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# Patients' Experiences With Illness, Treatment, and Decision-Making for Esophageal Cancer: A Qualitative Study in a Danish Hospital Setting

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## Abstract

Patients with curable esophageal cancer or cancer in the esophageal junction face several challenges during the course of their treatment because of the burden of uncertainty in their prognoses and complexity and side effects of the treatment. The aim of this study is to explore patient experiences with illness, treatment, and decision-making in the context of esophageal cancer. A qualitative approach using phenomenological–hermeneutical methodology was used. Data consisted of participant observations and interviews. We analyzed the data based on Ricoeur's theory of interpretation. The results show that patients with esophageal cancer are putting their ordinary lives on hold and experiencing the meal as a battleground during treatment. Patients strive to maintain autonomy, gain control, and take ownership. The results emphasize the need for a systematic approach to establish an ongoing dialogue with patients throughout the course of treatment.

## Keywords

esophageal cancer, patients' experiences, person-centered health care, qualitative research, decision-making, participant observation, interview, Denmark

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## Introduction

This study focuses on patient experiences with illness, treatment, and decision-making in the context of esophageal cancer (EC). EC and cancer in the esophageal junction are among the eight most common cancers in the world, with a worldwide overall 5-year survival of 15%–34% (Bollschweiler et al., 2017; Sjoquist et al., 2011). Patients and their families are aware of and affected by the poor prognosis of EC, and deal with uncertainty over the treatment outcome and future (Clarke et al., 2011; Larsen et al., 2019; Lewis et al., 2018; McCorry et al., 2009). Patients with early stage EC are offered treatment consisting of surgery and perioperative chemotherapy (Lagergren et al., 2017). The duration and the effects of treatment also add to the strain on patients and relatives (Andreassen et al., 2006).

Patients with EC can be burdened by the uncertain prospect of dying and in dealing with a complex and efficient health care system, in which tests and treatment are carried out quickly leaving them little time to adapt and consider decisions and the consequences of the treatment (Bull et al., 2019; Lagergren et al., 2017; Larsen et al., 2019; Mansour

et al., 2017). Having a life-threatening illness such as EC makes it challenging to patients and relatives to survey the treatment course and comprehend consequences to treatment (Andreassen et al., 2007; Dempster et al., 2011).

A qualitative meta-analysis on living with EC and clinically similar forms of cancer reported that patients and family members experienced crises as they were confronted with cancer and its aggressive treatment (Andreassen et al., 2007). Their suffering was associated with patients' symptoms and side effects of treatment, which affect their and their relatives' social world and relationships. Patients experience the treatment as strenuous and thus try to control everyday life and manage the effects thereof (Bull et al., 2019; Hellstadius et al., 2019).

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Forced to incorporate the new experiences of illness, people with EC distinguish between the old precancer self and their new identity as patients with cancer. For some, this is associated with feelings of loss (Clarke et al., 2011). Patients are forced to adapt and find meaning in a new life situation, and to relinquish control to health professionals to manage their treatment outcomes (Graham-Wisener et al., 2019). However, patients perceive a lack of personal control over the course of their illness and treatment, and self-efficacy is demanded of patients in controlling the everyday symptoms of their condition. Symptoms arising consequent to surgical treatment for EC include an early sense of satiety, bloating, nausea, diarrhea, and reflux (Ginex et al., 2013; Malmstrom et al., 2013). All these symptoms affect patients' quality of life on a physical, social, and emotional level (Malmstrom et al., 2013).

Health professionals play an important role in preparing and supporting patients, especially in educating them about what to expect during treatment and after discharge (Malmstrom et al., 2013). However, the challenge for health professionals is recognizing whether patients are ready to receive information, and to what extent. The rapidity of clinical change and number of courses of actions often involve multiple decisions for hospital inpatients (Coulter, 2011). Coulter (2011) contends that it is particularly important to involve patients in decisions at pivotal times of change related to a need to modify a treatment plan, try a different medication, or plan for discharge. Sharing information is an essential prerequisite for patient participation, and a core theme in patient-centered care (Kitson et al., 2013). Given the poor prognosis of EC and impact of surgery, it is important to address patients' information and support needs, because this can help patients regain control, reduce their anxiety, improve compliance, create realistic expectations, promote self-care, and generate feelings of security (Henselmans et al., 2012). However, McNair et al. (2016) found that health care professionals tended to underestimate the need for information of both patients and family members.

Previous studies provide knowledge on how patient adapt, manage symptoms, and react to the diagnosis (Clarke et al., 2011; Dempster et al., 2011; Lewis et al., 2018; Viklund et al., 2006). Several studies describe patient experiences of their new life after surgery, and how their quality of life is affected (Carey et al., 2013; Malmstrom et al., 2013; McCorry et al., 2009; Wainwright et al., 2007). However, few qualitative studies explore patient experiences during illness and treatment for EC or their experiences making decisions related to treatment. We address this gap in the literature by exploring the experiences of patients with EC to provide important insight into their perspectives on the illness, treatment, and decision-making, which can shape future services in the health care system. The aim of the study was to explore patient experiences with illness, treatment, and decision-making in the context of EC.

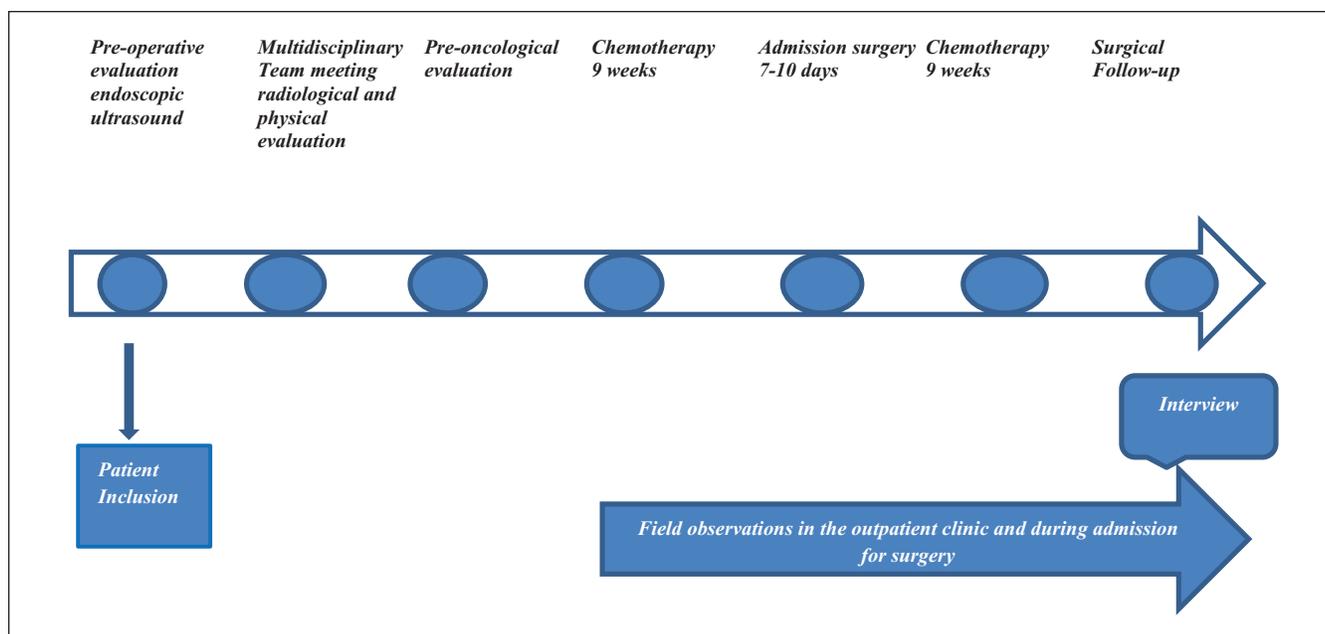
## Method

### Design

We adopted a phenomenological–hermeneutical approach, inspired by the work of Paul Ricoeur's philosophy about narrative and interpretation (Ricoeur, 1976, 1984), to guide data generation and data analysis. Ricoeur focuses on interpretation as the primary aim of hermeneutics. His theory of interpretation considers language, reflection, understanding, and the self (Ricoeur, 1976, 1984). Ricoeur combines phenomenology with a critical hermeneutic philosophy, making it possible to develop new understanding from the text through critical interpretation (Ricoeur, 1976). In this study, we applied a phenomenological approach because the focus was on descriptions of the lived life and experiences of patients with EC during treatment. As we also aimed to develop knowledge about the impact of the treatment course on patients, text interpretation was required, that is, the hermeneutic approach. Data were generated through participant observations (Spradley, 1979) and open in-depth individual interviews with patients with EC (Kvale & Brinkmann, 2014). Patients' narratives and stories informed and guided data collection in the interviews and participant observations. When conducting participant observations and interviews, we capture what is observed and said and transform this into a text (Simony et al., 2018). According to Ricoeur (1984), the way words and actions are expressed forms the basis of initial analysis and interpretation of the phenomena under investigation. Through observations, researchers can observe the way words and actions are expressed and document it as a field note (Emerson et al., 2011; Spradley, 1979). Thus, the lived experiences of patients with EC and factors surrounding their experiences of illness and treatment can be comprehensively understood.

### Setting

In Denmark, 875 patients are diagnosed with EC annually, and approximately 25% of these are offered surgical treatment with a curative purpose (Danish Esophagus, 2016). Treatment for EC is highly specialized and organized in four university hospitals. Patients are referred to the surgical department by specialist physicians from other hospitals in the region, specialist physicians in private practice, and from general practice. A typical patient has biopsy-confirmed EC before referral, and at the Department of Surgery, the patient undergoes an endoscopic ultrasound (EUS) plus a standard gastroscopy as preoperative evaluation. Based on the results of EUS and a computed tomography (CT) scan or positron emission tomography–computed tomography (PET-CT) scan, the patient and a specialist surgeon have a conversation about treatment options. Subsequently, a multidisciplinary tumor board concludes whether or not the patient can be offered curative treatment considering his or her physical condition. The patient is then informed about this decision.



**Figure 1.** Overview of the EC treatment course and data collection.

Note. EC = esophageal cancer.

In Denmark, curative treatment typically consists of three series with chemotherapy, surgery, and after a recovery period, treatment with three cycles of chemotherapy again (Danish Esophagus, 2016). This is aligned with international treatment standards (Lagergren et al., 2017). During chemotherapy, patients and relatives consult with an oncologist regarding the side effects thereof and possible changes in treatment. After chemotherapy and the recovery period, patients are admitted to the Department of Surgery for resection. Admission to surgery is 7 to 10 days on average. Patients then have a short recovery period before being scheduled for postoperative chemotherapy. Figure 1 shows an overview of the EC treatment pathway and data collection process.

### Recruitment and Participants

The first author (M.K.L.) recruited patients between March and November 2017. To meet the inclusion criteria, patients had to be aged 18 years or older, speak Danish, have biopsy-confirmed EC (adenocarcinomas), and be recommended for surgery and oncological treatment. Patients were included by M.K.L. during their first consultation about the treatment plan. They received oral and written information about the study from M.K.L. and an informed consent form to sign. No participants declined to participate in the study.

Table 1 shows the characteristics of the patients. The average age of patients was 67 years. In total, 16 patients agreed to participate in both the participant observations and interviews. Of these 16, the cancers of three patients were adjudged to have progressed too far for the planned surgery (revealed at surgery). Thus, these patients started palliative

**Table 1.** Characteristics of the Patients.

Total 16 patients	Number
Age, years	
45–60	2
60–70	8
70–80	6
Gender	
Male	14
Female	2
Living with partner	13
Employed	4
Retired	12
Did not get planned surgery	3
Received the intended curative treatment	9
Did not complete the postoperative chemotherapy	4

oncological treatment and discontinued in the study (data to that point were included in the analysis). Another four patients failed to complete the entire postoperative chemotherapy course due to side effects from the treatment, but remained in the study. The included sample is representative of the population, as men  $\geq 60$  years are overrepresented among patients with EC. The mean male to female ratio is 6:1 for patients with oesophageal adenocarcinoma (Lagergren et al., 2017).

### Data Collection

M.K.L. conducted the participant observations and interviews between April 2017 and September 2018. M.K.L. is an

experienced interviewer and clinical nurse specialist working in the Department of Surgery, although not in the units studied. Initially, participant observations were descriptive observations to get an overview of the situation. These became more focused observations related to patients' participation in the treatment and interaction with health professionals. Observations were performed at the oncological and surgical departments during outpatient consultations and admissions for surgery, where decisions regarding treatment took place. Participant observations occurred throughout the entire treatment period until the 6-month postsurgical checkup, and included one to 12 observations per patient. The variation in observations per patient is attributed to the three patients who discontinued in the study (patients who started palliative oncological treatment) and those who did not complete postoperative chemotherapy. Individual observation sessions were of differing durations according to the circumstances under which they occurred: one day with information and preparation for surgery, ward rounds during admission for surgery, and outpatient consultations at the Department of Surgery and Oncology. Observations lasted between 20 minutes and 5.5 hours. In total, 154 hours of participant observations were conducted. The observations were mostly passive and involved informal conversations, although the researcher sometimes asked the patients for clarifications after the observation. The participant observations focused on the following:

- How did patients express themselves over time in the context of the EC treatment?
- How did health professionals involve the patient in treatment and decision-making?
- What was the interaction between the patient and health professionals like?

Descriptive field notes including direct quotations were made during the observations and afterwards transcribed, as recommended by Emerson et al. (2011) and Spradley (Emerson et al., 2011; Spradley, 2006). The researcher adopted Spradley's nine dimensions (space, actor, activity, object, act, event, time, goal, and feeling) as a framework to ensure a systematic approach to participant observations (Spradley, 2006).

Of the 16 initial participants, 13 were interviewed 6 months postoperative after finishing chemotherapy treatment. The three patients who discontinued in the study because their cancer had progressed were not interviewed. Participants selected the setting for the interviews. Nine interviews took place in the participants' homes, and four were conducted at the hospital. The interviews lasted between 34 and 65 minutes and focused on open narratives on three areas: (a) the participant's lived experiences with being a patient with cancer and receiving treatment for EC, (b) the participant's lived experiences with decision-making, and (c) significant dimensions of the trajectory of the participant's

illness and treatment. Questions or descriptions related to participant observations were included so that participants could elaborate on situations. Interviews were audio-recorded and transcribed to text (in the native language).

### *Data Analysis and Interpretation*

To structure the data and facilitate further analysis, we used the software program NVivo version 12. Ricoeur's theory of interpretation (Dreyer & Pedersen, 2010; Ricoeur, 1976, 1984) inspired the analysis and interpretation. The analysis consisted of three steps: a naïve reading, a structural analysis, and a critical interpretation (Dreyer & Pedersen, 2010; Pedersen, 1999/2005; Ricoeur, 1976).

In the naïve reading, the transcribed field notes and interviews were read through several times to obtain an overall understanding of patients' expressions and descriptions. Immediate impressions were written down to grasp a first naïve meaning of the text as a whole.

The naïve reading was followed by a structural analysis. This is an explanatory procedure and mediates two stages of understanding, namely, naïve understanding and critical interpretation (Ricoeur, 1976). In the structural analysis, the text was opened up for further interpretation and read again, focusing on units of meaning across the data based on "what is said." This refers to quotations that illuminate meanings and represent the data. Through further interpretation, we identified units of significance as descriptions of "what the text talks about." The process of structuring units of meaning and significance and of extracting themes is a dialectic process. The analysis moves forward and backward from understanding to explanation, and then from explanation to comprehension; Ricoeur (1976) describes this as a process and dynamic interpretative reading. Final themes were further interpreted based on the units of significance. In the critical interpretation and discussion, we then discussed and interpreted the themes in relation to relevant theoretical concepts and research results, which expanded the interpretation from the individual to universal level. M.K.L. conducted the initial analysis, and the subsequent analysis was refined through continuous discussions and contributions by the coauthors R.B. and H.S.

### *Ethics*

The patients and health professionals received both oral and written information about the study in accordance with the Declaration of Helsinki (World Medical Association, 2013) by M.K.L. We prioritized respect and consideration for participants' well-being and integrity throughout the study. Before starting each participant observation and interview session, M.K.L. repeated the oral information to provide participants the opportunity to reconfirm their consent, and assure them they could withdraw from the study at any time without consequences for their care and treatment. The

health professionals (nurses, surgeons, and oncologists) involved in participants' treatment and care also provided their oral consent before the observations. Anonymity was assured in presentation of the data, and the recordings and transcriptions were processed and stored confidentially. The Danish Data Protection Agency approved the project. In accordance with Danish legislation, regional health research ethics committees were informed and ruled that the study required no ethical approval. To ensure patients' anonymity, we obscured all personal characteristics in this article. Thus, we refer to a small population in a specific geographical region (Morse & Coulehan, 2014).

## Results

The naïve reading and structural analysis revealed that patients regarded the course of the illness and associated treatment as something to overcome. Accordingly, they struggled to establish an overview of the treatment course. Four themes were identified: (a) putting everyday life on hold because of treatment, (b) being on guard, (c) feeling or not feeling ownership of decisions, and (d) the meal as a battleground. In the next section, we explore these themes in more detail.

### *Putting Everyday Life on Hold Because of Treatment*

Patients were aware that the treatment would be physically and psychologically taxing, and tried to prepare themselves accordingly. Undergoing treatment necessitated arranging their everyday lives around and remaining available for treatment, as shown in this field note:

The observer asks the patient how he experiences his situation. The patient answers, "It feels like ordinary life during treatment is put on hold. We have to be available for treatment the whole time. We do it willingly, but we are looking forward to getting our lives back." (Department of Surgery, Patient 11)

Being available for treatment schedules for chemotherapy, surgery, and postoperative chemotherapy meant that a patient's everyday life took a secondary position. As such, everyday life and activities were put on hold. The treatment schedule affected the plans of the patient's whole family and was always in the foreground, meaning that the schedule took ownership of their personal lives and dominated their structure. Patients needed to be constantly available and alert to how they were physically coping with the treatment. Patients were fully aware of the potential side effects and complications of chemotherapy and surgery, as health professionals constantly asked them about symptoms and evaluated how the treatments affected them. Furthermore, treatment in different departments made it necessary for

patients to navigate and manage different treatments, making it more difficult to keep perspective, as mentioned here:

We knew from the beginning the treatment course was extended. We couldn't cope with the entire treatment . . . Well, you can say, when you start in the Department of Oncology with chemotherapy, then you get some information beforehand. When you sit and try to piece all this information together, then you can get the impression that it's unavoidable that something will go wrong. There are so many side effects, right? You need to handle the information when you need it, because otherwise we would worry ourselves sick. (Interview, Patient 4)

Patients anticipated an extended course of treatment, leaving them to deal with an overwhelming volume of information about possible side effects, which increased their feelings of anxiety, hopelessness, and vulnerability. One way to manage such feelings is to take one day at a time. However, this was not always possible for patients:

I was having a difficult time, and I could not handle the strain. I was lying in my bed, staring at the ceiling, and when I finally got up, I was physically drained and afraid of falling over. Now I have made progress, and things are different. (Interview, Patient 10)

Patients found it difficult to handle the physical and emotional strain of treatment, leading to exhaustion and withdrawal from the outside world. Participant observations showed that health professionals were good at addressing the physical strain of treatment, but less frequently addressed emotional strain, often remaining silent about how patients could psychologically manage the illness and treatment.

Patients experienced the treatment schedule as constantly interrupting their everyday life. This was especially true of the chemotherapy sessions:

The patient details how every day in the following week is occupied with illness and treatment: one day with blood tests at the hospital, one day with a checkup on his diabetes, one day with chemotherapy, one day with dental problems caused by the chemotherapy, and one day at the surgical department for a postsurgical follow-up. He says, "Luckily, I haven't started my work yet, but I think I am rushing from one thing to another." (Department of Surgery, Patient 11)

During the treatment period, patients lacked mastery over their everyday lives and were subjected to the treatment schedule. Therefore, they struggled to adapt to a constantly demanding treatment schedule in which they did not know what to anticipate from a given treatment and were hurrying from one appointment to another, striving to maintain autonomy over their lives.

When patients were discharged after surgery, recovering before postoperative chemotherapy, they were physically weak and struggled with different issues:

There was a lot of stuff after discharge. I had pain, I couldn't sleep, I couldn't walk and this and that. I was so miserable. I phoned them at the Department of Surgery and they told me this was normal. Nobody can walk miles; it takes time. This calmed me because I was scared. I couldn't even tolerate my family's company. I didn't bother about them, and I needed to be alone. (Interview, Patient 10)

Patients were overwhelmed by their inability to do things they once did at home. Moreover, they were unprepared for the state of their physical condition, as they were struggling with issues such as eating, pain, and fatigue. The obstacles seemed frightening and insurmountable, and some patients chose to isolate themselves from the rest of their families, and struggled in solitude, which also had implications for their families, who were not invited to help.

### *Being On Guard*

The patients expressed feelings of anxiety concerning how their bodies would react to treatment and their chances of long-term survival. The results of biopsies from surgery gave rise to worries about the future, and waiting for these results caused anxiety:

The patient tells the observer about his worries over the results of the biopsies taken during surgery. The surgeons told him that more of the esophagus and stomach had been removed than expected to be sure no cancer was left. The patient is aware that the biopsies will clarify his prognosis. He says he considers the surgery the first hurdle, but he thinks about how much the cancer has spread to his lymph nodes. (Department of Surgery, Patient 15)

The awareness that EC posed a threat and that the entire treatment could be regarded as wrought with almost insurmountable obstacles in uncharted waters made it difficult for the patients to know what to expect. Consequently, they were always on guard. During treatment, patients were constantly in the position of waiting—for treatments, the onset of possible side effects or complications, for test results. This gave rise to concerns and insecurity, and the patients expressed their feelings of vulnerability during the treatment.

To handle their feelings of powerlessness and gain some perspective on their treatments, patients often became very active players, actively asking questions, taking responsibility for their treatment course, and ensuring that the timeframes for procedures remained appropriate across departments. This example illustrates this point: "The patient explains to the oncologist he has told the secretary to advance his appointment, because he is aware that the postoperative chemotherapy must not be postponed more than eight weeks" (Department of Oncology, Patient 2). Patients who were very knowledgeable about the course of treatment often took charge if they experienced time delays, taking a more active role in their treatment pathway and thus reclaiming control

over it. Being on guard concerning the treatment pathway and acting on delays seemed helpful in dealing with feelings of powerlessness and vulnerability.

Patients were also on guard regarding possible signs of recurrence of the cancer. Fear of recurrence could be overwhelming, especially at mealtimes: "The patient tells the observer that in general, he thinks he is doing well. But sometimes at mealtimes, when he has problems with eating too much too fast and is coughing, he wonders about the cancer recurring" (Department of Surgery, Patient 7). Because most patients here had a history of dysphagia—usually the symptom that first led them to contact a general practitioner—they were especially vulnerable to these thoughts at mealtimes if they experienced pain in the stomach or difficulties swallowing. This made them think about recurrence before their rational minds could tell them that their changed anatomy might be the cause of these pains or difficulties. The meal, usually an enjoyable social event, instead became a trigger for anxiety and distress.

### *Feeling or Not Feeling Ownership of Decisions*

In their recovery efforts, patients expressed a need to believe in their treatment, and were constantly looking for signs of positive effects. Participant observations indicated that patients often conveyed to the oncologist that they felt their dysphagia was improving during the preoperative chemotherapy. This confirmed for the patients the success of the treatment.

However, though participant observations showed patients could actively ask questions about their prognosis and treatment side effects, they often deferred to health professionals as experts and merely followed the proposed plan for treatment: "The oncologist tells the patient about the chemotherapy treatment and its possible side effects prior to the treatment, saying that the oncologist would not hesitate to agree to it. The patient nods in acceptance" (Department of Oncology, Patient 1). Patients accepted that the treatment package included adjuvant chemotherapy followed by surgery. They did not consider this their decision, relying on experts' opinions and advice in terms of accepting or rejecting the treatment package. Both surgeons and oncologists emphasized that EC was a life-threatening illness, and that there was no alternative but to accept the proposed treatment plan if there was to be any chance of survival:

The surgeon tells the patient about the surgery and possible complications, saying, "You could say that you are standing with your back against the wall, so there isn't any real option. But I have to tell you about the possible complications." Goes on to tell the patient about the admission for surgery. (Department of Surgery, Patient 14)

Patients were merely informed about an already-decided treatment plan devised by the experts and followed their

recommendations. It was also emphasized that the patient needed the entire treatment package if there was to be hope for the future.

Sometimes, regarding plans directly affecting their everyday lives, patients wanted to actively participate in decision-making:

The patient relates how the nurse ordered enteral nutrition without asking him. The equipment was delivered to his home, but he says, "I have said yes to so many things, but this is my decision. I will not proceed with this nutrition. There wasn't time for reflection. She just ordered it. I need to get rid of all these tubes and back to everyday life." (Department of Surgery, Patient 5)

Being presented with a fact with direct implications for daily life at home without the option to give meaningful consent drove patients to reflect on what they would agree to. In this spirit, they strove to maintain autonomy over their lives in the midst of treatment. Patients wanted to actively participate in decisions regarding their home lives. They saw such decisions as their natural domains that demanded their participation, and reacted strongly if health professionals failed to include them in such decisions. Moreover, patients longed to get rid of the surgical equipment. They saw this as a step toward getting back to everyday life and as manifest evidence that they were on the right track.

Decisions regarding discharge dates were another area where patients wanted, but did not always get, a chance for active involvement: "It came like a bomb I wasn't prepared for. I was told about the discharge the day it happened. They could at least have told me a day in advance. I was so frustrated because it happened so fast" (Interview, Patient 8). When patients were not invited to participate in planning their own date of discharge, but were merely asked to follow a prearranged plan, it led to frustration and powerlessness, causing them to lose footing in their lives and their perspective of their treatment plan. When patients were not involved in the decision regarding discharge, they lost the authority to be active co-players, and were forced into a subordinate position, leaving them insecure and anxious.

### *The Meal as a Battleground*

After surgery, the volume of the stomach was diminished, and patients had trouble getting used to eating smaller portions at mealtime. This posed several difficulties:

Sometimes I eat too fast, which can induce vomiting. I am trying to eat slowly and take breaks during my meals to avoid this. I do have days without vomiting. I haven't yet dared to go out for dinner. Just the thought of sitting there vomiting! (Interview, Patient 12)

Mealtimes were no longer an automatic procedure, but an event demanding thought and adjustment. Meals became an

event riddled with anxiety and nervousness regarding possible nausea, vomiting, or pain. The possible social consequences caused many patients to withdraw from social gatherings, leaving them alone in their fight to adjust to their new anatomy. Patients fought their individual battles at mealtimes:

Even though I didn't like the eating part, I said to myself that I must eat. Otherwise, I would run into a blind alley. I can't say, "Today I am tired." I need to set goals every day, also to overcome my fatigue. You can say that it's my part of it . . . When I am sitting with my small portion together with my friends, they can't understand why I am eating so little; they ask if I am not a man anymore. (Interview, Patient 6)

As shown here masculinity was associated with the ability to eat large portions. In addition, patients considered eating something they had to overcome and endure. For them, eating was work to be done, a battleground for a fight they had to win. They were also aware that there was much to be gained if they could overcome their difficulties with eating. Worries about weight were to a large extent associated with patients' progress and recovery, if the patient was struggling this could devastate hope for progress. Therefore, difficulties eating were viewed as an obstacle to overcome and something the patient was obligated to do. Furthermore, some patients expressed that eating also had social implications and they often had to provide explanations at social gatherings. This meant their everyday lives were affected, sometimes causing them to isolate themselves at mealtimes.

## **Discussion**

This study revealed that during the course of treatment, patients with EC were in a vulnerable position as their familiar everyday lives were put on hold. They were subjected to the treatment schedule, and strove to maintain autonomy in the midst of treatment, trying to gain control and take ownership. This was especially evident at mealtimes, which was experienced as a battleground. Patients did not feel ownership over decisions regarding the treatment package, but for decisions that directly affected their home domain, they got frustrated and anxious if they were not invited to participate.

Vulnerability seems to be a consistent and fundamental aspect of how patients manage the treatment pathway, and of how and when they feel eligible to participate in decisions. We discuss and critically interpret the essence of vulnerability, and how the patients' vulnerability is affected by the illness and treatment pathway (Heaslip et al., 2016; Koffmann et al., 2009; Spiers, 2000) and research results. We also address how the health care system can lead to institutional vulnerability (Koffmann et al., 2009) and patients' vulnerability in the decision-making.

Regarding vulnerability, Spiers differentiates between the concepts of risk and experience, and between vulnerability understood by the person (the emic perspective) and

vulnerability viewed by others outside the experience (the etic perspective). Whereas the etic perspective views vulnerability in terms of functional deficits, in the emic perspective, it emerges from exposure to harm through challenges to one's integrity (Spiers, 2000). In our study, patients' vulnerability had a dynamic dimension according to the treatment pathway and extent to which they were affected thereby. Moreover, we found that the patients struggled with adapting to the demands of changed eating habits, leading to possible social isolation at mealtimes. We consider this a disruption of the normal social world and relationships, similar to Andreassen et al. (2007), who found that patients experiencing symptoms and side effects could feel abandoned and lonely, and enter a mode of social silence. Here, vulnerability exists in an interface within the self and in the social world in how patients adapt to new habits. We found that some patients isolated themselves because of physical and psychological exhaustion related to the treatment, leading to despair and hopelessness, whereas others became active co-players, setting goals for themselves.

Awareness of a poor prognosis and the demanding treatment pathway triggered psychological distress, as patients gave expressions of their feelings of vulnerability. This was also evident in a longitudinal study by Hellstadius et al. (2017), which found that many patients with EC report psychological distress during the first year after treatment. Our study showed that patients felt overwhelmed by their inability to do things they used to do, and struggled during treatment with eating, pain, and fatigue. Patients' vulnerability was especially present at mealtimes. Meals as a battleground represented a challenge to and vulnerability of patients' integrity, as they were confronted with the illness and consequences of treatment. Thus, patients had to deal with a large upheaval in their everyday life and a feeling of loss.

Dysphagia and weight loss are the most common symptoms patients report prior to diagnosis, and therefore re-experiencing difficulties with swallowing posttreatment is likely to increase distress (Hellstadius et al., 2017). Vulnerability viewed as a functional deficit caused by the treatment (i.e., etic vulnerability) is associated with how patients experience and manage the course of treatment (the emic vulnerability; Spiers, 2000). The two aspects of vulnerability seem interwoven, and both influence patients' experiences during the course of the illness and treatment.

Institutional vulnerability arose from the fact that the treatment was administered based on the authority of the surgeon and oncologist—who determined whether or not patients were offered treatment at all—and from a busy treatment schedule that pervaded patients' everyday lives. As the patients in our study put their ordinary lives on hold to cope with the treatment schedule, they were subject to both the authority of the institution and treatment schedule, and exposed to institutional vulnerability (Koffmann et al., 2009). Patients had no option but to follow the treatment schedule, which meant their ordinary lives took a secondary

position. Patients were subjected to experts' authority and the demands of the treatment schedule, and had to follow the recommended plan. In addition, our study demonstrated that patients considered health professionals experts and acknowledged their professional authority. Patients had difficulties in handling the physical and emotional strain caused by the treatment and its interruptions to everyday life. Thus, these circumstances challenged the patient's integrity, as treatment more or less invaded their everyday lives, leading to distress and anxiety. To navigate this institutional vulnerability, patients remained on guard to control potential time delays and handle the threat and uncertainty caused by the illness and associated treatment.

Patients' vulnerability in the decision-making was related to their autonomy in decisions. As mentioned, the patients in our study did not feel ownership over decisions regarding acceptance of the treatment package, but wanted to participate in decisions that directly affected their home domains. This condition—a lack of control in maintaining a secure base one can call home, coupled with a lack of opportunity to exercise autonomy—is referred to as ontological security (Giddens, 1991). When patients were not invited to participate in decisions directly affecting their home domain, they felt vulnerable because of the loss of their autonomy, which damaged their sense of control. Again, vulnerability here seems to have both etic and emic aspects, as patients were subjected to the authority of health professionals and demands of the treatment regimen, leaving them feeling merely “done to,” and contributing to a loss of perspective as they struggled to remain active and contribute to their own treatment alongside health professionals. These circumstances can harm patients' integrity if they feel their perspective is not being included in treatment decisions.

This study demonstrated that patients needed an ongoing dialogue with health professionals to prevent anxiety and fear, and desired widespread treatment information to help them establish an overview of the treatment and its consequences. Other studies also found that patients want detailed information and that it is important to tailor information to the individual patient's needs (Blazeby et al., 2015; Henselmans et al., 2012; McNair et al., 2016). However, the timing of support can be difficult, as patients have individual needs. Our study emphasizes that patients with EC are vulnerable and experience the course of treatment as demanding, and as a challenge to their integrity. This emphasizes the need for a proactive support-care program to physically and psychologically address patients' vulnerability and prepare them for treatment and recovery.

In our study, 14 of the 16 participants were men. We thus consider how men manage the EC illness and treatment. Identity as a man and the masculine idea of autonomy, activity, strength, and problem-solving can be a concern and challenge to men in their adaption to illness and treatment (Wenger & Oliffe, 2014). The findings in our study, on integrity, desire for autonomy and viewing the meal as a

battleground could reflect masculine identity and how men respond to the challenges of a functionally limited body during treatment. Men can also be viewed as especially vulnerable because they understand their cancer experience through physical changes and their ability to do what they used to do (Kelly, 2009).

A systematic approach is needed to establish an ongoing dialogue between health professionals and patients with EC and their families throughout the course of treatment and in patients' rehabilitation after the treatment. Having an in-depth understanding of patients' vulnerability during the course of the illness and treatment for EC is important, as EC can cause distress and anxiety and lead to self-isolation. Specifically, it could help in formulating strategies for sharing information and addressing patients' vulnerability throughout treatment. Vulnerability should not be seen as static, but a dynamic state. Individualized follow-up programs during treatment might be a platform to address the needs of individual patients.

## Methodological Considerations

Because M.K.L. conducted all interviews and observations, it was especially important to ensure rigor and validity in the analysis. The analysis and findings were discussed in close collaboration with the other authors. This was insured from the beginning of data analysis and interpretation, and was an ongoing process throughout the study. Combining participant observations and interviews generated in-depth knowledge from data and improved a comprehensive understanding of the investigated phenomenon (Carter et al., 2014; Simony et al., 2018). The field study provided the interviews with context and facilitated ongoing interpretation, which was further explored in the interviews. Moreover, participant observations provided a unique opportunity to observe how patients were invited to participate in decisions regarding treatment, and to observe whether the need for participation evolved during the treatment period. The use of Spradley's observation tool, which guided a systematic focus on the observed situations, ensured the trustworthiness of the observations throughout the study (Spradley, 2006).

As mentioned, patients with EC are  $\geq 60$  years and mostly men, which may have impacted their experiences with decisions and how they reacted to the authority of the institution and treatment schedule. Possibly, younger people would ask to participate in decisions in a different way. In addition, the role of masculinity and men might influence the attitude toward meals and is reflected in the theme meals as a battleground.

A strength of this study is the combination of participant observations with in-depth interviews, which provides rich empirical material and a comprehensive understanding of patients' experiences and how they view their participation in decisions (Malterud, 2001; Simony et al., 2018). This provided a detailed picture of patients' experiences and

understanding of their participation in decision-making, gave the opportunity for patients to reflect about shared situations, and promoted a climate of confidence and trust between the researcher and the patients providing in-depth insight in the studied field. The presence of the researcher will always affect the topic under study (Malterud, 2001; Spradley, 2006), and may have influenced the process of treatment decisions.

The study was conducted in a public health-care setting in Denmark, which may limit its transferability to other countries with different health care environments. Furthermore, the patients were recruited from a single hospital in Denmark, which may reflect local factors and conditions. However, no patient asked to participate declined, which assisted in gathering rich descriptions and illustrating diverse aspects on the continuum of participation in decisions, thus promoting a high degree of information power (Malterud et al., 2015). A subsequent study following patients in their further rehabilitation and follow-up might be useful in adding further insights into long-term experiences and possible late complications that influence their lives and vulnerability.

## Conclusion

Patients with EC experience the course of the illness and treatment as a demanding process that requires them to put their ordinary lives on hold. Patients were in a vulnerable position as they struggled with difficulties related to eating and fatigue, and were mentally and physically exhausted. Patients were subject to the authority of the institution and demands of the treatment schedule, which challenged their integrity and active participation in treatment decisions. However, regarding decisions directly affecting their everyday lives, they expect active participation. Our results suggest a need for health professionals to establish an ongoing dialogue with the patients about their experiences during treatment and to assess their perceived vulnerability. Practically, this means establishing strategies to ensure information sharing so that patients' vulnerability is addressed throughout the treatment pathway.

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## References

- Andreassen, S., Randers, I., Naslund, E., Stockeld, D., & Mattiasson, A. C. (2006). Patients' experiences of living with oesophageal cancer. *Journal of Clinical Nursing, 15*(6), 685–695. <https://doi.org/10.1111/j.1365-2702.2006.01412.x>
- Andreassen, S., Randers, I., Ternulf Nyhlin, K., & Mattiasson, A. C. (2007). A meta-analysis of qualitative studies on living with oesophageal and clinically similar forms of cancer, seen from the perspective of patients and family members. *International Journal of Qualitative Studies on Health and Well-Being, 2*(2), 114–127. <https://doi.org/10.1080/17482620701305589>
- Blazeby, J. M., Macefield, R., Blencowe, N. S., Jacobs, M., McNair, A. G. K., Sprangers, M., . . . Brookes, S. T. (2015). Core information set for oesophageal cancer surgery. *British Journal of Surgery, 102*, 936–943.
- Bollschweiler, E., Plum, P., Monig, S. P., & Holscher, A. H. (2017). Current and future treatment options for esophageal cancer in the elderly. *Expert Opinion on Pharmacotherapy, 18*(10), 1001–1010. <https://doi.org/10.1080/14656566.2017.1334764>
- Bull, J., Oster, C., Flight, I., Wilson, C., Koczwara, B., Watson, D. I., & Bright, T. (2019). The role of rehabilitation in patients undergoing oesophagectomy for cancer and pre-malignant disease: A qualitative exploration of the views of patients, carers and healthcare providers. *European Journal of Cancer Care, 28*(2), Article e12996. <https://doi.org/10.1111/ecc.12996>
- Carey, S., Laws, R., Ferrie, S., Young, J., & Allman-Farinelli, M. (2013). Struggling with food and eating—Life after major upper gastrointestinal surgery. *Supportive Care in Cancer, 21*(10), 2749–2757. <https://doi.org/10.1007/s00520-013-1858-8>
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum, 41*(5), 545–547. <https://doi.org/10.1188/14.onf.545-547>
- Clarke, C., McCorry, N. K., & Dempster, M. (2011). The role of identity in adjustment among survivors of oesophageal cancer. *Journal of Health Psychology, 16*(1), 99–108. <https://doi.org/10.1177/1359105310368448>
- Coulter, A. (2011). *Engaging patients in healthcare*. Open University Press.
- Danish Esophagus, Gastroesophageal Junction and Gastric Cancer Group (DECV). Annual Report. (2016). Department of Epidemiology and Biostatistics, Regional Clinical Quality Development Program RKKP; 2016 Available at: [http://decv.gicancer.dk/Content/Files/Dokumenter/DECV\\_rapport\\_2016\\_til%20regionerne.pdf](http://decv.gicancer.dk/Content/Files/Dokumenter/DECV_rapport_2016_til%20regionerne.pdf)
- Dempster, M., McCorry, N. K., Brennan, E., Donnelly, M., Murray, L. J., & Johnston, B. T. (2011). Psychological distress among family carers of oesophageal cancer survivors: The role of illness cognitions and coping. *Psycho-Oncology, 20*(7), 698–705. <https://doi.org/10.1002/pon.1760>
- Dreyer, P. S., & Pedersen, B. D. (2010). Distanciation [sic] in Ricoeur's theory of interpretation: Narrations in a study of life experiences of living with chronic illness and home mechanical ventilation. *Nordic Nursing Research/Tidskrift for Sygeplejeforskning, 26*(2–3), 60–68. <http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=104955499&site=ehost-live>
- Emerson, R., Fretz, R. I., & Shaw, L. L. (2011). *Writing ethnographic fieldnotes* (2nd ed.). The University of Chicago Press.
- Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Polity.
- Ginex, P., Thom, B., Jingeleski, M., Vincent, A., Plourde, G., Rizk, N., . . . Bains, M. (2013). Patterns of symptoms following surgery for esophageal cancer. *Oncology Nursing Forum, 40*(3), E101–E107. <https://doi.org/10.1188/13.onf.e101-e107>
- Graham-Wisener, L., Hanna, J., Collins, L., & Dempster, M. (2019). Psychological adjustment in patients post-curative treatment for oesophageal cancer: A longitudinal interview study. *Psychology & Health, 34*(8), 901–921. <https://doi.org/10.1080/08870446.2019.1579910>
- Heaslip, V., Hean, S., & Parker, J. (2016). The etemic model of Gypsy Roma Traveller community vulnerability: Is it time to rethink our understanding of vulnerability? *Journal of Clinical Nursing, 27*, 3426–3435.
- Hellstadius, Y., Lagergren, J., Zylstra, J., Gossage, J., Davies, A., Hultman, C. M., . . . Wikman, A. (2017). A longitudinal assessment of psychological distress after oesophageal cancer surgery. *Acta Oncologica, 56*(5), 746–752.
- Hellstadius, Y., Malmstrom, M., Lagergren, P., Sundbom, M., & Wikman, A. (2019). Reflecting a crisis reaction: Narratives from patients with oesophageal cancer about the first 6 months after diagnosis and surgery. *Nursing Open, 6*(4), 1471–1480. <https://doi.org/10.1002/nop2.348>
- Henselmans, I., Jacobs, M., van Berge Henegouwen, M. I., de Haes, H. C., Sprangers, M. A., & Smets, E. M. (2012). Postoperative information needs and communication barriers of esophageal cancer patients. *Patient Education and Counseling, 88*(1), 138–146. <https://doi.org/10.1016/j.pec.2011.12.004>
- Kelly, D. (2009). Changed men: The embodied impact of prostate cancer. *Qualitative Health Research, 19*(2), 151–163. <https://doi.org/10.1177/1049732308328067>
- Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing, 69*(1), 4–15. <https://doi.org/10.1111/j.1365-2648.2012.06064.x>
- Koffmann, J. M. P., Edmonds, P., & Higginson, J. (2009). Vulnerability in palliative care research: Findings from a qualitative study of black Caribbean and white British patients with advanced cancer. *Journal of Medical Ethics, 35*, 440–444.
- Kvale, S., & Brinkmann, S. (2014). *Interviews: Learning the craft of qualitative research interviewing* (3rd ed.). SAGE.
- Lagergren, J., Smyth, E., Cunningham, D., & Lagergren, P. (2017). Oesophageal cancer. *The Lancet, 390*(10110), 2383–2396. [https://doi.org/10.1016/s0140-6736\(17\)31462-9](https://doi.org/10.1016/s0140-6736(17)31462-9)
- Larsen, M. K., Shults, H., Mortensen, M. B., & Birkelund, R. (2019). Encountering an alien world of disease and treatment. A qualitative study on oesophageal cancer patients' experiences before start of treatment and the process of participation in treatment decisions. *European Journal for Person Centered Healthcare, 7*(3), 518–529.
- Lewis, L., Marcu, A., Whitaker, K., & Maguire, R. (2018). Patient factors influencing symptom appraisal and subsequent adjustment to oesophageal cancer: A qualitative interview study. *European Journal of Cancer Care, 27*(1). <https://doi.org/10.1111/ecc.12745>
- Malmstrom, M., Ivarsson, B., Johansson, J., & Klefsgard, R. (2013). Long-term experiences after oesophagectomy/

- gastrectomy for cancer—A focus group study. *International Journal of Nursing Studies*, 50(1), 44–52. <https://doi.org/10.1016/j.ijnurstu.2012.08.011>
- Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *The Lancet*, 358(9280), 483–488. [https://doi.org/10.1016/s0140-6736\(01\)05627-6](https://doi.org/10.1016/s0140-6736(01)05627-6)
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2015). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>
- Mansour, N. M., Groth, S. S., & Anandasabapathy, S. (2017). Esophageal adenocarcinoma: Screening, surveillance, and management. *Annual Review of Medicine*, 68, 213–227. <https://doi.org/10.1146/annurev-med-050715-104218>
- McCorry, N. K., Dempster, M., Clarke, C., & Doyle, R. (2009). Adjusting to life after esophagectomy: The experience of survivors and carers. *Qualitative Health Research*, 19(10), 1485–1494. <https://doi.org/10.1177/1049732309348366>
- McNair, A. G. K., MacKichan, F., Donovan, J. L., Brookes, S. T., Avery, K. N. L., Griffin, S. M., . . . Blazeby, J. M. (2016). What surgeons tell patients and what patients want to know before major cancer surgery: A qualitative study. *BMC Cancer*, 16, Article 258. <https://doi.org/10.1186/s12885-016-2292-3>
- Morse, J. M., & Coulehan, J. (2014). Maintaining confidentiality in qualitative publications. *Qualitative Health Research*, 25(2), 151–152. <https://doi.org/10.1177/1049732314563489>
- Pedersen, B. D. (2005). *Sygeplejepraksis. Sprog & Erkendelse [Nursing practice. language and cognition]* (3rd ed.) [Doctoral thesis]. University of Aarhus. (Original work published 1999)
- Ricoeur, P. (1976). *Interpretation theory. Discourse and the surplus of meaning*. TCU Press.
- Ricoeur, P. (1984). *Time and narrative*. Chicago University Press.
- Simony, C., Specht, K., Andersen, I. C., Johansen, K. K., Nielsen, C., & Agerskov, H. (2018). A Ricoeur-inspired approach to interpret participant observations and interviews. *Global Qualitative Nursing Research*, 5, 2333393618807395. <https://doi.org/10.1177/2333393618807395>
- Sjoquist, K. M., Burmeister, B. H., Smithers, B. M., Zalcberg, J. R., Simes, R. J., Barbour, A., & Gebski, V. (2011). Survival after neoadjuvant chemotherapy or chemoradiotherapy for resectable oesophageal carcinoma: An updated meta-analysis. *Lancet Oncology*, 12(7), 681–692. [https://doi.org/10.1016/s1470-2045\(11\)70142-5](https://doi.org/10.1016/s1470-2045(11)70142-5)
- Spiers, J. (2000). New perspectives on vulnerability using emic and etic approaches. *Journal of Advanced Nursing*, 31(3), 715–721.
- Spradley, J. P. (1979). *The ethnographic interview*. Wadsworth Group/Thomson Learning.
- Spradley, J. P. (2006). *Participant observation* (New print ed.). Wadsworth.
- Viklund, P., Wengstrom, Y., Rouvelas, I., Lindblad, M., & Lagergren, J. (2006). Quality of life and persisting symptoms after oesophageal cancer surgery. *European Journal of Cancer*, 42(10), 1407–1414. <https://doi.org/10.1016/j.ejca.2006.02.005>
- Wainwright, D., Donovan, J. L., Kavadas, V., Cramer, H., & Blazeby, J. M. (2007). Remapping the body: Learning to eat again after surgery for esophageal cancer. *Qualitative Health Research*, 17(6), 759–771. <https://doi.org/10.1177/1049732307302021>
- Wenger, L. M., & Oliffe, J. L. (2014). Men managing cancer: A gender analysis. *Sociology of Health and Illness*, 36(1), 108–122. <https://doi.org/10.1111/1467-9566.12045>
- World Medical Association. (2013). World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects. *JAMA: The Journal of the American Medical Association*, 310(20), 2191–2194.

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