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VALIDITY OF BREAST CANCER REGISTRATION FROM ONE HOSPITAL INTO THE SWEDISH NATIONAL CANCER REGISTRY 1961–1970

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Abstract

The validity of the Swedish Cancer Registry data on invasive female breast cancer in Malmö 1961–1970 was investigated. A total of 1311 entries in the register were examined, each entry representing an individual tumour, and compared to data from medical records and local registries. In 137 cases (10.5%) registered in the Swedish Cancer Registry, divergencies were found, of which at least 121 were overregistrations (9.2%). Forty-three tumours were identified meriting inclusion but not registered, giving an underregistration of 3.5%. The age distribution among the excluded cases differed somewhat from that of the verified cases.

Key words: Breast cancer, registration, validity.

The female breast cancer incidence is reported to be increasing in Sweden. The official statistics published in 1985 by the Swedish Cancer Registry, reports an estimated increase of 1.4% in age adjusted incidence per year between 1960 and 1982 (1). These data are based on compulsory reports of incident cases from clinicians and pathologists. A similar trend has been shown by Fox (2) using data from the Connecticut Cancer Registry and by Ballard-Barbash et al. from the Mayo Clinic (3) using data from the Rochester, Minnesota area. In order to evaluate whether this increase in incidence is real or not it is important to examine the correctness of the registry data.

Material and Methods

The population studied included the city of Malmö, with a mean female population 127 500 during the years of study. Virtually all patients in Malmö with breast cancer are seen at the Departments of Surgery or Oncology at Malmö General Hospital, which is affiliated to the University of Lund. In the present study only four women were primarily treated at other hospitals. As a consequence virtually all histological and cytological diagnoses were made at the Department of Pathology of the hospital.

Furthermore, the number of autopsies was very high during the years of study, autopsy being performed on more than 80% of deceased persons (4), ensuring a high probability of detection of breast cancer even in patients, where the tumours had not been diagnosed before death.

The Swedish Cancer Registry started in 1958. Up to 1960 preoperative radiotherapy was routinely given to clinically suspected breast cancer in Malmö, making it difficult to assess the size as well as the histological type of the tumour. We therefore chose the year 1961 as the start of our study. We believe that during the period of study, which was before the introduction of mammography, diagnosis of breast cancer was fairly uniform.

All entries in the cancer registry of invasive malignant tumours of the female breast from the population at study were compared to relevant clinical records and local registries at the Departments of Surgery, Oncology and Pathology. In cases where divergencies between registry data and clinical records were found, copies of the original reporting forms were examined. In this way all entries could be traced to individual patients.

All available relevant slides were reviewed at the Department of Pathology. Slides were lacking in 10 cases. In 13 of the 1311 cases histological confirmation of the diagnosis was lacking. In one of these malignant cells were found in pleural effusion.

According to the instructions at the Swedish Cancer Registry suspicion of cancer was registered as cancer and,

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during the relevant period and up to 1980, intraductal in situ cancer as cancer (T. Möller, personal communication).

Results

In the Cancer Registry of Sweden covering the years 1961–1970, we found 1 311 entries from the city of Malmö representing individual tumours of the female breast, occurring in 1 261 women. When these data were compared to data extracted from clinical records, we found inconsistencies in 137 entries (10.5%) of which at least 121 (9.2%) represented overregistrations, giving a falsely high incidence.

Overregistration (Table 1)

In 24 cases (1.8%) the diagnosis had been made outside the period of study. In 18 cases the diagnosis was made before the start of the Swedish Cancer Registry in 1958 but recorded during the period of study at the time of diagnosis of metastatic disease or at death. Six cases were diagnosed just before or just after the period of study but recorded within the period, due to minor differences between the dates of diagnosis noted by us and that recorded by the registry.

In 19 cases (1.4%) single tumours had been registered twice. Of these, 6 cases were erroneously registered as synchronous tumours and in 5 cases as metachronous tumours. In 3 of the latter cases, the registration was made at the time of diagnosis of metastases in the opposite breast. In 8 cases the same primary tumour was registered twice under different identification numbers.

In 15 cases (1.1%) no breast cancer was found. Four cases should have been registered as other malignancies, and the remaining 11 represented benign conditions. Two cases had plasma cell mastitis, 3 cases had 'suspicion of malignancy' stated in the pathology report. Two cases had carcinoma in situ stated on the original pathology report, but were reclassified as epithelial proliferations in radial scars. In 4 cases cancer was reported on clinical findings only, the diagnosis being refuted at operation or at autopsy.

In 46 cases (3.5%) carcinoma in situ was found. This diagnosis was stated in the original pathology report in 45 cases, of which 9 had a suspicion of invasion. In one case there was no mention of invasion in the original report. In another 12 cases the diagnosis was changed from invasive to non-invasive carcinoma at the present review of the slides. These cases have not here been considered erroneous.

Seventeen tumours (1.3%) occurred in patients who were not residents of Malmö at the time of diagnosis.

Table 1

Overregistrations (No. of tumours)

Diagnosis made outside the period of study		24
Duplicate registrations		19
Not mammary carcinoma		
Other malignancies	4	
Benign conditions	11	15
In situ mammary carcinoma		
In situ ca. stated in the pathology rep.	36	
Suspicion of invasion	9	
Invasiveness not mentioned	1	46
Patients not resident of Malmö		17
Total		121

Ambigous cases

As ambiguous we have regarded 10 cases (0.8%). Three patients presented with adenocarcinoma of the axillary glands. All died from generalized cancer. In no case did the histological picture indicate a definite diagnosis of breast cancer, and at autopsy, which was performed on all three patients, no primary tumour could be identified.

The degree of histological confirmation of the diagnosis in the present material was high. In 13 cases no such confirmation was made either at diagnosis or at autopsy. In 4 of these the diagnosis was positively refuted as mentioned above. Two cases were accepted in one of which malignant cells consistent with mammary carcinoma were found in pleural effusion. In 7 cases we considered the clinical data insufficient to merit a diagnosis of breast cancer. Two of these were given radiotherapy. At autopsy no cancer could be identified.

In 6 cases (0.5%) entries were made under wrong identification number, but otherwise correct.

Completeness

In the clinical records and local registries we found 43 carcinomas in 42 patients which were not recorded in the Cancer Registry, although fulfilling the criteria for inclusion. Of these, 5 cases represented patients with synchronous tumours in the opposite breast registered with one entry and 4 cases of metachronous breast tumours registered correctly at first diagnosis, but not at the second. Fifteen of these 43 tumours could not be found elsewhere in the Register, whereas 28 could, all being registered as non-residents of Malmö.

Bilateral tumours

During the period of study 1 311 entries concerning primary breast cancer were made. Due to the occurrence of bilateral cancer either concurrently (synchronous cancer) or successively (metachronous cancer) these entries represent only 1 261 patients. Thus 50 patients were registered as

having bilateral cancer, both cancers occurring during the period, and a further 9 patients with their first cancer 1958–1960 were registered as experiencing a second cancer during the period. Of these 109 entries in 59 patients 83 cancers could be verified (76.1%) and bilateral cancer was verified in 36 patients (61.0%). In the clinical records we found 5 patients with bilateral cancer, of which 4 were registered with only one entry and one was not registered at all. Eighteen patients with metachronous cancer and the first tumour diagnosed before 1958 were correctly registered according to instructions as first entries and thus not identifiable as bilateral cancer cases by means of the registry data.

If the amendments mentioned above are made, 1 223 malignant tumours in 1181 patients can be considered verified. Two tumours in 2 patients were sarcomas, leaving 1 221 carcinomas in 1 179 patients.

Sources of error

Concerning the overregistrations except the ambiguous cases, we have studied the origin of the discrepancies (Table 2). Excluding the 6 cases with minor differences in the date of diagnosis we found the discrepancies to be due to notification error in 43 cases, coding error in 33 cases and the coding instruction in 39 cases.

For the diagnosis of cancer mammae in situ, we found that 5 out of 44 reports sent in by clinicians mentioned non-invasive cancer, whereas the reports from the pathologists did so in 31 of 46 cases. The 12 cases with diagnosis changed at the present review are not taken into consideration here.

Age distribution among valid cases and registered cases

The ratio valid cases/registered cases in different age groups is presented in Table 3. The ratio was lowest in the youngest and the oldest age groups.

Table 2

Causes of discrepancies between registered and verified tumours

	Notification error	Coding instruction	Coding error
Diagnosis made before 1958	7		11
Duplicate registration	14		5
Not mammary carcinoma			
Other malignancy			4
Benign condition	7	4	
In situ mammary carcinoma	15	31	
Patients not resident of Malmö		4	13
Total	43	39	33

Table 3

Ratio valid cases/registered cases in different age groups

Age group	Valid cases/Cases in register (percentage)
<35	10/ 14 (71.4)
35–39	45/ 50 (90.0)
40–44	77/ 86 (89.5)
45–49	140/153 (91.5)
50–54	122/138 (88.4)
55–59	157/169 (92.9)
60–64	172/181 (95.0)
65–69	174/183 (95.1)
70–74	114/139 (82.0)
75–79	96/108 (88.9)
80–84	74/ 83 (89.2)
>85	26/ 34 (76.5)

Discussion

In the present study of invasive malignant tumours of the female breast in residents of Malmö during the period of 1961–1970 we found discrepancies between entries in the Cancer Registry and clinical reports in 137 (10.5%) out of 1 311 cases.

Other studies of Swedish cancer registration have shown errors, but to a lesser extent. Larsson et al. (5) found evidence of overregistration in 101 cases of 2 691 (3.7%) in a demographic study of mammary carcinoma in Northern Sweden.

Rutqvist & Wallgren (6) studied inconsistencies in samples of patients with breast cancer in Stockholm county 1961–1963 and 1971–1973. They found errors in 56 of 855 cases (6.5%), of which at least 52 (6.0%) represented overregistration. In the report by Rutqvist & Wallgren the different types of errors are specified and can be compared to ours. The most obvious difference between their study and ours is the greater number of in situ cancers in our material: 46 of 1 311 cases (3.5%) in our material as compared to 8 of 855 (0.9%) in the study by Rutqvist and Wallgren.

In 32 cases non-invasive tumour was reported from either the clinician or the pathologist. Since the instruction at the Registry up to 1980 was to code non-invasive intraductal cancer as cancer, they were correctly registered as such, which should be taken into consideration when results based on data from before 1980 are evaluated. Only 16 cases of non-invasive breast cancer were registered as such during the period of the study. The increased awareness of in situ breast cancer as a clinical entity separate from invasive cancer, makes this kind of error less likely in more recent materials.

Most of the inconsistencies in the material reported by Rutqvist & Wallgren (6) were due to secondary manifestations being coded as new primaries: 35 of 855 tumours (4.1%). We found only 3 of 1 311 in our study (0.2%, see Table 3). On the other hand we found 18 tumours diagnosed before 1958, but registered in the period studied.

The difference mentioned above can to some extent be explained if this kind of error was recorded under a different heading in the work by Rutqvist & Wallgren than in our study.

The question of whether a sequential cancer growth in the opposite breast is a new primary or a secondary manifestation is difficult and sometimes impossible to answer. We have considered tumours with a histology different from the first tumour as primaries as well as tumours histologically consistent with new primary tumours, if there were no other signs of secondary disease at the time of the second diagnosis.

The extent of underregistration of diagnosed cases is less easy to ascertain. Mattsson & Wallgren (7) compared the Cause of Death Registry for 1978 to the Swedish Cancer Registry and found 1013 cancer diagnoses in the former not notified to the cancer registry, which made a deficit of 4.5% for all cancer sites. Tumours with a high degree of histological verification as breast cancers were reported more completely, giving a deficit for breast cancer of 35 cases (1.9%).

In a cancer with such a relatively low fatality rate as breast cancer, use of cause-of-death registries would be expected to give incomplete data concerning incidence. Data from population surveys or hospital registries are generally more reliable, as discussed by Nwene & Smith (8) who found deficient recordings of 7.2% of breast cancer cases in the north-west region of England. In another study Mattsson et al. (9) compared cancer registry data to data from the computerized in-patient register of Stockholm and found only 3 cases not notified out of 877 (0.3%). In the present study we found underregistration in 43 cases of 1223 (3.5%).

Carlsson et al. (10) studied the correctness of entries of colorectal cancers in patients from the city of Malmö for 1979 into the Swedish Cancer Registry. They analyzed the separate steps from diagnosis to registration and found that insufficient information on the reporting forms was the main source of error. In our study, we have found errors on the reports to equal approximately errors made at the registry.

Some errors are preventable by improving communication between the registry and the providers of information. Concerning the discrepancies due to coding instructions, it seems important for the cancer registries in their coding policies to be in accordance with clinical practice. Today it is obvious that in situ cancer should not be grouped with invasive cancer.

Concerning bilateral cancer we found the data in the Swedish Cancer Registry unreliable, which is in agreement with the findings by Rutqvist & Wallgren (6).

Young women with breast cancer are a group which is of special interest epidemiologically, and even if the numbers are small it is noteworthy that the data in the registry could only be verified in 71% of cases below 35 years.

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