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# **Patients' experiences of supportive care from a long-term perspective after oesophageal cancer surgery**

-A focus group study

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## **ABSTRACT**

After oesophageal cancer surgery QOL is severely reduced for a long time. Even though this is a well-documented fact no previous studies have focused on the patients' experiences of supportive care after surgery.

**Purpose:** To illuminate patients' experiences of supportive care from a long-term perspective after oesophagectomy or oesofagogastrectomy for cancer.

**Method:** Data collection was carried out using semi-structured focus-group interviews. Seventeen patients were included in the study, divided into 4 focus groups. Data was analysed with conventional qualitative content analysis.

**Results:** The patients' experiences of supportive care were captured in the theme "*The need for a guiding light in the new life situation*" and it was shown that support from the health care system as well as from the social network was experienced as important. The patients need support that starts at the hospital and that continues throughout the transition to out-patient care. This support should focus on developing a plan for the future and on providing the patients with information that will enable them to understand their new life situation.

**Conclusion:** The findings indicated that the patients need a plan for the future, help in navigating the healthcare system and the provision of clear and honest information as well as a healthcare system that better overarches the gap between in and out-patient care. This suggests the need of developing and testing a supportive care programme that is designed according to the patients' needs and with focus on the potential to enhance the patients QOL after this life-changing surgery.

**Key words:** Cancer, information, long-term follow-up, oesophagectomy, oesophagogastrectomy, support, supportive care.

## INTRODUCTION

It is a well-known fact that patients, after undergoing surgery for oesophageal cancer, suffer from several problems that affect most aspects of quality of life (QOL) for a long time (Djarv et al., 2008; Lagergren et al., 2007; Olsson et al., 2007; Viklund et al., 2006a). It is also known that the patients experience the new life situation as a struggle and that the remaining symptoms hinder them from feeling in control of their lives (Malmström et al., 2013). In spite of this awareness that the patients life is hampered by several ailments after surgery (Djarv et al., 2008; Lagergren et al., 2007; Malmström et al., 2013; Verschuur et al., 2006; Viklund et al., 2006a) there is still a lack of research focusing on their experiences of supportive care. In order to meet the patient's specific needs after this life-changing surgery a greater understanding of their experiences is essential.

Oesophageal cancer is the 8<sup>th</sup> most common cancer diagnosis in the world (Ferlay et al., 2010) and during 2010 there were 593 new cases (including cardia) reported in Sweden (National Board of Health and Welfare, 2012). After diagnosis the only established treatment for cure is surgery alone or in combination with chemotherapy or radiotherapy (Wu and Posner, 2003). Even though survival after surgery has gradually improved, the 5-year survival rate remains at only 28-31% (Anderson et al., 2011, Rouvelas et al., 2005). After surgery the patients suffer from problems with e.g. eating, appetite loss, fatigue and diarrhea (Lagergren et al., 2007; Olsson et al., 2002; Verschuur et al., 2006; Viklund et al., 2006a) resulting in a reduced QOL for a substantial time (Djarv et al., 2008; Lagergren et al., 2007; Olsson et al., 2007; Viklund et al., 2006a). It has also been shown that some patients feel depressed, lonely and abandoned and experience that the life have changed negatively due to remaining problems after surgery (Malmström et al., 2013; Olsson et al., 2002) facts that motivate the need of supportive care for these patients.

To be able to address the patients' needs after surgery a greater understanding of their experiences of supportive care is needed. Today there is no generally accepted definition of supportive care. However, it is stated that the concept is concerned with the optimal wellbeing of patients with cancer (Stiefel and Guex, 1996). The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS, 2002) define supportive care as care that 'helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment'. Helgerson and Cohen (1996) describe three broad types of support: emotional, informational and instrumental, the first two of which often are included in the concept of supportive care. Instrumental support, is concerned with practical issues and includes aspects such as finance/economy. To be able to address the patients' supportive care needs from a broad perspective the instrumental support is included into the concept of supportive care in the present study.

Meeting patient's needs after this extensive surgery is a complex task for the healthcare professionals (HCP) and it is realistic to state that the need of supportive care is extensively based on a poor prognosis (Anderson et al., 2011) reduced QOL (Blazeby et al., 2000; Djarv et al., 2008; Lagergren et al., 2007; Olsson et al., 2007; Viklund et al., 2006a) and the fact that the new life situation is affected both from a physical and psychological/emotional perspective (Clarke et al., 2011; Malmström et al., 2013; McCorry et al., 2009; Olsson et al., 2002; Wainwright et al., 2007; Watt and Whyte, 2003). Gender, emotional functioning (Ernstmann et al., 2009), age and time since diagnosis (Sanson-Fisher et al., 2000) are factors that earlier have been associated with enhanced psychosocial or supportive care needs for

patients with cancer. However, factors or characteristics that may impact the need of supportive care within this patient group needs to be further explored. Nurse-led models of supportive care have been shown within other cancer settings, to have the potential to reduce unmet supportive care needs, improve continuity of care and improve health-related quality of life of patients with cancer (Howell et al., 2008). Within this patient group there are studies concerning supportive care programmes and nurse-led follow-up focusing on the role of a special nurse (Viklund et al., 2006b) or the effect on quality of life and costs (Verschuur et al., 2009). However, there is still a lack of studies focusing on patients' experiences of supportive care that would be needed to be able to develop a supportive care programme that is designed after the patients' specific needs.

## **AIM**

The aim of the study was to illuminate patients' experiences of supportive care from a long term-perspective after oesophagectomy or oesophagogastrectomy for cancer.

## **METHOD**

### **Context**

Due to centralization and the complexity of the surgery, oesophagectomy and oesophagogastrectomy procedures for cancer are carried out at a limited number of university hospitals in Sweden. After surgery the median length of stay at the hospital is 21 days and after discharge clinical follow-ups with a physician are maintained for about two years.

During the follow-up time the patients are able to contact a clinical nurse specialist specialized in the patient's conditions, at the open-care clinic if needed. Thereafter, the patients are referred back to the primary care physicians and the municipal nurses without any

further follow-up at the department of surgery. At the time of the interviews, none of the authors were involved in the care of the patients included in the study.

### **Design**

This study had an explorative design. To be able to illuminate the patients' experiences from different perspectives, focus-group interviews were used as data collection method. Based on the study aim a conventional qualitative content analysis (Hsieh and Shannon, 2005) was chosen as a suitable method of analysis. Conventional qualitative content analysis is used to interpret the content of the data through a systematic process and aims to describe the patients' experiences from different perspectives. The method is often used when the research literature in the area is limited (Hsieh and Shannon, 2005).

### **Participants**

The former patients (hereafter referred to as patients) were identified by the first author (MM) in 2009 (January to April) using a database for oesophageal cancer at a University Hospital in southern Sweden. Patients that two to five years earlier had been through elective surgery for oesophageal (oesophagectomy) or cardia cancer (oesophagogastrectomy), had the ability to communicate in Swedish and place of residence in southern Sweden were included in the study. Patients that went through an acute surgery, had cognitive impairment or suffered relapse of the cancer disease were not asked to participate. In this study cardia cancer is included in the concept of oesophageal cancer based on the TNM classification system (AJCC, 2010).

All patients that was eligible for the study (N=27) were sent an information letter, and an informed consent form to sign. One week later the first author (MM) phoned the patients to

give further information about the study, and asked if they were willing to participate. Patients that decided to participate were asked to sign and return the consent form. Of the twenty-seven eligible patients, nine declined participation due to illness and one failed to come to the interview. A total of 17 patients were included in the study (table 1). The time between the first phone contact and the interviews varied between 3-9 weeks.

Table 1: Demographic characteristics of the patients (N=17)

	Gender		Age		Living alone		Working		Years since surgery		Surgery	
	Man	Woman	Median	Range	Yes	No	Yes	No	Median	Range	ES <sup>A</sup>	EGS <sup>B</sup>
	Interview 1 (n=5)	4	1	70	46-77	1	4	1	4	4	2-5	3
Interview 2 (n=4)	4	0	64	52-87	1	3	1	3	3	2-4	1	3
Interview 3 (n=5)	4	1	60	49-74	1	4	3	2	2	2-4	4	1
Interview 4 (n=3)	2	1	62	58-89	2	1	1	2	3	3	3	0

<sup>A</sup> ES: Oesophagectomy

<sup>B</sup> EGS: Oesofagogastrectomy

## Data collection

Four focus group interviews with between three and five respondents in each group were conducted during data collection. The interviews focused on the patients' experiences during the whole recovery period and were conducted 2-5 years after elective surgery. The interviews lasted between 110 and 135 minutes and were carried out in a separate room in the hospital library. When planning the interviews, variations in sex, age and type of surgery were taken into account but the patients had the opportunity to wish which interview occasion they preferred to attend.

The first and the last author conducted all interviews. The first author (MM) moderated the interviews with focus on helping the respondents to focus on the topic (Krueger and Casey, 2009) while the last author (BI) assisted by asking probing questions and keeping notes



during the process. The interviews focused on two different areas; patients' experiences of quality of life, reported in a separate article (Malmström et al., 2013), and patients' experiences and need of supportive care which is addressed in this study. As support, an interview guide helping to focus on the different areas of supportive care was used. The interviews started with an open question: *When you look back at the time since your operation, how would you describe 1, the support and 2, your support needs?* The first interview was conducted as a test interview, but since no subsequent changes were made after the initial analysis of that interview it was included in the study. After the third interview the researchers experienced that no new information emerged. In order to confirm that no further information would appear a fourth interview was conducted and confirmed data saturation.

### **Data analysis**

The interviews were recorded as a data file and transcribed verbatim. Data were analysed by means of a conventional qualitative content analysis (Hsieh and Shannon, 2005). The two authors that conducted the interviews (MM, BI) analysed all interviews together with a co-examiner (RK) that had not been involved during the focus group interviews. All authors analysed the interviews individually and then came together to discuss the analysis. Each author had considerable experience in caring for patients with cancer and the chosen research method. The analysis started with reading the text repeatedly as a whole to get an overall understanding. Thereafter, the text was read again, word for word, with a focus on identifying codes that captured key concepts and thoughts. As the analysis proceeded, labels for codes emerged that were reflective of more than one key word and together the codes resulted in the initial coding scheme. In the next step the codes were sorted into categories and sub-categories. During analysis similarities and differences in rating were discussed. In the final

step, a consensus was reached by all authors and resulted in one theme and two categories with sub-categories (table 2).

Table 2: Theme and categories.

Theme	
<b>THE NEED FOR A GUIDING LIGHT IN THE NEW LIFE SITUATION</b>	
<i>Categories</i>	
<b>1 Hospital-based support</b>	<b>2 Support in daily life</b>
1.1 The importance of planning for the future	2.1 The importance of support from one's social network
1.2 The need of support in a complex healthcare system	2.2 The need of support for dealing with the demands of society
1.3 Information: a prerequisite for realistic expectations	2.3 Peer-support from other patients, two sides of the same coin
1.4 Being transferred from specialist care to general care	

### **Ethical considerations**

The study was conducted in accordance with the Helsinki Declaration (WMA, 2008) and was approved by the Regional Ethics Board, Lund, Sweden (Dnr 2009/117). All patients received both written and oral information prior to the study. They were informed that they could withdraw from the study at any time without any explanation and that data was kept confidential. The patients had the opportunity to meet a social worker if a need would arise after the interviews, but no one felt the need for such a contact.

## **RESULTS**

### **THE NEED FOR A GUIDING LIGHT IN THE NEW LIFE SITUATION**

The new life situation after oesophageal cancer surgery is experienced as unknown and frightening for several different reasons. The patients described that they would leave a safe hospital environment where all HCP knew about their disease and their individual disease

history, and move into an unknown future where they felt alone and lost. The need for a guiding light throughout the recovery period and after discharge in the form of support both from the healthcare society and the patient's social network is highlighted.

## **1. Hospital-based support**

### **1.1 The importance of planning for the future**

Having a plan for the future was shown to be vital for the patients and the importance of following the plan after discharge was highlighted. Information regarding the care at the hospital was experienced satisfactory by most of the patients while the information concerning the plan for the future was experienced insufficient. Even though most patients stressed the importance of having a plan for the future some patients left all planning to the HCP and felt secure knowing that someone else had control of their follow-up. A meeting with the surgeon and a nurse at the hospital before discharge to be able to discuss plans for the future, what to expect with regard to recovery and where to turn to for help was suggested by several patients. These patients experienced that the lack of such a meeting resulted in insecurity about the future and a feeling of being out of control. The insecurity of not knowing if and when they should meet the surgeon or the clinical nurse specialist during the follow-up engendered a feeling of being alone without knowing if they were recovering as expected. After discharge the follow-up meetings were described as occasions on which the patients had the possibility of asking questions and confirming that they were recovering as expected. The patients' expectations before the follow-up meetings differed. Some patients felt that they went to the meeting to confirm that they were on the right track regarding recovery while others were concerned about what the surgeon would say and always expected the worst.

*Up until then (discharge) we'd received all the information we needed. But afterwards... I thought of it today, when am I going to the doctor the next time? They told me it was the last time... what did they mean by that? (No. 2)*

## **1.2 The need of support in a complex healthcare system**

Most patients experienced that they had a hard time navigating through the big and complex healthcare system after discharge and the distinction between different sources of caregivers was experienced as impossible to understand. Lack of understanding of the system engendered a feeling of being alone and many patients described that they did not know what responsibility the different caregivers had and who they should contact if they needed help.

*There's no-one who gets in touch with me from healthcare now. And then, when I phone they say that: You can't be under our care any longer; you have to be well now. You'll have to phone another doctor. What do they mean, "...phone another doctor"? Who'm I supposed to phone? (No. 3)*

The patients had a contact person at the open care clinic (clinical nurse specialist) whom they could contact for help after discharge. This contact was experienced as important for the patients and some of them stated that knowing who to turn to for help was enough to feel secure after discharge while other patients expressed that they would like to have a more active follow-up. It was proposed that one way of intensifying the contacts was by having regular telephone contacts with the clinical nurse specialist so that they could ask questions and detect possible deviations from normal recovery at an early stage, thus not leaving them with all the responsibility.

*She's a clinical nurse specialist; she takes care of everyone. It was to her I phoned on the Friday. The doctor wasn't there, she said, but he would be coming on the Monday. "So I'll speak to him and then we'll get in touch with you." She phoned on Tuesday morning and said that I could come the next day. (No.1)*

### **1.3 Information: a prerequisite for realistic expectations**

Expectations about recovery after surgery were generally based on the information that the patients received during their stay at the hospital. However, for most of the patients, the expectations that they had were not experienced as matching the reality after discharge.

Knowing what to expect after discharge regardless of whether it was good or bad was expressed as being important and the lack of honest and clear information resulted in many patients misinterpreting signs that were connected with the disease. These misinterpretations resulted in situations in which normal postoperative symptoms were interpreted as signs of recurrence of the actual cancer disease rather than as normal postoperative symptoms. The importance of honest information about e.g. self care were, for most patients, fundamental but there were some patients that felt that the truth could be terrifying and therefore did not want all information. However, all patients expressed that they needed information about how to manage their health in terms of knowing what is normal and what is not normal and how to prevent and self-manage symptoms if they emerged.

Knowledge about how long time the recovery period was expected to take was important for the patients and most of them experienced that the information that they were given was too positive. The lack of accurate knowledge engendered a feeling of failure since several patients thought that they were not following the expected developments after surgery. The majority of the patients felt strongly about wanting to know more about the prognosis, side-effects and

risks of getting a relapse of the cancer disease and only a few felt that they preferred not to know.

*One thing that I miss especially is this: What's the prognosis? Will I be around in five years' time, or three years or will I just kick the bucket? I'm not afraid of that // dying. It's just, I wonder about the future, I mean I've got kids and all... (No. 1)*

#### **1.4 Being transferred from specialist care to general care**

Apart from the medical follow-ups and the contacts with the clinical nurse specialist at the hospital, all nursing interventions were performed by the municipal nurse and nurse assistants after discharge. This change - from having a nurse who was specialized in their condition performing all the nursing interventions to having a person that had a limited knowledge about their condition - was a big concern for the patients since most of them did not fully trust the knowledge of municipal nurses. Even though some patients experienced that they were given good and valuable support by the municipal nurses the majority experienced that their condition was so complex that it required specialist trained nurses to perform the care. A concern for most patients was that the organisation around the municipal nurses was unclear and lacked continuity. This lack of transparency of the organisation resulted in that many patients felt insecure and some were even readmitted to the hospital in order to be able to get the help that they needed. For those patients that had had contact with the municipal nurses before the surgery the problem with the unclear organisation was not that troubling since they had a better understanding of the organisation based on earlier experiences.

*They [the municipal nurses] didn't really know what it was all about, many of them felt insecure. Maybe someone came who'd seen this sort of thing before and knew exactly what to*

*do but then the next day someone else would come. I think they came about five times and it was a different person every time. So, I thought on the Sunday evening, no, now I've had enough. They can't come anymore. (No. 2)*

Many patients experienced that the distinction between when to turn to which healthcare facility was unclear and when problems arose after discharge the patients did not know if they were supposed to contact the surgeon or the primary care physician. Most patients preferred to turn to the surgeons at the hospital for help since they are the experts in the area but there were some patients who decided to contact their primary care physician while they had a relation with that person since before the cancer diagnosis. The lack of knowledge about who to turn to resulted for some of the patients in delays because they did not want to disturb someone or risk contacting the wrong person.

*General physicians in healthcare, they're supposed to know about everything, but they're not specialists. Maybe they can't intervene in cases like yours and mine. They listen and all and maybe give you a certification of illness or something. But they can't help you in the way that specialists can. (No. 3)*

## **2. Support in daily life**

### **2.1 The importance of support from one's social network**

After surgery, support and understanding from one's social network, including relatives, friends and colleagues, was experienced as being important. After discharge, life was hampered by remaining symptoms and having to learn to live with the symptoms was a challenge for the patients in which they needed support. Most patients stated that they wanted their relatives to be involved and informed about their condition since that resulted in a

feeling of not being alone with the whole burden and enabled their relatives to support them in an appropriate way. However, there were also a few patients that did not want to involve their relatives because they were worried about how they would manage the information. Retrospectively, most patients wanted to involve their relatives in their care even more. However, the initiative to involve them was often made by the patients themselves without encouragement by of the HCP.

*I had my wife with me from beginning to end. Every single visit to the doctor, everything. Very good I advise everyone to do the same because she gets to know exactly the same things as I do. I don't make anything look better than it is for her. I can't do anything. She's heard the same things as I have, and that feels good. (No. 3)*

Energy and support was gathered from different sources and patients expressed that they received support when, for example, they attended social activities or religious gatherings. For many patients it was important that support was not only gained when talking about the disease itself or discussing disease-related issues. Being in a supportive environment where everyone knew about your condition without your having to talk about it was appreciated. Even though the support from the social network was important after surgery some patients experienced that the network of friends shrank successively, both due to their own lack of energy to maintain the contacts and to the fact that the social network began to evade contact because of the illness. For these patients the lack of support from their social network was experienced as a grief. There were also patients that experienced that the support from their social network was intensified after surgery and that people around them cared for them and their family even more.



*But there's one thing that I find enormously irritating and that is that previous friends // who I used to hang out with before the sickness. I haven't heard from them the last three years, that's irritating (No. 4).*

## **2.2 The need of support for dealing with the demands of society**

The value that the patients put into their work and the contacts with colleagues varied. Some patients experienced that going back to work was important both for the “normality” of it and for regaining the social contact they had missed. Other patients experienced work as a threat that demanded them to perform tasks that they were not sure that they would be able to handle. Regardless of however work was perceived as something positive or as a threat, thinking about work engendering ambiguous feelings. It was stated by several patients that they would have needed more information about their ability to go back to work after surgery so that they would know what was expected of them.

The long-lasting negative effects that were the result of the disease and the surgery led to contacts with the social insurance office. Many patients experienced that they needed to convince them about their disease and their inability to work, and that they were not always believed. This lack of understanding engendered anxiety about the future for most patients and some of them were seriously concerned about how they would manage their economy if they would not receive financial support. The contacts with the social insurance office were experienced as being energy-consuming and most patients felt the need for support from the healthcare system when it came to these contacts.

*It's a slap in the face for someone who's sick. It's not only that you're sick; the sicker you are the more rotten it is. So, it's not only the sickness that you need to have treated but you also*

*have to be on the alert about what's going to happen. It means that a person who's sick hardly gets better psychologically of something like that, rather that they [the social insurance office] add to the psychological thing you're already carrying around when it comes to cancer, relapse and all that. (No. 3)*

### **2.3 Peer-support from other patients, two sides of the same coin**

Many patients experienced a lack of opportunities to meet patients who had been through similar surgery as them self which resulted in a feeling of being alone with the disease. When the patients attended the focus-group interview and met each other several of them felt the contact to be very beneficial. They expressed that this meeting helped them to understand that many problems and symptoms were a part of the new life situation after surgery and that they needed to learn to live with these problems. Knowing that they were not alone and listening to how other patients managed their new life situation was reinforcing and gave them new strategies for handling their problems. Even if most patients experienced an unmet need of peer-support after surgery a few patients described how contact with other patients made them feel vulnerable. The knowledge about that people around them could get a recurrence of their cancer led to a greater awareness that they themselves were subject to the same risk.

*I thought I was alone with this. When it's good to hear that there are others going through the same thing. I feel exactly the same way and then you know that you're not alone with the disease you've been through. (No. 4).*

## **DISCUSSION**

The results show that the patients' needs of supportive care are comprehensive after surgery and the theme "*The need for a guiding light in the new life situation*" was found to capture the patients' experiences. The study shows that the patients need support that begins at the hospital and that focuses on developing a plan for the future and on giving information to the patients so they will be able to understand their new life situation after surgery. The support needs to start at the hospital and continue throughout the transition to out-patient care.

### **Methodological considerations**

Trustworthiness in qualitative studies is often evaluated in terms of credibility, dependability and transferability (Graneheim and Lundman, 2004; Polit et al., 2004). In this study the patients were asked to share their experiences of supportive care after surgery from a long-term perspective. Addressing the patients' experiences and needs of supportive care from a long-term perspective can be questioned, since it can be argued that the patients' memory could have changed during the years, a fact that can affect the credibility of this study.

However, this perspective was considered to be important if one was to gain a deeper understanding of how the patients experienced the supportive care from a long-term perspective. By conducting the interviews two to five years after surgery the patients experiences of supportive care during the whole postoperative period was illuminated and not merely the experiences that was affected by the acute reaction to the cancer disease or the direct postoperative symptoms. The results showed that the patients remembered the time well after surgery which is supported by Christiansson and Loftus (1991) who conclude that persons that go through traumatic events often remember those quite well. The fact that the time between the surgery and the interviews varied (2-5 years) was perceived as being an

advantage in this study since the patients were reminded by each other's stories and therefore found it easier to narrate their own experiences.

To be able to see the patients' experiences from different perspectives, focus-group interviews were chosen as data collection method (Krueger and Casey, 2009). The method was chosen in order to give the patients the opportunity to share their experiences of supportive care with patients that had gone through similar surgery. Through this method the patients could narrate their own experiences and in the same time relate to other patients' stories (Krueger and Casey, 2009). In the focus-group interviews the patients were encouraged to share their experiences without the pressure to reach consensus (Krueger and Casey, 2009) a fact that is considered to strengthen the credibility of the study. On the one hand, focus-group interviews are often criticized for not extracting deep enough information because the space for each person's story is limited (Krueger and Casey, 2009). On the other hand, the different characteristics and experiences of the patients can result in both a broader and a deeper description of the respondent's experiences. In the present study the dynamics of the groups characterised by tolerance and the patients had time to express their experiences based on the low number of participants in each group a fact that can be considered as a strength of the study. To be able to limit the potential influence of the authors' pre-understanding, a third person that had not been involved in the interviews was involved in the analysis. This way of seeking agreement with co-authors is another way of strengthening the credibility of the study (Graneheim and Lundman, 2004).

Nine patients declined participation due to remaining surgery related problems such as fatigue and nausea or other medical problems. There is a possibility that some of these patients would have chosen to participate if the interviews would have been conducted individually. It seems

reasonable to believe that those patients' supportive care needs would be even higher than those included in this study, a fact that needs to be taken into account when considering this result. However, the advantage of using focus group interviews in this study was experienced to exceed the possible disadvantages.

Both patients that went through surgery for oesophageal and cardia cancer were included in this study. When it comes to the surgical resection and the anatomy after surgery the two cancer types differ in several ways. However, the postoperative care and the patients life situation after surgery is in many senses comparable. The design of this study was explicit to address the patients experiences and needs of supportive care by focusing on the variety of experiences rather than specific needs related to de different surgical resections.

### **Result considerations**

To be able to understand, take control and manage the new life situation after surgery the patients in this study expressed that they needed honest and realistic information. However, the patients experienced that the information they were given were too optimistic and often did not match their experiences after surgery. From a clinical perspective it is often argued that honest information can lead to a lack of belief in recovery and also that withholding honest information can be a way of protecting the patients. These arguments are not in line with the results of this study where it is clear that the patients' experience that the HCPs underestimate their information needs; a fact that has also been shown in earlier studies (Andreassen et al., 2007; Wittmann et al., 2011). It is known that the patients wish to be given information about what to expect after surgery in relation to remaining symptoms and prognosis (Malmström et al., 2013; Sainio and Eriksson, 2003) but Stajduhar et al (2010) states that it is important to balance hope and honesty in the provision of information to

patients with cancer. Lack of accurate information may be one reason why the patients in this study was found to interpreted normal symptoms during the recovery period as being signs of recurrence of the disease. The results of this study therefore suggest that it is important that the HCP focus on the patients needs of information rather than their own beliefs about what the patients' need after surgery.

The patients expressed that finding their way around the healthcare system after discharge was difficult and energy-consuming. That fact resulted in that the transition to out patient care was experienced as even more worrying. In this study, as well as in a study by Viklund et al (2006b) the importance of having a specialist nurse with supporting and coordination functions after discharge was highlighted. However, in this study it was shown that the coordination needed to extend beyond the hospital care setting and also involve the primary and municipal care. The complex need for support that includes both in and out-patient care is a challenge for the healthcare system and requires better cooperation between the hospital and municipal and primary care. This calls for a better coordination and knowledge transition between the different caregivers. One way of realizing this could be by having a consulting team from the specialised care act as support in the transition, supporting both the patients and the municipal and primary care staff.

This study shows that support from the social network is important for the patients a fact that has been shown in earlier research (Symister and Friend, 2003). Unfortunately, patients experienced that their social network became reduced after surgery and the patients experienced that this was due to their increased lack of energy to keep the contacts going and to the fact that the social network evaded contact because of the illness. Encouraging the patients to maintain social contacts can therefore be one important aspect of indirect

supportive care after surgery. Another way of providing the patients with indirect support can be to encourage them to involve a relative during the whole cancer trajectory. The patients expressed that the involvement of family members in their care was important. However, the patients experienced that the healthcare lacked in encouraging them to do so.

The findings also showed that the need for a clear and structured plan for the future is one of the most prominent support needs for these patients. The patients expressed that knowing what to expect and having enough knowledge to build realistic expectations about recovery is fundamental after surgery. These findings suggest that the challenge from a healthcare perspective is that the support will have to be changed during the whole cancer trajectory. The support needs to involve information and support within the hospital setting as well as throughout the transition to out-patient care. Today there is no research concerning patients' experiences of supportive care and supportive care needs during the follow-up after this extensive surgery. This lack of knowledge may lead to uncertainty about what the postoperative support should focus on and in which degree information and support should be given. According to Moyes et al (2010) the aim with a follow-up should be to provide support helping the patients deal with new symptoms as they arise and thereby enhancing their quality of life. In earlier studies, supportive care programmes for patients within other cancer settings has been stated to be able to enhance QOL (Howell et al., 2008; Rosenbaum et al., 2004) as well as to reduce unmet supportive care needs and improve continuity of care (Howell et al., 2008). Based on the severely reduced QOL within this patient group (Blazeby et al., 2000; Djarv et al., 2008; Lagergren et al., 2007; Olsson et al., 2007) the need for supportive care is strongly indicated. Therefore, the knowledge from this study about the patients' experiences and needs for supportive care could be important knowledge when developing a tailored supportive care programmes for these patients.

The result of this study highlights the complexity of supportive care after surgery and show that beyond emotional and informational support the patients also need support to handle the contacts with the social insurance office which was experienced as a threat to their working and financial situation. The complex supportive care needs are related to the extensive surgical intervention and remaining problems after surgery. It is realistic to consider that patients that have gone through similar surgery and that struggle with remaining symptoms could have comparable experiences. However, transferability to other contexts in qualitative studies is according to Graneheim and Lundman (2004) up to the reader to decide and therefore needs to be further researched.

In conclusion, the findings indicated that the patients need a plan for the future, help in navigating the healthcare system and the provision of clear and honest information as well as a healthcare system that better overarches the gap between in and out-patient care. The results also show that meeting the patients' needs claims a new way of approaching the follow-up after surgery. This suggests the need of developing and testing a supportive care programme that is designed according to the patients' needs and with focus on the potential to enhance the patients QOL after surgery.

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**Conflict of interest statement**

None declared

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