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Gastric cancer completeness in Finnish Cancer Registry and Finnish Patient Registry: a population-based nationwide retrospective cohort study

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ABSTRACT

Background Gastric cancer is the fourth-leading cause of cancer-related deaths worldwide. The only curative treatment options of gastric cancer are perioperative chemotherapy and surgical resection. Many nationwide registries have high validity and provide vast range of opportunities for registry-based research. Cancer diagnoses in the Finnish Cancer Registry (FCR) are reported by pathology laboratories and clinician forms, while discharge diagnosis codes are reported to the Finnish Patient Registry (HILMO) automatically. Finland is known for complete registries but the completeness of gastric cancer in FCR and HILMO remains unclear.

Objectives The aim of this study is to assess the registry coverage for gastric cancer in FCR and HILMO and to explore potential reasons for possible differences between these registries.

Design Population-based nationwide retrospective cohort study.

Participants All patients diagnosed with gastric cancer in Finland during 1990 to 2014, with follow-up until 31 December 2019.

Results Out of 21 468 total gastric cancers reported to either registry, 17 107 (79.7%) had a gastric cancer diagnosis in both registries. A substantial decrease from 88.3% to 83.4% was observed in the proportion of cases reported to FCR over time. The completeness of FCR was estimated at 87%. For HILMO, the completeness was 92.7%. Death due to gastric cancer was most common in those with gastric cancer in both registries (80.8%), and less common in those reported to only FCR (36.3%), followed by those reported to only HILMO (9.3%).

Conclusions The study indicates that gastric cancer is well captured by both FCR and HILMO but there is an alarming decrease in the proportion of cases captured by the FCR over time. Some gastric cancer diagnoses in HILMO might, however, be misclassified due to cancer diagnoses being assigned based on clinical suspicion.

Strengths and limitations of this study

- ► The main strength of this study is the population-based nationwide design.
- ► The size of the cohort was large with a complete follow-up of all patients diagnosed with gastric cancer in Finland.
- ► The population-based design of this study and complete follow-up of participants counteracts any selection bias.
- ► The limitation of the study is the unavailability of medical records for the assessment of validity of diagnoses.

INTRODUCTION

Gastric cancer is declining in incidence but remains the fourth-leading cause of cancer-related death around the world.[1] Gastric cancers are anatomically classified into gastric cardia cancer, including Siewert type II cancer and gastric non-cardia cancer, including true gastric adenocarcinomas and Siewert type III cancer.[2–4] Currently, the only curative treatment of gastric adenocarcinoma, the most prevalent gastric cancer, is surgical resection with or without perioperative chemotherapy.[5]

The nationwide Nordic registries with high validity provide excellent opportunities for registry-based medical research and cohort studies with long and complete follow-up.[6] Finland is known for complete and accurate registries, for example, the Finnish Cancer Registry (FCR) reporting cancer statistics, and the Finnish Patient Registry (HILMO) collecting hospital discharge diagnoses and surgical codes for statistical and governmental purposes.[7 8]

A previous study in Finland showed that FCR data had good accuracy regarding colorectal cancer.[9] Completeness of both FCR and HILMO was found to be above 90% for oesophageal cancer.[10] However, completeness of gastric cancer diagnosis in FCR and HILMO still remains unclear. Therefore, the quality of these registries must be evaluated for their proper utilisation in future research.

The aim of this study is to assess the registry coverage for gastric cancer in FCR and HILMO and to explore potential reasons for possible differences between registries.

METHODS

Study design

A population-based nationwide retrospective cohort study of all patients with gastric cancer in Finland during 1990–2014 was conducted.[11 12]

Data sources

The data on gastric cancer were retrieved from FCR and HILMO. All the patients who had gastric cancer in either FCR or HILMO were identified using respective ICD-9 (151) and ICD-10 (C16) codes. Mortality was evaluated from the death registry held by Statistics Finland. Unique immutable personal identification number assigned to all residents in Finland were used to combine registry data.

The FCR and HILMO are comprehensive registries as all healthcare units in Finland are obligated to enter patient and treatment data into these registries. FCR includes all incident cancers from the population of Finland since the year 1953. These data are usually input by clinicians by using paper, and more recently electronical forms and semiautomatic reporting of cancer from pathology and cytology laboratories. FCR collects information on cancer type, date of diagnosis, location of cancer from laboratory notifications and treatment information from both clinical and laboratory notifications.[7] However, as these notifications are based on histological or cytological confirmation, or a form filled by a clinician, some cancers many be missed. HILMO on the other hand, is completely independent from FCR and includes information on discharge dates, diagnosis and operation codes assigned by clinicians to every patient during each admission. Codes for open and minimally invasive oesophagectomy and gastrectomy (codes 620x, 630x, 631x, 632x and 636x in the Finnish Surgical codes prior to 1996, and codes JCCxx, JDCxx and JDDxx in the Nordic Classification of Surgical Procedures (NOMESCO) from 1996 and onwards), and endoscopic mucosal resection (EMR) and endoscopic submucosal dissection (ESD) (NOMESCO codes JCA45, JCA52, JDA45, JDA52 and JDH52) were used for identification of surgical treatment in patients with a diagnosis of gastric cancer. As some gastric cardia cancers are assigned with oesophageal procedure codes, both oesophageal and gastric surgery codes were included when used with a gastric patient diagnosis. The hospital administration reports these codes electronically and automatically into the patient registry on discharge. Reimbursements from the municipalities are based on these same diagnosis and operation codes. Furthermore, these discharge codes are used by governmental bodies to calculate the healthcare district and municipality-specific rates of healthcare costs and morbidity indices, that serve as the basis of healthcare funding to the municipalities and hospital districts from the government. More than 99% of hospital discharges are reported to HILMO.[8]

Statistics Finland death registry provides information on patient death, date of death and its primary and secondary causes. Death information is input by clinicians into the death certificates which include description of patients' disease and cause of death based on evaluation or autopsies.[13] The correctness of all death certificates is checked by forensic physicians before they are recorded in Statistics Finland causes of death. The completeness of the registry is 100% for date of death and >99% for cause of death.[14]

Statistical analysis

The data were retrieved from FCR and HILMO from the period of 1987–2016. Cancer diagnoses during the first 3 years were excluded to reliably identify the earliest cancer incidence and the last 2 years were omitted due to potential time lag in reporting, resulting in time period of 25 years from 1990 to 2014. Patients diagnosed only in autopsies were excluded. Death data was available until 2019, resulting in a minimum follow-up of 5 years for all patients.

For analysis of completeness, the three subpopulations were derived from the total cohort: (1) those present in FCR only (2) those present in HILMO only and (3) those present in both FCR and HILMO. The proportions of patients in these three groups were calculated in total and stratified in terms of sex, age, calendar period, surgery, causes of death and gastric cancer records in HILMO and FCR. The death registry was used to identify those who died of gastric cancer. Survival analysis was conducted to examine the mortality patterns in the different groups with life table method[15] and plotted using Kaplan-Meier curves to indirectly evaluate whether there were major differences in the accuracy of gastric cancer recording, as these cancers are known to have high mortality.

Patient and public involvement

Patients or public were not involved in the development of the research question and study design or conducting this study.

RESULTS

Patients

Of the total 22 121 gastric cancers diagnosed in 1990–2014, 19 907 had a gastric cancer diagnosis in HILMO, and 19 321 in FCR. Considering all patients with gastric cancer in the FCR, the Death Certificate Only rate was 1.4% (n=268). Of those with gastric cancer diagnosis only in FCR, 653 were diagnosed during autopsy were excluded from further analyses.

After exclusion, there was a total of 21 468 gastric cancers reported in either registry of FCR and HILMO during the 25 years. Among these cases 17 107 (79.7%) were reported to both FCR and HILMO, 1561 (7.3%) were reported only to FCR and 2800 (13.0%) were reported only to HILMO (table 1). Based on these

Table 1 The characteristics and vital status with causes of death in patients with gastric cancer reported to Finnish Cancer Registry (FCR) and Hospital Discharge Registry (HILMO)

Variable	FCR only n (%)	HILMO only n (%)	Both FCR and HILMO n (%)	Total n (%)
Total	1561 (7.3)	2800 (13.0)	17 107 (79.7)	21 468 (100)
Sex				
Female	801 (8.3)	1271 (13.1)	7636 (78.7)	9708 (100)
Male	760 (6.5)	1529 (13.0)	9471 (80.5)	11 760 (100)
Age at diagnosis				
Up to 50 years	150 (8.3)	212 (11.7)	1452 (80.0)	1814 (100)
51–60 years	237 (7.8)	417 (13.8)	2367 (78.4)	3021 (100)
61–70 years	344 (6.7)	732 (14.2)	4087 (79.2)	5163 (100)
71–80 years	383 (5.7)	891 (13.3)	5431 (81.0)	6705 (100)
81–90 years	363 (8.4)	508 (11.8)	3429 (79.7)	4300 (100)
Over 90 years	84 (18.1)	40 (8.6)	341 (73.3)	465 (100)
Surgery				
No	1281 (10.2)	2200 (17.4)	9127 (72.4)	12 608 (100)
Yes	280 (3.2)	600 (6.8)	7980 (90.1)	8860 (100)
Time period				
1990–1994	385 (7.3)	613 (11.7)	4242 (81.0)	5240 (100)
1995–1999	318 (7.1)	438 (9.8)	3729 (83.1)	4485 (100)
2000–2004	280 (6.7)	570 (13.6)	3345 (79.7)	4195 (100)
2005–2009	271 (6.9)	573 (14.7)	3059 (78.4)	3903 (100)
2010–2014	307 (8.4)	606 (16.6)	2732 (75.0)	3645 (100)
Vital status*				
Alive	361 (23.1)	440 (15.7)	1270 (7.4)	2071 (9.6)
Dead	1200 (76.9)	2360 (84.3)	15 837 (92.6)	19 397 (90.4)
Cause of death†				
Gastric cancer	566 (47.2)	259 (11.0)	13 831 (87.3)	14 656 (75.6)
Other	634 (52.8)	2101 (89.0)	2006 (12.7)	4741 (24.4)

*Calculated as the percentage of total patients in each group.
†Calculated as the percentage of those who died.
FCR, Finnish Cancer Registry; HILMO, Finnish Patient Registry.

numbers, FCR captured 87.0% of gastric cancers, and HILMO captured 92.7% of gastric cancers.

Of the total cases, 11 760 (54.8%) were male and 9708 (45.2%) were female. The median age for diagnosis was 70 years. The highest number of patients were observed during the period of 1990–1994 which was 5240 (24.4%). Surgical treatment was received by 8860 (41.3%) of total patients, including 80 patients with ESD or EMR. No major differences were observed in the reporting to the registries in terms of sex and age group. Surgically treated patients were more often reported to both registries than those without surgery. A considerable decrease from 88.3% in 1990–1994 to 83.4% in 2010–2014 was observed in the proportion of cases reported to FCR over time (table 1).

Of all patients (19 397) who died, 14 656 (75.6%) died of gastric cancer and 4741 (24.4%) died of other causes. A majority of deaths were observed in those reported to both FCR and HILMO (table 1).

Patients reported in FCR only

Of 1561 patients who were reported to FCR only, 566 (36.3%) died of gastric cancer, 634 (40.6%) died of other causes and the rest 361 (23.1%) were still alive (table 1). No oesophageal cancer diagnosis was recorded in HILMO for 1311 (84.0%), suggesting low misclassification. Admissions for oesophageal cancers were recorded in 250 (16.0%) patients, but only 6 (0.4%) had oesophageal cancer recorded in FCR (table 2).

Patients reported in HILMO only

Of 2800 patients who were reported to HILMO only, 259 (9.3%) died of gastric cancer, 2101 (75.0%) died of other causes, leaving 440 (15.7%) alive (table 1).

Table 2 The number of admissions for oesophageal cancer and gastric cancer in Hospital Discharge Registry (HILMO), and oesophageal cancer diagnoses in the Finnish Cancer Registry (FCR) in patients with gastric cancer

Variable	FCR only n (%)	HILMO only n (%)	Both FCR and HILMO n (%)	Total n (%)
Total	1561 (100)	2800 (100)	17 107 (100)	21 468 (100)
No of gastric cancer admissions in HILMO				
0	1561 (100)	–	–	1561 (7.3)
1	–	1470 (52.5)	2465 (14.4)	3935 (18.3)
2 or more	–	1330 (47.5)	14 642 (85.6)	15 972 (74.4)
No of oesophageal cancer admissions in HILMO				
0	1311 (84.0)	2375 (84.8)	16 343 (95.5)	20 029 (93.3)
1	27 (1.7)	47 (1.7)	266 (1.6)	340 (1.6)
2 or more	223 (14.3)	378 (13.5)	498 (2.9)	1099 (5.1)
Oesophageal cancer diagnosis in patients with gastric cancer in FCR				
No	1555 (99.6)	2363 (84.4)	17 091 (99.9)	21 009 (97.9)
Yes	6 (0.4)	437 (15.6)	16 (0.1)	459 (2.1)

FCR, Finnish Cancer Registry; HILMO, Finnish Patient Registry.

Admissions for oesophageal cancers were recorded in 425 (15.2%) patients, and oesophageal cancer was recorded in FCR for 437 (15.6%) of the patients (table 2).

Patients reported in both

Of 17 107 patients reported to both FCR and HILMO (table 1), 13 831 (80.8%) died of gastric cancer, 2006 (11.7%) died of other causes and the rest 1270 (7.4%) were still alive (table 1). A majority (85.6%) had two or more gastric cancer admissions and no admission for oesophageal cancer (95.5%, table 2).

Mortality

As gastric cancer is known to have high mortality rate, survival analysis was conducted to further evaluate the accuracy of gastric cancer diagnoses in each of the groups. The 5-year mortality in all groups were high. Those who were reported to only HILMO, or only FCR had lower mortality than those who were reported to both FCR and HILMO (figure 1).

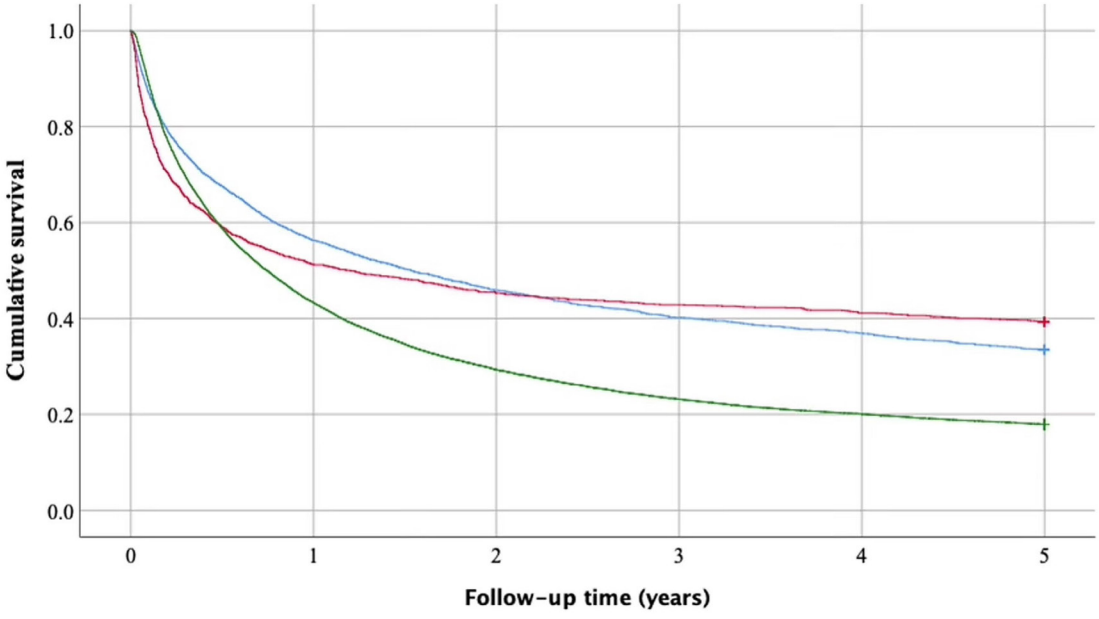

Figure 1 Kaplan-Meier curve depicting 5- year all-cause mortality in patients with gastric cancer stratified by registry status. The red line represents those in FCR only, the blue line represents those patients registered in HILMO only, and the green line represents those in both FCR and HILMO. FCR, Finnish Cancer Registry; HILMO, Finnish Patient Registry.

DISCUSSION

The study shows that gastric cancer is well captured by both FCR and HILMO registries but there is an alarming decrease in the proportion of cases captured by FCR over time.

Some of the strengths of the study include the population-based nationwide design and a large size of cohort with a complete follow-up of all patients diagnosed with gastric cancer in Finland preventing any selection bias. A weakness of the study is the unavailability of medical records for the assessment of validity of diagnoses.

The proportions of gastric cancer reported to FCR, HILMO and both were relatively similar between sex and age groups. Surgical patients were more often reported to both FCR and HILMO, suggesting that palliative and/or patients not undergoing surgical resection might be more often missed by either of these registries. A significant decline in reporting to FCR was observed over time. As reporting to HILMO is based on administration, but FCR relies on reporting by physicians, physician workload and lack of clarity in responsibilities of reporting might influence this phenomenon. Even though reporting to FCR is mandated by legislation, it might be that physicians do not see reporting new cancer cases to FCR as important part of cancer treatment, or that reporting is missed due to lack of impact on the treatment of the patient. Even though the laboratories automatically report these cases to the FCR, some diagnoses in which histological confirmation is not sought, might still be missed. Lastly, some malignant tumours of lower malignancy grade, such as gastric neuroendocrine tumours might be more likely to be missed by cancer registry, as suggested by better survival in those patients only reported to FCR compared with being reported to both registries.

Gastric cancer is associated with high mortality. FCR might have a higher specificity of cancer diagnoses in comparison to HILMO, reflected by slightly higher proportion of gastric cancer deaths reported to only FCR compared with those reported to only HILMO. Furthermore, half of those patients not reported to only HILMO had only one gastric cancer admission in HILMO, while the other half had two or more admissions, potentially reflecting cases where cancer diagnosis was assigned to a patient during evaluation for suspected cancer, but this diagnosis was then not confirmed later. In survival analysis, mortality in all groups was high, supporting the view that the specificity of gastric cancer diagnoses was relatively high in also those missed by either FCR or HILMO. The survival curves showed that the mortality was lower in those reported to only HILMO and those reported to only FCR, compared with those reported to both, suggesting that some misclassification or lower malignancy tumours might be included in patients not reported to both registries. Previously reported possible misclassification between distal oesophageal and gastric (cardia) cancer[10] was deemed low based on the low number of oesophageal cancer deaths and oesophageal cancer admissions in this cohort of patients with gastric cancer.

The estimated completeness of gastric cancer was 87.0% for FCR and 92.7% for HILMO. Previously, both FCR and HILMO have shown to have above 90% completeness for oesophageal cancer.[10] A good accuracy of FCR was also indicated by a similar study for colorectal cancer.[9] A Swedish study, on the other hand, indicated a substantial underreporting of pancreatic and biliary cancers in the Swedish Cancer Registry.[16] Based on these figures, both FCR and HILMO can be reliably used for registry research in gastric cancer. To turn the decreasing trend of reporting to FCR, clinicians are recommended to report all patients with gastric cancer to FCR at all stages of diagnosis and treatment. Automatic reporting to FCR during the assignment of cancer diagnosis to a patient in the electronic medical records could help improve the declining trend.

In conclusion, both FCR and HILMO have high completeness and validity in gastric cancer diagnoses. Clinicians are suggested to pay attention to reporting all new cases to FCR, and to consider not assigning cancer diagnoses during initial diagnostic workup to reduce potential false positives in the registries.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval The study has been approved by ethical committee in Northern Osthrobothnia (EETMK 115/2016), The National Institute for Health and Welfare (THL/169/5.05.00), Statistics Finland (TK-53-1478-17) and the Office of the Data Protection Ombudsman (Dnro 506/402/17), Finland. Individual informed consent was not sought from the patients, as obtaining the informed consent was waived by the Finnish law. The study was conducted in accordance with the Declaration of Helsinki.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. All data presented in this article are available from THL/Findata, Finland. Data access to collaborators can be granted given that relevant government and health officials approve the collaborative study.

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