

## Original Article

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# Palliative needs and illness trajectory associated with metastatic upper gastrointestinal cancer

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**ABSTRACT**

**INTRODUCTION.** Patients suffering from metastatic upper gastrointestinal cancer are burdened by physical, social, existential and psychological problems, though documentation of these problems may be insufficient. In Denmark, basic palliative care is fragmented and characterised by quality differences. This challenges cohesive palliative care interventions as patients experience transitions in the course of illness. The aim of this study was to identify and present the illness trajectory and to investigate the documentation of palliative needs for patients with metastatic upper gastrointestinal cancer.

**METHODS.** Data on the documented palliative needs and on transitions were retrospectively collected from the electronic medical records at a surgical ward at Herlev-Gentofte Hospital during a six-month period in 2019. Descriptive statistics were used to present the palliative care needs.

**RESULTS.** Pain and nausea/vomiting were documented in 62%, constipation in 35% and fatigue in 43% of the 63 patients included. Psychological, existential and social symptoms were sparsely documented. Several patients (41%) had more than one admittance to the surgical ward, 62% were treated in the oncology department and 35% received specialised palliative care.

**CONCLUSION.** The frequent transitions during the disease trajectory and the need to direct attention towards all four domains of palliative care should compel health professionals to adopt a systematic approach when identifying and treating their patients' palliative needs.

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Upper gastrointestinal (GI) cancer is a group of cancers involving tumours in the oesophagus, stomach, duodenum, liver, gallbladder, biliary tract and pancreas. Internationally, upper GI cancers constitute 16.6% of the annual total cancer cases [1]. In Denmark, the incidence is lower as upper GI cancers account for 7%. The most frequent type is pancreatic cancer, accounting for 2.4% of the total number of annual cancer cases [2]. The cancers have different curative potentials and cause different disease- and treatment-related problems. Upper GI cancers are frequent in an advanced stage before the patients experience symptoms, reflected in a relatively low chance of curative treatment of 15-50% depending on the diagnosis [3]. The group with metastatic upper GI cancer has a median survival time of 10-11 months [4], and only life-prolonging oncological treatment is available [3-6]. The patients suffer from diagnosis-specific symptoms including jaundice, stenosis, infections and

digestive issues, and from general symptoms such as pain, nausea, fatigue, bowel problems, and emotional and mental issues such as frustrations about deteriorating health, anxiety and fear of the future [5, 7-9]. The symptom burden and the short survival time result in a quickly deteriorating condition in which new symptoms demanding attention may arise quickly.

In Denmark, the palliative care provided for patients admitted to a surgical ward is defined as falling within the basic palliative care field. The provision of basic palliative care is mandatory in Danish healthcare and is provided alongside tasks of diagnostics, treatments and care provided by ordinary hospital departments. Specialised palliative care, however, focusses entirely on palliative care and, in Denmark, this care is provided by palliative care teams and palliative wards in hospitals and hospices [10]. Current basic palliative care in Denmark is described as fragmented, unstructured, characterised by quality differences and late initiation in the illness trajectory [11, 12]. In the national and regional palliative guidelines, the need to qualify basic palliative care is recognised [10, 13]. It is our experience that the patient suffering from upper GI cancer is burdened by symptoms and that they experience admissions at different hospitals and departments, and readmissions in the course of their illness, which might challenge the provision of well organised basic palliative care.

The two aims of the study were 1) to identify the illness trajectory and possible transitions for the patient with metastatic upper GI cancer and 2) to investigate the documentation of palliative needs.

## METHODS

This study was designed as a descriptive and retrospective study. Data were collected from electronic patient medical records. We included all patients with metastatic upper GI cancer admitted to the surgical ward for upper GI diseases at Herlev-Gentofte Hospital in the Capital Region of Denmark during a six-month period in 2019. When patients had more than one admittance during the data collection period, data on palliative care needs were collected from the latest admission to the surgical ward. Upper GI cancer was defined as malignant disease in the oesophagus (International Classification of Diseases, tenth version (ICD-10); C15), stomach (C16), duodenum (C17), liver and intrahepatic biliary tract (C22), gallbladder (C23), extrahepatic biliary tract (C240) and pancreas (C25). Reasons for exclusion were patients eligible for curative treatment, patients admitted for less than 24 hours and patients normally treated at different hospitals and only admitted for a planned procedure.

### Palliative care needs

Palliative care needs were defined as health-related suffering caused by upper GI cancer. All symptoms were predetermined and included issues from the physical, psychological, existential and social domains. The physical symptoms were pain, nausea/vomiting, constipation and fatigue. These symptoms were chosen as they are common for patients with advanced cancer, including patients with upper GI cancer [14, 15]. Psychological symptoms were descriptions of being anxious, afraid, shocked or in despair. Social issues were defined as problems relating to family, occupational and financial issues; and existential issues were those relating to end of life, hope and religion.

The palliative needs were collected revising all nurses' documentation and doctors' notes from the admission. If a symptom was either 1) a reason or a contributing factor to admission, 2) described as a problem in a doctor's note with or without a treatment plan, or 3) described in a specific form in the nurses' documentation (see below), it was considered a palliative care need. Furthermore, we recorded the number of patients who had used the patient-reported outcome (PRO) tool EORTC-QLQ-C15-PAL in the latest admission to the surgical ward.

Pain was rated on a numeric rating scale (NRS) ranging from 1 to 10. Three or more scores of  $\geq 4$  during the admission resulted in a positive score for pain. The cut-off point of NRS  $\geq 4$  was chosen as NRS 3 may be

considered the highest acceptable score since NRS 1-3 is mild pain, and NRS 4-6 is moderate pain [16]. Three or more documentations on vomiting or nausea resulted in a positive score for nausea/vomiting. A positive score was noted when fatigue, constipation, psychological, existential and social issues were documented in text in either the patient file or as a comment in nurses' documentation.

## The illness trajectory

The efforts made to outline the illness trajectory included informal conversations and e-mails between the departments involved in the treatment of upper GI cancer. The actual pathway was outlined by the first author and discussed within the author group. To map the patient group and transitions, we collected patient characteristics such as gender, age, diagnosis, information on discharge and patient status (alive/deceased), ensuring that patients who were deceased at the end of the half-year period, were registered as such. During the six-month data collection period, we recorded the number of admissions to the surgical ward and transitions to the oncology department and/or to specialised palliative care.

For data analysis, we used Microsoft Excel (Version 2008, Microsoft Corp., Redmond, WA, USA) and IBM SPSS Statistics (Version 25.0, IBM Corp., Armonk, NY, USA). Descriptive statistics by means of percentages, medians and ranges were used to assess and present palliative symptoms.

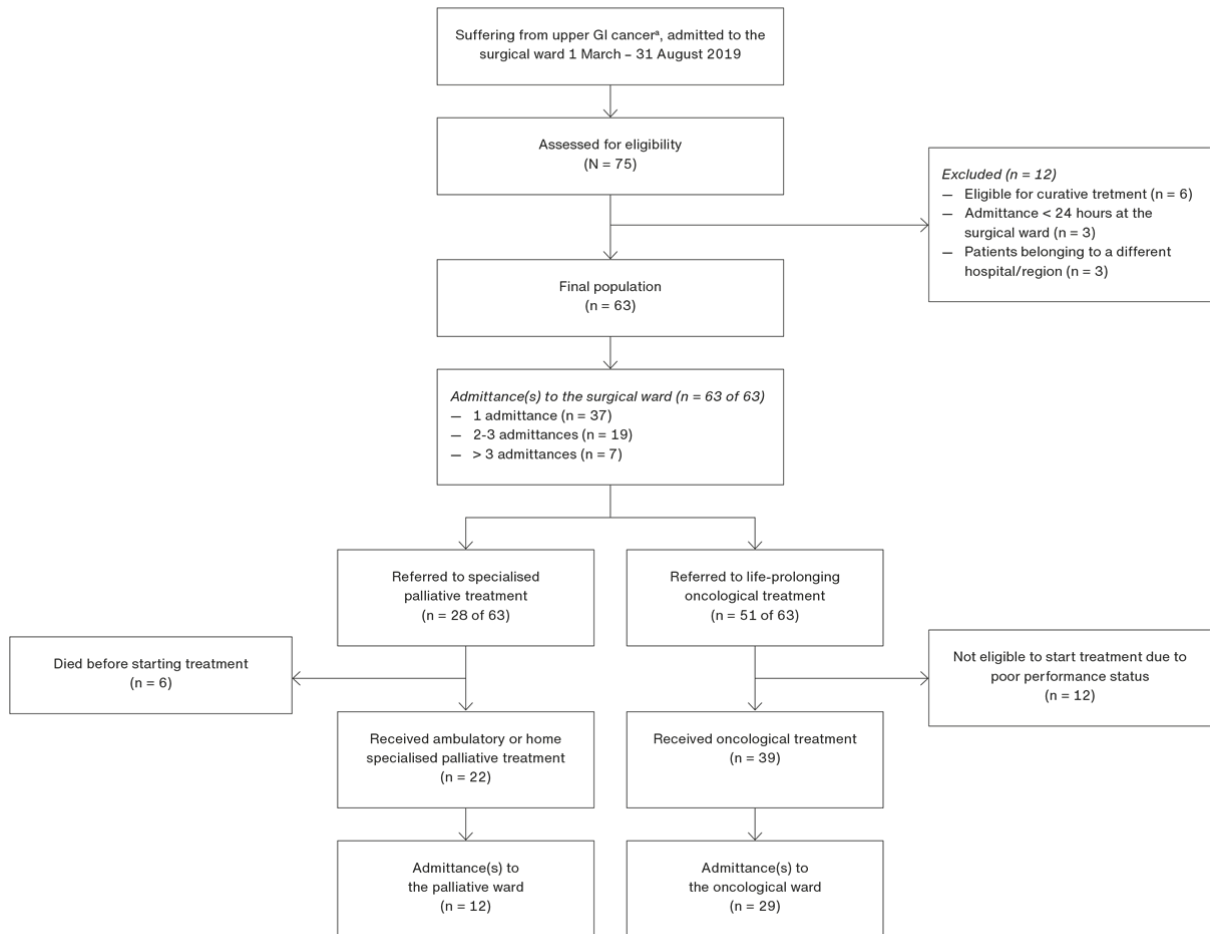
This study was exempted from ethical committee permission under Danish law.

Permission to obtain and store patient health data from electronic health records was obtained from the Capital Region of Denmark (case number 19051477). During data collection, data were pseudonymised. Each patient in the study population was provided with a number from 1 to 63. Data and identifiers, in this case social security numbers, were kept separate in closed files as per current regulations. Identifiers were deleted after analysis of data had been completed.

## RESULTS

The first part of the flowchart (**Figure 1**) presents the selection process. The final population of 63 patients presented all subtypes of upper GI cancer, pancreatic cancer being the most frequent ( $n = 35$ ). Patients had various illness durations leading up to the point of data collection. For patients who had died at the end of the data collection period ( $n = 44$ ), the median survival time from diagnosis to death was nine months (range: 1-42 months). A full list of patient characteristics is provided in **Table 1**. The second half of the flowchart provides an overview of patients' referrals and admittances. It was an inclusion criterion for the patient to be admitted to the surgical ward, which is why 63 out of 63 patients had admittances here. A total of 29 patients were admitted one or more times to the oncological ward and 12 patients experienced admittances to the palliative ward, which can be categorised as 'transitions in the course of illness' because the patients and relatives will need to relate to more healthcare professionals and perhaps a different culture and daily clinical work. **Figure 2** elaborates on the transitions shown in **Figure 1** by presenting the two palliative treatment trajectories available when curative treatment was not an option. It illustrates that transitions may occur in the illness trajectory and that basic palliative care is required in all parts of the illness course.

**FIGURE 1** Flow chart illustrating the process of patient inclusion, admittances to the surgical ward and referrals for oncological treatment and specialised palliative treatment.



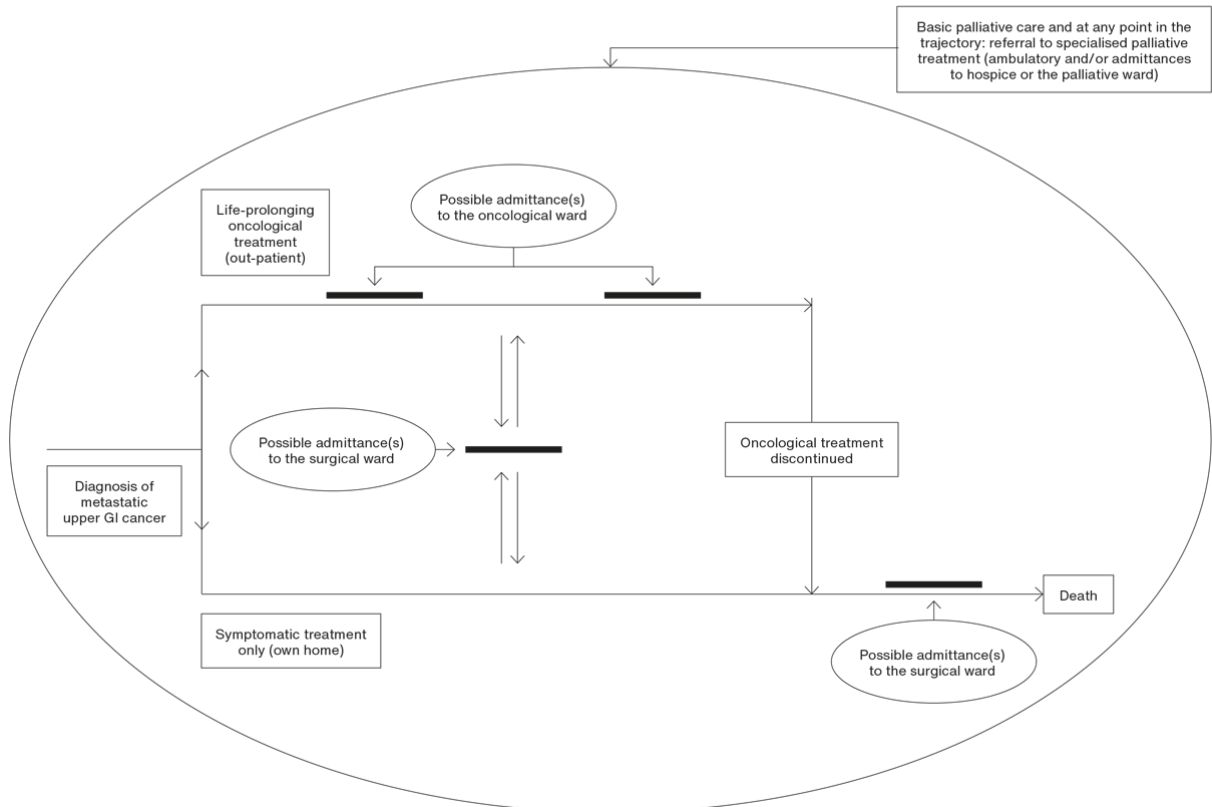
GI = gastrointestinal.

a) Defined as malignant disease in the oesophagus, stomach, duodenum, liver and intrahepatic biliary tract, gallbladder, extrahepatic biliary tract or pancreas.

**TABLE 1** Patient characteristics in total numbers and percentages (N = 63).

	n (%)
<i>Gender</i>	
Male	34 (54)
Female	29 (46)
<i>Age group</i>	
51-60 yrs	6 (9)
61-70 yrs	12 (19)
71-80 yrs	31 (49)
81-90 yrs	13 (21)
> 90 yrs	1 (2)
<i>Cancer diagnosis</i>	
Pancreatic	35
Extra hepatic biliary tract	3
Gallbladder	3
Liver & intrahepatic biliary tract	2
Duodenal	2
Gastric	12
Oesophageal	6
<i>Duration of illness at point of data collection</i>	
< 12 mos.	38
13-24 mos.	15
> 24 mos.	9
<i>Patient status at point of data collection</i>	
Alive	19 (30)
Deceased	44 (70)

**FIGURE 2** Possible trajectories for patients suffering from metastatic upper gastrointestinal (GI) cancer. Life-prolonging oncological treatment and symptomatic treatment. The thicker lines represent possible admittances.



The physical symptoms pain and nausea/vomiting were experienced by 39 patients (62%), and 41 patients (65%) had two or more physical symptoms (Table 2). Fatigue was a contributing or a sole factor for hospital admittance in eight patients (13%), yet in only one case a specific treatment plan against fatigue was prepared.

Psychological, existential and social symptoms were sparsely documented. Most commonly these were described in doctors' notes. All positive scores for social problems related to the family being upset, anxious, in shock or seriously ill. Occupational and financial issues were not mentioned in any cases. Only 13 of 63 patients (21%) had completed the PRO tool EORTC-QLQ-C15-PAL.

**TABLE 2** Palliative symptoms. Palliative needs experienced by patients suffering from metastatic upper gastrointestinal cancer (N = 63).

	n (%)
<i>Pain</i>	
Positive score <sup>a</sup>	39 (62)
Negative score <sup>b</sup>	16 (25)
Not mentioned <sup>c</sup>	8 (13)
<i>Nausea and/or vomiting</i>	
Positive score <sup>a</sup>	39 (62)
Negative score <sup>b</sup>	2 (3)
Not mentioned <sup>c</sup>	22 (35)
<i>Constipation</i>	
Positive score <sup>a</sup>	22 (35)
Negative score <sup>b</sup>	26 (41)
Not mentioned <sup>c</sup>	15 (24)
<i>Fatigue</i>	
Positive score <sup>a</sup>	27 (43)
Not mentioned <sup>c</sup>	36 (57)
<i>Psychological issues</i>	
Positive score <sup>a</sup>	13 (21)
Not mentioned <sup>c</sup>	50 (79)
<i>Social issues</i>	
Positive score <sup>a</sup>	9 (14)
Not mentioned <sup>c</sup>	54 (86)
<i>Existential issues</i>	
Positive score <sup>a</sup>	14 (22)
Not mentioned <sup>c</sup>	49 (78)

a) The symptom was present.

b) The symptom was not present.

c) No documentation on the symptom was found.

From the population, 24 patients (38%) were discharged to their own home and four patients (6%) to a rehabilitation facility, representing patients in a stable palliative phase. From the rest of the population, three patients (5%) were discharged to a care facility, six patients (10%) to terminal care in their own home, 19 patients (30%) to hospice, and seven patients (11%) died while admitted, representing patients in a deteriorating palliative phase.

## DISCUSSION

The results showed how patients with upper GI cancer have a risk of several admissions and transitions in the course of their illness. Physical symptoms were more frequently documented than psychological, existential and social symptoms, suggesting that all patients' symptoms may not have been identified, treated and evaluated in a structured manner. Few patients had completed the EORTC-QLQ-C15-PAL, meaning that patient-reported outcome measures are not implemented routinely.

Transitions may invoke positive feelings as it can bring hope of recovery [17]. This may be the case for patients who are eligible for curative treatment, and to some extent also for patients who are eligible for oncological treatment. Patients eligible for specialised palliative treatment may also benefit from transition. A systematic review [18] found improvements in pain, nausea and fatigue along with improved psychological functioning for patients with cancer in specialised palliative care and benefits were larger for inpatients than for outpatients [18]. However, transitions may lead to reduced quality of care by interrupting continuity. Patients express the stressful nature of meeting new care routines and being met with contradictory information from the old department/hospital and the new [17, 19]. Still, when in need of hospital admittance, a patient will be best placed in the department most suitable to take care of his/her needs: A patient with jaundice due to tumour growth and pressure on the bile ducts will be appropriately treated on the surgical ward, and a patient experiencing nausea due to oncological treatment will be appropriately treated on the oncological ward. This makes it all the more important that health professionals remain aware of the potential difficulties and pitfalls associated with providing coordinated and continuous treatment of palliative symptoms across the entire disease trajectory.

Physical symptoms were documented more frequently than needs from the other three domains and the results showed a substantial burden of physical symptoms. A need remains for use of PRO tools like the EORTC-QLQ-C15-PAL as discrepancies will exist between the doctors'/nurses' view and the patient's view. Thus, a described symptom may not be a problem for the patient and some symptoms like fatigue may seem too obvious to the doctor or nurse to even deserve mention in the medical records [20]. We found that psychological, existential and social symptoms were sparsely documented. A former Danish study [20] found that existential problems were sparsely documented in the medical records. Even though nurses' documentation was included in this study, we did not record a greater focus on existential issues. Rather, when these issues were described, this was done as part of the doctor's documentation.

The study is strengthened by its attempt to investigate documented symptoms relating to all four areas of palliative care, i.e. physical, psychological, existential and social issues. Symptoms were predetermined, meaning that some prevalent symptoms may not be described here. The study was also limited by the relatively small study population ( $n = 63$ ) and by the population being included from one department only. This limits the referability as focus on the documentation of palliative symptoms may vary. Additionally, patients with upper GI cancer were defined as having one of seven different cancer diagnoses, meaning that the lesser occurring ones only constituted a small part of the final group, making universal conclusions for these diagnoses difficult. However, all patients in the data collection period were included, leaving a comprehensive overview of the documented symptoms of the patient suffering from metastatic upper GI cancer. All data were collected by one person (first author). Therefore, all data were uniformly collected on all patients.

## CONCLUSION

The high burden of physical symptoms and the complex nature of the illness trajectory should compel health professionals to adopt a structured and systematic approach when identifying, treating and evaluating interventions aimed at alleviating palliative symptoms. Additionally, PRO tools such as the EORTC-QLQ-C15-PAL



should be implemented uniformly and supported throughout the course of illness, as this is a central and important approach to securing adequate palliative care interventions.

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