

COMPLETENESS OF THE SWEDISH CANCER REGISTER

Non-notified cancer cases recorded on death certificates in 1978

B. MATTSSON and A. WALLGREN

Abstract

Of the death certificates issued in Sweden in 1978 and stating cancer as the underlying or contributory cause of death, 1 634 cases were unrecorded in the national cancer register. In 62 per cent of the cases the criteria for cancer registration were fulfilled. The non-reported cases represented a total deficit of 4.5 per cent calculated on cancer deaths in 1978. The factors responsible for the deficit were investigated. When the diagnosis had been histologically/cytologically confirmed the deficit was less than 2 per cent but was about 30 per cent when the diagnostic basis was only clinical. More than half of the non-notified cancer patients were older than 75 years. Exclusion of this age group and of myeloma and leukaemia cases gave a cancer-register deficit of 2.3 per cent. Non-notification to the Swedish cancer registry can be diminished by supplementation with data from death certificates, as practised in other Nordic countries. On regional basis these death certificates will now be collected and used as a supplement to the cancer notification in Sweden.

Epidemiologic studies of cancer commonly are dependent on data from registers of cancer and mortality. The completeness and consistency of the registers thus are important for the quality of such studies. Many comparisons between data in cancer records and death certificates have been made for qualitative evaluation of the respective registers (2-5, 13). Analyses of cancer registers in comparison with morbidity or mortality registers in different countries are never fully comparable, however, because of disparities in systems of health care and in obligation to notify cases, routines for registration, etc. (1, 6). In the Nordic countries, cancer registers

are based primarily on notifications from diagnosing doctors. In Sweden the cancer registry does not accept information only on death certificates, whereas in other countries death certificates can suffice for this purpose. Record linkage between the cancer register and the register of deaths in Sweden identify for each year a number of cases recorded as cancer solely on death certificates and not entered in the cancer registry files.

A preliminary investigation of death certificates from 1970 stating cancer in cases not in the cancer register generated the hypothesis that the probability of cancer notification is appreciably increased if the obligation to notify applies to more than one source (14). The main purposes of the investigation now presented were to identify cases of cancer according to death certificates in 1978 but unknown to the cancer registry, to analyse the factors of significance for this non-registration, and to see if the results of the 1970 study could be confirmed in a more comprehensive survey.

The data that could be included in the study were diagnosis, diagnostic basis, age and domicile of the patients and interrelationships in these respects.

Material and Methods

The Swedish cancer register and the register of deaths for 1978 were utilized in the study. Both

From the Department of Oncology and Cancer Epidemiology, Radiumhemmet, Karolinska Sjukhuset, S-10401 Stockholm, Sweden. Accepted for publication 9 March 1984.

registers cover the total population of Sweden (c. 8.3 million). All population-based registers in Sweden which contain information on individuals are based on the unique identification numbers (ID numbers) allocated to all residents in the country. These numbers permit computerized record-linkage between the registers.

Information on deaths and causes of death is systematically collected by the National Central Bureau of Statistics. All deaths must be certified by physicians and the certificates are forwarded to the Bureau via population registrars. The underlying and contributory causes of death are coded and stored in computer files.

The Swedish cancer registry, which is managed by the National Board of Health and Welfare, was established in 1958. According to the medical statutes, every case of primary cancer must be separately notified to the cancer registry by the responsible clinician and also by the pathologist/cytologist involved in the case. In 1978, however, the obligation to notify had not yet been extended to general practitioners. Registrable cancer is considered to be present when the diagnosis has been histologically or cytologically confirmed, or from other investigations is judged by the clinician to be so reliable that it leads to therapeutic decisions.

Each diagnosed primary tumour is recorded by the registry as a separate case. Multiple tumours are sequentially numbered and can be assigned to the individual host by use of the ID-number. Many cases are reported on several occasions to the cancer registry: pathologists tend to notify every new recurrence of a tumour, and also the autopsy results. A patient referred from one clinic to another may be reported to the cancer registry from each department. Record linkage with the aid of ID-numbers, however, ensures that each tumour receives a single registration.

Identification of cases for the study. The annual record linkage between the Swedish cancer registry and the death certificate files is usually performed 2 to 3 calendar years after the year of diagnosis. The matching of the diagnosis year 1978 revealed that 1 632 individuals with 1 634 tumours were not registered in the cancer register. Copies of the death certificates in these cases were obtained from the National Central Bureau of Statistics. In the cancer registry files there were 21 581 tumours which had been recorded in 19 567 individuals who died in 1978 with a cancer diagnosis on the death certificate.

These 21 581 registered tumours were used as a control group in the analyses as they were considered to fulfil the same criteria as the study group of non-notified cases, namely the same year of death and a cancer diagnosis mentioned on the death certificate as underlying or contributory cause of death.

Retrospective classification. The cases which were not recorded in the cancer registry files were investigated mainly by questionnaires sent to the doctors who had signed the death certificates or to the institutions in which the patients had died. The questions included date of the primary cancer diagnosis, the basis for this diagnosis and the type of malignancy as stated in the case records. Year of diagnosis and tumour site were determining factors for fulfilment of criteria for cancer registration and were essential for comparisons with the already registered cases. Entries in the cancer register always include the diagnostic basis, which was reclassified for this study as 1) operation/autopsy with histologic examination, 2) cytologic analysis, 3) operation/autopsy without histologic examination, or 4) clinical/roentgenologic analysis. Only one diagnostic basis is recorded for each case, e.g. if a case primarily was notified as a clinically diagnosed cancer, a histologic confirmation of the case changes the basis of diagnosis. In myeloma and leukaemia, the diagnostic investigations, including bone marrow analysis were often not done in pathologic departments and thus did not result in separate notifications and the basis of diagnosis was often coded as 'clinical' at the cancer registry.

Altogether 1 239 questionnaires were distributed. In the remaining 395 cases the records were scrutinized by the authors with collaboration from doctors at the respective units. The units selected for this personal search were those with particularly numerous non-registered cases. They comprised departments in large cities as well as in other areas of the country. In 98 of 1 634 cases the requested supplementary information was not obtained, due to non-availability of the records or to failure to complete the questionnaires. The response rate to the inquiry thus was 94 per cent.

Statistical analysis. The percentage deficit in the cancer register was calculated from the sum of already registered persons who died of cancer in 1978 and the potentially registrable cases indicated by the death certificates. Persons with more than one tumour could appear a corresponding number of times in the analysed material.

Table 1

Classification from retrospective inquiry concerning cancer recorded on death certificates but not notified to the Swedish cancer registry

Result of inquiry (deaths in 1978)	No. of cases	Per cent
Criteria for cancer registration fulfilled	1 013	62.0
Non-registrable cases		
No cancer, according to records	227	13.9
Diagnosis made before 1958	69	4.2
Diagnosis doubtful	227	13.9
Information unavailable	98	6.0
Total	1 634	100

Table 2

Registrable cancer cases identified from death certificates in 1978. Year of diagnosis

Year of diagnosis	Already in cancer register	Registrable but not notified	Total No. of cases	Cancer register deficit (%)
1958-1974	4 273	114	4 387	2.6
1975	1 247	41	1 288	3.2
1976	2 134	52	2 186	2.4
1977	4 913	186	5 099	3.6
1978	9 014	620	9 634	6.4
Total	21 581	1 013	22 594	4.5

To illustrate how several of the variables could simultaneously influence the register deficit, a multivariate analysis (AID analysis, OSIRIS III) was performed. This analysis was chosen because most of the observed background variables, viz. diagnosis and its basis and patients' domicile, were of free type, while the dependent variable (registered versus non-registered) was of dichotomous type. The AID method implies study of relationships between the dependent variable and the background variables. The programme successively splits the outset material into a number of mutually exclusive subgroups. Of all possible splits in a given step, the one that explains most of the variations in the dependent variable is selected. The AID tree indicates the constituent groups of the material in which the loss is specially cumulated. In the present analysis the partitioning process was terminated when any further split would have produced a subgroup with less than 25 individuals, when a split would have reduced the total variance with less than 0.5 per cent or when

the difference between subgroups did not reach the significance level of 0.05 per cent. Significance was calculated as described by GAVATIN & EKLUND (7) and JEREB & EKLUND (10), which considers the risk of artifact splits due to the great number of possible divisions in each step. In the pilot study (14), multiple myeloma and leukaemia were distinguished by specially frequent non-registration. Due to the inconsistencies in coding of the basis of diagnosis in these diseases, AID analyses of multiple myeloma and of leukaemia were done separately in the present investigation. The coefficient of determination, R^2 , was calculated. This is a measure of the part of variance explained by the analyses.

Results

Classification of death certificates. According to the replies to questionnaires and findings at search of records, the death certificates stating cancer were allocated to one of three main groups (Table 1): 1) Criteria for cancer registration fulfilled, 2) non-registrable cases, and 3) no information available.

Registration criteria fulfilled. Of the 1 634 tumours (1 632 persons) stated on death certificates in 1978 but not notified to the cancer registry, 1 013 were undoubted malignancies. This figure included the two cases in which two tumours were present and accordingly should have had four entries in the cancer register. Cancer notification was claimed to have been made for 7 per cent of the group. The reason for non-registration was not clear, except when, in a few cases, the completed notification forms were found in the case records of the hospital. The death certificates in 29 per cent of the cases stated that autopsy had been carried out. In the remainder the diagnosis had been made before death.

Non-registrable cases. The diagnosis of cancer on the death certificate was shown by the inquiry to be wrong in 227 cases (Table 1). In 44 per cent of these patients with *wrong diagnosis*, autopsy had not confirmed the clinical diagnosis of cancer. The death certificate in some cases clearly had been issued before the autopsy and had not been altered thereafter.

In 48 per cent of the 227 wrongly diagnosed cases, the death had been certified by a general practitioner or at a long-stay hospital unit. Such errors were most commonly attributed to misinterpretation of data in the case records. The distribution of cancer

Table 3

Registrable cancer cases identified from death certificates in 1978. Diagnostic basis

Diagnosis based on	Already in cancer register	Registrable but not notified	Total No. of cases	Cancer register deficit (%)
Surgery/autopsy and histology	17 346	315	17 661	1.8
Cytology	2 567	191	2 758	6.9
Surgery/autopsy, no histology	531	75	606	12.4
Clinical/roentgenologic examination	1 137	432	1 569	27.5
Total	21 581	1 013	22 594	4.5

diagnosis on the death certificates in this group was similar to that of the control group in the cancer register. The classification of non-specified site of primary tumour was however found in 15 per cent of the misleading certificates but in only 5.8 per cent of the cancer-registered patients who died in 1978. This group of 227 cases thus had been erroneously included in the mortality statistics for cancer in 1978.

The Swedish cancer registry covers only cases diagnosed since its establishment, in 1958. The inquiry revealed 69 non-registered cases with *cancer diagnosed before 1958*. These cases thus were ineligible for cancer registration, but were rightly included in the cancer mortality statistics.

In another 227 cases the inquiry yielded such *doubtful or poorly grounded information* that inclusion in the cancer register was regarded as unwarranted according to the statutory guidelines (Table 1). Autopsy had been done in 10 per cent of the cases, but was described on the death certificate as 'clinical' autopsy, i.e. without microscopy. In many replies to the questionnaires concerning these cases, diagnostic uncertainty was stated to be the reason for non-notification to the cancer registry. The recording of cancer on the death certificate, rightly or wrongly, led to inclusion in the cancer mortality statistics for 1978.

Information unavailable. In 98 cases (6%) the records were not obtainable or the questionnaire was unanswered for other reasons. In 65 of the 98 cases the death certificate had been issued by a general practitioner or a clinician in a long-stay unit of the health services. Seventeen of the patients had died at home and no hospital records could be traced. In 78 cases the diagnosis was made by clinical examination at the time of death without preceding investigation in hospital and without autopsy

confirmation. The distribution of the reported causes of death in this group strongly resembled that in the control material from the cancer register.

Analysis of the clearly notifiable cases

These 1013 cases constituted 4.5 per cent of all cancer deaths in 1978 with sufficient diagnostic certainty for inclusion in the cancer register (Table 2). The variables diagnosis, year of diagnosis, diagnostic basis, age and domicile were compared with corresponding data from the 21 581 registered cancer cases who died in 1978.

Diagnostic basis. Between the cases in the cancer register and those with cancer noted only on the death certificate the grounds for diagnosis differed considerably (Table 3). Diagnoses without histologic confirmation were strongly over-represented in the latter group. Thus the cancer register deficit was 27.5 per cent for the clinically diagnosed cases but only 1.8 per cent among those with histologic confirmation, which constituted 78 per cent of the total series. Although the category with operation or autopsy but not microscopy was most common in the non-registered group, it described only a small minority of the total cases.

Diagnosis. All cases are presented according to diagnosis in Table 4. In two types of malignancy the deficit in notifications to the cancer register was specially high, viz. multiple myeloma and leukaemia (16 and 18%). Other groups with higher than average loss to registration were malignancies of the nervous system, pancreas, stomach and prostate (7, 6, 5 and 5%, respectively).

Within the various diagnostic groups there were wide discrepancies in regard to the registered basis of diagnosis. Clinical or roentgenologic detection was most common in myeloma (29%) and leukaemia (23%), followed by tumours of the nervous

Table 4

Registrable cancer cases identified from death certificates in 1978. Diagnostic classification

Diagnosis	Already in cancer register	Registrable but not notified	Total No. of cases	Cancer register deficit (%)
Cancer of				
oral cavity	371	4	375	1.1
stomach	1 654	82	1 736	4.7
colon	1 768	67	1 835	3.6
rectum	1 002	21	1 023	2.0
pancreas	1 157	69	1 226	5.6
other digestive organs	1 485	62	1 547	4.0
lungs	2 125	68	2 193	3.1
skin	574	4	578	0.7
breast	1 789	35	1 824	1.9
female genital organs	1 624	12	1 636	0.7
prostate	2 173	105	2 278	4.6
other male genitalia	67	1	68	1.5
urinary organs	1 542	49	1 591	3.1
nervous system	672	49	721	6.8
thyroid	134	3	137	2.2
other specified sites	342	7	349	2.0
unspecified sites	1 247	105	1 352	7.8
Lymphoma	706	27	733	3.7
Myeloma	386	75	461	16.3
Leukaemia	763	168	931	18.0
Total	21 581	1 013	22 594	4.5

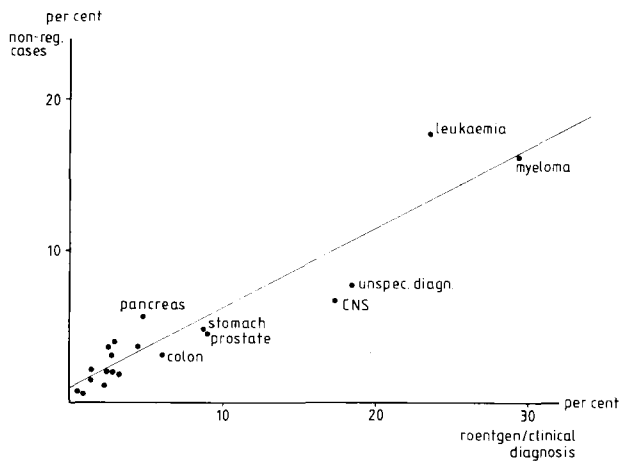


Fig. 1. The association between lack of histologic or cytologic confirmation of diagnosis and deficit in the cancer register.

system (17%) or of unspecified sites (19%). Many pancreatic, colonic and gastric cancers had been confirmed at operation or autopsy without histologic report. Cytologic confirmation was particularly common in cancer of the prostate and in myeloma and leukaemia (Table 5).

Fig. 1 illustrates the association between clinical-

ly based diagnosis and deficit in the cancer register. When this basis was common in a group, identification of cancer from death certificate only was proportionately more frequent than inclusion in the cancer register. This pattern was clearest in tumours of the nervous system and in multiple myeloma and leukaemia, with their high incidence of clinical (cytologic) investigations.

Age at diagnosis. Non-registration of cancer was most common among the patients who were 75 or older at the time of the diagnosis (Table 6). In age groups younger than 75 and with exclusion of the diagnosis myeloma and leukaemia the deficit was 2 per cent. Among the children younger than 15 years the figure was also relatively high, but the total in this age group was low. The contrasts between age groups diminished, however, when the cases were distributed according to basis for diagnosis (Table 7). The deficit in cancer registration was clearly greatest among the oldest patients with clinical diagnosis.

Domicile at diagnosis. The study of non-notified death certificates 1978 showed differences in registration deficit between the health care regions in

Table 5
Cancer register deficit (per cent) according to method of diagnosis

Diagnosis	Diagnostic methods (all registrable cases)				Cancer register deficit (%)
	Histology	Cytology	Surgery/autopsy, no histology	Clinical/roentgenologic	
Cancer of					
oral cavity	93.6	3.5	0.5	2.4	1.1
stomach	82.7	1.6	6.6	9.1	4.7
colon	86.2	1.5	8.0	4.4	3.6
rectum	95.1	0.5	1.6	2.8	2.0
pancreas	73.2	6.6	15.4	4.8	5.6
other digestive organs	90.0	4.1	2.9	3.0	4.0
lungs	79.5	17.4	0.4	2.7	3.1
skin	97.9	1.4	0	0.7	0.7
breast	85.6	11.0	0	3.3	1.9
female genitalia	95.0	4.1	0.1	0.8	0.7
prostate	47.2	43.3	0.5	9.0	4.6
other male genitalia	97.0	1.5	0	1.5	1.5
urinary organs	88.1	4.5	1.3	6.1	3.1
nervous system	80.0	0.8	1.8	17.4	6.8
thyroid	87.6	10.9	0	1.5	2.2
other specified sites	92.8	4.6	0.3	2.3	2.0
unspecified sites	57.2	21.8	2.4	18.6	7.8
Lymphoma	86.5	10.8	0.1	2.6	3.7
Myeloma	39.9	30.6	0.2	29.3	16.3
Leukaemia	46.6	30.0	0.3	23.1	18.0
Total	78.2	12.2	2.7	6.9	4.5

Sweden ranging from 4.1 per cent to 5.9 per cent. Each health care region consists of 2 to 5 counties. A chi-squared test (23 degrees of freedom) gave significant differences between the 24 counties ($p < 0.001$) in registration deficit ranging from 2.0 per cent to 8.4 per cent. These results remained if the basis of diagnosis was taken into consideration.

Year of diagnosis. More than 60 per cent of the non-notified tumours were diagnosed in 1978, i.e. the year of death (Table 2). In 13.2 per cent of these cases the basis of diagnosis was only clinical or roentgenologic compared with 6.9 per cent among patients with cancer diagnosed before 1978. These patients were also older, 48.8 per cent being 75 years of age and older compared with 29.9 per cent among the remaining cases. The deficit in notifications for 1978 thus was 6.4 per cent, which was significantly higher than the rates for the period 1958 through 1977.

Results of AID analysis

By a forced split according to diagnosis, the case material was divided into two groups, viz. group A

Table 6
Registrable cancer cases identified from death certificates in 1978. Age at diagnosis

Age (years)	Already in cancer register	Registrable but not notified	Total No. of cases	Cancer register deficit (%)
-14	107	9	116	7.8
15-49	1 494	30	1 524	2.0
50-64	5 134	126	5 260	2.4
65-69	3 205	103	3 308	3.1
70-74	3 680	161	3 841	4.2
75-79	3 643	174	3 817	4.6
80-	4 318	410	4 728	8.7
Total	21 581	1 013	22 594	4.5

with myeloma and leukaemia and group B with any of the other diagnoses (1 392 and 21 202 cases, respectively).

Group A (myeloma and leukaemia). The AID tree was first partitioned according to diagnostic basis,

Table 7

Cancer register deficit according to patient age and method of diagnosis. When the total number was less than 100 the percentage is given in parentheses

Age (years) at diagnosis	Diagnostic methods (No. =all cases; per cent=register deficit)							
	Histology		Cytology		Surgery/autopsy, no histology		Clinical/roent- genologic	
	No.	Per cent	No.	Per cent	No.	Per cent	No.	Per cent
-14	65	(6.1)	26	(15.4)	1		24	(42.0)
15-49	1 366	0.6	107	13.1	8	(12.5)	43	(16.3)
50-64	4 469	1.0	508	6.5	81	(11.1)	202	18.8
65-69	2 666	1.2	394	6.8	73	(12.3)	175	19.4
70-74	2 972	1.9	518	6.0	107	16.8	244	23.0
75-79	2 849	2.0	559	5.5	131	10.7	278	25.5
80-	3 274	3.4	646	7.9	205	11.7	603	37.3
Total	17 661	1.8	2 758	6.9	606	12.4	1 569	27.5

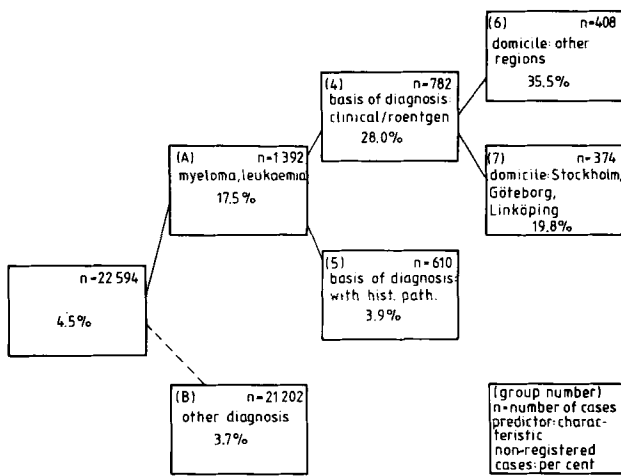


Fig. 2. AID-analysis of background variables (basis of diagnosis, age, diagnosis, domicile, year of diagnosis) with non-registered as dependent factor. Group A: Leukaemias and myelomas.

the cases with only clinical or cytologic diagnosis (28% cancer registration deficit) being separated from the histologically confirmed cases (3.9% deficit). The clinico-cytologic group was then split according to domicile at diagnosis, and the lowest deficit (20%) was found in three of the health care regions.

Group B (all other diagnoses). Here too the first split was based on diagnostic method, when clinical diagnosis (associated with 30% registration deficit) was separated from the groups with surgery or autopsy with or without histologic confirmation (defi-

cit 2%). In a second step the autopsy/operation cases without histology were detached from those with histologic confirmation. The registration deficit was lowest (1.8%) in this last group, which was the largest in the analysis (19386 cases). The clinically/roentgenologically diagnosed group was then partitioned according to diagnosis, but the notification deficit was relatively high in all splits. In certain diagnoses age was also a significant predictor.

The coefficient of determination, R^2 , for the total analysis was 16 per cent. An analysis only including the split according to diagnosis between myeloma/leukaemia and other diseases and the divisions according to basis of diagnosis resulting in groups Nos 4 and 5 of Fig. 2 and 8, 12 and 13 of Fig. 3 gave a coefficient of determination of 14 per cent. The additional splits, thus, reduced the variance very little.

Discussion

In the Swedish cancer register and the general statistics on mortality there are errors in the form of excessive as well as deficient registration. The reliability of diagnosis registration has been shown in a number of studies to be fairly good (2-5). In the cancer register such studies have been restricted only to a few tumour types (12, 13, 15).

Discrepancies between a register of deaths and a cancer register may be of several types and can

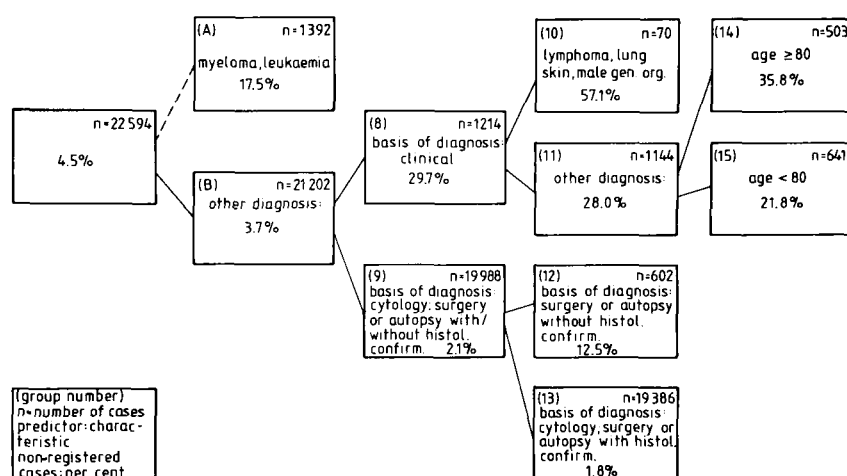


Fig. 3. AID-analysis of background variables (basis of diagnosis, age, diagnosis, domicile, year of diagnosis) with non-registered as

dependent factor. Group B: All diagnosis except leukaemias and myelomas.

variously influence findings from studies based on register contents. Statistics of incidence and calculations of trends can be misleading if one register is more comprehensive than the other, especially if a deficit is associated with particular diseases (17). Matchings against the registers, case-control studies and prospective evaluations may likewise be adversely influenced by incompleteness of a register.

In the present investigation, 4.5 per cent of the cancer cases known from death certificates issued in 1978 had not been recorded in the cancer register. If the age groups over 75 and the cases of multiple myeloma and leukaemia are excluded, the deficit falls to 2 per cent. These figures must be regarded as minima, since only death certificates were used to trace the cases.

The most important factor in the deficit of notifications to the cancer registry was diagnostic basis. Non-notification thus was significantly more common when the basis was solely clinical or roentgenologic than when histologic confirmation had been obtained. One probable reason was that the clinically diagnosed cases were reported from one source only, whereas in the cases with histologic confirmation there was at least dual notification—from clinician and from pathologist. Further, health service units with few cancer patients tend to omit notification to the cancer registry more often than do, for instance, surgeons and oncologists in specialized cancer care units (9). In the present study the cancer registration deficit was greatest (30%) among the only clinically diagnosed cases, while in histologically confirmed cancer it was less than 2 per cent.

About 80 per cent of cases notified to the cancer registry are histologically confirmed.

Some forms of malignancy were over-represented in the deficit of cancer notifications, while others were under-represented. The smallest deficit was found among tumours of the oral cavity, melanoma of the skin, breast and genital organs (Table 4), in which there was also a high incidence of histologic confirmation. Multiple myeloma and leukaemia were over-represented in the cancer registration deficit. This observation agrees well with results in other studies (8, 9, 11). The diagnostic investigations, including bone marrow analyses, were done in many cases in internal medicine departments, which routinely submit clinical reports to the cancer registry, and thus the cancer notification should have been made from only one source. All the cases of leukaemias (Table 5) probably had a cytologic diagnosis, but because of the lack of a report from a pathology department, the coding routines at the cancer registry resulted erroneously in 'clinical/roentgenologic' basis of diagnosis. The deficit in the present study (16–18%) was so great that cancer registry data concerning multiple myeloma and leukaemia should be used with great caution.

Other over-represented diagnoses on the death certificates comprising the cancer register deficit were cancer of the pancreas or the nervous system, or with unknown site of the primary tumour. In all of these categories the proportion of diagnoses without histologic confirmation was high.

The oldest age groups were most frequently represented in the deficit of notifications to the cancer

registry. To some extent this was attributable to a relatively low frequency of histologic investigation. Many old people with cancer receive only a clinical diagnosis in nursing homes, etc. At the time studied (1978), doctors at such homes were not legally obliged to notify cases to the cancer registry. More than half of the non-notified patients were older than 75 when cancer was diagnosed.

The group of patients with short survival, that is the same year of diagnosis and year of death, had a higher proportion of non-notified cancers than patients diagnosed during the period before 1978. In this group a comparatively high percentage of the patients were old, and the basis of diagnosis was often without histopathologic confirmation, both factors being associated with a high frequency of non-notification (Table 7).

There was a significant regional difference in cancer registration deficit among the 24 counties in Sweden. The interregional variations in registration deficit are however not large enough to solely explain the geographic variations in cancer incidence shown in the annual cancer incidence reports (16).

In the present study about 60 per cent of cases with only a death certificate of cancer fulfilled the criteria for inclusion in the cancer register. To supplement the register with these cases, however, investigations of the medical records was required in all death certificate cases. On the other hand, death certificates cannot replace the compulsory cancer notifications as a certain proportion of the death certificates issued each year for cancer-registered patients carry no mention of cancer.

In order to estimate the total loss to cancer registration, case identification from death certificates does not suffice. The Swedish system of registering patients according to personal identification number permits identification also of non-fatal cases which, for various reasons, are not notified to the cancer registry. A complementary study of this group is being carried out at the Oncologic Centre in Stockholm.

ACKNOWLEDGEMENTS

This investigation was supported by grants from the Delegation for Social Research, Ministry of Health and Social Affairs, and the Stockholm Cancer Society.

Request for reprints: Dr Britta Mattsson, Department of Oncology, Radiumhemmet, Karolinska Sjukhuset, S-10401 Stockholm, Sweden.

REFERENCES

1. BENN R. T., LECK I. and NWENE U. P.: Estimation of completeness of cancer registration. *Int. J. Epidemiol.* 11 (1982), 362.
2. BRITTON M.: Diagnostic errors discovered at autopsy. *Acta Med. Scand.* 196 (1974), 203.
3. — Clinical diagnostics. Experience from 383 autopsied cases. *Acta Med. Scand.* 196 (1974), 211.
4. CRAWFORD B. and PHILLIPS A. J.: The accuracy of cancer diagnosis on death certificates. *Cancer* 15 (1962), 5.
5. DE FAIRE U., FRIBERG L., LORICH U. and LUNDMAN T.: A validation of cause-of-death certification in 1156 deaths. *Acta Med. Scand.* 200 (1976), 223.
6. FREEDMAN L. S.: Variations in the level of reporting by hospitals to a regional cancer registry. *Brit. J. Cancer* 37 (1978), 861.
7. GAVATIN A. and EKLUND G.: Automatic interaction detector (AID) analysis. *In: On the role of the viruses in acute infectious disease of the central nervous system.* Edited by B. Sköldenberg. *Scand. J. Infect. Dis.* (1972) Suppl. No. 3, p. 89.
8. GEARY C. G., BENN R. T. and LECK I.: Incidence of myeloid leukemia in Lancashire. *Lancet* II (1979), 549.
9. INCIDENCE OF CANCER IN NORWAY 1978 and 1979. Annual report from the cancer registry of Norway. Oslo 1981, 1982.
10. JEREB B. and EKLUND G.: Factors influencing the cure rate in nephroblastoma. A review of 335 cases. *Acta radiol. Ther. Phys. Biol.* 12 (1973), 84.
11. KEMP I. W., STEIN G. J. and HEASMAN M. A.: Myeloid leukemia in Scotland. *Lancet* II (1980), 732.
12. LARSSON S.: Completeness and reliability of lung cancer registration in the Swedish Cancer Registry. *Acta Path. Microbiol. Scand. Sect. A* 79 (1971), 389.
13. MALEC E., EKLUND G. and LAGERLÖF B.: Re-appraisal of malignant melanoma diagnosis in the Swedish Cancer Registry. *Acta Path. Microbiol. Scand. Sect. A* 85 (1977), 707.
14. MATTSSON B.: Completeness of registration in the Swedish Cancer Registry. (In Swedish.) *Statistics of the National Board of Health and Welfare HS 1977:15.* Stockholm 1977.
15. PERCY C., STANEK E. and GLOECKLER L.: Accuracy of cancer death certificates and its effect on cancer mortality. *Statistics. Amer. J. Public Health* 71 (1981), 242.
16. RINGERTZ N.: Cancer Incidence in Sweden 1959–1965, National Board of Health and Welfare, Stockholm 1971.
17. SAXEN E.: Trends. Facts or fallacy in trends in cancer incidence. Causes and practical implications, p. 5. Edited by K. Magnus. Hemisphere Publishing Corporation, New York 1982.