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PO Box 117
221 00 Lund
+46 46-222 00 00

Department of Surgery, Clinical Sciences Lund
Lund University, Sweden, 2013

Quality of Life and Supportive Care after Oesophageal Cancer Surgery

Long-term experiences and evaluation of a telephone based
nurse-led supportive care programme

Marlene Malmström



LUND
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AKADEMISK AVHANDLING

Som med vederbörligt tillstånd av Medicinska Fakulteten vid Lunds universitet för avläggande av doktorexamen i medicinsk vetenskap kommer att offentligen försvaras i aulan, Skånes universitetssjukhus i Lund torsdagen den 19 september 2013, kl 13.00.

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Professor Pernilla Lagergren
Institutionen för molekylär medicin och kirurgi
Karolinska institutet, Stockholm

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Abstract: After oesophageal cancer surgery it is known that patients have a reduced QOL and that they suffer an unmet need of support. The overall aim of this thesis was to investigate patients' experiences of QOL and supportive care as well as to evaluate a telephone based nurse-led supportive care programme to patients after oesophageal cancer surgery. The thesis comprises two quantitative (I, IV) and two qualitative studies (II, III). The aim of Study I was to evaluate changes in QOL over time as an indicator for the timing of support. The results showed that there is a significant QOL nadir at 2 months compared to 12 months after surgery. This was true for general QOL both for symptom- ($p<0.001$) and function scales ($p<0.001$) as well as for diagnose specific (oesophageal cancer) QOL symptoms ($p<0.001$). The aim of Studies II and III were to illuminate patients' experiences of their QOL (II) and of supportive care (III) from a long-term perspective after surgery. Data collection was conducted with focus group interviews and the analyses were conducted with conventional qualitative content analysis. The results of Study II show that the patients' lives are severely hampered by adverse symptoms for a long time after surgery and that the recovery period is experienced as a struggle. The main problems in the patients' new life situation are those connected with nutrition and diarrhoea that was shown not only to affect the patients from a physical perspective but also on a social and emotional level. The results from Study III showed that the patients experienced that support after surgery was fundamental for their life after surgery. However, the patients experienced that their health care system was unclear and hard to navigate in and that there was a big gap between in- and outpatient care. The support needed to include physical, psychological and social issues throughout the whole cancer trajectory. Study IV was conducted as a RCT evaluating the effect of a telephone based nurse-led supportive care programme. The results show that the intervention group was significantly more satisfied with received information for items concerning ways in which they could help themselves ($p=0.001$), written information ($p<0.001$), and for the global information score ($p=0.021$) compared to the control group. The control group scored significantly higher on the item regarding the wish to receive more information ($p<0.001$). No effect of the intervention was shown on QOL or on the number of health care contacts. In conclusion, the results of this thesis show that the patients' QOL is negatively affected after surgery (I-II) and that the patients are in a great need of supportive care to manage a life that is hampered by several remaining physical, psychological and social issues (III). The support needs to be individualised according to the patients' needs, to be introduced at an early stage after surgery (I, III) and to continue throughout the whole cancer trajectory (III). The telephone based nurse-led supportive care programme was shown to have a significant effect on the patients' experience of perceived information but no effect on QOL or health care contacts (IV).		
Key words: Experiences, Information, Intervention Long-term follow-up, Oesophageal cancer, Oesophagectomy, Oesophago-gastrectomy, Support, Supportive care, Telephone follow-up, Quality of life.		
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Quality of Life and Supportive Care after Oesophageal Cancer Surgery

Long-term experiences and evaluation of a telephone based
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ABSTRACT

After oesophageal cancer surgery it is known that patients have a reduced QOL and that they suffer an unmet need of support. The overall aim of this thesis was to investigate patients' experiences of QOL and supportive care as well as to evaluate a telephone based nurse-led supportive care programme to patients after oesophageal cancer surgery.

The thesis comprises two quantitative (**I, IV**) and two qualitative studies (**II, III**). The aim of Study **I** was to evaluate changes in QOL over time as an indicator for the timing of support. The results showed that there is a significant QOL nadir at 2 months compared to 12 months after surgery. This was true for general QOL both for symptom- ($p<0.001$) and function scales ($p<0.001$) as well as for diagnose specific (oesophageal cancer) QOL symptoms ($p<0.001$). The aim of Studies **II** and **III** were to illuminate patients' experiences of their QOL (**II**) and of supportive care (**III**) from a long-term perspective after surgery. Data collection was conducted with focus group interviews and the analyses were conducted with conventional qualitative content analysis. The results of Study **II** show that the patients' lives are severely hampered by adverse symptoms for a long time after surgery and that the recovery period is experienced as a struggle. The main problems in the patients' new life situation are those connected with nutrition and diarrhoea that was shown not only to affect the patients from a physical perspective but also from a social and emotional perspective. The results from Study **III** showed that the patients experienced that support after surgery was fundamental for their life after surgery. However, the patients experienced that their health care system was unclear and hard to navigate in and that there was a big gap between in- and outpatient care. The support needed to include physical, psychological and social issues throughout the whole cancer trajectory. Study **IV** was conducted as a RCT evaluating the effect of a telephone based nurse-led supportive care programme. The results show that the intervention group was significantly more satisfied with received information for items concerning ways in which they could help themselves ($p=0.001$), written information ($p<0.001$), and for the global information score ($p=0.021$) compared to the control group. The control group scored significantly higher on the item regarding the wish to receive more information ($p<0.001$). No effect of the intervention was shown on QOL or on the number of health care contacts.

In conclusion, the results of this thesis show that the patients' QOL is negatively affected after surgery (**I, II**) and that the patients are in a great need of supportive care to manage a life that is hampered by several remaining physical,

psychological and social issues (**III**). The support needs to be individualised according to the patients' needs, to be introduced at an early stage after surgery (**I**, **III**) and to continue throughout the whole cancer trajectory (**III**). The telephone based nurse-led supportive care programme was shown to have a significant effect on the patients' experience of perceived information but no effect on QOL or health care contacts (**IV**).

Key words: Experiences, Information, Intervention, Long-term follow-up, Oesophageal cancer, Oesophagectomy, Oesophago-gastrectomy, Support, Supportive care, Telephone follow-up, Quality of life.

ABBREVIATIONS AND DEFINITIONS

ASA	American Society of Anaesthesiologists
Clinical nurse specialist	A registered nurse with an academic specialist education in nursing (in this thesis surgical care)
Contact nurse	A registered nurse working as a contact person for a specific patient group
C15, C16.0, A, B, C Disease	Diagnose codes according to TNM7 Problems related to the biological dimensions such as alterations in the structure and function of body organs and systems that are concerned with factors such as epidemiology and treatment (Eisenberg 1977).
EORTC	European Organisation for Research and Treatment of Cancer
EORTC QLQ-C30	European Organisation for Research and Treatment of Cancer, Quality of life questionnaire-core30
EORTC QLQ-OES18	European Organisation for Research and Treatment of Cancer, QOL module for oesophageal cancer
EORTC QLQ-OG25	European Organisation for Research and Treatment of Cancer, QOL module for cancer in the oesophagus, oesophago-gastric junction and stomach.
EORTC QLQ-INFO25	European Organisation for Research and Treatment of Cancer, information questionnaire
EORTC IN-PATSAT32	European Organisation for Research and Treatment of Cancer, in hospital patient satisfaction questionnaire
HRQOL	Health Related Quality of Life
HCP	Health Care Professionals
HC	Health Care
Illness	The human experience of symptoms and suffering referring to how the disease is perceived, lived with and respond to, by the sick person and their relatives (Kleinman 1988)
PROM	Patient Reported Outcome Measurements
PREM	Patient Reported Experience Measurements
QOL	Quality of Life
TFU	Telephone Follow-Up

ORIGINAL PAPERS

This thesis is based on the following studies referred to in the text by their Roman numerals;

- I Malmström M, Klefsgård R, Ivarsson B, Roman M, Johansson J. Quality of Life measurements as an indicator for timing of support after oesophagectomy for cancer - A prospective study. *Submitted*
- II Malmström M, Ivarsson B, Johansson J, Klefsgård R. Long-term experiences after oesophagectomy/ gastrectomy for cancer -A focus group study. *International Journal of Nursing Studies* 2013 50(1):44-52
- III Malmström M, Klefsgård R, Johansson J, Ivarsson B. Patients' experiences of supportive care from a long-term perspective after oesophageal cancer surgery -A focus group study. *European Journal of Oncology Nursing*, <http://dx.doi.org/10.1016/j.ejon.2013.05.003>
- IV Malmström M, Ivarsson B, Klefsgård R, Persson K, Jakobsson U, Johansson J. The effect of a nurse-led telephone supportive care programme on patients' quality of life, perception of received information and health care contacts after oesophageal cancer surgery - A six month RCT follow-up study. *In manuscript*

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INTRODUCTION

Surgery has long been the cornerstone in oesophageal cancer treatment [1]. From the patients' point of view, irrespective whether treatment is for cure or palliation, the diagnosis of oesophageal cancer is life changing and includes some permanently altered body functions. Today, it is known that these patients' lives after surgery are hampered by reduced Quality of Life (QOL) [2-5], and that they have trouble adapting to their new life situation [6, 7]. Support aiming to help these patients to live as well as possible after this life changing surgery is therefore fundamental, but it is nonetheless still only sparsely studied. This thesis focuses on the patients' life after oesophageal cancer surgery and aims to evaluate QOL during the first postoperative year, to illuminate the patients' experiences of QOL and supportive care from a long-term perspective, and to evaluate a telephone based nurse-led supportive care programme that is optimised and timed according to the patients' needs.

It is known that patients who undergo oesophagectomy or oesophago-gastrectomy for cancer have a low expected 5-year survival rate (approximately 30 %) [8, 9], run a high risk of having postoperative complications (33-44 %) [10, 11], and often suffer from a severely reduced QOL after surgery [2, 3, 5, 12]. This is usually manifested as diarrhoea [2, 3, 5], fatigue, appetite loss [2, 3] and reflux [3, 5, 13], side effects that change life after surgery. *Oesophageal cancer as a disease* has been studied for a long time focusing on, for example, epidemiology and treatment. During recent years studies regarding *oesophageal cancer as an illness* have been more common. Illness is concerned with the experiences of changes in symptoms and suffering and refers to the subjective response to ill health [14]. Within this group of patients studies from an illness perspective have mainly focused on postoperative QOL. However, studies addressing the patients' experiences have shown that they have a hard time adapting to the new life situation that is hampered by several surgery-related problems that affect them physically, psychologically, emotionally and socially [6, 7, 15]. It is also known that the patients need of information is not adequately met by the health care professionals (HCP) [16], and that they are in need of support to be able to manage their new life situation [6]. The hampered life situation after surgery indicates that these patients need support, but studies that focus on how to support these patients are still lacking. This thesis focuses on the illness perspective of oesophageal cancer and aims to illuminate the patients' experiences after surgery and to develop and test a supportive care programme that is adapted to the patients' needs after surgery.

BACKGROUND

Oesophageal cancer as a disease

To be able to understand the illness perspective of oesophageal cancer, knowledge about the disease perspective is needed. The concept of disease refers to problems related to the biological dimensions such as alteration in the structure and function of body organs and systems and is concerned with factors as for example epidemiology and treatment [14].

Epidemiology

Oesophageal cancer is the eighth most common cancer worldwide with a prevalence that varies largely geographically. In the western world oesophageal cancer is still relatively rare, and approximately 80 % of these cancers occur in developing countries [17]. In Sweden the incidence of oesophageal cancer (including cardia) in 2011 was approximately 663 [18].

There are two main histological types of oesophageal cancer, squamous cell carcinoma and adenocarcinoma. Squamous cell carcinoma is associated with risk factors such as high alcohol intake and tobacco smoking, especially in combination [19, 20] while the strongest risk factors for adenocarcinoma is gastro-oesophageal reflux, Barret's oesophagus (a columnar cell metaplasia in the distal oesophagus associated with gastro-oesophageal reflux disease, GERD) and obesity [20, 21]. During the last few decades the incidence of adenocarcinoma has increased rapidly in the western world in contrast to the squamous cell carcinoma which has a declining incidence. This has resulted in that adenocarcinoma has surpassed squamous cell carcinoma and is now the dominant histological type of oesophageal cancer in the western countries [21].

Symptoms

Symptoms of oesophageal cancer are mostly based on the localisation and growth of the tumour. Dysphagia is the most dominating symptom and occurs when the tumour growth causes strictures in the oesophagus [22]. Symptoms often occur gradually and it is not until about half of the lumen is occluded that the symptoms are so severe that the patients seek medical attention. At that time, the patients often describe dysphagia as trouble swallowing solid food [23] and in a longer

perspective also beverages. Although dysphagia is the dominating symptom, and present in 74 % of patients with oesophageal cancer, symptoms such as weight loss, odynophagia (oesophageal pain) [22], chest pain, coughing, and hoarseness (resulting from tumour overgrowth of the laryngeal nerve) are also connected with oesophageal cancer [22-24].

Diagnostic procedures

To be able to decide upon treatment alternatives, the patients need to go through several diagnostic procedures. These procedures all aim to give information on the tumour stage (TNM stage) in which the depth of the primary tumour, occurrence of regional lymph node metastases, and occurrence of distant metastases are evaluated [25]. There are some differences regarding diagnostic procedures between surgical clinics. However, they often start with a gastroscopy with biopsies, followed by a computer tomography scan (CT scan) aiming to get an overall assessment of the tumour stage and potential metastases. An additional position emission tomography scan (PET scan) may add information mainly about distant metastases, and in some cases endoscopic ultrasound (EUS) may add information about local tumour depth in the oesophageal wall [23, 24, 26]. When all necessary information is collected, the plan for the patient is discussed in a multidisciplinary team conference including surgeons, oncologists, pathologists, radiologists and a contact nurse.

Treatment

About 50 % of patients with oesophageal cancer have unresectable or metastatic disease at time for diagnosis [24]. For those patients palliative treatment is the only alternative. Palliative treatment within this group of patients consists mainly of symptomatic treatment to reduce the dysphagia in forms of self-expanding stents, palliative radiation, chemotherapy [23, 27], endoscopic Argon plasma coagulation therapy, or pharmacological symptomatic treatment.

For patients available for treatment for cure, surgery is today the standard treatment of oesophageal cancer. It is not until lately that it has been shown that oncological treatment in combination with surgery can improve the survival rates [28]. There are two main surgical approaches for oesophageal cancer resections: the transthoracic and the transhiatal [1, 24]. In Sweden the most common approach is the transthoracic approach where a laparotomy is combined with a thoracotomy. The advantage with the transthoracic approach is that it allows for a better visualization of the tumour and thereby also a more likely of removing lymph

nodes. However, it is a larger surgical intervention with a high risk of complications. The advantage of the transhiatal resection is that it is done without opening the chest, a fact that a pulmonary compromised patient can benefit from. An additional incision in the neck allows a chest dissection simultaneously done from the abdomen and the neck, but without opening the chest. The disadvantage of the transhiatal dissection is that the lymph node harvest is minimal, a fact that may leave tumour positive nodes behind after surgery [1, 24]. The transthoracic approach is the mainstay surgical approach at the hospital where the studies in this thesis was conducted.

In this thesis, patients with tumours in the cardia (C16.0) with extension to the upper stomach (C16.0.C) were operated on with an oesophago-gastrectomy and a Roux-en-y reconstruction, whereas patients with their tumours in the oesophagus (C15, C16.0.A), or at the gastroesophageal junction but without infiltration to the stomach (C16.0.B) had an oesophagectomy with a gastric tube reconstruction (figure 1). In accordance with the TNM classification system 2010 [29], patients with cancer in the cardia are in this thesis classified and staged as oesophageal cancer. The postoperative in-hospital routines were identical for both reconstructions, and from a clinical point of view the patients were treated as a single group. Oesophagectomy and oesophago-gastrectomy are both major surgical procedures with regards to the extent of dissection, the long duration in the operating room (approximately 8-10 hours), the long postoperative care (median 21 days), and the long and strenuous recovery period. Additionally, the risk of postoperative complications is about 33-44 % and includes postoperative respiratory, circulatory or surgery related complications [10, 11].

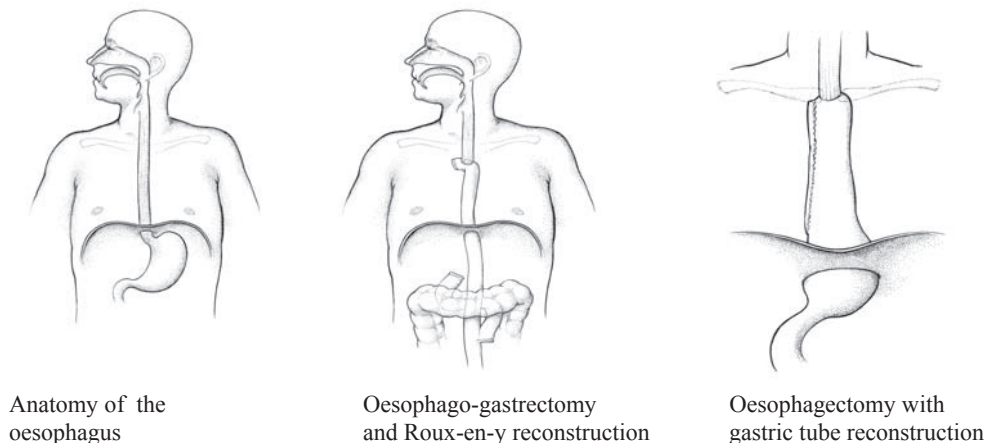


Figure 1. The anatomy before and after oesophageal cancer resection. (thesis Jan Johansson [30]).

Prognosis

Irrespective of histological type, oesophageal cancer is an aggressive cancer. Although modern surgical principles are applied, the prognosis remains poor after surgery, with a 5-year survival rate of only about 30 % [8, 9]. The outcome in terms of survival depends mostly on an tumour stage at the time of diagnosis [9].

Oesophageal cancer as an illness

Oesophageal cancer affects the patients' life from the first day of diagnosis and for many years to come. This makes oesophageal cancer not only a disease but also an illness that the patients need to live with for the rest of their lives. Eisenberg [14] stated that 'patients suffer from illnesses and doctors treat diseases' which shows upon the distinction between the two concepts. Illness is described as the human experience of symptoms and suffering referring to how the disease is perceived, lived with and respond to, by the person with the disease and their relatives. This means that illness refers to the subjective response to the ill health [14] which includes both the patients' experiences of ill health and the meaning that they put into that experience [31].

Life after oesophageal cancer surgery

Experiences of life after oesophageal cancer surgery

There are several physical problems that affect the patients life after surgery. Eating is one important aspect of life that is heavily affected. After surgery eating is no longer experienced as a source of pleasure but rather a stressful and joy-less activity [7, 15, 32]. Eating is important for physical reasons but is often also connected with social aspects and, for these patients, it has been shown to be associated with feelings of embarrassment and nervousness when eating in public places [6, 7]. Other ailments that the patients experience are for example problems with changed bowel habits [33, 34] and fatigue problems that the patients experienced to be associated with social isolation and feelings of hopelessness [33]. Most studies addressing the patients' experiences of life after oesophageal cancer surgery report that life is affected in several different ways. Even if these studies have focused on different perspectives of the patients' life they conclude that life is affected not only physically but also socially and psychologically/emotionally [6, 7, 15].

The high prevalence of problems with remaining symptoms, and the risk of recurrence of the cancer after surgery are big concerns for the patients [6, 34]. The patients struggle to readjust, and adapt their life and their identity to their new life situation [6, 7, 15] and they often distinguish between the pre- and post-cancer self - a fact that results in existential issues [15]. It is stated that patients strive to remain positive and to gain control of their situation [6], and many patients reprioritize things in life [15, 32]. The longer the time after surgery the less dependent the patients feel and although they still suffer from several remaining problems, it has been reported that they gradually accept to live with these problems [34]. When the physical problems decrease, and the feeling of regaining strength and vigour increases, patients describe a feeling of having reached a turning point [33].

Quality of Life

When evaluating the patients' life situation after oesophageal cancer surgery, quality of life (QOL) has often been used as an outcome measurement. The most common means of assessing QOL is to use self-administered QOL instruments. Today, there is no universally accepted definition of QOL and it is known that the meaning of the concept varies in different areas of application [35, 36]. The lack of one accepted definition has resulted in many different definitions being used [35]. In 1995 the World Health Organization, Quality of Life Group [37] defined QOL as 'individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'. Even if there are several other definitions available what is often stated is that QOL is considered to subjective referring to that it can only be understood from the patient's or person's own point of view. Also it is seen as multidimensional and should thus cover a wide range of aspects such as physical, functional, emotional, and social well-being [36-38]. In order to be able to distinguish between QOL in the broader sense and QOL connected with a patient's health in particular, the concept of Health Related Quality of Life (HRQOL) is often used [35, 36]. It has been stated that the concept HRQOL could be used when referring to how physical, emotional, and social well-being is affected by a disease or a treatment. According to Fayers and Hays [39], HRQOL is a multidimensional construct which refers to the 'subjective evaluation of one's ability to perform usual tasks, and their impact on one's everyday physical, emotional and social well-being'. Within this patient group the concepts of QOL and HRQOL have been used interchangeably without a clear distinction or description of what they are intended to measure. In this thesis the concept of QOL is used when referring to the patients' HRQOL.

Several studies have evaluated QOL after oesophageal cancer surgery [2-5, 13, 40-42]. Most studies conclude that QOL symptoms and functions are severely

affected [2, 3, 5, 12] and the most frequently reported general problems after surgery are fatigue, diarrhoea and appetite loss [2, 3]. When addressing oesophageal and gastric-specific symptoms, eating problems, reflux, coughing and oesophageal pain are frequently reported [3, 5]. Nutrition problems [2, 3, 5, 7, 34, 43], changed bowel habits [2, 3, 5, 34] as well as fatigue [2, 3, 43], are often highlighted as the dominating problems for the patients. When it comes to functions three years after surgery negative impact is shown with regards to physical [5], role and social function [2]. Most studies are in agreement that these aspects of QOL are severely affected after surgery but there are differences regarding for how long time the QOL of the patients is described as reduced and at what time after surgery their QOL is most severely affected. In a study evaluating HRQOL of patients five years after oesophageal cancer surgery it was shown that for most patients HRQOL remained stable or improved over time but in about 14 % of the patients HRQOL stay deteriorated [40].

Support and follow-up after oesophageal cancer surgery

Support

Support following a cancer diagnosis or treatment is important for helping the patients cope with the new life situation. However, the patients' needs of support and information are often not satisfied [16, 44, 45]. Defining support is complex since support needs to be seen from different perspectives. Helgerson and Cohen [46] described three broad types of support: emotional, informational and instrumental. The emotional support refers to verbal and non-verbal communication alike and includes being there for the patient, empathizing, encouraging and comforting. The informational support refers to the provision of information and advice to support the patients in ways to manage the illness and to cope with symptoms. The instrumental support involves the provision of material goods and includes aspects such as support with money or household chores [46]. Another aspect of support is often described as social support which is composed of emotional and instrumental support. Social support is described as an interpersonal process characterised by the mutual exchange of information and as being aimed to result in mental health [47].

Within this patient group, no studies that focus on the patients' experiences of support and support needs have been found. However, several studies emphasize that the patients' life situation are complex after surgery and affect their life from a physical, psychological/emotional and social perspective [6, 7, 15]. These studies provide valuable information about the need of support. However, knowledge about how the patients experience support from a long-term perspective after surgery and what the support should be compromise of in order to satisfy their

needs is still lacking. Even if there is a lack of studies addressing these patients' support needs after surgery, some studies have focused on different aspects of information showing that the patients' information needs are not adequately met [16, 48]. The health care professionals (HCP) tend to underestimate the patients' needs of support [16] and it has been shown that there is a distinction between what the patients' experience that they need and what the HCPs believe that the patients needs are [48], a fact that contributes to the unsatisfactory information to these patients.

Supportive care

One aspect, when adapting support during follow-up, is which concept, theory or philosophy the follow-up programmes are to be built upon. There are several different concepts, theories and philosophies that in different ways and to different extents focus on support to individuals. Two examples are palliative care and supportive care which both focus on the individual patient, and aim to support them in their specific life situations. According to the European Association for Palliative Care (EAPC) there is no clear differentiation between the two terms. However, they state that supportive care are more appropriate than palliative care when patients still receive therapy and for patients that survived treatment [49]. In this thesis the concept of supportive care is used, since it is concerned with support to patients throughout the whole cancer continuum regardless of whether or not the treatment has been for cure [49]. Today there is no generally accepted definition of supportive care [50]. However, the concept is stated as being concerned with the optimal wellbeing of patients with cancer [51] and is concerned with all aspects of management that do not aim to control the tumour [52]. The National Council for Hospice and Specialist Palliative Care Services [53] defines 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'.

The content of a supportive care programme is not clearly described but it is stated that it should focus on the patients' multiple and complex needs in all stages in the cancer trajectory [51]. Earlier studies concerning supportive care within other contexts have described that supportive care as including teaching and coaching for symptom management, counselling, support and navigation of the HC system [54]. Furthermore, O'Berle and Davies [55] describes that supportive care includes establishing a continuous and good relationship with the patients and their families by empowering and supporting them to solve various problems, to find meaning

and to perceive their integrity. This indicates that supportive care comprises all aspects of support that may be needed in the patients' specific life situation.

Within other cancer contexts, nurse-led models of supportive care have shown an improved affect on different aspects of the patients' life. For example Howell et al. [54] evaluated nurse-led community based supportive care to cancer patients showing that this care had the potential to reduce unmet supportive care needs, improve continuity and enhance overall QOL. Also Rosenbaum et al. [56] showed indications of positive effects of the supportive care programme on patient satisfaction and on QOL. However, to date and to my knowledge, no previous supportive care follow-up programme has been reported within this patient group.

Providing support

When designing a supportive care programme after cancer surgery it is important to address the issues of by whom and in which way the support should be provided. Post-treatment support to cancer patients is often provided as different follow-up programmes, and different approaches to follow-ups have been tested within various cancer contexts. Since cancer survivorship increases and since many patients experience long lasting problems after surgery, the traditional models of follow-up is no longer sustainable and do not fully meet the patients needs [57]. Follow-up has traditionally been provided by a physician during face-to face meetings in an outpatient clinic. However, during recent years, the involvement of nurses in follow-up programmes has become more common. The role of nurses in follow-up in cancer care have been addressed in several studies [58-62], and studies have shown that nurses, as providers of support during follow-up, need to be specialised in the patients' condition as well as to have sufficient communication skills [63, 64]. In a systematic review of nurse-led vs. physician-led follow-up programmes for patients with cancer varying results were shown, but the report concluded that patients appeared to be satisfied with nurse-led follow-ups [60]. In a study testing the same concept in rectal cancer patients, it was shown that patient satisfaction was equal for physician- and for nurse-led follow-up programmes [62]. Furthermore, studies have shown that nurse-led follow-ups after ovarian cancer are preferred by the patients since they had a good relationship with and could talk easily to the nurses [65], and a study concerning head and neck cancer suggests that nurse-led follow-up have a positive effect on HRQOL [66].

An alternative to traditional face-to-face meetings is, for example, telephone follow-ups (TFU) which have been tested within other cancer care contexts with varying results [59, 63, 65, 67-69]. TFUs are said to be suitable when the patients have a long travelling distance to the out-patient clinic [68] and when the patients need support during a longer time period. Earlier studies state that nurse-led TFUs

for patients with cancer are acceptable, appropriate and/or effective [59, 65]. When evaluating nurse-led TFUs in ovarian cancer it was shown that the majority of the patients preferred nurse led-follow ups based on the relationship they developed with the nurses and the convenience of having follow-up appointments over the phone instead of having to go to the clinic [65]. However, based on a low methodological quality of the studies testing TFUs (no studies focusing on oesophageal cancer patients included) a Cochrane review failed to prove any effectiveness regarding TFUs and therefore stresses the need of large scale, high quality studies testing TFU interventions [67].

Studies regarding follow-up within this context are still sparse and have been focusing on, for example, describing the care pathway [70], and the role of a specialist nurse in the team [71]. A few studies have evaluated interventions during follow-ups showing an effect on QOL when testing a self-care education programme [72], and a psychological nursing intervention [73]. No effect on QOL or satisfaction with care was seen when testing a follow-up programme with regular home visits by a nurse as compared with conventional follow-up programmes [61]. When evaluating the cost effectiveness of nurse-led follow up two studies conclude that nurse-led follow-up are likely to be cost effective however, no significant differences was shown [61, 74].

Rationale

Oesophageal cancer surgery offers a chance to cure, but there is a high risk of long lasting negative effects on the patients' life after surgery. Today, it is known that the patients' QOL is severely hampered and that their need of support is inadequately met. To be able to support these patients to adjust to a life situation that may include several ailments, a greater knowledge about their new life situation is needed. Knowledge about how QOL changes the first year after surgery as well as about the patients' experiences of QOL and supportive care is fundamental in order to be able to time and optimise the follow-up according to the patient's needs. To be able to enhance the patients' life situation after surgery there is a need of developing and testing a supportive care programme that focuses on support to the patients in their new life situation

AIM OF THE THESIS

The overall aim of this thesis was to investigate patients' experiences of QOL and supportive care as well as to evaluate a telephone based nurse-led supportive care programme to patients after oesophageal cancer surgery.

The specific aims were to:

- evaluate changes over time, and factors that may impact patients' quality of life the first year after oesophagectomy for cancer (Study I).
- illuminate patients' experiences of their quality of life and how they handle their new life situation from a long-term perspective after oesophagectomy or oesophagogastrectomy for cancer (Study II).
- illuminate patients' experiences of supportive care from a long-term perspective after oesophagectomy or oesophagogastrectomy for cancer (Study III).
- evaluate the effect of a nurse-led telephone supportive care programme on quality of life, perception of received information and the number of health care contacts compared to conventional care following oesophageal resection for cancer (Study IV).

METHODS

Design

This thesis is designed to address the illness perspective of the patients' life after oesophageal cancer surgery and comprises four studies (table 1). Study **I** is a quantitative prospective study that is a part of an RCT from which descriptive data has been used [75]. Studies **II** and **III** are qualitative studies and Study **IV** is an RCT with an experimental approach. Study **IV** is designed as complex intervention [76, 77]. What makes an intervention complex according to the MRC-framework is that complex interventions are built upon a number of components which may act independently as well as inter-dependently making it difficult to define what the active ingredients are [76]. By using different methodological approaches the aim was to highlight, from different perspectives, the patients' life situation after surgery. This is referred to as method triangulation. The aim with the triangulation was to limit potential bias that is specific for each method [78].

Table 1. Overview of the designs, sample, data collection and analysis method of the studies in the thesis

	Study I	Study II	Study III	Study IV
Design	Longitudinal Quantitative	Qualitative	Qualitative	Experimental, RCT Quantitative
Sample	N=79	N=17	N=17	N=82 IG n=41, CG n=41
Data	2002-2007	2009	2009	2009-2013
Collection	Instrument measuring Quality of life	Focus group interviews	Focus group interviews	Instrument measuring Quality of life Information received Patient satisfaction Health care contacts
Analysis	Repeated measures ANOVA Within group over time	Qualitative content analysis	Qualitative content analysis	Repeated measures ANOVA Between groups over time

IG: Intervention group, CG: Control group

The intervention

Study IV was designed as a two-armed RCT including a control group that receive 'conventional care', and an intervention group that, in addition to receiving conventional care, also participated in a telephone based nurse-led supportive care programme (table 2). To ensure the feasibility of the intervention a pilot testing including an evaluation of the study design of the first five patients included in the study were conducted [77, 78]. The pilot testing was aiming to evaluate whether or not the intervention could be delivered as intended [77]. The evaluation of the pilot testing did not result in any changes of the study design. The intervention was developed through multi-professional collaboration and was built upon the supportive care concept that aims to support the patients in their specific life situation. While developing the supportive care programme, knowledge gained from studies within other cancer settings, our own clinical experience with oesophageal cancer patients, the results from Study I, and preliminary results from the pilot interview of Studies II and III, were used.

Conventional care

Conventional care was based on a clinical follow-up programme including clinical visits to one of the operating surgeons at 1, 3 and 6 months after discharge, with the possibility for the patients to contact a nurse in the out-patient clinic if needed. Before discharge, the patients had a meeting with one of the operating surgeons. This meeting was not formally structured, but tailored to the individual patient, and to his or her estimated needs. Additionally, a nutritionist informed about diet and weight controls, and a physiotherapist informed about postoperative exercises. After discharge, there was no structured information given, or proactive contacts planned, with the exception of telephone follow-ups by the nutritionist. All nursing interventions, except for occasional contacts with the nurse in the open care clinic, were performed by the municipal nurses who had not met the patients in hospital before discharge.

Intervention

In addition to 'conventional care' the intervention group participated in a telephone based nurse-led supportive care programme. The intervention was provided by one nurse only, a clinical nurse specialist, who was specialised in postoperative oesophageal cancer care. The clinical nurse specialist was employed by the hospital, and worked in the ward where the postoperative care took place after the initial postoperative care at the intensive care unit. The intervention programme included a meeting with the clinical nurse specialist on the ward before discharge where the patients had the opportunity to ask questions, and discuss their concerns and where they received both oral and written information focusing on life after surgery, self care, plans for the future, and where to turn to for help if needed. The

information meeting took between 10 and 30 minutes. Thereafter, the nurse proactively contacted the patients once a week during the first two months, every second week during month three and four and once a month during month five and six, plus extra contacts if the patients needed extended support. The telephone contacts lasted as long as the patients desired, usually between 5 and 15 minutes. The contacts focused on the patients' specific needs and concerns and included a dialogue about how the patients experienced their health, potential concerns and questions as well as an evaluation of issues that had been discussed during earlier contacts. The contacts were structured in the sense that they always covered areas that are known to be problematic for patients after this type of surgery such as: nutrition, elimination, pain and psychological issues. The aim with adding the structured approach to the general dialogue was to detect possible problems at an early stage, and to help patients to manage them. The role of the nurse was also to mediate contacts with other caregivers if needed.

Table 2. Overview of the intervention including measurement points and follow-ups

Time since Surgery	Control Group	Intervention Group	Measurement points	Follow-up Surgeon
Before discharge	<u>Information</u> Surgeon Nutritionist Physiotherapist	<u>Information</u> Surgeon Nutritionist Physiotherapist <u>Additional info</u> Oral and written Self care Follow-up plan		
Discharge			X	
2 weeks			X	
1 month				X
2 months		Proactive telephone contacts 1/week and when needed	X	
3 months				X
4 months			X	
5 months		Proactive telephone contacts 2/month and when needed		
6 months		Proactive telephone contacts 1/month and when needed	X	X

Patients

The inclusion criteria for all patients included in this thesis were: electively operated cancer patients who had a transthoracic oesophagectomy with a gastric tube reconstruction or an oesophago-gastrectomy with a long Roux-en-Y reconstruction with an intention to cure, adults (>18 years), and patients with the ability to communicate in Swedish. Specific inclusion criteria are presented for each study. Except for the patients included in Study II and III, no patients were included in more than one of the studies in this thesis. A total of 178 patients were included during the progress of this thesis. An overview of the patient characteristics at baseline is presented in table 3.

Table 3. Patient characteristics in all studies (N=178) at baseline.

	Study I (N=79)	Study II-III (N=17)	Study IV (N=82)		P-value *
			IG (n= 41)	CG (n=41)	
Age					
Mean (SD)	64.9 (8.7)		64.4 (9.4)	68.5 (9.4)	0.071 ^a
Median (range)		64.0 (46-89)			
Gender, n (%)					
Male	61 (77.2)	14 (82.4)	30 (73.2)	34 (82.9)	0.286 ^b
Female	18 (22.8)	3 (17.6)	11 (26.8)	7 (17.1)	
Living with partner, n (%)					
Yes		12 (70.6)	33 (80.5)	33 (80.5)	1.000 ^b
No		5 (29.4)	8 (19.5)	8 (19.5)	
Type of surgery, n (%)					
Oesophagectomy	79 (100.0)	11 (64.7)	30 (73.2)	35 (85.4)	0.173 ^b
Oesophago-gastrectomy	0 (0.0)	6 (35.3)	11 (26.8)	6 (14.6)	
Disease recurrence, within 6 months, n (%)					
Yes		0 (0.0)	10 (24.4)	9 (22.0)	0.691 ^b
No		17 (100.0)	31 (75.6)	32 (78.0)	
Preoperative oncological treatment					
Yes			10 (24.4)	8 (19.5)	0.594 ^b
No			31 (75.6)	33 (80.5)	

* P-value for the difference between IG (intervention group) and CG (control group) at baseline in study IV.

^a Mann-Whitney U-test, ^b Chi-square test

Study I

The patients in Study **I** were consecutively included between 2002 and 2007. In this study, the specific inclusion criteria were patients who underwent oesophageal resections with gastric-tube reconstruction due to oesophageal cancer in the distal oesophagus or at the gastro-oesophageal junction without major postoperative complications, and with tumour-free resection margins. During data collection 129 patients were available for the study. A total of 79 patients were included in the study (figure 2).

Study II-III

The patients in Studies **II** and **III** were identified through a database for oesophageal cancer at the department of surgery, Skåne University Hospital, Sweden in 2009. In these studies the specific inclusion criteria were: patients who underwent oesophageal cancer surgery, as described above, who were between two and five years after surgery, and who had their place of residence in southern Sweden. Patients who suffered from a known relapse of the cancer disease were excluded. A total of twenty-seven (N=27) patients were identified as eligible for the study. Nine patients declined participation due to illness and one failed to come to the interviews. A total of 17 patients attended the focus group interviews. When planning the interviews, variations in sex, age and type of surgery in each focus group were taken into account, but the patients also had the opportunity to express their preferences which interview occasion they preferred to attend.

Study IV

The patients in Study **IV** were consecutively included between 2009 and 2013. The specific inclusion criteria were: patients that underwent oesophageal cancer surgery, as described above, but without severe postoperative complications that prolonged the hospital stay (>6 weeks). Prior to inclusion, a power analysis was conducted [79]. To detect a mean difference of 20 on the global quality of life scale of QLQ-C30 with an SD of 23, a power of 80 % and a significance level of 0.05 a total of 70 patients (35 per group) were needed. During data collection 120 patients were available for inclusion. The patients were randomised through a block randomisation (10 patients/block) to a control group (“conventional care”) (n=41) or to the intervention group (conventional care and nurse-led telephone follow-up) (n=41). An overview of the sample and attrition is shown in figure 3.

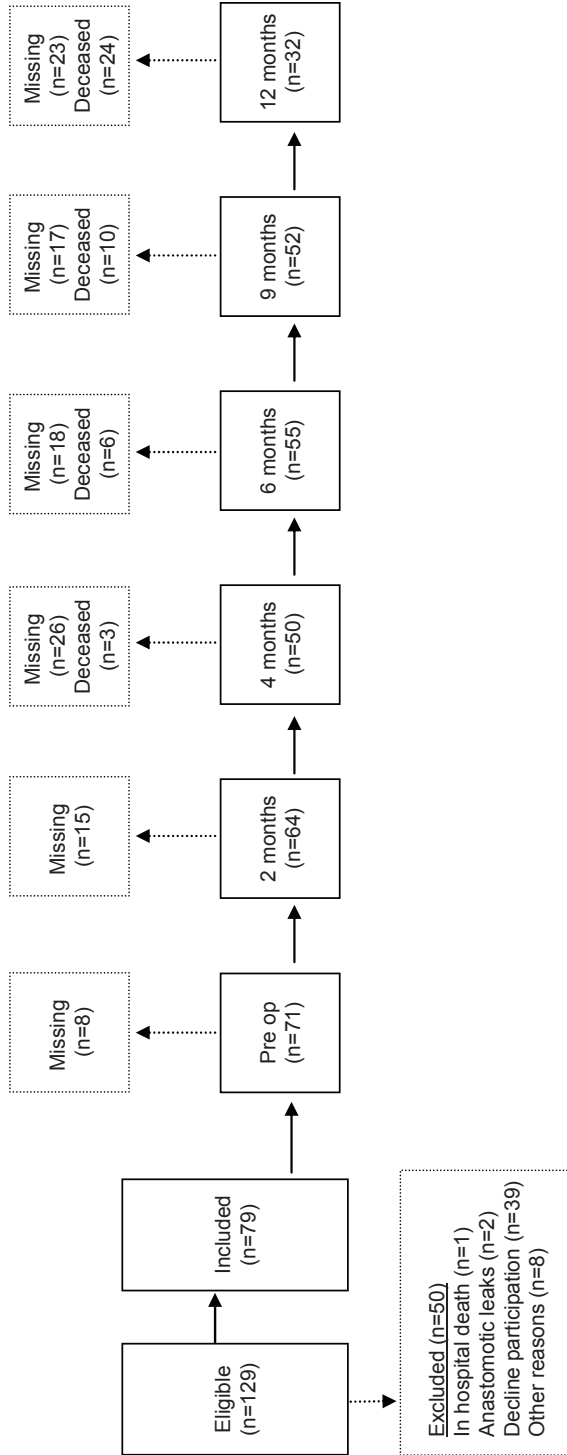


Figure 2. Overview of the sample and attrition in study I.

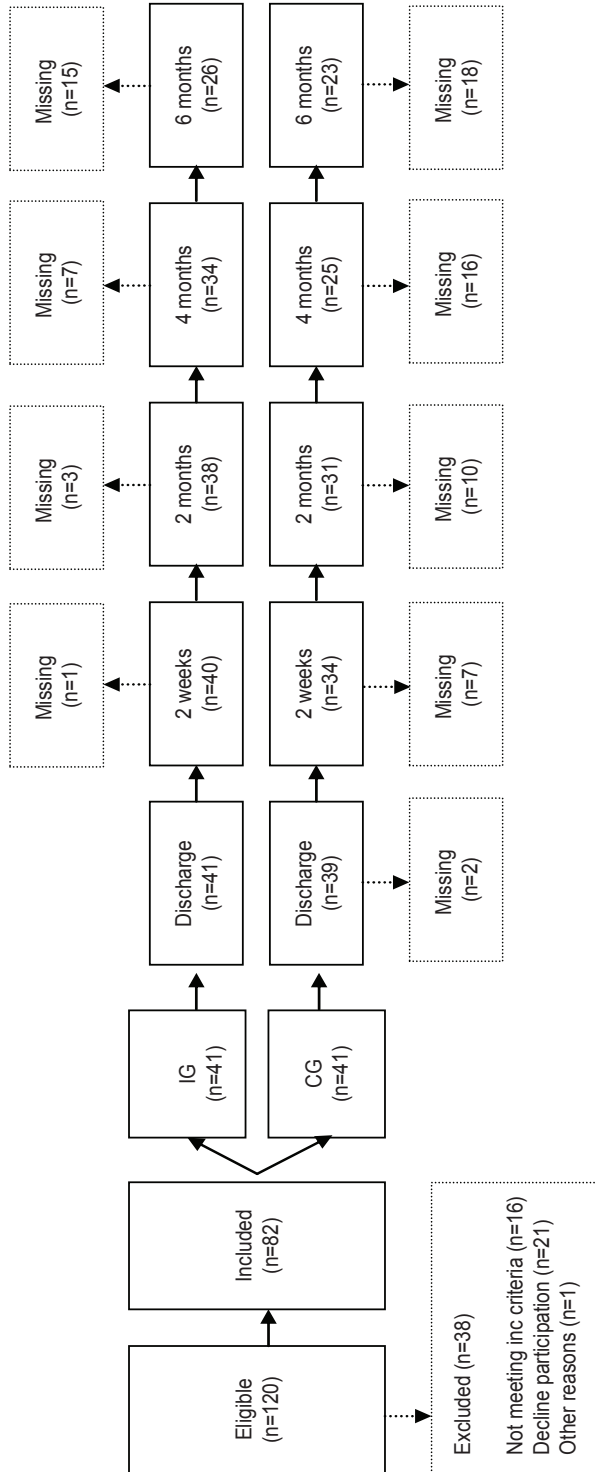


Figure 3. Overview of the sample and attrition in study IV. IG: Intervention group, CG: Control group.

Data Collection

Data collection was conducted at different time spans after surgery starting preoperatively in Study I and ending up about two to five years after surgery in Studies II and III (figure 4).

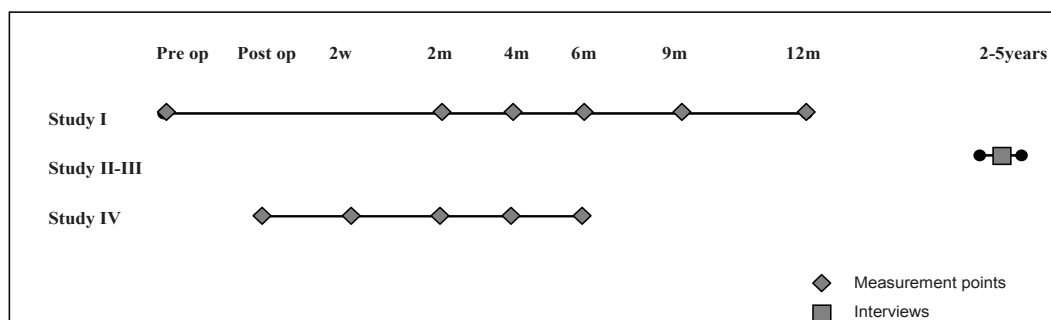


Figure 4. Measurement and interview points in the four studies.

Interviews

Four focus group interviews with between three and five respondents in each group were conducted during data collection (II, III). The interviews were conducted 2 to 5 years after elective surgery and focused on the patients' experiences during the whole recovery period. The interviews lasted between 110 and 135 minutes, and were carried out in a separate room in the hospital library. The interviews focused on two different areas: patients' experiences of quality of life (II) and patients' experiences and need of supportive care (III).

The interviews were conducted by two of the authors. One of the authors moderated the interviews with the aim of helping the respondents to focus on the topic while the other author assisted by asking probing questions and keeping notes during the process [80]. For support, a semi structured interview guide with a focus on the different areas of QOL and supportive care was used. The interviews started with an open question which was followed up by probing questions to gain a deeper understanding of the patients' experiences [81].

Examples of open questions:

When you look back on the time since your surgery how would you describe:

- your QOL/health?
- the support you have received?

Examples of probing questions:

Could you tell us more about that?

How did you experience that?

How did you react to that?

In order to test the design of the study the first interview was conducted as a test interview. No subsequent changes were made after the initial analysis which is why it was included in the studies. After the third interview the authors experienced that no new information emerged. In order to confirm that no further information would appear, a fourth interview was conducted and this confirmed that no new data emerged.

Measurements

When evaluating outcomes of treatment or interventions, a focus on both the outcomes of the surgery, referred to as patient-reported outcome measurement (PROM), and the patients' experiences of the outcome, often referred to as patient-reported experience outcome measurements (PREM), are of interest. PROM are factors that have a direct relationship with the treatment per se, such as survival and QOL while PREM focus on the patients' experiences of the outcomes such as experiences of perceived information or satisfaction with care [82, 83]. In Study **I**, we evaluate PROM through instruments measuring QOL preoperatively and 2, 4, 6, and 12 months after surgery. In Study **IV** we evaluate PROM and PREM using instruments measuring QOL, patient satisfaction and perceived information at discharge, at two weeks and 2, 4, and 6 months after surgery as well as measurements of health care contacts using self reported diaries and two health care contact registers during the whole 6 month follow-up. Due to the limited timeframe between randomization and discharge the additional information meeting, included in the intervention group, took place before the first measurement at discharge.

All instruments used in this thesis are developed and validated by European Organisation for Research and Treatment of Cancer (EORTC). The instruments are answered on Likert scales and are transformed into scales ranging from 0-100 before statistical testing [84]

Quality of life, perceived information and satisfaction

The EORTC quality of life instrument, QLQ-C30 v3.0 is the core instrument and assesses Health Related Quality of Life (HRQOL) in patients with cancer [85]. To supplement the core instrument, disease-specific QOL modules can be used to add information. Due to the development of a combined oesophageal and gastric

cancer module during the progression of this thesis the oesophagus cancer specific module QLQ-OES18 [86] used in Study **I**, was replaced by the oesophagus, oesophago-gastric junction and stomach specific module QLQ-OG25 in Study **IV** [87]. EORTC has also developed the QLQ-INFO25 instruments which evaluates the patients perception of received information [88] and the IN-PATSAT32 instrument which evaluates cancer patients perceptions of the quality of hospital-based care [89] of which both are used in this thesis. An overview of the instruments and how they are used is shown in table 4.

Health care contacts

Health care contacts were evaluated using three different data sources. Self-administrated diaries were used to register the number of health care contacts the patients had after discharge from the hospital. The patients were asked to note each contact with any health care provider, and to add information on what type of contact came into question, for example, a clinical nurse specialist, a surgeon, a primary care physician or a municipal nurse. The diary was pre printed as a week schedule with pre defined boxes to tick for each contact and with extra space to write if they would like to make a comment. Health care contacts within public in- and out patient care were collected from a computerised hospital care registry, the Patient Administrative Support in Skåne (PASiS). Contacts from this register were collected for total contacts during the follow-up period and for surgery related contacts only. Identification of the surgery related contacts were confirmed by an individual search in the medical records of each patient. Health care contacts within private health care settings were collected from the PRIVA-C register which is a register for all private organised health care. Contacts from this register were collected for the whole follow-up period.

Other measurements

The American society of anesthesiologists (ASA) score was collected from the patients` medical records in Study **I**. The ASA score classifies the patient`s physical status, and ranges from 1 (“normal healthy patient”), to six (brain dead patient”) [90].

Table 4. A description of the construction of scales, interpretation of the scores and psychometric evaluation of the instruments used in Study I and IV.

Instruments	Measuring	Range	Direction	Study	Cronbach's alpha*	Reference
QLQ-C30	QOL			I, IV	0.71-0.89 ^A	Aaronson et al., 1993
<i>Function</i>		1-7	↑ value better QOL			
Multi-item scales (5)		1-4	↑ value better function			
<i>Symptom</i>		1-4	↑ value more symptoms worse QOL			
Multi-item scales (3)						
Single-item scales (6)						
OES-18	Oesophageal cancer specific QOL	1-4	↑ value more symptoms worse QOL	I	0.63-0.77 60% > 0.70 ^B	Blazeby et al., 2003
<i>Symptom</i>						
Multi-item scales (4)						
Single-item scales (6)						
QLQ-OG25	Oesophagus, oesophago-gastric junction, stomach specific QOL	1-4	↑ value more symptoms worse QOL	IV	0.67-0.87	Lagegren et al., 2007
<i>Symptom</i>						
Multi-item scale (6)						
Single-item scales (10)						
QLQ-INFO25	Perception of received information	1-4	↑ value higher level of information received, higher satisfaction and higher information wishes	IV	0.70-0.91	Arraras et al., 2010
Multi-item scales (4)		Yes/No (4)				
Single-item scales (8)						
Global score (1)						
IN-PATSA T32^o	Patient satisfaction hospital-based care	1-5	↑ value higher level of satisfaction	IV	0.80-0.96 ^A	Bredart et al., 2005
Multi-item scale (11)						
Single-item scale (3)						

* Cronbach's alpha coefficients. ≥ 0.7 = acceptable, ≥ 0.8 = good. □ Used at baseline only. () = Number of scales within the instrument.

^A: For all multi-items except one. ^B: 60% of the multi-item had a Cronbach's alpha > 0.07. All Likert scales are linearly transformed to a 0-100 scale before statistical testing.

Analyses

Qualitative content analysis

The analysis of data from the focus group interviews (**II, III**) was conducted with qualitative content analysis. Hsieh and Shannon [91] describes three types of qualitative content analyses: the direct, the summative and the conventional. When literature within the area is limited, conventional qualitative content analysis is often used. In this thesis conventional qualitative content analysis was used to interpret the content of the data through a systematic process aiming to describe the patients' experiences from different perspectives. Graneheim and Lundman [92] have described qualitative content analysis as focusing on the manifest content illuminating the explicit, visible content of the text, or the latent content illuminating the interpretation of the meaning and the underlying meaning of the text. In this thesis, we consider the latent content analysis and the combination of latent and manifest content analysis as described by Graneheim's and Lundmans [92] to be fitted in Hsieh's and Shannon's [91] concept of conventional content analysis.

The analyses were performed by the two authors who conducted the interviews together with a co-examiner who had not been involved during the focus group interviews. Thereby, this author could see the data without being affected by the interview occasions. The authors analysed the interviews individually, step by step, and then came together to discuss the analyses. The analyses started by reading the text repeatedly as a whole in order to get an overall understanding of the text. Thereafter, the text was read again, word by word, with a focus on identifying codes that captured key concepts and thoughts. As the analyses proceeded, labels for codes emerged that were reflective of more than one key word, and together the codes resulted in an initial coding scheme. In the next step, the codes were sorted into categories and sub-categories. During the analytical process, a continuous discussion regarding similarities and differences of the analysis was held between the authors. In the final step, all authors came together and agreed about how data should be categorised and about the overall theme.

Statistical testing

As described earlier, all validated instruments used in this thesis were based on Likert scales that were lineally transformed to a 0-100 scale before statistical testing, according to the instructions of the providers [84-89]. A priori, we decided

that if an item had an answer frequency of less than 50 %, the item would be excluded from the analysis. This was the case only for the item hair loss (QLQ-OG25) in Study **IV**. Imputations of missing values were done in two steps. Missing values within the forms were replaced according to the scoring manual of the instrument [84] and missing values due to missing forms were replaced with mean value imputation for each group [93]. The analyses were conducted according to the Intention-To-Treat principle (ITT) [79]. Baseline data were compared between groups (**IV**), with the Chi-square test for nominal data, and for ordinal and higher levels of data the Mann-Whitney U-test was used. A p-value of less than 0.05 was considered as a significant deviation. The calculations were done with the SPSS package v18 (**I**) and v20 (**IV**) (Chicago, US).

In both Studies **I** and **IV** a repeated measures analysis of variance (ANOVA) was used for statistical testing of the changes over time. In Study **I** the aim was to evaluate general trends for the scales rather than to perform separate analyses for each transformed scale. A priori, it was decided to set up three separate statistical analyses. One for the set of function scales (QLQ-C30) and two separate sets for the symptom scales (QLQ-C30 and QLQ-OES18). Preoperative and postoperative assessments at 2, 4, 6, 9, and 12 months after surgery were included into each of the three statistical analyses. The results of the first postoperative year were evaluated as a composite time parameter, and adjusted for the potential impact factors of: gender, age, ASA score, the result of the randomization of the study population (PPI or no treatment), and whether or not an anastomotic stricture appeared after surgery. Contrasts were used to compare the results from each evaluated pre- or post-operative occasion with the results of the 12 month assessments. In Study **IV** the aim was to test whether there were any differences between the intervention and control group during the six months follow-up. Measurements at discharge, at 2 weeks and at 2, 4 and 6 months after discharge were included in the analysis. A univariate repeated measures analysis of variance was used in both studies to test the hypotheses. If Mauchly's test of sphericity indicated violation of sphericity, Huynh-Feldt corrections of the degrees of freedom were used to achieve valid F-ratios to the analyses. The residuals were graphically checked for constant variance, normality, independence and linearity.

Health care contacts (**IV**) were statistically tested between groups both for diary contacts (tested for contacts the first two weeks and contacts the first four weeks), for contacts registered in the PASiS system (tested for total contacts during the whole follow-up and for surgery related contacts only) and for contacts in the PRIVA-C (total contacts) using the Mann-Whitney U-test.

Context

The studies included in this thesis were conducted at Skåne University Hospital in Lund, Sweden, where approximately 40 patients undergo oesophagectomy or oesophago-gastrectomy annually. Due to an increased centralisation of oesophageal and gastric cancer surgery, the majority of the patients within the catchment area were operated at this hospital and consequently some patients had to travel longer distances than to their home town for medical treatment of their conditions.

The patients' care pathway is complex and builds upon multi-professional and multidisciplinary collaboration. The clinical coordination of the patients' care pathways is done by two contact nurses who are specialised in this patient group. None of these nurses have participated scientifically in the study, but have been available during office hours to all patients, irrespective of randomisation in Study **IV** or not. The clinical nurse specialist that was specially trained to perform the interventions (**IV**) did not participate in the routine coordination of the patients in the outpatient unit as described above. In brief, the pathway starts with a referral to the surgical clinic and is followed by several diagnostic procedures (described earlier), a multidisciplinary meeting that finally ends with a treatment recommendation. Within one week, the patients are informed about the treatment recommendation from the conference by one of the operating surgeons. Patients who undergo this major surgical intervention are postoperatively treated at the intensive care unit for 1-3 days before the start of postoperative care in a designated surgical ward for oesophageal and gastric cancer care. The median postoperative length of stay at the hospital is 21 days.

After discharge from the hospital, patients were followed according to a programme that was based on clinical visits to one of the operating surgeons (1, 3 and 6 months and 1 and 2 years after discharge), and with the possibility of phoning one of the two contact nurses in the open-care clinic if needed (described earlier as conventional care). The majority of these patients were discharged from the hospital with a feeding jejunostomia catheter for supplemental nutrition given at night time for approximately one to three months after surgery. This nutritional support aims to prevent weight loss after surgery and make the sometimes troublesome eating process less stressful. However, the use of the feeding tube requires the patients either to learn to tube-feed themselves or to receive help from the municipal care nurses. After discharge from the hospital, all nursing interventions except for occasional contacts with the contact nurses at the open-care clinic were performed by the municipal nurses.

Ethical considerations

During the progress of this thesis, a continuous discussion regarding ethical aspects has been conducted. Ethical discussions have been based on the four ethical principles of autonomy, beneficence, non-maleficence and justice [94] and the Helsinki declaration [95]. All studies have been approved by the Regional Ethics Board, Lund, Sweden (Study **I**, Dnr LU-693-02, Study **II-IV** Dnr 2009/117) and Study **I** and **IV** have been registered in databases for clinical trials (Study **I**, EudraCT database 2009-009997-28, Study **IV** clinical trials.gov NCT01657175).

Autonomy refers to the individual's right to make his or her own choices [94]. To ensure autonomy, all patients included in this thesis have been given both written and verbal information prior to the study. All patients were informed that their participation was voluntary and that they could withdraw from the study at any time without any explanation or effect on their care. Before the start of the studies all patients signed and returned a consent form.

Beneficence refers to acting with the best interest of the other person in mind [94]. The patients' best has, throughout the whole process, been in focus and therefore discussion about the patients' participation and burden of participating in the interviews has been discussed. One example of acting for the best of the patients was that the patients in Studies **II** and **III** were asked where they would prefer to meet for the focus group interviews, in order to ensure that the burden on the patients was as low as possible. Another aspect of beneficence was that the burden on the patients when filling out the instruments was limited by using as few instruments as possible in the studies.

Non-maleficence refers to the Hippocratic Oath 'Above all, do no harm'[94]. This principle has been addressed by treating all data (e.g. instruments, interview scripts) confidential and by ensuring that no patients could be identified in the presentation of the studies. All instruments were coded and the code key was stored separately.

Justice, refers to fairness and equality among individuals [94]. This was considered when including patients in the studies. In Study **I** and **IV** the patients were consecutively included and in Study **II** and **III** all eligible patients were asked to participate. By this approach we ensured that all patients had the same chance of being included in the studies. The justice principle was also considered when patients were randomised to control or intervention group in Study **IV**. The

randomisation was conducted by closed envelope technique leaving to chance the determination of within which group one was to be included.

Participation in the studies has not been expected to have a negative impact on the patients. However, participation in the focus group interviews two to five years after surgery and talking about the time since surgery could bring forth thoughts and concerns connected with the cancer disease and surgery for which the patients were not prepared. A plan to support patients if this would occur was therefore prepared. Prior to conducting the interviews, information and contact information both to the social worker at the hospital and to the contact nurses at the open care clinic was gathered to offer to the patients if needed. However, there were no patients who were in need of such contacts.

RESULTS

The result will be presented in two parts. Firstly, the *patients experiences of QOL and supportive care* and, secondly the *evaluation of the telephone based nurse-led supportive care intervention*.

Patients experiences of QOL and supportive care

Quality of life after oesophageal cancer surgery

Quality of life

Patients' QOL after surgery is shown to be negatively affected during the first postoperative year, both regarding symptoms and functions (**I, II**). However, as long as for up to five years after surgery patients still experience that their QOL is reduced. After surgery, the patients' lives are severely hampered by adverse symptoms and the patients express that it is a struggle to move on with life and to learn to live with the remaining symptoms and concerns. The patients experience that physical and psychological functions, that before surgery were taken for granted, were no longer uncomplicated parts of life. From a psychological and an emotional perspective, the patients experienced that their QOL was affected in many different ways. One aspect of this was that the patients experienced a loss of control of their future, described as not being in control of life and that they were not able to affect their life and their health. Another aspect is described as hovering between hope and despair, which was experienced, for example, when not knowing whether a symptom was a sign of recovery or of recurrence. This uncertainty affected the patients' life and QOL since many patients expressed that they lost hope about the future and about recovery (**II**).

From a physical perspective the patients experienced that the impairment in bodily function hindered them from living the kind of life they wanted. The main problems were those connected with eating, elimination and disturbed sleep. The experiences regarding eating after surgery varied. Most patients experienced that eating was connected with anxiety, fear and frustration related to not being able to eat as much as they needed and the risk of losing weight. Incorporating the new way of eating in the new life situation, for example, being able to know how much they were able to eat, was described as finding a balance – a balance that they lost after surgery and that they needed in order to feel in control of their life. Also, the loss of control of elimination, often in terms of sudden diarrhoea or constipation,

gas and a rumbling stomach were affecting the patients' QOL. They described that they avoided going to social events due to the risk of getting diarrhoea or the embarrassment of a rumbling stomach. Disturbed sleep was another problem that the patients experienced had a negative impact on their QOL. The patients experienced that factors such as not being physically active during the day and problems such as reflux, diarrhoea and existential concerns hindered them from sleeping in the night. The patients described that all physical problems that they experienced limited their lives not only physically but also psychologically and socially (II).

QOL changes over time as a key aspect in the timing of support

To be able to optimise support after surgery, Study I focused on how QOL changed over time during the first postoperative year. The patient-reported instruments measuring QOL showed that QOL was most severely hampered at two months compared to twelve months after surgery. This was true both for general functions ($p < 0.001$) and symptoms ($p < 0.001$) (QLQ-C30) (figure 5) and diagnose-specific symptoms ($p < 0.001$) (QLQ-OES18) (figure 6). Age, sex ASA scores and whether or not an anastomotic stricture appeared after surgery were not associated with altered QOL but treatment with proton pump inhibitors (PPIs) had a significant positive impact on general QOL symptoms ($p = 0.003$), and oesophageal cancer specific symptoms ($p = 0.015$) (I). Another perspective on how QOL changed after surgery was gained by asking patients, two to five years after surgery, about how they experienced their QOL during the period from surgery until the interview occasion (II). The patients expressed that their QOL was most severely affected when they left the hospital and that the first postoperative year was hampered by several remaining symptoms. Although QOL was experienced as being reduced during several years after surgery, time was experienced as a healing parameter. The fact that the symptoms that the patients suffered from remained unchanged were in some ways experienced as a relief since the patients were afraid that they would become even worse (II). The patients QOL were severely affected the first year after surgery (I, II) and long lasting negative effect on aspects of QOL such as trouble with eating, diarrhoea and disturbed sleep were experienced for as long a time as two to five years after surgery (II).

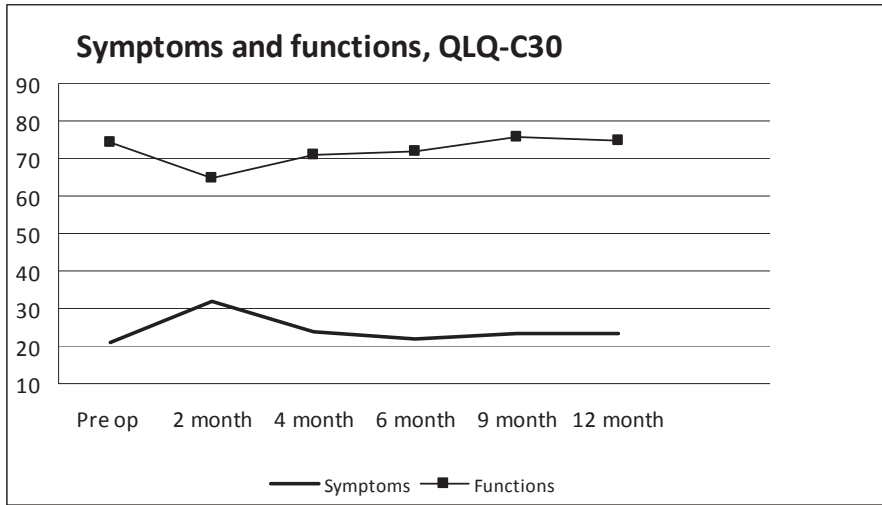


Figure 5. QOL measured in symptom and function scales of the QLQ-C30 form. The patients scored significantly worse in both symptom ($p<0.001$) and function ($p<0.001$) scales at two months compared with 12 months after surgery. A higher value on the function scales= better function and a higher value on the symptom scales= more symptoms/problems.

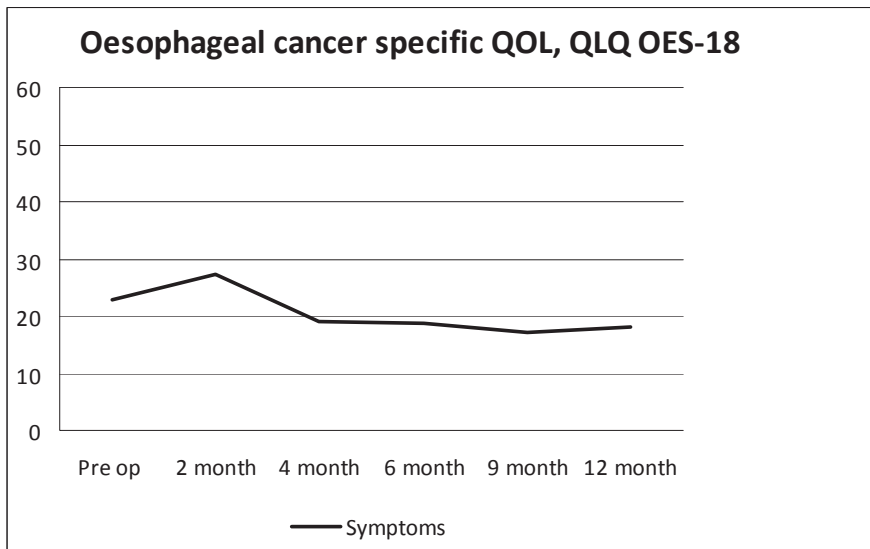


Figure 6. QOL measured in symptom scales of the QLQ-OES18 form. The patients scored significantly worse at two months compared with 12 months after surgery ($p<0.001$). A higher value represents a higher level of symptoms/problems.

Support after oesophageal cancer surgery

Experiences of supportive care

The severely affected life situation and the hampered QOL after surgery was, for many patients, experienced as a shock (II, III). They experienced that they were not prepared for what life would turn out to be, and therefore when leaving the safe hospital environment they felt alone and lost. The patients' supportive care needs are complex and need to include support from many different perspectives. 'The need of a guiding light' was chosen as a theme that captured the patients' experiences of supportive care after surgery (III). Although some patients experienced that after some time their QOL slowly enhanced (II) they needed support in handling the new life situation throughout the whole recovery period (III).

The patients experienced that information and support was sufficient during their stay in the hospital, and that they felt secure as long as they stayed there. However, when they were discharged from the hospital the health care system was experienced as fragmented and hard to navigate, a fact that had a negative impact on the patients' experience of control. A clear plan for the future, including information about follow-up and where to turn for help, was experienced as important. Many patients experienced that information was too sparse and that the received information was too optimistic. Honest information was stated as a prerequisite for realistic expectations regarding recovery. The lack of accurate information resulted in patients misinterpreting postoperative symptoms and problems as being signs of recurrent disease rather than normal postoperative problems (III).

After surgery many patients were concerned about not recovering as expected and about the risk of recurrence of the disease (II). Support in how to relate to these concerns and how to try to adapt to the life situation was therefore experienced as important. Talking about their problems and concerns so that they would know what is normal and what is not, as well as getting practical advice about, for example, how to balance eating or how to manage changed bowel habits was experienced as important. Since patients expressed that friends, relatives, and colleagues did not always understand how severely affected their life was, recovery would be improved by discussing these issues with someone who knew about their illness (III).

Except from support related to their health and their reduced QOL, the patients also experienced that they needed support in how to relate to the demands of society. The hampered life situation after surgery resulted in the fact that many patients were not able to work for a long time, leading to contacts with the social

insurance offices. Some patients experienced that the employees at the social insurance offices were sceptical when they presented their problems, and that they did not understand how sick the patients felt. Therefore, some patients desired that a better communication between hospital employee, for example, doctors and nurses and social insurance employees would be needed (III).

Support in navigating a fragmented health care system

The complex situation after surgery, including both physical and psychological ailments, was described as placing high demands on the HCP when it came to support. This was because the patients expressed that they needed support from several different sources in the health care system, an organisation that they experienced as being fragmented. The patients described that they had occasional contacts with the surgeon, the contact nurse in the open-care clinic, their primary care physicians, the municipal care nurses, and the nutritionists. This was experienced as confusing, since the patients were not sure about whom to contact when they needed help or support. The contacts with the surgeon during follow-ups focused mostly on issues about recovery, and on confirming that they did not suffer from a recurrence. The contact nurse in the outpatient clinic was the primary contact for many patients when it came to questions and problems, and was often the one who they contacted when they did not know to whom to turn. The contact nurse was experienced, competent and helpful but was only involved in the patients in hospital-based issues. The contact nurse had no regular collaboration with municipal nurses and primary care physicians, something that was frustrating for some patients. The patients experienced that they lacked a person with an overall supportive function who had knowledge about their situation and their follow-up, not only regarding surgery related issues but also with regards to other instances within the hospital, primary- and municipal care. This person, preferably a nurse, needed to be specialised in their conditions, life after surgery, and the health care system, and should bridge the gaps between different health care settings by coordinating the patients' care after discharge. The patients suggested that support after discharge should initially be proactive since they did not know what to expect or what they were supposed to be alert about. The need of support decreased gradually after surgery. However, as long as two to five years after surgery the patients still found it extremely important to have a contact person to get in touch with in case problems would appear (III).

Other sources of support

Although the HCP was experienced as an important source of support, the patients also gained support from their social networks including friends and family. However, not all patients had a social network from which they could get support. This since some patients had no social network at all, and other patients experienced that the friends that they had before the illness avoided contact after

surgery. Patients who had involved someone from their social network during the whole cancer process experienced this as a very valuable help. By having someone who was involved and who knew about their illness, the patient always had someone close that they could talk to if they needed, and who understood what their concerns were about. The involvement of a close relative or friend was, however, expressed as a decision of their own to make, since no one encouraged them to do so. The patients strongly desired the HCP to actively encourage patients to involve a relative or friend during the whole process. This would confirm that it was permitted to bring someone to follow-up meetings, a fact that was not clear for all patients (III).

Another source of support that the patients asked for, but lacked after surgery was support from other patients that had undergone the same surgical procedure. A vast majority of the patients expressed strong desires to have the possibility of talking to other patients, of listening to how they experienced their life, how they had solved problems, and how they had adapted to their new life situation. The patients suggested that support groups should be arranged by the HCPs where they could share their experiences with each other. This was completely lacking, and therefore many patients expressed that they felt unreasonably alone with their illness (III).

Handling the new life situation

The strategies that the patients had for handling the new life situation varied. Many patients experienced that they were controlled by the disease and that physical problems made them stay at home resulting in social isolation. Others stated that they refused being controlled by the disease and tried to attend social events as much as they could. These patients described that they felt that being around people who knew about their illness was appreciated. The fact that people knew about their illness, and the fact that they did not need to explain their problems all the time was a relief. How the patients handled the situation and their ability to take control of their new life situation was not always connected with how many problems they experienced, but rather as active choice about how much impact the illness was allowed to have on their lives. For many patients it took a long time before they realised that they needed to adapt to their new life situation, enjoying life here and now, instead of fighting symptoms and waiting for complete recovery (II).

Evaluation of the telephone based nurse-led supportive care intervention

Between groups comparisons were conducted for patient characteristics (table 3), patient satisfaction, general and diagnose-specific QOL and for experience of perceived information at baseline (discharge) (data not shown). No significant difference was shown regarding patient characteristics, patient satisfaction or QOL. In the scale measuring patients perception of received information the intervention group scored significantly higher for the scales measuring 'received information about treatment scale' ($p=0.045$), and on the 'written information scale' ($p=0.032$).

The evaluation of the effect of the telephone based nurse-led supportive care programme showed a significant effect on the patients' perception of received information during the six-month follow up after discharge. The intervention had a significant positive impact on the patients' satisfaction concerning the information about 'things to do to help yourself' ($p=0.001$), and about 'written information' ($p<0.001$) and scored higher in the global score ($p<0.021$) compared to the control group that obtained conventional care. There was also a significant difference between the groups concerning 'wishing more information' ($p<0.001$) where the control group had a higher wish for information. In addition significant changes over time across the groups was shown for several items such as information about the disease ($p<0.001$), information about medical tests ($p=0.001$) and whether the information has been helpful ($p=0.012$) (table 5) (IV).

A significant change over time was shown for most scales and items regarding general and diagnosis-specific QOL across the groups during the follow-up period (table 6 and 7). No significant difference was shown between the groups regarding general quality of life during the follow-up period for the function- and symptom scales (QLQ-C30) except for the symptom dyspnoea ($p=0.041$) where the intervention group scored significantly higher compared to the control group (table 5). No significant difference between the groups was shown for diagnosis-specific QOL (QLQ-OG25) (IV) (table 6).

Health care contacts were evaluated using self administered diaries, PASIS (public health care contacts) and PRIVA-C (private health care contacts) (table 8). There were no significant differences between the groups for the number of health care contacts. Diary contacts were evaluated for the total number of contacts the first two weeks and for the first four weeks only. No significant difference was shown for either the first two ($p=0.628$) or the first four weeks ($p=0.345$). There were no significant differences of health care contacts registered in the computerised

hospital registry (PASiS) during the whole six-month follow-up for total contacts ($p=0.341$) or for surgery related contacts only ($p=0.549$). No significant difference regarding health care contacts within the PRIVA-C register for private health care settings was shown ($p=0.061$) for the total number of contacts during follow-up **(IV)**.

Table 5. Mean values at each measurement point for patients perception of received information (QLQ-INFO25) divided on intervention (IG), control group (CG) and total sample (Tot) and comparison between groups and across groups over time during the follow-up period.

	Discharge			2 week			2 month			4 month			6 month			Changes over time ^B		Between groups
	IG	CG	Tot	IG	CG	Tot	IG	CG	Tot	IG	CG	Tot	IG	CG	Tot	P-value ^C	n=82	P-value ^C
	n=40	n=39	n=79	n=40	n=34	n=74	n=38	n=31	n=69	n=34	n=25	n=59	n=25	n=23	n=48			(n=41/41)
QLQ-INFO25^A mean																		
Info about the disease	65.6	65.5	65.6	63.8	62.3	63.1	74.1	69.2	71.9	70.6	69.0	69.9	73.7	67.4	70.7		<0.001	0.399
Info about medical tests	75.7	79.9	77.7	72.8	69.6	71.3	78.4	78.1	78.3	76.3	78.7	77.3	83.6	75.8	79.9		0.001	0.769
Info about treatments	58.3	47.6	53.2	56.4	46.5	51.8	55.3	52.6	54.1	57.9	53.5	56.0	54.3	50.0	52.1		0.410	0.085
Info about other services	43.8	40.4	42.1	45.6	39.5	42.8	41.4	38.4	40.1	43.3	38.1	41.0	49.0	40.2	44.8		0.348	0.131
Info about different places of care	36.9	40.3	38.7	47.4	36.5	42.4	36.9	35.6	36.3	43.4	36.0	40.2	44.0	27.3	36.2		0.670	0.141
Info about things to help yourself	59.8	50.5	55.3	60.8	42.2	52.3	49.1	43.3	46.5	61.6	38.7	51.7	57.3	42.0	50.0		0.185	0.001
Written information	72.5	48.7	60.8	82.5	32.4	59.5	52.6	30.0	42.6	69.7	40.0	56.9	44.0	30.4	37.5		<0.001	<0.001
Info on CD tape/video	5.1	5.1	5.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	2.1		0.009	0.460
Satisfaction with received info	75.8	72.8	74.4	74.2	65.6	70.4	76.3	71.1	74.0	75.0	68.0	71.9	77.8	68.2	73.2		0.512	0.054
Wish to receive more info	20.0	38.5	29.1	20.0	41.2	29.7	7.9	46.7	25.0	12.1	32.0	20.7	12.0	17.4	14.6		0.009	<0.001
Wish to have received less info	2.5	5.6	3.9	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0		0.006	0.467
Overall the info has been helpful	79.2	74.1	76.8	70.8	67.7	69.4	67.5	70.1	68.7	70.7	74.7	72.4	74.7	63.8	69.4		0.012	0.379
Global score	49.8	47.0	48.4	49.5	41.6	45.9	44.9	44.7	44.8	48.1	44.0	46.3	47.8	40.2	44.2		0.035	0.021

^A: Score range 0-100. A higher score represent a higher level of information received, higher satisfaction (better) and higher information wishes.

^B: Changes over time during the 6 month follow-up for the total sample.

^C: Repeated measures ANOVA. Based on items/scales with mean value imputation.

Table 6. Mean values at each measurement point for quality of life (QLQ-C30) divided on intervention (IG) and control group (CG) and total sample (Tot) and comparison between groups and across groups over time during the follow-up period

	Discharge			2 week			2 month			4 month			6 month			Changes over time ^c		Between groups	
	IG	CG	Tot	IG	CG	Tot	IG	CG	Tot	IG	CG	Tot	IG	CG	Tot	P-value ^d	n	P-value ^d	n
	n=41	n=39	n=80	n=40	n=34	n=74	n=38	n=31	n=69	n=34	n=25	n=59	n=26	n=23	n=49	n=82	(n=41/41)	n=82	(n=41/41)
QLQ-C30 mean	44.5	45.3	44.9	50.2	50.0	50.1	60.5	56.7	58.8	62.4	60.3	61.5	65.4	64.9	65.1	<0.001			0.698
Global health status ^a	59.8	53.9	56.9	64.7	59.4	62.3	78.8	77.9	78.4	83.5	79.5	81.8	79.5	82.6	81.0	<0.001			0.357
Function^a	11.4	7.7	9.6	29.6	28.4	29.1	55.3	52.2	53.9	59.8	66.0	62.4	65.4	70.3	67.7	<0.001			0.871
Physical function	66.7	67.1	66.9	74.3	70.1	72.4	78.1	77.4	77.8	79.0	82.0	80.3	74.4	80.1	77.0	<0.001			0.806
Role function	70.3	64.1	67.3	77.9	72.1	75.2	87.3	87.1	87.2	86.4	84.0	85.3	84.0	84.1	84.0	<0.001			0.380
Emotional function	50.0	50.0	50.0	66.7	52.9	60.4	70.2	61.8	66.4	71.7	68.7	70.4	72.4	75.4	73.8	<0.001			0.285
Cognitive function	60.9	64.9	62.9	55.8	56.9	56.3	37.4	42.6	39.8	38.4	34.7	36.8	35.0	31.9	33.6	<0.001			0.823
Social function	19.9	17.5	18.8	25.0	16.7	21.2	25.9	24.2	25.1	23.0	13.3	18.9	17.3	13.8	15.6	0.028			0.092
Symptom^b	49.2	51.7	50.4	40.4	39.2	39.9	25.4	19.9	22.9	25.0	20.0	22.9	25.6	16.7	21.4	<0.001			0.303
Fatigue	60.9	56.4	58.8	51.7	45.1	48.6	39.5	34.4	37.2	37.3	30.7	34.5	35.9	18.8	27.9	<0.001			0.041
Nausea and Vomiting	65.9	68.4	67.1	42.5	39.2	41.0	25.4	23.7	24.6	24.5	22.7	23.7	32.1	17.4	25.2	<0.001			0.278
Pain	55.3	57.0	56.1	59.2	50.0	54.9	42.1	38.7	40.6	38.2	29.3	34.5	20.5	18.8	19.7	<0.001			0.288
Dyspnoea	14.6	25.6	20.0	16.7	20.6	18.5	7.0	15.6	10.8	11.8	13.3	12.4	6.4	7.2	6.8	<0.001			0.078
Insomnia	43.1	41.0	42.1	25.8	28.4	27.0	40.4	34.4	37.7	33.3	32.0	32.8	34.6	27.5	31.3	0.001			0.458
Appetite loss	10.0	10.5	10.3	7.5	10.8	9.0	6.1	12.9	9.2	9.1	14.7	11.5	6.4	11.6	8.8	0.542			0.241
Constipation																			
Diarrhoea																			
Financial difficulties																			

^a: Score range 0-100. A high score represent at higher level of quality of life or a higher level of functioning (better).

^b: Score range 0-100. A high score represent at higher level symptoms/problems (worse).

^c: Changes over time during the 6 month follow-up for the total sample.

^d: Repeated measures ANOVA. Based on items/scales with mean value imputation.

Table 7. Mean values at each measurement point for quality of life (QLQ-OG25) divided on intervention (IG), control group (CG) and total sample (Tot) and comparison between groups and across groups over time during the follow-up period

	Discharge			2 week			2 month			4 month			6 month			Changes over time ^B	Between groups
	IG	CG	Tot	IG	CG	Tot	IG	CG	Tot	IG	CG	Tot	IG	CG	Tot	P-value ^C	P-value ^C
	n=41	n=39	n=80	n=40	n=34	n=74	n=38	n=32	n=70	n=34	n=25	n=59	n=25	n=23	n=48	n=82	(n=41 /41)
QLQ-OG25^A mean																	
Dysphagia	32.2	37.3	34.7	28.5	19.6	24.4	21.3	19.8	20.6	15.7	8.9	12.8	13.8	7.7	10.9	<0.001	0.222
Eating	53.8	61.0	57.3	57.9	49.2	53.9	38.6	38.0	38.3	33.9	31.7	32.9	28.7	29.3	29.0	<0.001	0.840
Reflux	13.0	16.7	14.8	17.5	16.2	16.9	13.6	15.1	14.3	15.2	20.0	17.2	15.3	22.5	18.8	0.198	0.352
Odynophagia	19.6	18.4	19.0	22.2	14.7	18.7	19.3	15.1	17.4	21.1	14.7	18.4	17.3	13.8	15.6	0.631	0.116
Pain and discomfort	22.9	22.4	22.7	31.2	19.1	25.7	28.9	20.0	24.9	27.9	24.7	26.6	23.3	24.6	24.0	0.733	0.163
Anxiety	53.3	55.1	54.2	48.7	46.6	47.7	43.4	40.9	42.3	41.7	37.3	39.8	41.3	39.9	40.6	<0.001	0.677
Eating with others	16.7	14.8	15.8	12.3	18.8	15.2	11.4	8.0	9.9	17.6	5.3	12.4	16.0	11.6	13.9	0.128	0.358
Dry mouth	60.0	56.4	58.2	58.3	48.0	53.6	27.2	32.3	29.5	24.5	29.3	26.6	28.0	18.8	23.6	<0.001	0.507
Trouble with taste	38.3	40.7	39.5	40.8	41.4	41.1	32.5	30.0	31.4	25.5	24.0	24.9	16.0	21.7	18.8	<0.001	0.816
Body image	40.8	52.6	46.6	35.0	41.4	37.9	26.3	25.8	26.1	20.6	18.7	19.8	25.3	24.6	25.0	<0.001	0.481
Trouble swallowing saliva	13.8	21.4	17.5	8.3	18.6	13.1	11.4	6.5	9.2	12.7	5.3	9.6	14.7	4.3	9.7	0.004	0.737
Choked when swallowing	13.3	12.3	12.8	13.3	14.1	13.7	16.7	20.4	18.4	14.7	12.0	13.6	12.0	11.6	11.8	0.128	0.978
Trouble with coughing	45.0	44.4	44.7	45.0	45.1	45.0	43.9	50.5	46.9	35.3	33.3	34.5	26.7	31.9	29.2	<0.001	0.646
Trouble with talking	24.8	29.1	26.9	17.5	18.6	18.0	13.2	12.9	13.0	15.7	13.3	14.7	16.0	10.1	13.2	<0.001	0.876
Weight loss	15.0	23.1	19.0	32.5	36.3	34.2	24.6	31.2	27.5	33.3	25.3	29.9	22.7	30.4	26.4	<0.001	0.421

^A: Score range 0-100. A high score represent at higher level symptoms/problems (worse).

^B: Changes over time during the 6 month follow-up for the total sample.

^C: Repeated measures ANOVA. Based on items/scales with mean value imputation.

The item Hair loss was removed since the answer frequency was less than 50%

Table 8. Registered number of health care contacts during follow-up.

Time since diagnosis	Type of contact	Diary			Public			Private		
		CG Mean (SD)	IG Mean (SD)	p-value ^A	CG Mean (SD)	IG Mean (SD)	p-value ^A	CG Mean (SD)	IG Mean (SD)	p-value ^A
2 weeks	Total	17.0 (11.6)	14.3 (8.6)	0.628						
4 weeks	Total	29.5 (23.0)	21.0 (14.2)	0.345						
6 month	Total				8.7 (4.2)	8.0 (5.2)	0.341	2.0 (5.79)	0.1 (0.5)	0.061
	Surgery				7.1 (4.2)	6.6 (3.9)	0.549			

^A Mann-Whitney U-test. CG= Control group, IG= Intervention group. SD: standard deviation.

DISCUSSION

Methodological considerations

Four studies with three different designs are included in this thesis. The aim with using different study designs was to gain a broader understanding of the patients' life after surgery. Since the study designs vary, the indicators for quality also differ. In qualitative studies trustworthiness is evaluated using the concepts credibility, dependability, confirmability and transferability while the quantitative studies are evaluated with regards to validity [96] and reliability [97]. There are threats to quality during all phases in the research process. Therefore a discussion about potential threats, and measures conducted to limit these threats is needed.

Trustworthiness

Credibility

The concept of credibility refers to how well the data covers the intended focus of the study and to the believability of data [78, 98]. One way of strengthening credibility is to select participants with varying characteristics since this increases the possibility of acquiring fruitful descriptions of the participants' experiences [92]. In these studies (**II**, **III**) all patients that were available and who fit the inclusion criteria were asked to participate. However, when dividing the patients into the focus group interviews, variation in sex, age and type of surgery was taken into account in order to strengthen credibility.

Choosing the data collection method that is most sufficient for the study aim is another aspect of credibility [92]. In this thesis, two studies are based on focus group interviews. This choice of method can be questioned within this frail patient group since it postulates that the patients meet for the interviews. The fact that those patients that declined participation did so because of illness could have affected the result since it is likely that they suffered from an even more compromised QOL. However, focus group interviews are sufficient when participants have a certain experience in common and when the aim is to achieve interaction between the participants to maintain a richer description of the experiences. During the interviews it is important that the researchers make sure that all participants have the opportunity to share their experiences [80], a fact that was considered during the interviews. Based on the study aim that focuses on illuminating the patients' experiences in an area that is sparsely studied, the data

collection method, and the choice of conventional qualitative content analysis as an analysis method was considered to be suitable.

Even if former studies have stated that patients that go through traumatic events remember these quite well [99] there was a risk that the credibility would be compromised by focusing on the patients' experiences from a long-term perspective. Since no studies had previously focused on these questions from a long-term perspective by using qualitative research methods, and since such information is important in order to optimise the support after surgery, the choice to conduct the interviews as long as two to five years after surgery was considered to be appropriate. With this design the patients had the opportunity to share their own experiences and to relate to those of other, a fact that may benefit their memory. During the interview occasions it was clear that the patients could coherently remember their experiences during the time after surgery and that their stories were rich and detailed, a fact that strengthened the credibility.

Another way of enhancing credibility is to seek agreement with co-authors, experts or participants [92]. Polit and Beck [78] recommend that member checking in focus group interviews should be done during the interviews by way of the moderators summarising the interviews and presenting the summary to the participants at the end of the interview as feedback to see if they agree with what is presented. This kind of member checking was conducted in the interviews. To further strengthen credibility the interviews were conducted by two of the authors with an experience of working with this patient group who, together with a third author, conducted the analyses. When the analyses were completed, a fourth author, who is an expert on this group of patients, had the opportunity to read the results and to agree about the final version.

Dependability

Dependability is concerned with the stability of data over time [92, 98]. One factor that can compromise dependability is if data collection progresses over a period of time or if different questions are asked in the different interviews. In this study all interviews were conducted within a two-months period and were conducted by the same researchers. To ensure that all interviews included the same overall questions a semi-structured interview guide was used during the interview sessions.

Confirmability

Confirmability is concerned with the researchers' pre understanding and the risk of researcher bias due to subjectivity [78]. To deal with this issue, efforts were made to have an ongoing discussion throughout the progression of the studies concerning any possible impact of the authors' pre-understanding on the interpretation of data. The use of research triangulation [78], in this case where

four authors, with different professional backgrounds and experiences of the patient group, participated during different phases in the analysis, limited the impact of the authors' pre-understanding.

Transferability

The term transferability, refers to the extent to which the results of the studies are transferable to other groups and settings [78, 92]. In qualitative studies the author can make suggestions but it is up to the reader to decide whether or not the results are transferable. To enable such a decision it is important to thoroughly describe the data collection and the process of analysis [92]; a fact that has been considered when writing the papers. The suggestion for the transferability of the results of Studies II and III was that they could be transferred to comparable contexts including patients with comparable postoperative symptoms. However, patients who undergo oesophageal cancer surgery are frail and differ from patients with other cancer diseases in many aspects. It is also likely that postoperative follow-ups and support differ between health care settings. These facts need to be taken into account when evaluating the transferability of these results.

Validity

Trustworthiness of quantitative studies is often evaluated with regards to different aspects of validity. Validity is concerned with the accuracy of the measures and includes different perspectives of validity such as internal validity, external validity, construct validity and statistical conclusion validity [96].

Internal validity

Internal validity refers to the risk that there are factors other than the independent variable that may affect the outcome of the results. Threats that are connected with internal validity are: external events, other than the independent variable that may affect the results (history), changes over time within the subject as growing older (maturation), potential effect of repeated testing (testing), changes in how measuring devices are used (instrumentation), the tendency of patients with extreme values to answer closer to the mean value in repeated measurements (statistical regression), selection bias and attrition problems [96].

Attrition is a usual problem in studies where data collection progresses for a long period of time [96]. The patients included in this thesis are frail due to the high prevalence of remaining problems and high risk of recurrence, a fact that has negatively affected the attrition. In both Studies I and IV there were drop outs during data collection. Drop out analyses in both studies showed that the reasons were mainly due to the patients' physical ailments. There were also patients who

suffered from recurrent disease during the progress of data collection. It is possible that these patients would suffer from more problems compared with patients without recurrent disease, a fact that needs to be taken into account when interpreting the results. A threat to internal validity in Study **I** was that no reminders were sent out, a fact that negatively affected the attrition in that study. In Study **IV** the drop out analysis showed that there was no difference in drop outs between the study groups with regards to tumour recurrence during follow-up, a fact that limited the possible impact of this factor. A slightly higher dropout frequency was shown for the control group compared to the intervention group. Despite this, no differences in the reason for drop outs were shown and no systematic difference was shown for drop out in relation to patient characteristics, which is interpreted as limiting the risk of violating the internal validity. In the experimental study (**IV**) internal validity is connected with the equality of the groups which was strengthened by the RCT design. Baseline comparisons between the groups showed no difference regarding patient characteristics indicating that the randomisation was successful in dividing the study population equally.

Another aspect that may affect the internal validity of this thesis is the change in treatment regime for the patients during the progress of this thesis. When Studies **I-III** was conducted, the standard treatment for these patients was surgical treatment only. In the hospital where these studies were conducted we have in recent years gradually introduced additional oncological therapy for patients with gastric and cardia cancer and during the this last year we have done the same thing for oesophageal and cardia cancer based on encouraging reports of better survival [28, 100]. This may have a negative effect on the patients in Study **IV** since combined oncological and surgical treatment could, at least from a theoretical viewpoint, have compromised QOL. However, since the study was designed as an RCT, and since there were no differences between the groups regarding the occurrence of additional pre-operative oncological therapy, the threat to internal validity is limited.

Measuring health care consumption is complex, since the health care system involves both public and private health care providers. The use of self-administered diaries is one way in which to monitor the patients' health care contacts, but it is often considered to be of low internal validity. Also, in this study, the quality of the registrations in the diaries after the first month was low, a factor that resulted in the fact that only the first month's contacts were used for the statistical testing. To complement the diaries and to strengthen the internal validity, health care contacts registered in the public health care register (PASIS) and the register for private health care contacts (PRIVA-C) were also evaluated. None of the measures showed any significant difference between the groups.

External validity

The questions about the generalizability of the findings are related to external validity [96]. To be able to evaluate the external validity it is important to present a thorough description of all phases in the studies, a fact that has been taken into account in both Study **I** and **IV**. The samples that are used in the studies are considered to be representative of for the population of patients that undergo oesophageal cancer surgery. However, since there are differences within the national as well as international health care systems regarding, for example, follow-up after oesophageal cancer surgery, this result needs to be interpreted with potential contextual differences in mind.

Construct validity

Construct validity is concerned with the construction of an intervention and the theoretical assumptions and underpinnings upon which the intervention is built. The construct validity therefore refers to the relationship or causality between the result of the study and the experiment [96]. Study **IV** is designed as a complex intervention, a fact that makes the construct validity complex to evaluate since there are several factors that together could affect the outcome measurements [76]. A threat to construct validity could be the confounding effect the researcher may have on the participants [96]. The intervention in Study **IV** is comprised of several different factors such as an information meeting, proactive support, information and the coordination of the patients' health care contacts after surgery. The intervention is provided by one nurse only to ensure that all patients in the intervention group receive the same basic intervention. However, since it is known that support and information needs to be individualised, the information and support within this intervention was adjusted according to the patients' needs and therefore differs between the patients. This results in the fact that we are not able, and do not intend, to draw conclusions about which component in the intervention was the most effective but only about the effectiveness of the whole programme [76, 77].

Statistical conclusion validity

The possibility of confirming the relationship between different variables is referred to as statistical validity. Statistical validity could be threatened by type I or type II errors. A type I error (alpha) occurs when a statistically significant difference is shown even if there is no difference [93, 96]. The risk is determined by the p-value that in this thesis was set to 0.05 indicating that there is a 5 % risk for a type I error in each analysis. This type of error is often caused by mass significance when performing multiple tests. To minimize type I errors in this thesis (**I**, **IV**) we used repeated measures ANOVA instead of performing repeated tests between each measurement point. In Study **IV**, where the aim of the study

was to evaluate potential differences between the groups over time, we avoided post-hoc tests to minimize the risk of type I errors. The opposite to type I errors is type II errors (beta). Type II errors occur when no significant difference is shown even if there is a difference in the population. This type of error is often related to a small sample size. To minimize the risk of type II errors in the experimental study (IV), a power calculation was performed indicating that a minimum of 35 patients in each arm (N=70) was needed. Based on the risk of dropouts during the data collection 41 patients in each arm were included (N=82), a fact that reduced the risk of type II error.

Reliability

Reliability refers to the consistency of a instrument [96, 97]. All instruments used in this thesis have been developed by EORTC and have been psychometrically tested showing good or moderate results for validity and reliability [85-89]. The reason for choosing these instruments was that the core instrument, combined with the diagnosis-specific modules, provided the possibility of measuring both general and specific QOL with a validated instrument. Moreover, the fact that the EORTC instruments are commonly used within this context enables a comparison of the results with other studies.

There are several aspects that need to be considered regarding reliability. One is the internal consistency of the instruments which refers to the extent of how multi-items are inter-related [35]. Internal consistency is often measured with Cronbach's alpha, which in the instruments used in this study have been shown to be moderate or good for all scales. Coefficients above 0.7 are often considered as acceptable and a value above 0.8 is considered as good [35]. This was the case for most scales within the instruments used in this study. Also, stability is connected with the reliability of an instrument and refers, for example, to the agreement between different observers and the stability of a instrument over time [97]. Stability of an instrument over time is important when performing repeated measurements as has been done in both Studies I and IV and can be evaluated with test-retest reliability often in forms of intra-class correlations (ICC). ICC is concerned with the relationship among multiple observations within the same variable [97]. The cut-off value for good stability measured with ICC is not clearly defined but it has been recommended that it should exceed 0.7 in clinical trials [35]. For the core quality of life instrument as well as for the oesophagus cancer specific module it is reported that the instruments are sensitive for clinical changes in health over time [86] and the instrument measuring experience of perceived information has been tested with test-retest reliability indicating a good stability (ICC >0.7 for all scales). However, we failed to find an evaluation regarding

stability over time for the combined oesophagus, oesophago gastric junction and stomach specific QOL module. These facts need to be taken in account when interpreting the results of Study I and IV.

General discussion of the results

Patient experiences and patient reported QOL

There are several different problems that have previously been reported to have an effect on the QOL of patients after oesophageal cancer surgery. The most commonly reported problems are eating-related problems, such as weight loss, lack of appetite, and a changed sense of taste [2, 3, 7, 15, 34, 43], changed bowel habits such as diarrhoea [2, 3, 34, 43, 101] and fatigue [2, 3, 43, 61, 101]. These results correlate well with the findings in this thesis. Contrary to quantitative QOL studies, there are few previous reports about the patients' experience of their QOL from a qualitative perspective. By comparing the results of the patients' QOL as determined by QOL forms with the results of the interviews, information was gained not only regarding how patients experienced their QOL, but also about how different problems affected each other and how the patients handled them. This is in line with an earlier study testing qualitative interviews vs. self-reported instruments [102]. That study states that by addressing QOL both from qualitative and quantitative perspective a deeper understanding of the patients' QOL could be gained. They also highlight that the risk in the exclusive use of instruments is that important information about the patients' QOL risks to remain unobserved. In order to be able to adapt supportive care for these patients, a greater knowledge about the relationship between which problems the patients have and how these problems affect their lives is needed. For example, it has previously been stated that eating and balancing food intake [6, 7, 15] as well as changed bowel habits [2, 3, 34, 43, 101] are big problems for the patients, a fact that is strengthened by the results of this thesis. However, by addressing the patients' experiences of their QOL we also show that these problems are often connected with each other and that they also affect social life. For example, the patients describe that their fear of getting diarrhoea results in the avoidance of eating, or that they do not dare to test new food. This fear results in patients preferring to stay at home instead of going to social events with a risk of being embarrassed by sudden diarrhoea or a rumbling stomach. In a long-term perspective, this may lead to social isolation which, in this thesis, is shown to negatively affect the patients' experience of their QOL. In order to be able to prepare the patients for life after surgery HCPs need to have a good knowledge about the complexity of the patients' life after surgery.

This implies that it is important that HCPs focus on supporting patients in how to handle their new life situations, and how to live with the illness in order to be able to limit the impact of the physical problems on their psychological, emotional and social lives. It also underpins the importance of combining different study designs to be able to understand the patient's life situation from a wider perspective.

Identification of vulnerable patients

The result of this thesis shows that the patients' needs of support vary and that it is not only the amount of problems that affect their experience of QOL. In a newly conducted study evaluating QOL of patients five years after surgery it was shown that most patients recover well with regards to QOL but that in about 14 % of the patients QOL is considerably worse five years after surgery [40]. Based on the severely hampered QOL of patients who underwent oesophageal cancer surgery, it is likely that most patients have an extensive need for support after surgery. However, some patients may be satisfied with telephone contacts with the clinical nurse specialist, while others need a more active contact with the nurse or the surgeon as well as a referral to, for example, a physiotherapist or a social worker. This motivates the need for identification of those patients that are in need of extended support at an early stage but also the identification of those patients who run the risk of long-lasting negative effects on their QOL. By identification of these vulnerable patients the HCP could better optimise and individualise support. However, the question about how to identify these patients is still unanswered and needs to be addressed in further studies.

Optimising supportive care

When aiming to adapt support to patients after surgery timing is fundamental. In this thesis different methodological designs were used to address the question of timing and the optimisation of support. It was shown the patients' QOL was most severely affected at two months after surgery (compared to 12 months after) but also that it was experienced as negatively affected as long as for 2-5 years after surgery. The patients expressed that their need of supportive care was most prominent during the first postoperative year. However, they also stated that they needed the availability of support as long as up to 2-5 years after surgery. These results suggest that when timing support to these patients it is important that the support is given the most intensely during the first postoperative months, and then gradually decreases but that it remains for several years after surgery.

This thesis shows that in order to be able to understand, take control over, and manage the new life situation after surgery the patients need honest and realistic information about the remaining problems and about the future. However, many patients experienced that the information they were given was too optimistic, leading to unrealistic expectations about recovery. The importance of realistic information about prognosis has been highlighted earlier [103]. However, balancing the information so that the patients remain hopeful during the long and strenuous recovery period and at the same time being honest about the prognosis is often considered to be a balancing act [104]. In studies concerning nurses as providers of support it is stated that it is important that the nurses are specifically trained and that they have good communication skills to be able to satisfy the patients' needs [63, 64]. Despite this knowledge, it has repeatedly been shown that patients are not satisfied with the information that they receive [16, 45] and that the HCP often underestimates their information needs [16, 48]. The results of this thesis suggest that information should be given proactively, through a dialogue with the patients focusing on their individual concerns. By such an approach, information could be repeated and adjusted to the patients' needs. In Study **IV** support and information was provided by a combination of a discharge meeting and proactive telephone contacts. The results showed a positive effect on the patients' experiences of received information, a fact that motivates proactive, individualised support and information after surgery. The importance of individualisation of information and support has been reported earlier in studies concerning, for example, individualised nursing care [105]. Individual nursing care is designed to meet the specific needs of patients at a specific time and takes into account the patients' beliefs, hopes, needs, and desires [106]. The level of individualisation has earlier been shown to be positively correlated with patients' satisfaction with care [105]. Even though the concept of individualised nursing care is not used in this thesis it is connected with individualisation which was considered an important factor when designing Study **IV**. In this thesis patient satisfaction was only evaluated at baseline and not over time and therefore we are not able to draw any conclusions as to whether or not the individualised supportive care programme had an effect on the patients' satisfaction with care.

The results of this thesis indicate that the patients experience support from the social network as being important after surgery. However, not all patients have a social network that they could rely on, which may affect their need for support from the HCP. Another aspect of supportive care, which has not been addressed in this thesis, is support to the social network. It has been shown earlier that the patients' relatives are in great need of information and support [107]. It is realistic to believe that the patients' hampered life situation that affects them physically as well as psychologically and socially also affects the life of their social network. Thus, further studies that aim to optimise supportive care after surgery should

include an evaluation of the impact of the patients' illness on the social network in order to be able to optimise the support also to them.

The transition from in- to outpatient care

The transition from in- to outpatient care has been studied earlier, and has repeatedly shown that it involves a variety of problems for the patients [108-110]. Problems connected with the transition is, for example, not getting the help and information they need [108] and feeling as being 'in between' [110] facts that was also shown in this thesis. The results of this thesis show that the patients experience the HC system as fragmented and hard to navigate after discharge. In addition, the importance of having a specialist nurse with a supporting and coordinating function after discharge has been highlighted in this thesis, as well as in a earlier study [71]. However, in this thesis it was also shown that the coordination needed to be extended beyond the hospital care setting to include the primary and municipal care facilities. The complex need for support that includes both in- and outpatient care is a challenge for the healthcare system and requires better cooperation and knowledge transfer between the hospital and municipal and primary care. Since the primary and municipal care staff are not specialised in the patients complex illness it is especially important that specialists from the hospital support other HCPs who are involved in the care of these patients. The need of better cooperation between HCPs in cancer-related follow-up has been stressed earlier [111]. The challenge, as pointed out in this thesis, is that the health care society is fragmented, without a specific person who has an overall responsibility for the patients throughout the whole cancer trajectory. Instead, all units work within their isolated area in the trajectory without an overall understanding of the patients' experiences. Another challenge is the gap of knowledge that the patients experience when they leave the specialised hospital care for other hospitals or for municipal or primary care. Our findings indicate that the patients need help in navigating the healthcare system, they need clear and honest information as well as a health care system that better bridges the gap between in- and outpatient care.

Earlier studies on 'nurses as providers of support after discharge' have shown that patients often regard this support as positive [58, 60]. This has mainly been due to the fact that the support enables a dialogue about their problems that they do not experience that they have with their doctors [65]. However, this thesis indicates that support by a nurse does not replace the need for follow-up meetings with the surgeon. According to the patients, meeting with a nurse and a doctor provide different types of information and support. Based on the complex life situation with several remaining problems that affect all aspects of the patients' life after surgery, the importance of the team in supporting the patients becomes clear.

Based on the result of this thesis and on previous studies [59, 63, 64], we suggest that nurses who are specialised in the patients' needs, and who have extensive knowledge about their lives after surgery, could provide important support. These nurses' could be the contact persons for the patients throughout the whole cancer trajectory not only when it concerns hospital-based issues but also in the contact with other caregivers. By such a function the patients always have a person who they know understands their situation and who could support them in the communication with other caregivers. However, in order to support these patients there is a need for team cooperation. Therefore, a continuous dialogue between the nurse and other specialists, for example, the surgeon, nutritionist and physiotherapist is needed. With such an approach the patients could get adequate support and information throughout the long and strenuous follow-up period without having to fumble around in a health care system that they experience as fragmented and hard to navigate.

Interpretation of the outcome of the intervention

With knowledge about the patients' reduced QOL and their unmet need of support and information, a telephone based nurse-led supportive care programme was developed and tested. It has been stated earlier that an RCT testing a supportive care programme provided by a specialised nurse compared with a traditional follow-up would be needed within this patient group [112]. The effect of interventions concerning support in the transition from in- to outpatient care is limited. However, interventions that combine discharge planning with post discharge support, as in this study, tend to show the greatest effects [109].

The results show that the intervention group was significantly more satisfied with the received information in several scales compared to the control group throughout the six month follow-up, but no significant differences were shown for QOL. This indicates that an increased satisfaction with information is not automatically connected with an increased QOL. An important question is therefore: If we do not enhance QOL does it matter that the patients perception of received information is enhanced? Information to patients with cancer has been highlighted as important and as a prerequisite for handling the life situation and coping with a disease [45]. It has also been pointed out that patients are often not satisfied with the information they receive [16, 45]. In the beginning of this thesis we addressed the difference between disease and illness and also the importance of measuring both the outcome of the treatment (PROM) and the patients' experiences of the outcome (PREM) [82, 83]. It has previously been shown that these patients' lives are severely hampered by remaining symptoms after surgery [2-7] and in this thesis it is also shown that the patients need support to learn to

live with the problems instead of fighting them. The interpretation of these results could be that the major surgical procedure as such (the disease) severely hampers QOL (the illness) and therefore when evaluating the outcome of surgery (QOL) no effect is shown since it is connected with the surgical trauma and the anatomy after surgery. However, when evaluating the patients' experiences of the outcome it was shown that there is a significant positive effect by the intervention on the patients perception of received information. This indicates that the intervention may not enhance QOL but it may help the patients to adapt to their new life situation and to cope with the illness irrespective of the reduced QOL. However, since no evaluation was conducted regarding how the patients cope with the illness or of their level of distress, we cannot conclude that the positive effect of the intervention on experiences of perceived information affects the patients' ability to handle and cope with the illness. Therefore, the effect of the intervention on the patients' life situations needs to be further addressed.

The results of this thesis showed that the intervention had no impact on the number of health care contacts during the six-month follow-up. Earlier studies have stated that follow-up programmes and nurse-led follow-ups is likely to be cost effective and that this may affect health care consumption [61, 74]. In this study we evaluated health care contacts from three different data sources to gain valid data. Since there were no effects on the number of health care contacts for any of these data sources, it can be concluded that the intervention does not affect the number of health care contacts. However, only the number of contacts was evaluated and no health economic analysis was conducted, a fact that may be a weakness of this thesis. Therefore, when performing further studies aiming to optimise supportive care to these patients, health economic aspects could be of interest.

CONCLUSIONS AND CLINICAL IMPLICATIONS

The findings of this thesis show that the patients' QOL is most severely affected at two months, compared with twelve months after surgery, that the patients experience that their QOL was substantially reduced during the first postoperative year, and that QOL remains negatively affected as long as 2-5 years after surgery. This indicates that support to these patients needs to be introduced at an early stage after surgery and continue throughout the whole cancer trajectory.

Further on, this thesis shows that the patients' ability to adapt to the new life situation is not only connected with their experiences of their QOL, but also with their ability to take control of the situation and learn to live with remaining symptoms. This indicates that patients need support in how to handle remaining problems after surgery in order to be able to adjust to their new life situation. Such support need to be proactive and include information about self care, honest information about what to expect with regards to recovery and a clear plan for the future.

The patients experience the health care system as fragmented and hard to navigate, that there is a gap between in- and outpatient care, and that they lack one person who has an overall responsibility of their care throughout the cancer trajectory. These results indicate that support to patients after surgery needs to include help in navigating the health care system as well as a better cooperation and knowledge transition between the hospital and municipal and primary care.

The telephone based nurse-led supportive care programme was shown to have a significant positive effect on the patients perception of received information in several scales. However, no effect was shown on QOL or the number of health care contacts. This implies that extended support and information, provided by clinical nurse specialist, could enhance satisfaction with perceived information.

In conclusion, the result of this thesis shows that these patients' life situations are severely hampered and that they suffer an unmet need of support for a long time after surgery. These findings indicate that the patients need individualised support and information from a contact person who acts as a support through the whole cancer trajectory. The findings also suggests that to be able to support these patients it is necessary that the health care system works with interest of the patients in the centre of focus and that they cooperate more extensively than they do today. The findings of this thesis could be used as a base for future development of new routines for follow-ups after oesophageal cancer surgery.

FURTHER STUDIES

The experimental study tests a supportive care programme that is focused on the patients and their needs only, and does not include the patients' social network or extended cooperation with primary or municipal care. Therefore, further studies that include an extended cooperation with other caregivers as well as support to the patients social network are needed in order to evaluate the most effective follow-up programme for these patients. Since it is likely that follow-ups for patients in other settings may differ, and since this relatively small patient group makes data collection time-consuming, further studies would benefit from a multi-centre design.

The result of this thesis shows that the telephone based nurse-led supportive care programme had a significant effect on patients perception of received information. Earlier studies have implied that enhanced information could impact the patients' ability to adapt to and to cope with an illness, an issue that has not been evaluated in this thesis. Further studies are therefore needed to evaluate in what way an enhanced satisfaction with perceived information affects the patients' ability to adjust to their new life situation.

The importance of individualised support to these patients has been highlighted in this thesis. We used a complex intervention that allows individualisation of the support within the follow-up programme. However, to further optimise support to these patients, an early identification of those patients who may need additional support could be of importance. Therefore, studies evaluating valid known potential factors on supportive care needs would be of great interest to perform.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Bakgrund

Patienter som drabbas av cancer i matstrupen står inför en framtid som med stor sannolikhet kommer att vara negativt påverkad en lång tid framöver. Matstrupscancer är idag den åttonde vanligaste cancer formen i världen och den sjätte vanligaste cancerrelaterade dödsorsaken. De två vanligaste formerna av matstrupscancer är körtelcancer och skivepitelcancer. Under 2011, drabbades 662 personer av matstrupscancer i Sverige. Kirurgi har länge ensamt varit huvudbehandling, men under senare år har onkologisk behandling adderats. Flertalet patienter i denna avhandling har genomgått enbart kirurgisk behandling. Av dem som drabbas, har cirka hälften redan vid diagnostillfället en för avancerad sjukdom eller har andra problem som gör att de inte kan behandlas med kirurgi. För resterande patienter erbjuds kirurgi med eller utan onkologisk tilläggsbehandling. Det kirurgiska ingreppet är ett av de mest avancerade kirurgiska ingrepp som genomförs och innebär omfattande kirurgi från såväl buk- som bröståla. Operation är förknippad med en betydande risk för allvarliga komplikationer (33-44 %) och en dödlighet inom de första 30 postoperativa dagarna på mellan 5-15 %. Efter operationen är den förväntade femårsöverlevnaden endast runt 30 % vilket innebär att en stor del av dessa patienter redan under det först året efter operationen återfår sin cancer. Forskning kring denna patientgrupp har visat att patienternas livskvalitet är starkt negativt påverkad efter operationen framförallt när det gäller problem relaterade till ätande, förändrade avföringsvanor och uttalad trötthet. Det har också påvisats att patienterna ofta har svårigheter att återhämta sig efter operationen på grund av att de fysiska påfrestningarna även påverkar deras liv ur ett psykiskt och socialt perspektiv. Idag finns det en betydande mängd studier som påvisar att patienternas livskvalitet och livssituation är påtagligt negativt påverkade efter operationen och det finns också forskning som pekar på att patienternas behov av information och stöd är bristfälligt tillgodosedda. Trots detta finns det idag endast ett fåtal studier som fokuserar på att utveckla och testa stödåtgärder för dessa patienter. Denna avhandling fokuserar på patienternas liv efter operationen och syftar till att belysa hur patienterna upplever sin livskvalitet, hur de hanterar sjukdomsrelaterade problem och hur de upplevde stödet efter operationen. I denna avhandling har ett telefonbaserat sjuksköterskelett stödprogram med syftet att främja patienternas livskvalitet efter operationen utvärderats.

Metoder

Avhandlingen omfattar fyra delstudier, två med kvalitativa ansatser där datainsamling skett med hjälp av grupp intervjuer och två med kvantitativa ansatser där datainsamling skett med hjälp av frågeformulär. I delstudie I utvärderades patienternas livskvalitet genom att patienterna fick besvara frågeformulär som mäter allmän samt sjukdomsspecifik livskvalitet vid inskrivningen och sedan 2, 4, 6, 9 och 12 månader efter operationen. Analysen genomfördes statistiskt genom att utvärdera skillnaden mellan mätningarna över tid. Syftet var att identifiera när under det första året efter operationen patienternas livskvalitet var mest påverkad för att mer optimalt kunna anpassa stödåtgärder efter patienternas behov. Delstudierna II och III bygger på data från fokusgruppintervjuer med patienterna 2-5 år efter operationen. Syftena var att belysa patienternas upplevelser av sin livskvalitet (II) och av stöd efter operationen (III) ur ett långtidsperspektiv. Analysen genomfördes med hjälp av innehållsanalys. Syftet med studierna var att belysa patienternas upplevelser för att kunna anpassa stödåtgärder efter deras specifika behov. Delstudie IV är en experimentell studie där ett specialanpassat telefonbaserat sjuksköterskelett stödprogram testats och jämförs med ”ordinarie vård” för att utvärdera om patienternas livssituation kan främjas genom utökat stöd. Stödprogrammet innefattade att en specialistsjuksköterska hade kontinuerlig kontakt med patienterna under de första sex månaderna efter operationen. I programmet ingick ett utskrivningssamtal där patienterna fick muntlig och skriftlig information om livet efter operationen, om planen för framtiden och råd angående hur de kan hantera eventuella problem efter operationen. All information gavs i form av en dialog som utgick från patientens specifika behov samt i förväg definierade områden som sedan tidigare är kända som besvärande för patienterna. Efter utskrivningen tog sjuksköterskan kontakt med patienterna per telefon enligt ett givet intervall. Datainsamling genomfördes med frågeformulär som mäter livskvalitet och upplevelse av information samt genom registrering av de sjukvårdskontakter patienterna haft efter utskrivningen. Mätningarna med frågeformulären genomfördes vid utskrivning och sedan 2 veckor och 2, 4, och 6 månader efter utskrivning. Analysen genomfördes statistiskt genom att de mätta parametrarna jämfördes mellan grupperna och över tid.

Resultat

Resultatet av Studie I visar att patienternas livskvalitet är mest negativt påverkad 2 månader efter operationen jämfört med 12 månader efter operationen. Detta resultat gäller både för generell livskvalitet och för livskvalitet som är förknippad med matstrupscancer. Resultatet visar även att ålder, kön eller grad av sjuklighet inte påverkar patienternas livskvalitet men däremot att behandling med syrahämmande läkemedel (proton pumps hämmare) har en positiv effekt på

patienternas livskvalitet. Resultatet av Studie II påvisar att patienternas upplever sin livskvalitet som negativt påverkad ända från utskrivningen från sjukhuset till och med upp till 2-5 år efter operationen. Problem som är förknippade med mat och ätande, förändrade avföringsvanor och försämrade sömn beskrivs vara de faktorer som påverka patienternas liv starkast. De många fysiska problemen har även en negativ påverkan på patienternas sociala liv då de väljer att inte medverka vid sociala tillställningar på grund av de fysiska problemen och på deras psykologiska hälsa då de går i en ständig oro för att drabbas av återfall av sjukdomen. Patienterna beskriver att deras liv förändrats och blivit en kamp för att anpassa sig till den nya livssituationen. Förmågan att anpassa sig till den nya livssituationen beskrivs delvis bero på hur mycket problem patienterna upplever sig ha men också på den egna förmågan att ta kontroll över sin situation och leva så gott som möjligt trots problemen. Resultatet av Studie III visar att patienterna upplever ett stort behov av stöd efter operationen men att delar av deras stödbehov inte tillgodosetts. Patienterna upplever att de behöver stöd som innefattar ärlig information om vad de kan förvänta sig av framtiden, information om hur de ska hantera eventuella problem som är förknippade med operationen samt en klar och tydlig plan för uppföljningen efter utskrivningen. De upplever vidare att det stöd de får från sjukhuset är bra men att det bara fokuserar på sjukhusrelaterade problem och eftersom deras fortsatta vård efter utskrivning involverar flera olika vårdinstanser upplever de sig lämnade i ett sjukvårdssystem där ingen har en helhetsbild och där ingen helt förstår deras situation. Patienterna efterfrågar en kontaktperson som kan fungera som stöd från diagnos och genom hela sjukvårdskedjan. Med sådant stöd menar patienterna att de bättre skulle klara av att hantera sin sjukdom. Resultatet av Studie IV visar att det telefonbaserade sjuksköterskeledda stödprogrammet positivt påverkade patienternas upplevelse av information. Gruppen som fick ta del av programmet ansåg sig ha fått mer tillfredställande information om hur de kan hantera problem, fått mer skriftlig information och önskade i mindre utsträckning än kontroll gruppen mer information. Däremot påvisades ingen statistisk säkerställd skillnad mellan grupperna för livskvalitet eller för hur många sjukvårdskontakter patienterna haft efter operationen.

Slutsats

De samlade resultaten av denna avhandling visar att patienterna livssituation är starkt påverkad av kvarvarande problem efter operationen. Resultaten visar även att patienterna är i behov av stödåtgärder redan i ett tidigt skede efter operationen och att detta stöd bör fortgå en längre tid efter operationen. Vidare finns det tydliga indikationer på att patienterna inte känner sig trygga i hälso- och sjukvårdssystemet som de upplever fragmenterat och svårt att hitta i. Det finns ett stort behov av en kontaktperson som har ett helhetsansvar för patienternas vårdkedja och som arbetar för att överbygga klyftorna mellan slutenvård och

primärvård men också mellan olika vård instanser inom slutenvården. Genom den experimentella studien kan vi påvisa att utökat stöd positivt påverkar patienternas upplevelse av information men att det i denna studie inte påverkar livskvalitet eller antalet sjukvårdkontakter. Resultaten från avhandlingen kan ligga till grund för framtida utveckling av nya rutiner vid uppföljning av dessa patienter efter operationen. En fråga för fortsatt forskning blir att utvärdera huruvida den positiva effekt av stödprogrammet som påvisades på upplevelsen av information också påverkar patienternas förmåga att anpassa sig till livet efter operationen.

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