a further two cases the DC accurately stated the death as due to lymphoma of the testis but the cases were incorrectly assigned to the site, testis. A correct application of ICD coding rules to testis lymphomas would thus have resulted in nine fewer cases, that is, there were nine false positives in published statistics.

Table 3 presents rates which estimate the accuracy of the certification process.[13] The detection rate reflects the proportion of total testis cancer deaths which were correctly certified. The confirmation rate is the proportion of cases ascribed to testis cancer on DCs which are substantiated by other means. Concordance measures the overall agreement between DCs and medical records.

Table 4 demonstrates the degree of reliability of particular histological terms used on the death certificates. The accuracy of diagnosis varied considerably over the range of histological types of testicular malignancy, the low confirmation rate of seminomas (50%) and low detection rate of lymphomas (21%) being particularly note-worthy.

Although peripheral to this study, a further error in mortality statistics should be recorded. Two deaths were listed as having occurred in 1961, and included in published figures for that year. Examination of the DCs revealed that the deaths actually occurred and were registered in 1960. Thus the published figure of 13 deaths for 1960 is short by two, and that for 1961, also 13, in excess by two.

Table 4

Reliability of pathological terms on Victorian testis cancer death certificates

Pathological Term on Death Certificate	Pathological Review								Detection Rate (%)
	Seminoma	Teratoma	Combined Seminoma & Teratoma	Yolk Sac Tumour	Lymphoma	Interstitial or Sertoli Cell Tumour	Sarcoma	Total	
Seminoma	58	36	10	2	8	1	-	115	50
Teratoma	4	95	10	1	2	-	-	112	85
Combined	1	3	3	-	-	-	-	7	43
Yolk Sac Tumour	-	-	-	-	-	-	-	0	0
Lymphoma	-	-	1	-	3	-	-	4	75
Sarcoma	2	-	-	-	1	-	6	9	67
Total	**65**	**134**	**24**	**3**	**14**	**1**	**6**	**247**	
Confirmation Rate (%)	89	71	13	0	21	0	100		

Discussion

This study investigated the accuracy of testis cancer mortality data at two levels: the accuracy of the cause of death data on death certificates and the resultant effect on published cause of death statistics.

As Nairn and her colleagues found, a major problem is unsatisfactory narrative on the certificates themselves.[5] Eighteen of the 33 inaccurate DCs failed to mention or inaccurately recorded a clinically and pathologically established diagnosis. Such inadequate certificates have been called the "lazy" group.[16] The observation that the majority of patients in this category in our study died in hospital indicates that the inaccuracy was generally not due to lack of access to medical records.

The DCs examined in this Victorian study proved to have a better accuracy rate than that found in a US study which compared DCs with information from the Third National Cancer Survey.[6] Their detection rate was 83 per cent and confirmation rate was 90 per cent for testis malignancies, and a concordance rate of 76 per cent can be derived from their published figures. The only other available study which presents accuracy rates for testis cancer found a concordance of 100 per cent.[17] Although they do not give the number of cases it is likely that only a small number of their 1405 autopsied malignancies were of the testis.

A major source of inaccuracy in DCs of testis tumours is in the use of pathological terms. The most common error is the use of the term seminoma when a non-seminomatous germ cell tumour has been histologically verified. Only on 50 per cent of DCs where the term is used was that diagnosis confirmed on review. This suggests that the term is being used generically as an equivalent to "testis cancer". Only three out of fourteen histologically demonstrated lymphomas were so named on the DC. This may be due to the pathologist lacking experience with testicular malignancies. The low confirmation rate for combined tumours may be due in some cases to the use of the term "mixed" on DCs. It is possible that, rather than referring to combined seminoma and teratoma, it may have been used to describe a mixture of tissues of varying differentiation, that is, malignant teratoma intermediate type in the British classification.

Certifying physicians are not required to specify histological terms on the DC. But since the practice is common in the case of testis cancer it would be preferable for the terms to be used more accurately. Correct certification also depends on an accurate pathology report which, in the case of a comparatively rare malignancy such as testis, will depend partly on the experience of the pathologist.

Histology may be important to researchers and clinicians. Williams, for example, suggested

following up a study correlating occupation with testicular cancer mortality rates by scrutinising DCs for histological type.[18] Treatment varies according to histology, and a user concerned with the outcome of therapy may well wish to distinguish between seminoma and non-seminoma germ cell tumours, as well as lymphomas, interstitial cell tumours or sarcomas. Given the inaccuracies demonstrated in this study it would be inappropriate to use DCs to form any estimate of the breakdown of testicular tumour types.

Unlike other malignant neoplasms, according to ICD rules lymphomas should be grouped by morphology rather than topology. While lymphomas and leukaemias can infiltrate the testis from other primary sites, they also occur as primary tumours of the testis. Our results show that coding by morphology was done inconsistently in the case of primary lymphomas of the testis. Where the site was given on the DC, or the morphology was not stated, (or proved to be lymphoma only upon review), the tendency was to group them with testis cancer. The result, applying ICD rules, has been nine false positives.

Others have noted difficulties with reporting lymphomas. Saxen pointed out that a low histological confirmation rate would lead to lymphomas being grouped on a site basis which would result in very differing rates of malignancies of the small intestine, since up to 90 per cent of tumours of this site are lymphosarcomas.[19]

Pike et al. have also drawn attention to the incorrect coding of primary lymphomas of the testis as primary testicular tumours (ICD 186) in Britain, which inflates the rates in older age groups.[20] Their recommendation that the issue be investigated by the appropriate government authority should also apply in Australia.

A similar problem arises with sarcomas. Failure of the certifier to note that the tumour is primarily in an appendage such as the spermatic cord results in coding of the malignancy as 186 (testis) rather than 187 (other male genital). Errors also occurred with incorrect categorization of some non-testicular germ cell primaries, resulting from a failure to record the site on the DC or from incorrect coding of adequate narrative.The consequence of the errors in DC narrative and ABS coding is a total of 33 false positives and 15 false negatives in published cause of death statistics relating to testis cancer for the period 1950-1977. As others have found, the number of false negatives partly counteracts the number of false positives.[21] For many users, the data could be adversely affected nonetheless, as age and other attributes might vary.

This study has shown that the accuracy of Victorian DCs for testis malignancy would be acceptable for most purposes except where histological sub-type is required. The major inaccuracies are related to differences of pathological interpretation and an apparent inadequate use of information which should have been available when the patient died in hospital. Interns are not often instructed in the importance of accurate certification of death. Coding errors were nearly as frequent as those of certification. This is a matter for the ABS whose methods were not examined in this study.

The user of DCs and mortality statistics should be aware of potential errors and the consequences of those errors on their work. Provided it is merely the fact of testicular malignancy and not the detailed histology which is being researched, the use of Victorian death certificate data is satisfactory as a measure of mortality due to testicular malignancy.

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