



Patients' experiences of supportive care from a long-term perspective after oesophageal cancer surgery – A focus group study



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A B S T R A C T

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

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

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

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

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

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Introduction

It is a well-known fact that patients, after undergoing surgery for oesophageal cancer, suffer from several problems that affect most aspects of quality of life (QOL) for a long time (Djäv et al., 2008; Lagergren et al., 2007; Olsson et al., 2007; Viklund et al., 2006a). It is also known that the patients experience the new life situation as a struggle and that the remaining symptoms hinder them from feeling in control of their lives (Malmström et al., 2013). In spite of this awareness that the patients life is hampered by several ailments after surgery (Djäv et al., 2008; Lagergren et al., 2007; Malmström et al., 2013; Verschuur et al., 2006; Viklund

et al., 2006a) there is still a lack of research focussing on their experiences of supportive care. In order to meet the patient's specific needs after this life-changing surgery a greater understanding of their experiences is essential.

Oesophageal cancer is the 8th most common cancer diagnosis in the world (Ferlay et al., 2010) and during 2010 there were 593 new cases (including cardia) reported in Sweden (National Board of Health and Welfare, 2012). After diagnosis the only established treatment for cure is surgery alone or in combination with chemotherapy or radiotherapy (Wu and Posner, 2003). Even though survival after surgery has gradually improved, the 5-year survival rate remains at only 28–31% (Anderson et al., 2011; Rouvelas et al., 2005). After surgery the patients suffer from problems with e.g. eating, appetite loss, fatigue and diarrhea (Lagergren et al., 2007; Olsson et al., 2002; Verschuur et al., 2006; Viklund et al., 2006a) resulting in a reduced QOL for a substantial time (Djäv et al., 2008; Lagergren et al., 2007; Olsson et al., 2007;

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Viklund et al., 2006a). It has also been shown that some patients feel depressed, lonely and abandoned and experience that the life have changed negatively due to remaining problems after surgery (Malmström et al., 2013; Olsson et al., 2002) facts that motivate the need of supportive care for these patients.

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

Meeting patient's needs after this extensive surgery is a complex task for the healthcare professionals (HCP) and it is realistic to state that the need of supportive care is extensively based on a poor prognosis (Anderson et al., 2011) reduced QOL (Blazeby et al., 2000; Djärv et al., 2008; Lagergren et al., 2007; Olsson et al., 2007; Viklund et al., 2006a) and the fact that the new life situation is affected both from a physical and psychological/emotional perspective (Clarke et al., 2011; Malmström et al., 2013; McCorry et al., 2009; Olsson et al., 2002; Wainwright et al., 2007; Watt and Whyte, 2003). Gender, emotional functioning (Ernstmann et al., 2009), age and time since diagnosis (Sanson-Fisher et al., 2000) are factors that earlier have been associated with enhanced psychosocial or supportive care needs for patients with cancer. However, factors or characteristics that may impact the need of supportive care within this patient group need to be further explored. Nurse-led models of supportive care have been shown within other cancer settings, to have the potential to reduce unmet supportive care needs, improve continuity of care and improve health-related quality of life of patients with cancer (Howell et al., 2008). Within this patient group there are studies concerning supportive care programmes and nurse-led follow-up focussing on the role of a specialist nurse (Viklund et al., 2006b) or the effect on quality of life and costs (Verschuur et al., 2009). However, there is still a lack of studies focussing on patients' experiences of supportive care that would be needed to be able to develop a supportive care programme that is designed after the patients' specific needs.

Aim

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

Method

Context

Due to centralization and the complexity of the surgery, oesophagectomy and oesophagogastrrectomy procedures for cancer are carried out at a limited number of university hospitals in Sweden.

After surgery the median length of stay at the hospital is 21 days and after discharge clinical follow-ups with a physician are maintained for about two years. During the follow-up time the patients are able to contact a clinical nurse specialist specialized in the patient's conditions, at the open-care clinic if needed. Thereafter, the patients are referred back to the primary care physicians and the municipal nurses without any further follow-up at the department of surgery. At the time of the interviews, none of the authors were involved in the care of the patients included in the study.

Design

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

Participants

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

All patients that was eligible for the study ($n = 27$) were sent an information letter, and an informed consent form to sign. One week later the first author (MM) phoned the patients to give further information about the study, and asked if they were willing to participate. Patients that decided to participate were asked to sign and return the consent form. Of the twenty-seven eligible patients, nine declined participation due to illness and one failed to come to the interview. A total of 17 patients were included in the study (Table 1). The time between the first phone contact and the interviews varied between 3 and 9 weeks.

Data collection

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

The first and the last author conducted all interviews. The first author (MM) moderated the interviews with focus on helping the respondents to focus on the topic (Krueger and Casey, 2009) while the last author (BI) assisted by asking probing questions and keeping notes during the process. The interviews focused on two different areas; patients' experiences of quality of life, reported in a

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