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ORIGINAL ARTICLE

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Abstract

Background. The Swedish Patient Registry provides data about diagnoses and surgical procedures for research purposes. There are, however, almost no validation studies of the data on surgical procedures, and none of oesophageal cancer surgery. *Material and methods.* This was a validation study of the accuracy of codes representing oesophageal cancer resection, surgical approach and oesophageal substitute in the Swedish Patient Registry during the period 1987–2005. The registered data were compared with a thorough review of the corresponding operation charts collected from medical records. *Results.* Among 1358 patients with a code representing oesophageal resection in the Patient Registry, the positive predictive value was 99.6%. The dominant surgical procedures in terms of surgical approach (transthoracic) and type of oesophageal substitute (gastric conduit) had positive predictive values of 99.8% and 99.4%, respectively. The more rare procedures with regards to approach (transhiatal) and substitute (bowel) had lower positive predictive values of 68.8% and 68.5%, respectively. *Conclusion.* The high accuracy of the data regarding oesophageal cancer resection in the Swedish Patient Registry stresses its appropriateness for research purposes.

The Swedish Patient Registry contains data on hospitalisations and surgical procedures performed in Sweden since 1964, with a nationwide complete registration since 1987. It records data on the patients' age, sex, personal identity number, and the dates of hospitalisations, discharge diagnoses, and surgical procedures. Data from the Swedish Patient Registry is often used for research purposes, but the validity of this data has been evaluated only in a limited number of studies and for a few selected diagnoses [1]. There are, to the best of our knowledge, only two studies that have validated the accuracy of the codes representing surgical procedures, one evaluating a range of different operations [2], and one evaluating gynaecological operations [3]. Our research group has used the Swedish Patient Registry for studies of factors influencing survival after oesophageal cancer surgery [4–6], but there are no validation studies concerning the codes for oesophageal cancer surgery in this registry. Such information should be of relevance for future studies of oesophageal cancer research based on this registry. We therefore conducted a large validation study of codes representing oesophageal cancer resections within the Swedish Patient Registry.

Material and methods

Study design

This nationwide Swedish validation study addressed the operation codes representing oesophageal cancer resection in the Swedish Patient Registry from 1987 to 2005, a period when the Patient Registry had complete national coverage. The study cohort was based on a combination of an oesophageal cancer diagnosis according to the Swedish Cancer Registry (codes 150 and C15 in the 9th and 10th versions of the International Classification of Diseases, respectively) and an oesophageal resection according to the Swedish Patient Registry (codes 282.X, 2821, 2822, 2829 before 1997 and codes JCC00, JCC10, JCC11, JCC20, JCC30, JCC96, JCC97 since 1997 of the Swedish version of the Classification of

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Surgical Procedures). A validation study of oesophageal cancer diagnoses in the Cancer Registry has shown it to have 98% completeness [7]. The operation codes from the Patient Registry were compared to a thorough manual review of the corresponding operation charts, collected from medical records from all hospitals in Sweden. The personal identity numbers, 10 digit identifiers assigned to all Swedish residents, were used to trace these records. The information from the operation charts was transferred into codes; this was conducted independently by two reviewers, who were kept blinded to the codes of the Patient Registry. Finally, the operation charts codes were compared with the corresponding codes from the Patient Registry. The correctness regarding oesophageal cancer resection (yes or no), surgical approach (transthoracic, transhiatal, or other) and oesophageal substitute (gastric, bowel, or no or unknown) was assessed.

The Swedish Patient Registry

The Swedish Patient Registry is a major source of data for numerous research projects. The Registry is held by the governmental agency the National Board of Health and Welfare in Sweden. Counties in Sweden gradually started to report their data to the registry during the period 1964–1987. There were six counties that reported to the registry in 1964, and since 1987, the registry has had a complete nationwide coverage of the in-hospital care at the public hospitals. The Patient Registry contains four different kinds of data: 1) Patient data, including personal identity number, sex, age, area of residency, and congregation; 2) Hospitals and hospital departments, including their names and addresses; 3) Route of each specific care episode, including information about enrolment date, discharge date, length of hospital stay, entry way, and discharge way; and 4) Medical data, including the main discharge diagnosis, up to six co-diagnoses, and data on all surgical procedures. All hospitals in Sweden are obliged by law to report all in-patient care to the Swedish Patient Registry. The information submitted from the hospitals undergoes regular quality controls by the National Board of Health and Welfare.

Study variables

The main analysis addressed the accuracy of the recorded operation type, i.e. oesophageal cancer resection. We also analysed codes representing surgical approach, which were available from 1997. This variable was categorised into three groups: transthoracic, i.e. opening of the chest wall (operation codes

JCC10 and JCC30), transhiatal, i.e. no opening of the chest wall, but dissection through the diaphragm and the neck (JCC00 and JCC20), or other approach (JCC11, JCC96, and JCC97). Moreover, we analysed the codes representing oesophageal substitute, which was coded before 1997. It was determined whether the substitute replacing the resected oesophagus was gastric (operation code 2820), bowel (2821 or 2822), or whether no or an unknown substitute was used (2829).

Statistical analysis

The operation codes from the Patient Registry of each patient were compared with the operation chart of that patient. The number of procedures incorrectly classified as oesophageal resection in the Patient Registry was assessed, and positive predictive values were calculated for the main codes.

Results

Patients

There were 1481 patients with a recorded diagnosis of oesophageal cancer resection eligible for the study. Among these, the medical records and operation charts were successfully collected from 1358 patients (91.7%), who comprised the final cohort for this study. Some characteristics of the study participants are shown in Table I. There was an expected male predominance, and few patients were older than 75 years at the time of surgery. The

Table I. Characteristics of 1358 patients undergoing esophagectomy between 1987 and 2005 in Sweden.

Characteristics	Number (%)
Sex	
Men	1015 (75)
Women	343 (25)
Age	
<65	599 (44)
65–75	571 (42)
>75	188 (14)
Stage	
0–I	244 (18)
II	435 (32)
III	340 (25)
IV	111 (8)
Missing	228 (17)
Histology	
Adenocarcinoma	495 (36)
Squamous carcinoma	809 (60)
Missing	54 (4)
Operation code	
<1997	724 (53)
≥1997	634 (47)

most common tumour stages were stages II and III, and the histological type squamous cell carcinoma was more common than adenocarcinoma.

Oesophageal cancer resection

The codes representing oesophageal cancer resection in the Patient Registry were correct in 1352 out of 1358 patients, rendering a positive predictive value of 99.6%.

Surgical approach

It was possible to validate the surgical approach for 634 patients with an oesophageal cancer resection code classified after 1997. The accuracy of the surgical approach data in the Patient Registry compared to the operation charts is presented in Tables II and III. A transthoracic approach was indicated in 544 patients in the Patient Registry and this was the case for 543 patients according to the operation charts, rendering a positive predictive value of 99.8% (Table II). The corresponding data for a transhiatal approach was 32 in the Patient Registry which was correct in 22 of the patients, rendering a positive predictive value of 68.8% (Table III).

Oesophageal substitute

The oesophageal substitute was coded in 724 patients who had an oesophageal cancer resection code classified before 1997. A gastric substitute was used in 631 patients according to the Patient Register and was true in 627 patients according to the operation charts, rendering a positive predictive value of 99.4% (Table IV). The number of patients with a bowel substitute according to the Patient Registry was 73, while the number according to the operation charts

Table II. Positive predictive value (PPV) and 95% confidence interval (CI) for the transthoracic approach variable as part of oesophageal cancer resection in the Swedish Patient Registry compared to operation charts.

		Transthoracic approach in the Patient Registry (number)		
		Yes	No*	Total
Transthoracic approach in the operation charts (number)	Yes	543	60	603
	No	1	30	31
	Total	544	90	634
		PPV 99.8% (543/544), 95% CI 99.0–100.0%		

*No, transhiatal approach, unclear, or not oesophageal cancer surgery.

Table III. Positive predictive value (PPV) and 95% confidence interval (CI) for the transhiatal approach variable as part of oesophageal cancer resection in the Swedish Patient Registry compared to operation charts.

		Transhiatal approach in the Patient Registry (number)		
		Yes	No*	Total
Transhiatal approach in the operation charts (number)	Yes	22	9	31
	No	10	593	603
	Total	32	602	634
		PPV 68.8% (22/32), 95% CI: 50.0–83.9%		

*No, transthoracic, unclear, or not oesophageal cancer surgery.

was 50, rendering a positive predictive value of 68.5% (Table V).

Discussion

This study revealed that the Swedish Patient Registry had over 99% accuracy regarding oesophageal cancer resection, as well as the most common surgical approach (transthoracic) and the dominant oesophageal substitute (gastric).

Advantages of the present study include the population-based design, the large sample size, and the good availability of medical records with operation charts, counteracting selection bias, chance errors, and providing a robust standard, respectively. The manual review of the operation charts could, however, introduce a misclassification, e.g. by human error or technical translation errors. To reduce such misclassification, the operation charts were assessed by two independent reviewers who were both kept blinded to the codes of the Patient Registry. Another potential problem was the missing

Table IV. Positive predictive value (PPV) and 95% confidence interval (CI) for the gastric substitute variable as part of oesophageal cancer resection in the Swedish Patient Registry compared to operation charts.

		Gastric substitute in the Patient Registry (number)		
		Yes	No*	Total
Gastric substitute in the operation charts (number)	Yes	627	29	656
	No	4	64	68
	Total	631	93	724
		PPV 99.4% (627/631), 95% CI 98.4–99.8%		

*No, bowel substitute, no substitute, unclear, or not oesophageal cancer surgery.

Table V. Positive predictive value (PPV) and 95% confidence interval (CI) for the bowel substitute variable as part of oesophageal cancer resection in the Swedish Patient Registry compared to operation charts.

		Bowel substitute in the Patient Registry (number)		
		Yes	No*	Total
Bowel substitute in the operation charts (number)	Yes	50	6	56
	No	23	645	668
	Total	73	651	724
		PPV 68.5% (50/73), 95% CI 56.6–78.9%		

*No, gastric substitute, no substitute, unclear, or not oesophageal cancer surgery.

data on some medical records, but since only a very small percentage was missing this should not greatly influence the results.

A recent review of the published validity studies shows that these have mainly addressed selected diagnoses in the Swedish Patient Registry. These studies suggest that the overall positive predictive value of diagnoses recorded in the Registry is about 85–95% correct, but there is substantial variation between specific diagnoses [1]. There are, however, very few validation studies of surgical procedures in the Patient Registry. One study of 1338 gynaecological operations found an overall completeness of 99% and a correct classification of 95%, while the positive predictive values ranged from 86–100% depending on the specific operation [3]. In another study, medical records for 962 hospital admissions in 1986 showed that only 2% of patients with any type of surgery had incorrect procedure codes, and that in 9% such codes were missing [2]. No other studies of the validity of operation codes have been undertaken.

The results of this study suggest that the operation codes representing oesophageal cancer resection surgery of the Swedish Patient Registry are highly correct, allowing high-quality research based on the data. The accuracy of the more specific surgery variables, i.e. surgical approach and oesophageal substitute, was also impressive regarding the dominant procedures. This good validity is important for future studies of oesophageal cancer surgery using this source of data. The Patient Registry uses computerised data collection, which results in a high correctness when it comes to codes and other collected data,

e.g. personal identity numbers, dates and hospital numbers. Reasons for the incorrect data regarding rare procedures, i.e. transhiatal approach and bowel substitute, are probably mainly due to physicians entering the wrong codes for the operation, since these codes are rarely used. This finding indicates the need for complementary clinical data collection whenever less common surgical procedures are specifically evaluated in association with oesophageal cancer surgery. Moreover, this finding requires further investigation for other surgical procedures and in other registries.

In summary, this Swedish nationwide validation study of all patients that underwent oesophageal cancer resection in 1987–2005 indicates that the Swedish Patient Registry is a reliable data source when it comes to oesophageal cancer surgery, and it is recommended for further research purposes. However, evaluations of less common surgical oesophageal cancer approaches should be supplemented by clinical data collection.

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