

## Original Article

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# The symptom burden and the assessment of palliative symptoms in patients with metastatic upper gastrointestinal cancer: A qualitative interview study

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**Abstract**

**Objectives.** Patients with metastatic upper gastrointestinal (GI) cancer may experience a large physical symptom burden. However, less is known about existential, social, and psychological symptoms. To provide the patient with palliative care, quality-of-life questionnaires are used for structured needs assessment. These are sporadically implemented, and there seems to be uncertainty to the efficiency of current practice. The aim of study was to explore the experienced assessment-process and treatment of palliative symptoms, as well as the experienced symptom burden, in patients with metastatic upper GI cancer.

**Methods.** Qualitative, semi-structured interviews were conducted in 10 patients with metastatic upper GI cancer. Data were analyzed using content analysis.

**Results.** The patients did not expect treatment for all physical symptoms. Existential symptoms revolved around death and dying, social issues were mainly related to family, and psychological issues were based in the continuous dealing with serious illness. Existential, social, and psychological symptoms were mostly not considered part of the expected care when admitted to hospital. Patients had only vague recollections of their experiences with structured needs assessment, and the process had been inconsequential in the treatment of symptoms.

**Significance of results.** Patients with upper GI cancer experience symptoms related to all 4 areas of palliative care being physical, existential, social, and psychological, but these are differentiated in the way patients perceive their origins and treatability. Structured needs assessment was not routinely carried out, and in cases where this had been done, no follow-up was effected. This calls for increased focus and proper implementation for the process to be relevant in the treatment of palliative symptoms.

**Introduction**

Suffering from upper gastrointestinal (GI) cancer is associated with a substantial burden of physical symptoms and a low and deteriorating quality of life as the illness progresses (Maharaj et al. 2019; Merchant et al. 2019). The burden of physical symptoms in these patients includes pain, loss of appetite, nausea, vomiting, fatigue, malignant bowel obstruction, and bowel dysfunction such as constipation and diarrhea (Beesley et al. 2016; Merchant et al. 2019; Uitdehaag et al. 2015). Patients with metastatic upper GI cancer not eligible for curative treatment is the population of focus in this study. They will receive life-prolonging oncological treatment if the performance status allows it, and they are offered basic palliative treatment and care throughout the course of their illness (Maharaj et al. 2019). Unless in active oncological treatment or referred to the palliative ward, the surgical ward for upper GI diseases is the department base for a patient with metastatic upper GI cancer and in need of hospitalization (Tarp et al. 2023).

Palliative care is designed to improve quality of life by relieving physical symptoms, but seeks also to include existential, social, and psychological symptoms (Wen et al. 2018; World Health Organization 2021). Generally, more is known about the burden of physical symptoms and less about the existential, social, and psychological symptoms in patients with cancer (Bolmsjö 2001; Selman et al. 2018). This is also true for patients with upper GI cancer (Karlsson et al. 2014), even though this group of cancers are known to have low chance of curative treatment and a short duration from diagnosis to death for patients with metastases (Deftereos et al. 2020; Maharaj et al. 2019). This means that the timespan from feeling healthy to being life-threatening ill can be short, and it puts the group of patients at risk of carrying a large burden of symptoms relating to existential, social, and psychological issues. To provide the patients with palliative care, clinicians need to have a clear understanding of the complexity and the diverse-ness of symptoms, as well as on the patients' expectations in receiving treatment, care, and

guidance in relieving symptoms (Beernaert et al. 2016; Dong et al. 2016). Studies have shown how health-care professionals' documentation of symptoms not always coincide with patients' experiences of symptoms (Strömberg et al. 2002). Therefore, the natural source of information on symptom burden is the patient, and therefore current practice recommends the use of quality-of-life questionnaires and patient-reported outcomes for structured needs assessment and evaluation (Groenvold et al. 2006; Hui et al. 2016). These are manifold and implemented differently across the health-care system, which provides an uncertainty to the efficiency of current practice at assessing and alleviating symptoms (Haraldstad et al. 2019; Kouzy et al. 2020; Sundhedsstyrelsen 2012). It seems obvious that quality improvement through structured needs assessment requires effective detection of concerns, distress and/or unmet needs by the assessors (Johnston et al. 2019). Thus, the assessment-process is of importance to improve treatment of palliative symptoms.

To rationalize further research and quality improvement within this clinical field, we wanted to explore the experienced assessment-process and treatment of palliative symptoms, as well as their experienced symptom burden in patients with metastatic upper GI cancer and admitted to the surgical ward.

## Methods

The present study had a qualitative design. Semi-structured interviews were conducted in patients with metastatic upper GI cancer. Data were analyzed using content analysis and results are presented according to the "Consolidated criteria for reporting qualitative research" (COREQ) guideline (Tong et al. 2007).

Participants were patients with metastatic upper GI cancer. Further inclusion criteria were for participants to have been admitted to the surgical ward for upper GI diseases for a minimum of 5 consecutive days before the interview, this to make sure that the participants had personal experiences of the day-to-day care and treatment on the ward. Patients who were in a terminal phase (all active treatment discontinued, and the patient is irreversibly dying) or patients with dementia or other debilitating mental disorders were not included. Moreover, patients with other cancers or other symptomatic illnesses not connected with the cancer disease and where it would be difficult to dissect the origin of symptoms were also not included. Convenience sampling was used for the selection process. On days where the interviewer was available, all patients admitted were screened and the patients who met all inclusion criteria were approached. Potential participants were approached while admitted to the surgical ward. The first author screened patients according to the selection criteria, identified eligible patients, and gave them written and oral information and time to think about their decision to participate. Participants were informed that interviews could be held during their admittance or after discharge in their own home or by phone. In all instances, patients preferred to do the interview while admitted and these were carried out in a private meeting room or at their private patient room.

The interview guide was constructed by the authors and based on literature and clinical experience. The guide was discussed within the author group as well as with stakeholders among the department staff. The interview guide was not modified during the data collection process. The guide was constructed from 4 themes: (1) The experienced physical symptoms and the diagnosis and treatment of the symptoms during the admittance.

(2) The experienced existential, social, and psychological symptoms, and the assessment and treatment of the symptoms during the admittance. (3) Structured needs assessment. Subjects were shown the 2 quality-of-life questionnaires used in our region, being the EORTC-QLQ-C15-PAL and the Danish questionnaire "Støtte til livet med kræft" (Support for life with cancer) (Region Hovedstaden 2014), and asked if they had ever filled out the forms and how the experience was. The "Support for life with cancer" questionnaire consists of 48 yes/no questions as well as 4 open-ended questions. It is meant to be used as a preparation tool before a conversation about rehabilitating and palliative needs. (4) The experienced involvement in decisions regarding the treatment of palliative symptoms. All interviews were performed by the first author and were conducted using open-ended questions to ensure that symptoms mentioned were important to the patient and not prompted by the interviewer. This proved difficult especially when asking about existential symptoms. In those cases, participants were given examples that being religion, the meaning of life, hope/hopelessness, and the end of life. In a few instances, the same was necessary for social issues. These were defined as issues relating to family, work, and finances. Interviews were recorded and transcribed using the concept of "slightly modified verbatim" (Malterud 2011). Where it was important to the understanding, moods and feelings were recorded. For major themes, data saturation was reached after 8 interviews, but a further 2 interviews were carried out to better capture the complexity of the topic. Saturation was discussed between authors.

Data were analyzed by the first author, closely supervised by a specialist in qualitative research. Content analysis was used to analyze the data. Content analysis provides the opportunity to reveal descriptive content where little interpretation is required, as well as latent content requiring various levels of abstraction and interpretation (Graneheim et al. 2017). In the present study, focus was mainly on the manifest content. In content analysis, categories and themes are often used interchangeably and with various meanings (Graneheim et al. 2017). Here, it displays the hierarchy, meaning that categories are the collection of codes that share the same characteristics, and themes the collection of categories sharing the same meaning. For example, Theme 2 is derived from the 3 categories "Social problems and symptoms," "psychological problems and symptoms," and "Existential problems and symptoms." The category "Social problems and symptoms" is a collection of the following codes: The meal as a social activity, leaving family behind, economic uncertainty, feeling isolated, the dilemma of how much to inform family members, work and career, the impact of physical symptoms on social life, other serious illness in the family, getting affairs in order, feelings on receiving care, help and advice from family and friends. A mixed inductive and deductive method was used to code and analyze the data. The transcripts were initially read and reread to get an overall sense. First step of the analysis was an inductive approach where the texts were split into meaning units, and these were condensed into a few sentences with focus on maintaining a strictly descriptive approach and preserving the core. The condensed meaning units were then provided with a code. All codes about experienced symptoms were tested against the 4 preset categories of physical, existential, psychological, and social symptoms (deductive approach), and from the 4 categories, themes were defined. To analyze the remaining data, the inductive approach was maintained, and codes were compared and sorted into categories and finally formulated into a theme.

The study was approved by the Danish Data Protection Agency (P-2021-491). The study was exempt from ethical committee

**Table 1.** Patient characteristics

Participant number	Age	Gender	Cancer origin	Duration of illness	Duration of interview (min)
1	52	M	Esophagus	<1 year	52
2	84	F	Pancreas	<1 year	29
3	90	F	Stomach	<1 year	39
4	60	F	Stomach	4 years	41
5	65	M	Extrahepatic biliary tract	<1 year	51
6	73	F	Pancreas	3 years	24
7	71	M	Stomach	<1 year	39
8	74	M	Extrahepatic biliary tract	<1 year	40
9	77	M	Duodenum	4 years	33
10	75	F	Esophagus	<1 year	20

M = male, F = female.

approval according to Danish law. Potential participants received oral and written information about the study, and written informed consent was obtained from all participants.

## Results

Data comprised 10 interviews performed from November 2021 to April 2022. In the selection process, several patients denied participating. They explained feeling too weak or tired, that the task felt too overwhelming, or that their physical or emotional functioning did not allow it. Most patients had a short duration of illness of <1 year, and the rest had been ill for several years (Table 1). Interviews lasted between 20 and 52 minutes (median, 39 minutes). The total number of symptoms recorded for each patient were between 4 and 15, and only 2 patients reported fewer than 10 symptoms (Table 2), indicating a substantial symptom burden for this population.

### Theme 1: The treatment of physical symptoms

In general, patients were content with the treatment of physical symptoms. There was a sense of “easy access” to medicine aimed at relieving physical symptoms.

P3: “And I can get antiemetics, and I’ll get it if I ask for it. There are no discussions because it’s written down that I can get what I want”.

P7: “I’ve got a sense that the register is wide open. I can take more, or I can take less, but of course it has to be prescribed for me”.

Patient’s way of presenting a physical symptom in way of origin and expectations of getting treatment for it, differed from symptom to symptom. The 2 most reported symptoms were fatigue (9 patients) and pain (8 patients). Fatigue was presented as an indistinct symptom and patients gave several different reasons for why they might be tired, mostly secondary to the disease, relating it to medication, high age, lack of sleep, or lack of nutrition. To that, no one requested any treatment for fatigue; instead it was presented as something to endure.

P8: “I feel an immense tiredness. Sleeping in the middle of the day. I haven’t done that in recent times. That, well, that is what comes with the medication, there is nothing to do about that.”

P3: (On why she feels tired) “But I don’t get a lot to eat. The small amount I do eat doesn’t give me much energy, does it?”

For pain, as well as for other common physical symptoms like nausea and constipation, we saw a different picture. Patients had a clear perception of this being symptoms originating directly from the cancer disease, they expected a treatment plan, and many also had opinions on the treatment and expected to be involved in the decisions.

P8: “Well, I struggled a bit with them (the doctors), finding out how much I needed, for me to be free from pain. And I think they were a bit too hesitant...”

P1: “I think you’ve all been very attentive to my pains, like the doctor who’s been doing rounds for the last few days, he has made sure, he has upped the doses on my pain relief patch”.

### Theme 2: Existential, social, and psychological symptoms

The existential issues mainly revolved around dying and the question of what comes after death, much in relation to believing in a higher power or not.

P1: “No doubt I’m a Christian, and God will get a proper ass-kicking when I see him, because this is completely unfair, I’m so happy with my life.”

P3: “But you know, I don’t believe in that thing (pointing up indicating God) ... I remember when my husband died, the priest came, and we had a really good conversation. I told him that for me, eternal life is what I’ve given to my children, it’s not that I will be resurrected as somebody”

Social issues were diverse, touching on financial and practical issues but mainly focusing on family. These were issues relating to day-to-day living (the meal as a social activity and the impact of physical functioning on social functioning) and issues relating to the severity of their illness, e.g. speculations on when and how much to inform close family members, especially children, and feelings relating to the realization that they would be leaving family behind and knowing how this would hurt them.

P5: “For us, food has always been of great importance. Eating well and cooking good food and drinking good wine.... It has always been a part of our life. And this (loss of appetite) has been the most difficult thing to get used to.”

P4: “We have chosen to inform the kids every time there’s been something to inform about. Had it been better not to say, that now they think it has spread to the liver? Then maybe they wouldn’t be scared. I don’t know if that has been the right choice.”

Psychological issues mainly focused on the continuing process of dealing with an incurable illness. They expressed the dueling feelings of trying to keep up spirits and allowing emotions of sadness, anger, etc., as well as trying to find reason for their illness, e.g. age, history of cancer in the family, way of life, etc.

P7: “But I try to keep my spirits up, because it’s no use letting everything be deadly serious. You could easily let yourself fall down that big, black hole, but that wouldn’t help a thing.”

P2: “And now this has happened, and I’m not surprised. My grandmother died of cancer (names three more relatives who have died from cancer).

**Table 2.** Symptoms reported by the patients

Participant number	1	2	3	4	5	6	7	8	9	10
Physical symptoms										
Fatigue	X	X	X		X	X	X	X	X	X
Pain	X	X	X		X	X	X	X	X	
Loss of appetite	X	X		X	X	X	X			X
Nausea and/or vomiting		X	X	X			X	X		X
Difficulty sleeping			X	X		X		X		
Pressure ulcers (bedsores)			X	X	X					
Constipation						X	X		X	
Ascites/edema				X	X					X
Infection					X			X		X
Problems swallowing food/medicine	X						X			X
Diarrhea		X		X						
Weight loss	X				X					
Loss of general function	X			X	X					X
Gastrointestinal bleeding							X			X
Urinary retention							X			
Shortness of breath							X			
Existential symptoms										
Religion: Life after death	X	X	X			X				X
The funeral		X	X	X		X				X
Hope/hopelessness	X				X	X	X			
Social symptoms										
Impact of physical symptoms on social functioning	X					X				
Family issues (leaving family behind, and who and how much to inform close family members)	X	X		X		X		X	X	
Financial insecurity	X				X					
Practical issues (testament, etc.)		X	X	X	X					X
Psychological symptoms										
Depression	X									
To find meaning/to come to terms with the situation		X	X	X		X	X			X
Restlessness				X						
Identity loss					X					
Dueling feelings of sadness vs. keeping up spirits	X	X	X				X			X
Total number of symptoms reported by the participant	13	11	10	12	12	11	12	6	4	13

Someday, before I fell ill, I was thinking about my family and I thought: God knows if it will be my turn someday?"

Patients expressed little or no expectations of receiving help and advice concerning existential, social, and psychological issues when admitted. The explanations can fit into 3 categories:

- 1) Patients who expressed a wish for emotional care to be a part of the treatment, but who had no expectations as they saw the work environment as not allowing time for it.

P7: "Yes, I think it would be great if it was an integrated part of the treatment and the stay, but I see the practical possibilities as being very poor, and, well, as I see it, with the current staffing, there is no time ..."

- 2) Patients who expressed that they would use their network for emotional support. Some patients even expressed that asking about these matters would not be welcome.

P8: (When asked about the need for information about support options i.e. grief support groups for children and grandchildren): "I think that would be stepping too far."

I: "That would be too much?"

P8: "Support groups would probably be good for some, but the thing is, my wife has all of that covered."

P10: "No, well, you know, it's not that I'm being negative, but I've realized that the bells will toll at some point and now it's my turn."

I: "So talking to us about life and death and the larger things in life ...?"

P10: "No, I've done those talks with some close friends ..."

- 3) Patients who did not recognize the cancer diagnosis as being the focus of attention during their admittance, and consequently did not recognize a focus on existential, social, and psychological issues as being a part of the care and treatment provided.

P5: "It's a question about reaching a point where you realize that you need it. When I was offered rehabilitation and offered seeing a psychologist in the beginning of this, I didn't see myself as a patient with cancer yet."

P9: "Because I don't see myself as being admitted here because of my cancer, I am here because I am constipated."

### Theme 3: The assessment of symptoms

Half of the patients had filled out a quality-of-life questionnaire in the course of their illness: 1/10 had filled out the EORTC-QLQ-C15-PAL questionnaire, and 4/10 had filled out the "Støtte til livet med kræft" questionnaire. The patients who had experiences with quality-of-life questionnaires had a hard time remembering details about the process. To that, they had no sense of this being determining for a subsequent initiation or change of treatment of symptoms. Most remembered no follow-up after completing the questionnaire and 1 misunderstood the intention of it being for research purposes and not as an active tool in the treatment.

P1: "This one, I've seen this before" (Støtte til livet med kræft) ... Yea (uncertain), yes I think I filled it out in connection with an appointment. But I don't recall using it."

P7: "It was a bit meaningless. I've filled them out and answered to the best of my abilities, and handed them in, and then I haven't heard anything about it ... So probably they've been a bit meaningless because they haven't been evaluated afterwards. I assumed they were used as a general evaluation or for statistics."

Patients who had not encountered quality-of-life questionnaires in the course of their illness were explained the intention of the forms. Both patients who had experiences with the questionnaires and patients who were explained the idea were not overly positive about the process and rather expressed a confidence of being able to communicate symptoms needing attention, without the need of a form.

P1: "But I think people are different. I tend to be good at expressing my needs and what I'm not satisfied with. But some people will struggle doing that, both identifying their needs but also to express them. Then this kind of list (referring to the questionnaire) would be good. So, well, I think it has a lot to do with who you are as a person."

## Discussion

The patients experienced many symptoms and in all 4 categories of palliative care. They were mainly pleased with the medical treatment of physical symptoms, but not all physical symptoms were

perceived as something they could expect treatment for. Existential symptoms mostly revolved around death and dying, social issues were mainly related to family, and psychological issues were based in the continuous dealing with serious illness. For various reasons, existential, social, and psychological symptoms were mostly not considered part of the expected care when admitted to the surgical ward. Patients had only vague recollections of their experiences with structured needs assessment, they questioned the appropriateness as general tools for all patients, and the process had been inconsequential in the treatment of symptoms.

It is not surprising that patients with metastatic upper GI cancer experience symptoms relating to existential, social, and psychological issues. They are common and numerous and are experienced across the entire disease trajectory (Beernaert et al. 2016; Ripamonti et al. 2018; Selman et al. 2018). It was surprising though, that patients did not expect treatment, as other studies have shown a general wish for treatment, help and guidance for those symptoms, and an improved quality of life when they are addressed (Bolmsjö 2001; LeMay and Wilson 2008; Selman et al. 2018). Many barriers are present in the provision of existential, social, and psychological care. As it is presented in this study, other studies have also indicated the work environment as a barrier. Clinicians expressed lack of time and knowledge and patients expressed not wanting to bother or waste the sparse time of the clinicians, but also expressed a low prioritization and motivation of the part of the clinicians in dealing with these issues (Rattner 2021; Selman et al. 2018; Sommerbakk et al. 2016). From our results, it seems that symptoms that patients could easier connect directly to the cancer disease or to their reason for admittance like pain, nausea, and constipation, were the symptoms for which patients were more likely to expect treatment. On the contrary, more impalpable symptoms that patients might categorize secondary to the disease were perceived as symptoms to either endure or to solve without the help of the clinicians. In these cases, patients might rate their problem as unimportant or irrelevant, or as unsolvable for the clinicians, resulting in underreporting and thus undertreating of the problems and ultimately poorer quality of life (Beernaert et al. 2016; Johnsen et al. 2013). One of the patients said that he did not think he was hospitalized because of the cancer but because of the constipation. If patients do not see us as their primary ward during their cancer treatment, but a place where we treat complications of the cancer, this may mean that they do not expect a focus on overall palliative needs.

The results showed that half of the patients had no experience with structured needs assessment. A few patients had a short duration of illness when interviewed, thus maybe partly explaining that low number, but this result also suggests poor implementation and use of structured needs assessment in daily clinical practice. Surprisingly, we saw a relatively negative response to the process. The 5 patients who had experience with the process gave similar accounts in that no follow-up was performed after completion of the quality-of-life questionnaire. Follow-up on the questionnaire by means of a conversation between the patient and the clinician is the step where important clinical action can be taken (Biddle et al. 2016; Carlson et al. 2012). Patients link the success of the process with an outcome being a referral or a treatment plan, whereas clinicians are more likely to see the screening as an intervention (Biddle et al. 2016). It has been demonstrated that structured needs assessment does not always result in clinical action (Seow et al. 2012). This for many reasons ranging from lack of time to feeling ill-equipped at dealing with the needs described, resulting in the more readily fixed physical symptoms being treated

more frequently than symptoms related to psychological distress (Biddle et al. 2016; Seow et al. 2012). Without clinical action after completion of the questionnaires, we must expect minimal consequence for the patient by means of symptom relief and improved quality of life (Greenhalgh et al. 2005; Seow et al. 2012). Therefore, the results in this study do not necessarily discredit structured needs assessment per se, but rather it indicates poor implementation and use of the tools and stresses the importance of active use of answers given by the patient for the process to add value. Thereafter, thus after proper use, it would be important to explore patients' opinions about structured needs assessment.

Results presented in this study were from qualitative interviews. Results on symptoms were therefore undoubtedly influenced by the researchers in some sense. For physical symptoms, patients were asked to share what physical symptoms and problems they felt. Several more might have experienced, e.g. weight loss and loss of general function if measured objectively or if asked specifically, but if it was not mentioned by the patients it was not considered to be an important symptom. This was intentional and preferred, as focus was on the experienced symptoms. For existential and social symptoms, it was often necessary to give examples of what might constitute, e.g. an existential issue, and this will undoubtedly have steered the conversation to revolve around the examples given. In most cases though, these examples worked as a clarification, allowing the conversation to move to other symptoms not mentioned by the interviewer. Also, symptoms relating to these categories are sensitive and are topics that can take time and trust to be unfolded properly, and suggest that results on existential, social, and psychological issues in the present study might be superficial. Therefore, more research is needed, e.g. in the form of follow-up interview studies where trust between interviewer and patient has a better chance of developing. Patients were interviewed during admittance to hospital. This fact is likely to affect the severity of symptoms experienced by the patients and may have added on symptoms that would not be prompted if the patients were interviewed at a more stable phase of their disease. The study is limited by the small sample and by the fact that the sample was recruited from a single surgical department. The qualitative study design does not allow for extrapolating our results to the entire population of people living with metastatic upper GI cancer. However, it shows, in an unselected sample, that patients had multiple symptoms, and we got the impression that not all symptoms were dealt with adequately. Several patients declined participating, and we must therefore assume that the sample portrays the resourceful part of the population.

In earlier work (Tarp et al. 2023), we have shown that this group of patients experience an illness trajectory with several intra-hospital transfers. In addition, they are likely to have a short illness duration meaning a quickly deteriorating condition and thus a risk of rapidly changing and worsening symptoms (Tarp et al. 2023). Our results show that common physical symptoms like pain, nausea, etc., seem to be in daily focus and are treated efficiently while admitted. However, it seems important to deal with the more impalpable symptoms like fatigue, as well as the wide array of existential, social, and psychological issues that often do not have our routine attention as clinicians. This is the *raison d'être* of structured needs assessments, but not an easy task in clinical practice for this group of patients experiencing transfers, many symptoms, and a short duration of illness.

In conclusion, patients in this study with metastatic upper GI cancer experienced symptoms related to all 4 areas of palliative care being physical, existential, social, and psychological, but these

were differentiated in the way patients perceived their origins and treatability. Interestingly, the data showed that structured needs assessment may not be relevant or wanted by all patients, and this should be studied further. Also, structured needs assessment was not routinely carried out, and in cases where this had been done, no follow-up was effectuated, meaning that the process had no consequence in the treatment of palliative symptoms. Thus, better implementation and use are warranted, including a follow-up conversation between the patient and the clinician resulting in clear treatment plans for this to be a tool relevant for patients and usable in clinical practice.

**Supplementary material.** The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951523001335>.

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