ACTA ONCOLOGICA
2020, VOL. 59, NO. 11, 1329–1332
https://doi.org/10.1080/0284186X.2020.1792547

Taylor & Francis
Taylor & Francis Group

LETTER TO THE EDITOR

Completeness of esophageal cancer diagnosis in the Finnish Cancer Registry and hospital discharge registry, a nationwide study in Finland

Joonas H. Kauppila[a,b]

[a]Surgery Research Unit, Medical Research Center Oulu, Oulu University Hospital and University of Oulu, Oulu, Finland; [b]Upper Gastrointestinal Surgery, Department of Molecular Medicine and Surgery, Karolinska Institute and Karolinska University Hospital, Stockholm, Sweden

ARTICLE HISTORY Received 24 April 2020; Accepted 2 July 2020

Introduction

Esophageal carcinoma is the sixth most common cause of cancer death in the World [1], with 10% five-year survival [2]. The data in Finnish Cancer Register (FCR) [3] and Finnish Hospital Discharge Registry (HILMO) have been estimated to be of good quality [4]. The national incidence of cancer and cancer mortality are estimated based on FCR, and both FCR and HILMO are used in research. The national registries in the Nordic countries are very similar with high specificity and completeness [5]. A Swedish study showed that the Swedish cancer registry is 98.3% complete for esophageal cancer diagnosis [6].

Distal esophageal and gastric cardia cancers are often misclassified due to difficulties in defining the exact location anatomically, radiologically, and endoscopically, as well as due to changing and overlapping definitions [6,7]. However, no studies have assessed the potential misclassification and completeness of esophageal cancer specifically in FCR or HILMO.

The aim of this study was to explore the potential misclassification and evaluate the completeness of esophageal cancer diagnoses in the FCR and HILMO, considering misclassification.

Methods

Study design

The present study was a population-based, nationwide, retrospective cohort study of all esophageal cancer patients in Finland in 1990–2014. All patients who had esophageal cancer in FCR or HILMO were included. Mortality was evaluated using Death Registry. Registry data were combined using the immutable 11-digit personal identification number assigned to all residents in Finland.

Data sources

All healthcare units in Finland have a statutory obligation to enter data into the national registries making them highly comprehensive.

The 'Finnish Cancer Registry' covers all incident cancers in whole population of Finland since the 1953 [3]. The data on cancer diagnoses and given treatment are reported to the FCR by clinicians i.e., general practitioners, surgeons and oncologists (clinical notifications), as well as by laboratories, i.e., pathologists (laboratory notifications) on paper or more recently, using electronical submission forms. FCR provided information on cancer, including date of cancer, and the topography (location) of the cancer.

The 'Finnish Patient Registry', held by the Finnish Institute of Health and Welfare, provided information on the discharge dates, diagnosis codes in the final discharge notes and operation codes assigned for each patient during their admission [4]. The reporting to HILMO is done by the hospital administration after a discharge of a patient.

'Statistics Finland' provided data on the dates and causes of death of the patients. In addition to the main cause of death, underlying and secondary causes of death are reported to the death registry by clinicians writing death certificates with an accurate description of the patient's illness leading to death or by pathologists or forensic physicians conducting autopsies. All death certificates in Finland are manually checked and validated by forensic physicians employed by the government [8]. As esophageal cancers are of high mortality, the reporting to death registry is independent from the other registries used in this study and individually validated, death data was used to estimate the specificity of esophageal cancer diagnosis.

Patient identification

FCR and HILMO were used to identify patients with cancer of the esophagus (150.0–150.9 in the International Classification of Diseases (ICD)-8 and ICD-9, and C15 in the ICD-10).

CONTACT Joonas H. Kauppila Joonas.kauppila@oulu.fi Surgery Research Unit, Medical Research Center Oulu,Oulu University Hospital and University of Oulu, P.O. Box 5000, 90014, Oulu, Finland; Upper Gastrointestinal Surgery, Department of Molecular Medicine and Surgery, Karolinska Institute and Karolinska University Hospital, Stockholm, Sweden

Supplemental data for this article can be accessed here.

The year of diagnosis was based on the first occurrence of cancer diagnosis in either FCR or HILMO. Surgical treatment status was defined based on operations codes for esophagectomy, gastrectomy or endoscopic mucosal surgery [9].

Ethical approval

The study has been approved by ethical committee in Northern Ostrobothnia (EETMK 115/2016) and governmental agencies [9]. Individual consent from patients is not required in Nordic registry research.

Data analysis

The data was retrieved from the registries from 1984 until 2016. To reliably identify the earliest cancer incidence date for each patient, all patients with first esophageal or gastric cancer diagnosis prior to 1 January 1989 were excluded. Due to potential time lag in reporting, the two most recent years were excluded, resulting in a 25-year study period of 1990–2014. Death data were available until 31 December 2016.

Three subpopulations were derived from the total cohort: (1) those present only in FCR (with exclusion of esophageal cancer diagnosed in only autopsy), (2) those present only in HILMO and (3) those present in both FCR and HILMO. The proportions of patients in the three groups were calculated in total, and stratified by sex, age, calendar period, surgical treatment, causes of death and esophageal and gastric cancer records in HILMO and FCR. Survival analysis was conducted with life table method [10] and plotted using Kaplan-Meier curves.

Completeness of the FCR and HILMO registries were assessed by calculating the proportion of total patients with esophageal cancer captured by FCR or HILMO. Due to previously described misclassification between esophageal and gastric cancer diagnoses, the gastric cancer diagnoses for those missing in either FCR or HILMO were included as captured cancer cases.

Results

Patients

After the exclusion of 188 patients diagnosed only by autopsy, there were a total 7,431 patients with esophageal cancer reported in either registry. In total, 5,601 (74.6%) of the 7,431 patients had esophageal cancer diagnosis in both FCR and HILMO (concordant cases), while 203 (2.7%) of the patients were reported to only FCR and 1,627 (21.9%) to only HILMO (Table 1).

Of the total cohort, 4,771 were male, the median age for diagnosis was 69 y. The highest number of patients (1,884, 25.4%) were observed during period 2010–2014. Operative treatment was given to 1,843 (24.8%) patients. No striking differences in reporting to the registries were observed between age groups, sexes or operative treatment. There was a considerable decrease in the proportion of cases reported to both FCR and HILMO over time from 79.2% in 1990–1994 to 73.7% in 2010–2014 (Table 1) due to decrease in reporting to FCR. Of all the patients, 6,800 (91.5%) died until the end of 2016 and 6,441 (86.7%) of them during five-year follow-up.

Table 1. Number of patients by time periods by registries reporting cancer diagnosis.

Variable	FCR only *n* (%)	HILMO only *n* (%)	Both FCR and HILMO *n* (%)	Total *n* (%)
Total	203 (100)	1,627 (100)	5,601 (100)	7,431 (100)
Time period				
1990–1994	62 (30.5)	184 (11.3)	938 (16.7)	1,184 (15.9)
1995–1999	50 (24.6)	235 (14.4)	988 (17.6)	1,273 (17.1)
2000–2004	24 (11.8)	329 (20.2)	1,086 (19.4)	1,439 (19.4)
2005–2009	25 (12.3)	425 (26.1)	1,201 (21.4)	1,651 (22.2)
2010–2014	42 (20.7)	454 (27.9)	1,388 (24.8)	1,884 (25.4)
Vital status				
Alive	7 (3.4)	264 (16.2)	360 (6.4)	631 (8.5)
Dead	196 (96.6)	1,363 (83.8)	5,241 (93.6)	6,800 (91.5)
*Cause of death**				
Esophageal cancer	130 (66.3)	285 (20.9)	4,940 (94.2)	5,355 (78.8)
Gastric cancer	23 (11.7)	606 (44.5)	70 (1.3)	699 (10.3)
Other	43 (21.9)	472 (34.6)	231 (4.4)	746 (11.0)

FCR: Finnish Cancer Registry; HILMO: Hospital Discharge Registry.
*Calculated as the percentage of those who died during follow-up.

Table 2. The number of admissions for esophageal cancer and gastric cancer in Hospital Discharge HILMO and gastric diagnoses in the FCR in esophageal cancer patients.

Variable	FCR only *n* (%)	HILMO only *n* (%)	Both FCR and HILMO *n* (%)	Total *n* (%)
Total	203 (100)	1,627 (100)	5,601 (100)	7,431 (100)
Number of esophageal cancer admissions in HILMO				
0	203 (100)	–	–	203 (2.7)
1	–	646 (39.7)	483 (8.6)	1,129 (15.2)
2 or more	–	981 (60.3)	5,118 (91.4)	6,099 (82.1)
Number of gastric cancer admissions in HILMO				
0	168 (82.8)	849 (52.1)	5,190 (92.7)	6,207 (83.5)
1	5 (2.5)	85 (5.2)	181 (3.2)	271 (3.6)
2 or more	30 (14.8)	693 (42.6)	230 (4.1)	953 (12.8)
Gastric cancer diagnosis in FCR				
No	201 (99.0)	612 (37.6)	5581 (99.6)	6,394 (86.0)
Yes	2 (1.0)	1,015 (62.4)	20 (0.4)	1,037 (14.0)

FCR: Finnish Cancer Registry; HILMO: Hospital Discharge Registry.

Patients reported only in FCR and not in HILMO

Of those 203 patients who had esophageal cancer reported only in FCR (Table 1), 130 (64.0%) died of esophageal cancer and seven (3.4%) were alive. No gastric cancer diagnosis was recorded in HILMO for 168 (82.8%, Table 2), suggesting high validity of the esophageal cancer diagnosis.

Patients reported only in HILMO and not in FCR

For those 1,627 patients who had esophageal cancer diagnosis only in HILMO (Table 1), 285 (17.5%) died of esophageal cancer and 606 (37.2%) died of gastric cancer. Admissions for gastric cancers were recorded in 778 (47.9%) patients. Gastric cancer was recorded in the FCR for 1,015 (62.4%) of the patients (Table 2), suggesting misclassification.

The admissions for esophageal and gastric cancer were further explored *post hoc* (Supplementary Table 1). Those that had two or more admissions for esophageal cancer died often of gastric cancer and had a record of gastric cancer in FCR, while those with only one esophageal cancer admission often died of other reasons than esophageal or gastric cancers and had less often a diagnosis of gastric cancer in FCR.

Patients reported to both FCR and HILMO

Of the 5,601 patients reported to both FCR and HILMO (Table 1), 4,940 (88.2%) had died of esophageal cancer and only 360 (6.4%) were still alive. The majority (91.4%) had multiple esophageal cancer admissions and none for gastric cancer (92.7%, Table 2), suggesting high validity of esophageal cancer diagnosis for these patients.

Mortality

For all-cause five-year mortality (Figure 1) those who were reported to only HILMO had the lowest mortality, and those who were reported to only FCR had the highest. For esophageal cancer-specific mortality (Supplementary Figure 1), the mortality was clearly lower for those who were reported to HILMO only, compared to those reported to the FCR.

Estimated completeness of esophageal cancer in FCR and HILMO

There were 5,804 records of esophageal cancer in the FCR. If the true number of esophageal cancers were 7,431, based on esophageal cancer diagnosis in either FCR or HILMO, the completeness of FCR would be 78.1% for esophageal cancer. After including the 1,015 patients with gastric cancer records, the completeness of FCR was 91.8%.

There were 7,228 records of esophageal cancers in HILMO. With 203 missed cancer cases, the completeness of HILMO was 97.3%. After including the 35 gastric cancer records, the completeness of HILMO would be 97.7% for esophageal cancer.

Discussion

The present study shows that incident esophageal cancer cases are relatively well captured by both FCR and HILMO. Misclassification between esophageal and gastric cancer [6,7] was present and prevented accurate estimation of the completeness of esophageal cancer.

The strengths include the population-based nationwide design and large size of the cohort, and complete follow-up. The three registries all have separate and independent registration for diagnoses, including esophageal cancer. Furthermore, the systematic validation of FCR records [3] and death certificates by forensic physicians in Finland increase the validity of FCR and death registry [8]. The weaknesses include the unavailability of the medical records for assessing the validity of the diagnoses. Misclassification between esophageal and gastric cancer prevented robust evaluation of esophageal cancer completeness in the registries.

The proportions of esophageal cancer reported to only FCR, only HILMO and both FCR and HILMO were relatively similar between the sexes, age groups and surgical treatment. However, the proportion of esophageal cancers reported to the cancer registry decreased dramatically over time. Reasons for this might include increased clinician and

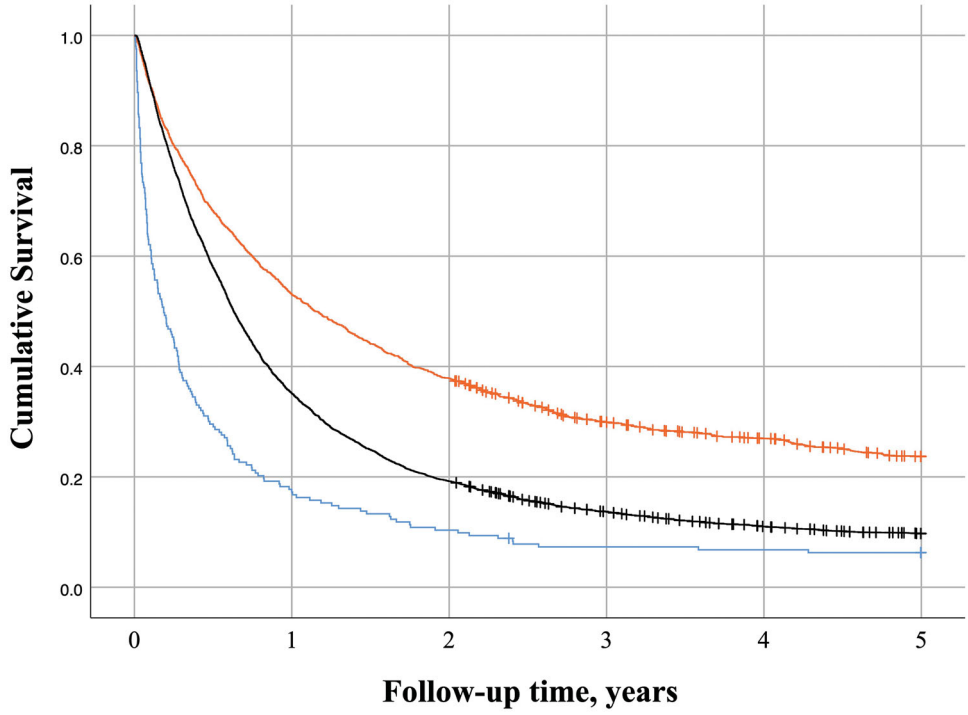

Figure 1. Kaplan-Meier curve depicting five-year all-cause mortality in esophageal cancer patients stratified by registry status. The black line represents those patients registered in both FCR and HILMO ($n = 5,601$), blue line those registered only in FCR ($n = 203$) and orange those registered only in HILMO ($n = 1,627$).

pathologist workload, as well as unclear responsibilities on which clinician should report the patient to the FCR. On the other hand, the introduction of electronical medical records during 1996–2007 in Finland might have led to more complete registration of all diagnoses in HILMO over time. As the reporting to HILMO is automatic from the hospitals, it is likely that some suspected cancers will be permanently reported to the HILMO registry with a cancer diagnosis, even when the condition is confirmed benign or another cancer location on next admission.

The high proportion of esophageal cancer deaths in all patients reported to FCR reflects the high specificity of cancer diagnosis in the FCR. In those patients not reported to FCR, there were 1,078 deaths by other causes than esophageal cancer, compared to 285 esophageal cancer deaths, implying a lower specificity of esophageal cancer in HILMO. Furthermore, most esophageal cancer patients not identified to have esophageal cancer in FCR had gastric cancer diagnosis in FCR. Many of these patients had multiple gastric and esophageal cancer admissions in HILMO, suggesting misclassification between esophageal and gastric cancer.

Survival curves reflected the observation of HILMO having a significant number of either early-stage cancers not requiring oncology consultation and thus having less opportunities to be recorded in FCR, healthier patients, or false-positive diagnoses. Mortality was lower in those reported to only HILMO compared to those reported to the FCR.

The estimated completeness of FCR was 91.8% for esophageal cancer when cancers recorded as gastric cancer in the FCR were considered. Similarly, the completeness of HILMO was estimated to be up to 97.7%. However, due to misclassification and potential false positives in HILMO, these numbers should be interpreted with caution.

Researchers should be aware of the misclassification and that complete inclusion of esophageal cancer patients could be achieved by using both registries and including gastric cancer data. Evaluation of the proportion of false-positive esophageal cancers in FCR and HILMO, and the extent of misclassification with gastric cancer are important future research questions. For clinicians, it is recommended to carefully report all cancer cases to the FCR at all stages of diagnostic and treatment pathways to ensure that quality data is available in the future. Furthermore, esophageal cancer diagnosis should be confirmed before assigning the patient the cancer diagnosis, and unclear tumor diagnoses should be used before confirmation.

In conclusion, the results indicate both FCR and HILMO separately captured up to 91.8 and 97.7% of esophageal cancer patients, respectively. There seems to be misclassification between esophageal and gastric cancers requiring further assessment.

Disclosure statement

The author states no potential competing interests.

Funding

This work was supported by research grants from the Sigrid Jusélius Foundation (Sigrid Juséliuksen Säätiö), The Finnish Cancer Foundation (Syöpäsäätiö), Päivikki and Sakari Sohlberg Foundation and Orion Research Foundation (Orionin Tutkimussäätiö).

ORCID

Joonas H. Kauppila http://orcid.org/0000-0001-6740-3726

References

[1] Fitzmaurice C, Abate D, et al. Global, regional, and national cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life-years for 29 cancer groups, 1990 to 2017: a systematic analysis for the global burden of disease study. JAMA Oncol. 2019;5(12):1749–1768.

[2] Anderson LA, Tavilla A, Brenner H, et al. Survival for oesophageal, stomach and small intestine cancers in Europe 1999–2007: results from EUROCARE-5. Eur J Cancer. 2015;51(15):2144–2157.

[3] Leinonen MK, Miettinen J, Heikkinen S, et al. Quality measures of the population-based Finnish Cancer Registry indicate sound data quality for solid malignant tumours. Eur J Cancer. 2017;77:31–39.

[4] Sund R. Quality of the Finnish Hospital Discharge Register: a systematic review. Scand J Public Health. 2012;40(6):505–515.

[5] Maret-Ouda J, Tao W, Wahlin K, et al. Nordic registry-based cohort studies: possibilities and pitfalls when combining Nordic registry data. Scand J Public Health. 2017;45(Suppl 17):14–19.

[6] Lindblad M, Ye W, Lindgren A, et al. Disparities in the classification of esophageal and cardia adenocarcinomas and their influence on reported incidence rates. Ann Surg. 2006;243(4):479–485.

[7] Kauppila JH, Lagergren J. The surgical management of esophagogastric junctional cancer. Surg Oncol. 2016;25(4):394–400.

[8] Lahti RA, Penttila A. The validity of death certificates: routine validation of death certification and its effects on mortality statistics. Forensic Sci Int. 2001;115(1–2):15–32.

[9] Kauppila JH, Ohtonen P, Karttunen TJ, et al. Finnish National Esophago-Gastric Cancer Cohort (FINEGO) for studying outcomes after oesophageal and gastric cancer surgery: a protocol for a retrospective, population-based, nationwide cohort study in Finland. BMJ Open. 2019;9(1):e024094.

[10] Cutler SJ, Ederer F. Maximum utilization of the life table method in analyzing survival. J Chronic Dis. 1958;8(6):699–712.