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COMPARISON BETWEEN DIAGNOSES IN THE STOCKHOLM REGIONAL CANCER REGISTER AND CERTIFIED UNDERLYING CAUSES OF DEATH

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Abstract

Data in the Stockholm Regional Cancer Register were compared with death certificates for persons who died of carcinoma in 1978 and were domiciled in Stockholm County. Concordance between cancer register diagnosis and certified underlying cause of death was 87 per cent. Many malignant tumours in organs which often show metastases were unspecified by one of the registers. In many other cases of discordance, differing site codes denoted anatomically close-lying organs. Age distribution did not differ between concordant and discordant diagnostic groups. Coordination of the cancer register and the mortality statistics as regards coding routines and disease classification presumably would enhance inter-register comparability.

Investigations on cancer epidemiology are often dependent on access to reliable assessments of incidence of the relevant disease within a population. Such data are commonly obtained from cancer registers or registers of mortality. Possible sources of error in the use of such registers for assessing incidence were exhaustively discussed by earlier authors (7).

In the Scandinavian countries, the prospects for use of registers of cancer and of mortality are favourable, as the population is well charted, the mortality statistics are based on obligatory death certificates issued by attending doctors, and population-based cancer registers have existed since the 1940s

or 1950s. The Swedish cancer register is compiled from statutory notifications of disease. Nevertheless, we found in previous studies that the cancer register showed a 3 to 4 per cent deficit when compared with the register of causes of death or the register of in-patient care (10, 11). Discrepancies between statistics from the cause-of-death register and the cancer register sometimes originate in differences in the recording routines. When a case of multiple malignant tumours is notified to the cancer registry, each tumour is recorded as a separate case, whereas in the cause-of-death register the record would be that of a single case with one underlying cause of death. Some registered tumours, moreover, will not be recorded as cause of death, for instance if the affected person dies of intercurrent disease.

Many death-certificate reports of cancer were shown in several studies to be unreliable when comparisons were made with the case records and the autopsy findings, e.g. metastatic disease being reported as primary tumour (1, 3–6, 13). The purpose of the investigation here presented was to compare diagnoses of malignant tumour in the Stockholm regional cancer register with underlying causes of death recorded at the National Central Bureau of Statistics (NCBS).

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Table 1

Survey of diagnoses according to cancer register and death certificates. Figures in bold face denote inter-register concordance and those in parentheses cases with discordant diagnoses

Primary site in cancer register (ICD 7)	Underlying cause of death, site (ICD 8)						
	Head, neck	Stomach	Colon, rectum	Liver	Pancreas	Lung	Breast
Single tumours	140-149, 160, 161	151	153, 154	155, 156	157	162, 163	174
Head, neck	140-148, 160, 161	68 (8)			1	2	1
Stomach	151	200	1	5	1	2	
Colon, rectum	153, 154		314 (32)	1			
Liver	155, 156	1		153 (9)	3	4	
Pancreas	157		1	4	187	2	
Lung	162, 163, 164			3	4	487 (1)	
Breast	170	1		4		1	241
Cervix uteri	171	1	1				
Corpus uteri, uterus NOS	172-174		1				
Ovary, other fem. gen. org.	175, 176				1		1
Prostate	177			2	2	2	
Kidney, urinary bladder urinary organs NOS	180, 181		1		1	2	
Skin, malignant melanoma of skin	190, 191	1	2	2	1	3	1
Lymphomas, leukaemia	200-209	1				1	
Other spec. sites		1	3		2	2	
Unspecified sites	199	1	3	9	9	26	
Total		82	206	359	192	212	244

Material and Methods

The Swedish Cause-of-Death Register and the regional Stockholm County Cancer Register formed the basis for the present study. The comparisons concerned persons with malignant tumours who appeared in both registers and who were domiciled in Stockholm County and died in 1978. The age at diagnosis and the time between diagnosis and death were calculated, and the diagnostic distributions in the two registers were compared.

Registration of causes of death at NCBS. Data on deaths and causes of deaths are systematically collected by the cause-of-death registry at NCBS. The basic data are obtained from the obligatory death certificates issued by medical officers after all deaths and sent to NCBS via local population registrars. The information on the death certificates is processed and coded at NCBS in accordance with

internationally accepted rules (15). The recorded 'underlying cause of death' then forms the basis for the entry in the official mortality statistics. These statistics require a single underlying cause of death in each individual case. For the present study we accepted the coding of underlying causes of death used at NCBS.

Registration at Swedish cancer registries. The Swedish Cancer Registry was established in 1958. Notification of diagnosed cancer is obligatory for the attending clinician and also for any pathologist and/or cytologist involved in the case. Since the late 1970s the primary processing of cancer notifications is done at six regional registries, which each year deliver coded data to the Central Cancer Registry. Stockholm County, which is largely urban, has a population of about 1.5 million. The Regional Cancer Registry receives each year more than 6000

Table 1 (cont.)

Cervix uteri	Corpus uteri, uterus NOS	Ovary, other fem. gen. org.	Prostate	Kidney, urinary bladder, urinary org. NOS	Skin, malignant melanoma of skin	Lym- phomas, leukaemia	Other spec. sites	Unspec. sites	Benign	Total
180	181, 182	183, 184	185	188, 189	172, 173	200- 209		195- 199		
		2			2		4	1		87
			1			1	1	3		215
				2				6	1	356
								17		189
		1	1	2			1	4		198
	1	1		1			2	12	1	513
64	10	1						3		255
										78
2	46	3					1	2	1	56
	3	121 (2)						7		135
			220	2		1		2		231
				188 (4)		1	3	2		202
					33 (1)			4		48
		1		3	1	209 (36)	4	4	1	257
	2	2	1	2	4	2	179 (15)	7	13	235
					1	3	11	40	1	112
66	62	134	223	204	42	253	221	114	18	3 167

notifications of malignant tumours (12). The register contains information on all notified cancer cases diagnosed within the region since 1958. The cases diagnosed before 1974 were obtained from the Central Cancer Registry.

The cancer registry records multiple malignant tumours in single patients as separate 'cases', which are allocated to the same host via the patient's personal identity number according to the WHO recommendations (9).

Inter-register record linkage. The cause-of-death register and the cancer register both rely on the above-mentioned personal identity number (ID-number), allocated to all residents in Sweden at birth or at immigration. The ID-number consists of the year, month and day of birth and a four-digit serial number.

By computerized record linkage, using the ID-

numbers, dates and causes of deaths are transmitted yearly from the register of deaths to the cancer registry. The records in the cancer registry thereby are supplemented with information on underlying cause of death. If cancer is stated as a contributory cause of death, this is also notified.

Selection of cancer cases for the investigation. From the regional cancer register in Stockholm we selected 3 167 persons with a single malignant tumour in the cancer register (ICD7 140-209) and who died in 1978 with a tumour stated as the underlying cause of death (ICD8 140-239).

This restriction implied that 408 persons recorded in the cancer register with a total of 855 malignant tumours were excluded as, because of the single registration in the mortality statistics, the diagnoses were not directly comparable. Also excluded were 941 registered cancer patients who died in 1978 from

Table 2

Cases recorded as single tumour of colon or rectum. Detailed comparison of cancer register and death certificate diagnoses

Classification in cancer register (ICD 7)	Classification on death certificates (ICD 8)								Total	
	Colon					Rectum				
	Caecum, Trans-ascending colon and appendix	verse	De-scending	Sigmoid	NOS	Recto-sigmoid	Rectum	Anus, etc.		
	(153.0)	(153.1)	(153.2)	(153.3)	(153.8)	(154.0)	(154.1)	(154.2)		
Colon										
Caecum, ascending colon and appendix	(153.0)	36			1	30		3	70	
Transverse	(153.1)	1	7			22		1	31	
Descending	(153.2)		1	1		5			7	
Sigmoid	(153.3)	2			39	22	1	9	73	
Multiple parts	(153.8)				1	4		1	6	
NOS	(153.9)	2	1		2	31			36	
Rectum										
Rectosigmoid	(154.0)		1		5	11		104	2	123
Total		41	10	1	48	125	1	118	2	346

non-neoplastic disease. A separate analysis of these groups is in progress.

Comparison between the coded cancer diagnoses. The diagnoses recorded in the cancer register were compared with the certified underlying cause of death according to the NCBS register. The comparisons were made at individual level, to assess accord or discord between the registers.

During 1978, diagnostic coding in the Cancer Registry was done according to the 7th revision (ICD7) of the WHO classification (16), whereas at NCBS the 8th revision (ICD8) was used (17). Because of this difference, the four-digit code used by the Cancer Registry was 'transcribed' to fit the NCBS code. For assessments of concordance between the registers, however, comparisons were made at three-digit level (ICD8).

Although there were difficulties in direct transcription of the codes for some sites, these problems were without major importance for most tumour sites in comparisons at three-digit level. As regards the respiratory organs, however, the three-digit transcription implied that pulmonary tumours of uncertain primary/secondary nature (ICD7 163) were grouped together with primary lung cancers (ICD8 162.1). 'Liver cancer, unspecified as primary or secondary' (ICD7 156) had no direct equivalent in the NCBS coding system. In analogy with lung carcino-

ma, these cases were grouped together with 'primary cancer of the liver' (ICD8 155.0). Concerning non-Hodgkin's lymphomas, coding practice has not been consistent at the Cancer Registry. Consequently, separation into subgroups was not feasible. Similar inconsistencies applied to the leukaemias, for which the coding practice has been changed several times at the Cancer Registry. In both ICD7 and ICD8 there are several codings which indicate more or less unspecified tumour sites, e.g. 'malignant abdominal tumour, no further specification'. In such cases, concordance between tumour sites was accepted even when the coding in one register was somewhat more specific than in the other. Thus 'malignant abdominal tumour, no further specification' according to a death certificate was regarded as concordant with 'malignant tumour, no further specification' in the cancer register.

Discordance between the registers arose in some cases from differing rules for use of the coding system. The cancer register records both the clinical and the histologic diagnoses. Certain histologically benign tumours which, according to the statutory guidelines, are eligible for registration in the cancer register have been included in the study. These cases receive the same site codes as malignant tumours, e.g. benign brain tumours, papilloma of the urinary bladder and certain benign tumours of endo-

Table 3

Cases recorded as single tumour of liver or biliary tract. Detailed comparison of cancer register and death certificate diagnoses

Classification in cancer register (ICD 7)	Classification on death certificates (ICD 8)					Total
	Liver primary (155.0)	Intra-hepatic bile ducts (155.1)	Extra-hepatic bile ducts (156.0)	Gall-bladder (156.1)	Vater's papilla (156.2)	
Liver primary (155.0)	56	6		1		63
Gallbladder, extrahepatic bile ducts and Vater's papilla (155.1)	3	5	65	10	4	87
Liver NOS (156)	11	1				12
Total	70	12	65	11	4	162

crine origin. In the mortality register, however, with the record based only on the clinical diagnosis as stated on the death certificate, the coding will be benign tumour (ICD8 210–239).

Results

Table 1 presents a detailed comparison of the diagnoses in the cancer register and the recorded underlying causes of death. For convenience, the figures for some anatomically close-lying sites are grouped together. The diagonally arranged 'bold' figures represent cases with concordance between cancer register diagnosis and underlying cause of death. The figures in parentheses denote cases with discordant diagnoses at the three-digit level, though falling within the broader groups used in the table.

The diagnoses were concordant in 2750 patients (87%), i.e. the same tumour site was recorded both in the cancer register and in the NCBS cause-of-death register. The recorded underlying cause of death was benign tumour in 18 cases (0.7%). Among the 13 cases included among 'other specified sites' according to the cancer register (Table 1), 11 were, in fact, benign brain tumours which, because of the histologic coding, had received the same site code as malignant tumours.

Discordant cancer diagnoses were recorded in 399 cases (13%). Of these malignant tumours, 146 (37%) were attributed a specified site in one register but were of unspecified site according to the other register. Among the cases with death certificate

stating lung carcinoma, for instance, 26 of the 48 showing inter-register discordance were described as unspecified in the cancer register. Similarly, 36 of the malignant tumours classified as liver carcinoma in the cancer register showed inter-register discordance, including 17 stated on the death certificates to be of unspecified site.

In many cases with discordance of cancer diagnoses, the different site codes denoted anatomically close-lying organs, e.g. tumours of the head and neck region, or of intraabdominal organs. Discordance of cancer diagnoses was also relatively frequent within the lymphoma/leukaemia group. No difference between the concordant and discordant groups could be demonstrated either in respect of age distribution or time from primary cancer diagnosis to death.

Detailed analysis of certain tumour sites. Some sites showing inter-register discrepancies within the site groups used in Table 1 were analyzed in more detail (Tables 2–6). These tables also exemplify some of the aforementioned difficulties in transcription of the ICD codes.

At the four-digit level of the ICD code there were great discrepancies in the coding among the combined group of malignant tumours in *colon and rectum* (Table 2). The tumour site in the colon was more often stated as unspecified on death certificates than in the cancer register. At the three-digit level the diagnoses were concordant in 314 (91%) of the cases. In 15 cases recorded as colon carcinoma in the cancer register, the underlying cause of death

Table 4

Cases recorded as single tumour of the respiratory tract. Detailed comparison of cancer register and death certificate diagnoses

Classification in cancer register (ICD 7)	Classification on death certificates (ICD 8)			Total
	Trachea (162.0)	Bronchus (162.1)	Pleura (163.0)	
Trachea (162.0)	1			1
Bronchus and lung primary (162.1)	2	441		443
Lung not specified as primary (163)		37	1	38
Pleura (162.2)			6	6
Total	3	478	7	488

Table 5

Cases recorded as single tumour of female genital organs. Detailed comparison of cancer register and death certificate diagnoses

Classification in cancer register (ICD 7)		Classification on death certificates (ICD 8)							Total
		Cervix uteri 180.9	Corpus uteri 182.0	Uterus NOS 182.9	Ovary 183.0	Ovary NOS 183.9	Vulva 184.1	Unspec. female genital org. 184.9	
Cervix uteri	171	64	2	8				1	75
Corpus uteri	172		22	16	3				41
Uterus NOS	174	2		8					10
Ovary	175.0		1	2	111	1		1	116
Vulva	176.0						6		6
Unspecified female genital org.	176.9				2			2	4
Total		66	25	34	116	1	6	4	252

was stated to be rectal carcinoma and, conversely, in 17 cases with colon carcinoma as cause of death, the cancer register stated rectum as the site of malignant tumour.

Tumours of the *liver and biliary* tract were grouped together in Table 1 because ICD7 and ICD8 were not fully comparable. The detailed comparison in Table 3 shows that in 12 cases with death certificate stating primary liver tumour, the record in the cancer register showed uncertainty as to whether the tumour was primary or secondary.

Although 487 cases of *respiratory tract* cancer were found to be concordant at the three-digit level (Table 1), the comparison at the four-digit level revealed some differences (Table 4). The most important of these differences arose from 37 cases in

which the death certificates stated primary carcinoma of the lung (ICD8 162.1), but in which the distinction between primary and secondary lung carcinoma was regarded as uncertain (ICD7 163) in the cancer register.

Of the 252 malignant tumours of *female genital organs* according to both registers, 213 (85%) were diagnostically concordant (Table 5). Non-specification of tumour site within the uterus was more common on death certificates than in the cancer register. Moreover, of 75 cervix uteri tumours in the cancer register, 11 were stated on death certificates to be carcinoma of the corpus uteri or of unspecified site.

Within the *lymphoma/leukaemia* group there were also inter-register differences. Table 6 shows that in altogether 209 cases (85%) the diagnoses were iden-

Table 6

Cases recorded only as malignant lymphoma or leukaemia. Detailed comparison of cancer register and death certificate diagnoses

Classification in cancer register (ICD 7)		Classification on death certificates (ICD 8)							Total
		Non-Hodgkin's lymphomas	Hodgkin's disease	Multiple myeloma	Lymphatic leukaemia	Myeloid leukaemia	Monocytic leukaemia	Other leukaemia	Polycythaemia vera
		200+202	201	203	204	205	206	207	208
Non-Hodgkin's lymphomas	200+202	56	5		1				62
Hodgkin's disease	201	5	26						31
Multiple myeloma	203			58	1				59
Lymphatic leukaemia	204	4			21	1		3	30
Myeloid leukaemia	205				3	33		4	40
Monocytic leukaemia	206						1	3	4
Other leukaemia	207			1	1	2	1	4	9
Polycythaemia vera	208								10
Total		65	31	59	27	36	2	14	245

tical at the three-digit code level. Unspecified leukaemia diagnosis was stated in one or other of the registers in 15 of the 36 discordant cases. Among 92 diagnoses of either Hodgkin's or non-Hodgkin's lymphoma in the two registers, the diagnoses were the same in 82 cases (89%).

Discussion

Population-based cancer statistics are often utilized as a basis for epidemiologic research. Registers of incidence and of mortality are used to estimate cancer incidence in populations. The type of register selected for such studies is often decided by the quality of the available registered data.

Both of the mentioned register types have advantages and disadvantages. The purpose of a cancer register is to record all types of malignancy, including multiple malignant tumours, but the completeness in regard to number of cases may be questionable (2, 8, 10, 11). Cause-of-death registers based on obligatory death certificates usually are fully comprehensive but errors in accuracy of cancer diagnoses have been shown to occur in such registers, however (1, 5, 13).

In Sweden both the Cancer Register and the Cause-of-Death Register are population-based, and reporting to them is obligatory for clinicians involved in cancer cases. Two earlier investigations on the completeness of cancer registration in Swe-

den nevertheless showed a deficit of about 3 to 4 per cent in comparison with other sources of information (10, 11). The aim of the present study was to evaluate the degree of accordance between diagnostic information in the cancer register and underlying causes of death as recorded in the mortality statistics. The comparisons comprised persons with single malignant tumours who died in 1978 and at the time of diagnosis were domiciled in Stockholm County.

Concordance was found between the cancer register data and the cause-of-death register data in 87 per cent of the studied cases. Between the registers, however, there were discrepancies which were not insignificant in regard to certain tumour types, such as carcinoma of the respiratory organs or liver. In such cases the cancer register relatively often recorded uncertainty concerning primary or secondary nature of tumours which on death certificates were simply described as primary. Lungs and liver are often sites of metastases, and also from other studies dealing with death certificates some over-registration of tumours in these organs has been reported (5). The widest inter-register discrepancies were demonstrated in regard to tumours of the lungs, pancreas and liver.

This circumstance may explain why the Swedish mortality statistics in some years show more cases of lung carcinoma than the numbers indicated by the incidence statistics from the Cancer Registry. In

such lethal diseases as lung and liver carcinoma, deaths during a given year should reach approximately the same total as the number of cases diagnosed in the same time.

Furthermore, in many of the discordant cancer diagnoses the differing site codes represented anatomically close-lying organs, e.g. intraabdominal or female genital organs, as other authors also have found (13).

Inconsistencies in coding routines within the registries could have contributed to discordance between diagnoses recorded in the cancer register and those certified as causing death, as in the lymphoma and leukaemia groups.

Since the present investigation was based solely on data from the two registers, it does not show which of the two was the more reliable concerning diagnoses. Entries in the cancer register, however, are in most cases based on double notification, made independently by clinicians and pathologists. Possibly, therefore, cancer register diagnoses are more reliable than death certificates, many of which are issued by doctors who have attended the patients only in the terminal phase of the disease (5, 14).

A supplementary study is now in progress to investigate further the validity of both registers, with detailed exploration of individual diagnoses, utilizing hospital records and thereby seeking clarification of the most likely reasons for discrepancy in individual cases.

Although the present comparisons between diagnoses in the cancer register and on death certificates showed fairly good concordance, apart from some types of malignant tumours, there are several other differences which are important when both registers are used as a basis for epidemiologic research. Examples are the differing principles for registration and the deficit in the cancer register. For use in epidemiologic studies and for health service planning, therefore, coordination of the two registers would seem to be desirable. Use of the same coding routines and the same ICD revision should enhance inter-register comparability.

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