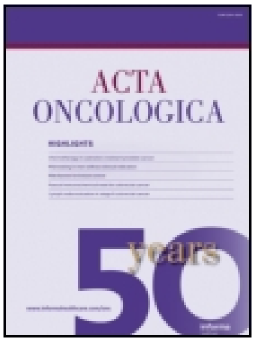

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ORIGINAL ARTICLE

A study of patients not registered in the Swedish cancer register but reported to the Swedish register of palliative care 2009 as deceased due to cancer

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Abstract

Background. The Swedish Cancer Register (SCR), an old and reputable health data register, contributes a large amount of data used in research. The quality of the research using SCR data depends on the completeness and validity of the register. In Sweden, every healthcare provider is obligated to report newly detected cases of cancer to the SCR regardless of the diagnostic basis. This study aimed to clarify whether there is an under-reporting of patients with cancer to the SCR or an over-reporting of cancer as cause of death to the SRPC as all patients do not appear in both registers. In addition, this study looked at the distribution of under-reporting or over-reporting related to age, sex, type of cancer, diagnostic basis, and department responsible for cancer diagnosis. *Material and methods.* Of the 10 559 patients whose cause of death was cancer as reported to the SRPC (2009), 1394 patients (13.2%) were not registered in the SCR (1958–2009). Medical records from a representative sample of 203 patients were collected and reviewed. *Results.* The medical records for 193 patients were obtained; of those, 183 (95%) patients should have been reported to the SCR. Among these, radiologic investigation was the most common basis for diagnosis and there was a significant over-representation of cancer of the pancreas, lung, liver, and bile ducts. *Discussion.* This study cannot quantify the completeness of the SCR. The findings indicate that 12.5% of patients dying of cancer in palliative care are not reported, that specialized hospital departments diagnose the vast majority of the unreported patients, and that routines for how to report patients to the SCR based on radiological findings should be revised.

Background

The Swedish Cancer Register (SCR) was founded in 1958 and it is maintained by the National Board of Health and Welfare. It is compulsory for every healthcare provider in Sweden, public or private, to report newly detected cancer cases to the register [1]. The diagnosis can be set on the basis of clinical examination, morphological examination, surgery, autopsy, or other laboratory examination.

The SCR is used to monitor cancer incidence in Sweden and to provide data for clinical and epidemiological research [2].

Previous studies have shown that the completeness of the SCR is generally high: 95.5% of patients with death certificates stating cancer as the underlying or contributory cause of death in 1978 [3] and 96.3% of patients reported to the Hospital Discharge Register with a cancer case in 1998 were registered in the SCR [4]. Completeness of the SCR, however, is lower for elderly patients who are in a bad general condition and when the diagnosis is not based on morphological examination [3,4]. The completeness is also lower for certain types of cancer; e.g. only 73% of pancreatic cancer cases that were registered in the National Patient Register between 1987 and 1999 were reported to the SCR [5].

The SCR does not use information on cancers based on death certification – death certificate only (DCO) and death certificate notification (DCN). In 2009, 2942 persons in the Cause of Death Register with cancer stated as the underlying cause of death were not registered in the Cancer Register (1958–2009). This discrepancy composes 13.1% of the total number of persons reported to the Cause

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of Death Register with cancer as underlying cause of death. The most common cancer sites among those not reported to the SCR were bronchus/lung, pancreas, and prostate [2].

The most recent studies [4,5,6] of the completeness of the SCR were made by comparing the SCR and the Swedish National Patient Register (SNPR). The SNPR has a validity of 85–95% when compared to patients' charts and national quality registers [7], but the SNPR does not cover primary healthcare. Therefore, the under-reporting to the SCR could be even larger than has been shown in these studies especially when most of the older patients in bad general condition (the group with the highest under-reporting) often are handled by primary healthcare physicians.

Established in 2005, the Swedish Register of Palliative Care (SRPC) is a national quality register financed by the Swedish Association of Local Authorities and Regions. The register evaluates and aims to improve care at the end of life. Although it is not compulsory to report to the register, healthcare providers with a high grade of reporting receive state funding. According to the National Board of Health and Welfare, SRPC registration is one of 10 quality indicators for cancer health care [8]. The SRPC is based on an end-of-life questionnaire (ELQ) that is answered by ward staff as soon as a patient dies at their unit and is meant to reflect the end-of-life care provided during the last days/week. The ELQ asks the healthcare providers to identify the main cause of death. For 2009, the SRPC had coverage of 49% for deaths caused by cancer of the ones reported to the Cause of Death Register [9]. The congruence between data reported to the SRPC's ELQ and the medical record on the question "which disease was the main cause of death?" was 93% [10].

The completeness of a cancer register is essential for insuring the quality of the incidence and survival statistics as well as other register-based research [11]. Former studies might have underrated the under-reporting to the SCR because of their methodology. Concurrently, it is essential to investigate whether the mismatch of results between the SCR and the SRPC was caused by a substantial false reporting of cancer deaths to the SRPC. This study also investigates whether the distribution of under- or over-reporting is related to age, sex, type of cancer, diagnostic basis, and department responsible for cancer diagnosis.

We have two hypotheses: 1) the majority of the mismatch between the two registers depends on an under-reporting to the SCR; and 2) the majority of the under-reporting concerns older patients cared for by general practitioners in nursing homes.

Material and methods

Sorensen et al. suggest that administrative databases could be evaluated in three ways [12]: A) by comparing with another independent reference source case-by-case; B) by comparing patient chart reviews; and C) by comparing the total number of cases in different databases. This study is based on methods A and B.

In 2009, the cohort of patients reported to the SRPC with cancer as main cause of death (10 559 persons) was compared with the SCR for the years 1958 through 2009 (ICD-10 C.00-D.48) (except C.44, basal cell carcinoma) by using the patient's personal identification number. This comparison revealed that in 2009 the SRPC listed 1394 cancer deaths that were not listed as cases with cancer in the SCR (except ICD-10 C.44). From this group of 1394 patients, we randomly selected 203 patients for medical record review. The sample was representative for age, sex, geographical distribution (county and healthcare region), and type of department reporting to the SRPC. For all 203 cases, the medical records for the last year of life were collected. For patients who died in a nursing home, the medical records were collected from the locally responsible general physician (GP). In some cases, the medical records from the department where the patient died indicated that the patient had a cancer but did not identify the diagnostic basis or what department was responsible for the diagnosis. When the medical records did not provide enough information to verify cancer death/disease, diagnostic basis, and department responsible for diagnosis, we collected older records or records from other departments. In the cases where the additional medical records were not acquired, the patient was registered in the study as a cancer death, but the diagnostic basis and/or department responsible for diagnosis were registered as unknown. The obtained medical records were reviewed to define whether the patients should have been reported to the SCR or not according to board directives [1] and whether the patient should have been reported to the SRPC with cancer as main cause of death.

Patient information about age, sex, site of care, and type of department reporting to the SRPC was derived from the SRPC. If the patient should have been reported to the SCR, additional information was extracted from the records such as type of cancer, diagnostic basis, presence of metastasis, and department responsible for cancer diagnosis. Fisher's exact test (two-sided) and non-parametric methods were used to compare groups. Ethical approval was given by the Ethical Research Committee at Umeå University, 2011-293-31M.

Results

Attrition

We requested medical records for 203 individuals (15% of the original study population). Medical records for 10 of the 203 patients could not be obtained (Figure 1). For six of those patients, the department (or the locally responsible GP) that had reported to the SRPC did not have any medical records for the patient. For four patients, the responsible healthcare unit did not send in required records despite repeated reminders.

Cancer, main cause of death?

Medical records for 193 of 203 patients (95%) were obtained and reviewed by the author; these patients compromised 14% of the population we wanted to study. Of the 193 patients reported to the SRPC with cancer as main cause of death, 10 did not meet the criteria to be reported to the SCR according to the reviewed medical records. Nine of those 10 patients died due to non-cancer diseases such as pneumonia, ALS, and cardiac failure. The reviewed medical records did not document any current or prior non-lethal cancer. One patient died due to cancer of the stomach but was not a resident in Sweden at the time of diagnosis and therefore should not have been reported to the SCR (Figure 1). However, that patient was correctly reported to the SRPC with cancer as the main cause of death. Five of these patients were reported to the SRPC from nursing homes, three patients from specialized palliative care, and two patients from hospitals. Of all the studied patients, the vast majority – i.e. 183 of 193 patients (94.8%) – died from cancer and should have been reported to the SCR.

Type of cancer

The most common cancer diagnoses were pancreatic and lung cancer (40 patients each). These two diagnoses and cancer of the liver and biliary tract (18 patients) were significantly more common in this study than expected when compared with data from the Cause of Death Register for 2009 [13]. Cancers of the prostate (nine patients), breast (two patients), and skin (none) were significantly less frequent than expected (Table I). According to the medical records, 85 (46%) of the cancers were diagnosed with metastases, and the most frequent sites for metastases were liver, lung, and skeleton.

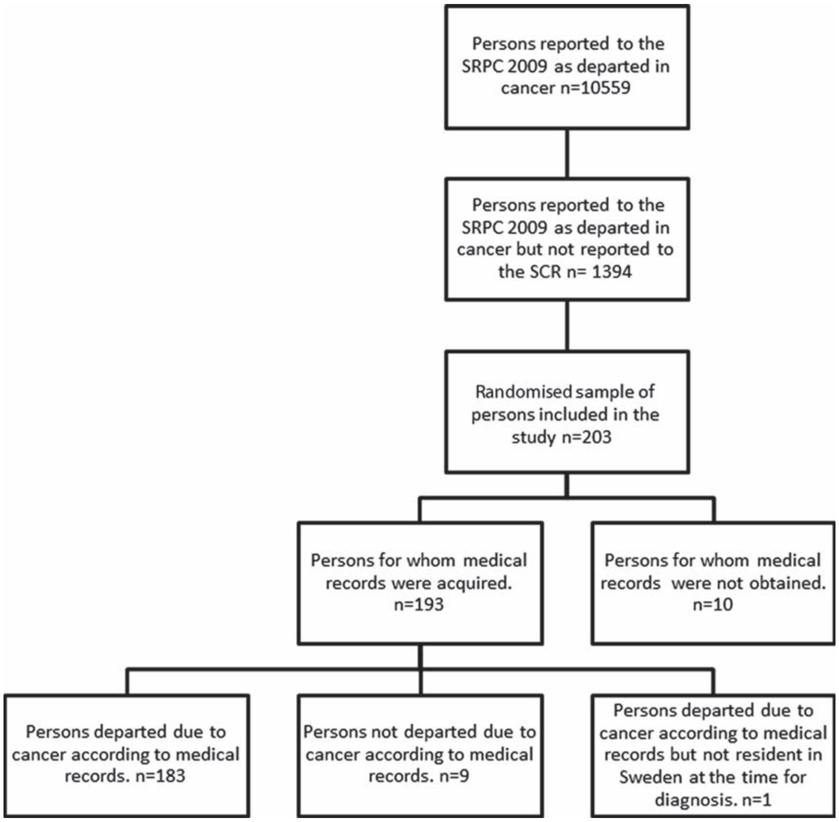

Figure 1. Selection of study cases.

Table I. Site distribution for the 183 cases in the study and the 21717 cancer deaths in 2009 in Sweden according to the Cause of Death Register.

	Cases in the study		Died in 2009		
Site	n	%	n	%	p-value
Lung	40	22	3486	16	< 0.05
Pancreas	40	22	1543	7	< 0.001
Breast	2	1	1396	6	< 0.001
Colorectal	15	8	2631	12	n.s.
Prostate	9	5	2424	11	< 0.01
Liver & biliary tract	18	10	634	3	< 0.001
Skin	0	0	560	3	< 0.01
Other sites	59	32	9043	42	< 0.05
Total	183	100	21717	100	

Basis of diagnosis

In total, 39 of the diagnoses (21%) were set by histological (n = 32) or cytological examination (n = 7). Most patients (n = 123; 67%) were diagnosed by radiological investigation, and the most common modality was CT scan of the brain, thorax, or abdomen (n = 108) (Table II).

Age and sex

One hundred of the patients who died from cancer were men and 83 were women (Supplementary Table I, to be found online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2013.819115).

Table II. Distribution for basis of diagnosis for the 183 cases in the study.

Basis of diagnosis	Number of cases	Percent of cases
Histological examination	n = 32	17%
Transcutaneous biopsy	n = 13	
Bone marrow biopsy	n = 6	
Colonoscopy	n = 2	
Bronchoscopy	n = 1	
Operation	n = 8	
Autopsy	n = 2	
Cytological examination	n = 7	4%
Radiological investigation	n = 123	67%
CT	n = 108	
MRT	n = 3	
Ultrasound	n = 7	
X-ray	n = 3	
Scintigraphy	n = 1	
Unclear	n = 1	
Operation without histological examination	n = 1	0.5%
Clinical examination	n = 12	7%
Gastroscopy	n = 1	
Laboratory tests	n = 3	
Tumor markers	n = 5	
Manual examination	n = 3	
Unclear	n = 8	4.5%
Total	n = 183	100%

Table III. Department responsible for cancer diagnosis in the 183 cases not reported to the SCR.

Department responsible for diagnosis	Number of cases	Percent of cases (%)
Internal medicine	68	37
Surgical	82	45
Gynecological	6	3
Oncological	6	3
Primary healthcare	14	8
Unclear	7	4
Total	183	100

The mean age was 78.7 years (men: 77.3; women: 80.1) with a range of 35–97 years. The mean age among patients reported to the Cause of Death Register 2009 who died of cancer was 73.9 years (men: 74.0; women: 73.7). Of the 10 persons who should not have been reported to the SCR according to the reviewed medical records, eight were women and two were men and the mean age was 83.9 years for both men and women combined. The medical records for eight women and two men could not be obtained and their mean age was 78.4 years.

Department reporting to the SRPC and department responsible for cancer diagnosis

Hospice/palliative hospital ward and specialized palliative home care were the most common departments reporting to the SRPC (Supplementary Table II, to be found online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2013.819115). The most common departments responsible for diagnosis were departments of surgery and internal medicine (Table III). For the 10 persons where medical records could not be obtained and the 10 persons who were wrongly reported to the SRPC as dying from cancer (in total a group of 20 patients), the distribution for department reporting to the SRPC was not significantly different compared to the study group (n = 183).

Discussion

This study showed that 183 of 193 individuals (95%) had died of a cancer disease that should have been reported to the SCR. When this proportion is applied to the total number of patients registered as cancer deaths in the SRPC but not registered in the SCR (total = 1394), as many as 1322 of 10 559 (12.5%) patients should have been reported to the SCR as cases of cancer.

The major part of the mismatch between cases of cancer in the SCR and the SRPC, the basis of our first hypothesis, depended on an under-reporting of cases to the SCR. In the SRPC, the validity of cancer as the main cause of death is high. As the SRPC is a register of mortality and the SCR is a register of incidence, the number of cancers not reported to the SCR that were detected in the study and their distribution according to site must be compared with data from the Cause of Death Register for 2009. This comparison showed a significant over-representation of cancers of the pancreas, liver-biliary tract, and lung. The results also showed a significant under-representation of cancers of the prostate, breast, and skin.

The results reveal that the major part of the unreported cases of cancer deaths consists of tumors of the visceral organs (lung, pancreas, and liver) that are easily visualized by modern imaging techniques such as CT scan but are hard to reach for biopsy. This hypothesis is further supported by the finding of higher completeness in the SCR for tumors in superficial organs such as skin, breast, colorectal, and prostate. For the year of 2009, 98% of the reported cases to the SCR were morphologically verified [2].

Cancers of the pancreas, lung, liver, and biliary tract progress very fast and there are few therapeutic possibilities and survival is short. These characteristics may contribute to their under-reporting. Interestingly, the under-reporting was low for cancers associated with high socioeconomic status (skin, breast, and prostate) and high for a cancer associated with low socioeconomic status (lung cancer) [14]. Only one patient was diagnosed abroad, so this does not explain the mismatch between the registers.

The mean age (78.7 years) in our material was higher than the mean age in the Cause of Death Register (73.9 years). This indicates that higher age may increase the tendency to not report the patient to the SCR.

The finding that there is an under-reporting of lung and pancreatic cancer to the SCR agrees with the results from the comparison between the SCR and the Cause of Death Register 2009 [2]. Our study could not confirm that study's finding that prostate cancer was under-reported. The under-reporting of pancreatic cancer found in this study also agrees with the results from the study performed by Lambe et al. [5]. The high level of under-reporting of sarcoma, brain tumors, leukemia, and lymphoma seen in Barlow et al. [4] could not be observed in our study; however, hospital units treating these relatively rare diagnoses did not report to the SRPC at the time of this study. In addition, our study includes only cases dead from cancer in contrast to Lambe et al. and Barlow et al. which also includes patients who survived the cancer. Furthermore, the lower proportion of not reported cancer cases to the SCR as reported by Mattsson et al. [3] in 1978 may have been due to a much higher rate of autopsy at that time.

This study has some limitations and some advantages. The sample was representative and the attrition was low (5%). Medical records were obtained and reviewed for 14% of the population we wanted to study. Primary healthcare data were included in the study, data that were not used in most of the recent studies [4,5,6]. A problem is that we used a register of mortality (the SRPC) to identify cases not reported to the SCR, which is an incidence register. Consequently, we have studied the completeness of the SCR in a population that has received end-of-life care, so the results are not generalizable to the Swedish population as a whole. In addition, we cannot evaluate the reduction in the annual cancer incidence caused by the under-reporting to the SCR. As the cohort of patients reported to the SRPC in 2009 as cancer deaths was compared with the SCR (1958–2009) and as patients with a notification of cancer in the SCR were excluded from the study, there is a possibility that a patient could have had a cured cancer earlier in life and registered in the SCR but later in life developed a new cancer not registered in the SCR that caused the patient's death. Therefore, the under-reporting to the SCR found in this study could be underestimated.

In the majority of cases, the departments responsible for cancer diagnosis were internal medicine or surgery. This is not surprising as these departments handle the most common cancers. Noteworthy is the low proportion of primary healthcare. Consequently, our second hypothesis was proven wrong: only a small minority of the under-reporting was due to older patients cared for by GPs in nursing homes.

The SRPC has been criticized for vague and subjective items in the ELQ [15]. This study shows that the validity on the question "which disease was the main cause of death?" with the answer cancer is high (95%).

This study reveals that routines need to be improved for reporting patients to the SCR only using radiological findings. An increased rate of autopsy in cases when the cancer diagnosis was doubtful may also decrease under-reporting.

Until an increased completeness of the SCR is achieved, there must be an awareness of the shortcomings of the register and the research and statistics produced from it, especially for lung, pancreatic, liver, and biliary cancer cases. The results of this study should not be used as an argument to expose incurable cancer patients to more extensive investigations for the purpose of the completeness of the SCR. Nevertheless, it does tell us that there is an under-reporting to the SCR according to current board directives and that the cancer diagnosis reported to SRPC has high validity.

Declaration of interest: The SRPC has financed the request for ethical approval and proofreading of the study. Bertil Axelsson is a member of the board of the SRPC.

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Supplementary material available online

Supplementary Tables I & II.