

The Symptom Burden and Hospital Utilization in Patients with Upper Gastrointestinal Cancer Recommended Best Supportive Care – Is There Anything To Improve?

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Abstract

Purpose

Upper gastrointestinal (UGI) cancer carries a poor prognosis. A substantial proportion of patients are ineligible for curative treatment and are considered too vulnerable for oncological therapy. Hence, best supportive care (BSC) focusing on symptom management and quality-of-life preservation is often recommended. Structured follow-up has previously been shown to benefit patients receiving BSC, yet such a follow-up program is of limited availability. This study aimed to characterize symptom burden, health-care needs and survival among patients with UGI cancer recommended BSC.

Methods

This retrospective registry-based study included patients discussed at the regional multidisciplinary team (MDT) meeting at Sahlgrenska University Hospital between 2018 and 2021 who were recommended BSC without prior curative or palliative tumor-directed treatment. Data on symptom burden, interventions, inpatient care and survival were extracted from medical records.

Results

Three hundred and fifty-five patients were included. Mean age was 79.3 years and 52% of the patients were male. The overall symptom burden was high, with pain, weight loss and nausea being the most frequently recorded symptoms. Median survival from the MDT recommendation of BSC was 69 days. Eighty-two percent of the patients required at least one hospital admission after the MDT and the mean duration of inpatient care was 14 days.

Conclusion

Patients with UGI cancer receiving BSC demonstrate a high symptom burden and substantial need for hospital-based care along with a short overall survival. We hypothesize that structured follow-up initiated after the BSC decision may improve patient-centered outcomes while reducing unplanned admissions.

BACKGROUND

Upper gastrointestinal (UGI) cancer, i.e., cancer in the esophagus, stomach, biliary tract, gallbladder and pancreas have a poor general prognosis. In Sweden, approximately 3300 patients were diagnosed with UGI cancer in 2023 and the overall 5-year survival was 17–32% for gastric and esophageal cancer, 20–22% for cholangiocarcinoma (CCA) and gallbladder cancer (GBC) and only 6–9% for pancreatic cancer Socialstyrelsen [1]. The primary reason is largely because many patients present with locally advanced or metastatic disease at diagnosis, preventing curative treatment [2–4].

Consequently, a substantial proportion of patients are recommended either palliative oncological treatment or – depending on their performance status – no tumor-directed cancer treatment at all, which in some subgroups accounts for over 60% of patients [5]. Management for these patients is then focused on symptom control and quality-of-life preservation, an approach commonly referred to as best supportive care (BSC) [3]. The symptom burden in this setting is often complex and multifactorial including pain syndromes, cachexia, malnutrition and weight loss, biliary and gastrointestinal obstruction as well as anxiety and depression [6].

Between 1990 and 2005, a surgical outpatient clinic was established at Sahlgrenska University Hospital in Gothenburg, Sweden, with the aim of managing patients with a recommendation of BSC. Patients with advanced cancer – either with or without prior surgery or oncological treatment – were followed according to a BSC protocol and invited to participate in prospective studies involving pharmacological [7, 8], hormonal [9–11] and nutritional interventions [12]. Several scientific publications related to its activities have been published, including metabolic, nutritional and functional assessments as well as evaluation of health-related quality of life in the context of disease progression and cancer cachexia [13–15]. These studies demonstrated that altered metabolism, systemic inflammation and anemia were strongly associated with decline in the terminal stage of the disease. Multimodal strategies aimed at reducing inflammation [8], preventing anemia [10] and improving energy balance through intensive dietary support or artificial nutrition [16] showed potential benefits in physical function, quality of life and even survival [12]. The project was eventually discontinued for practical and logistical reasons and following this reorganization BSC has been managed by several different units.

The absence of a structured follow-up ever since highlighted a possibility for improvement in care for this patient group. In 2023, a clinical initiative called Health Related Quality of Life and Optimized Care for Patients with Palliative Upper GI Cancer (HOPE) was therefore initiated at the Department of Surgery at Sahlgrenska University Hospital. The project aimed to improve BSC for patients with UGI cancer in all its aspects. As a first step, this study aims to characterize the symptom burden, interventional needs and survival among patients with late-stage UGI cancer who are recommended BSC following a multidisciplinary team (MDT) meeting.

METHODS

The study was designed as a retrospective, registry-based study. Patients residing in the region of Västra Götaland in western Sweden (approximately 1.7 million inhabitants) who were diagnosed with esophageal, gastric cancer, cholangiocarcinoma, gallbladder cancer or pancreatic cancer and recommended BSC at the regional MDT meeting at Sahlgrenska University Hospital between 2018 and 2021 were eligible for inclusion. Patients who had received curative surgery or palliative oncological tumor-directed treatment prior to the MDT recommendation of BSC as well as patients referred from outside the region Västra Götaland were excluded. Data on patients discussed at MDT meetings were obtained from the Swedish national cancer registry, INCA (Information Network for Cancer Care).

Due to the higher incidence of pancreatic cancer [1], all cases from 2018 were included, while cases diagnosed between 2019 and 2021 were down-sampled by selecting a random sample of ten patients per year. This approach was used to achieve more comparable group sizes across cancer subgroups and to ensure representation from multiple study years.

Data collection and definitions

For all included patients, complete hospital-based medical records were reviewed. An overview of all collected variables is presented in Table 1. Baseline demographic data and laboratory values were collected at the time of the MDT recommendation of BSC. Measurements of body mass index (BMI) and weight loss obtained no more than one month prior to the MDT were accepted, while laboratory values obtained no more than two months prior to the MDT were considered eligible. Performance status (ECOG) was assessed by the referring physician.

Table 1
Collected data

Baseline demographics	Laboratory values	Symptoms	Interventions and inpatient care	Mortality data
Age	CRP	Pain	Gastroscopy	Time of death
Sex	WBC	Nausea	Esophageal stent	Place of death
BMI	Hemoglobin	Vomiting	Duodenal stent	
Involuntary weight loss	Bilirubin	Constipation	Biliary stent	
ECOG	Ca 19 – 9	Diarrhea	Nutritional drink	
Cardiovascular disease		Dysphagia	Total parenteral nutrition	
Diabetes		Pruritus or jaundice	Hospital admissions	
Pulmonary disease		Gastrointestinal bleeding	Inpatient days	
Stroke/TIA				
Previous or synchronous cancer				
Description of collected data. BMI – body mass index. TIA – transient ischemic attack. CRP – C-reactive protein. WBC – white blood count. Ca 19 – 9 – carbohydrate antigen 19 – 9.				

Data on symptoms, interventions, inpatient care and mortality were collected from the time of the MDT recommendation of BSC until death. Prior to data extraction, predefined symptom keywords and relevant

synonyms were established. Symptom data were extracted from free-text medical records based on documented symptoms or clinical findings. Involuntary weight loss was recorded as a binary variable based on documentation in the medical record. Pain was defined as the use or prescription of any analgesic medication. Inpatient care was defined as any hospital admission occurring after the MDT recommendation of BSC. Ongoing hospital admission at the time of the MDT was not included. Only medical records from specialist (hospital-based) care were reviewed as documentation from general practitioners were not available.

Statistical analysis

Patient characteristics are presented as absolute numbers with percentages for categorical variables and as mean (standard deviation, SD) or median (interquartile range, IQR) for continuous variables as appropriate based on distribution. Comparison between the three groups was performed with Pearson Chi-Square test for dichotomous variables, with ANOVA for approximately normal distributed variables and with Kruskal-Wallis rank test for skewed distributions. Prognostic factors known at baseline were explored and analyzed with Cox Regression models and are presented as hazard ratios (HR) with 95% confidence intervals. All significance tests were two-sided and conducted at the 5% significance level. Analyses were conducted in SAS System (version 9.4). Graphs and figures were produced in Graphpad Prism (GraphPad Software version 10.6.1) and SPSS (IBM, version 29.0.2.0).

RESULTS

A total of 355 patients with UGI cancer were reviewed. One patient was excluded because death occurred at home one day prior to the MDT meeting without the event being known at the time of the conference, leaving 354 patients for analysis. Two patients were still alive at last known follow up in November 2023. Baseline characteristics for all patients are presented in Table 2.

Table 2
Baseline characteristics

Variables	Total N = 354	EGC N = 122	CCA/GBC N = 104	PC N = 128	p	Missing of total
Age (mean, SD)	79.3 (8.4)	79.7 (9.5)	80.0 (8.3)	78.4 (7.4)	0.28	0
Male sex	185 (52.3%)	77 (63.1%)	42 (40.4%)	66 (51.6%)	0.0029	0
ECOG						
0	26 (7.3%)	4 (3.3%)	10 (9.6%)	12 (9.4%)	0.0002	110 (31.1%)
1	60 (16.9%)	20 (16.4%)	12 (11.5%)	28 (21.9%)	-	-
2	74 (20.9%)	40 (32.3%)	9 (8.7%)	25 (19.5%)	-	-
3	70 (19.8%)	42 (34.4%)	8 (7.8%)	20 (15.6%)	-	-
4	14 (4%)	10 (8.2%)	3 (2.9%)	1 (0.8%)	-	-
BMI (mean, SD)	24.1 (5.2)	22.7 (5.2)	26.1 (5.1)	24.1 (5.0)	< 0.0001	65 (18.4%)
Involuntary weight loss	210 (59.3%)	96 (78.7%)	36 (34.6%)	78 (60.9%)	< 0.0001	59 (16.7%)
Past Medical History						
Cardiovascular Disease	231 (65.3%)	87 (71.3%)	69 (66.3%)	75 (58.6%)	0.30	9 (2.5%)
Diabetes	90 (25.4%)	26 (21.3%)	22 (21.2%)	42 (32.8%)	0.031	8 (2.3%)
Pulmonary Disease	69 (19.5%)	31 (25.4%)	20 (19.2%)	18 (14.1%)	0.12	9 (2.5%)
Stroke/TIA	64 (18.1%)	34 (27.9%)	12 (11.5%)	18 (14.1%)	0.0039	10 (2.8%)
Previous or synchronous cancer	77 (21.8%)	37 (30.3%)	21 (20.2%)	19 (14.8%)	0.023	11 (3.1%)
Blood samples						
CRP, mg/L ^a	49 (24–99)	45 (25–92)	63 (33–110)	48 (13–99)	0.32	52 (14.7%)

Variables	Total N = 354	EGC N = 122	CCA/GBC N = 104	PC N = 128	p	Missing of total
WBC, 10 ⁹ /L	9.4 (6.9–12.5)	9.4 (6.5–12.3)	10.9 (8.7–15.2)	8.3 (6.5–11)	0.016	33 (9.3%)
Hemoglobin, g/L (mean, SD)	114.1 (19)	110.2 (19.5)	115.7 (16.9)	116.7 (19.8)	0.020	22 (6.2%)
Bilirubin, µmol/L (median, IQR)	23.5 (9.7–111.5)	10 (5.6–20)	75 (15–198)	32 (11–130)	< 0.0001	54 (15.6%)
Ca 19–9, kE/L*	-	-	781 (151–6110)	736 (93–7300)	-	97 (41.8%)
Baseline characteristics and number of missing data for entire cohort and subgroups. EGC – esophageal and gastric cancer. CCA/GBC – cholangiocarcinoma and gallbladder cancer. PC – pancreatic cancer. BMI – body mass index. CRP – C-reactive protein. WBC – white blood count. Ca 19 – 9 – carbohydrate antigen 19 – 9. *Ca 19 – 9 is not routinely acquired in esophageal or gastric cancer and only presented in CCA/GBC and PC groups.						

The mean age was 79.3 years and 52% of patients were male. Of the included patients, 122 had esophageal or gastric cancer, 104 had cholangiocarcinoma or gallbladder cancer and 128 had pancreatic cancer. Involuntary weight loss was reported in 59.3% of patients with marked differences between subgroups. Inflammatory markers were elevated at baseline and patients showed a slight tendency of anemia across all groups. Median survival from the time of BSC recommendation was 69 days (IQR 28–172) in the entire cohort, 81 days (IQR 20–203) for esophageal and gastric cancer, 66 days (IQR 28–167) for cholangiocarcinoma and gallbladder cancer and 69 days (IQR 32–161) for pancreatic cancer (Fig. 1).

A full description of the symptom burden is presented in Table 3 and Fig. 2. The most common symptom was pain which was recorded in 87.9% of all patients with the highest prevalence among patients with esophageal or gastric cancer (90.2%). Nausea was reported in 50.8% of the entire cohort and was most prevalent in patients with esophageal or gastric cancer (55.7%). Certain symptoms such as pruritus or jaundice were more common in patients with cholangiocarcinoma and gallbladder cancer (58.7%) as well as pancreatic cancer (50.8%) whereas dysphagia (61.5%) and gastrointestinal bleeding (36.9%) were most common in patients with esophageal or gastric cancer.

Table 3
Symptom burden

Symptom	Total N = 354	EGC N = 122	CCA/GBC N = 104	PC N = 128	p	Missing of total
Pain	311 (87.9%)	110 (90.2%)	90 (86.5%)	111 (86.7%)	0.033	19 (5.4)
Nausea	180 (50.8%)	68 (55.7%)	50 (48.1%)	62 (48.4%)	0.28	24 (6.8)
Vomiting	129 (36.4%)	65 (53.3%)	25 (24%)	39 (30.5%)	< 0.0001	28 (7.9)
Constipation	118 (33.3%)	52 (42.6%)	30 (28.8%)	36 (28.1%)	0.059	32 (9.0)
Diarrhea	85 (24%)	21 (17.2%)	35 (33.7%)	29 (22.7%)	0.0098	51 (14.4)
Dysphagia	94 (26.6%)	75 (61.5%)	12 (11.5%)	7 (5.6%)	< 0.0001	29 (8.2)
Pruritus/ jaundice	135 (38.1%)	9 (7.4%)	61 (58.7%)	65 (50.8%)	< 0.0001	27 (7.6)
Gastrointestinal bleeding	80 (22.6%)	45 (36.9%)	16 (15.4%)	19 (14.8%)	< 0.0001	15 (4.2)
Symptom burden and number of missing data for entire cohort and subgroups. Symptoms were recorded if documented at any time between the MDT recommendation of BSC and death. EGC – esophageal and gastric cancer. CCA/GBC – cholangiocarcinoma and gallbladder cancer. PC – pancreatic cancer.						

All interventions and inpatient care needs following MDT can be found in Table 4. Forty-six percent of all patients underwent a gastroscopy. Esophageal stenting was performed in 33.6% of patients with esophageal or gastric cancer. Biliary stenting was performed in 51.9% of patients with cholangiocarcinoma or gallbladder cancer and in 53.1% of patients with pancreatic cancer. In total, just over half of the patients (52.3%) received at least one endoscopic stent following the MDT recommendation of BSC. Overall, 291 patients (82.2%) had at least one hospital admission following the MDT recommendation of BSC and 147 patients (41.5%) were admitted twice or more. The mean duration of inpatient care from MDT to death was 14.4 days (SD 19.9). Twenty-eight percent of all patients died in hospital.

Table 4
Interventions and inpatient care needs after MDT, n (%)

Event	Total N = 354	EGC N = 122	CCA/GBC N = 104	PC N = 128	p
Gastroscopy	163 (46)	63 (51.6)	45 (43.3)	55 (43)	0.53
Esophageal stent	41 (11.6)	41 (33.6)	0	0	< 0.0001
Duodenal stent	20 (5.6)	6 (4.9)	4 (3.8)	10 (7.8)	0.49
Biliary stent	124 (35)	6 (4.9)	54 (51.9)	68 (53.1)	< 0.0001
Nutritional drink	226 (63.8)	94 (77)	59 (56.7)	73 (57)	0.0034
Total parenteral nutrition	65 (18.4)	37 (30.3)	16 (15.4)	12 (9.4)	0.0016
Inpatient care after MDT discussion					
At least one admission	291 (82.2)	104 (85.2)	85 (81.7)	102 (79.7)	0.93
Twice or more admissions	147 (41.5)	54 (44.3)	41 (39.4)	52 (40.6)	-
Days of inpatient care (mean, SD)	14.4 (19.1)	12.2 (15)	15.9 (26.8)	15.5 (14.4)	0.27
Place of death					
Home	151 (42.7)	51 (41.8)	61 (58.7)	39 (30.5)	< 0.001
At hospital	100 (28.2)	30 (24.6)	32 (30.8)	38 (29.7)	-
At hospice	50 (14.1)	16 (13.1)	5 (4.8)	29 (22.7)	-
Description of interventions and inpatient care needs following MDT recommendation of BSC. Total inpatient days were calculated as the cumulative number of hospital days from MDT recommendation to death. Both diagnostic and therapeutic gastroscopy included and recorded separately from interventional stent placement. EGC – esophageal and gastric cancer. CCA/GBC – cholangiocarcinoma and gallbladder cancer. PC – pancreatic cancer. MDT – multidisciplinary team					

An exploratory univariate Cox regression analysis of baseline prognostic factors and their association with overall survival is presented in Table S1. Across the entire cohort, older age, lower hemoglobin and elevated white blood cell count and bilirubin were each associated with shorter survival. Results stratified by cancer subgroup are also provided in Table S1.

DISCUSSION

In this retrospective registry-based study of patients with UGI cancer who were recommended BSC without prior curative or palliative tumor-directed treatment, a substantial symptom burden and a high need for hospital-based care were identified along with a noticeably short survival.

In recent years, several studies have described both high symptom burden and substantial in-hospital care needs for patients with advanced cancer at the end of life [17–24]. However, many of the patients included in these studies received oncological treatment or were admitted to specialized palliative care with symptom assessment relying on structured patient-reported outcome measures. In contrast, the present study only included patients receiving BSC without prior surgery or oncological treatment representing a population that is less frequently described in existing literature. This distinction is clinically relevant, as patients receiving oncological treatment typically maintain regular contact with healthcare professionals, which may facilitate earlier recognition and management of both disease-related and treatment-related symptoms. In the region of Västra Götaland, access to specialized palliative care teams for symptom management is available, but referrals are generally accepted only at the terminal phase of the disease. Consequently, patients in the interval between an MDT recommendation of BSC and referral to specialized palliative care lack structured follow-up potentially contributing to suboptimal symptom management during this period.

The high symptom burden observed in the present cohort is consistent with findings from recent studies [21–24]. Regarding specific symptoms, pain, involuntary weight loss and nausea were the most frequently recorded symptoms throughout the disease course, in keeping with previous literature describing patients with late-stage UGI cancer [6]. However, in prospective studies using patient-reported outcome measures, a somewhat different symptom profile is often observed. In such studies, fatigue, loss of appetite, drowsiness and impaired well-being are typically reported as the most severe and burdensome symptoms whereas pain and nausea, although common, are generally assigned lower intensity scores [21, 25, 26]. This discrepancy may in part reflect differences in symptom assessment methodology. Many prospective studies employ the validated Edmonton Symptom Assessment Scale (ESAS), which systematically captures patient-reported symptom severity and explicitly addresses symptoms such as fatigue, appetite loss and well-being [27] – symptoms that may be insufficiently captured in routine clinical documentation alone.

The hospital utilization in the present cohort was substantial – both in terms of interventions and hospital admissions. Of all patients, 82.2% were admitted at least once following the MDT recommendation, 41.5% were admitted twice or more, the mean duration of inpatient care was 14.4 days and 28% of patients died in hospital – findings consistent with previous literature [17–20]. In the context of an overall median survival of 69 days, the proportion of remaining life spent in a hospital setting is considerable and is of particular concern given that death at home is widely regarded as the preferred outcome [28]. Previous studies, primarily in pancreatic cancer, have demonstrated that access to palliative care is associated with reduced healthcare utilization including both fewer interventions and emergency department visits, as well as overall improved survival [29–31] and an increased likelihood of death at home [19].

Given that our cohort occupies the interval between an MDT recommendation of BSC and referral to specialized palliative care, a structured outpatient follow-up program initiated at the point of the MDT recommendation may represent an opportunity to anticipate and address unmet care needs at an earlier

stage, potentially reducing the burden of unplanned hospital admissions. In support of this, previous work has demonstrated that altered metabolism, systemic inflammation, and anemia are observed and treatable in the terminal phase of disease [7–13]. Consistent with these observations, the present cohort exhibited elevated inflammatory markers and anemia at baseline, findings that in the exploratory survival analysis were also associated with shorter overall survival. Although these associations should be interpreted with caution, they may identify patients at particularly high risk of rapid deterioration – and therefore those most likely to benefit from early structured follow-up.

A strength of this study is its real-world design, which allows for a comprehensive description of the full spectrum of symptoms and medications used in this patient population. In addition, all clinical interventions and hospitalizations are systematically captured providing a detailed and clinically relevant representation of routine care. This enhances the external validity of the findings and supports their applicability to everyday clinical practice.

Several limitations to this presented study need to be acknowledged. Retrospective assessment of symptom burden relies on documentation in medical records and may therefore be subject to potential misclassification, particularly when symptom descriptions are incomplete or inconsistently recorded. For example, classification of symptoms such as pain being defined as the use or prescription of pain medication may overestimate the true prevalence of cancer-specific pain in an elderly population. Furthermore, psychological symptoms such as anxiety and depression were not captured in the present study, which likely leads to an underestimation of the total symptom burden. Prospective studies may provide a more accurate assessment of symptom burden and would additionally allow for the use of patient-reported outcome measures.

Moreover, only data from hospital-based specialized care were included. Symptoms managed exclusively in primary care are not captured, potentially resulting in underestimation of symptom prevalence in patients with advanced UGI cancer. Structured follow-up across care settings could enable a more comprehensive assessment of symptom burden.

In conclusion, the present study identifies a potentially underserved patient population characterized by a high symptom burden and a substantial need for hospital-based care along with a short overall survival. We hypothesize that structured outpatient follow-up initiated immediately after the BSC decision may improve patient-centered outcomes while reducing unplanned hospital-based care.

Declarations

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DISCLOSURE STATEMENTS

The authors report no conflicts of interests.

DATA AVAILABILITY STATEMENT

Data can be made available on reasonable request to the corresponding author.

CONSENT TO PARTICIPATE

Given the retrospective nature of the study, the use of pseudonymized registry data and a palliative cohort in which a majority of participants had died at the end of the study period, the Swedish Ethical Review Authority waived the requirement to obtain informed consent.

ETHICS DECLARATIONS & TRIAL REGISTRY INFORMATION

The study was conducted according to the World Medical Association's Declaration of Helsinki and was approved by the Swedish Ethical Review Authority, ref. no. 2022-07049-01.

AUTHOR CONTRIBUTIONS

CE, B-M I, HT, CB and JW provided the study design. EL and BW performed the data collection, data analysis and drafted the manuscript. All authors reviewed, edited and approved the final manuscript.

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Figures

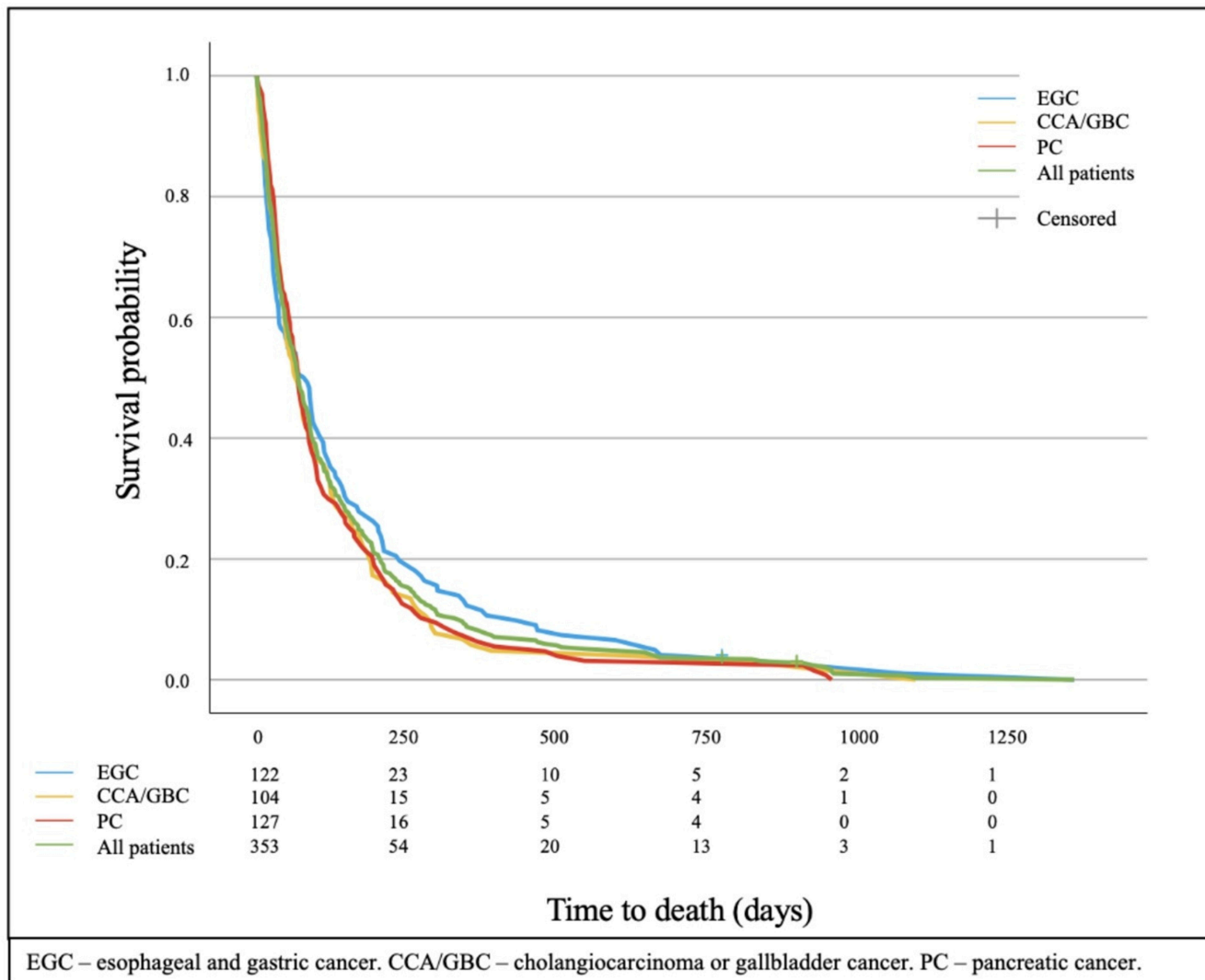


Figure 1

Kaplan-Meier survival curve from MDT to time of death for entire cohort and subgroups (n = 353)

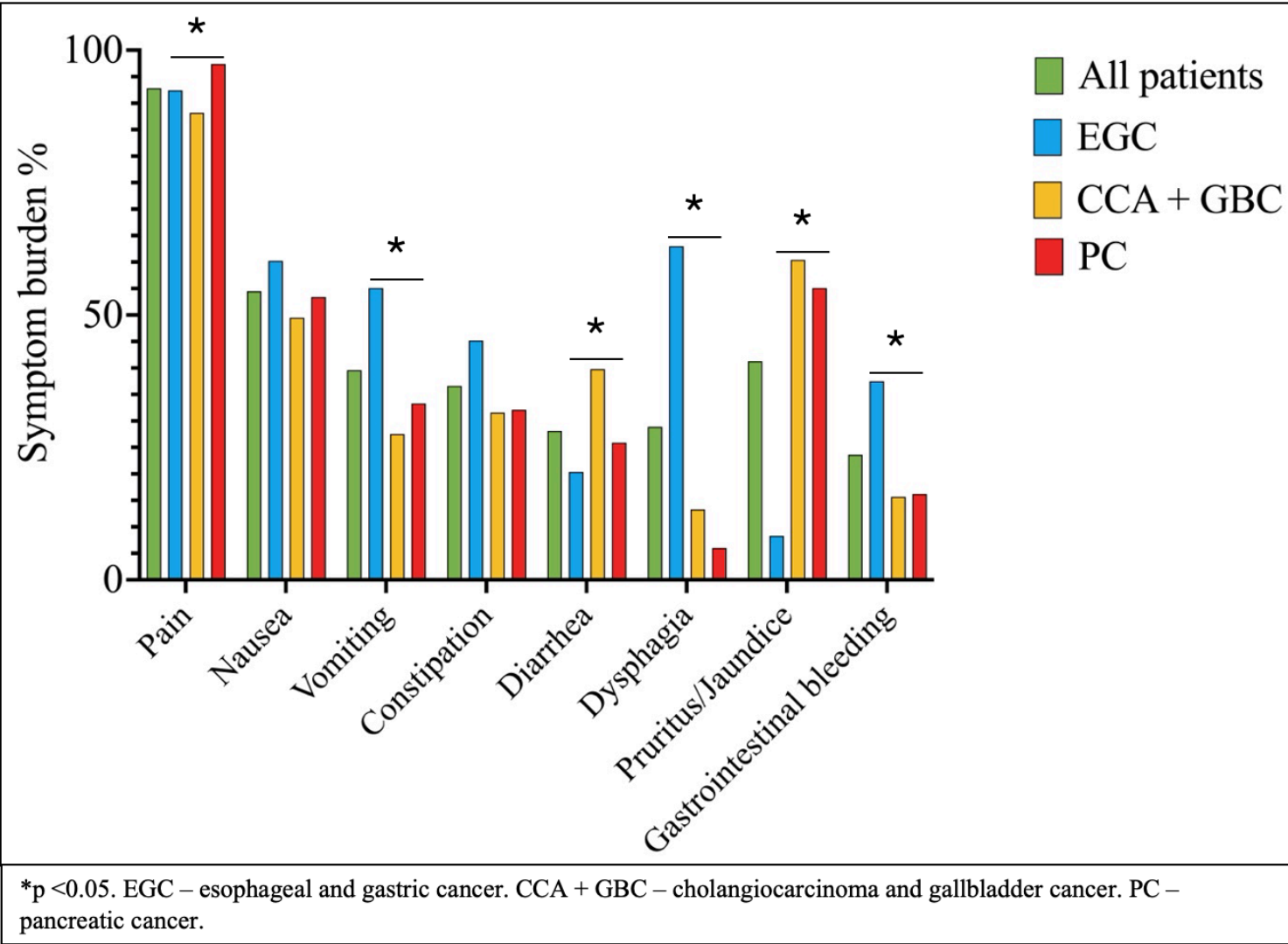


Figure 2

Symptom burden from MDT to time of death for entire cohort and subgroups

Supplementary Files

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- [SUPPLEMENTARYTABLE1.pdf](#)