

ORIGINAL ARTICLE

The completeness of the Swedish Cancer Register – a sample survey for year 1998

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Abstract

Introduction. The Swedish Cancer Register (SCR) is used extensively for monitoring cancer incidence and survival and for research purposes. Completeness and reliability of cancer registration are thus of great importance for all types of use of the cancer register. The aim of the study was to estimate the overall coverage of malignant cancer cases in 1998 and to reveal possible reasons behind non-reporting. **Methods.** We selected all malignant cancer cases in the Hospital Discharge Register (HDR) from 1998 and compared these records to those reported to the SCR. There were 43 761 discharges for 42 010 individuals of whom 3 429 individuals were not recorded in the SCR. From these 3 429 records we randomly selected 202 patients for review of their medical records to determine whether they should have been registered on the SCR as incident cases in 1998. **Results.** About half of the 202 cases (93 malignant and 8 benign) should have been reported, which translates into an additional 1 579 malignant cases (95% CI 1 349–1 808), or 3.7% of the cases reported in 1998. The crude incidence rate for males and females combined would increase from 493 per 100 000 to 511 (95% CI 508–514) if these cases were taken into account. **Conclusion.** The overall completeness of the SCR is high and comparable to other high quality registers in Northern Europe. For most uses in epidemiological or public health surveillance, the underreporting will be without major impact. However, for specific research questions our findings have implications, as the degree of underreporting is site specific, increases with age, and does not seem to be random, as diagnoses without histology or cytology verification are overrepresented. An annual comparison of the SCR against the HDR could point to hospitals, geographic areas or specific diagnoses where organizational and administrative changes should be introduced to improve reporting.

The Swedish Cancer Register is extensively used as an important tool to monitor cancer incidence and survival, and for research purposes. Users of the register data depend on the completeness and reliability of registration for their findings to be valid. The Swedish Cancer Register is generally considered to be of good quality as approximately 99% of the cases are morphologically verified [1]. The proportion of cases not reported was estimated to be less than 2% in the late 1970s, based on information from death certificates [2].

Currently, clinical databases built for quality assurance are increasingly informing the register, and in the near future new methods of electronic data capture will hopefully increase completeness

further. There is a need for estimates of completeness for the period between the late 1970s and the present and, to raise the future quality of reporting, identification of problem areas is needed.

The Hospital Discharge Register started as a trial in 1964 and covers the whole population of Sweden since 1987. This register is potentially a good source of material against which to evaluate the completeness of the Swedish Cancer Register.

The aim of the present study was to estimate the overall coverage of malignant cancer cases in the Swedish Cancer Register by measuring the number of patients diagnosed with cancer in the Hospital Discharge Register who should have been reported to the Swedish Cancer Register in 1998 [3]. We also

studied reporting by type of tumour, age, gender, type of hospital, and mode of diagnosis to identify possible amendable reporting problems.

Material and methods

The Swedish Cancer Register, maintained by the National Board of Health and Welfare, was founded in 1958 and covers the whole population of Sweden. The register is based on notification of malignant and certain benign tumours. The objectives for maintaining the register are to produce health statistics, to follow-up and make evaluation and quality assurance assessment of health care, and for epidemiological and other research. It is compulsory for every health care provider to report newly detected cancers to the Swedish Cancer Register. A cancer report has to be sent for every cancer diagnosed at clinical, morphological and other laboratory examinations, and those diagnosed at autopsy. Since the mid 1980s six regional cancer registries have been responsible for registration, coding, verification and correction as an aid to health care providers to deliver data to the national registry in a correct way. The regional registries are associated with the oncological centres in each of the six health care regions of Sweden. The regional registries report newly registered cases and corrections concerning those previously reported to the national registry on an annual basis. The information available in the Swedish Cancer Register comprises patient data (personal identification number, sex and place of residence); medical data (site of tumour, histological type, basis and date of diagnosis); follow-up data (date and cause of death, date of migration, and whether a patient was registered as a resident in Sweden at the end of a specific year) [1]. Cases without a cancer notification according to the above requirements, but reported to the Cause of Death Register, i.e. cases denoted as DCO (death certificate only) and DCN (death certificate notification), are however not included.

The Hospital Discharge Register covers all public, in-patient care in Sweden since 1987 and contains data on patients (personal identification number, sex, place of residence), hospital identification, administrative data (date of admission and discharge, acute/planned admission) and medical data (main and secondary discharge diagnoses and major interventions). Information provided to the Hospital Discharge Register is delivered once a year to the National Board of Health and Welfare from each of the 21 county councils in Sweden. Every discharge corresponds to one record in the database. The proportion of in-hospital stays for short-term somatic

care not reported for the period 1987–1991 has been estimated to be less than 2%. In 2005, the main diagnosis was missing in 1.2% of the hospital stays reported. The underreporting of main diagnosis is confined to a few county councils. For acute somatic and psychiatric care, the main diagnosis was missing in 0.8 and 9.4% of reports, respectively [4].

We selected all malignant cancer cases (according to ICD-10: C00-C96, except C77-C79) in the Hospital Discharge Register from 1998, irrespective of whether the cancer diagnoses were main or secondary. In total, there were 43 761 such discharges. If an individual had several discharges within one of the 11 groups of diagnosis described in Table I, they occur only once within that diagnostic group, since one cancer can result in several discharges. Thus, the underreporting as studied here represents individuals rather than cancers. After elimination of reporting of multiple tumours and of multiple discharges for the same tumour, where the last record was kept for each tumour, there remained 42 010 combinations of individual and diagnostic-group. Use of the patient's unique personal identification number, a number assigned to each Swedish resident, permitted linkage of individuals to the Swedish Cancer Register for the period 1958–1999, thus giving the hospitals an additional year to report the case to the cancer registry. The results of this linkage revealed 3 429 combinations of individual and diagnostic-group that appeared for the first time in the Hospital Discharge Register in 1998 and were not recorded in the Swedish Cancer Register.

From the group of patients in the Hospital Discharge Register with a cancer diagnosis that had not been reported to the Swedish Cancer Registry we randomly selected 202 patients for review. The sample was not stratified for site, age or geographical distribution. Requests for further information on these patients were sent to the hospitals and all their medical records were found. For the 202 cancer cases, the medical records were carefully reviewed by a trained medical secretary with 25 years of experience of cancer registration from one of the regional cancer registries in Sweden. Two questions were to be answered: had the individual really had a malignant tumour, and should the case have been reported to the Swedish Cancer Registry as an incident case in 1998?

Results

We first studied the possible underreporting as indicated by the discrepancy between the Swedish Cancer Register and the Hospital Discharge Register.

Table I. Number of malignant cancer cases, according to ICD-10: C00-C96 except C77-C79, in the Swedish Cancer Register in 1998. Number of cancer cases in the Hospital Discharge Register in 1998 and the number of cancer cases that were not registered in the Swedish Cancer Register in 1958-1998.

Site	Reported to the Cancer Registry in 1998		Reported to the Hospital Discharge Registry in 1998	Reported to the Hospital Discharge Registry only	
	Number of tumours	Number of persons	Number of persons	Number of persons	Ratio (%) ¹
Head and neck	988	982	1 140	99	10.1
Digestive organs	8 715	8 579	9 979	863	10.1
Lung	2 997	2 982	3 470	329	11.0
Soft tissue	1 316	1 312	1 527	165	12.6
Skin	4 232	4 092	1 653	398	9.7
Breast	6 225	6 091	6 118	84	1.4
Female genital organs	2 936	2 909	3 354	100	3.4
Urology	9 996	9 865	8 207	509	5.2
Nervous system	1 410	1 407	1 376	195	13.9
Leukemia and lymphoma	3 171	3 157	3 884	534	16.9
Other sites	784	784	1 302	153	19.5
Total	42 770	42 160	42 010	3 429	8.1

¹Ratio in per cent of the number of persons with a tumour reported to the Swedish Cancer Registry.

We then did a detailed study of the medical records in order to find possible reasons for the non-reporting. Cancer cases (according to ICD-10: C00-C96, except C77-C79) identified in the Swedish Cancer Register and in the Hospital Discharge Register are shown in Table I. There was a total of 42 770 cancer cases (in 42 160 persons) reported to the Swedish Cancer Register in 1998 compared with 42 010 persons in the Hospital Discharge Register. The number of persons with a malignant cancer diagnosis reported only to the Hospital Discharge Register was 3 429. The underreporting for breast, female genital organs and urologic sites was low,

while it was high for soft tissue, nervous system and for leukaemia and lymphoma.

When the non-reporting was further studied by gender and age (Table II), we found that it was worse in ages over 70, and for cancers of the soft tissues and nervous system the underreporting was highest in the 70+ age group. The non-reporting was also notable for lung cancer in the elderly and for male breast cancer, though the number of male patients with breast cancer was very low. There was a tendency for underreporting of cancers in women to be worse in the elderly, and in men to be worse in the younger age group.

Table II. Number of persons diagnosed with a malignant tumour, according to ICD-10: C00-C96 except C77-C79, reported to the Swedish Cancer Registry in 1998 by age and sex. The ratio of persons reported to the Hospital Discharge Registry in 1998 but not to the Swedish Cancer Registry (n = 3 429), to the number of persons reported to the Swedish Cancer Registry in 1998, by site, age, and sex.

Site	Males				Females			
	0-69		70+		0-69		70+	
	N	Ratio (%)	N	Ratio (%)	N	Ratio (%)	N	Ratio (%)
Head and neck	380	7.1	293	8.9	161	13.7	148	16.2
Digestive organs	1 855	7.8	2 627	10.5	1 509	5.1	2 588	14.1
Lung	850	7.4	986	13.7	639	6.1	507	18.1
Soft tissue	328	13.7	169	23.7	493	9.3	322	10.6
Skin	870	7.9	1 384	7.9	731	9.3	1 107	13.6
Breast	12	25.0	16	31.3	4 023	1.1	2 040	1.6
Female genital organs	-	-	-	-	1 732	1.9	1 177	5.5
Urology	3 247	3.3	5 647	5.3	382	7.1	589	12.7
Nervous system	509	5.5	148	43.9	534	7.1	216	29.6
Leukemia and lymphoma	951	13.0	797	19.7	656	11.3	753	23.8
Other sites	136	8.8	155	38.7	183	8.2	310	21.3
Total	9 138	6.8	12 222	9.6	11 043	4.4	9 757	11.8

Table III. The ratio of persons reported to the Hospital Discharge Registry in 1998, according to ICD-10: C00-C96 except C77-C79 but not to the Swedish Cancer Registry (n = 3 429), to the number of persons reported to the Swedish Cancer Registry in 1998, by site and hospital type.

Site	University hospital	County hospital	Local hospital, nursing home etc	Total
Head and neck	17.3	8.3	9.4	10.1
Digestive organs	8.9	10.0	11.6	10.1
Lung	28.8	9.1	8.9	11.0
Soft tissue	22.1	13.9	10.3	12.6
Skin	4.6	11.7	10.5	9.7
Breast	1.1	1.5	1.5	1.4
Female genital organs	2.3	4.0	3.5	3.4
Urology	5.1	6.0	4.5	5.2
Nervous system	48.2	⁽¹⁾ 121.1	4.5	13.9
Leukemia and lymphoma	18.7	18.9	14.1	16.9
Other sites	20.8	18.2	19.9	19.5
Total	8.0	8.7	7.8	8.1

¹There were 86 tumours unreported and 71 reported to the Swedish Cancer Registry.

The discrepancy between the Swedish Cancer Register and the Hospital Discharge Register was also stratified by type of hospital (Table III); the ratio of non-reported cases was similar, but for the three previously mentioned problematic sites and for lung and head and neck cancer, the University hospitals did worst.

We then estimated the true proportion of under-reporting by reviewing the sample of medical records. Table IV shows the results of the review of the

Table IV. Basis of diagnosis for the 93 malignant cancer cases that should have been reported to the Swedish Cancer Registry in 1998, and the reasons why the remaining 109 cases should *not* have been reported to the Swedish Cancer Registry in 1998.

	Number of cases	%
Cases that should have been reported to the Swedish Cancer Registry	93	46.0
<i>Basis of diagnosis</i>		
Clinical diagnosis only	12	5.9
Radiological investigation	44	21.8
Histological diagnosis	18	8.9
Autopsy with histological examination	1	0.5
Cytological diagnosis	10	5.0
Gross examination at surgery	5	2.5
Autopsy without histological examination	3	1.5
Cases that should <i>not</i> have been reported to the Swedish Cancer Registry	109	54.0
Benign tumour	8	4.0
Not cancer	39	19.3
Basal cell carcinoma	23	11.4
Not resident in Sweden in 1998	5	2.5
Cancer – but should not be included in 1998	33	16.3
Benign tumour – but should not be included in 1998	1	0.5
Total	202	100.0

sample of 202 medical records selected from the 3 429 cases reported exclusively to the Hospital Discharge Register. Five cases were shown to be of patients not resident in Sweden and should therefore not be included. There were 93 malignant and 8 benign cancer cases diagnosed in 1998 that should have been reported to the Swedish Cancer Registry. Thus, we estimate that about half of the cancer cases only reported to the Hospital Discharge Registry displayed in Table I–III represent true under-reporting. The estimated number of missed cancer cases, which should have been reported to the Swedish Cancer Registry, is 1 579 for the year 1998 (95% CI 1 349–1 808), which equals 3.7% of the reported cases in 1998 and would bring the estimated crude incidence from 493 per 100 000 up to 511 (95% CI 508–514) if taken into account [5]. The site, sex, and age distribution for the patients in the reviewed sample and the number deceased during 1998 are shown in Table V.

Only 18 of the 93 cases of malignant tumours that should have been reported to the Swedish Cancer Registry in 1998 had histopathology as the basis of diagnosis; ten had cytology and as many as 61 had clinical diagnosis only, macroscopic finding at surgery or imaging as underlying documentation (Table IV). The medical records for those 12 with a clinical diagnosis only and 44 with a radiological diagnosis were studied in further detail to understand why they were not reported. Fourteen of the patients were under 70, ten were between 70 and 74, and 32 were 75 years or older. With only one exception (a patient with a malignant melanoma of the eye), all presented with advanced disease, and no primary treatment with either curative intent or specific anti-tumour therapy was undertaken. About half of the patients had a severely deteriorated general condition and/or

Table V. Site, sex, and age distribution for the 202 patients in the reviewed sample and the number deceased in 1998.

Site	Reviewed records		Males	Age at discharge				Deceased in 1998			
				0-69		70+		all causes		of cancer	
	N	%	%	N	%	N	%	N	%	N	%
Head and neck	6	3.0	66.7	3	50.0	3	50.0	0	0.0	0	0.0
Digestive organs	51	25.2	43.1	16	31.4	35	68.6	31	60.8	24	47.1
Lung	19	9.4	47.4	5	26.3	14	73.7	10	52.6	8	42.1
Soft tissue	10	5.0	90.0	3	30.0	7	70.0	2	20.0	1	10.0
Skin	23	11.4	43.5	7	30.4	16	69.6	0	0.0	0	0.0
Breast	5	2.5	40.0	3	60.0	2	40.0	0	0.0	0	0.0
Female genital organs	6	3.0	0.0	1	16.7	5	83.3	2	33.3	2	33.3
Urology	30	14.9	86.7	8	26.7	22	73.3	12	40.0	3	10.0
Nervous system	12	5.9	50.0	5	41.7	7	58.3	7	58.3	6	50.0
Leukemia and lymphoma	31	15.3	54.8	9	29.0	22	71.0	8	25.8	6	19.4
Other sites	9	4.5	55.6	0	0.0	9	100.0	7	77.8	4	44.4
Total	202	100.0	54.5	60	29.7	142	70.3	79	39.1	54	26.7

significant comorbidity. The typical case was of an elderly person in poor general condition with an inoperable pancreatic, bile duct or kidney cancer or an inoperable brain tumour. Only in three of all 56 patients can some doubts be raised about a malignant diagnosis; according to the medical records all others had a clinical presentation and disease progression that clearly indicate that a cancer was present.

Many of the patients in the reviewed sample had a severely deteriorated general condition which is emphasized by the observation that 55% of the 93 patients with malignant tumours that should have been reported to the Swedish Cancer Registry in 1998 also died in 1998, and 41% had cancer as the underlying cause of death. An additional 18% died in 1999, nearly all of whom (17%) had cancer as the underlying cause of death.

Of the 3 429 cases from the Hospital Discharge Register that were not reported to the Swedish Cancer Registry, 41% of patients died in 1998, and an additional 15% and 5%, respectively, during the two subsequent calendar years. Thirty-one per cent had cancer as the underlying cause of death in 1998, and an additional 10% and 2%, respectively, during the following two years.

Discussion

We found an underreporting of 3.7% of individuals with malignant disease in the Swedish Cancer Register for year 1998. Based on this estimate, the crude incidence would increase from 493 to 511 per 100 000 persons in 1998. This study implies a relatively large variation in underreporting by diagnostic group and by age. While the underreporting for breast cancer, female genital cancer, urologic cancers, skin and digestive organs was low or

modest, it was higher for soft tissue and the nervous system and substantial for leukaemia and lymphoma. The detailed study of the randomly selected cases indicated that around 70% of those not reported lacked information from a pathological or cytological report.

We used the population-based Hospital Discharge Register with 98% completeness to validate the Swedish Cancer Register. The medical records for the 202 individuals in the sample were abstracted and carefully reviewed by a trained medical secretary with many years' experience of cancer register coding. Even if the sample is too small to quantify the underreporting with high precision in potentially interesting substrata, the findings indicate qualitatively where the important problem areas of reporting may lie, and the linkage as a whole of Hospital Discharge Register to Swedish Cancer Register yields sufficient numbers for high statistical precision as to the overall estimate of completeness. From the validation of these medical records, we could also make important inferences about all cancer cases not included in the Swedish Cancer Register.

The study has some limitations that should be incorporated into the interpretation of the findings. Since only cancers reported in 1998 were studied, we cannot draw inferences about time trends of completeness of registration. Furthermore, if more years had been studied, we might have found cases recorded in the Hospital Discharge Register after 1998 that should have been reported as incident cancers in 1998. Our sample of 202 individuals indicates that this problem could involve one quarter of all underreporting, as 33 cases were found to belong to other years. If we also had included in the validation a search for multiple tumours and reporting to the Causes of Death Register, it is likely that the estimate of underreporting would have increased. Such a

validation would, however, have required a study of a much larger scope. Since the main data set indicated differences in reporting by type of tumour and age, the sample could have been stratified on these factors. However, our goal was to determine larger, general problem areas of reporting and a more detailed understanding of the mechanisms of underreporting by subcategories would have required more work in addition to the study of medical records.

Studies of completeness in other population-based cancer registers have similar findings to this study [6–9], with a variation between 91 and 98.6%. These studies used a similar method to ours, i.e. using the Hospital Discharge Registers as a source. The Scottish study [7] used multiple sources of information, for cases diagnosed in 1992, and may therefore be a more rigorous test of completeness, although they still only reached a level of 96.5% completeness. Of the missed cases 23% were based only on death certificates. Five site categories had estimates of completeness below 90%: lip, oral cavity and pharynx, uterus (both unspecified and body of uterus), other and ill-defined sites and multiple myeloma. The other studies found, parallel to our results, that completeness varied with site. The other registries, though, have recorded cases based on information obtained from death certificates only. The inclusion of cancers identified through death certificates only has implications for both incidence and survival statistics, especially among the elderly. In the case of the Finnish cancer register [8], that has a very high overall completeness, problems were also noted with capturing brain tumours and haematological disorders for the years 1985–1988 in comparison with the hospital discharge register. The Estonian study [9] shows that their cancer register has a completeness of 90.8% compared with the records of two hospitals. However, our study and the Estonian study from 1998 show practices that go back ten years in time while the other studies represent the situation in the late 1980s and early 1990s. The clinical management has changed considerably for many cancer sites during the last two decades, and this may have an affect on the pattern of registration since the specialisation among health care personnel has hopefully led to better awareness of the need for proper registration. Studies of registration for specific sites have shown very high completeness for breast (99%) in Denmark [10] based on clinical records from one county for the period 1983–1989, for ovaries (99.6%) in Norway [11] based on eight hospitals in three counties in 1987–1996, and for prostate [12] in Norway based on eight selected hospitals in 1957–1986. These findings are in line with our results, although on a slightly lower level.

The overall completeness of the Swedish Cancer Register is high, and for most uses in epidemiological or public health surveillance the underreporting will be without major impact. However, for specific research questions our findings have several implications. The degree of underreporting is site specific, thus introducing larger problems in some areas such as leukaemia and lymphomas. Earlier studies on the Swedish Cancer Register data have shown that there is a problem with the coverage of leukaemia [2,13]. Further, the underreporting does not seem to be random. Cancer diagnoses without histology or cytology verification, and thus individuals not as actively investigated and treated, are overrepresented. As a consequence, the individuals who are not reported may have a worse prognosis as a group compared with the registered individuals for the same site, which may artificially improve the survival rates. This seems likely since 61% of the 3 429 patients in the Hospital Discharge Register who were not reported to the Swedish Cancer Register in 1998 died before the beginning of year 2001, with 43% having cancer as the underlying cause of death. Furthermore, underreporting increases with age of the patient, and that together with the selective underreporting of cases with worse prognosis has to be taken into account in the highly relevant investigational fields of cancer burden, cancer prognosis and outcomes of cancer treatment in the elderly.

Our study points to amendable problems in reporting. We are aware of a misunderstanding among some clinicians that only cases where the cancer diagnosis has been proven by histology or cytology should be reported, thus they neglect to report cancers diagnosed only clinically. This problem seems to be greater for patients with advanced disease and in a deteriorated condition where no specific anti-tumour therapy is undertaken. Our findings also indicate that there can be a misunderstanding about which clinic or pathology department has the responsibility to report cancer diagnoses where patients and/or their samples are referred to central specialised clinics and laboratories. This is the case e.g. for leukaemia and lymphomas and soft tissue tumours. For these two problem areas, increased and repeated information about the mandatory reporting procedure can increase completeness. According to the Regulations set out by the National Board of Health and Welfare [14] every health care provider under public or private administration in Sweden must report all cases of cancer to the Swedish Cancer Register. The reporting should include clinical information, information from pathologist and cytologist on surgically removed tissues, biopsies, cytological specimens, bone marrow aspirates and autopsies. Further, the

Swedish Cancer Register can undergo an annual comparison against the Hospital Discharge Register as a source of validation. Even if the resources for tracking underreported cases are sparse, register linkage could indicate whether there are hospitals, geographic areas or specific diagnoses where organizational and administrative changes should be undertaken to improve reporting. The Cause of Death Register has not been used as a resource to add cancer cases to the Swedish Cancer Register. Since coding and registration are done at the regional cancer registries, it would be useful if they also could obtain information on cases identified through the Cause of Death Register. This has not been possible due to the Official Secrets Act that prohibits this data to be sent to the regional cancer registries since it is for administration of the cancer register and not for scientific research. However, a Swedish Government Official Report [15] is proposing a change to the Official Secrets Act, which would make this possible in the future. Finally, clinical databases for quality assurance of care for all major cancers are growing and maturing in Sweden. In these registers the health care providers are often motivated to report all individuals with cancer, independent of mode of diagnosis, both for quality assurance and for monitoring workload, which in turn has consequences in budget negotiations. Thus, regular linkage of the cancer register against the clinical databases may improve completeness.

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